4/20/2006

2:19pm
Okay, I'm going to try to summarize here. Gary was in a car accident on Friday and suffered a severe injury to the spine, broken ribs, bruised lungs, broken pelvis, and broken rt. index finger. He was flown by helicopter to UAB Hospital in BIRMIngham, where he was first in Emergency, then the Neurosurgery ICU. The first surgery he had, Friday, was a spinal decompression, during which they took care of a hematoma next to the spinal cord (I may not have everything technically correct, but this should be close). Unfortunately they discovered the injury to the spine was worse than they initially hoped -- in one doctor's words, the spinal cord was completely destroyed at the T4 level, about nipple height. Below that level, he has permanently (they say, but never say never) lost all feeling, in particular he has lost the use of his legs. However, he's still got his "Gary-ness" -- no damage to brain/mind. He also has the use of his arms. They put him on a breathing tube (mouth) and feeding tube (nose). Both of which he detested and mimed a strong desire to yank them out. He is flat on his back and cannot speak or use his right hand, so we communicate by him writing left-handed on a piece of paper I hold up in the air for him. In case you want to know, he can write pretty damn good with his left hand -- I've been able to make out everything. He was concerned about his classes, and also wanted to make sure everyone knew he was fine from waist up (actually, not that far, only nipple level up, but he hasn't quite taken everything in). He has definitely maintained his desire to do as much as he can by himself -- if I try to guess what he is writing, even if I guess correctly to save him the effort of writing, he still insists on writing it out. Even if I guess a synonym of what he is trying to write, he'll continue to write his own word, thank you very much.

He had a second spinal surgery yesterday to stabilize -the spine -- the ligaments holding the vertebrae -together had been stretched and torn. So screws were -put into the spine to give it strength. He also had -bone grafting done at the same time, so that the bones -will fuse and take over from the screws and other -metal supports when those inevitably fail. (Again, I'm -not sure I have all this quite correctly stated, but -it should be close). In a second procedure done right -after the spine surgery, they took out the mouth and -nose tubes (yea! says Gary) and put in a trache (sp?) -tube for breathing and a peg-tube for feeding (there's -a metaphor in there somewhere). This afternoon he -should be having his last surgery, where they put pins -in his right index finger so hopefully he'll have the -full use of his right hand again.

His lungs are weakened from nerve damage and -contusions, so it will be at least a few days, up to 2 -weeks, until they can wean him off the breathing -apparatus. Eventually, the hole in the trachea will -heal so he can talk again. Once he's off the -ventilator, they'll begin easy therapy, then hopefully -more intensive therapy in about 2 weeks.

All for now, as I'm about to dash over for the next -visiting half-hour. - - -I've conveyed all your words of concern and wishes for -a speedy recovery to him.

Peg

4/21

10:18am
The surgery on his finger yesterday went fine -- they -put in a metal plate -and six pins. He jokes that he now has a bionic finger -and asks whether that -scared us or excited us (me and my sister Janet and -brother-in-law John and -my mom). I told him it depends what he does with it. -It will be in a metal -splint for 6-8 weeks, and he won't be able to use it -until then. They had -x-rays of it for him to see.

One thing that I don't like is he now is having -trouble hearing, like his -ears are plugged up as they get during flying. I've -been pestering the -nurses about it to get on the doctors about it. The -neurological docs say -there is no neurological reason for it. Wouldn't you -know it -- I finally -pestered the staff enough so they tell Gary what they -are doing when they -come in the room with him and do stuff to him, and now -he can't hear them. -They had to suction him a lot with all those tubes in --- I'm hoping it's -just something like irritated sinuses, or maybe all -the anesthesia. I will -see him in about 20 minutes so I will see if the -doctors are doing anything -about that yet.

All for now.

Peg

I forgot. When I first wrote some of you about Gary's -address, he was in NICU (N=neurosurgery), but then he -was moved to TBICU, Trauma and Burns ICU, where he -still is now, just a floor up from where he was before -. I got on his university email account and see -someone has said his address is MICU --I'm not sure -where they got that info; perhaps that is a correct -address as well. I will try to remember to doublecheck -that when I go over for next visiting time. Anyway, -the Browns' card made it, and I believe that was sent -to NICU, so if you already sent one off, it will -presumably eventually make it to him.

The hearing loss, the doctors say, is due to the all -the anesthesia he has been getting for his different -surgeries, so will return. We have a new method of -communication -- we've written the letters of the -alphabet on a piece of paper and he points to the -letters with a pen. I know, I know, I should have thot -of that earlier.

All for now,
Peg

Staff assured me that anything that was sent to him at -the NICU will be sent up to the Trauma and Burns ICU -(TBICU) where he is now. His new address (put his -name at the top): - -

TBICU/North Pavillion 9th Floor
Room 9508
1802 6th Avenue South
Birmingham, Al 35249

4/21

10:23pm
Gary is sitting much more upright now -- about a 60 -degree angle (see the advantage of a mathematical -background?). They will start weaning him off the -trache tube by alternating it with a trache collar -(which they said looks like an oxygen mask, but fits -over the hole they made in the trachea) starting -tomorrow. He has had a bit of a fever since last night --- 100.2 -- but they said that was normal for after -all these surgeries. He got a little pooped out after -the last visit with my mom and Janet &John , but -should be all right. He is looking better and better -each day. Our spirits are good -- it really helped me -to have some family around for this short while -- -they left tonight. I think we all got a little -slap-happy Thursday night. I hope the other people in -the trauma unit didn't object too much to the laughter -coming out of our room -- I can't even remember what -we were all laughing about.

Peg

4/22
sometime between 3:30 and 5 pm, I forget exactly when.

Well, now the surgeon who did Gary's second spinal -operation tells me the hearing loss is NOT due to the -drugs (he wasn't given the ones that could cause -that) but either due to drainage from the feeding tube -that was in his nose or possibly to blood in his inner -ear from trauma during the accident. Sigh -- bottom -line is, they don't know for sure, but they don't -think it is anything to be worried about.

He is "on schedule," progressing nicely. Today they -start weaning him off the trache tube. They are -optimistic that this will go quickly, meaning 2-3 -days, until he is just wearing the trache collar for -24 hours, meaning the machine won't be giving him a -little extra help and he will be breathing normal air -(now he's getting a higher concentration of oxygen).

Hmm, what else. Oh. He would like a vanilla caffe -latte (he's going thru caffeine withdrawal). I'm not -sure the experience would be the same going thru one -of his tubes, but as long as he gets the caffeine kick -. . .

He complained that you would think that with all the -technologically advanced equipment surrounding him, -they would have a decent TV system. The remote works -randomly --it's anybody's guess when hitting the "on" -button will actually turn the damn thing on -- I think -this is cruel, making the patients wonder about their -sanity (half-joking). they also have a lousy selection -of channels. The attending (male) nurse told Gary he -needed to get into the soaps. Gary said the nurse -probably watched them all, to which the nurse -agreed, saying he watched them right in the ICU. I told -Gary the guy watches them instead of the patients. The -nurse said if Gary kept up his complaints about the -TV, he would be sedated. Gary called the nurse cruel, -to which the nurse responded, "If you want to see -cruel, I'll call Bobby Lowder and have him come visit -you." Gary said he didn't think he better write out -his response to that. (To the non-Auburnites, Lowder -is all the faculty's favorite AU trustee. Not.)

Many of you have asked how I am. What can I say? I was -petrified he was going to die on me. I am deeply -grateful that he's had no brain injury and am very -glad he's still got the use of his arms. A good friend -(hi, Connie)brought me back to Auburn last Monday for -the day where we did what had to be done -- getting -tax stuff in, getting the accident report, seeing -State Farm, packing up some stuff I needed, or wanted -for Gary's entertainment -- and one thing I did was go -to his car to retrieve what could be retrieved. -Definitely not an experience I would like to repeat, -seeing the car. Thank God he wasn't hit on the -driver's side (the impact was on the front passenger -side).

i am ensconced in a hotel where I can literally be at -Gary's side in less than 5 minutes. Hotel living isn't -my thing, but if it has to be, this place is good for -it. Convenient to the hospital so I don't have to -drive. Reasonably quiet for a hotel -- I'm betting -the majority of people here are here because they have -someone in the hospital. I use my hot plate and my -rice cooker for my meals -- I'm allergic to most all -foods, so am able to meet my needs this way. Actually -it was a few days before I could choke anything down. -Sleep is lousy, but I'm sure that will get better. My -major worry in that regard is to try to get enough -rest so I don't have a CFS crash. If this had happened -even a few years ago, when I was much worse off, I -don't know if I could have even made the trip here. So -in that regard, after my visits with Gary, I go back -to the hotel room to unwind. Some people literally -live in the waiting room of the hospital, but I -wouldn't be able handle that. Even waiting there in -between visits would be too much, in terms of comfort -for my back and getting some rest.

I am grateful for all the help I've been given and -offered. When I received the news to call the -emergency room, I had just arrived at Paneera's for my -writing critique group. One of the group members, an -Auburn junior -- Eve -- drove me to my house where I -threw the necessities in my car (unfortunately with my -food allergies I am high maintainence)-- or rather I -should say i threw them in boxes and Eve carried them -to the car, because I have been having back problems -(in fact, when I talked to the emergency room doctor, -he told me Gary had told him I couldn't come to B'ham -because of my back, and later when he found out I was -on my way up, he told me he wanted them to call me and -tell me not to chance it, but that they couldn't -because I didn't have a cell phone -- I told him that -if he thought that would have stopped me, to let me -assure him as long as I had breath in my body I -would've been there. As you can see from this he has -been quite lucid throughout the ordeal; the only thing -he can't remember is the gap in time from heading home -from the golf course to waking up in the emergency -room, tho he evidently even aswered questions of the -police at the accident scene). Eve also carried all my -boxes up to the hotel room for me. Connie hauled me -around last Monday on the various errands, and then -she and Jamie, another critique writing group member -(and on the English Dept faculty) formed a caravan to -take me back to B'ham so I would have a car up here -(so I can buy my zuchinni :-))but wouldn't have to -drive it up myself.

Various neighbors --Sue Rodger, Sylvia Goldman, Hilary -Wyss and her husband James whose last name escapes me -now -- have offered to see to the house and cats (who -were pretty mad that I hadn't made the trip back home -on Monday in order to spend the day petting them). -

All of you have helped me by sending your emails of -sympathy and support, and replying to various -questions I had re insurance stuff, etc, taping "24" -so we won't miss an episode (Gary was concerned about -that <G>, thanks Jim). I've probably forgotten people -I should single out for thanks, so if I have, I'm -sorry. I'm grateful for all the help I've received and -all the offers of help.

What do I need? My massage therapist Connie and my -chiropracter. I assume those aren't possibilities (at -least, affordable ones), so I will have to look for -ones up here. I imagine we'll be up here for at least -another month.

Well, this is probably MUCH more than you ever wanted -to know but I figure you can always hit "delete."
;-)

All for now.

Peg

4/22

Since this ordeal first began on the 14th, I have been writing individual emails to various people about Gary. Thinking I would cleverly combine all of you into one -big list, I have been writing about Gary's condition and sending that off in one shot starting about the 20th. -Unfortunately I then heard today that some of you aren't getting -the mail because of span filters (if you check your trash, maybe you can recover some of the emails – in fact, maybe some of the emails I wrote to individuals are in their trash, because I never got replies to some of them when I would have expected to – I have replied to every single email I have received, so if you didn’t hear back from me, it must have been marked as spam). Janet Rogers suggested my mail was being marked as spam -because I was sending my email thru my charter -acct. So I made a new yahoo acct and so am testing it -out now. If there are still problems, I will get on -Gary's university acct and try that. I was going to -try to avoid that so I didn't "take over" his account. -Unfortunately because I stuck in everyone's address -that I know, it may be getting rejected because of the -number of people in the address list.

Of course, how will I know if some of you don't get -this <G>?

What follows below is some mail you might have missed. If you've already seen it, -sorry, please ignore. You may get yet another copy if -I have to move to Gary's account.

Peg

(Note – later this evening I decided to try to put all this stuff up on a webpage. Excuse the inelegance, I know nothing of blogging etc. I have, hopefully, rearranged this in reverse chronological order.)

April 23, 2006 (12:01pm)

Well, breathing turns out to be hard work. They have been weaning him off the trache tube, making him do the work of breathing (but with a trache collar through which he gets medicines for his lungs). According to his blood gases he is tolerating it well, but it is definitely fatiguing him. He had said it was okay for a few of his grad students (Brad, Asli – and Robert F. joined in the group) to visit, and the morning visit on Sat. went fine – that was the first time he was on the trache collar – but when they came back for the afternoon visit he was definitely showing signs of wear. They didn't cause that, let me assure them (heck, if anyone would've tired him out, it would've been my brother-in-law the previous days (JUST joking, John)).

Gary enjoyed the visit. They brought up a get-well card from the math dept. (which reminds me, I forgot to read it) and a Sudoku (sp?) book. He did the first one after we left that morning. When we came back he said it had been an easy one. Brad told him the challenge was to do it left-handed.

I called Gary's mom after that visit, filled her in. She told me a story from when he was a kid, when they lived on his grandpa's farm. She was listening to a local radio station, a call-in program, I guess, and someone started saying something about what a bad mother some boys had because she was letting them play up in some tall trees. The caller described the location, and Gary's mother said, "That's OUR area!" She went out and found Gary and some other boys (probably including his trouble-making older brother, Donne) up in some trees – Gary the farthest up. She calmly informed him he needed to come down right now, which he did. She then forbade any of the boys from climbing those trees again. Not sure if she was obeyed. She blames the boys from the town for their bad influence. Personally I would still blame Donne, even if he was nowhere around. He, after all, was the one to get Gary to blow on the rocket fuel in a spoon because they couldn't get it to ignite. It then did. And Gary practically blew his face off. I'm also betting it was Donne who got Gary to ski off the roof of the barn. He broke his foot that time. Hmm. I suppose I can get sued for libel by Donne now.

After hanging up with his mom, she called me back almost immediately, cautioning me not to let Gary get too tired out with visitors. When I saw Gary at 5:30, he was still tired. The nurse said he was doing well adjusting to the breathing. They roll him on to one side or the other to prevent pressure ulcers, and he is on blood thinners and wearing compression bandages to prevent blood clots from forming. The three students just stopped in that time to give Gary a present – I understand Regina chipped in as well – the first 2 seasons of our favorite TV show, "24." That should keep us occupied. I informed Gary that Season 3 of Remington Steele had just been released on DVD and I was having it forwarded from our house so we could watch it. He spelled out something, but I'm sure I must have mis-read it. It looked like "Whoop de do." I can't imagine why he would say that – he enjoyed watching the full five seasons with me just a year or so ago. I would think it would be even better now that we have it on DVD instead of on tapes of tapes I've gotten from various people. I mean, now we can actually see the faces of the actors.

He was too tired for any talk, so I asked him if he wanted me to read to him. He said yes, and between the choices of the paper, Newsweek, and a book, he chose the book, Bob Dylan's new autobiography. Gary must like it pretty well because the bookmark was more than half-way when I started reading it to him last week. It's not really my cup of tea tho. Dylan was slightly before my time, so I'm not intrinsically interested in him, and the book strikes me as rather stream of consciousness. The imagery is vivid – I keep wondering, can he really remember what he was wearing on that occasion back in the 60s? what those places and people look like? (Heck, I didn't even remember we had wallpaper in our kitchen before it was repainted a few weeks ago when that topic came up (the person putting in our new kitchen floor, who had seen our place one time, a month earlier, commented to Gary (I wasn't there) how nice the repainting job was, that she liked it so much better than the wallpaper. Gary had been impressed she remembered that detail and told me about it, and I said to Gary, "We had wall paper?" Of course, I am the person who when asked if our house was wood or brick had to tell the person I would have to go home and check. I am definitely not a sensate person.) The book reads somewhat like poetry. I'm thinking "beat poetry," though I don't know if that is an accurate assessment because I've never read any. Perhaps Gary finds the book soothing. I find it confusing.

When I came back at 8:30, Gary was so tired out he didn't even want me to read to him. In his usual polite way he spelled out, "If you don't mind, I would just like to sleep." I think if I were in his position I would be spelling out, "Go away." Or if I felt wordy, "Go the hell away." Anyway, I told him no visitors until he's more perky, and then left. Mom knew best.

I had seen Gary's neurosurgeon in the morning – the one who kept me waiting around until 1 am Thursday morning for an update on Gary's surgery and then never showed up. There wasn't anything new to report, really. Everything is looking good, no complications. They took out the stitches in his back and put in staples (youch!). They've taken out the drain he had in his back that he had had in for the surgery. They given him some blood cuz his red blood cells were low, and given him some extra minerals and electrolytes that were a little low.

Okay, that was Saturday. Today, Sunday, I have so far seen him just on the first visit. He is still tired, from the breathing adaptation, which they say is still going well, and it may be that things are catching up to him. For one thing, ICU isn't very restful, it's like day all the time. They like to get people out of there ASAP because patients can get "ICU psychosis" because of the lack of REM sleep they get from the constant interruptive activity that goes on – they get tired, cranky, and can even start hallucinating. So far he is just tired. Since I don't even need one hand to count the number of times I've known him to be cranky in 25+ years, that would be noticeable. The nurse told me he is doing so well that they may even move him out of there today. He would go just down the hall. I believe it's called Trauma and Burn Nursing Unit, but I'll check on that when he moves. Yep, another change of address.

All for now.

April 23, 2006 (9:23pm)

Tonight was upsetting to me. Gary had to be put back on the ventilator, which gives him the little extra push to breathe, because his oxygen saturation was down. He was concerned he had had a setback, though the nurse tried to assure him he has been doing better than most people do when going through the weaning process. I think he thought the problem might have been due to them doing a marathon suctioning session on him – they used something called a bag on him, which evidently does deep suctioning. The whole ordeal, as he termed it, took thirty to forty minutes. He called it the suction from hell. His hearing got worse again, even though when I saw him earlier this afternoon he had said it had gotten a little better. Also this evening he wrote out big notes for the nurses while I was there to hold the paper for him: "Turn me: yes no" "Pillow: yes no" "Sit me up so I can watch the TV: yes no" So obviously he doesn't feel he is being able to communicate to the nurses. The nurse tonight told me he needs to practice taking deep breaths and to cough deeply when they suction him. I told that to him, and he indicated that that was news to him, so obviously there is a failure of communication. The nurse also said for him to be sure to rest, and when I relayed that to him, he spelled out, "speaking of rest . . ." and gave me a significant look. I took the hint.

Maybe I read too much into the things that happened tonight, but I felt upset because I felt that he was frustrated. Yet when I asked if he was, he answered, "a little." Maybe that's true, he's an even sort of guy. I hope so. All I know is that it put my stomach in knots and brought on another session of the weeps.

April 23, 2006 (7:08pm)

Gary seemed perkier at the 2:30 visit. I guess a sign he's getting better is he made out a to do list for me: buy electric shaver (I forgot to bring his from Auburn, not used to thinking about such "men things") and buy a big clock so he doesn't have to bug the nurses about what time it is (they keep the clock on the wall to the side but behind him, and he can't twist and see it). So I had my big adventure: finding and surviving Wal-Mart. Did I tell you how much I hate driving? The hotel desk clerk gave me good directions, which weren't at all difficult, but I always managed to be in the wrong lane for turning. Fortunately there were polite people who let me cut over to the correct lane – even with my "No George W" and "Freedom of Choice" bumper stickers (Gary actually designed the latter on some site on the internet and bought them). Once I got in Wal-Mart I faced the second challenge: find the stuff. Did I tell you how much I hate big stores? Once I located the stuff, time for the adventure of getting back. I realized I had forgotten to make sure exactly how to do that – which exit to take off the freeway – but fortunately it turned out to be obvious. Except once again I was in the wrong lane.

The worst part is even that little driving set of my sciatica-like symptoms (the chiropractor said I have more than just sciatica, but I don't know any technical name for it; some of the disks are bulging). This is a drag. I tried walking it out and stretching it out, but things are definitely worse. I hope the pain doesn't interfere with sleep too much. (For months now I've also had the sensation like someone is holding onto the bottom of my foot and shaking my leg very fast, or that a current is going through it – that sensation isn't painful, but you try sleeping with someone shaking your leg all night.) So I hope I don't have to run such errands very often.

I gave Gary his presents at the 5:30 visit, and then we read more Dylan.

He didn't get out of the ICU because they didn't have a bed available in the other section for him to move to.

April 24, 2006 (11:58am)

Someone suggested we do a blog, so you can post your comments and Gary can read them when he gets the internet. I was told about blogspot.com and am trying that out. Will let you know if it seems successful (note – I think it works. Check out http://drpeg2003.blogspot.com/). I am well aware that some of you may want to send me emails responding to what I have been writing, as has been happening, but would not want your comments available for public consumption. If that is the case, please don't let the fact that I am putting this on a blog stop you from sending me the private emails – I won't post them. I read them, but be aware you may not always get a timely response (ironic grin).

This next paragraph you may want to skip because I am going to vent. I had a rotten night. My leg hurt and I was upset from my visit with Gary, although writing about it actually made me feel better. Then my typical bad karma with hotel neighbors returned with a vengeance – what is it about people who go to hotels and act like they're the only ones there? First I had the people to one side and across from me going in and out, talking in the hallway, and worst of all, visitors banging LOUDLY and frequently on their doors until after midnite. Perhaps that went on even later, but my exhaustion took over about then. My critique group friend Eve has told me, in a different context, that the penance for murder in the Catholic church is only 10 Hail Marys. I got to the point where I was willing to say a novena. Then at 4 am somebody decides to check into the room next to me on the other side . And can they do it quietly? Of course not. They had to talk to each other in the hall and bang their door for thirty minutes. I was ripped out of a sound sleep, shaking, and my heart going a mile a minute. Just when I had started to calm, someone started knocking on their door. I lost it. I went out there in my jammies and asked if the person was the same one who had been knocking on the door before, intending to request that they find a different mode of communication. The woman looked at me, said she just got there, for me to go back to sleep, and that sometimes we don't get what we want. At which point I burst into tears and said, "I am well aware of that. My husband is lying paralyzed in the hospital." Obviously not the response she expected. She walked away, then came back and said, "I'm sorry, I'll pray for you." I felt like telling her that was all well and good, but I'd appreciate it more if they would just be more considerate and not make so much noise. Oh, well. At least I think I guilted them into being more quiet. Unfortunately, I didn't get back to sleep. So I meditated. I have been putting a lot of extra mileage on my mantra this week. I had intended to get up at 9, on the theory that it would be better to get up and going and hope I would be tired enough tonight to get a good night's sleep, but at 8:30 I finally fell asleep until about 9:45. I pulled myself out of bed at 10 and got ready for the 10:30 visit.

I felt anxious going over there, worried how Gary would be feeling this morning, but the difference was like the difference between, well, night and day. Things seemed back to "normal." He had two questions for me to ask a doctor – when he would get off the breathing tube, and about the deep breathing exercises. Good timing. A respiratory doctor came in and I asked the questions, and the doctor told Gary weaning him off the trache tube was a trial and error thing. That they just had to see how he was responding to the weaning process and go by that. This was not any new news, but I think Gary likes to have the reassurance of a doctor. I asked the doctor how much Gary should practice deep breathing. At first he said like the nurse had, "when he thinks of it." I don't know about y'all, but I'm standing there thinking, wouldn't that be all the time? I mean, it's not that he has a lot of other stuff on his mind right now. Fortunately the doctor then gave a specific, that a good routine would be 1-2 min. every hour. Now that's something I can wrap my mind around. Tell me how often to do something and I'll do it. Give me a vague "whenever you think of it" and I'm bewildered by how much I should be doing it. Anyway, just having the doctor say this to him helped ease Gary's mind, I think.

Another good piece of news, when he yawned this morning his ears popped and he got part of his hearing back, so it's a relief to know that is just is a matter of his ears being stuffed up from drainage.

A bunch more cards came – from his brother Donne and family – Phyllis, Carissa and Justin; Jack and Janet Rogers; Judy Roitman and her husband Stan whose last name I regret to tell you I can't remember and I can't make out the writing; the KU group; Sheldon and Brenda (? again, forgive my memory and the fact that I can't make out the name for sure) Davis; and Gary's sister Norma, who wrote that Gary could give anyone there a hard time except me – Gary pointed that out to me and nodded emphatically.

I think that's all for now . . . Oh. Someone (since this is going up on the web, I'm not naming names for the most part, except to let those people who sent cards know that they arrived) wondered whether my leg problem might be " restless leg syndrome." I haven't heard it called that, and from what I've read on it in the past, I don't think that's it. I HAVE had what I thought was that in the past, the need to move the leg to get some kind of relief. But I haven't read that a symptom of that is the "shaking" sensation. This shaking is something that can actually be felt – when the massage therapist works on me, she can feel the internal shaking. And sometimes the shaking can be felt in the small of my back. Someone else thought an acupuncturist might help. I did actually go to one – she is a Chinese medical doctor who does acupuncture in Auburn – but I got scared after the first treatment. Not the acupuncture part, tho I was uncomfortable lying on the table that long, but when she finished up, it was with some kind of massage. I don't know what the official term for it was, but for us Americans she termed if "Kung fu massage." (Her English is pretty bad – I understood about one word in ten – like maybe the pronouns.) Anyway, the name fit. She was slapping me all along the back of my body with her palms, and I mean hard. I was really afraid she was going to hurt me, make my symptoms worse. But I couldn't get off the table. I told her to stop, that I was afraid this was too much. She said, "No, no, good for you, wake up chi." I said, "No, no, not good for me, beat the chi out of me." She didn't understand. Or chose not to. But I had been thinking of giving it a try again, so when I get the chance I'll see if I can locate a traditional Chinese acupuncturist around here. Let's see. I've gone thru an M.D., two physical therapists, three massage therapists, and a chiropractor so far. Everyone helps a little but no big breakthroughs. Actually, I think the latest thing the chiropractor was doing – stretching me on the rack (all right, decompression table), was definitely helping. Another thing to look into, to find someone up here who does that.

Okay, time for next visit.
All for now,
Peg

April 24, 2006 (3:59pm)

Gary seemed downright chipper at 2:30. The physical therapist had come for the first time, earlier; he said she was nice and they talked about family stuff, etc. His exercise was to look at his feet and legs while she exercised them. He said his legs felt like blobs, and that when he touches them, it's like feeling someone else's body. She got a baseline evaluation for him, and told him the hard part was to come. He seemed happy to have this concrete sign of progress in his recovery.

April 25, 2006 (8:00pm)

Gary had another CT scan of his head this afternoon to see if they might have missed some fracture that could be causing some mechanical difficulty with his hearing, but they found nothing to indicate that. They did find a mass of fluid (the doctor illustrated by rubbing his hand along his neck under the ear) that they feel is the source of the problem, and are hoping that it will soon be absorbed. I hope that happens soon; mostly for his comfort, but also so I don't have to raise my voice so much. I feel like I am straining it when I read Dylan to him. He asked me to bring the Jimmy Carter book this afternoon ("Our Endangered Values"), but I forgot. I have it packed to go for this evening. We listened to a book on tape for awhile, one borrowed from my critique group friend Jamie, but I confess I didn't pay much attention to it. I was standing there thinking that what he really likes is biographies, and wondering if I should try to find a place to rent some, or to go on the web and make use of a service my sister Janet found where you can rent books on tape. I don't know if the latter would be worth it. Hopefully soon he'll be where he can use his laptop, and then we'll make use of the Netflix subscription my brother Joe and sister-in-law Dolores have offered to get for us.

They may soon remove the huge cast he has on his right hand and replace it with something lighter. It seems amazing how they've got that whole hand so wrapped up when all he broke on it was one finger. Of course, it was a serious break.

Today I sallied forth to buy a printer for my laptop – this way I'll be able to print off some of the emails you've been sending and show them to him. I was proud of myself for figuring out how to get it working (though I won't admit to you how long that took me); the only problem is that there is something wrong with the power cord – it keeps falling out of the back of the printer. Granted, I am not the most mechanical of people (like not at all), but I am sure I am sticking that cord in right. So now I'll have to go back for a replacement. I hate having to do that kind of thing – feels like a waste of time to have to correct someone else's mistake. Maybe I'll get lucky and there will be a place to rent books on tape nearby.

Found a grocery store about 8 blocks away from the hotel. Being used to Kroger I found this place anachronistic. The overhead signs were uninformative and I ended up going up and down every aisle for the few things I wanted. Fortunately it was a small store. At the checkout counter was a booklet, "Pregnancy for Dummies." I'd rather the dummies not get pregnant. :-) Gary said they're going to get pregnant anyway, so it's good to have this book.

One thing that makes me smile, is that when Gary wants to ask the nurse something and I am there but have moved out of the way to let her do her thing, instead of tapping the words out on the paper to her, he insists on having me come over and read what he is saying. Personally, I don't think I do it any better than the nurses do, but it touches me that he wants me to do it. (I hope he is not going to be too embarrassed when he reads some of the things I've been writing. Maybe I shouldn't give him the address of the web page.)

I am happy to report that the neighbors from hell were only here that one day. Turns out there was some "big" motorcycling racing going on, and Michael Jordan was here. This is the kind of thing *I* would print out whoop-de-do for. Well, now I'm not surprised at the type of people who were inhabiting the hotel that day. (Oops, my prejudices are showing.) I also found out that there is some big car racing event coming up, so I wouldn't be surprised if a similar thing happens.

Someone said the hospital should have some kind of housing for families of people in the hospital, and in fact, they do. I have been on the waiting list for it since I got here, but it's anyone's guess as to when something might open up for me. It would be like a small apartment with a kitchenette, and would cost about a tenth of what I am paying for my hotel room. It is a bit farther than where I am right now – I'd have to walk through another building of the medical center and then walk outside for a block. At night, they tell people not to walk outside, because this isn't the best of areas – one calls for a shuttle. But who knows if something will open up. There are two women who have been here a few days longer than me. They literally live in the 8th floor waiting room of the NICU where Gary was at first. There are a few couches there that they have taken over. I wouldn't survive that kind of setup.

All for now.

April 27, 2006 (9:25am)

Today's stream:

A few corrections/ clarifications. It was my older sister who told me where the grocery store was – I didn't find it myself. Not that she's really going to care that I didn't give her proper credit, but just to set the record straight. :-) Also, Gary is not really at the point where I can get him a latte. That was a joke, with reference to the earlier remarks about caffeine withdrawal. BUT my understanding is that he will eventually be able to eat normally. Now he is being fed through a peg-tube going into his stomach, and through IVs in his arm. Last night, when I was trying to wade through all the tubing coming from him in order to get close to him in the bed, he joked, "Don't step on my dinner."

We are still concerned about his hearing. He had a hearing test yesterday and it showed a moderate-to-severe hearing loss. :-(They plan to do more testing. Again, they don't think it is nerve damage, but they haven't found a definitive cause – they keep saying something about the accident, and I keep saying it never showed up until after the second surgery. I would just rather he didn't have to cope with this on top of everything else.

A speech therapist came by with the wonderful idea that Gary could point out the letters of the alphabet on a sheet of paper in order to communicate. Way ahead of you, lady. (I'm not complaining – I know they have a lot of patients to see to.)

On my way back from one of my visits, I arrived at an elevator just when it had opened and a white-coated doctor stepped into it. "Are you going up or down?" I asked. "Uh, I don't know," he replied. "Stay the hell away from my husband," I thought.

I managed to set off the fire alarm in my room yesterday afternoon. I have been cooking in the bathroom, and I forgot to keep the door closed that time. The steam from my rice cooker set off the alarm. I rushed over to the phone to call the front desk to assure them there was no fire. When they answered, they said, "Ms. Daniels, are you all right? We were just trying to reach you." "I'm fine," I replied. "I set the alarm off." "Were you in the shower?" he enquired. "Uh, yeah," I lied (that's the ticket). "We'll reset the alarm. Keep the door closed when you shower," he instructed. "I sure will." I was afraid to tell them it was due to cooking, as I have carefully avoided reading any fine print on the card hanging on the back of my door that might say that no hot plates, etc., are allowed.

I have discovered I actually DO NOT know how to plug a cord into a printer without guidance, and the less said about that the better.

(1:25pm)

It's early afternoon now, and at the morning visit I found out that Gary has a wound infection from one of the staples in his back. They claim this is not unusual, and will put him on antibiotics. They may also remove the staple, clean out the area, and let it heal without putting the staple back in. They have also found fluid in his lungs, which they feel may be the reason he is not progressing with being weaned off the ventilator as fast as they thought he would be. When I left, they were prepping him to put a camera into his lungs and check things out, then "bronch" (pronounced "bronk," don't know how they spell it) him, meaning they would suction some fluid out of his lungs. He also was feeling hot, even though the room was about 68 (and I was cold), but his temperature was only 99. I wish there weren't all these extra things to be concerned about.

He decided not to finish the letter to his family, and I am glad. It was about cancelling his trip to Alaska with them. Yesterday, when it became clear that that was what he was writing, I told him that he could write it if he wanted, but that the trip was still more than two months away, and we had no idea how far along he might be in his rehab by then, maybe the trip was still a possibility. He didn't think that was realistic and continued to write. But after I left, the physical therapist came, and he talked to her about it. She told him the trip was still more than two months away, who knew how far along he might be in his rehab by then, and that maybe the trip was still a possibility, so he decided he was writing the letter prematurely. Hmm. Of course, the therapist had the weight of medical authority behind her when she spoke those words. :-)

Somebody asked if I had accidently forgotten to include myself as going on the cruise. I did not. Although the level of severity of my CFS is less than it was a few years back, I haven't really chanced taking trips. A year ago last Jan. I took the first one in about 10 years, a short one to visit my older sister in Nevada and to go to L.A. because the story I've been working on is set there and I needed to do some on-site research. I *almost* thought of chancing the Alaska trip, though I was nervous about it, but then the back problems haven't cleared up, so I don't think it would be wise to take such a trip.

More Mail! Thanks Ronnie, Michel, Krystyna and Piotr, Stan Schneller of COSAM, the Barjenbruch family, Alexander and Lauren Shibakov (who sent a hospital survival kit), Mom G once again, and Jo – who made me laugh with the lifetime supply of earplugs she sent.

April 26, 2006 (11:54am)

Okay, now for the next stream-of-consciousness entry.

WE'VE GOT MAIL! Thanks, Debra, and Judy and Stan – your cards made it to the Marriott. And the other cards made it to the TBICU: Debra, the Nyikos's, the Carolinas Topology Seminar, Justin Moore, the Szulgas, the Kuperbergs (thanks for the CD – Mary Jane said she is getting a player to us), Ralph and Norma Grotelueschen (relatives of Gary's, as you might guess from the name ;-)), Mirko's, Mary Ellen's, the Smiths, Randy Holmes and Liza Weisbrod, and another one from Gary's mom, which included a cute picture of Gary as a, in her words, "one-and-three-quarter- year-old" (actually, Mom G, since that was a Christmas picture, he would have been one and five-sixths, less a day ;-)). We spent this morning composing a letter to his sister, Norma. He was supposed to go on a cruise with them to Alaska in two months, but he feels there is no way that is going to happen. The letter isn't finished yet – he is insisting on writing it out left-handed, even though I told him if he pointed the letters out, I would write the letter. He should learn to take me up on my transcription skills while they are still being offered ;-) Anyway, we'll probably finish the letter this afternoon. Just as I was to leave he wanted the Sudoku book, so thanks again to his grad students for bringing that.

Gary is looking healthier, has more color in his face now. When I came in he was hooked up at the trachea to some kind of machine that made noises like a steam locomotive. It's supposed to shake up his lungs to help break up the secretions (not being technically correct here, I'm sure). The weaning process is taking longer than he'd hoped. They put him on the trachea collar again last night, hoping to keep him on for 2 hours, but had to put him back on the ventilator after thirty minutes because he was having difficulty. I was told it could take up to two weeks to wean him, but I know Gary had been hoping for the minimum time of two-three days. We have learned to preface everything the nurses tell us with "maybe" – like that he was going to be moved out of ICU, or that he is getting a lighter cast on his hand, or that they're going to adjust the bed so his legs can drop down into a more of a sitting position. One person will tell us one thing is going to happen, and the next thing we know they will say it isn't. Personally I wish they wouldn't do that. It seems like getting his hopes up and then dashing them. He wrote me that he understands that a lot of different people are coordinating this. Like with letting his legs drop – the orthopedic guys say it's okay, and then the neurosurgery people say no.

I heard from Auburn Eye Care that his new glasses are ready and they will UPS them to me. What happened to the glasses he was wearing at the time of the accident, I have no idea. Neither of the emergency rooms (first Auburn, then Birmingham) have any record of them. When I went to clean out his car, I looked around for them as best I could, but they were no place I had access to. They could have flown off and gotten wedged between the front passenger seat and the divider, but that area is so crunched together I couldn't put my hand in to find out. Another mystery is what happened to his keys. He claims they were in the pants he was wearing, but the emergency room only salvaged his wallet, belt, and watch – his clothing had to be cut from him, so wasn't saved. I did manage to find an old pair of glasses of his when I was home that Monday, so he hasn't been too bad off that way. I'd be miserable without my glasses, since I would have to put things about 4 inches from my nose to read them, and people would remain a blur.

They are opening a Starbucks on the first floor of his hospital wing on May 9th, so hopefully by then I can sneak in a latte for him – yes, I know this sentence just appears stuck in.

One of the people who is in a similar boat as me (his wife was in a car accident) jokingly calls me "our leader." I have the time down so I always arrive a few minutes before they are to let us in (tho they are often late in doing so), and then I march up to the front of the door to the ICU and plant myself so I am the first one in. Then I barrel down the hall when they give the okay. Outta my way, folks. Gotta get there before the selfish people do, as my older sister says. But they fooled me this morning, and opened a few minutes early, and some other people beat me in. That blew my track record for being first off the block, but being small I squeezed by them and still managed to pull ahead at the finish.

This speed reference reminds me. The elevator at the hotel is the slowest one in existence. I and others make jokes about it, commenting that we should have brought something for entertainment to pass the time until we get to our floor. I have received condolences for being on the sixth floor. The experience of traveling in it was even more delightful when my mother was here. The elevator makes this loud obnoxious beeping sound ever time it passes the floor. My mom decided to imitate the sound ever time she heard it. Great. Like standing next to the Road Runner on sedatives.

A couple people wondered if I got bored here (which really made me wonder if I was boring them with my writing. JUST KIDDING, I know that's not what you meant. I hope). I am not. I am a slow writer, so it takes me quite a while to compose these updates. I am behind in my emails to people. Plus there are always little things that crop up that have to be taken care of, related to house and home, or little errands to be run. I have finally found a massage therapist who will work on me in her home, 5 minutes away. (One of the reasons I am looking forward to my little sister visiting next week, I admit, is that she is a massage therapist, and I plan to take advantage of her skills – and so is Gary!) Mary Jane recommended a chiropractor, and I am debating whether or not to go to her. It would be about a 20 minute trip, and I'm a little bit wary of having to travel that far and thereby ruining any adjustment she makes. There are a couple of acupuncturists listed in the yellow pages and I need to check their websites. When things get more settled, I plan to return to working on the mystery story I have been writing. I can't focus on it now, as it takes a good deal of concentration, and I am not up for it. Probably even before then, I will return to critiquing stories written by my fellow members in my writing critique group. That will keep me busy – Jamie has written a story that is about 1200 pages long, and is willing to have the installments sent up with my mail. It is a wonderful story, and I have so enjoyed critiquing it. It is in the fantasy genre, which never before held any interest for me, but I couldn't put her story down. All four times I've been through it (wink to Jamie). AND AS OF TODAY I HAVE MY SEASON 3 REMINGTON STEELE DVDs! Yes, I know, you're thrilled. I am looking forward to watching them to unwind. I am debating on whether to save some of the eps and subjecting

Gary to them – oops, I mean, offering to let him watch them with me. It's not like he can voice any complaints. And if he pounds on the bed, I can just put that down to involuntary muscle spasms. (Sorry, a little black humor.)

All for now.

Friday April 28, 2006 (9:47am)

A scattering of thoughts, as they occur to me:

I guess I'm going to have to get used to things yo-yo-ing. Gary was a little groggy during the later visits last night, but otherwise seemed fine. I had been hoping for things to always move in a forward direction, so didn't like hearing about any new problems. I received reassurances from my email friend Vicki and also from my brother Joe, who at one time was a med tech and so hung out in a hospital, that pneumonia wasn't at all that unusual in Gary's situation and that it wasn't something to panic about. It's just that I hate seeing Gary lie there, me feeling helpless to do anything to make him all better, or at least to not let things get any worse.

Speaking of Joe, he and his wife Dolores have a home remodeling business in Colorado, and have offered to help make our house accessible for when Gary comes home (now it's official, Joey, and you can't weasel out ;-)). Dolores worked with accessibility issues when she was a real estate agent in Florida, so will also have information on that. My brother-in-law John has a brother who was in a car accident that put him in a wheelchair when he was around twenty, if I remember that age right, and who, again if I'm remembering correctly, has helped construct accessible homes, so there is another possible resource. I know a neighbor of ours also had her home re-designed for wheelchair accessibility so I hope we can tap her for local information. Phil has offered an electric wheelchair for use if we want it. I imagine when Gary gets into therapy they'll be telling us more about what needs to be done to the house.

It's way too early to say what Gary will or won't be able to do. I sure hope he's going to be able to lift himself, as the physical therapist believes he will, because I know I won't be able to do that. I joked to Gary we may both end up going around the house on motor scooters.

Gary's hearing seemed even worse this morning. I walked in and raised my voice as usual, and he told me to repeat what I had said louder. (Unfortunately that resulted in my yelling so everyone up and down the hall could hear, "Hold on a second, I forgot to tie the drawstring on my pants, and they're falling down." I heard suspicious giggling coming from the nurse's station.) Gary said the audiologists were supposed to see him again today, and I told the nurse to give them the message that I thought the hearing was worse. But they never showed up – I'm not sure Gary had the information correct. Later in the day a doctor told me that further testing would have to wait until Gary was off the ventilator and able to sit up in a wheel chair so they could take him down to a special soundproof booth. For now they were still hoping that once the fluid in the mastoid air cells was resorbed the problem would clear up on its own.

Gary wanted to know how the kitties are doing. I talked to Connie this morning, and she was going to the house to pick up the mail the neighbors have been bringing in so that she could send it on. She later reported that both kitties ran up to her for petting, even Blackjack (named because I like the assonance, not for the card game), who usually runs out the cat door or under the bed at the appearance of humans other than Gary, me, or for some reason my older sister – perhaps because her voice sounds similar to mine. Anyway, I was pleased to report to Gary the kitties are doing fine and haven't left any "presents" for Connie to forward to us. (I was glad I remembered to tell Connie to do walk-throughs of the house – all we would need would be to come home to a houseful of decaying ground squirrels and lizards.)

We finished the morning by Gary shaving himself with the electric razor I bought. A nurse had shaved him with a safety razor days before and volunteered to do so again Thursday night, but Gary didn't want her to – he's afraid of being cut. For some reason she refused to do it with the electric razor – I didn't understand the reason why. Anyway, she said I could do it the next morning with the electric razor. I said that would be an interesting experience, figuring I'd botch the job. But when I wielded the razor at him, he wanted to shave himself. Smart move on his part. He shaved by feel and only missed one spot. I guess if you do that for forty years you get the routine down without needing to look at yourself. He didn't do the throat area, though, for fear of getting too close to the trache hole.

After that visit I took another jaunt out to Wal-Mart for doodads. The clock I had bought for Gary fell off the thermostat I had it propped up on, and the hands fell off. Seeing that the clock wasn't keeping the correct time anyway, no great loss. I was hoping to avoid another trip out into the real world, but Gary gave me such a mournful look when I told him the clock was broken that I couldn't *not* go out there. So I got him a new cheapo clock, trying out one with a square bottom. Unfortunately the top of the thermostat is rounded, so I don't know if this will work any better. Gary had the idea of getting him a cheap light watch that we could tape to the cast on his right hand, so I bought him one and taped it to him. I also happened upon a dryboard and bought it in case he would prefer writing on that, but he didn't, which is fine with me – this way I can keep the notes he writes.

It seems odd to me that they don't have more "patient amenities" for those in the ICU. I know the physical care of the patients is well taken care of and of primary concern, but it seems to me that there are some simple things they could supply that would make recovery more comfortable. I brought my laptop holder (aka "bed table") from home to set things on so Gary could write or read, etc. I've had a couple of enquiries from other people asking where I got it so they could get one for their family member as well. Seems like that could be made standard equipment. And I know many other patients here are on ventilators and cannot talk – seems like it should be SOP (standard operating procedure) to aid them immediately with printed out alphabets instead of people having to think of that on their own. The only reason the speech therapist came by and made the suggestion of pointing to the letters of the alphabet was because of Gary's hearing loss, but that happened days after he'd been there and his inability to communicate verbally wasn't because of that.

After writing the above, when I walked in for the early evening visit, I found Gary's new clock had been hung up on an IV stand near the end of his bed (okay, to be honest I didn't notice it right away, but I did discover it later when I looked to see what time it was). I made the comments I wrote above to Gary, and the nurse overheard me. She came in and said she agreed with me, and that I should make my suggestions to the nurse manager. She also thought there was a place on the UAB webpage where I could leave such comments. She said whoever had been designing the rooms had been thinking of the staff, not the patients, and that the clock was convenient for them, but that there should be a second clock for the patients. She also said that most patients on the ward were not aware enough to communicate, many in comas, but that there were always a few like Gary who were able to communicate, so she also thought bed tables should be standard equipment.

Got the mail at the 2:30 visit. Thanks to David Turner, J.P. and Pam Holmes, and the parents of Gary's sister-in-law, Daniel and Lydia Munoz.

We tried out a few local visitors at the 2:30 visit: Mike O'Farrell, who was a grad student at Auburn the same time I was and who now lives in Huntsville (he also brought his wife, Carmen); John Mayer and Lex Oversteegen, mathematicians at UAB. Gary was happy to see them. John recommended biographies of John Adams and Oppenheimer if Gary wanted some ideas for books to read. John also brought a Calvin and Hobbes book, which Gary said was more his speed right now. Gary was whipping his pen around the alphabet board so fast I had a hard time keeping up. When Mike came in for the second fifteen minutes (they only allow three visitors at a time, and since I didn't graciously allow it to be the three of them . . .), I was a little worried at first. Mike has always been soft-spoken, and couldn't speak loud enough for Gary to hear. I thought I might have to repeat everything Mike was saying, but the two of them decided to just write each other their conversation, so that worked out fine. All the visitors mentioned Gary looked good, and they could see what I meant about him still being Gary.

One thing that Gary is confused about, and which I don't know how to help him with, is how to balance his day's activities. He likes to have the visitors, says they really lift his spirits. He enjoys doing Sudoku and the little reading he does. Now the physical therapist has given him an exercise band to pull on with his left arm for a little exercise (again without any instructions as to how often for how long). But he also knows he should rest. I asked the nurse if there was someone we could talk to about how to balance his activities, and she put in an order for a consult with one of the hospital social workers. To me that really didn't seem to be who we should talk to about this. Gary said he would talk to the physical therapist about it when he sees her on Monday, and I will continue to ask every nurse that is caring for him (since that regularly changes and they don't alway give the same advice) and every doctor of his that I run into. (Note: I told the nurse about this on Sat. morning, and she said that as long as he was sleeping well at night, he could do as much of the non-resting activities as he was comfortable with – that reassured him.)

Note to anyone who stays at the Marriott long enough to run out of underwear so you have to do laundry: bring lots of change. The clothes dryer is pathetic; you will probably have to spend at least $3 to get your clothes dry. A dollar gets you half an hour. I spent that and am letting the clothes finish drying somewhere in the room. I'll probably find them again some day – my room looks like the wreck of the Hesperus, as my mother would say.

Speaking of change, you might also want to bring lots for the panhandlers in the vicinity. One came up to me when I was waiting in front of the Marriott for my sister to pull up in the rental car and deposit my mom. I stood there like a deer frozen in the headlights as this guy said a lot of things I couldn't make out. I did get that he wanted $5 from me. I gave him a buck. He cursed me. I felt like saying, "Hey, I'm a Daniels. We don't give out five dollar bills." (Probably a line only my family will appreciate – the Scott in us makes us frugal. Well, Gary says he is frugal and I am extremely frugal – I think that was his polite way of saying I'm miserly.) When I went out for a walk a couple days ago someone else asked for money. That time I had left my purse in the hotel so I could honestly say I didn't have a penny on me. I never have figured out the proper response to panhandlers.

I couldn't quite persuade the chiropractor to accommodate my schedule, but Gary said for me to take care of me, so I will have to skip a visit with him on Monday in order to see her. :-(
(Yes, I know this is another paragraph that just seems stuck in. Get used to it.)

Something that amused me today. I called Jo to give her some information. I had to spell something out (literally) and she mistook an "n" for an "m." I said, "No, 'n' as in . . ." – my mind went black and then I said the first word that came to me. "Not." There was a pause and then Jo said, "That starts with a 'k.'"

I forgot I was talking to a topologist.

Okay, some stuff on me, now, so you may want to skip to the next Gary part. ;-) Some people have wondered if, or said they hoped that, I am doing as well as my writing about this experience seems to indicate I am (actually I figured my writing might be leading you to think I had flipped out). I think I am holding up pretty well – I guess we'll find out as time goes on. The hardest part was the first four days. I was afraid Gary could still die on me, and I felt so all alone, even though I knew both our families were with us in spirit. I could hardly get a word out those days without crying, even though I did my best not to do that when I was in the room with Gary – I didn't always succeed there. The worst time in that regard was Easter Sunday and I was reading the paper to him. I would give him the title of an article, maybe read out a few sentences, and ask him if he wanted me to read out the entire article. He wanted me to continue with one about Easter and Resurrection in the Life section. I could barely get through it. The gist was how Good Friday (the day of Gary's accident) was a time of darkness and death, and Easter was new life. All I could think was the person who wrote this couldn't possibly have experienced the type of thing I was experiencing, that his words were meaningless, that there would be no resurrection here. I took no comfort in the words I was reading, and I couldn't imagine that Gary was either. I wanted to ask Gary if he really wanted me to continue reading this, what with me crying all through it, but he just kept patting my hand (who was comforting who?), so I continued reading.

Sometimes when I start thinking about what's happened, or when I write this blog, tears still come to my eyes. And I can't promise that if I talk to you you won't occasionally hear the tears in my voice. But it's not as overwhelming as it was at first. Then it was almost unreal, unbelievable that this was happening, surely it was a bad dream from which I would wake up and find Gary just as he was before; or if he had really been hurt a little, it would soon be over and he would be walking out of the hospital with me.

Once it seemed clear that he was going to survive with his mind intact I felt I could handle anything else that was to come (although when at a visit he seems a little worse than the previous one, the anxieties creep in). I am very glad he has the use of his arms. Otherwise, I think this would have been hundreds of times harder, and if he'd died or been a vegetable I don't know how I could have borne it. But I guess I would have had little choice to do otherwise.

I've only once asked the question, "Why did this have to happen to the most wonderful person I've ever known?" because I know there is no answer to that. Oddly, though I never thought I'd be thanking having CFS for anything, I may be thanking it for helping me cope now. I've already been through my own life-changing experience, one that was out of my control: it seemed like such a cruel joke – take someone who prided herself on her mental and physical abilities, destroy those abilities, and top it off with chronic pain and fatigue. It was years before things stopped getting worse and more years before thing started to turn around at all (I came down with this in June '92). But I still no longer have the brain power to pursue something such as my former passion of math, nor the physical stamina for much activity. In recent years I finally got to the point where physically I could handle a little gardening, and that became a new passion. But I deeply missed the creativity of using my mind in something like math research (what I always loved most about research was how my mind worked, not the problem per se), and I mourned that loss continually – it wasn't something I could get away from. Until fairly recently I didn't even have the concentrative power to read a book – I'd keep reading the same paragraph over and over again, not able to take it in. But couple years ago, something happened, I can't say why, though I suspect it has to do with the antigen shots I had been giving myself daily as a result of going to the Environmental Health Center in Dallas, one of a number of treatment protocols I tried, and ironically, the one I was most sure was a complete waste of money but was desperate enough to try. Anyway, I suddenly noticed that I could concentrate better – I could read again. By accident I found a small group on the web that wrote a particular kind of fiction that I enjoyed reading – fanfiction about Remington Steele, meaning stories written using the characters of that TV show, which I'm sure the vast majority of people would find pretty silly, but is my guilty pleasure, and hey, it breathed new life into me. I made a comment one time on the fanfic list about something someone had said, saying wouldn't such and such be an interesting story line, and someone said, well, why don't you write the story. My first reaction was, "because I can't write." But then I thought, what the heck, surely I can do it better than some of the ones I've read (Peg says arrogantly ;-)). Thus began my new passion. So I wrote some short pieces, and then over a year ago I wrote the first draft of a novellete-length such piece of fanfic. But I felt it didn't have the emotional impact I wanted it to, so I asked the neighbor behind us, an English professor, if she could suggest a way I could improve on my writing, given the restriction that I wouldn't be able to take a class. She pointed me to the local writing critique group that had just started up. So I wrote them an email saying I was interested in joining their group and listing all the reasons why they probably wouldn’t want to let me into it (I’m a beginner writer, my background is math, I don’t know if I have the stamina to attend the meetings, and what I write is just fanfic). They were desperate enough for another member (the “group” consisted of two English faculty members at the time) that they invited me to one of their meetings. (I found out later their biggest reservation to letting me join was that my background was math :-).) Through their suggestions I improved the story, and they told me to try to write one with original characters, instead of using someone else’s. So that is what I am trying to do now, though I’ve discovered it is a heck of a lot harder, and if my critique group ever sees the result, they may tell me to go back to writing fanfic ;-).

So at last I’ve found something that dovetails with what my mind and body can handle (and thankfully mind and body can handle more than they could there for a long while). I can once again have that same aha! experience I had in creating math, only this time it comes when I write a sentence I like or work out a plot point. Sometimes it seems a little silly because I spend all this time on something that may never be read by more than a small group of people, but Gary always told me that first of all, the important thing was that I enjoyed doing it, that second of all, probably more people had read my stories than had read both of our math papers combined, and third of all, maybe some day I’d write a script for a movie and make us a million bucks. Hmm. I liked his reasoning until he got to number three, as I’m highly doubtful of that (he assured me he didn’t expect that . . . but that it would be nice).

It took time – too much (ironic grin), a heck of a lot longer than three days – but I’ve had my own death and resurrection experience. (I guess that Sunday article held some meaning after all, but I couldn’t see it this past Easter, not for Gary.)

So if you’re still with me, my point is that in terms of my being able to handle this, I’ve already gone through an experience that has parallels to what has happened to him. Life goes on and you find ways to deal with the new givens, even if it takes time (and even if you bitch about it occasionally). I believe Gary is a strong person, and I believe he’ll find his way to make the best of the situation. That helps me deal with it. I wish he didn’t have to go through this, and I am hoping he won’t find the transformation into his new life as painful as I did. My main concern, as I’m sure it is for all of you, is for him to keep his spirits up; I don’t want this to break his spirit. He still has his mental abilities, so he can continue doing what he has loved all these years, the math and the teaching, so that’s one of the most important pluses.

Oops. I see I’ve spent quite a bit of time talking about myself here. Let me finish this part by saying I also want you to know it helps me tremendously to know that there are people out there who are concerned for us. And I have tangible proof – I open my email and look at my inbox :-), which I am way behind in replying to. (A consequence of my “dependency,” however, is I nearly had a panic attack the day the service provider here went down for half a day (okay, a “panic attack” is a bit of an exaggeration, but I did feel “cut off”)).

Well, I thought I was finished with the above topic, but coincidently, Gary told me last night after I had written the above that he thought he had already mentioned how impressed he was with how I have been dealing with this stuff (not that I feel all that impressive), and how grateful he was, but also how sorry he was for making me deal with this stuff. At which point we both burst into tears. I told him I knew it was an accident, something out of our control, just like my having CFS has been and I had always been sorry that he had to deal with a wife who has that (many spouses leave their partners who have the illness). I told him the hardest part of him having the accident was over, because I had been afraid he was going to die. He said he had been too. I told him we could deal with whatever had to be done now, and that the most important thing was for him to keep his spirits up, that he had so many people out there rooting for him, and that Jack and Michel had been writing me about how they were going to do everything possible to get him back to teaching as soon as he was ready for it. I could tell this really meant a great deal to him. He also tapped out "I'm not Superman." I missed the reference and told him I hated to inform him that he never was. He said neither was Christopher Reeve until he became quadriplegic, and then his life was heroic. I didn't want Gary to put any pressure on himself, so I told him no matter what, he was always my hero.

April 29, 2006 (1:52pm)

At this morning's visit, Gary again wanted to resume writing the letter to Norma, because he doesn't think it's realistic to go on such a complicated trip so early, and because, he said, we would need the time to get our house wheelchair friendly and to take care of the things that need to be done so he could return to teaching in the fall (that was good to hear, that he's got it foremost in his mind that he's going to be right back in the thick of things ASAP). I asked the nurse about it, still reluctant for Gary to give up this trip with his family, and she paged the doctor on call. He said medically it would be likely Gary could physically make the trip, but being in a wheelchair was going to be a new experience for him as it was, so he probably wouldn't enjoy the trip as much as he would a year from now – he wouldn't be able to do much, it might be frustrating, etc. So I think it's likely he's cancelling his part in the cruise, unless I get back there this afternoon to find he's changed his mind. (I doubt that though.) When I left him he was writing a letter to Norma. This is the first time he has attempted to write anything totally without my help in holding the paper, getting out new sheets of paper, etc., so I take it as a positive sign. I only hope I can read what he writes. :-)

April 27, 2006 (4:10pm)

The 2:30 visit left me agitated and worried. Gary was completely wiped out from the "bronching." The doctor told me they had suctioned a lot of gunk out ("gunk" evidently being official medical jargon), and that hopefully that would speed the weaning process (before Gary dozed off, he did tell me he was breathing easier). But the doctor also told me there was pus in one lung and that Gary was in the early stage of pneumonia. Hospital + pneumonia = frightened Peg. The doctor said that it wasn't uncommon for pneumonia to be induced by the ventilator, and that that was one reason they were trying to wean him off of it as soon as possible and get him out of ICU, a place that in itself increases one's chances of infection. But the doctor said it is now something of a Catch-22, because the pneumonia makes it harder to get weaned from the ventilator. *Sigh* They have put Gary on an antibiotic to hopefully wipe out the pneumonia quickly – the cleaning out of his lungs should help with that too.

Another unwelcome bit of news is that the bottom staple in his back is draining, meaning there is some infection there. The neurosurgeon who assisted at Gary's second spinal operation told me the antibiotic would also help with that, but they would keep an eye on it to see if they need to remove that staple; they feel the infection is superficial. The nurses' orders are to keep him turned to keep pressure off that area, and to keep a dry gauze bandage on it.

I talked to the neurosurgeon again about the hearing situation, but he didn't tell me anything new. He did say he would pass on to the audiologists that the hearing loss had surfaced after that second surgery.

Well, at least Gary's new glasses came, so he'll be able to see better.

April 30, 2006 (9:00am)

Today's stream:

I forgot to mention in the previous post: It also helps me cope with this to write about it, which is probably obvious!

Note to his family: I again conveyed to Gary that from the beginning you have been chomping at the bit to come see him. He still would rather you wait until he can talk to you, but he definitely feels your love and concern, have no doubt. (This was written before I talked to you, Donne.)

The rest of yesterday was pretty quiet. Gary was on the trache collar at the 5:30 visit and wanted to concentrate on his breathing, so I just read more Dylan to him. Near the end of the visit a sharp pain went through my left knee and my leg nearly collapsed under me – uh-oh, haven't had that happen before. Glad I'm seeing the massage therapist today (Sunday) at noon. Also had a couple spells of light-headedness Saturday, also not something I usually experience, so will have to keep a watch on that.

Gary did "2 and 6" on the trache collar, meaning 2 hours on the trache collar alternated with 6 on the ventilator. I noticed he kept watching the clock during that early evening visit; since he'd told me they were supposed to put him back on the ventilator at 6pm I thought that might mean he was feeling the effect of all that breathing on his own, but he told me he felt pretty good during it. He has discovered the sessions go easier if he tries to nap for a while before they start. I was told that on Sunday they may bump him up to "4 and 4." He looked a little dubious when I relayed that to him. I forgot to ask him if he was dubious because he didn't think he was ready for that or because he didn't believe the words of the medical personnel.

I felt a wave of depression when I went back to my hotel room Saturday night; haven't had that happen before over this, but I know it's a reasonable reaction. There was nothing in particular that caused it, just wondering what we were going to face when we got back home and in the future. I *am* looking forward to being back in my own bed and getting a decent night's sleep and petting my kitties and getting back to my story-writing, but I know that's still some time off.

At the Sunday morning 10:30 visit I asked Gary how he was doing – a former student of his, Alex Shibakov, and his wife Lauren were going to be visiting today so I wanted to make sure Gary was up for it. He said he was fine, just a little tired. I asked him if he'd slept okay during the night, and he said "no." They had the trache collar on him at midnight for two hours, and he says he can't really rest during that because it is harder to breathe with it on as opposed to being on the ventilator. Plus they turn him every two hours. To top it off they take an x-ray EVERY night at 3 am. I did not know that. I just don't get the scheduling of such a procedure. The doc told Gary he was going to prescribe a drug so he can sleep better at night, and I'm thinking, "forget the damn drug, quit bugging him at 3am for an x-ray."

At that visit Gary and I chatted a bit, listened to the book-on-tape for a while, and then it was time for me to go. What happened next, I debated not divulging, but since there are witnesses, I feel I must 'fess up. I went back to my hotel room, ate a little something, and then at 11:40, in preparation to leave for my massage at noon, reached into my purse for my car keys. No keys. Panic. After dumping everything out of my purse and searching to no avail, I had the horrible thought that I must have left them in the car ignition after returning from Wal-Mart. Two days ago. I left a garbled message on the massage therapist's answering machine and then chugged my way to the parking garage, hoping no one had stolen the car. Fortunately it was still there, as were my keys, taunting me from the ignition. So near, and yet so far. I went into the sky deck area (which connects the parking garage area to the hospital and is where you pay your ticket at a machine) and talked to a woman manning a desk there. She gave me the number for "Pop-a-lock," and I called them, unfortunately forgetting that we have AAA, and I could have had this service done for free. Pop-a-lock said they'd be there in forty minutes. I figured they were in the same time dimension as construction workers, so would be there in a couple of hours. Goodbye massage. I decided to chance that my car would be safe without me for another two minutes and started back to my hotel room to get a book to read while I was waiting at the car. While in transit, the massage therapist returned my call (I have now joined the 21st Century and own a cell phone as of last week). She attempted to calm me down, giving me the old New Age spiel of how nothing ever happens without a reason, etc., etc., words that I'd like to believe, but don't always manage to. She thought we could still work in a massage, though I was dubious. She told me she had a nice warm table ready, soothing music going, and would give me a good massage. Sounded lovely. I ended the conversation feeling better, though I forgot to tell her I would probably be allergic to the scented candles :-)

So I guarded the car for about an hour when who should pull to a stop in front of me but Alex and Lauren, no doubt wondering what I was doing standing in the parking garage reading a book. They took a spot near me, and we talked a short time. Lauren said she could get my keys for me by breaking my window with a rock, but I declined her kind offer. I had Alex stand guard while I went inside to get the phone number of Pop-a-lock again and see what they were up to. The guy claimed to be a short distance away (13th and 3rd) and asked me how to get where I was, on 18th and 4th. I told them I didn't know my way around Birmingham very well, but it seemed to me that if he went five blocks up to 18th and one block over to 4th, he would be here. :-) That conversation really inspired my confidence in his abilities. He took an inordinately long time to travel those few blocks, but he did get here. He popped the lock, and I rescued my keys and paid the $35 (I tried to get a discount because he was wearing an Auburn cap, but that didn't work). Ah, well. It could have been worse. I could have locked the keys in the car and obliviously walked away with the motor still running, only to realize this when I returned to the car. I've done that as well. Dolores, even though I'm not quite old enough, can I pass this off as a "senior moment" too?

By this time it was too late for the massage, though the therapist told me to call after the 2:30 visit to see if something could still be arranged, depending on how things worked out with the other appointment she had scheduled for the afternoon. The Shibakovs and I moved to the hotel lobby and visited a bit before going over to the hospital. When Alex walked in for the visit, the first thing Gary tapped out was, "Can I get you a beer?" There was small talk for a short time – Alex offering Gary insights as to how he could get legally high by manipulating the push button on his painkiller dispenser – and then Gary turned to math. I was glad I figured out "Lindelöf" after the first four letters, cuz I don't know how Gary would have communicated the umlaut ;-)

The time flew by quickly, and Alex and Lauren left with promises of coming back with coffee and chocolate for Gary when he was able to have it (great, with all that caffeine he'll be buzzing around the room), and organic zuchinni for me.

I tried to call the massage therapist again, but there was no answer, so that was a bust for today. Oh, well. I've got the chiropractor tomorrow, and then my sister the massage therapist for Tues thru Fri.

At the 5:30 visitation, Gary was fast asleep, so I didn't bother him. Unfortunately that meant the Currys didn't get to say hello to him. They brought over their CD player and lots of classical music, so that will be great, especially because of all the TVs on the ward, Gary's is the one that has broken, as of today. Maintenance didn't see this as the emergency it is, so it will not be fixed until at least tomorrow. We are contemplating buying a DVD player if the TV isn't fixed by tomorrow morning's first visit; he needs a little something of that nature to occupy his time when he is not up to more active stuff like Sudoku and Calvin and Hobbes and Newsweek.

Well, it is getting late, so I will post this now. Wouldn't want you to get worried like the last time you were when I failed in my duty to give you your daily update. :-)

Oh. Jamie wishes to correct my statement that the writing critique group could ever have been described as desperate for members. She says they only let the truly brilliant people in. Who am I to argue? :-)

Sorry I worried some people when I didn't post Friday. I got too tired out to finish what I had been writing.

May 1, 2006

Today's stream:

(Warning: This one is going to be very disjointed, as I ran out of time to organize it.)

Part of Donne's response to Gary telling his family to hold off until he can talk: "As he requested, I am waiting to visit until he can talk and gets out of ICU. So tell him to start talking and get out of ICU."

LOL. I can hardly wait for the above myself. It'll be nice to hear his voice again.

BTW, I occasionally throw in some "netspeak," so I'd better explain the few terms I use (I don't know many). BTW = "by the way." LOL = "laugh out loud." TTYL = "talk to you later." IMHO = "in my humble opinion." Some of you may want to use IMNSHO, which I'm sure you can figure out (I won't mention for which mathematicians or critique group members this phrase is the better fit).

My neurotic need to be first in line at the door to the ICU unit (we wait in the hallway until a nurse comes and opens the door and lets us in) has its dangers: I get blamed for others' actions. Some people get impatient because the nurses hardly ever open the doors on time – I think some of those nurses are sadists – and these impatient people push the call button. The nurse always replies to hold on, they're not ready for us. A few days ago when this happened, the nurse eventually came to the door to let us in, and as I passed, she whacked me with the stack of papers in her hand, telling me (but with a smile on her face) to quit pushing the call button. I told her, hey, just because I'm first in line doesn't mean I do those dastardly deeds. The woman who HAD pushed the call button that time shrank guiltily against the wall. Then yesterday the doors opened for no discernible reason (and I have learned that that doesn't mean you can come in – if you do you get yelled at), and again I got blamed for pushing against the door. I pleaded innocence and the woman behind me backed me up. I still have old Catholic guilts that prevents me from doing what I "shouldn't." Well, most of the time it prevents me. Sometimes I just suffer the guilt. :-)

Speaking of nurses, I have found most of them very nice and helpful, but there is always one. Gary told me at the 2:30 visit a couple of days ago that they had put the IV needle in a place where it ended just where the wrist bends in the back, and it hurt. I asked the nurse if they could put it in somewhere else, and she said she would do it when she had time. When I came back at 5:30, it still hadn't been moved. She said she hadn't had time. Finally when I came back at 8:30 it had just been moved. Maybe she really hadn't been able to do it before, but it seems like somebody could have done it in all that time. I mean, he has enough to put up with without the extra discomforts.

I’ve also noticed most nurses stay available closeby, but others seem to disappear. I was trying to find something for Gary the other day, I forget what, and I eventually gave up on seeing his nurse and went out into the hallway to find someone who could help me. I got chastised for coming out of Gary’s room in my “lemon yellows” – the gowns everyone who enters the room has to wear (along with gloves). I wasn’t in a good mood at the time and snapped, “Well, I wouldn’t have had to come out if I his nurse had put in an appearance some time during the visiting half hour.” They then took care of whatever task it was that Gary had requested.

Gary has mentioned on several occasions that time passes slowly in ICU. I remember the first few days, at the beginning of every visit he asked me for the date and time. He felt like he’d been there weeks when it had only been a day or two. I felt the same way. Now he is bored, and the suggestions I offer for when I am gone – watch a DVD, listen to tapes or CDs doesn’t seem to be what he wants. He has mentioned wanting to write with his right hand, which he can’t do because of the cast, or to be able to turn magazine pages. I’ve tried slipping a magazine behind a rubberband on the laptop holder so he can read the page, but it’s still a big rigamarole to try to turn the page with one hand in a cast and the other full of tubes. If anyone thinks of something to try (short of cutting the cast off him), let me know. Of course, the problem is time-limited.

They gave him something to help him sleep last night, and he did feel he rested better, but he was still sleepy during the 10:30 am visit. He didn’t know if that was from whatever they gave him (I think it was Halcyon?) or if things were just catching up. His back is healing well, for the most part. The skin where the bottom staple is didn’t completely close up, so down the road they will put some kind of cream on it to help debrade it. He also has a bed sore, and they are keeping an eye on it, not letting him lay on his back, making sure to turn him every two hours, all to keep the pressure off it. The nurse I probably like the best smiled as she said Gary won’t let them forget to turn him, a reference to how he keeps his eye on the clock and issues the instruction at the appropriate time. On several occasions when it has been time to leave and I ask him if there’s anything else I can do for him before I go, he’s said, “Tell the nurses to turn me.” :-) They are going to try him at 8 hours on the trache collar today, alternated with 4 hours on the ventilator. I hope he does well. He now likes the collar better than the ventilator, because the ventilator does enforce its own rhythm.

Some people have asked about his view. Alas, all he can see is the curtains covering the wall-sized window that faces the inside of the building. It is impossible to turn him around, given the setup of the machinery in there, but even if they did, the view would mostly be of buildings, though there is a thin strip of trees on a mountain visible in the distance. On the TV there is a channel with nature sights and sounds, for those who have mentioned that that would be healing, and I have gone in there when he has had that on (though mostly it seems to be tuned to sports or CNN – not sure if anyone has done a study on the healing effects of those channels – oh, and by the way, they fixed the TV). I’m not sure about the fish suggestion, though. There doesn’t seem to be anywhere we could put them that he would be able to see them. Unless we could somehow hang them from the IV stand. :-) Gary says we would have to get two, so each of Blackjack and Tigger could have a treat when we get home.

I tell you, we're going to need a U-Haul when it comes time to move him out of ICU, what with the books, papers, magazines, tape recorder, CD player, CDs, books-on-tape, shaver and other personal items, laptop holder, cards, etc., etc. :-)

One thing Gary asked me pretty much right after he found out he would be wheelchair-bound was if he could drive. I wasn't sure why he thought I would know :-), but I said we had seen TV shows where people with such disabilities had vans they could drive using hand controls, and that we would have to look into that. Jo looked into that on her own and has discovered through a friend that there is a place in Sylacauga that converts vans for the disabled, so Gary perked up at that.

I will have to save the rest of today's news for tomorrow – the chiropractor excursion, etc. Nothing new to report on Gary, except that they are going to try to get him a special bed to help with the bed sores problem, and that he made it all 8 hours on the trache tube without a problem. Yea!

May 2, 2006

Oh, lovely. The hotel is under lock-down, for how long, I don't know. This means no one gets in without using their door key to open the front entrance doors, or unless they convince the concierge over the intercom that they have a "good reason." I forgot to ask the guy at the desk what that meant, whether they were even taking new occupants. The reason for the lock-down is McAlister's, a restaurant just to the other side of the parking garage from me, was robbed yesterday (during the day!), plus a hotel guest had a gun put to his head and was robbed at the Texaco station behind the hotel – I can see the station right outside my window. I could do without this additional excitement – I will be running the twenty yard dash between the front of the hotel and the entrance to the parking garage from now on.

Back to more mundane stuff.

As you could probably have guessed, my trip to the chiropractor was not smooth sailing. I never noticed that 280 split into 280 and 31, and I ended up on 31, the wrong road. I didn't discover my error until way too late, and my twenty minute trip thus took me an hour. I have concluded I need a GPS navigational system in my car. :-) Not that I will get one – I think I can handle Auburn traffic. I had gotten directions originally from a person at the chiropractic clinic, and I again called them when I got lost, telling them someone at a gas station had told me how to get back to 280 (I was down at 65, for those familiar with the area), but that I wasn't confident I could get to the clinic once I was back on 280. Unfortunately I spoke to the same person I had originally, and she told me once again to "look for the Office Depot on the left." I don't like directions like that. I can't be looking for landmarks while I am driving – I need street names, distances. If you tell me I can't miss the landmark, believe me, I will miss it (well, except I was able to spot the art museum on College Street in Auburn with the big lake in front of it). Unfortunately the clinic receptionist was unable to supply street names and distances. Right-brain versus left-brain? Anyway, I did find it after much anxious driving. Next time I will go on Yahoo and blow up the area around the final destination. I had tried to use Yahoo to get directions from my hotel to the clinic, but the directions were very different, and the person at the clinic made it sound so easy.

I am seeing various indications that I am getting more tired out – I never get enough rest, no matter how long I lay in bed or meditate. Examples (besides the fact that I think I'm crabbier): The clinic person had told me it would probably be about six lights after I got back on 280, but I couldn't keep track of how many I had passed. At the clinic I kept misplacing my belongings, repeating things I would then realize I had already said, and I couldn't remember what had been said to me moments before, even when I consciously tried to repeat them to myself several times so I would remember. And when I am with Gary sometimes it gets very hard to string his letters into words, and if he asks for something and the nurse isn't available and I forget to write it down, it goes out of my mind. Anyway, I can see the increase in these occurrences. This is frustrating.

Back to the clinic. It was a different experience than what I've had at others. It started out with some computerized testing, supposedly "thermal testing" and "EMG testing," showing the problem areas, etc., by placing electrode-like devices down me spine. Part of me wants to believe the testing is useful, but my cynical side feels like it's for show: impress the customers with the computer readouts. Next time, if I think of it, I'm going to ask whether the results had any bearing on the treatment she gave me – I could have told her my upper back was tight and my lower back was screwed up without that. :-) She'll probably tell me it gave her a baseline.

After the computer scanning, I laid on the "intersegmental treatment table" – a new experience. It felt good. A roller ran up and down my spine, concentrating on a small area at a time. It felt like laying in the ocean on my back and riding the waves, only the wave would be at only one part of the spine. I had the thought that you would not want someone watching you while this was being done to you, as your body is literally lifted up and down wherever the wave is concentrated. It was very relaxing, except that the "wave" was ice cold – probably good for the spine, but it chilled me. (Note to sister Janet – I think those aquamassage machines we tried in that shopping gallery in the casino in Vegas were even better than this.) After ten minutes of having my intersegments treated, I moved to the room to get "crunched." (My chiropractor in Auburn informed me that "we (chiropractors) do not 'crunch' people," but I think that describes the sensation.) First she pumped up and down on the drop table while pushing with her hands up and down my spine, also a different technique from my Auburn chiropractor. Then came the adjustments. I don't know if it was the intersegmental treatment or just her skill, but she was good – very little effort on her part, whereas in Auburn I sometimes feel like I am being wrenched.

I got directions back to the hotel, unfortunately from the same person who had tried to get me there and who couldn't figure out how to use mapquest. So she gave me her own directions – I was supposed to be watching for Red Mountain Expressway and veer onto that, but I am sure there never was a sign for it. Really, I am sure. I was afraid I had missed something again, but saw the University exit off 280.Then I was home free. After making a zucchini stop, I arrived back at the hotel at 5, so in total spent three hours on this adventure. I'm not absolutely sure I'll continue the treatments. Admittedly, my back feels better, but the treatment did nothing obvious for the leg symptoms, and in fact the driving aggravated them. And though hopefully next time I'll find the clinic more easily, it's still a bit of a distance to drive, and I don't like the Birmingham traffic. I'll try the treatment a few more times and see how I do. If it seems helpful I might have to dig in the old wallet and take a cab, like city folk do. ;-) I must say I did like the people at the clinic – they were all very caring.

After I dropped off the zukes and took a quick breather, I headed toward the hospital, belatedly realizing that poor Phil Zenor had probably been sitting there a while. Gary was up to the visit, and the nurse even allowed us to stay longer than the visiting time, though Gary got tired after about forty-five minutes. There was small talk, and talk about Gary's class, which Phil and Stu are taking care of for Gary, and some math talk. Phil brought Gary a biography of R.L. Moore and a DVD of "Walk the Line," which the two of us had wanted to see but haven't yet.

By the way, Gary today (Tuesday) said he answered Phil incorrectly when asked if he was bored. Gary said that he wasn't bored, that he was too tired and felt too weirded out to be bored. I'm sure that's a combination of the drugs and the unnatural sleep.

After the visit Phil asked if I wanted to see a movie, but I said I had to make my dinner (and I also needed to meditate). I think Phil thinks I need to get out to get away from this, but I think that is an extrovert speaking. :-) For me, I recover by going back to my room, resting, writing this blog, slowly working through the emails, reading, meditating, watching DVDs, taking a hot bath, getting a massage, etc. I am very much the introvert and need lots of quiet time.

Monday's mail call: Thanks to Liljana and Marion Scheepers, Michel, Gary and Elise Grabner, Mirna Džamonja (not sure if that "j" at the end is the right letter), and Gary's mom.

Something I want to pass on: when Phil told Gary that he was glad Gary seemed to be in good spirits, Gary replied that the emails, letters, and cards have been a great help in that regard. (Of course, he hasn't seen the emails yet, but I tell him who has written.) So know that you are a very important part of his recovery.

Now for Tuesday's news. Even though I still have no idea how long I'll be here, I extended my stay for another week to the 26th so I don't run into the problem where I almost get kicked out because they are booked for some event (which happened with the motorcycle racing day). The hotel manager tells me they are renaming the sixth floor "The Daniels wing." They should – I'm sure I've paid for it by now. ;-)

For the magazine problem: Someone (I will name your name if you wish :-)) told me that there are machines that will turn pages but that they cost hundreds of dollars, so I agree: we'll just wait for the cast to come off. :-) Turning down the edges of the pages, as was also suggested, didn't seem to help. I thought of putting two rubber bands vertically instead of one horizontally and that helped a little. Manipulating his reading material is even harder for Gary now, because they won't let him raise the head of the bed very high anymore because of the bedsore.

My tender-hearted little sister arrived at about 11:30. We talked, relaxed, ate, and then headed over to Gary for the two-thirty visit. He was more out of it than I have ever seen him, and I was worried, but it turned out that they had bronched him again and he was still under the influence of all the drugs they use for the procedure. So basically Diana and I just stayed there talking quietly while I "petted" Gary's head to let him know we were there. His trauma doc came in and told us the procedure went fine and there wasn't much fluid to pull out from his lungs this time. There wasn't anything new to report, really. Their main goals are to wean him off the ventilator and take care of the bedsore. They may up him to "10 and 2" on the trache collar tonight, but they want to make sure they don't do so too quickly. He was told not to use the exercise band because it might pull on the staples on his back (the result of having so many different specialists working on him is that they don't always agree in their recommendations). I worried that since he had been using it there might have been more damage because of it, but he admitted he hadn't been using it. So I guess it was a good thing he hadn't been doing as he had been told ;-) (or perhaps that they had said "do it when you feel like it," and he hadn't felt like it).

After that visit Diana offered me a massage. Yes! Bliss. She is *very* good – it is the first time I've gotten one from her. Connie, if you ever need another therapist in your office, try to lure Diana away from Ocean City, N.J. And if anyone reading this is ever in Diana's area, check her out. She did a combination of trigger-point therapy and deep massage. Ahhhh. (She can also do Swedish massage for the wimps.) It was a good kind of hurting, though when she got to my feet I considered yelling "uncle!" She informed me my back was full of cords and "crunchies" (not a technical term ;-)) – and it was like trying to massage bubble wrap. When it was over (saved by the bell of it being time for the next visit with Gary), I felt limp as spaghetti. The endorphins kicked in shortly thereafter and I felt really good. Too bad I can't afford to hire her as my personal masseuse for at least the duration of my stay here.

The person who I was supposed to get the massage from on Sunday had generously offered to let Di use her massage table while she is here. I couldn't find the numbers I had written down for her (leading my sister to crack when I later said I had to write something down or else I would forget that it didn't matter if I wrote it down because I would lose the paper – thanks, sis), but then I realized I would have her home number on my cell phone under "numbers called." This cell phone definitely has its uses. :-) The massage person was reached, and she is even going to come by and drop the table off for us at the hotel tomorrow morning! Amazing!

At the 5:30 visit, Gary was a bit more alert, but his eyes kept closing. So the talking was pretty subdued. Di went off to the Curry's after that visit, and I did my usual routine and then returned for the 8:30 visit with Gary. I asked how he was feeling, and he spelled out "perky." I raised an eyebrow. He spelled out "joke." He was obviously still sleepy, so I read him some Dylan until it was time to go.

And thus ends the night. With my sister here I probably won't have the time to be so chatty (yea! you say), but I will be sure to tell you of any developments with Gary.
May 3, 2006

Ahem. I corrected it in the blog and on the website, but for those who read the email, my sister found cords in my body, not chords (unless they were composed by Shostakovich). In my critique group, we have a particular name for such bloopers, but perhaps I shouldn't embarrass the person they are named after ;-)

Thanks to those who have expressed concern about me burning out. I am trying to do all I know how to in order to minimize that – but sometimes things backfire, such as simple trips to chiropractors that are meant to make me feel better but turn into major undertakings. I do know I need lots of time to myself, and I'm sure when we finally get to the point where Gary can more than the merest trickle of visitors, people will understand that I will not be spending much outside time visiting with them.

Of course, it would be a big help if I could get a decent amount of normal sleep, but my body isn't letting me.

My Auburn chiropractor had given the okay for me to start walking again, and I have been slowly increases the amount of time I do it for in 5 minute intervals. I am up to 25 minutes, and the store where I get my zukes is now just a block away from what I can make in half that time. So I may buy the zukes in small enough amounts that I can make that walk to the store ever day or two – I'll have to see how heavy carrying those zukes turns out to be.

I am pleased to report my little sister ended up getting majorly lost going from the Currys to the hospital this morning, taking an hour and a half to go a fifteen minute distance, so it is not just me. Maybe it's genetic. : -)

I got a note during the morning visit that a townhouse opened up. My sister and I checked it out. Nothing fancy, dorm room feel – two small beds in a good-sized main room, a kitchenette, another small room, like a study, I guess, and a small bathroom. It would be a good deal for a more adaptable person. At first I thought I would try it out for a couple of nights while still hanging on to the Marriott room (since the townhouses area only $16 dollars a night, that seemed like a drop in the bucket), but after lugging a couple of boxes over there with the night's essentials, I decided I just couldn't do it. The bed was so small, and not very comfortable. The third-floor room faces University Ave, and I am hypersensitive to noise. I laid on the bed for a while and felt myself grow tenser and tenser. I knew I'd be so worried I couldn't sleep that I wouldn't. Since Gary has no objection to my staying put at the Marriott – saying that it was important to him that I feel good since he had a vested interest in it ;-) – that is what I'll do. So we hauled the boxes we'd brought in right back out again – fortunately the same people we'd passed on the way in weren't still in the lobby. The excursion wasn't a total bust: Di will stay there for the two nights I paid for so she doesn't have to attempt to get to the hospital from the Currys again (she just called me on the cell phone to have me talk her through getting back to the Currys this evening – I'm sure "the blind leading the blind" has popped into your minds. She has taken to calling ourselves Dufus and Dorkus :-))

After we returned to the Marriott, Di spent some time trying to pull my head out of my shoulders, and then we went to the 5:30 visit. Gary seemed to be catching up on much-needed sleep, so we crept back out. My consolation prize for not being able to visit with him was my sister continued the massage. :-) I really don't think she should leave this Friday.

Gary was on the trache collar for 12 hours today! So things are progressing. He told me he'd been learning to cough instead of having the nurses suctioning him – the medical personnel had wanted him to do this. (What he coughs up comes out the hole in his trachea.) He wrote "it ain't easy." But I take these advancements as a sign that his lungs are getting stronger.

I was a little apprehensive about having to tell him that a dear friend, one he'd known since grad school, had passed away last Monday, but I knew he'd want to know. He said he'd prepared himself for the news. (The friend had been in a coma since before Gary's accident.)

Mail call: Thanks to the Telschous, the Crisis Center personnel, Max Burke, the Fremlins, Wilma Rafferty, Suzanne Bryson, and the Mincs, who sent up a CD set of "The Book of Pi."

May 4, 2006

Last night I asked Gary if it felt strange to go for so long without eating. He said "surprisingly, no." I asked him how about not being able to talk, and he said it was frustrating. I asked if that was because he had so many thoughts that couldn't be expressed without going through the laborious procedure of tapping out letters, but he said that wasn't it. It was the inability to communicate even the simplest things to the nurses. Some don't seem to know of the alphabet board (I didn't realize that and have now put it smack dab on the counter where they can't miss it) and others, though they know of the board have difficulty stringing his letters into words – hmm; evidently I do do it better than some of them. He says that they are getting better at interpreting his signals, though, and some can read the board quite well. Seems like there should be some sort of training – another thing to add to my list of recommendations :-)

We finished up the night rather tearfully as Gary dictated a short note to the family of his friend. I know the man meant a great deal to him. I wished I was more able to "get at" Gary to give him a better hug of comfort, but with all the tubes and the width of the bed it isn't possible.

I notice that the young man who had been in the room next to Gary's is no longer there, and I no longer run into his parents in the waiting room hall. I wonder what happened. They have been here as long as I, there son having been in a truck wreck – tossed around the inside of the truck and then thrown out the window. His parents had told me that medically there wasn't anything wrong with their son, except that he wouldn't wake up. That would, at least in the short run, be far more anxiety-producing than what I am going through, I would think. Since the time he's been removed from that room I haven't seen the same nurses Gary had been having before (the two of them always shared the same nurse), and the new ones don't seem to know what happened to the young man, so it feels odd just to have him disappear like that.

I don't talk to a lot of the other families here, except occasionally very briefly. I know some people probably find it a help to talk to the others here in situations similar to theirs, but at least for now, I find it too much to bear.

In the morning Di informed me I had made the right choice about the townhouses; even she heard the traffic – including ambulances – go by. "Princess and the pea" me probably wouldn't have gotten a wink.

This morning (Thursday) I found that they plan to keep Gary on the trache tube for as long as he tolerates it (according to how he is feeling and his blood gases, etc.) rather than replacing it with the ventilator after a certain number of hours. Definite progress! His bed sore also looks much better than even yesterday. During my conversation with the nurse Gary started wiggling the fingers of his right hand as a "signal," and I asked whether there was any word on when that big cast might be removed. The nurse said no word yet, and that she bet there was a certain finger he really would like to move.

After that visit I returned to the hotel to find a package had come for me. The desk clerk said he had one question for me: what was up with the Pierce Brosnan sticker on the front of it? I started laughing and knew immediately who had sent it. Thanks, Kitn, for the People's article on the 2001 Sexiest Man Alive, for the card to me and Gary from you and "the groups," and for the journal, altho I am pretty much letting it all hang out here ;-)

When we returned to the hospital for the early afternoon visit (after getting in another massage :-)) we found that they had given Gary a different bed – an "airflow bed." Evidently air flows through it constantly, which is supposed to help keep the pressure off his wound and also keep the area dryer. It looks really comfy and is a pretty aqua blue color, much more cheery than the usual hospital beds. Gary asked if he could take it home. They told us it cost $80,000 dollars, so we haven't bought it yet ;-)

When we returned to the hotel after that visit, the doors were, as they have been, locked, and the desk clerk was the one who jokes around with me (the same one who had made the comment about the sticker). He could've just buzzed me in, but instead he came running around the desk to stand in front of the doors where we were, and then he started jumping up and down and making faces at me and Di. We cracked up and shook our fists at him.

After a little break, Di hauled me to Wal-Mart where we picked up a few things, most importantly a DVD player. I got the cheapest, lightest one (7" screen), and when I set it on the laptop holder upon returning to Gary's bedside, it looked like it would work really well. We spent the rest of the 5:30 visit trying to figure out how to charge up the battery. I think we figured out how it basically works and will try it out tomorrow.

I managed to nearly mow someone down at the eight-thirty visit. I couldn't figure out why all these people were parked just inside the left door, which was open, so I opened the right one. Unfortunately a woman was standing right there and I hit her with the door. She was definitely not in a forgiving mood when I apologized. Oh, well, something more to feel guilty about.

Gary looked asleep when we arrived. I stood next to the bed for a few minutes and when he didn't open his eyes, we turned to leave. I wrote him a note saying we'd come and gone, but just after Di and I had removed our gowns, she noticed his eyes had popped open. He waved us in, but he was very sleepy. After Di and I carried on most of the conversation, I asked if he wanted me to read Dylan. He said yes, but almost immediately he decided he was too tired to listen. So we cut the visit short.

The nurse told us that tomorrow they might move him to the "other side" – the TB nursing unit, as opposed to the TBICU. I won't hold her to it, but I take this as a positive side that that time is getting close.

May 5, 2006

Gary is still on the trache collar as of this morning, no change out to the ventilator! Yea! The next step, the doc says, is to decrease the amount of oxygen they give him. Gary says this is cruel. The nurse said Gary is actually having to learn how to using his breathing muscles in a new way, so it is no wonder he finds it hard work.

I tested out the DVD player on a Remington Steele DVD last night. It works great, except even I would like the volume to go up a little more. We'll see what Gary thinks when he uses it. I forgot to buy him headphones for it but have the pair I brought for my own use, so will lend them out to him for a while. I brought the player back to his room this morning so he could use it when he gets in the mood. Really, I did.

I woke up this morning about the usual time I've been doing here (4:30, blchh), shaking with cold. Not that anyone else would have thought the room was cold, but that is a tendency of mine. I realized that even though I've been keeping the room temperature up where I like it (and Gary would fry), maybe my temp is still dropping too low during the night, and on some subtle level that might be what is waking me up and preventing me from going back to sleep for a long time. At home, year-around, I use a bed warmer that fits over my entire mattress, and I had brought it here "just in case," though I hadn't thought it seemed necessary since I am the sole controller of the thermostat. I am going to bring it in from the car and test it out tonight. Assuming my car is still there ;-) (I probably shouldn't joke about such things.) I'll bring the comforter in too, even though I use the two supplied by the hotel, as an additional touch of home. Thinking of when the time comes for me to go home, do the Okie Transfers still exist? ;-)

I had the thought that when Gary is turned on his left side, it is harder to read what he is spelling out because his hand covers it up, and so he needed some kind of pointer. My solution was to ask the nurse for a spare suctioning tube – it's light to hold; it works pretty well, though I am not quite satisfied with it – would like something with a more pointed end so there is no mistaking what letter he is pointing at. Probably by the time I figure something out they will remove his cast and he will be able to write.

We had a big mail call this morning. Since my name had come up on the townhouse list, they were evidently rerouting it to over there. What a pain! Hopefully they'll now reroute it back to the ninth floor since I'm off the list, but who knows how long it takes for such things to get down the pipeline. The receptionist at the townhouses said she'd just mark it "return to sender," and I had to hasten to inform her that we were still here (actually, I said, "Ack, don't do that!"), and told her to have them send it up to the ninth floor as addressed. So, we'll see.

Mail call: Thanks to the Harts, Paul Szeptycki, Bob Daverman, Gary Johnson, and Beth Fletcher. Beth sent a card that played "I will survive" when Gary opened it up, which made us smile – how true. Also, cards from Gary's brother Bob, and one from Gary's mom, who included another cute picture of Gary, this time from when he was thirteen, the eager schoolboy. Word of the accident has spread to Poland, and Gary got a joint card from Roman and Elzbieta Pol, Witek Marciszewski, Taras Banakh, Kazik Alster, Josek Chaber, Ryszard Engelking, Henryk Toruncyk, and Piotr Koszmider. The Vaughans sent a card and also a set of tapes of old-time radio programs. (When I left this morning, Gary wanted me to put on "Jack Benny," and when I went back in the early afternoon, he said he'd really enjoyed it.) Gary's sister Norma and her family sent along a big care package, and we had fun unpacking that. Books (I like the title of the one, "Weird History 101") and puzzles (Gary says he hopes the "Thirty-minute crossword puzzles" means they're easy), and a huge stuffed cat from their family cat Jake, who knows we are missing our own kitties. Hopefully the nurses won't make off with that. My sister nearly did ;-). In the letter Norma enclosed, she expounded on the merits of the Texan NFL draft, and Gary said he'd been wondering about her views on it.

After the morning visit, Di took me to a health food store. I had found one in the phone book that I recognized from years before (some hoary memory of a UAB Topology Conference was in the back of my mind), and the address seemed to indicate it shouldn't be too far away. I tried to walk it this morning, but didn't get quite close enough before my time was up to see if it was where I thought it should be. When we returned by car, we found it easily (for a change :-) , and I picked up a few essentials like shampoo – natural shampoo at Wal-Mart means shampoo stuffed full of chemicals and topped off with green apple blossom essence (no doubt synthesized).

The 2:30 visit consisted of going over an insurance form (my favorite activity), and making sure I was correctly deciphering everybody's handwriting on the cards that were sent so I could make our thank yous. I hope I succeeded fairly well at that. I noticed my spell checker doesn’t think the Poles know how to spell their own names and kept changing them on me, so I hope I got them all changed back.

Saturday, May 06, 2006
Mike O'Farrell in his hospital gown. In the ICU we have to wear these and gloves.
I told Mike I hated having my picture taken. He said, "Good." When the picture was about to be taken, I wondered if I should smile. That is what we usually do, but it felt weird to be smiling in such a place.
John Maher foreground, Lex Oversteegen wisely hiding in the background.
The waiting room area to the TBICU (go right) and TB nursing units (g0 left). Gary was moved to the TBICU from the NICU. He'll next be moved to the nursing unit.

Blog at http://drpeg2003.blogspot.com/

May 6, 2006

Today’s stream:

As of yesterday Gary is officially off the ventilator (on the trache collar ’round the clock)! When they wheeled it out of his room yesterday, we gave a cheer. Gary said that everyone had been telling him that being weaned from it would be a big step, and he had been feeling like he was never going to get off it, so I’m sure this is a big relief to him. I’m not sure why, but he also seems to have far less tubing coming from him – at last I can get at him better without fear of pulling something out. The nurse also told me that his sore is looking a lot better.

Gary claimed that the doc told him the cast would be replaced with a lighter one this weekend, but a nurse told me it would be another five days. So I hope Gary’s information is correct.

I haven’t been over there yet this morning. I probably shouldn’t get my hopes up that he’s been moved to the nursing unit already. A nurse told me that in the room he’ll be going into there is a pull-out bed that I could use to stay there 24 hours a day. I don’t think so, not if I’m to keep relatively sane ;-). Of course, being on our 25th year of marriage, Gary knows me well enough to know that to say that would not be a good idea is an understatement :-)

On a similar track, I was not able to give my bed warmer experiment a proper controlled environment. It was frat night here last night, by the sounds of things. I hope they all checked out today, as otherwise we’re going to have a remake of Friday the 13th or some such, with me in the role of Freddy Krieger. I tried stuffing all 50 pairs of earplugs that Jo had sent up into my ears, but it didn’t help ;-). (I also had 2 fans from home going, as white noise, but it couldn’t drown them out. I would think that with my name on this wing of the hotel, I should have some say as to who could occupy it.)

I am hopeful about the bed warmer tho, as I did find it nice to snuggle into in the early morning hours.

At the morning visit, the nurse told us that if all goes well, Gary should be able to talk and to start eating in a couple of weeks!

I just re-read an email from my brother, and I had the thought that I wonder if anyone else outside our family uses the expression “pain in the patutie” (actually, Joe, I always spelled it in my head as “patootie ;-)). We also had the endearment “patootie-bug” (as in, “you little patootie-bug”). I tried looking these spelling variations up at dictionary.com. There is a patootie, meaning sweetheart, possibly derived from potato, and usually prefaced with “sweet.” Anyway, I just wondered if the expression “pain in the patutie” was something my mom made up. She sometimes invents her own words, not always intentionally ;-) I want to make a character in a story do this – malapropisms, etc. – but it is hard to do that kind of thing intentionally. I’ll just have to keep a list of such as they come up and plagiarize them ;-)

I have put up on the blog some of the pictures Mike O’Farrell took when he visited. I know I could figure out the html code to get them on the website too, but I am too lazy right now, so check the blog. They wouldn’t let Mike take pictures of the equipment back in ICU, I think he said.

At the afternoon visit, Gary composed a mother’s day card, and then the nurse came in and said it was TIME FOR GARY TO GO TO THE NURSING UNIT! They had me leave and are settling him in now. Then I will be able to go back and check out his new digs. We are so excited!

So he has a new address. Don’t worry about mail sent. It should make it to the right place eventually. We hope.

His new address (put his name at the top):

TBNU/North Pavillion 9th Floor
UAB Hospital
Room 9324
1802 6th Avenue South
Birmingham, Al 35249

Just got back from seeing him in his new surroundings. His room is more private, a nice soothing blue color, nature picture on the wall, much more homey-feeling. There is a couch in there too. What they really need in there is another bed in which I can stretch out beside him. ;-) It still isn’t visitor friendly (ergonomically speaking), IMHO.

We tried out the DVD player tonight but it doesn’t play loudly enough. I guess I’m going to have to get the more expensive one and hope that solves the problem.

May 7, 2006

Today’s stream:

I hope the bottle of shampoo in the paper bag from Dayspring left anonymously at the hotel for me the other day doesn’t mean that a certain person traveled all the way from Auburn just to bring it (and I thought I had a guilt complex ;-))

I ran smack dab into my limitations last night. Since there is far less restriction on when I can visit Gary now, I stayed longer yesterday than I have been doing but paid the price during the night with intensified leg pain. They are just not set up to accommodate me over there ;-) It’s hard on this body to stand next to Gary’s bed, lean over it with the alphabet board, and talk loud for periods much longer than I’ve already been doing. Gary says he doesn’t have the energy for more than we’ve been doing anyway and of course wants me to take care of myself, but I wish I was up to more. I will, however, be able to lay on the couch and listen to the tapes, etc., with him when he wants to do that.

Even though I got the benefit of my sister’s massages while she was here, I am going for one at noon. I am lucky to have found this person who is willing to massage me in her home on a weekend. . . .

Went for the massage. It is interesting to me how different the techniques are of different therapists, even if they term what they do the same. This therapist didn’t work nearly as deeply as Di, but she wasn’t light either. One thing she did that I haven’t had done in quite a while was some assisted stretches of my back and legs. I thought she went a little too far on the hamstrings, but she claimed she was going by the feel of the stretch. I’m sure I’ll see whether what she did was good for me or not. She is good for my ego, however – she said when she saw me at the hotel the day she dropped off the massage table for my sister to borrow that it didn’t occur to her that I was me because she thought I was some kid, and today during the stretches she said “No way is this body of yours fifty years old.” My body might argue that point, but I like to hear it.

When I returned from the massage I walked toward the sky deck area from the parking deck area, and who should I see but today’s scheduled visitors, Piotr Minc and Jo and Bob Heath, walking toward the elevator. We had set a meeting time of 2:30; they were early and so were just killing time. But with the new visiting hours we could all go right in. Since they had brought earphones for Gary to try, I picked up the DVD player in my hotel room (thus exposing my lack of housekeeping skills to the visitors), and then we went to visit Gary. Gary was happy to see them, even though they brought Topology Proceedings business. (Actually when I went back later in the day he spelled out that it had been a nice visit, and that it had even been nice to do the business :-)) Gary had wondered if there was math dept news or any gossip about the trustees but there seemed to be a dearth of such. So now the new rule is: visitors must always bring juicy information.

In the course of the visit Gary acquired another book of Sudoku puzzles to feed his addiction. The earphones they brought that Gary tried on worked really well, so now he will be able to hear the DVDs – including the "Good Night, and Good Luck" that Piotr brought up. Unfortunately, if Gary is wearing the earphones I won't be able to hear any sound. I am wondering if they make speakers for DVD players – I guess I will call Radio Shack and see if they know; if such aren't made maybe we'll have to get speakers for the laptop, though we would rather not use such a heavy thing as a laptop on the laptop holder placed in Gary's bed – wouldn't want it to fall over on him.

All for tonight, except to note that apparently the expression "pain in the patootie" also made it to New York and Nebraska, besides my mother's native Michigan.

May 8, 2006

I didn't really finish yesterday's thread, so I will start with it. I felt like I was smiling absurdly with delight when Gary was going through the Topology Proceedings stuff with our visitors yesterday. It made me very happy to see him just treating it as business as usual. Our visitors mentioned, as others have, that it is good to see that Gary seems his normal self – same sense of humor, same positive attitude, same spirit. (And I will add "same sweetness.") When afterwards I mentioned to them that I still wondered about what would happen when we got home and Gary came more face to face with how this was going to affect his life, Piotr gave words of reassurance along the lines of, "With his attitude, he's going to be fine." I immediately felt at greater ease – I mean, I think that's the case too, but it's good to hear it from others.

Soon after that visit I went back to my hotel room and sat on the bed and returned a call from my sister while heating up a small frying pan in the bathroom. At one point we hung up so she could look up some information. I never heard my cell phone when she called a few minutes later because I was . . . occupied. I think the fire alarm in my room is entirely too sensitive. Perhaps not coincidentally I was told my room rate is increasing soon. (When I called my sister back and started, "You're not going to believe what happened," she returned, "Oh yes I would." She followed up by saying that I should just call down to the front desk and tell them to be prepared for a fire drill once a week. Who needs little sisters anyway?)

When I returned to see Gary about five-ish, they had just turned him and changed his dressing and he was on the tired side from that and from the visiting, so after a few minutes I left him so he could rest. When I returned at eight I found him in the most talky mood he's been in with me since being here – his pointer was in near-constant motion whereas normally there are lots of long gaps of silence between us (for one thing, it's not like I'm doing a lot of interesting things that I can regale him with tales thereof, and for another, I find it far easier to write than talk; I told him in our first days here I was sorry, but I wasn't a very entertaining person; he said just my being there was enough; I said good, because it wasn't like he had a choice ;-)). One thing he related was the odd thing that had happened to him in the afternoon – his bed deflated on him. He said all of a sudden he felt himself sinking. He kept pushing the call button but no one came (great – nice to know they're on their toes here). By the time the nurse finally showed up the bed was completely flat. She was quite surprised, but got it pumped up again. Maintenance people have come to look at it, but no one knows what happened. Just a few days earlier I had told Gary I received an email from a person in England who was relating her hospital experiences from the time when her daughter was in for major heart surgery. One day her daughter's bed started moving back and forth about three inches in both directions. The bed wasn't electric nor was it attached to anything. The brakes on the wheels were on. When a nurse came to check, the bed moved even faster, and the nurse left the room squealing. Then the bed stopped. It turned out this woman's daughter's cubicle had a legend of being haunted – usually people reported seeing a man dressed in a black suit opening some of the cabinet doors just before he walked through the wall. We're hoping the ghost hasn't crossed the ocean.

Gary mentioned that the staples in his back were supposed to come out Monday (today). We exchanged a skeptical look. I said we should get a bulletin board where we put up the schedule of when the doctors are supposed to do what, according to their own words to us. So let's see – his staples should've been removed today, but we haven't heard anything. His cast was supposed to be replaced maybe a week ago. Etc. Etc. Etc. Gary smiled and said we had to be careful not to make them mad cuz they had all the power. I asked him, by the way, how was communication with the new nurses going, if they spoke loudly enough for him. He said it was going fine – if he couldn't hear them and put his hand by his ear, they got the message. I told him not to be shy of doing that, not to be like me with the Chinese acupuncturist, nodding agreement, not knowing what she was saying. Gary spelled out "We are now going to cut off your head," then gave a big smile, widened his eyes, and nodded eagerly.

Another thing Gary mentioned was that he'll be glad to eat. I asked him what he wanted to eat. He said it didn't matter.

We said some mushy stuff too, but I've probably told you too much of that as it is. ;-)

I still felt loose and relaxed from the massage when I returned back to my room. There was still the calf cramping, though, and I had the thought to put an instant ice pack on it just when I went to bed. The result of all this is that last night I slept the best I've slept since I've been here. I'm hoping that keeps up. In the morning I took a leisurely stroll to the health food store and picked up a small bottle of potassium. The massage therapist had mentioned potassium deficiency as being a possible cause of my leg cramps, saying it didn't feel like it had a muscular cause. I have been aware that that is a typical cause but felt unable to do much about it since I can't eat the foods nor take the supplements to offset it. Since it had been a while since I'd tried a potassium supplement, I thought, what the heck, try it now. I had the tablet with plenty of rice, but my stomach has been upset from it ever since shortly after taking it – I realize now I should have tried taking only part of a tablet. After my stomach settles, I'll try it again but in a small dose.

At the morning visit the nurse explained what was next on the agenda in terms of breathing. They are weaning Gary off the supplemental oxygen now – at one point he was getting an about 45% concentration if I remember correctly. Now it is 38. Then they will go down to 31, then 28, and then he'll go off the extra oxygen (recalling your chemistry, air is 21% oxygen). He'll still be receiving humidified air through the trache collar until the trache hole is closed up. So tied in with this is getting him off the collar. They will be putting in smaller cannulas into the trachea (he's on an eight, which I assume means an eight mm diameter cannula; then they'll go to a six, then a four, then they'll remove it completely and the hole will heal up naturally). The putting in the smaller cannulas is dependent on how he does with the less oxygen concentration. I asked him afterwards if they had let him know when they had decreased the oxygen concentration. He said no, and that psychologically he thought it best they didn't tell him that kind of thing. He spelled out, "We are decreasing your oxygen," then stuck his tongue out like he was being asphyxiated.

After that visit I had an appointment at the chiropractor. I gave myself forty-five minutes to make it. What a difference a week (and some sleep and, in general, less discombobulation) can make. Armed with my Yahoo! map, which made sense this time as opposed to the last time when it was gibberish, I made it with ten minutes to spare. I continue to be impressed with this chiropractor. For any Auburn-Opelikans familiar with the former resident of the area, I rank her up with Steve Garrett.

Oh, and she claimed the computer stuff helped her determine how deeply she should work, etc. <shrug>

After that it was off to Radio Shack – a couple blocks away – to see about speakers for the DVD player. The young guy manning the store didn't seem to know anything about it and sent me over to the Walmart across the street. You know you are in trouble when a Radio Shack person is recommending you talk to someone at Walmart. Actually, the older guy at Walmart did know what I needed, but his section of the store was being reorganized and he didn't know where the speakers were at the moment. He thought using headphones on a splitter might work better, in terms of being able to hear, but was also unable to put his hands on a splitter. So I went back to Radio Shack and got a splitter. Further down in the same mall I saw an Office Max, so went in and asked if they had speakers for a DVD player. The guy who I asked showed me their speaker section and told me I could look through them to see what would work. Gee, thanks. I sat on the floor and looked through several booklets of nonsensical instructions until another worker came by and asked if I needed help. Astute observation. Turned out any of the speakers would do, and I made him show me exactly how everything should be plugged in, having brought the DVD player along so as to make sure I got things right. It turned out to be far simpler than I thought (I never did make heads or tails of the diagrams that were the only instructions provided on the speakers I went for) and I went away with a feeling of success.

I had some food and then went to tell Gary about the day's adventures. His news was that the physical therapist had come by. He still cannot do any therapy until his sore is healed – they're thinking Thurs. Gary and I had, in the morning, looked over some material that my older sister had gotten off the web about spinal rehab hospitals, in which the closest one to home ranked in the top 25 by U.S. News and World Report is in Atlanta (Birmingham didn't make it). Gary had asked the therapist about his options of where to go for the more intensive therapy when it comes time. She said Atlanta was a good place. She also said most everyone from Alabama comes here. She mentioned that another advantage to here was this was where his spine docs were. I pointed out that since we hadn't seen them since that first week, I wasn't sure why that was such an advantage. He tapped out: good point. So, anyway, we are just beginning to think about things like that.

I then went to have a rest. When I returned, Gary was fast asleep, so I wrote him a note and returned to the hotel. When I went back around eight, Gary said the nurses got a big kick out of my note. Maybe it was because I had unthinkingly referred to him as "Pookie" in it. I set up the DVD speakers, and they worked well. He put one on his chest, and I took the other and propped it up on the head of his bed, which I stood behind. We watched about forty minutes of "Walk the Line," and then Gary told me he thought I shouldn't stand anymore and sent me off for the night.

Today's mail call: Thanks for cards go to Debra Talley, Marilyn and Steve Foreman, Bruce Noda, the Auburn Math Dept, Ferenc Fodor of Hungary, and Kenichi Tamano of Japan, who sent along a beautiful card made as only the Japanese can do – he told us that the picture (done in some collage-like technique; I don't know what the proper name for it is) represents the Chinese legend that the carp has the strength to swim up even waterfalls.

And there was another card from Gary's mom, this time with a Christmas picture taken in the early nineties of Gary putting together a race track for his nephew Justin.

May 9, 2006

Another pretty good night's sleep. I'm on a roll now. Called the health food store and they had some organic zukes in, so I moseyed over and cleaned them out of it. As I neared the store, in Little Five Points, I passed a young man with a mohawk, a man in his twenties with dreadlocks who was tending the landscape of some business, a woman in tie-dyes. I like areas like this, except the man walking down the street calling out, "I'm Jewish" had me a little worried(because he was doing so repeatedly and loudly, I mean). I don't usually think of such areas as having a huge Baptist Church on the corner, though. On the walk back, as I made my way through the concrete jungle where all the medical buildings are, I gave wide berth to a man standing on the sidewalk smoking a cigarette. Next to him was a sign that read, "No smoking on the UAB Hospital Campus." I considered making a citizen's arrest ;-)

As I walked through the hospital complex to Gary's I noticed the new Starbuck's has opened up. Medical staff were lined down the hall to get their fix. Upon arriving at Gary's I saw mail had already come. There was his mail sent up from the math dept., and more cards. Thanks to the Heinrichs; Virginia Cook, who sent up an audio book of "I'm a Stranger Here Myself" by travel writer Bill Bryson (and Gary likes contemporary travel writing); and Donne, Phyllis, Carissa, and Justin Leigh, who told Gary again to hurry up and start talking and sent along an audio book, "The Rise of Theodore Roosevelt," and a DVD, "Napoleon Dynamite."

Thanks also to Debra Talley for the card.

When I tried to find Gary's nurse so she could suction him, from the next room came four women in scrubs rolling out a bed with the male patient in it. As they passed by me, they banged the bed into the nurses' station's desk. The man let out a scream, and horror at his suffering flashed through me. The staff pushing the bed didn't look phased nor apologetic; the man continued to moan. If I find out beforehand that they are taking Gary for any procedure, I'm going to accompany him as far as possible. Gary said fortunately he didn't have anything that would feel any pain, but to me that wasn't the point. Sometimes I'm not sure about the staff here. In the ICU they were brushing Gary's teeth every evening after his bath. He told me it had been a while and asked if he could have them brushed. I talked to the nurse, and she told me all I had to do was put the toothpaste on the brush and either I or Gary could brush them. For spitting he rinses his mouth from a cup of water I give him, then uses the same tube he uses to remove secretions from his mouth, like what they do at the dentist's these days. I would think it would be hard not to give into the inclination to swallow any water, but he managed all right. He also told me they had forgotten to bathe him over the weekend – I have gotten the impression before that the weekend staff consists of more newbies. I told Gary he should let me know things like this. He said he hadn't because he hates having them bathe him. I did, however, verify with him that they are changing his dressing on his bed sore twice a day.

I returned in the early afternoon and when the nurse came in to change the dressing on his sore she said it had been a crazy day. She turned him on his side toward me, and I couldn't get the bed rail up, so I stood there blocking the side with my body because I could tell he was afraid of falling out of the bed, even thought the nurse reassured him he wouldn't. She evidently thought I was going to be able to help, but I told her I couldn't help her turn him over any more. She then thought she could mostly do it herself but then had to give up and went out for help. Meanwhile Gary is partway over and I'm hanging onto him using more effort than I should but I didn't have much choice. Help finally came and I moved to the other side. This was the first time I had seen the staples in his back, running down his spine for maybe 8 inches from near the top of his back. They look exactly like staples! I hadn't really thought they would. I could see where the wound had gapped at the bottom, causing the skin not to neatly close. They said they'd debride that later. I wonder if he'll have a scar. I saw the bedsore too. It doesn't look all that bad, and they say it is looking better each day. Soon after he got re-situated I made to leave and asked if he wanted anything. He wanted a blanket. I told the nurse, and she said she'd get one as soon as she finished filling out a chart. Ten minutes later, she was still filling it out, so I asked the person who had come in to give Gary his breathing treatment (they put medicine into his trache tube – it's in gas form, very cold, and smokes a little. When Jo had seen the smoke coming out from around his trache hole during her visit, she pointed it out, wanting to make sure nothing was wrong. Gary had spelled out, "I'm cooking now."). The breathing treatment person returned with something, and it wasn't until she'd left that I realized it was a bottom sheet. I went out and told the nurse, who told someone else to get a blanket. This person came with a top sheet. I lifted the blanket already on Gary to illustrate what a blanket looked like. Finally we got our blanket, twenty minutes after it was requested. I left, the nurse still filling out her chart. I know those charts are important, but it seems to me she could have spared the minute to get Gary a blanket. Had I thought it was allowed, I would've gotten it myself. I'm afraid to bitch about it, because he seems to have the same nurse during the day, and I don't want to make the situation worse.

The rest of today will be continued tomorrow ;-) The only medical news to report is he was on 28% oxygen all of today.

May 10, 2006

Mail call: Thanks to the Schlagels and to the Toronto Set Theory Seminar.

I know I am way behind in responding to emails. Let me assure everyone that the next visit after getting your email, I tell Gary you wrote. He always says "Be sure to thank them for the nice email and for the nice offers they make."

Oh, about the bathing. I thought that might need further explanation. Gary hates it because it's tiring. They do it at weird hours – like 4 am – and it's a rigamarole. They have to remove the boots he wears to prevent foot drop and his electronically pressured socks, which help return the blood from his legs to his trunk. Then at some point comes the rolling over, requiring two nurses, and the changing of the dressing on his bedsore, and at the finish the socks and boots have to be put on again.

Last evening I went to a class offered by the chiropractor here. I wasn't sure it'd be worth it. When I had asked her at my appointment what it would cover when she brought it up, she was rather vague but mentioned that she would talk about posture and other things that would help or hinder the adjustments I was getting. It turned out not to be too useful. The only thing I learned was that in standing so much I should shift my weight completely off one leg and onto the other every short while (like every ten seconds). This was not worth sitting in rush hour traffic, particularly given that sitting aggravates my symptoms more than anything (it took forty-five minutes to go the fifteen minute distance), nor having to drive back in pouring rain – at one point a car went by and threw up a sheet of water so thick I couldn't make out anything, which scared me half to death as I couldn't see the car ahead of me. The class was very basic, talking about how we need to deal with the various stresses in our lives – physical, emotional, chemical – by getting exercise and keeping our posture correct, by not overindulging in alcohol or smoking and by eating properly, and by keeping a positive attitude. Hardly news to me. And when someone starts enthusiastically lecturing about how we can keep improving our health just by making these changes, I feel like standing up and saying, "honey, I know firsthand a person can be very conscientious about all those things for many years and then get hit with something that takes a lot of those things out of their control." But I didn't because that probably wouldn't have been in keeping with the spirit of the evening. ;-)

So I'm afraid her words of inspiration fell flat with me. I did take note there was a beautiful sky when I got out of my car – pinks and purples on the horizon – so I suppose I should find some symbology in that ;-) . Back in the hospital Gary told me the BC/BS social worker had come and said it looked like there would be a time when he wouldn't need be in the hospital but also wouldn't be ready for therapy, so he'd have to go home and then come back again. This certainly wasn't good news to me. She said she'd come by in the morning to talk to us again. We finished the night by watching more of "Walking the Line" until the salt in Gary's tears got to bothering his eyes too much ;-)

In the morning I was surprised to come into his room and see him sitting up in a chair while the physical therapist exercised his legs. He was still somewhat inclined – maybe about 75 degrees. He looked really grim and didn't really respond when the therapist directed conversation to him – not even with one of his smiles to either her or me, so I knew he wasn't feeling that great. When the therapist left for a moment to bring in a hoist like we would probably have to use at home at first, he spelled out that he felt weird but knew it was to be expected after lying flat for a week. The therapist showed us the hoist, saying to me, well, first you'll help him roll over, and after he is lifted up by the hoist, you'll swing the hoist around to his chair, and I'm thinking, I'm not sure about helping him roll and I wouldn't dare swing that hoist even without him in it. So I guess we'll be hiring some help, at least at first. The goal is for him to get strong enough that he can eventually scootch himself over in the bed to a board so that he will get to the chair himself. But for now his exercise is to sit in that chair for thirty minutes twice a day. Also, when he is in the bed now, he is supposed to practice rolling himself over as best he can, though he is hampered by the hand in the cast. We may need to get a nurse to help with this, as I am supposed to lift and bend his knee up for him to get him in position, and I'm not sure I can even do that. The wound care person came and changed his dressing. She measured the wound and said it is about half the size of last week. The breathing person came in and gave him his treatment. The social worker came and said that one of the doctors thought Gary might be able to put weight on his right hand in two weeks, so that he could just be moved to Spain (the rehab center, not the country) without having to go home first. The social worker said she needed to talk more to the doctor about this, as otherwise we would have to explore our other options. She is supposed to return this afternoon with the news. I sure hope it works out that he can stay.

Everyone that came in commented that Gary needed a shave, his morning nurse being the final entrant, saying that she was going to shave him this morning. To them all, Gary kept shaking his head and pointing at me. The nurse told him that's what he'd been saying for days. I protested that I had been wanting to shave him, telling him he looked like a bum and that everyone was going to think I was neglectful, but that he wouldn't let me, saying the scruffy look was in.

When they'd all left I wielded the shaver at him and asked if I could shave him now. He spelled out, "Oh, all right" and made a face. Afterwards, he was feeling tired out from all the activity and so wanted to rest. It took me ten minutes to track down someone to suction him, as his nurse had disappeared, and then I left.

When I returned Gary had been put on a six (the units are “dci,” so I don’t know what that is). He said it was work, as it was harder to breathe and for some reason it made him cough more. I could see it really was demanding of him; he wasn’t up to watching any more of the DVD as we had planned, or even to being read to, as he said he wouldn’t be able to enjoy it. So I just stood there and stroked him. The social worker came in and told us she had no definite news, but that one of two things would happen. Either she would get word that the docs thought it likely Gary would soon be able to bear weight on his right hand, in which case tomorrow he would be moved to Spain Rehab Center. If they don’t think he is ready, then we will have to look into some live-in nursing facility – she didn’t recommend I try to take over his care at this point, and she got no argument from me – no way could I do it at this stage. But I then told her we had heard about the Shepherd center in Atlanta and were considering going there. She has given me the deadline of tomorrow morning to let her know of our decision of where to go for rehab, Spain or Shepherd. Gee, it’s nice they gave us such advance warning. I would be in a tizzy if not for the fact that we had some information about Shepherd already – thanks to Debra Talley for first putting the bug in my ear about the place, to my sister Janet for running off related info from the web, and Krystina Kuperberg for sending an email about some recent mentions of Shepherd. I’m pretty sure we’ll say we’re interested in Shepherd, and then the social worker will get that ball rolling. My understanding is that Shepherd will send someone out here to evaluate Gary to see if he is suitable for their program, and when. So it’s still not clear if we’ll need to find temporary nursing, or will be going directly into a rehab program. I’m afraid the thought that we will soon be moving to a new phase has worn me out today. And Gary is worn out from the breathing adjustment. Soon after the social worker left, he said he wanted to rest, so I left him and looked up some stuff about Shepherd on the web. I notice I’ll get to see him much less when he starts rehab, as the visiting hours are just 4pm to 9pm. I’ll also have to get used to staying at a new place, and the places Shepherd lists looks like they’re at least 2 miles away. They have some condos available, but looks like a waiting list thing as it was here with the UAB Towers. So I must say Birmingham has spoiled me by having the convenient accommodations.

Poor Gary. He’s so miserable today. When I went back at five, there hadn’t been much improvement in his ability to breathe. He said the new tube tickles and makes him want to cough all the time. He doesn’t feel like doing anything. I talked a short time about Shepherd and stroked him, but then he said maybe he should rest, so that was my cue to leave. I hate seeing him like this.

May 11, 2006

When I went back for yesterday night's visit, Gary was breathing easier – and therefore, so did I. In fact, he said he hadn’t coughed at all in two hours, whereas ever since his breathing has been supported he has coughed regularly. It seems he has more trouble breathing when they put him on his left side – the conjecture is that that is because it makes the right lung work harder, and that is the more damaged one. We watched more of “Walk the Line” until his nurse, somebody he hadn’t had before, came in. “Bull in a china shop” came almost immediately to mind. After suctioning him – which he hadn’t sounded like he needed – she decides to look at his cannula and yanks it out of his trache hole, causing a look of surprise tinged with alarm to register on Gary's face. Then she shoves it back in, fooling around with the collar, and Gary immediately starts coughing again. He obviously starts struggling for breath, and at one point it looks like he can't breathe at all. "He's having trouble," I all but shriek. Fortunately the next moment he starts being able to get air exchange. She asks if he's been having trouble breathing. He spells out "I was fine until you removed the cannula." She explains it's something they have to do once a day, that this is normal. Yeah, right. Get someone else to remove it then, someone with a more gently touch. Then she decides to turn him, and again it appears to me he is being roughly handled. "Oops, sorry about that," she says as lets go of him too soon. I'm standing there deciding between having a heart attack or throwing her out of the room. "Be careful," I want to yell. Of even better, "Just leave him alone." When she finally gets him situated he does sound like he needs suctioning. I'm wishing I could do it as I don't want her near him. She pokes that tubing down his trache hole but can't give him any relief, and I want to yell, "Get someone who knows what they're doing." She apparently reads my thoughts and finally takes off to find the charge nurse. I stand next to the bed trying to give Gary an encouraging smile – or at least not let my anxiety show. The charge nurse, an older woman, determines that Gary has slid too low in the bed and it's causing the angle of his neck to obstruct the suctioning tube. She gets him taken care of in short order. The two nurses leave and I stay next to Gary stroking him and trying to appear nonchalant as I hover over him, not wanting to leave him to this nurse straight out of Stephen King's "Misery," wondering how long before she bathes him and if I dare stay that long to keep my eye on her. Gary reads my thoughts, spelling out, "The old nurse seems to know what she is doing. I'm okay now." I'm dubious, but leave after a few minutes more.

I found it hard to settle down for a long while after that, but once I fell asleep I again slept pretty good, comparative to my first three weeks here.

Before seeing him this morning I searched on the web for anything that might allow me to compare Spain and Shepherd more closely. I didn't find anything, but maybe I'm not looking in the right places. When I went over to see Gary, I ran into the BC/BS case worker. She said she'd just spoken with Gary. They still hadn't gotten the information from the docs about whether Gary can bear weight on his hand. Blue Cross will pay for only 21 days of rehab, so we don't want to send him to either place until he can get the most use out of it. Gary and I talked some more about it, and we're still leaning toward Shepherd. A little later, while Gary was reading the sports section, a trauma doc came in. He said Gary could bear weight on his right elbow for any rehab purposes. He also said he was sending in a speech therapist this morning to see if Gary could be fitted for a speaking valve, which might also enable him to start eating, and that he would probably be downsized to a four tomorrow – or they may even remove the tube completely. I told him Gary had said his breathing had suddenly improved yesterday evening after being difficult for so long after the new tube had been put in. The doc said that Gary's trachea was hypersensitive, so the jostling around that they had done in downsizing the tube had probably irritated his trachea and caused him to produce more secretions – but that it would be good to downsize him again, anyway, to which of course we agree. I also mentioned about the cast. Naturally, it wasn't his area, but he said he'd mention it to the orthopedic docs to see if Gary could be reevaluated to see if he could have a lighter cast. Finally I told him what BC had told us, and that we would like some input from the doctors as to when the optimal time would be for Gary to have rehab, as it was our understanding that it is good to do it as soon as possible on the one hand, but we have the fact that he can't yet bear weight on . . . er, the other hand. The concept of determining an optimal time for someone to have rehab seemed a new one to the doc, but it obviously piqued his interest, and he said he would bring it up to the other docs. I hope he carries through.

After the doc had left, I brought up the previous night, asking Gary how he'd gotten along with the new nurse, saying I'd been a little afraid to leave him alone with her. He spelled out, "I doubt any of the nurses would kill me." I wasn't so sure that that particular one wouldn't have managed to do so and probably conveyed that it in my look. He spelled out, "You are a mother hen. It's sweet." I'm glad he thinks so – my little sister probably would've tied me down.

Next, the speech therapist came in to do a few simple tests. First had him breathe in, then she closed his trache hole with a finger while he said, "Gary." It was very soft, and he sounded a little like Donald Duck. Next she had him try "Gruenhage," and that sounded more like his own voice but with little volume. Next she did some swallowing tests – he took little sips of water colored with green food dye. After doing that a short time, she suctioned him. No green came up, so that was an indication he hadn't aspirated any of the water into his lungs, but it is too simple a test to determine that decisively. Later today she is returning to put a camera down his nose (!) and watch while he eats a few things, to make sure things go in the right place. She said not to worry if he wasn't successful at the talking with the trache cap or the eating right away, but that the results of her simple tests were encouraging. After she left I asked him how he thought he'd sounded, and he said "airy."

The speech therapist also was interested in the laptop desk, and I told her I'd gotten it off the web at lapgenie.com. Maybe B'ham will soon be incorporating this piece of equipment for their patients. In which case, maybe I should ask lapgenie for a commission ;-)

We then read the mail, after which Gary wanted to rest. I set up one of the tapes of "Car Talk," which had just arrived from the Vaughans, and left.

Mail call: Thanks to Gary's mom, Raushan Bouziakova, Jan van Mill, Paul Larson, Jed Keesling, the Auburn Math Dept., and the Vaughans.

Someone asked me how it is that Gary can breathe on his own, given the severity of his injury. It is because of where the injury took place – T4, nipple height. Had the spine been as severely injured at the cervical levels C1 or C2 a ventilator would be a necessity for breathing. See www.sci-info-pages.com/function.html for other details.

During my afternoon visit the speech therapist returned. First she stuck the speech valve over Gary's trachea hole and had him say his name. This time I couldn't really hear him, though after a few tries some sound did come out. He didn't really like the experience, later telling me he felt like he had for so long yesterday when it was so hard to breathe. The therapist asked if the valve made him feel anxious, and he nodded. She had him keep it on for a minute while just breathing, all the while assuring him that his oxygen saturation level (which has been kept track of constantly since he's been at UAB, showing up on a little screen behind him) had stayed above 96 the whole time – they want it above 92. I volunteered to aid her in the rest of her tests instead of getting a nurse to do it. She stuck the camera down his nose (on the end of a filament of wire), and while she held it in place, I gave Gary green-dyed things to eat while we watched his windpipe on the view screen. We started out with ice chips. What the therapist was looking for was to make sure no green was seen going down the trachea (which would indicate the food was going the wrong place). Next we did applesauce (which Gary later pronounced "good"). Next some thickened juice, then water, then little chunks of peaches (I took her word for what those little green chunks were). No problems whatsoever (except for me dribbling green dye all over Gary's chest), so she said he could start getting back on a normal diet, starting with a full liquid one. That got a big green smile out of Gary (we brushed his teeth afterwards). This is the first thing that has happened ahead of what we were told – we thought he wouldn't be able to start eating for another two weeks.

One thing the camera did show was that Gary has a lesion on his vocal cords. The therapist said that may have happened when he was first intubated (when he was on the ventilator) at his first surgery. The hope is that that will naturally heal up.

Soon after that the orthopedic doc came in and took out the stitches in Gary's bionic finger, the finger still looking rather swollen. Gary had only a brief respite from the plaster cast since the doc put it right back on. He said it would stay on the full six weeks, then x-rays would be taken to see what should be done next. It seemed to be news to him that we were ever told Gary could have a lighter cast put on earlier than when those six weeks are up.

As the doc was removing the stitches, someone brought in Gary's first meal: cranberry juice, another juice I'm guessing was grape, fluorescent yellow jello, and a cream soup we thought was probably potato. I set up the tray on Gary's lap, and he fed himself a little bit of the soup and of the probably grape juice. Then I left him to rest.

May 12, 2006

Mail call: Thanks to Mom G, the Auburn Math Dept, Piotr Minc, and Ronnie and Pam Levy. The Levys sent up some books: The Mayor of MacDougall Street by Dave Van Ronk, whose name we recognize from the Dylan book (which we just finished); Patrick O'Brian, Master and Commander (we saw and enjoyed the movie); and Calvin Trillin's Obliviously On He Sails, the Bush Administration in Rhyme – even the title had us laughing.

Gary had a little more to eat when I returned last night. He liked everything but had trouble with the jello (evidently there's not always room for it). We think that is probably because he wasn't sitting upright enough and he choked on it a little. He said what he really wanted was a chocolate milkshake, so I later told the nurse this to see if they could put in a request for it, which they said they could. Gary practiced with the speaking valve for only a few seconds – saying, “this is work,” so we decided not to push it. The nurses then came in and sat him up for a while in a special chair. He always feels uncomfortable with it at the beginning, but then seems to adjust. While he sat, I read some of the Jimmy Carter book to him. After they put him back in the bed, we watched some more of “Walk the Line.”

In the morning, some of his first (spelled out) words to me were, with a smile, “Where’s my milkshake?” I said I didn’t know when he would be getting that. He said the nurse told him I could go out and get one for him. We double checked and they said that would be fine. I asked him if he wanted it badly enough for me to go and get it now (there’s a place about a block away that would have them), but he said he could wait until I returned from the chiropractor. The speech therapist came in and gave Gary a different speech valve to try. Theoretically this one was supposed to offer more resistance and so be harder to use, but Gary found it easier. His voice is still very weak, and the therapist thinks this is due to the ulcers on his vocal cords, causing the cords to vibrate irregularly. I asked if the purpose of the speech valve was to exercise his lungs; she said it was partly that, but primarily for communication, and also that the valve normalized the pressure in his airways and so would he would be able to cough and swallow more easily. Gary likes this therapist a lot – she explains things and is upbeat and friendly and intelligent.

After seeing the chiropractor I went and did some shopping for him – I told him this is a sign of my true love because I absolutely hate shopping, and most particularly in real space as opposed to cyberspace. From the Shepherd website I had gotten a list of clothing he would need there. Since I’m not sure I’ll be making a trip to Auburn first to pick up any of his own clothing, he needed the basics as well – underwear and socks. Sweat pants were on the list but no one carried them. A Walmart person suggested something called sleep pants that were of a weight between pajamas and sweat pants and which she claimed men wore on the street. They did seem suitable, so I bought a pair. When I showed them to Gary he liked them, so I will have to get some more. I got him a button-down shirt and a crew shirt, but when the physical therapist here saw them she said I should get him some T-shirts (and by the way, she said Shepherd was the place to go – the only one from here to admit that). Oh, well, now he has two new shirts for other purposes – at least he liked the looks of them. I also picked him up swim trunks, picking out the most sedate design I could find – I have learned over the years that he will not wear the flashier things I buy for him ;-). He liked them, as he did the other things I’d bought, so I was quite pleased with myself. The last thing on the list was athletic shoes in a size bigger than he normally wears, but I decided to hold off until we’re at a place where I can easily return them in case they don’t fit. I finished off the shopping excursion by buying him a triple-thick chocolate shake, the biggest one they had – which was definitely over-optimistic on my part, though he did savor what he could drink of it.

When I returned, I found that they had already downsized Gary to a four. Hooray! He said that, knock on wood, he was finding the breathing to be easier. He also seems to be able to talk better with it when we put the speaking valve over it. Talking is still work, so we only did it for a few minutes. In order to make out his words I have to practically put my ear on his mouth. But at least it now pretty much sounds like him (with a bit of Darth Vader in there, which he said would be good for teaching).

Well, I’m stopping mid-stream tonight.

May 13, 2006

After the physical therapist exercised Gary’s legs yesterday, she gave him a stretching program for his shoulders, so now he is supposed to do things like shrugs and arm circles and punches three times a day for three-four minutes. She also noticed his skin was drying out around his knees, and I told the nurse. She put in an order for skin cream. I imagine that, like the donut pillow for his head and the waffle pillow for his tushie, it will arrive a few months after we’ve left ;-). (I tried to find such pillows at Walmart yesterday, but they didn’t have them. I will pick up some skin cream at the health food store, having misplaced the cream Alex sent.) In a similar vein, we think the neuro people forgot about the staples in Gary’s back, because every medical staff person I’ve mentioned it to (and I mention it to everyone I see) says they should have been removed by now. It’s a question of getting that message to the right docs – the people I speak with all claim to be passing on my message. I’m thinking they might remove the staples this weekend, as Monday Gary is being seen by the Shepherd people, and I wouldn’t think the people here would want to be embarrassed to having it known that the staples have been in a week longer than they should have been. But who knows.

I thought it might have been my imagination that the nursing care is more lax in this unit, but yesterday I was stopped in the hall by a woman who has been here about as long as me and whose fiancee has been on about the same schedule as Gary in terms of the being on a ventilator in ICU and being moved to this step-down unit, etc. (her fiancee was in a helicopter crash and was badly burned), and she asked me if I was satisfied with the nursing. Her evaluation was that they took far longer to respond to calls, didn’t seem as helpful and friendly, and many didn’t seem nearly as skilled as those on the other side. I told her I agreed. She said she is not usually a complainer but had complained to the doctors about this when they were doing their rounds, and they said no one else had ever complained. So I am thinking of adding my voice to hers, though I will have to screw up some courage. She has been keeping a log of how long it takes the nurses to respond to their calls, saying that, for example, one time it took them forty minutes before coming to check on her fiancee. I forgot to tell her that it would never take that long with Gary, because if the nurse doesn’t come in about five minutes, I go out and corral someone else. (They will probably be glad when I am gone ;-)) This woman stays in her fiancee’s room all night long (one person is allowed to stay overnight with the patient on this side) because her fiancee is actually afraid to be left alone – he fears something might happen with the breathing tube or whatever and the nurses won’t respond in time. Naturally this shot my anxiety level up. When I got in Gary’s room I said the nursing on this side didn’t seem to be as good as where we’d been and I had been wondering if I should try to stay during the night. He spelled out “then you will crash and that would be a disaster for both of us.” I didn’t exactly voice my thought that if something happened to him, that also would be a disaster but said I worried about things like maybe this smaller tube clogging and the nurses not answering the call button, like they hadn't when his bed had deflated. He told me I worried too much (ya think?) and that even if it got clogged completely he could still breathe through his mouth and nose, that it would be hard, but he could do it. I was mostly looking for this kind of reassurance, as I know I couldn't really tolerate being in there overnight with the activity that goes on – baths at weird hours (like 4am), vital signs check, breathing treatments, turning from one side to the other, all done every two hours (and not done simultaneously).

When I came into his room this morning, he made a face, saying they'd fed him grits for breakfast. He asked if I'd brought him a banana as I had offered to do yesterday. I reminded him I hadn't cleared that with the morning nurse – there is a sign at the entrance which says no fresh fruit or flowers should be brought into the unit. So I went and asked her. She said he could have a banana if I mashed it up for him. She put in a request for it and asked if he wanted anything else in particular. He said applesauce and juice. She said to be sure to remove the banana from the room the same day if not eaten – they don't want gnats, etc., to be attracted to things in this unit as the critters would get in the burn patients' wounds. Definitely not a good thing. Just to make sure he got his banana I put it on my list of things to get (along with paper cups, straws, and plastic spoons as they are very stingy with such objects here, and some canned peaches as he also requested). I had asked him yesterday if he wanted me to get veggies and make him some homemade soup in my crockpot or to juice some apples in the juicer the chiropractor loaned me as soon as she heard Gary was eating a little. But he said to wait on that until later. He may soon change his mind as last night's dinner menu was essentially identical to the previous night's: cream of potato soup, jello, juice, tea.

Before lunch I left and walked to the store to pick up the things then returned to his room about noon. His lunch was delivered shortly after that: cream of vegetable soup, jello, juice, tea, vanilla pudding. So much for his requests. His appetite is good and he says the stuff is tasty, but I suspect the tastiness comes from additives and not herbs and spices and so reminded him I could make stuff for him. He put me off, maybe trying to save me from the extra work, which, to tell the truth, is why I am not insistent. Right now I'm using all my energy to be there with him – he has much more energy now than he did in ICU, no doubt helped by the fact that he is sleeping better (even with all the nursing disturbance that goes on now, it is much less than when he was in ICU), so I've been over there on my feet with him longer, especially the last couple days. We "talk" some, I read from Carter to him, we watch some DVD (we just finished Walk the Line this afternoon), or I just stand there in silence stroking him. I may have overdone being with him this afternoon, though, as I was feeling tired and a bit antsy. On the other hand I keep thinking of how I would feel if I was in his situation . . .

He sat up in his special chair for an hour and a half this morning, twice as long as he's gone before. I worry a little about his sitting up that long and how it affects his bed sore – the staff claim it's looking better, but to me it and the area surrounding it looks awful (raw) – but the nurse said his sitting that long was good for him. She'd better be right.

He can now also tolerate wearing the speech valve for a much longer time but only for breathing, not speaking. That still feels like quite a strain to him, so he only speaks a small amount.

In the evening I fed him some supper (ice cream seemed to be the biggest hit; he also had cream of chicken, jello, juice, and I mashed him some banana). We listened to “My Word,” and talked a bit. He said maybe the blog, which he hasn’t seen yet (I told him I wasn’t going to give him the URL), would be turned into a movie starring Tom Cruise and Reese Witherspoon. I told him I’d seen a headline in U.S. Today that Cruise was losing his popularity with women so we would have to get someone else to play him. He suggested Pierce Brosnan. I then said Salma Hayek should play me because we look so much alike (for those not in the know, the two of them co-starred in “After the Sunset”).

May 14, 2006

I have already received an outline for a movie script. To make sure the movie is a commercial success, however, the plot has been . . . tweaked. A key figure in the story is a graduate student obsessed with Gary, whom Gary has been rebuffing (typical, a graduate student falling in love with her professor ;-)). I, on the other hand, am racked by guilt because I have been carrying on an affair during those times I said I was at writing group meetings, but now I realize how much I truly love Gary. And at the hospital, what I put down as actions due to the incompetence of the nurses are really attempts by the graduate student to take her revenge on Gary. The climax comes when I figure out that that is what is going on and rush to the hospital just in time to save Gary from the student. I am injured during my scuffle with the student, however, so I end up in a bed next to Gary, where we renew our vows to each other. Think this plot has possibilities? (This is a quick overview – the author actually fleshed out over a page of synopsis. Note to the author – Gary was laughing away as I read to him what you wrote, as I had done when I read it beforehand. Gary says to tell you you have a very good imagination. . . . Does this mean you now believe he exists and is not merely the figment of my imagination you have been claiming he is?)

Gary sat for two and a half hours straight this morning, so is making a little progress every day. His voice is a bit stronger, though he can’t use it much yet (he did inform me with it that the hospital coffee is terrible, so I will get him some from Starbucks tomorrow). In an emotional conversation, he talked to his mom on the phone this afternoon, and he talked the longest yet. He hadn’t been sure he could talk loud enough for her to hear, but there was no problem. I got a little worried he might strain his voice because he was talking much more than he had (although it really wasn’t much), but it seemed to be fine – though he did say he got pooped out at the end.

As I suspected, they did remove his staples today. I was happy to see that even the bottom part of the incision, which had previously appeared to gap, has healed up nicely.

We did our usual stuff – talked, listened to Car Talk and Jack Benny, etc. In the mid-afternoon I had another massage, this time with a different person as the one I had seen before had gone to see her mother. I paid extra for the therapist to come to the hotel and give the massage, but it was worth it. (Note to my family. When I made the appointment with her I was standing in the room with Gary. She asked how he was doing and I told her about the sitting up and eating. When I got off the phone, Gary asked if I'd seen her before. I said no. He spelled out, "You gave her details." I told him she had been the first massage therapist I had talked to here, and she knew the reason why I was in Birmingham and had recommended the other therapist. He spelled out, "Oh. So you are not like your dad." I protested some and he smiled and spelled out, "I knew that would get a rise from you," my dad having been infamous for telling all and sundry about all and sundry.

Oh, God. I just realized that with this blog I have now become my dad.)

When I went back for the evening visit Gary told me the nurse had said his bed sore was a little aggravated after his sitting this morning and that he shouldn't sit at all tonight. :-(It seems like that thing is never going to heal.

I wrote out a list of the things that we wanted to bring up to the people from Shepherd tomorrow, and then I took out my phone, intending to call my mom while with Gary so he could talk to her a bit. Right then my older sister called me. She started out by saying she liked to read the blog. I said "Really?" I told her I felt uncertain about writing it, saying people probably thought I was strange. She replied, "You are strange. But I like reading it anyway." Hmmm. We talked a bit and then she asked me to put the phone to Gary's ear. I hadn't yet had the chance to tell her he could talk a little, so I let it be a surprise. Gary said hello and they had a short conversation. When I got the phone back, she said she'd nearly fallen off her chair, not expecting to hear his voice. She wondered how it felt to him to finally be able to talk. I asked him afterwards, and he said that since it had been such a gradual thing – first being able to mouth words, then whisper -- that there hadn't been a well-defined moment when he could say "now I'm talking again."

I next called my mom and told her someone wanted to say something to her. Gary wished her a happy mother's day. His next words were "that's what my mom said," in response to something she said to him. I found out later that both our moms said hearing his voice was the nicest mother's day gift they could have.

It *is* lovely to hear his voice again.

May 15, 2006

A busy day. First Gary got the trache tube completely removed. "Finally!" he exclaimed hoarsely but with feeling, pumping a fist in victory. He mentioned several times during the day how glad it was gone, one less discomfort to bear. To help project his voice, he now holds a finger over his trache hole (which has a gauze bandage over it). He still can't speak for long and has to take big pauses, but things are moving in the right direction. He is still getting extra oxygen but now through tubing that extends just into the tips of his nostrils.

For some strange reason they forgot to bring him breakfast; when I told his nurse and at the same time asked when he would get more solid food, she came back with the information that he could start on solids at lunch today. Breakfast was similar to what he'd had before – grits, juice, yogurt, tea. I got him a "bold tall" at Starbucks; he smacked his lips at the taste but couldn't drink much of it. For lunch he had a "regular" meal, southern barbecue style I'd call it – barbecued pork, barbecued bread (which he skipped), baked beans, corn, potato salad, peach cobbler. He very much enjoyed his meal.

An occupational therapist came by and replaced his big ol' cast with a very light splint. He can now move all his fingers except for the broken one, though the other fingers of his hand are stiff – from not having moved for so long, we guess.

The person from the Shepherd Center came at midday. We liked her a lot. She explained some about the program, how it would be intensive and get him ready for daily living and for his return to his job – Gary told her his number one goal is to be teaching his classes on the first day of the fall semester.

They will also give us information about modifying our house, though that won't come until toward the end of the rehab period when it becomes more clear what Gary can and cannot do.

The major sticking points right now to starting rehab are the restrictions due to his inability to put weight on the right hand and due to the bedsore – he cannot, for example, learn transitioning from bed to chair, etc., because he can't be sliding along surfaces on his bootie. In fact he can't even learn how to balance himself in an upright sitting position because he can't put any pressure on the sore. BC/BS wants to send him to a sub-acute facility – which would probably be along the lines of a nursing home – until he is ready for rehab. The problem is, such places are not going to doing anything in terms of advancing his rehab. The ideal would be for him to go into Shepherd's acute medical level of care, where rehab as tolerated would be incorporated, but BC/BS has not seen it this way (a similar proposal was put forth by Spain Rehab here in B'ham, but BC/BS didn't go for it). The Shepherd person is going to recommend the acute medical level of care and push for it for us, but has told us it would also be a good idea to call Auburn University and try to get them to go to bat for Gary on this point. So tomorrow we are going to call Human Resources at the University (she thought that might be where to start), to see if they will advocate for Gary with BC/BS in order to send him to Shepherd's acute medical level of care and not a subacute skilled nursing facility. We are hoping Gary's 32 years of service at AU and his desire to return to his job ASAP will hold some sway with AU's willingness to be his advocate, even if it's not in the University's BC/BS policy.

The Shepherd person said if BC/BS can be so persuaded, Gary could be moved to Shepherd as soon as Thursday. If not, we'll end up at some subacute place until he can go to Shepherd.

I took a bunch of notes at our meeting with the Shepherd person, and as I get time I will relate more of it.

CAN ANYONE HELP?

I was just informed Gary is being transported to Shepherd tomorrow morning, leaving aroung 11 central time, supposedly. Yea! But I have a little problem, namely getting me there. Given my back, etc., I would prefer not to drive myself. The people who caravaned me to Birmingham are not available to do the same for me tomorrow. I am wondering if there are two people who live reasonably close to each other who would be willing to do this. These two would have to come in the same car, help me get my stuff in my car (not trivial :-)), and then one would have to drive me to Shepherd while the other one tagged along in the other car (so that after getting me situated in my new place in Atlanta -- Shepherd Center has a condo available for me -- these two could drive back to their own homes in the one car).

Anyone willing and able to do such a long day on such a short notice? If not, I'll manage.

If you are so willing, please email me (drpeg2005@yahoo.com) and leave your phone number so I can coordinate you with the other person, assuming I get two takers. I do not do mornings easily, so am thinking I wouldn't be leaving before Gary is, and it certainly could be later. In no case do I plan to follow the ambulance, because I need to stop every 20-30 minutes to stretch out my legs/back.

Thanks,
Peg

P.S. This is a mass email/blog announcement, sent to everyone like the other emails have been. I certainly do not expect people from Bulgaria and France to fly over here and help me ;-)

May 18, 2006

Cut off. Alone. I have no internet connection in my apartment! I'm like an addict without ready access to her fix. I haven't decided yet whether to just make do with using the Shepherd hospital access during library hours, or to spring for Earthlink, or to look into prepaid internet access (anyone done that before and have any advice?).

Anyway, to start bringing you to the present. BCBS came through (with the help of Shepherd's admission liason Sheryl Hope, who evidently knew how to get to the right people), and Gary was admitted into Shepherd's acute medical care. When he is ready, he will enter their intensive rehab. Unfortunately his bedsore is quite serious – there is an area that is necrotic (dead) and they don't know how deep it is yet (he will be examined). It may be that he will have to have surgery to help fix it. If that is the case, that is, the sore is that serious, the guesstimate is that he will need five weeks for the sore to heal after the surgery. And they are projecting that he will need six weeks of rehab. So we are looking to be here from six to eleven weeks. I will let you know when that guesstimate gets refined.

Gary's doctor is himself a paraplegic, having been that way since he was about twenty (the nurses said he is in his late thirties). I didn't meet him, but he told Gary that it may be over-optimistic to expect to be able to teach at the start of fall semester. The doctor said that it took him five months before he was able to physically handle returning to school. When Gary told me this, I reminded him that he could still work with his grad students. I later had some additional thoughts on the subject (I wasn't thinking all that clearly last night, being worn-out from my drive) and I shared them with him this morning. I told him that if he couldn't teach by then, then he couldn't teach by then, but first of all, being a teacher was different then being a student – he wouldn't be running all around campus but would be fairly fixed – and that secondly, I had already been told by either Michel or Jack Brown (sorry, I forget who it was at the moment) that they would get the Disability Office to work with him. Michel also mentioned the possibility of teaching remotely over the web. Anyway, Gary then said that he would still have as his goal teaching at the start of fall semester. We'll just have to see what happens.

All for now.

Blog at http://drpeg2003.blogspot.com/

May 18, 2006 (4:41pm)

Oops, I forgot an important thing. Our address! Want to encourage those cards and letters to Gary. Send them to:

Gary Gruenhage
Shepherd Center
2020 Peachtree Rd. NW (Don't forget to put the "Road" – there's a million Peachtree something-or-others in Atlanta)
Atlanta, Ga. 30309

Address anything to me identically to the above, since there are no mailboxes at the apartments.

Anything that didn't make it to us by the time we left Birmingham will be forwarded to our home address, and from there to here, so it should make it eventually.

Warning: Moaning and Groaning Ahead.

Neither Gary nor I had a real great day Wednesday. Gary had been significantly more congested and doing a lot more coughing starting the day before we left UAB, so much so that he wasn't getting much rest and commented that he wished everyone would just leave him alone. I commented on the coughing to the nurses but they kept saying it was good he was coughing the stuff out. But then the night nurse indicated that in fact Gary was not coughing it up and that he needed to be doing his breathing exercises with the "incentispirometer" (incentive +spirometer, apparently) to help clear the congestion. "With the what?" we asked. The nurse seemed surprised Gary hadn't been given the device. He got one for Gary and showed him how to use it. To me the nurse's tone was chastising, saying Gary should be doing this or he risked getting pneumonia.

After the nurse left, I groused to Gary, “Yeah, well, you would have been doing it had you known about it.” I couldn’t help asking when the nurse returned why we hadn’t been told of this earlier. The answer was basically because the other nurses hadn’t paid close attention to what was going on with the coughing. I don’t know, maybe I’m just too much of a perfectionist. It just makes me mad that here was another thing that Gary had to suffer for because the nurses didn’t recognize the signs in time. Another irritation, excuse the pun, is they hadn’t changed for several days the special pressure socks that Gary has to wear to prevent blood clots, and when they took them off, Gary had a big blister on the top of his foot. But I’m mostly mad about the bed sore. He was never turned until after he already had it. And bed sores are such a stereotypical hospital complication. Ah, well, I suppose I should let it go. Shepherd told us they treat bed sores aggressively, so I don’t think I have to worry about it now. Time will tell if I end up bitching as much about the nurses here ;-) At least they look older – I swear most of the nurses we had at UAB looked about twenty, and I’m wondering if they just didn’t have the experience for the job.

Anyway, Gary was having a lot of trouble breathing during his ambulance ride to Shepherd, he told me later, and he ended up back on oxygen. Meanwhile I was coping with the traffic from B’ham to Atlanta (I do want to thank Lex Oversteegen here . Lex came at my call and helped me pack up my car – that was a fantastic help). Six miles out of B’ham we slowed to a stop then continued at a crawl. Turned out the three-lane highway was gradually being thinned down to one. My timer went off for me to get off the highway and stretch, but no way was I going to exit and then try to get back on. My right calf was cramping, my left leg was tingling from bun to toe, my back was aching. We eventually got to the fifty yards where the actual construction was taking place. The traffic cleared after that point and I saw a road sign for Atlanta. “Great,” I muttered, “only 135 miles to go.” There were more parts of the highway where traffic slowed way down for construction, but nothing as bad as that. I was pooped by the time I hit Atlanta, my mind starting to play little tricks on me, but I gutted it out. Fortunately Shepherd had provided great directions to their place (even to one who “directionally impaired,” as sister-in-law Norma puts it), and I found it easily. I checked on Gary, who I knew had arrived safely because Sheryl had called me while I was driving (thus becoming one of those dopes who talks on their cell phone while driving) to say he had gotten there and to tell me where to pick up my housing packet. Gary looked somewhat tired out, but said he felt very positive about the people he had met, commenting that these people seemed to know what they were doing. He seemed like he wanted my company, so I stayed a couple of hours, then left to check out my new digs. The part I was dreading was carrying just what I would need for the night (including my cooking stuff) up to my second (top) floor apartment (not condo – I don’t know where I got that). My first impression was positive. The housing guy had also called me while I was driving (yikes!) because he wasn’t going to be there by the time I got there. That had its positive aspects, cuz I asked for top floor (I don’t like people walking above me) and in a quiet part of the complex, not facing the street, if such existed. There are twenty-five units on a dead-end street off Peachtree, and he gave me the apartment on the back, far side, opposite the side where the parking lot is. I noted a small living room, a small kitchen, and a small bathroom (as Norma said, at least the kitchen and bathroom are two different rooms). I looked out the windows, which face the rear, and saw trees lined the area right off my balcony. Through them, down a small hill, is another apartment building. And out the kitchen window I could see another apartment building a reasonable distance away. Can't get much better than that in terms of location for housing in Atlanta. And the apartment is free! But only for thirty days, and since I will definitely be here longer than that, I guess I'm going to end up in a hotel again. Anyway, after checking out the windows, I realized I had seen no bedroom. I wondered in dismay if I was supposed to sleep on the couch. As I looked at the couch, my eye was caught by the big arch-shaped mirror that hung behind it. In the mirror I could see the reflection of a bed. Confused, I looked behind me. Nope, there was a dining table behind me, and the rooms to the side of it were the kitchen and the bathroom. Looking back at the "mirror," I realized I was looking thru an arch-shaped hole in the wall. I wondered if I was supposed to crawl over the couch through that hole to get to the bed. (Hey, I was tired.) It dawned on me that didn't make any sense, so I went to the long narrow hall I had entered through, and saw the door to the bedroom. If that door had registered at all when I first entered, I had put it down to leading to a closet. I unloaded from the car what I needed, and by that time I was shaking. I got my dinner started, meditated, then called Janet and Norma to spread the word to both our families that we had arrived safely – seeing that I wasn't going to be able to send out the word over the internet. Then I ate and got ready for bed.

It felt nice to be in "my own place" rather than a hotel, and it seemed fairly isolated so I was hopeful that it would be quiet. I taped up a sheet over that archway between the bedroom and the living room – I like a bedroom to be like a cave, not open to the rest of the place. I turned on the hotel-like environmental controls in the living room to "fan," then turned on my own two small fans in the bedroom, all for the white noise value. I took a bath and discovered that unfortunately the one thing this place lacks is really hot water. Then I climbed into bed, stuck a cold pack on my leg, and eventually fell asleep.

Until a damn bird woke me up at 6am. As I lay there listening to Tweetie-Pie, I thought it unfortunate that they didn't allow cats here. I wondered how they felt about guns. A couple hours later I drifted back to sleep for another forty-five minutes. Then I got up and soon made my way over to Shepherd.

Some more about Shepherd (be prepared for some upcoming non sequiturs). They have about 45 SCI (spinal cord injury) patients here and they group them by age. When Gary is ready for the intensive rehab, he will be in the senior program, which is ages 50 to 65 (Gary asked if that meant he got a senior discount) and consists of a group of eight patients. I found it surprising, and ageist, to learn that they don't take anyone older than 65 on the theory that such a person would not be returning to a vigorous lifestyle.

The case manager we've been assigned, according to Sheryl Hope, is a rehab-specific nurse, so she'll be familiar with rehab-specific medical issues, unlike a "regular" nurse, so we should have less difficulty with BCBS from this point on, again according to Sheryl.

One thing I noticed here – the nurses are much quicker to answer the call button. While eating his lunch Thursday, Gary started choking, it seemed to me, so in a panic I pressed the call button.

The nurse came right away. Fortunately Gary had managed to clear the food on his own by then.

Thursday the occupational therapists did some testing of Gary's ability to sense touch – a light with a cotton swab, the dull and sharp tests with the two edges of a safety pin. No surprises – Gary's sensations end at the T4 level, just as the x-rays would indicate. It is called a "complete" injury, because all sensation and movement is lost below it. They also did some spatial testing, to see if he could tell how his limbs were oriented. He couldn't do this with his legs. Finally was some muscle testing. His right arm was weak (triceps, etc.) but this is felt to be because he was in that big heavy cast for so long, and not due to any nerve damage.

They are wanting to get him in a chair soon and wheel him around the facility and to the gym to do some therapy there, but can't until the doctor looks over his new x-rays, taken yesterday (Thursday), and decides if Gary needs to wear a brace at first. Gary was disappointed because he had been told he would be in the chair this morning (Friday), but the O.T. came in and said the doctor still hasn't looked at the x-ray. After that Gary told me he needed to listen to something funny and I went out to the car to find a tape of Car Talk. While we were listening to it the OT came back with some 3,4,5 pound weights and showed Gary some exercises to do. Gary cheered up at this (he told me he had wanted to listen to something funny because he was disappointed about not getting to get up in the chair) – he said it felt good to be getting in some movement again, instead of just laying there all the time.

All for now.

Blog at http://drpeg2003.blogspot.com/

May 20, 2006 (9:25am)

Another thing I forgot to mention: Judy Roitman has discovered you can send electronic messages to Gary here, if you wish. The URL is http://www.shepherd.org/shepherdhomepage.nsf/Message!OpenForm

The message will be hand-delivered by one of their volunteers. Thanks, Judy.

We got some mail that last day at B'ham, but I have left it out in my car (I am currently sitting in a Paneera's a couple blocks from my apartment, as the hospital library is closed on the weekends), so will have to wait on sending out our thanks. I do remember that the Rogers' DVD of Dylan arrived. We will probably start that next, as we just finished "Good Night and Good Luck," which we really enjoyed.

It feels good to be getting some decent sleep again. This morning a bird did wake me, but I fell right back to sleep. The previous night was good too, except for waking up with a nightmare at 3am. Zombies were after me. I wished I could go to Shepherd and crawl into bed with Gary for a short time, but as that wasn't possible, I had to settle for locking the bedroom door. I know, that was silly. I mean, the zombies could have come right through that archway from the living room. But they didn't get me – or if they did, I am not aware of it, kind of like the Stepford wives.

Gary said he is sleeping pretty good here too, but unfortunately one of his roommates has a speaker phone he uses, and he uses it at late hours – the previous night 2am, last night at 11:30. I told Gary if I were him I'd have to kill the guy. Gary said if I were him, I wouldn't be able to. I said I'd find a way. Gary then mimicked someone giving a report: "Peg's rehab is going well."

Gary is in a room with three other patients. They are separated from each other only by curtains, so it isn't all that private. Fortunately Gary isn't as sensitive to noise as I am. There isn't much room for maneuvering in the area assigned him, and it's full of hospital equipment so is not homey-looking. It's not a big deal to him, so I haven't done anything to "decorate." They had mentioned he could be reassigned a room at any time, so to me it's not worth the effort, since he doesn't seem to care. I'd rather spend my energy just being with him than on sprucing the place up.

Turned out the nurses bugged the orthopedic surgeon enough yesterday that he looked at the x-rays and decided Gary didn't need a brace. So when I returned from lunch yesterday it was to find Gary upright in his loaner wheelchair (he will be getting one fitted especially to him later). The PT showed me how to do a "weight shift" with the chair, which is something he is supposed to do every half-hour for a minute until his bed sore heals (and before I forget, there is a 70% chance he will have to have surgery on that, according to a doctor, but the final determination will be made Monday). Anyway, this involved lowering the back of the chair until he is in a prone position. I told the PT I didn't think I could hold his weight as I was lowering the chair, but she guilted me into trying it. I wish I hadn't, as I think it wrecked up my leg more, and especially as it turned out the nurses were completely willing to do it for me. I did wheel him around the floor for a few minutes – the chair was very easy to push. We checked out the patient snack area, which has a fridge for the patients if I want to bring things in (which I already have – I broiled him a salmon kabob I picked up at a yuppie market just a block away, "Fresh Market," since they want him to get in lots of protein to help heal that bed sore). The snack room also has juices and milk and coffee and water for the patients. We also looked at the gym where he will be doing most of his rehab exercises, and the laundry area which looks too high for him to be able to use so looks like I'm going to be stuck doing his laundry for a while ;-) (I hope he doesn't think I'm going to suddenly become domestic. He probably doesn't – he asked with amazement the other day, "You made the bed?" when I told him I had had to make up my bed in the apartment. I told him only because I had had to put the bed warmer on.) I also found out where the towels and blankets are, just down the hall, so now I won't have to bug the nurses when we need those. Then I wheeeled him back to his room. He still feels weird when he first sits up, but is okay after a while. They had him sit for two hours yesterday, and they are shooting for longer today.

Speaking of which, time to go back.

Blog at http://drpeg2003.blogspot.com/

May 20, 2006 (2:10pm)

I think that when Gary was worse off and I wasn't with him as much, my writing of the emails/blog might have been more coherent. Now that I'm spending more time with him, I have time only for snatches of writing here and there. So if you've noticed a decrease in quality, that is why. (Or so I'll say ;-))

Okay, catching up on the last mail we got at B'ham. Thanks to Mom Gruenhage, Beth Fletcher, Lois Staving, the Barjenbruchs, and Wanjun Hu.

And I would like to mention the email from Bob, Gary's younger brother – I hope Bob won't mind. It was very sweet. Bob mentioned how one time when both he and Gary were living in California, Bob got mad over some trivial thing, and Gary told him not to get mad, but to solve the problem. Bob said he always remembered that, that it helped him, and how he could see how Gary still lived by that. I was reminded of Bob's email yesterday, when the counselor assigned to Gary came by to meet Gary and tell him they had an appointment scheduled for some time next week. She asked if Gary had any questions, or if there were any issues he wanted to discuss. Gary told her he thought everything had pretty much been covered – then later worried she might not appreciate the way he had put that, indicating she wasn't necessary :-). I told him that it had seemed to me he had taken this pretty well from the beginning, and asked if that was really the case (since communication had been somewhat limited there for a while). He said maybe he was kidding himself (I don't think he is), but he felt he had accepted that this was the way it was going to be, and that the only thing to do was to make the best of it. I mentioned how I had felt that it was useless to ask the why's because I felt there was no answer (at least that I could comprehend). He said even if he knew the answers to why the accident had happened, it wouldn't matter because it didn't change how things were.

Broadening that from this specific instance to a life-view, that has pretty much been my guiding philosophy for years now – beliefs, understanding, *in a sense* don't matter – it's how you live your life (I put "in a sense" because I know there are those who would argue that it is beliefs and understanding that guide how life is lived).

Besides a counselor, Gary has an entire "team" assigned to him: his doctor, case manager, physical therapist (for mobility issues, like sitting up, transferring between surfaces, rolling, and also for working on his lower body (keeping it flexible)), occupational therapist (for functional issues – learning how to bathe, dress – the details of daily living – and strengthening his upper body), speech therapist (for learning how to speak with the hole in his trache), recreational therapist, counselor.

I got a homework assignment from the OT the first full day we were here: to do a house survey, where particulars about our house are filled in (width of doorframes, details about bathrooms and bedrooms, etc.). Based on this they will make recommendations for alterations that should be made.

Jumping to a new topic, Saturday Gary wheeled himself around for the first time, the trip being down to the gym on the second floor (he's on the third). So he had to maneuver down the hall to the elevators and then to the gym (the PT told him he should do all the driving himself, not to let others push him – needs to build up those muscles). To get into the chair from the bed, and from the chair to the gym mat, he was lifted by a device the nurses call a "hoyer," maybe named after the manufacturer :-). He lays on a "net." Hooks then go into eyes on the net on both sides of his shoulders and hips. He pushes a control button, and the hoyer lifts him. Then he lowers himself onto the chair (or mat). The PT gave him arm and shoulder exercises to do – bicep curls, flyes, tricep extension. I loved lifting weight when I used to be able to. I loved it almost as much as swimming. So when the PT walked over to the other mat to help someone else, I couldn't resist correcting Gary's form, telling him to slow down so he was using the muscle and not momentum, that quality was more important than quantity, telling him how he should be breathing out on the exertional phase, informing him when he had miscounted and still had more to go (cheater! ;-)). The PT told me I should have been a PT. Gary told me I was a hard taskmaster. I said he probably wanted to fire me, but he said no, it was good. He is supposed to do his arm exercises twice a day. Even if he has the skin flap surgery done on his bed sore, which will again render him on his back for at least two weeks, he is supposed to continue with the arm and shoulder exercises. Building these muscles will be vital for his rehab. We are expecting him to be quite buff by the time he goes home ;-).

Today, Sunday, he was more active in the chair. He wheeled down to a Sunday service on the third floor for the singing, then we went down to the first floor and outside to the garden they have here. They had a ramp down from the door of the building to the garden level, and I had to hang onto the wheelchair so Gary wouldn't go flying down it. I almost lost him in the bushes (just kidding – though I did have to hang on tight). The garden was a very small area – I had been hoping for something larger. While we were there, a person came around with a dog, a black lab. She was from "Canine Assistants," which trains dogs for people with mobility issues – the dogs open doors, pick up items, pull wheelchairs, go for help, turn on lights, etc., and the service is free. She said the dogs came with eighty commands, which made me laugh, since it made the dogs sound like programmable machines. That impression was reinforced when she said the dogs could then be customized to their owners' needs. Gary asked how they do with cats, and she assured him that the dogs were raised with cats and so took to them very well. I couldn't help saying, yeah, but I doubt our cats would take to a dog. She said the dog would so identify with Gary that the cats wouldn't think of it as a dog, but I am dubious. Besides, I don't really want to take care of a dog (not to mention I am afraid of them, though I'm sure the ones chosen wouldn't justify any fears). Of course, if Gary really wants one, I wouldn't deny him. (I just asked him – he said he'd rather try to get along without one first, but it was a nice program.) We left the garden after a little while, Gary not quite able to make it up the slope of the ramp on his own – but all I did was prevent him from going backwards, not push him up it. (There's a reason he calls me a hard taskmaster – he later said, "I see you took those words to heart about not pushing me in the wheelchair :-).) We then went along the hall on the first floor where they have pictures of various people up. I still haven't taken the time to see exactly who these pictures are of, but I recalled seeing one of Christopher Reeve, so we went looking for it. We found it – it was a poster for the '96 Para Olympics which were held in Atlanta. By this time Gary had been active for two hours – definitely more active than he's been at any time in the past five weeks. So we went back to the room, and he turned on the TV and watched golf. I got out the laptop and am composing this, later to be sent out as emails and put on the blog.

For some reason meal times are crowded together today – we're not sure if it's because it's Sunday. Normally he's been having breakfast around seven, lunch at twelve, dinner at six. But today's breakfast was at 9:30, lunch at 11:30, and now dinner is here at five! They are really pushing protein on Gary – fish/meat at every meal, plus ensure, plus a protein drink – they say this will help heal the bedsore. But we are not usually impressed with the meals (I in particular raising an eyebrow at it). "Southern cooking," Gary declares it. Fried steak, stuff smothered in gravy, tough, overcooked veggies. The beef they gave him for lunch was so tough he could hardly chew it. Fortunately we still had some salmon from the kabob in the fridge, so Gary had that, and I reminded him that I would get him whatever he wanted from elsewhere and cook it for him if he so desired – I think good nutrition is supremely important right now, though of course he and I are not always in agreement as to what good nutrition is ;-).

He has to be very careful and concentrate with his chewing, because they saw signs that some of his food is going down the wrong tube and ending up in his lungs. This could cause an infection. Everything is such a balancing act. If he has the surgery for the bed sore, he is supposed to lay flat for the incision to heal properly, but the respiratory people don't want him lying flat because of breathing and eating issues – we'll see how they resolve this dilemma if it comes to that. And for bladder issues first he was on a foley and now they do "ic's" on him (incentive catheterization (sp?)), which he will be doing to himself, once his finger heals up. But now he has a bladder infection, I assume from having those tubes in him.

Speaking of that bed sore, it is amazing to us the trouble it causes. If he has the surgery, it turns out it will affect how he is able to take care of other personal issues for about a year. And he will have to be vigilant to make sure it is healing properly and doesn't return.

And we still have the breathing issues. Because of the damage to his lungs during the accident and also probably due to all the various breathing tubes he had to have in him during this ordeal, he still has problems with congestion. He has been getting breathing treatments every four hours, as he did at B'ham.

Oh, I haven't mentioned his hearing in a while. It seemed to slowly improve at B'ham. They tested him again the day before we were to leave B'ham (no doubt not wanting Shepherd to think they hadn't followed through ;-)), and found him to be on the edge of normal. They still think it will completely clear up once he is more active. At least I don't have to yell anymore, just have to raise my voice slightly above normal.

Another thing that will come into play that we hadn't realized is temperature regulation. Evidently his body won't do that so well, so he may need to layer clothes, or at least to bring jacket with him when he goes to school, etc. They said even in hot weather, sometimes people like him find they might suddenly need a jacket for a while.

And to finish, some parting lessons I learned at Walmart in Birmingham: 1)Their instant ice packs are worthless – you will get a hernia trying to crush them so as to release the magic crystals. 2) If you are a woman and you accidently walk into the men's room, it is best not to emit a loud "oops." And if you do, be like me – stay in the women's room extra long so as to avoid meeting up with anyone you accidently got too personal a look at.

May 23, 2006

I was told it was time to get Gary some athletic shoes, and he also asked for some long-sleeved T's, so on Sunday evening I took another shopping trip. Blcchh, this one was not fun. At Target I went through the entire men's department and scrounged up only two long-sleeved T's. Fortunately Gary likes the Braves (that's a baseball team, for my French friend), as the shirts bear their logo. In the shoe department, the sizes were only mostly together. Same with the styles. So I ended up looking through the entire wall-full of shoes, and found only one pair with velcro straps, which is what he needs at the moment. Unfortunately they were not the correct size. The Target salesperson sent me off to another store (I have told you how much I hate driving in traffic, haven't I? At least Atlanta's was easier than Birmingham's). The store was closed. No way was I going to head back in the direction I'd just come from and hack my way through the jungle of Lenox Square Mall searching for shoes. I chalked the trip up as a failed attempt and consoled myself by going to a Publix grocery store and perusing their "organics and natural" section. I got Gary some organic yogurts and smoothies and milk, some definitely nonorganic Hershey's cocoa, some zukes for me, and also such exciting things as natural toilet bowl cleaner.

Gary had told me that in talking to his mom Saturday night he'd found out that he had a cousin who lived very close to Shepherd, about a mile away (give me a second – this is actually related to the above paragraph). This cousin, Helen, called on Monday. We talked a bit and she asked if there was anything we needed. Not really serious, I said Gary needed tennis shoes (I had been planning to go out to find them a couple of hours hence). She said she was doing errands and would be near the place I had been told might have them, so would check it out and give me a call. She did this, found the place didn't have velcro shoes either, but found them at a nearby place. She picked them up for us and said she would bring them when she came to visit that evening! We knew it was her when she walked through the curtain shortly after seven. Okay, there were some giveaways: she said she was coming about seven, and she was not dressed like one of the medical personnel. But I could tell she was of Groteleuschen stock because she has the same facial features and coloring as Gary's mother. She was full of stories, and kept us well-entertained. She brought a beautiful begonia, and the tennies – which she probably has no idea how grateful I am that she got them so I didn't have to hunt them down.

Okay, to the medical stuff. Gary will have to have the "sacral flap" surgery for his bed sore. The doctor's opinion is that it wouldn't easily heal on its own – could take five months to do so – and wouldn't heal as well with the natural scar tissue as opposed to having a skin flap put over it. The doctor came in the afternoon to take another look at the sore (bellowing "Gary!" as he walked through the curtain, thus destroying the nap of the person in the next area who had recently asked us to turn down our tape recorder because he wanted to take a nap – we had turned it off because if we turned it down Gary wouldn't have been able to hear it). I immediately liked the guy because he asked if I was Gary's daughter. (Of course, this could have just been very bad news for Gary, not good news for me.) Anyway, the doctor said the sore was worse than when he'd seen it on Friday and that it was sitting right on the bone.

So on Friday Gary will be wheeled over to Piedmont Hospital, which is connected to Shepherd through a tunnel. He will be put under anesthesia (just the usual general type – he won't be put on a breathing tube). Then the doc – a plastic surgeon – will debride the area ("debride" sounding so much better than "digging the icky stuff out"). He will also remove Gary's tailbone (!) because evidently it is more trouble than it is worth for Gary's condition. Then he will take muscle from Gary's glutes to fill in, then fold his skin over the area and use staples and sutures on it to close it. Gary will then have to lay flat, or nearly so (no more than a 20 degree angle), for three weeks. If he can tolerate "proning" (laying on his stomach), the success rate of this surgery goes up significantly. During the last of these three weeks he will undergo gentle stretching of the scar tissue until they have increased the stretch of the hips to 110 degrees. Then they will start to gradually sit him up in bed, then get him gradually used to sitting in his wheelchair again – in total, it is a five week healing process. At which time he will be back to where he was about the time he first arrived here. Sigh. The good part about this is his finger should be just about healed then, so he can better take advantage of the rehab.

So a lesson for anyone who reads this: bed sores are a very serious matter, and don't trust your nurses to be taking the proper preventive care of them.

On the plus side, Gary's coughing problem seems to have improved (keep your fingers crossed). Those first days here sometimes it was so bad that he was totally exhausted by it. But now they are thinking of reducing his nebulizer treatments to twice a day, then as needed, so with any luck I soon won't be able to joke "put that in your pipe and smoke it" anymore (he breathes in the medicine through something that looks like a pipe and "smoke" comes out the end of it). (Another phrase we bandy about is "knock on plastic" (there no being any wood around), whenever an improvement seems in the making. It got us to wondering how that phrase had originated. Normally I would immediately go on the internet and track the phrase down, but I haven't had the time.)

May 24, 2006 (12:47pm)

Much of what I'm going to say here about Gary's injuries I already said at the beginning of this blog or in the emails sent out, but for those who've jumped in recently, here it is again – we had it recently reviewed for us in a conference with Gary's doctor, Dr. Lin, on Monday. First Gary's orthopedic injuries were reviewed, complete with newly-taken x-rays: fractures in the spine, the pelvis (two such fractures), and the finger. The doctor explained how the spinal column has a two-fold function. It acts as scaffolding for the head, neck, and shoulders, giving rigidity to support their weight and flexibility for bending. Secondly, it gives protection for the spinal cord, which functions like wiring to the body, allowing our movement, perception of sensation, sense of orientation; it also is responsible for bowel and bladder functioning, ability to breathe, heart rate, temperature control. The top part of the spine, the neck area, is the C spine (cervical), then comes the T spine (thoracic = chest), then the lower lumbar L spine. The cord is like a garden hose, says the doctor. Pinch it somewhere, and the messages have a harder time getting through. Pinching it closed or severing it makes it very difficult for signals to get through (doctor's words). The spinal cord, like the brain, doesn't really get better after being bruised (the doctor likened it to a bruised banana); it doesn't heal well at all. Gary's injury was at T4, nipple level. When he had his first MRI in the emergency room, the docs saw a hematoma choking the cord. They went in to try to relieve the pressure. When they did that, they saw the spinal cord had been severed, separated, disconnected – take your pick of words, they all mean the same thing. They took the pressure off the spine, and in a later operation stabilized the spine with rods and pins. We saw the x-rays of this. The doctor pointed out how they had removed some of the bone to take off the pressure (they removed 5 of the bony ridges that you could see if you look at the back a skeleton model of the body), then later put in the rods as "replacement."

His pelvis has two breaks. They heal by not putting pressure on them, which with all the bed rest he's been getting satisfies that requirement.

The doctor said that perhaps down the line stem cell research could possibly help restore some functioning, though with the political climate of today who knows when such breathroughs might happen. He also mentioned China was better able to do the research, having an abundance of fetal tissue, but that they were so disorganized over there that no useful data was coming out. He mentioned them having some success in Portugal . . . But anyway, for practical purposes this is still very much in the future.

The doctor's own spinal cord was severed at T1, by the way – armpit level – giving him less functionality than Gary. That surprised us greatly, given the way he moved in his chair.

Medically Gary has no great issues, according to the doctor. But there are four reasons why he is in such a place as Shepherd.

First is for medical stabilization. The trachea hole, broken bones, skin sore, need healing. The breathing issues. Etc.

Second is mobility issues. Learning first how to get from bed to wheelchair, later such things as participating as fully as possible in the community – driving a car, etc. A paraplegic with Gary's level of injury is expected to be fully independent (though he probably won't be cleaning gutters, the doctor demurred). Shepherd consistently rates as number one or two as a Model Spinal Cord

Injury Center in the nation, meaning this is a very good place to go for this purpose.

The third reason is body acclimatization. Checking the skin frequently for pressure sores (the doctor warned that once a person has had a problem with them, things never get completely better – like trying to smooth a crumpled paper back to its original look), checking the legs for blood clots. Learning the bowel and bladder routines – neither operate as they normal would, so Gary has to learn catheterization for urine removal and rectal clearing (sphincter stimulation) for bowel evacuation. The doctor says it takes about six months for a paraplegic to learn his body well enough to have these routines down.

In addition, the digestive system in general is slowed down and doesn't operate as well. I mentioned I though Gary's belly looked swollen and wondered if that was a part of it, but the doctor said that Gary no longer has control of the abdominal muscles, so they go slack and result in the "beer belly look." That had confused me because Gary hadn't looked like he had lost weight around his middle, but I noticed his legs were definitely skinnier, and maybe even his arms. I thought it may be due to atrophy, but it turns out that in addition to that, he really has lost weight – he's dropped 13 pounds since the accident.

The fourth reason for Gary being here is OT (occupational therapy): learning to dress, wash, shower.

And after he's done with the program here, Gary's work is, of course, not done. He will still want to work at increasing his fitness, strength, stamina.

Since I'm behind in posting stuff, I'll get this off now.

Blog at http://drpeg2003.blogspot.com/

May 24, 2006 (1:37pm)

Well, I guess they never promised speed when it came to the delivery of those electronic messages here at Shepherd. A bunch were delivered to Gary last night (Tuesday). Thanks to: Ronnie Levy, Mirko, Donne, Bill Kelly, David Fremlin, and Janet and John. We also got snail mail: a joint card evidently written during a mini-War Eagle from Janet and Jack Rogers, Jane and Jack Brown, Sam and Diane Young, Margie Fitzpatrick, Pam and J.P. Holmes, John Henrichsen (sorry if I mispelled that John – I can't remember exactly how to spell it and I can't read your writing ;-)), Donna Bennett, and Cathy Colquett. And of course another card from Gary's mom :-) This time she didn't send a picture, but I forgot to mention that Gary's cousin brought one. It was really cute, from when Gary was about six years old, is his guess, taken on the farm Gary grew up on. Gary and Bob and their cousin John are in the foreground, Grandpa Groteleuschen and a milk pail behind them, and behind them, some cows.

More mail just came in: a card from Beth Fletcher. And a Lucky Bamboo plant from Janet and

John!

Back to the medical stuff. On Monday after the conference with the doctor Gary had his first session on the mat in the gym. First came learning how to balance on his spine – remember, he no longer has abdominal muscles he can recruit for any of the things I tell you he is learning – most of us would no doubt unconsciously recruit ab and leg muscles to help, whereas for him everything below nipple level is dead weight. In balancing, head placement becomes very important. If you're falling forward, you need to lean your head backwards, etc.

So he practiced sitting, and reaching from a seated position without falling over, and also how to go to and from a sitting position to a leaning back position (supported by a wedge).

On Tuesday he learned how to roll from lying flat on his back over to his side. Not so easy when you don't have leg or abdominal muscles to recruit. You have to swing your arms vigorously from the side away from the direction you want to go in to the side you want to end up on, and you do that a few times to build up momentum (one, two, three!). You also have to tuck your chin to your chest and use your head to help throw your weight in the direction you want to go – this is definitely not the time to feel self-conscious about how your body is moving. I could tell by the look of intense concentration on Gary's face that this rolling business was not an easy task. But he actually was successful at it fairly quickly – I was impressed, and Gary was quite pleased.

Next came weight shifts to the side – so I don't have to be with him to lower the back of his wheelchair every thirty minutes for the rest of our lives ;-). In this procedure he learned how to manage the wheelchair so he can lean way off the side of it to make sure his butt lifts off the seat of the chair. This is to make sure he doesn't develop any skin sores on his booty. He has to hold that position on each side for a minute, and must do this every thirty minutes he is sitting. There is an alternative kind of weight shift where he would use his arms (triceps) to lift himself straight up from the chair (balancing on the arm rests), but he isn't strong enough yet to hold his body up in the air just balancing on his hands for anywhere close to a minute (can you?).

They then showed him how to stretch his legs using looped pieces of cloth. It will be important for him to maintain the flexibility in his legs for postural considerations. I asked if there was anything that could be done to maintain the muscle mass of his legs, or if they would just atrophy. Evidently if a doctor approves, Gary can be put on a bike where electrodes would go to his legs and stimulate the muscles to move so he would be "riding" the bike. They didn't make it sound like this was standard for patients in his situation to do, so we'll see about that later. They definitely stressed the flexibility, tho.

After this (an hour's worth of work), the therapist asked how tired Gary was on a scale of 1 to 10. 1 meaning, he could do this all day; 10, meaning he needed a nap. Gary said "9." Fortunately it was time to go. In fact, we had gone over the allotted time, and Gary was late for the skin wound class. We caught the tail end of it – full of gross pictures of bed sores on people. Then it was time for lunch. I think the order of events should have been changed. (I'm sure the intent of that class is to scare people with what could happen if they don't take care of themselves, and at that they succeed eminently.)

In the afternoon on Tuesday Gary had another session of therapy. The therapist asked how he felt. Gary said he was almost recovered from the morning session. The therapist smiled mercilessly. The tasks were harder. Gary practiced going from laying on his back to the roll to the side position to sitting up. The sitting up part involves a lot of technique and strength – you have to place your elbow to the side just so, and then walk your upper body around with it until you're kind of folded in half to the side, then push yourself to a sitting position, which again involves hand and head placement so you don't lose your balance and fall over. The therapist had to help Gary on this – he wasn't yet able to do this on his own. He also practiced scooting – but not too much because of the bed sore. We also watched someone else practicing a board transfer, where the guy placed a little board from under his butt to over to the matt, then he scooted over on it. When Gary can accomplish that, he won't have to be airlifted on that hoist appartus ;-) Unfortunately that sacral flap surgery means he won't be able to scoot for a year (!) afterwards. Unless and until he gets strong enough to lift his body entirely off one surface to another, we're not sure how he is going to be able to do transfers – I certainly can't be lifting him. Someone is going to talk to us more about this. I know they had mentioned a mechanical hoist at Birmingham, but it's still a two-person operation, one that requires more physical ability than I have, because of my back. So I don't know if this means we'll have to spring for an electrically operated hoist or what.

After that therapy session, Gary was ready to go back to the room, but they weren't through with him. He was supposed to wheel around the place for another hour, taking breaks as needed. After forty minutes he said that was enough. It was enough for me too, since I had just started having a migraine aura and the floor was tilting beneath my feet. He went back to his room for a nap, and I went off for a massage at a place I had seen a couple blocks from my apartment. In the same building is a rolfer, an "energy work person," a chiropractor, and an acupuncturist, in case I want to do a sampling :-) . In the evening I had a brief phone conversation with Gary's cousin, who gave me choices from her books-on-tape and her DVDs, and a phone conversation with my older sister. After eating, I returned to the hospital just at the time cousin (cousin-in-law?) Helen was about to leave Gary's room. She is letting us borrow a CD player along with her book and movie selections, so we are starting to line up our entertainment for when Gary can't get out of the bed again.

So that was Tuesday. I got up a little early on Wednesday cuz Gary had run out of clothes to wear so I had to do laundry (I can hardly wait for him to become independent ;-)). I knew the volume of water had been low in my faucets in my apartment, but I didn't anticipate how low it was in the laundry room. With the merest trickle coming out, I was afraid it would take a couple hours to fill the washing machine. Fortunately it didn't, but the dryers sucked too, and since I didn't want to spend all day there, I removed the clothes from the dryer after a half hour and hung them around the apartment. Next time I'll use the washer and dryer provided for the patients on Gary's floor; I may even try to sneak some of my own stuff in with his. When I got to Gary's room I found he'd missed his "Alcohol and Drug" class (how spinal injury affects the ingestion of such). Not that he was all that dismayed by that (he will have to make it up), but the reason he missed the class is because his replacement chair hadn't come. When he first got a wheelchair on Monday, it was definitely meant to be a temporary one until they had a better idea of what he needed. He got one on Tuesday that was supposed to be better – smaller, lighter, more mobile – but turned out to be worse. He was sliding around in it – it was too big and gave him no support around his midsection, and he couldn't keep himself upright in it. So he was supposed to get another one this (Weds) morning. He didn't want to miss his OT class, so I went to find his therapist to see if they could at least get the first chair he had been in so he could come to the class. She told me she would find a chair for him. When she came about a half hour later, it was with his new chair. This is not the one he'll take home; when that time comes close, he'll go to a seating clinic and they'll customize one to him. The chair she brought is still one of the ones they pass on from patient to patient at the hospital. It is still too big for him, causing him to catch his arm on the bars that support the back when he wheels it, but at least it has "wings" that circle around him below his armpits and help keep him centered in the chair. He said it was significantly better than the one they had him in yesterday. But actually he didn't spend much time in it then – I had brought up that Gary wanted to practice proning, which they want him to do after the sacral surgery if at all possible, and she thought this would be a good time for it. So she brought a wedge and a face cradle for Gary to try. The face cradle is similar to the type massage therapists use. If you are not familiar with that, picture a padded toilet seat, where your face would go into the hole part (okay, that is probably not something we'd like to picture ourselves as doing, but at least it describes it pretty well). Using the wedge instead of the cradle seemed more comfortable for Gary. The wedge goes under his chest, and he either would support his weight on his elbows if he wants to read, or he would put a pillow under his forehead to rest his head. He said it seemed pretty comfortable, though to me it didn't look it. I can't imagine laying like that for hours on end, but we'll see what happens when the time actually comes. The therapist gave him some exercises in that position to stretch his shoulders, which have always been very tight, and to strengthen the muscles in his back (like his traps), both the strengthening and stretching intended to help him maintain that prone position.

After that session was a two hour break for lunch and "whatever" until his next scheduled activity in the early afternoon. This they called a "group activity," and when we had first asked about it, they'd made it sound like fun – a scavenger hunt or some kind of outing. Some people scheduled for this group activity started playing pictionary. Gary was told to lie on the mat, another guy next to him, and the two of them started to do stretching (or rather, to be stretched). The area of the gym where Gary was was pretty crowded and noisy, and it didn't look like there was room for me (besides, I'm not a game player) so I slipped off to work on the blog. When Gary came back, he looked worn out – definitely not like he had been spending a lot of time playing pictionary.

I asked him what activities he had gotten to do. "Some group activity," he said with his tongue hanging out. "Me and that other guy got to do weights for an hour and a half." I asked if he'd had to do that the whole time (they take breaks, of course), and he said, no, he'd gotten to practice going from a leaned back sitting position to a sitting forward position and then back again – which again, is work, because he doesn't have his abs to help with this – it's balance and hand and arm positioning and upper body strength. They had done this over and over again. Some fun <ironic smile>.

And of course he'll have to start all this over from the beginning five weeks from now after the flap surgery. But I'm glad they're having him do this rather than just languish, and he will know what to expect next time around.

A short time after he returned, Jamie, from my critique group, arrived. She had come to Atlanta to visit with us and to whisk me away for a short while. So she met Gary for the first time and acknowledged that he did indeed exist (having been skeptical of that fact for so long; Gary brought that up and she told him she knew he had to exist when she and others in the critique group found me on the floor, crying, at Paneera's (the restaurant where we hold our meetings) – that was when I first got the message to call the emergency room and got the news of Gary's accident and they told me he had a severe spinal cord injury and was paralyzed nipple level down; Jamie said no one was that good of an actor to fake my reaction (I didn't tell them but I was petrified Gary was going to die)). After a short time she and her son and I left to find a restaurant. Her son, Jesse, is an interesting character (better not let him read this, Jamie). He's just turned ten and has the energy of that age, but his talk is atypical (in my limited experience) – full of scientific facts about animals (they went to the zoo before seeing us), about chemistry, and about other areas of science, and how Bush is our worse president ever (of course his similes (and he used that word, his mother being an English teacher) were of the type "Bush is like barf" – not that he used the word "barf," he merely pantomimed the act of upchucking). Such an intelligent young man. At first Gary and I weren't sure Jesse would be allowed on the ward, having thought we read that no one under twelve was allowed, but I found out from the nurses that all he would have to do is stop at the security desk and answer a few questions about whether he had any infectious illnesses, including a cold. I forgot to tell Gary that, and when I told him Jesse was coming up too, Gary said he thought the boy wouldn't be allowed. I explained about the security procedures and Gary started laughing. He'd thought that kids weren't allowed not to protect the patients from childhood illnesses but to protect the children: the sight of all these cripples would scare them. A roommate of Gary's overheard Gary's explanation and started laughing too, and they both resolved to be on their best behavior so as not to scare Jesse. We all agreed that when we were ten we probably would have been scared in such a situation. Gary said he probably would have fainted, since he was known to do so whenever they'd shown medical films at his school.

But Jesse wasn't phased at all, not batting an eye when Gary wheeled over to the other side of the room to do his weight shifts, and merely looking on with interest when Gary was hoisted through the air from his wheelchair to his bed.

Jamie had suggested we go to an Indian restaurant, having the idea I could order a big plate of rice. Through Yahoo we found an Indian restaurant that was only about a mile away, but when we got there we found the business was closed. We found another restaurant in easy walking distance – fortunately, since the $5 she paid for parking was nonrefundable. It's been a long time since I've been to a restaurant – I thought her paying $14 for a plate of roast chicken ridiculously expensive, but Gary told me afterwards it wasn't. We thought it odd that the waiter kept removing and replacing drinks (Jamie and Jesse's diet coke and lemonade) and refilling my water when they'd been only partially consumed. The place didn't have anything I could eat, of course, but I had come prepared, bringing along a container of cooked rice. Fortunately they didn't say anything about it.

It was great spending some time with Jamie. She left to go back to Auburn soon after we finished eating. I went back to the hospital for another hour, and Gary and I watched more of the Dylan DVD. I like it marginally better than the book, neither of them really giving me a feel for the man. At least the DVD has music, which is why Gary likes the DVD better, too.

I mentioned a little about that day of the accident a few paragraphs ago, and that reminds me. Gary mentioned that he can remember being at the intersection where it occurred, but then there is a gap. He doesn't remember being hit. The next thing he remembers is being in the rescue vehicle. They found fluid in his lungs and told him they would have to put in a chest tube. They pounded it in just below and to the side of his armpit. It hurt a lot and that was the first time he had the thought he might be in a little trouble. He said he was never really worried, though, until days later, after the second surgery, and the doctors started mentioning things about infections (in the staples, etc), because he knew infections in a hospital were a serious thing.

According to the accident report, however, he wasn't unconscious as long as the above makes it seem. The reporting police officer claims Gary made the statement at the scene that he never saw the other car (which is what Gary has told me and others). It seemed bizarre that here Gary was lying there with a severed spine and the police officer is taking his statement about the accident, but I suppose that's standard operating procedure.

Jumping about here – Gary's splint was removed from his index finger. Yea! Now all he has on it is tape – it is taped to his middle finger for a little extra stability. It hurts to bend it, but that will get better. Even his "good" fingers were stiff for a couple of days after they removed his cast.

Another non sequitur. The other day we were in his room when we heard someone call through the curtain, "environmental services." I thought that was something to do with temperature control, Gary later joked that he thought it was someone to whom he could complain that he didn't like the environment here. But it turned out to be someone who emptied the trash and swept the floor. So, they don't have janitors at Shepherd, they have environmental service technicians ;-).

This morning (Thursday) when I arrived I found out that Gary had had his first shower since the accident. They put him in a special wheelchair that can go in the shower. He felt light-headed, so they had to put his pressure socks back on him, and in addition he wore the chest strap while he bathed himself. Both the socks and the strap help maintain his blood pressure. His doctor told him that the very first time he had had a shower, he had fainted. I assume it was because he hadn't been wearing those extra supports – ideally, in the shower, they wouldn't be wearing socks and straps.

We have noticed that Gary always gets cold after they bathe him, and this was true of the shower. So I first warmed him up with hugs ;-), then brought him some hot tea. Soon after that he asked to be put in his chair so he could go to his class, and that's where he is now, in a class on male sexuality. No females allowed. We had thought maybe I could attend, but they kicked me out ;-). (We can see where other men might not want other people's female partners to attend. So I will have wait to find out what went on in the boys' club meeting. ;-))

Non sequitur. In the restrooms at Shepherd they have these paper towel dispensers that you just hold your hands under and the dispenser senses you and out rolls a small bit of paper towel (I always have to hold my hands under there twice because they are too stingy with their toweling). Restrooms are getting so automated these days. Toilets flushing automatically, towels rolling out automatically . . . Of course, such automation in our world can lead to false expectations. When I went to get my massage, I couldn't figure out where the buttons were to call the elevator to go up to the second floor. The only button that registered as a button had the symbol of a fire chief hat on it, so I didn't think I should press that. At the top of the panel where I thought the buttons should be, it read "automatic elevator." So I thought maybe all I had to do was stand in front of that panel and it would sense me and the elevator would come (you're probably thinking that was stupid, aren't you? :-)). After a couple minutes it became clear the elevator wasn't sensing me or reading my brain waves. I heard someone down the hall so I called out, "How do I call the elevator?" "Push the button," came the reply. "I would if I saw one," I muttered under my breath. I told the guy I knew this was stupid, but I couldn't find the button. He came over, and pushed it. It was on the bottom of the stainless steel panel, made out of the same stainless steel, and nearly flush with the panel. Okay, it was round, like a button should be, but there was no "up, down" arrow next to it, and it just didn't register that that was something to push.

Non sequitur. It is interesting seeing the various spinal cord patients here. Some have quite a bit more functionality than Gary will ever have, and I can't help feeling a bit, what?, envious? That's not quite the right word I don't think cuz it's not me in the situation. Others we see have C-level injuries, and will have to operate their wheelchairs the way I think Christopher Reeve did, the "sip and puff," method, blowing through a straw-like device to steer their wheelchairs. We were told they could use similar methods to operate a phone or the TV. If they have the use of even one finger, it may be possible to even drive a car by pushing a button.

But I am glad we don't have to take advantage of the wonders of science and technology to that extent.

All for now.

Blog at http://drpeg2003.blogspot.com/

May 25, 2006 (9:18pm)

Oops, how embarrassing. I caught another blooper. I should have written “Jesse wasn’t fazed at all,” not “Jesse wasn’t phased at all.” He may have undergone a phase shift, I don’t know. ;-)

Mail on Thursday afternoon – thanks to Ruby Juracek, Roland and Joyce Groteluschen, Norma, Donne, and, of course ;-), Gary’s mom. Someone in Gary’s family is going to have to explain the spelling of Gary’s mom’s maiden name, as Gary isn’t sure. I notice Roland spelled it as above, but some other relative spelled it “Grotelueschen.” I had been spelling it “Groteleuschen,” because Gary had told me it meant “great people.” From high school German I thought I remembered “people” being “leute,” so I got it in my head that to spell the last part of Gary’s mom’s maiden name with an l-e-u. But now I’m betting, given the above two spellings by family members, that there was originally supposed to be an umlaut in the name, “lüschen.” I don’t have my German dictionary, and can’t get on the ’net right now to check if “lüschen” is indeed a German word.

Oh, a shipment of four DVDs from Donne just arrived (Friday)!

And later on Friday, the hospital delivered an email from the Vaughans. More Car Talks are coming! Yea!

Thursday afternoon Gary came wheeling back from his male sexuality class with a big grin on his face. “Good news,” he proclaimed. “We can still have kids.” Funny guy. I never wanted them before, and I don’t want them now (which, of course, he knows). I asked him if he’d learned anything new. (I think we both basically knew the score well before this – not having movement or sensation below nipple level, having signals from the brain not make it through that T4 level as they did before, puts the kibosh on certain abilities, but kissing and cuddling can continue unabated and be as enjoyable as ever.) He said he’d learned there were drugs that had a certain noticeable side effect that would last 32 hours, and there was some kind of pump that could be used with shorter term benefits. I told him he’d have to time that drug very carefully, in terms of teaching classes . . . . Actually I was kidding about taking the drug at all – in general, I’m not a fan of taking drugs, and I wouldn’t want him to take them for this; he said that’s what he suspected I’d say.

We might have to look into that pump, tho . . . And there are other electrical devices . . . ;-)

He said he felt sorry for the young guys – a couple of the men in his class were in their twenties, another guy maybe about forty. “Sorrier for them than for you?” I asked. “Been there, done that,” he joshed; but he was serious that he thought it much worse for them. It didn’t seem to me that this was a significant blow to him – one more thing to accept as fact and make the best of.

In the afternoon he had another OT session – two hours worth, the first hour with a “tech assistant,” the second with an occupational therapist. First he did stretching of the legs. Then came practice at rolling. For some reason he wasn’t as successful at that as before. The tech said it might be because he was tired out, but I thought she didn't have him positioned right and tried to hint how to change that. The tech he has isn't, IMHO, as skilled as the therapists, but as she didn't take my hints I didn't feel I could very well be more forceful in my opinion as to how to try it differently.

The second hour the therapist took over. She started out by showing us how the portable hoyer works – this is the type of thing we may have to get for home for use during Gary's continued recovery from the flap surgery, which can take up to a year (or longer, or significantly shorter, like three weeks – it just depends on how he heals). I really don't know if this is something I'm going to be able to physically handle, as it needs to be pushed with him in it for a short distance – I tried it, and it didn't seem too bad, but by evening my back felt worse. We may have to look into putting a track in the ceiling and/or hiring someone for at least the beginning and the end of the day until his flap heals – someone who could help get him ready in the morning for school or whatever, and help get him to bed at night. I need to see if there is someone here at the hospital who can help me find some help with my own back problems, see if there is anything more I can be doing so I can be in as good a shape as I can be to deal with this. I did mention to Gary that I could just keep him in the trunk of the car until he was healed from the flap surgery, but he seemed reluctant about that.

We keep learning of more restrictions this flap surgery can result in :-(. I or someone else may have to be quite involved in some of the other personal care issues that Gary will eventually be able to take care of on his own. When the doctor who is performing the surgery came to talk to Gary in the afternoon (Thurs), Gary asked if the doctor wanted to check the sore, that maybe it had improved (he said hopefully) and he wouldn't need the surgery. The doctor told him there was no reprieve (and then joked how he, me, and the nurse were going to go out partying until the early hours of the morning but that we'd be back in time for Gary's 7:30 am operation; I don't think Gary was in the mood to appreciate the doctor's jocularity). Later in the afternoon Gary again brought up with me the topic of restrictions. He detailed more things I might have to do for him, and I joked that he was testing the limits of my love. He said "I'm afraid so." I lightly told him not to worry, the limits of my love were beyond these new tasks. He choked up. I hadn't realized until he choked up that he been seriously concerned about how all this information about the restrictions due to the surgery was affecting me. Hugs were in order.

It is now 9:30 am of Friday. The doc came shortly after nine to tell me the surgery went well and that the sore had been much deeper than it had looked so we'd (the all-inclusive "we") made the right choice in having the surgery. Gary should be back from it in about a half hour.

This coming Weds some medical people will come to take casts of Gary's lower legs and feet. He will wear the casts for a day, then they will be cut off, the cuts made down the sides, to make "molds." At night, he will have to wear these molds in order to keep his ankles from dropping. (Lie down in your bed or whatever, relax, and check your feet. They are probably pointing fairly upward. Gary's are pointing significantly downward, which evidently is a common side effect of spinal cord injury. Since this would make it difficult to sit in a wheelchair if they become fixed in that position, the molds are to train his feet not to drop.) At Birmingham he had special boots to wear for this purpose, but they can causing skin breakdown because they are not specially tailored to him as the casts will be.

Gary returned from the surgery. He's doing fine, but is sleepy from the anesthesia. I read E.H.'s email to him for its entertainment value. It is an understatement to say it certainly did keep us entertained, detailing the events of her date (she will probably never write or speak to me again once she sees this has made it to the blog). By the way, E.H., after hearing your adventure, Gary asked me if I would have thought it strange if he had wanted to take me to a cemetery after "the first thing we ever did together socially" (I write it that way since I don't think we ever had an official "date.") Seeing that that first thing was to see the movie "Friday the 13th" (I hadn't admitted to him that I didn't like scary movies) I would have thought it more than strange. And I wouldn't have gone.

And tell your mother, E.H., that there are other females who never did anything approaching going out with anyone until they were twenty-four (in fact, they never had any intention of getting married at all). And they have been happily married for nearly twenty-five years. So she doesn't need to push you ;-)

Bob and Rosina Stephenson and Bob's sister Alice Stevens came for a short visit in the afternoon, but that was pretty much all the activity Gary could handle today. He seemed sleepy for most of the day. At night, we watched a little more Dylan, and then the nurse came to put him on his stomach to try the proning (he did it for about two and a half hours the previous, Thursday, night). Since he was face down, I read another chapter of Jimmy Carter to him, and then we called it a night.

I couldn't help thinking when Gary's night nurse, a huge woman, flipped Gary over onto his stomach, that he looked like this limp rag doll laying there on its tummy on the bed. I feel so sorry for him seeing him lie there. And this seems almost like starting over again, like time is dragging its feet. . . .

Well to finish up, reading about E.H.'s date made me think of my beginning time with Gary. So if you are only interested in reading about updates of Gary, exit this entry now ;-)

This is how we met. I went to an appointment with Ben Fitzpatrick, the head of the math department at the time, to go over what classes I should take. I was interested in topology, having had a couple of Moore/Texas style courses in it as an undergrad. Dr. Fitzpatrick didn't know how much I had had would overlap with what Dr. Gruenhage would be teaching, so he suggested I take my notebooks full of my coursework up to Dr. Gruenhage's office to show him so that he could decide if it was appropriate to be in his course. I kept wanting to give Dr. Gruenhage's name the German pronunciation, so asked Dr. Fitzpatrick for the correct pronunciation. I then proceeded up the steps to Gary's office, left foot, right foot, left foot, right foot, Grune, Hague, Grune, Hague. Had to be some sixty year old with white hair and a goatee. Left, right, Grune, Hague.

I got to Gary’s door, knocked, went in. He turned from where he was seated at his desk.

Those eyes. That smile. Wow. I’d never believed in love at first sight, but . . . But surely this was some graduate student in the professor’s chair? But would a graduate student be so bold as to do that? “Are you Doctor . . .” Uh-oh. I’d completely forgotten his name. I snuck a quick peak at the nameplate on the door. “Grünhage?” I asked, giving the name the German pronunciation.

It turned out that though there was overlap between what I had done in my coursework and what Gary would cover, there was enough new stuff that he thought it would be fine for me to take the course. Lucky me. I confess, I had the occasional lapse of concentration in class when my attention would wander to how good he looked in his jeans, especially this one pair he used to wear that were on the tight side . . . . But of course such lapses were rare.

In those beginning days, I couldn’t believe he was as nice as he seemed.

As time went on I realized he was as nice as he seemed.

(He still is.)

Somehow (surveillance work probably; I don’t remember) I discovered he ate lunch at the War Eagle Cafeteria.So I ate at the War Eagle Cafeteria. Yuk. But a person’s got to do what a person’s got to do. I saw him eating with Jo. It hadn’t occurred to me he might be married. But how could he not have already been snapped up? I had to investigate this. I somehow managed to work his marital status into a casual conversation with Margie Fitzpatrick (I was staying at the Fitzpatricks after having fled the abode of the toga-party-loving roommates my dad had somehow managed to fix me up with; however, the cows mooing at 4 am and trains going by through the night on the tracks near where the Fitzpatricks lived on Gold Hill weren’t an improvement on that, so I looked to find another place). I found out Gary was single. Somehow I determined Jo was married. Good deal.

Gary played racquetball. I took up the sport. Not that I would ever be in his league to play him, but at least I had a quasi-legitimate reason for seeing him at the courts. A friend visited me over Christmas vacation and we devised a plan. We managed to time it so we came off the courts the same time Gary and his partner, Butch, did. We talked. Just as I opened my mouth to suggest we all go somewhere to eat, Butch invited Gary – and just Gary – out for pizza. :-(.

By spring break it was clear that Gary was still oblivious to all my machinations, and I couldn’t bring myself to being more direct (what if I was rejected?). So I recruited my parents. They came for the break and invited Peg’s professor out to eat so they could meet him. (I was there too, of course.) Gary told me later that at this affair it was the first time he finally got the inkling that I was interested in him other than mathematically. (Much later I worked up the nerve to ask him what he'd thought of me up to that point. He said the only thoughts he'd had about me were that he really wanted me to go into topology so he could direct me through a masters and Ph.D. (And for those of you who don't know me very well, for instance, Gary's current students, he wanted me to be his student for *mathematical* reasons. Jack Brown (my other graduate course professor at the time), you'll back me up on this, right?))

I think that when someone who doesn't know me very well reads here about how Gary and I got together, they must get the completely wrong impression of me (I sound like some stereotypical schemer). This kind of behavior was so out of character for me. Up to this point I hadn't been interested in more than friendship relations with males because even if I could find one who was interested in me (there hadn't exactly been a plethora of such), 1) he couldn't possibly meet my standards, and 2) even if he did, such as Gary seemed to, he wouldn't be able to put up with my idiosyncracies (I still haven't figured out how Gary has managed to do so; the mysteries of love ;-)).

Anyhoo, sometime soon after that we went to that movie – neither of us remember how that happened, but it wasn't a formal asking – it never was. I remember someone from the math dept showed up in the ticket line soon after we did and started talking to Gary. Gary moved about five feet away from me. I remember thinking there might be a problem with this student and teacher thing. (As Gary said when I tried to prod his memory about this today (not that he knows I'm writing this), "It shouldn't have happened. Those things tend not to work out and then it's a big mess. But after twenty-five years of marriage, I'm comfortable with the decision.") I remember that over that weekend long ago I thought about the kosherness of the relationship, and knew I really didn't want to wait until after I had a Ph.D to pursue a relationship with him. But it would have to be his move – I'd practically had to hit him over the head to get him to notice me, but now he knew.

And obviously he must have decided it was okay with him. (When I asked him some time later, he said he too had spent the weekend thinking about pursuing a relationship with me and decided he wanted to continue seeing me.)

Well, time to wrap this up. Anything more I want to relate? Oh, yeah. I made a lasting impression on him the first time I went to his house. I ripped off my jeans in his front yard. Why? you ask. Overcome by lust? you speculate.

"You're standing on a fire ant hill," Gary said.

"Oh?" I replied, wondering why he felt the need to point out an ant hill.

I found out.

May 27, 2006 (9:48pm)

I want to thank Jo Heath for coming to my aid with the house survey. I faxed her the form, and she went to our house and took all the asked-for measurements and pictures (she took about forty of those!). I am so grateful for her generous offer to do this. I really, really didn't want to make a trip to Auburn and back to do it myself.

I had to laugh at one of the pictures she took. Amazingly, Blackjack was in the photo. Poor kitty. Normally the sight of any human other than Gary or me would send him under the bed or out the cat door, so he must be craving attention if he braved being seen by an unknown person. Sylvia, our neighbor who is feeding the cats, says they've both become quite friendly to her. I hope they remember us when we come home. (About a year after we got them, Gary went off on sabbatical for a quarter. For about a week afer he came back, the cats hid behind the couch every time they saw him.) I showed Gary Jo's picture of Blackjack, and he got a wistful look on his face, saying that he really missed "the boys" and was really looking forward to going home and petting them. He wondered if they'd be afraid of the wheelchair. I said they might be at the beginning but I was sure they'd quickly get used to it, and that they'd probably like his readily available lap. He said probably so, and we both simultaneously realized he'd have to put a pad on his lap to protect him from getting scratched when they "make biscuits," as he won't be able to feel that any more.

Gary was snoring away when I came in this (Saturday) morning, but he soon woke up. He said he'd only managed two hours of proning last night. He also said the doc who'd done his flap came in to look at it and said it looked excellent. Keep your fingers crossed that it continues to do so.

I got a look at it myself a bit later, and I couldn't help thinking that the area in question reminded me of those old horror movies where the Frankenstein is held together by big zippers. I told Gary he had a huge (on later reflection, I shouldn't have used the word "huge") triangle of staples on his behind, and at the apex of the bottom left angle another short line of staples extended. I also told him he had three slim tubes coming out of the small of his back, leading to small attached bags that collect the drainage from the wound. I told him, combined with his finger, he was looking more and more Borg-like. He joked that they had grafted tails onto him (meaning the "drains").

Though he was still a little worn out from the surgery, he had already done some weights. He also told me he'd been able to eat all his breakfast again. I said I'd noticed his appetite had improved this past week and he was eating much more than before. He said his primary doctor (Lin) told him that as long as he wasn't nauseous (which had happened one time a few days after he got here) he should pack it in; as a result his increased eating isn't completely a matter of appetite but of determination. It also helps that his jaw muscles are getting used to eating again; I guess after a month of not being used, they atrophy too – he said they definitely tired out when he first started eating again.

He asked for the copy of one of his papers that he'd had me print out so he could make final corrections for publication, and while he did that and snoozed some more, I looked over yesterday’s blog entry and then uploaded it, put it on the website, and mailed it out to people – we got internet connection in his room a few days ago, though Gary still isn’t up to doing anything on it. He did want to know the URL of the blog, but I wouldn’t tell him. I’m afraid that when he looks at the blog he’s going to be embarrassed by what I’ve written and then I’ll either have to stop writing it or I’ll have to start censoring myself about what gets written (of course, maybe neither of those outcomes would be a bad thing ;-)), or another possibility is it might cause him to censor what he says to me because he’ll be acutely aware that it could show up on the blog.

Around noontime they turned him to his other side, and he decided to do a bit more of the weights, since being on his side means it really isn’t convenient/possible in the same session to do all the exercises with both arms. He said the OT had come in earlier and told him she expected him to look like Arnold Schwarzenneger by the time these five weeks of healing from the surgery were up. I joked that that was better than Pee Wee Herman (hey, I can be cruel). He laughed, then said he had noticed his laugh was different and said he had been told that nerves for laughing were below the T4 level . I said I hadn’t noticed and to laugh again so I could see. He looked nonplused, then started laughing at my request that he laugh. Then I saw what he meant – his laugh seemed like it was from the throat up. “No belly laughs,” he put it. “But I still find things funny,” he assured me in complete seriousness, which sent us in to more peals of laughter (we’re easily amused) at the thought that I might have worried it was otherwise – I mean, I have enough evidence to the contrary. He sobered and said it would be terrible not to find things funny anymore.

But we had plenty of opportunity to see that his funny bone hadn’t been broken, since as he did his weights we went into Schwarzenneger routines. “I’ll be back,” “You’ll no longer be a girly-man,” etc. I wish I could remember those skits from old Saturday Night Lives where they parodied musclemen.

As he worked out, I told him again that I was very lucky with my apartment, that I thought I might have gotten the best location in terms of noise. In the apartment building across the parking lot, I notice the people on the upper floor like to sit on their terraces, which face the parking lot, and socialize. Their voices carry, but as I’m tucked into the back side of the other building, I can’t hear them unless I go outside. Also in the apartment kitty-corner to me, I always hear some little kid crying when I pass by, so I am glad I don’t have the apartment next to them. This started Gary laughing again. He told me that the previous night after I’d gone, his roommate’s speaker phone had gone off, and he’d recalled how I’d said if I were him I’d have to kill the guy. He said he’d flashed on the image of the people from CSI confronting me with incontrovertible evidence of how I’d been the one to commit the murder, and how I’d then laughed and said with a maniacal gleam in my eye, “Yes, I killed him, and I’m glad.” Maybe no one else has noticed this, but it seems to us the CSI’s seem to have gone down in quality from how they first were, with the perpetrators seemingly always completely unrepentant about killing someone, indeed feeling the act was justified for some trivial reason.

I could empathize with them if the reason was because they found their victims too noisy ;-).

Norma called me about that time, and when I asked if she wanted to talk to Gary, she seemed astonished that it was now possible to do so. They happily chatted away. She and the rest of Gary's siblings, as well as one of his nephews, will be visiting us mid-June. (Hmm, I just realized they'll be coming the day before I'm getting kicked out of my apartment; I may recruit some moving help ;-) Gary's cousin Helen has offered me the use of her condo for a few days at that time (!), and perhaps longer depending on when the remodeller needs to work on it.)

My little sister then called, and she wanted to know the URL of the blog. Unthinkingly, I gave it to her. After we hung up, Gary pointed out he too now knew the URL. Damn. I'll just have to keep his computer out of reach. Or get one of those parenting programs that disallows children from accessing certain websites.

Non sequitur. When I walk down the hall from the elevator to Gary's room, I often see one or more of the patients just sitting in wheelchairs close to the nurses' station; I often see one young man in particular. It occurred to me that he and these others might be people who don't have anyone here with them and so they are sat close to the nurses' station (I'm not sure these patients can move their own chairs) so that they can be around others and the bustle of activity and not always stuck in their rooms on their own. I told my theory to Gary, and he thought it likely, saying it would be very hard to go through this on one's own. He's said that several times, and he pointed out that he can never say that without choking up, that he so appreciates me being here with him through this. I remember how hard it was for me that fall a year after I got CFS. I felt so sick most of the time, and Gary was off on sabbatical. I didn't feel it fair to ask him to come home, but I felt very alone (my fault, since I didn't reach out to anyone). Anyway, when this happened to him, I knew I didn't want him to feel alone the way I had.

Sasha and Lauren Shibakov came to visit us in the evening. They brought Gary six bars of dark chocolate (the kind he likes), two of them organic, so they're healthy ;-). Combined with the four bars I had bought him, I think he's set for a while. (But he does have room for the French chocolates, Laura ;-).) They also brought me some organic zukes :-). I had emailed them and asked that if they went by an Indian store (they were going to the DeKalb Farmers Market and I knew there were such stores close by) could they pick me up some Indian Basmati rice (American basmati is different, actually being a hybrid of American and Indian rices). I was going to be out of basmati as of Sunday (today), and strangely that seems to be the only kind of rice I tolerate on a regular basis (more strangely, in the past I discovered that the brand makes a difference, so always get one particular brand to be safe). They agreed to do this, but I had forgotten to tell them where they could get it, and a later email didn't make it to them on time. So when they were here, after already having done their shopping, they still offered to take me to the store to get some. Then they said I didn't need to come along, that I could stay with Gary. I felt funny about sending them off on some trip just for my rice, especially if I wasn't going to accompany them, but they said it was fine; besides, Sasha pointed out, based on my blog it wasn't like I was going to be useful as a navigator.

So they got my rice and did some shopping of their own at Patel Brothers. They picked up some wonderful mangoes for themselves and Gary – I brought one back to the hospital this morning cuz it looks and smells ready for eating. Ripe mangoes give off such a wonderful perfume. I am an expert at cutting them so that they open up into a diamond pattern, having picked up this technique from some gourmet cooking show I watched long ago.

Sasha and Lauren said they thought of transferring my rice and the mangoes to my car, which they had parked right next to, solving the problem of my car being locked by Lauren using a rock. You may remember this was the same solution she put forth the last time they visited when they found me next to my car with my keys locked inside (is this the type of thing they taught you in engineering school, Lauren?). They stayed awhile longer, and then we said our goodbyes, and shortly after I said goodnight to Gary.

Now it is Sunday morning, and so far it is pretty much a repeat of yesterday. He says he always feels off in the mornings, maybe cuz his sleep isn't deep and uninterrupted for eight hours here. He generally feels better by noontime though. I found him doing his weights, and now he is snoring away again.

A short time later, the nurse came in to turn Gary to his other side. I asked her some questions about Gary's position, because he seemed too far over on his back. He had slipped over some, and she showed me how to reposition him. But she also told me that I was being too much of perfectionist about the positioning, and to relax and take a deep breath. Of course, being told to calm down just makes me mad ;-). Anyway, now I know how to reposition him. But I do understand it is a compromise between the ideal position and his comfort – he isn't comfortable being over on his side as much as the ideal would be, and since he's the one who has to put up with it for the next five weeks, I can't very well fuss about it to the extent I would like to.

But I reserve the right to fuss a little. ;-)

We called his mom in the early afternoon and got the news that she will be making the trip to come visit him when the rest of her children do. Gary was thrilled that she would be able to make the trip too.

 Janet Rogers read my account of getting together with Gary, and told me she had a photo of the two of us from May '79. Since I started at Auburn in Fall '78 and didn't start doing things socially with Gary until after spring break '79, this was at the start of our life's journey together.

Blog at http://drpeg2003.blogspot.com/

May 29, 2006 (10:23am)

Janet Rogers read my account of getting together with Gary, and told me she had a photo of the two of us from May '79. Since I started at Auburn in Fall '78 and didn't start doing things socially with Gary until after spring break '79, this was at the start of our life's journey together. I have uploaded that photo to the blog, at http://drpeg2003.blogspot.com/ . If you are currently reading the blog, scroll down.

Pretty cute, huh? ;-)

(Gary thought so. I didn't tell him about the picture beforehand. I downloaded it to his laptop and then held his laptop above his head so he could see it. "Oh, wow," he said. "Who would have thunk it? That's a cute picture." He looked at it a long time. I later asked him what he'd meant by the "Who would have thunk it?" That we'd ended up getting married? That the Rogers had the picture? "That everything that's happened in the twenty-five years since has happened," he replied.)

The other morning, when I hadn't arrived yet, the OT came in and hinted that Gary was indeed going to need to hire someone to come in to help him at least in the morning. We started wondering where we would find such a person. Shepherd has a "bridging program" that is supposed to aid in easing a patient back into life and home and work, but when I looked through the binder they had given Gary, tho it covered various useful topics, they only had general suggestions for where to find such people – hospitals (nurses), rehab programs. A lot of the suggestions for where to look I doubt we'd consider – high schools, frats, sororities – as we'd want someone with experience at this kind of thing and medical knowledge. So if some Auburn-Opelikian reading this knows of such services in our area . . . We're not sure yet exactly what we'd need the person for.

Coincidentally I got an email today (Monday) from a Canadian friend who does this sort of thing; up there they call such a person a "Personal Service Worker." My sister-in-law Dolores had suggested we look into "Independent Living Centers" for resource information, so I looked on the web to see if there was one near Auburn and if it would have such a program. The only such center in Alabama I could find was in Birmingham, tho Montgomery seems to have some related offices that might prove useful.

This reminds me, I forgot to mention, when Alice Stephens, Bob Stephenson's sister, came, she showed us pictures of Canine Assistance dogs interacting with their new masters at a training camp. (She works with the program.) It is really amazing what the dogs can do, and I'm sure they're also a great emotional comfort to their owners. I wonder if Tigger and Blackjack could learn how to do what these dogs do. . . . Nah, they're too old to be learning new tricks. The only tricks they've mastered in fourteen years is to come out to their cat bowls when food is being put into them and to jump onto the table and stare down at Gary's plate at dinnertime.

No, that's not fair. They've learned to obey one command. Sort of. When they were kittens they got fat, so I devised an exercise program for them: they had to walk around the outside of the house with me before they got to eat. Over the years, Tigger's walk has devolved into a rather random one, though Blackjack is desperate enough to pretty well keep on track – he is a bottomless pit when it comes to food. Fortunately neither of them has been fat in a very long time, but I kept up the practice just because. Somehow I doubt that Sylvia is walking them, so trying to get them in the habit again when I return will probably be like pulling cat's teeth.

Today seemed rather a quiet day – a lot of the staff had Memorial Day off, Gary's roommates are mobile and seemed to be spending the day elsewhere. There was a picnic lunch out in the garden, which of course Gary couldn't go to. I brought him a plate containing a hamburger on a bun, baked beans, potato salad, a slice of watermelon, and in addition brought him a bowl of vanilla ice cream with Hershey's chocolate sauce, a chocolate chip cookie, and a Sprite (not that he was able to scarf this all down – I warned him at the start that my eyes were probably bigger than his stomach). He said the food was far better than the hospital fare he'd been eating. I reminded him I'd make/bring him anything he wanted, but other than that kabob he had awhile back and a mango shake yesterday, he hasn't taken me up on the offer. (BTW, Sasha and Lauren, Gary said the mango was great!). The rest of the afternoon he read from the book "Incompleteness," a biography of Gödel (fortunately it was a paperback, since he discovered that while lying on his side as he is he can't hold a hardback), while I did a search for hotel possibilities in the area (I found about five – I'll have to take a day soon and go around to them to check them out) and also finally got around to answering a few ancient emails. Then we watched more of Dylan. I am liking the DVD more – they've finally gotten to the point where I'm familiar with the songs (Blowing in the Wind, for example).

Tonight I am having a massage with a different person (it'll be odd having it at eight at night, but that was the only opening until next Friday). Tomorrow afternoon I am trying the local chiropractor. On June 13th I have an appointment with an orthopedic doctor – who is connected with Shepherd. Shepherd has outpatient rehab, so it's conceivable I'll being doing some rehab program here as well.

So, I am hoping one of these avenues will lead to improvement in the state of my back. :-)

All for now.

Blog at http://drpeg2003.blogspot.com/

May 30, 2006 (9:36pm)

I read some old emails to Gary today. He commented that he was touched at how many nice emails, cards, and letters he'd received from so many people since the accident.

My older sister called while he was trying to get down lunch (he's been feeling nauseous today, and that chicken and rice just didn't agree with him). I passed the phone to Gary, and he thanked her for finding out all the information on Shepherd she had. He said he really liked the people here, that they all seemed knowledgeable, and that the place was definitely more organized in terms of aftercare and starting him on rehab (oops, I automatically wrote "research" there!). While they were talking, the flap doc, wearing a bright blue bold-printed shirt and giving his usual hearty greeting, came in to check Gary's surgical wound. We like this guy, him and his showboat streak. We liked him even better when he told Gary his wound was looking good.

Today they took off Gary's pressure hose (not sure what their technical name is – maybe those are the ted hose) – the ones that wrap around his legs from ankle to mid-thigh and are plugged in to inflate and deflate, the aim being to prevent blood clots. Instead he goes back to getting shots of blood thinner in his belly.

Supporting his point about the rehab program here, after lunch the tech and OT came in to put him through his paces – arm and back exercises using dumbbells. We asked what his program should be – I knew from my weight training days that for strength one would do low reps and high weight, with at least a day's rest between sessions, but for endurance one would use high reps and low weight, possibly more frequently. They want him to develop both, so want him to work out every day with three sets of each exercise using low reps (8) and high weight, meaning the last couple reps of the last set should definitely be an effort. (If he isn't recovered by the next day, he can take that day off.) I left him to his workout and went back to the apartment to blend him another requested mango smoothie to make up for his not eating his lunch entree. When I got back he was on his stomach sweating out the last of his exercises. After the tech left I asked if they'd given him more exercises to do than the ones he'd been doing since his flap surgery. "No, they didn't," he replied. Then why was he sweating? I asked. He hadn't been when he'd been doing the exercises over the weekend. "Because I didn't realize that even on my side I can do all the exercises they'd given me before." So it's great that they came to his bedside and showed him how to adapt his exercises to his new state. At least I think it's great – I'm not sure he does. (Just kidding – he again told them when they came in he wants to get as strong as possible.)

Since he was still on his stomach, I wasn't sure how to get the smoothie into him. The stuff seemed to thick for a straw. I was going to find some juice and thin it, but he said to try a spoon on it. That actually worked quite well. Though he found it tiring to have to lift his head up for each bite, he said eating that way was actually easier than when I spooned the stuff into him while he's lying on his side (particularly since the head of his bed is not allowed to be raised very much). He was no doubt thinking of lunch time when the peas kept ending up on the towel I'd put around his neck instead of in his mouth as the airplane entered the hanger from the side so that the peas wouldn't go straight down his throat and choke him (my little friend from France might need the airplane reference explained). (I did learn it made a big difference if I put on the spoon only a few peas at a time.)

After that, I set up a tape of "Bob and Ray" and left one of "The Shadow" in Gary's reaching distance while I went off to the chiropractor. I had been prepared not to like the chiropractor because neither massage therapist gave him a resounding recommendation. He did some testing no other chiropractor had done, but it seemed reasonable – range of motion, etc – and the adjustments were smooth, IMO, and I left with a good feeling toward him. I am going to see him again before making a final decision, but I feel I may stick with him.

Back in Gary's room I discovered a ton of mail had finally caught up with us! Thanks to Norman and Margaret Groteluschen; Brad Bailey, who sent a bar of chocolate and offered to help Gary make some room in his office so a wheelchair can get in there (and if you've ever seen the stacks of papers all around Gary's office you will know why a reorganization is necessary); J.P. and Pam Holmes, who sent a three-set DVD collection of mystery stories (that's great – we love to watch mysteries); Ferenc Fodor, who scrounged Hungary for Sudoku books, couldn't find any, so made a trip to Italy to get some (okay, he didn't really make the trip just for that, but he did find three Sudoku books there for Gary); Mom Gruenhage, who sent along three more pics of Gary, all of these with Bob (I liked best the one with four-year-old Gary on the trike, three-year-old Bob next to him); Donne Leigh, who sent another DVD; Jerry and Theresa Vaughan, who sent more tapes (Jack Benny, Car Talk) – and the Car Talk tapes they first sent to Birmingham finally arrived as well!; a postcard from some of the attendents at the 2006 ASL Summer meeting (I'd list your names, but there are two I can't make out and I forgot to ask Gary if he could); Marilyn and Steve Foreman; Lois Stavig.

Also arrived was email thru Shepherd's setup from Dave Gauld, and two from Dimitrina Stavrova.

Also finally arriving from Birmingham were cards from Mom G, Mr. and Mrs. Muñoz, Dave Johnson. Sorry, little Laura – yours hasn't arrived yet.

And today (Weds.) we got 18 long-stem roses from Judy Roitman and Steve Lombardo! (Gary and I are going to split them between "his" place and "mine.")

Whew!

To finish up what should have been Tuesday's entry:

To the person who looked at my '79 picture and said I looked like a hippie wannabe . . . Hippie wannabe? Okay, there are certain aspects of me that could be used to support your contention (um, er, om, what could I mean?), but I was much too straight to seriously aspire to hippiedom. (Gary told me soon after we were together that I was the straightest person he knew). . . . I told Gary what you said, telling him I couldn't see what about the picture might make you say that, and he said he could see how you might get that impression, what with the long hair and the wire rims. I pointed to myself, currently sporting long hair and wire rims. "You're still a hippie wannabe," he said.

Groovy.

(And by the way – your little printer mishap you blamed on me because you were discombobulated by seeing that picture has nothing to do with me. It was your own karma.)

Blog at http://drpeg2003.blogspot.com/

May 31, 2006 (9:46pm)

Today was a class day for me. Unfortunately class began at the ridiculous time of 7:15 am. Which of course meant I shot awake at 3 am, heart pounding, worried I would wake up too early, not be able to go back to sleep, feel really lousy during the class (thus not taking full advantage of it), and then feel really lousy the rest of the day. So I laid there going through a progressive relaxation procedure. Forty-five minutes later, after going through the procedure three times, I gave up on that tack and meditated. Over an hour later I lay back down and drifted off into sleep for about an hour, then got up. I do not know why I react that way to first-thing-in-the-morning obligations, but I have since my college days. In fact, I considered not returning for a second quarter at Auburn when I started graduate school, because the pressure I put myself under in my coursework combined with the stress of having classes at 8 am (the only times the classes I was interested in were being offered) was so great. I know that I should just accept that this is the way I am, and then paradoxically, the problem would cease, but I haven't managed to do that yet.

I didn't have too bad of a day despite the inauspicious start. From 7:15 to 10:15 I learned about the bowel and the urinary tract; the programs those with SCI (spinal cord injury), possibly aided by their care givers, need to follow in order to keep these systems functioning as well as they can given the injury; the problems that can arise in these systems under the circumstances; and the symptoms and treatment of those problems. The problems can be quite serious, not simply the social embarrassment that can result because the signal no longer gets to the brain that bowel or bladder are full. For example, if one consistently allows the bladder to get too full, the urine can back up into the kidneys and cause kidney disease. In fact, the lecturer told us, as recently as ten years ago, kidney disease was the number one cause of death in those with SCI, because at that time it wasn't understood how important it was to keep the bladder under 500 cc full. On the other hand, one doesn't want to keep it constantly drained by using something like a Foley catheter (which is what is put in first in the emergency room) because a) there's a high risk of infection because it is opened to the outside when emptied, thus allowing the possibility of germs getting in and b) the bladder shrinks to the size of the balloon at the end of the Foley (which is what anchors it in the bladder) and one ends up with hardly any capacity for the urine at all. The lecturer did a demonstration of how the catheterization is done (later we will learn hands on, as we will all the other things covered; someone will have to do these things for quadraplegics, and do them for paraplegics at least temporarily under certain circumstances – illness, as a result of surgical procedures, etc.). She asked the young male pharmacist who was sitting in on the class if he wanted to be the model, but he declined (turning a pretty shade of red in the process). So she used a plastic model of the male apparatus. At the end, she said, "And now we're all done." She then vigorously yanked the catheter tubing from out of the model. All the females in the class laughed uproariously. The pharmacist nearly fainted. The lecturer commented that one develops a certain twisted sense of humor when living with/working with people with SCI (and probably in being such a person too) – that it is necessary to deal with it. Her husband is a T12, her father a C4, by the way.

That reminds me. It's interesting how everyone labels the patients here by the level their injury took place at. It starts with the medical staff, and then patients and their families pick it up. In the class I was in there were three T's – paraplegics – and five C's – quadraplegics. One of the quadarplegics is a fourteen-year-old boy.

We also learned about autonomic dysreflexia, which is a blood pressure disorder that *can* happen (but it won't necessarily) to those with SCIs above the T6 level (and thus Gary is at risk, being a T4). Apparently it is a disorder unique to SCIs, that is, if you don't have a spinal cord injury, you won't suffer from the disorder. It is the reaction of the body caused by painful nerve signals trying to get to the brain. If not treated immediately it can lead to stroke or death – it is an emergency situation. There is a sequence of steps to go through in order to relieve the problem, and one knows it is relieved by an immediate cessation of the symptom or symptoms (only one of these need occur – sudden pounding headache, sudden heavy sweating or blotchy skin or goose bumps above the level of injury, sudden stuffy nose, sudden high blood pressure). One needn't go through all the steps – stop when the symptom stops. The sequence is: sit straight up; loosen clothing; do the bladder program, even if that means catheterizing in the middle of a crowded concert – that's preferred to dying there; do the bowel program; strip and check the skin for any changes (Were the shoes too tight? Was there a pebble in the shoe? Was something pressing into them somewhere? No patient at Shepherd's wears jeans, and it is recommended that they no longer wear them "on the outside": too many seams and pockets and rivets that can press into the body); check hands and feet for ingrown nails; if all the above has failed, go to the emergency room or call 911.

As you might surmise from the above, the number one cause of dysreflexia is a full bladder, number two (pardon that) is a full bowel; number three is a skin problem.

Another thing that was noted throughout the lecture is that in general, doctors, hospitals, etc., are not familiar with SCI, so anyone Gary needs to see will need to be educated. He will need to find a doctor willing to work with and become educated about SCI. He will need to go to a urologist every other year for an x-ray or something called an IVP because SCIs have increased risk of kidney stones. An interesting "little" thing, is that even though he might not feel the pain sensations, any procedure that is typically done using numbing (such as when a doctor removes an ingrown nail) will still require that he be numbed – otherwise those pain signals will still try to get to the brain and dysreflexia can result.

Throughout the three hours I kept thinking to myself, "God, I hope that doesn't happen to Gary, God, I hope that doesn't happen to Gary." I know they wanted to present the serious consequences of not taking the care that is needed with these thing, and they certainly succeeded with me. I can just picture myself quizzing Gary daily on certain matters one would normally keep to oneself ("How's your poop today, honey?") We'll (or should I say "I'll") have to find the balance between being concerned and neurotic (I'm sure my critique group can think of the other very appropriate adjective they've used to describe me). I think I tend to the latter. ("No," you say in disbelief.)

Well, I took fourteen pages of notes, but I think I'll spare you the rest of the details here. If anyone is interested in more details, the course is actually up on a website, www.myvitalconnections.org You'll need a username and password, which you can get from me (if a lot of people request it, I'll put it on the blog in the "my profile" section – I'll let you know if I do this).

In the early afternoon the PT and OT came with housing recommendations based on the information about and pictures of our house that Jo had gotten. It appears that it won't be as drastic a renovation project as we feared it might be. A few doorways need widening, screen doors and some inner doors need to be removed, roll-under sinks were recommended, and carpeted floors would be better changed to hardwood. Other things are furniture changes – remove some book shelves, get a smaller bed in the master bedroom and take out some of the other furniture in there so Gary can get around to the bathroom. Our entryways have only about a 2" step-up, so Gary should be able to roll right in, or at worst do wheelies over them, no ramp likely being needed.

The floor nurse came in and told Gary that they were going to make up a schedule for him so that he could still attend some of the classes he'd been scheduled to attend. They are going to find ones that don't have many other people in them (the classes are offered regularly, and people are assigned to certain ones on certain days), and then they're going to wheel his entire bed down to the classroom! I think it's so great that they're finding ways he can still participate in their program, rather than just lie there in that bed. I think it's good he'll get the little change of scenery and be able to do some interaction with others.

Other people came in and looked at his boots he'd been wearing. They decided they were too small and will come in next Tuesday to make casts for him (I had been under the impression they were going to do that today). Until then, they want him to keep his feet flexible by stretching them – so they will bring one of those belt loops he'd been using before for stretching his legs. I'll put it around his feet and then he'll pull on it to stretch his feet.

Gary mentioned he can still feel the rods and pins in his back. It's not painful, he says, but can get quite uncomfortable.

It had been a long day for me. At the end, while turning off the light, I asked as always , "Anything more you want me to do before I go?" His roommate's speaker phone went off. Gary looked at me. "Murder that guy on your way out," he said. We laughed.

Aye, aye, sir.

Blog at http://drpeg2003.blogspot.com/

June 1, 2006 (7:44pm)

Gary was able to prone five hours last (Weds.) night! This is good not only for the healing of the bedsore, but also for when we go home – if he can prone, he can go longer without having to set an alarm and turn himself during the night. (If he can’t prone, he will have to turn himself every two to six hours, depending on skin responses, whereas if he can prone, he can stay in that position up to eight hours.)He said he thought the position was getting more comfortable, and I sure hope that continues.

Gary's breathing has significantly improved since those beginning days. At the start of his breathing therapy with his spirometer apparatus while in Birminham, he could only get up to 750 ml of "inspired volume." He told me today he is up to 1750. He asked "the breathing nurse" what his goal should be. She said someone his size should go for 1500 to 2500. He told her he would aim for the high side.

Also on the spirometer is a separate chamber that has a float valve that raises to "good,” “better,” or “best," when he inhales. He is supposed to inhale slowly and try to get that valve to hold steady at the "better" or "best." He consistently gets it to stay at the "better" level.

Non sequitur. Gary got an email from someone today (and just to note, because he must still lay flat, not to mention on his side, he finds it essentially impossible to use the laptop as of yet), who mentioned I have gone a bit self-conscious in my blog/emails. True, and that may still pop up, though I keep telling myself there's no one holding a gun to your heads making you read this.

This person wrote "If logorrhoea helps her, that's good." I had to look up "logorrhoea," a sinking feeling in my stomach.

From dictionary.com:

Main Entry: log?or?rhea
Variant: or chiefly British log?or?rhoea
/"log-&-'rE-&, "läg-/
Function: noun
: pathologically excessive and often incoherent
talkativeness or wordiness that is characteristic
especially of the manic phase of manic-depressive
disorders —log?or?rhe?ic or chiefly British
log?or?rhoe?ic /-'rE-ik/ adjective

I later found out that the British use of the word doesn’t suggest pathology, just loquaciousness (and the email author is British, and I do want to emphasize that the person said many nice things in the email), but at the time I didn't know that and the use of the word fed into my fears. Excessively detailed, incoherent – that was what I was afraid my blog entries were (along with "boring" in parts). That was why I had warned people that it had become diary-like (stream of consciousness). Because of its form/flaws I have been surprised, and pleased (odd as that might sound under the circumstances), that some people have suggested I turn the blog into a small book, that it might help others in similar situations. After we go home, after things get more settled, I will have to think about that. I know that in its present form it is not like my fiction pieces, which I slave over, but polishing it too carefully might not be wise in this case – though I'm sure editing will be a necessity – people don't need to hear quite so often about my "noise problem." ;-)

I read the email and then the definition to Gary. He misheard "excessive" as "obsessive," and said that it was indeed true that I was obsessive, obsessive when it came to getting him recovered and back to independence and that that was great.

Typical Gary, finding something good in my neuroses ;-)

I organized his room a bit – it had become quite cluttered. When I thought I'd finished, Gary said, "Hide the chocolate." The bars were sitting on top of the chest of drawers, now clearly visible, and it didn't seem like him to worry that the nurses would take any. "In case anyone else brings some," he clarified. Evidently he wouldn't turn more down ;-)

(The above paragraph is an example of incoherence in writing since it has nothing logically to do with what came before or what comes after.)

We had a nice visit with the Browns in the afternoon. They brought up some lovely, fresh-from-the-garden, blooms-still-on, organic zukes from the Transues! (Oddly, I have grown Oriental eating squash family members like mo qua and luffas and pickling melons in abundance, but have never had any success with zukes.) The Browns hadn't seen the '79 picture of me and Gary, and since we'd just received a print of it from the Rogers, I showed them that. I told them that Janet Rogers had included a note that said that they must not have known who I was at the time, because the only name on the picture was Gary's!

Earlier in the day when we'd read the card from Janet Rogers, we'd laughed that it was like a Remington Steele moment: "Gary Gruenhage and unidentified woman." (Probably only the Steelewatchers will get the reference.) Gary had then recalled our first meeting (I haven't told him I've put the whole saga on the blog). He said he remembered me coming into his office with all my notebooks, and when he'd opened them, there were all the things he'd intended to cover in his course. He couldn't remember exactly what he said (and evidently I was still in a daze at the time because I can't remember either ;-)), but it was something like, "We'll work it out." (I don't remember not being allowed to present a lot of theorems, so he must have added material.) He said he hadn't wanted to discourage a student from taking the class because there were so few of us. The previous year the same course – which he'd been scheduled to teach – hadn't made. He said that at the time he wasn't well-known by the graduate students, and they would wait until someone like Ben Fitzpatrick was teaching it and sign up for it then.

Things might have been very different for us both if I hadn't gotten in that class.

And for no good reason I will end this entry now. :-)

June 2, 2006 (2:34pm)

Don't tell Gary, but I complained to our case manager about Gary's noisy roommate. I know Gary tends not to complain about such things – and was definitely not inclined to do so these past few days. His other roommate left the hospital, so it was only Gary and the loud guy in the room and thus it would be clear who was voicing the complaint if it were brought to the loud man's attention. I thought today was a good time to complain about it because two more people have moved into the room, so now it is full and the loud guy won't know who made the complaint.

The case manager knew who I meant, because all his roommates over the time he's been here have complained about his taking and making calls on his blaring speaker phone during the night – even though quiet time officially starts at 9pm. She and I went to the charge nurse, and the nurse said she is going to work on getting Gary transferred to another room, possibly a semi-private one (two people). They would have tried to get him transferred to a semi-private room once he starts his rehab anyway, the four-people room generally occupied by the "skin patients" and the sem-privates by the rehab patients, the theory something like the skin patients needed less privacy cuz all they do is lay around and therefore can sleep any time of day or night. It doesn't seem right that the solution is to move the complainers and foist the guy on a new set of people, but that was the only solution offered, and since it's to Gary's benefit . . . . Apparently it does no good for the hospital staff to talk to the man about it – I was told he'd been talked to before about it, and he just ignores what is said to him. The calls come directly to him, not through a switchboard, so they can't shut them off that way. I have thought of pulling the plug on my way out at night. ;-) Actually, that wouldn't do any good, because he is mobile and still in his chair when I leave at night, so he could plug it back in (he has full use of his arms and has no hearing problems, so there is no medical reason he needs the speaker phone, especially at the volume he keeps it).

I told the case manager that Gary would probably tell me I shouldn't have complained, that he could put up with it, but she said he needs his sleep and that they move people all the time here, so he need never know I was the one who caused him to be put in another room.

So, shhh, it's a secret between you and me.

(Another thing that prompted me to complain about this now is I've noticed he's been sleeping more during the day since his surgery, so I feel his sleep during the night is of even greater importance.)

I went to the chiropractor again today, and since he was running slightly late, I tried out his massage chair, shaped like a lounge chair. I'd never been in a massage chair, and it was an interesting experience. It felt like some alien being with pairs of appendages running down the length of its body dwelled in the back of the chair and was kneading and tapping various parts of my body. I came to no conclusion about the effectiveness of the chair. I will have to give it another trial. Maybe a few more.

At one point during the chiropractic adjustment I felt I had fallen through the head cradle part and asked him if he'd been able to push hard enough because of that. He said he had and that the art of chiropractic was in not killing the client. I told him that was a good goal. He said the insurance companies preferred that as well.

I am happy with his technique, and I've signed up for his "monthly plan," which will give me eight adjustments for the price of four. Besides his technique, I also like the fact that he has done more than just give the adjustments. For one thing, he has given me stretching exercises to do. He also suggested that for my laptop I get a carrier that rolls on wheels. He told me to try the Office Depot across the street when I asked where I'd find one. I went there, and they had one on sale at half-price – $33. I bought it and am really happy that I did. Not only does my laptop fit in the padded middle section, but everything I was carrying in my backpack fits in there as well. The handle pulls out to the height of my waist for when I want to roll the carrier, and in closed position the handle pushes down to the height of the carrier – then the carrier can just be held by two handles. I suppose travelers know of such things, but this is a new nifty item to me.

While I was in the massage chair, our State Farm agent called to ask about Gary. She has done this a couple of times, and it surprises me. She always says if there's anything she can do, now or when we get home, to let her know. I wonder how far I can take her up on that ;-)

When I returned to Gary's from the chiropractor, I found him asleep. That was when I slipped off and complained to the case manager. I also asked her at that time if she knew if insurance would cover any of the home modifications, since my brother had asked me that question. She said they don't, but perhaps I could find some ideas for resources in what she called "the Christopher Reeve book." She gave me a copy – it is actually called "The Paralysis Resource Guide." I didn't find anything related in it, but it looked like an interesting book, and I brought it back to Gary's room. Later in the evening, when I returned from dinner, Gary said he'd read some in it and liked it – he said it really "told it like it is."

Sometime during the day the tech brought around Gary's schedule for next week, and we were amazed. We expected they'd have a few things for him to do, but they've got him scheduled for up to two hours of activity for each of four days next week. He'll have an intro class, a community class, a counseling class, a "been there done that class" (I'm not sure what any of those thus far mentioned entail), a bowel class, and a bladder class. He'll also meet with the psychologist, the recreational therapist, and I'm sure his tech will be in every day, as she has been this past week, for his weight training (and I'll stretch his feet). He also goes to vocational rehab one day.

All for now except for mail call: Thanks to Norma, Beth Fletcher, and Jean Schmidt.

June 3, 2006 (9:10pm)

The charge nurse told me the noise problem in Gary's room had been solved: they had talked to the loud guy again, and he agreed to turn off his phone at 10 pm; also if anyone uses a TV after that time, they must use headphones. Yea! The first thing Gary said to me this (Sat) morning was that he had slept really good. Double yea!

This afternoon was filled with more classes for me. We spent three hours learning about the spinal cord, the respiratory system, and the skin, and how each is affected by SCI. The lecturer first labeled all the vertebrae and told us what is affected by each. I won't go thru all that with you, but just mention a few things. One thing I hadn't realized about Christopher Reeves' injury is that he couldn't hold his head up because of it – he could've used straps to do so, but apparently chose just to always be slightly reclined. Something else that we've noticed come into play is that with a injury above T8, there is a problem with balancing the trunk. In general, people with such injuries when sitting in their wheelchairs must use a chest strap as well as a lap belt so that they don't fall forward, and must have lateral support so they don't fall sideways.

One very significant change is that one doesn't have the full use of abdominal muscles until T12, which means if one's injury is above that, one can't cough as one did before, which means one can't get rid of secretions as well as before, which means bugs can grow, which means the risk of pneumonia is increased – in fact pneumonia is the number one killer of those with SCIs (sometimes I think I'd be happier not knowing this stuff).

The lecturer gave us the signs of pneumonia, and pointed out those which meant call the doctor immediately (mucus that is green or yellow or red; fever of 101 or more, no matter the reason for it). The lecturer gave us the treatment of it (in addition to calling the doctor): cough frequently, using the assistance of a family member if one can't cough up the secretions on one's own (the lecturer illustrated how to do this, and at some point we will each have "hands-on" classes where, under the supervision of a nurse, we practice on our family member this and other things we have learned); drink plenty of fluids; turn every two hours; try postural changes to help the drainage; percuss the chest. Prevention methods include getting pneumonia shots every five years and flu shots every year – not just the SCI person but all family members (I was not happy to hear this, as there is some controversy about CFS people getting flu shots – I haven't gotten them in ages, avoiding the flu by just not being around other people, which brings us to –); avoid people who are sick; dress for the weather (not as straightforward as before injury, which I'll explain momentarily); eat a balanced diet; do not smoke and do not let others smoke around you – second-hand smoke kills off the cilia in the lungs, and the cilia are necessary to help pull "the bugs" out.

Oh, I just realized one of the Environmental Health shots I give myself is an antigen for flu (the antigen changes each year). So I think I don't have to get a regular flu shot. I'll have to look into this and also see if they offer some antigen corresponding to the pneumonia shot.

Back to the lecture. A few other of the potential changes after SCI that are governed by the spinal cord are changes in heart rate and blood pressure and temperature regulation. Heart rate tends to go down, and the body might do such unusual things as have the heart rate decrease when one exercises, which means it might take some time to get used to exercise. Blood pressure tends to be lower, and this reminds me of something I forgot to mention concerning dysreflexia. One needs to know what one's normal blood pressure is now, because in dysreflexia it goes up, which could put it in the "normal" range for an adult, but be way too high for the one with SCI – for them 140 over 100 could be like an average person being at 180 over 120.

Another thing about the blood pressure is that since the blood will now collect in the legs since they aren't being moved about, the person needs to wear a binder around their belly to keep the fluids from collecting there and ted hose on their legs to help the blood move back up and prevent clots; if that's not enough, that is, the person still experiences dizziness, ace bandages are wrapped around the legs.

In terms of temperature regulation, the person may not be a good judge of how hot or cold they are, and it could change from moment to moment. So they should dress in layers, always have a jacket with them, etc. The best way to see what their temperature really is is to feel them. They may be able to do this themselves – touch themselves somewhere they still have sensation – and see if they feel too hot or too cold. But they may not be able to judge this for themselves, and so someone might have to do this for them. If they are too cold, more clothing is the obvious solution. If too hot, less clothing, misting them, or wiping them with wet cloths are solutions (they may not be able to sweat like they used to, but the misting or wiping with cloths will result in the evaporation process, which will cool them).

The last part of the lecture was on the skin, focusing on the horrors of "pressure ulcers" (bed sores), which of course we are all too familiar with. The guy pointed out that it was far easier to prevent them than to have to have the $130,000 flap surgery and then undergo the inconveniences that result from it. Don't we know it. Some time ago we were bitching about the care at Birmingham to the skin nurse here, saying that you'd think hospital personnel would be aware of such things and take preventative measures. She said believe it or not, a significant number of patients arriving at Shepherd had the sores. She said Shepherd people go around and lecture other hospitals about it. Apparently other places don't think of the possibility with those with SCIs, they think of it as a geriatric problem.

Anyway, back to the lecture. Other potential skin problems and how to deal with them were discussed, such as using a draw sheet to position a person in the bed instead of dragging them, which can cause shearing of the skin; avoiding burns by watching that one is not sitting too close to sources of heat and by keeping the water heater set at 120 degrees, etc.; avoiding yeast problems by not sitting around in wet bathing suits, drying oneself off properly after bathing, etc.; avoiding pressure sores by making sure the seat cushion on the wheelchair is properly inflated, by doing the weight shift program, by turning in bed on schedule, by being properly padded in bed (pillows must be placed in certain positions to keep the weight off bony areas), etc.

Etc.

The various problems are detected by doing skin checks twice a day, morning and evening. One looks over every inch of the skin to note any changes – color changes, bruises (figure out the source, e.g., did you get it because you are repeatedly hitting the wheel of your wheelchair when you are doing transfers?), swelling, cuts, scrapes, open sores, rashes. Figure out the cause for the change and treat it.

One must also touch every inch of the skin, looking for swollen areas, hard areas, warm areas. Those with SCIs are at increased risk of blood clots, because they aren't moving their leg. Signs were given – usually one limb is larger than it mate. Call 911 immediately and don't move the extremity or massage it. If they don't find a clot at the hospital, the cause for the change may be heterotopic ossification - abnormal bone growth in tissue - usually a joint. Blood tests or x-rays can be done to determine if that is the problem.

The lecture finished with a demonstration on a model of how to turn and pad a person. Hands-on learning will come later for me.

Unfortunately sitting all that time through the lecture set off my sciatica-like symptoms. I tried to shift around and discreetly get the pressure off my left bun, but obviously I didn't succeed. One of these days I'll learn to just do what I have to do, even if that means kneeling on the floor during the lecture or standing in the back – it's just that it's hard to take notes that way.

Non sequiturs:

- Gary told me that he can tell that the hole in his trachea is almost healed, though he can still feel something internally in that area – he knows something went on there.

- They've removed one of the three drains in his back, so that is a sign of progress (I found out in the lecture that the reason for the drains is so that fluid doesn't build up in the area of the incision – the increased pressure there could cause the incision to open).

- I was giving him a neck and upper back massage cuz he's gotten sore there from his weight training. When I started to go down his back, he told me to stop. Evidently I'd hit the line between where he feels normal sensations, and where things start to "go weird" (before sensation stops completely). He doesn't like being touched on the "weird" area, which of course is understandable.

Apparently the British use of "logorrhoea" does not suggest pathology. I will be editing that later blog entry where it was used. Be assured, I didn't seriously think it was being suggested that I had a pathological condition. But the American definition of it fed into my fears: all along I have thought that if I had more time I would polish my entries more, that I am a little embarrassed by the raw, unrevised state they are in. But if I took the time to get the entries in the form I'd like to, there wouldn't be many entries – just ask my critique group how long I go without showing them anything because I don't feel it's ready to be seen by anyone.

All for now.

Blog at http://drpeg2003.blogspot.com/

June 4, 2006 (5:39pm)

A large part of today was spent in trying to figure out where I would go after Shepherd kicks me out of my apartment on the 16th. Shepherd had given me a sheet that listed nine "Shepherd partner hotels," meaning they'd contracted with these places for special rates. One place Gary and I have stayed several times before, and I had already made my reservation for it but wanted to see if I could do any better. Three of the remaining places I eliminated due to price or the fact that there was no kitchen listed as coming with the room. Another place was eliminated because I somehow overlooked it. I called the remaining four places and put one on the "check it out if the others don't seem suitable" list because they said they really didn't have a room available for the dates I wanted it but would try to do some finagling if I wanted them to. That left three, and I added to that two Residence Inns in the area that I had found through travelocity.com.

I braved Atlanta. ;-) The first place, a Residence Inn, gave me a good feeling. It's on Peachtree Rd, but is a large property, and way in the back row are units that face a wooded area. The units are what they call "cottage style," a small number of rooms per building, each room entered from the outside. They let me see a room, and as the employee and I walked toward it I felt that it was far enough away that traffic noises wouldn't be a problem. The wooded side seemed very peaceful, and the inside of the suite seemed more than adequate – a queen bed, fully equipped kitchen, large bathroom and closet area. The "Shepherd" price is $79/night.

The next place was another Residence Inn, further away – one has to go through the Lenox area and turn on Wiecu where the Target is that I went to. It also seemed reasonable in terms of noise, being down a road leading off the main road into what I guess would be called a residential park – clusters of apartment buildings and I'm not sure what else. I didn't pay that much attention to what else was there, because I was a little frazzled – I had gotten mixed up by the Yahoo directions (surprise!) and had ended up past Buford Highway on North Druid. I turned around and somehow accidently ended up in the right place, fortuitously seeing the Residence Inn sign, but there were so many other buildings in that residential park I had to hunt for the hotel. Unfortunately the hotel was completely full, and they couldn't let me see a room, but it probably wasn't necessary. The main thing I noted was that it was a HUGE place, and it was more like the stereotypical hotel, with all the rooms housed in one building (or it could have been more than one, I'm not sure), all entered from the inside. They couldn't quote me a Shepherd rate, saying that I needed to work through the Shepherd Housing Director (who had arranged for my present accommodations). I will find out about that tomorrow, but unless the rate is fantastic, I would probably choose the first place over it.

The next place was just down Peachtree Road apiece (trying out my Southern), suites $65 a night. I choked on the cigarette smell as I entered the suite – I hadn't asked if they had rooms designated smoking and nonsmoking. The suite was small but would be adequate. My main concern was that if I ended up on the Peachtree side – and I wouldn't necessarily get to choose – it would be too noisy, as the place sits right on the street. And then there was . . .

"Have you stayed here awhile?" I asked the young man sitting on the sofa in the lobby.

"Yeah."

"Do you like it?"

"It's good."

"Is it quiet, in terms of your neighbors?"

"Yeah."

"What about external noise, traffic or whatever?"

"It's good. You don't hear much, even though a train track runs right behind here – "

Next!

The next place was the cheapest one listed – $220 a week – which made me skeptical that it would be suitable, but I thought I'd check it out (always looking for a bargain). It was close to some busy roads – including I-75 – and though the office was closed so I couldn't actually get in to see a room and see how soundproof it was, I decided to cross the place off my list. Neither the area it was in nor the patrons I talked to instilled confidence in me that it would meet my noise standards. You get what you pay for in this case.

My last stop was another Residence Inn, also right on Peachtree. Again I was dubious because the building sat right on the road. I was surprised when I checked out a one bedroom room and a suite. Neither was on the street side, and the building was solid enough that I didn't hear any traffic noise. But they can't guarantee that you won't be on the street side, and even in the rooms I checked out I could see the traffic. Psychologically I'd rather not be able to look out my window and see the cars go by on Peachtree – weird, I know. The place was a bit more expensive than the other Residence Inn I liked, being $99 for a suite (open floor plan) and $109 for a one-bedroom (French doors separate the bedroom from the living and kitchen areas). The only advantage to it *might* be that a large portion of their clientele consists of long-term residents with family members in Piedmont hospital, so one wouldn't think such people would tend to party. I'm hoping that if I end up in the first Residence Inn I checked out that I'll get in the last row and that the only other people who want to be way back there are ones who want the quietness of the woods. Let's hope they don't want to be back there just so they can throw huge parties ;-).

I made a brief stop to see Gary, and then I went back to my apartment to recover – it'd taken me about four hours to do all this. Later, when I went back out to my car to return to the hospital, I discovered that I had left my lights on. Fortunately the car started right up, but then I had to travel around for about twenty minutes to make sure the battery was charged. Soon after I got back to Gary's, my phone rang, and I did the obnoxious thing of answering it by saying, "Hi, Norma," cuz I knew it was her from Caller I.D. I always felt funny when someone did this to me, uneasy with the idea that someone knew ahead of time it was me who was calling, but now I find myself doing it to others to freak them out ;-).

Gary kept holding his hand out for the phone, so I finally gave in and passed it over ;-) As they conversed, I could sort of see the value of a speaker phone, as getting only half of it did not enlighten me much as to its content ;-). But Gary filled me in on what he could remember. We are looking forward to his family coming up. It won't be long now!

I will finish tonight's entry by passing on something my sister-in-law Dolores sent me:

The Washington Post asked readers to take any word from the
dictionary, alter it by adding, subtracting, or changing
one letter, and supply a new definition.

Here are this year's winners. Each is
an artificial word with only one letter altered to form a
real word:

a.. Intaxication: Euphoria at getting a tax refund, which
lasts until you realize it was your money to start with.

b.. Reintarnation: Coming back to life as a hillbilly

c.. Bozone (n.): The substance surrounding stupid people
that stops bright ideas from penetrating. The bozone layer,
unfortunately, shows little sign of breaking down in the
near future.

d.. Cashtration (n.): The act of buying a house, which renders the subject financially impotent for an indefinite period.

e.. Giraffiti: Vandalism spray-painted very, very high.

f.. Sarchasm: The gulf between the author of sarcastic wit and the person who doesn't get it.

g.. Inoculatte: To take coffee intravenously when you are running late.

h.. Hipatitis: Terminal coolness.

i.. Osteopornosis: A degenerate disease. (This one got extra credit.)

j.. Karmageddon: It's like, when everybody is sending off all these really bad vibes, right? And then, like, the Earth explodes and it's like, a serious bummer.

k.. Decafalon (n.): The grueling event of getting through the day consuming only things that are good for you.

l.. Glibido: All talk and no action.

m.. Dopeler effect: The tendency of stupid ideas to seem smarter when they come at you rapidly.

n.. Arachnoleptic fit (n.): The frantic dance performed just after you've accidentally walked through a spider web.

o.. Beelzebug (n.): Satan in the form of a mosquito, that gets into your bedroom at three in the morning and cannot be cast out.

p. Caterpallor (n.): The color you turn after finding half a worm in the fruit you're eating.

Blog at http://drpeg2003.blogspot.com/

June 5, 2006 (1:30pm)

The other Residence Inn called me and, through the Shepherd coordinator, offered me the $79 per night rate. Helped in my decision by the fact that the rates were the same, I decided to try out the first, more conveniently located Residence Inn. The good news is that when I called them this morning they gave me a $55 a night rate! The bad news was they didn't have the availability of a room for sixty days, just thirty. I took it, hoping that at some time while I am there something will open up for my remaining time in Atlanta. And if it doesn't, I'm still covered – the other Residence Inn person told me that if the first Residence Inn doesn't work out for any reason, I could still book with them at the $79 rate for the remainder of my time here. Great, huh?

The recreational therapist came and talked with Gary for about a half hour late in morning. We thought it funny how she would, in all seriousness, ask Gary's questions like: I am a recreational therapist, what do you think I do? (Um, help me adapt my recreational activities to my current circumstances?) Part of our program is community re-entry, what do you think that is? (Um, helping me get back into the community after I go home?)

She told us Shepherd is one of the largest Therapeutic Recreational (TR) Centers in the country. They have a team of specialists that help the patients adapt their interests to their new situation. The specialists are in: horticulture (Gary wants to learn how to continue to grow his tomatoes and peppers – I'm sure this will involve raised-bed techniques; however, he said he has no interest in learning how to mow the lawn or trim the bushes); art (the person said many patients were surprised to discover they had unknown talents in this area – I said I'd be very surprised if Gary showed such talent (snicker); Gary told the person to move on to the next area of speciality. But I should mention, besides painting the art program covers photography, sewing, and more); music (Gary also passed on this, being a listener rather than a performer); sports (Gary said he'd be interested in table tennis, billiards, cardio, strengthening, board games, card games (those last two are considered sports??? ;-)); aquatics (Gary would be interested except for the fact that for the next six months, because of the flap surgery, he cannot be submerged in water); and outdoor recreation (Gary passed on that, but it includes camping, fishing, boating, hunting, canoeing, kayaking).

When Gary is ready to participate in these activities, they will assess whether his needs in the different areas will be better served by being with a group or with individual attention.

As I mentioned, the therapeutic recreation program also includes community re-entry: the participants go on outings such as going out to dinner (but they are only given $12 to spend, and Gary joked that there was no place in Atlanta that he would like to eat where a meal cost only $12), to the grocery store (which he definitely needs to re-learn how to do ;-)), out shopping (he says that's a necessity, not a pleasure, and I agree), to a movie, on a camping trip, to the airport (unfortunately he won't be flying until the flap is fully healed, probably 6-12 months, since he won't be able to do the sliding on his booty necessary to get from the wheelchair to an airplane seat; he'll have to learn this type of thing – including the basic skill of the sliding transfer – later, either by returning to Shepherd's day program for a while, or by seeing if there's someplace closer to home that teaches such things).

She finished by doing an “eval,” asking Gary about how he’d typically spent his time before the accident, what actitivites he’d done, what he enjoyed doing. Based on this they will come up with a TR program for him and schedule that into his days when he is ready.

Gary then took a nap, then did his weights on his right side – he’d already done them on the left in the morning – while I stretched his feet. While he was doing his weights the “bridge builder” came and talked to us for a while. The bridge program kicks in for a year after Gary is discharged; they will contact us once a month, and we are supposed to bring any problems at all to them. He asked if we had any questions now, so we asked about home help, and the guy said he would get a list of agencies that hopefully can help us out (though the Browns said they might know of someone who can help us, if he is available).

Next we went to a class – they wheeled Gary’s bed down to the second floor classroom. It was the first hour of what I had already heard on Saturday, but I figured it would only be to our benefit for me to hear it again. I learned two new things: 1)Gary doesn’t have to worry about the possibility of his heart having a weird response to exercise (decreasing in rate instead of increasing), because that could only happen to someone with an injury at T3 or above; 2) the low blood pressure happens (or may happen) because the signals from the brain telling the veins and arteries in the legs to constrict don’t get to them, so that’s why binders and ted hose may be necessary (I should have been able to figure this out, but didn’t think about it).

I was the only non-patient attendee, and it was a totally different experience hearing the lecture with the patients than with the family members, and not just because all throughout the hour people’s timers were going off, reminding them to do their weight shifts. The patients seemed much more somber, which is understandable, not cracking smiles at the lecturer’s jokes.

But I could be misinterpreting. Gary, for instance, said he had a hard time staying awake during it. Maybe the others were dozing off as well.

When we got back to the room, Gary commented that it had been a nice day, because three different things had happened (the TR, the bridge builder, the class), and he had enjoyed the variety. Just then, the day was made even nicer, when a bunch of helium balloons from Gary’s brother Bob were delivered. That made us laugh.

It was then time for me to go to the chiropractor, but before leaving, since Gary had just finished the Gödel book, I set up the CD player Gary’s cousin had brought with one of her CDs – “The Orchid Thief”. We had seen the movie based on it and enjoyed it, and I know Gary really likes the author of the book, Susan Orlean – I’ve gotten him several of her books over the past couple years. He particularly likes her short pieces. He does, in general, like collections of short works (though he likes longer books too): each Christmas I get him, or have others get him, the year’s volumes of Best American Essays, Best American Travel Writing, Best American Sports Writing, Best American Magazine Writing. As he generally prefers nonfiction to fiction, we skip the Best American Short Stories, etc.

When I came back in the evening and asked, he said he'd enjoyed what he'd heard of The Orchid Thief, but as is typical these days, he'd dozed off during it, and then it took him awhile to figure where to back up to.

We finished the evening with "practical stuff" – correspondence concerning the adaptations to be made on our home. My brother is planning to go to Auburn in about a week to start in on the remodeling. Sasha Shibakov has volunteered his labor. He says he is particularly good at destroying things. I hope it is safe to let him in our house ;-)

I'm sure the kitties are going to be quite put out with all the activity. Blackjack, I'm sure, will take up residence in the woods on our back lot. Probably Tigger too. I expect they'll still find their way to their food bowls, though perhaps I should tell Joe to move the bowls outside to the back patio, so the cats don't have to brave entering the house.

During the night I had another "performance anxiety" dream. I recall having one in Birmingham as well. In it, I was supposed to be giving a talk at a math conference, and I got up to the podium and realized it'd been ages since I'd looked over my notes and I was completely unprepared. I've had variations on this – sometimes I look down at my notes and they're on a completely different topic than what I'm familiar with – sometimes it's not even math – or the notes are complete gibberish. When I tell Gary I had such a dream, he always says, "hey, that's my dream," so I know he has them too. Sometimes mine are about swimming – I can't find the heat sheet that tells what race I'm in, I can't find my suit or am wearing one too large, etc. (My mom said she has similar dreams, usually involving some large dinner party she is supposed to be giving, where the cooking becomes an endless task and she can't get the food on the table.) Since I haven't been to a math conference or a swimming meet in about ten years, I don't know why these are still the subjects of my dream. I'm not sure why I'm having them now – maybe a feeling of being unprepared for my current situation. I've heard such dreams serve a positive purpose – since the dreamer doesn't want to experience such anxiety in real life, they are more likely to prepare themselves for their real-life tasks. I'm not sure I need the extra goading. :-)

All for now.

Blog at http://drpeg2003.blogspot.com/

June 6, 2006 (11:36am)

Mail call. Thanks to my sister Janet; Lois Stavig; the Vaughans, who sent more tapes of radio shows, old and new; and the Browns, who sent a DVD of Fever Pitch, which they said at least Gary should like, baseball being part of the story ;-)

When I came in this morning Gary was having the casting done on his legs, during which he pointed out to me that the tape had been entirely removed from his fingers. He still can't bend the one that was broken very much, and it looks fatter than it used to. We're not sure if that's due to swelling or to the rod and pins. After that came his bath, and then they wheeled him down to the auditorium for a Vocational Rehab meeting – which lasted about ten minutes! The voc person met Gary and told him she'd come to his room and meet with him later when it was closer to his discharge date. She will help with any issues that arise in returning him to his job (though Gary expects AU will be very cooperative about this), and will also help with the details about the special car he will need when he is able to drive. Again this may be awhile because of the flap surgery, we're not absolutely clear on this – we know he won't be able to do the sliding transfers to get in and out of a car, though we're hoping he gets strong enough to do the depression transfers, where he uses his arms (triceps) to lift his entire body weight straight up and then does little "hops" on his butt to get over to where he wants to go; otherwise he and someone else, possibly me, will be using the hoyer lift to get him in and out of the car.

After lunch, just before wheeling him to another class, a nurse came in with a staple remover (I asked her if she'd bought it at Office Depot ;-)) and took out every other one of Gary's staples on the side of him she could get to, telling us she'd do the same thing on the other side after they turned him after the class. If the skin in that area looks good tomorrow, they will remove all the remaining staples.

His hour-long class was "Wellness and Leisure Ed. 1" In the first half the lecturer asked the audience what they thought wellness was, and she touched on the different areas it encompassed – mental, physical, emotional, social, vocational, spiritual. She mentioned the basic stuff to do to enhance them – eat right, exercise, keep a positive attitude, etc. She spent a lot of time saying very little, IMHO.

In the second half she talked about leisure, again supposedly trying to involve the audience by asking them what they thought leisure was (I thought this kind of thing a little patronizing). The depressing stuff came next. She made a pie chart of work, leisure, and maintenance (eating, sleeping, dressing, etc.). She talked about how when most people go home after a spinal cord injury their pie becomes half maintenance, half leisure – no work. Maintenance takes longer than it did before for reasons like it takes a half hour to get dressed, bathing takes longer, etc. Leisure takes up more time because many people can't go back to work, at least right at first, and some not at all. Many people will no longer be able to do their former occupations (for example, if they are laborers) or at least not handle the duties they had before. Gary is so grateful that this kind of thing does not apply to him.

She said that, typically, a month after a person gets home they will be starting to get used to the home situation and to the accessibility issues they run into when going outside the home. At six months their routine will be more established and maintenance time will decrease. A year after they get home is when they typically return to work.

She next gave us statistics:

- 30% of those with SCI become socially isolated. Reasons given: it's easier to stay home, social stigma, they can’t interact with their peers the way they used to, transportation issues.

• 30% start watching six or more hours of television a day.

• 40 to 60% become substance abusers (they are currently doing new research on this, so the estimate isn’t very exact).

She ended the lecture by telling the crowd she wanted them to think how they were going to use all that new leisure time.

I told Gary I thought the first half was boring, and the second depressing. He said he thought the same thing; he said it was depressing seeing that pie chart of half maintenance and half leisure. But then he rallied, saying he didn’t see how anything we’ve learned since we’ve been here would mean that he wouldn’t be able to handle a class in the fall (I agreed, telling him the people here who might think otherwise weren’t familiar with the flexibility of his job), and then he went on to say that if for some reason he couldn’t be ready to be on campus for the first day of classes in the fall, that he would still have his graduate students to work with, and Topology Proceedings stuff to attend to (he is an editor of the journal and is even doing a bit with it while here), and could do his research (I reminded him that many of his colleagues have emailed him about being ready to talk math with him when he is ready). The problem with not being able to teach, he went on with a sad smile, was that he wouldn’t get paid.

So, obviously, he wants to return to his job fully ASAP. We’re still having him being able to do that for fall semester as our goal for him.

When he returned to his room, the tech turned him to his other side and the nurse removed more of the staples. When she left, I asked Gary if he wanted me to stretch his feet now, and he said that would be hard – I had forgotten he was wearing those casts.

This reminds me. We had a funny-sad thing happen while I was stretching his feet yesterday. There are two stretches per foot, each to be held for a minute. I asked him to time it. When I was on the second foot, it seemed to me I had been holding the stretch for a long time, and I looked up to find him reading a book. “Isn’t the minute up yet?” I asked. “Oops, I forgot about it,” he replied. He couldn’t feel me stretching his ankle, so it’d gone out of his mind. I wonder, had I not said anything, how long it would have been before he wondered what I was doing down at the end of his bed :-)

Shortly after his class, in a call prearranged yesterday, Piotr Minc called so Gary could walk him through getting files from Gary’s computer and emailing them. Gary wants to referee a paper that he thought was on there (turns out it was not where he thought it was, but he can get the paper another way).

After that, he took a nap, I wrote this, and then I slipped off for a massage. The woman, the first therapist I had seen here, suggested I needed psoas work. I agreed to it, though not without an ironic smile. Agreeing to psoas work is like agreeing to have dental work without anesthesia. No, I exaggerate. I have had dental work without anesthesia because I have reactions to the anesthesia. The entire time I have all I can do to not bite the dentist's hand off. It's debatable whether it is better to suffer that short-term intense pain, the worst being over in about an hour, or to suffer feeling overall sick and aching from the anesthetic for about a week afterward. Psoas work is easier – I only feel like hitting the therapist for about ten minutes (maybe it's less than that – time expands when you're in pain) while she inflicts torture on the muscles around the pelvis, and then the pain is over entirely.

After the massage I started my dinner, and while it was cooking I meditated. Then I returned to Gary's room. He was still thinking about that leisure lecture, I surmise, since he talked about how the people in Birmingham had certainly been over-optimistic about what he would be capable of, saying that they thought he could go on the cruise with his family in July, whereas he now knows that even without the flap surgery there was no way he could have done that and gotten ready to teach in the fall. I asked him if he thought it'd been a bad thing for them to be that optimistic with him. He said no, that even though he had been skeptical, it'd made him optimistic. But it had made him surprised, and not in a good way, when his doctor here had told him he wouldn't be ready for school for about six months. I made some noises about that likely not being the case either, and we then had somewhat a repeat of previous discussions. Gary said his doc here should know. I said the doc knows how it was more than fifteen years ago to go back to trying to be a student and that he didn't understand what a professor's job is like. Gary said, "Yeah." I told him he should be optimistic about going back to teaching in the fall until proven otherwise. He said "Yeah," again, with conviction.

We finished the Dylan DVD. Gary said he found it very surprising that Dylan's songs seem to say so much (at least, the early ones), yet in interviews he has nothing to say of note. I said maybe it was really true what he seems to claim, if I'm understanding what he said on the DVD correctly, that he writes his songs without anything in mind as to what they mean, though I can't imagine writing anything without having some meaning for it in mind. Gary said maybe that was true, that maybe the guy was just good at stringing words together to create a mood, the lyrics in themselves signifying nothing. "Sound and fury, signifying nothing," I joked.

It was about time to go, and I asked him if he wanted anything at the store when I went tomorrow for zukes, thinking protein, fruit, vegetables. "Hagen Daz chocolate chip ice cream," came the request. I gave him a baleful eye, then left.

I will get it for him, of course.

Tonight's final non sequitur. I am so very grateful Gary doesn't have to experience chronic pain. One of the first things I read about spinal cord injuries was that those with them could suffer chronic pain. I had hoped Gary would be spared that, having familiarity with it from my early CFS days (at that time I thought "Chronic Fatigue Syndrome" could just as well be named "Chronic

Pain Syndrome," since pain and fatigue went hand in hand for me and it was debatable which was the more debilitating, not to mention that both names summarized the malady about as well as calling tuberculosis "Chronic Coughing Syndrome" – fortunately, as a result of the shots I give myself, obtained through the Environmental Health Center in Dallas, for the past five years I have not been in that kind of pain, the kind of pain that made me quite seriously wonder how much longer I could live with it; and now this parenthetical thought has gone on for so long you've forgotten what I was saying and will have to go back and look at what I wrote before it) and so far he seems to have been. I remember in the lecture on the spinal cord I attended without Gary the speaker went over that possibility in some detail, describing what it might feel like and the possible ways to deal with it (pain medicine to acupuncture). Interestingly, in the lecture Gary heard that covered this topic, the lecturer didn't dwell on it to as great an extent.

So, anyway, I am glad Gary has never been in pain with this and I hope it stays that way.

All for now.

June 7, 2006 (2:44pm)

Someone emailed me about what I called my "performance anxiety dream" (the person mentioning as an aside that "performance anxiety" could have a different meaning for a middle-aged male). He then conjectured we all have that kind of dream, and told me about dreams of that nature that he'd had. His were "traveling dreams," where the bags weren't packed and the train was about to go. He wondered why his dreams involved trains, since he used planes much more often.

Hmm. Performance anxiety, trains . . . were there tunnels in your dreams? . . . no, I won't go there ;-)

Mail call: thanks to Beth Fletcher – you find greatly amusing cards!

Okay, to the day. I came in to find Gary's casts had been removed. The casting people said they'd come back later in the day with these casts split down the sides, turning them into what they called "bivalves." Gary will then wear them for an hour to make sure the fit is right, and after they get the right fit he will wear them for eight hours a night for the rest of his life in order to keep his ankles from dropping.

The flap doc came in, took a look at his handiwork, and said Gary's flap looked excellent. The rest of the staples are to be removed today (and they were). They will start stretching the flap area (by increasing the bend in his legs) starting on Friday. He will start sitting up on the 14th (starting with a half hour and increasing by a half hour per day), and he will start back in on rehab on the 19th! So assuming no setbacks, we are ahead of schedule.

At 11 he was wheeled to his bowel class. I had already subjected Gary to listening to what I had learned in my class, and neither of us picked up anything new from this lecture – but that's all right. Lunch came afterward, and I told Gary it was better timing than having lunch after the skin lecture (where they show awful pictures of bed sores). We thought it ironic how part of the lecture was on the increased importance of good nutrition for a person with SCI, and yet the hospital food was dismal. Today's lunch was particularly bad, the entree being deep-fried fish that seemed mostly breading. I removed as much breading as I could, per Gary's request, and he filled out his lunch with some nuts I had bought him. I offered to go to the Fresh Market and get him something more, but he declined the offer.

After lunch was another hour-long class, this one on counseling. It turned out to be like a group therapy session, this one on communication. The counselors and class members talked about how to deal with others upon returning to the outside world, how to let others know what had happened to them and what their abilities and disabilities were (I told Gary he shouldn't run into too many problems that way – everyone already knew about his situation by reading the blog ;-)). All agreed they didn't want others to feel sorry for or pity them, but that empathy was a good thing. The counselors told the patients they might find it helpful to take the initiative to put others at their ease, that by starting the conversation, it would help others to treat them normally, but on the other hand, if there were people they didn't want to share with, they were under no obligation to do so.

Later in the afternoon the PT came, and I asked her about vans. I had checked my email earlier and discovered that a couple people – Phil and Jo – had mailed me to tell me my expectations for a wheelchair-friendly van are too low. (Unfortunately, during my earlier talks with the voc person and the PT and OT about cars and hoyers and such, I hadn't remembered Jo's previous email on the topic.) I showed the PT Jo's email where Jo describes a friend's van, which comes with a lift, and the PT said sure, there were vans like that. I'm not sure why she and the other Shepherd people didn't bring up the type of van Jo talked about themselves (maybe that would have come up later in the driving class), but the PT did say many people didn't have the financial resources to get vans that had lifts in them, or even for vans that had ramp entrances. I'm not sure about that, since in the catalogue she then gave us, there were used ones for about $2000 (granted, they were 70's models). She told us that certain companies that supply vans thus equipped will bring the vans out to Shepherd for the patients and their family members to try.

This will still be in the future, though. When Gary first gets back home after rehab, we will have to use a regular car or van for a while, we believe, with a hoyer or with Gary doing depression lifts. Because, first of all, we will have to buy the van, which we don't believe we'll have time for here. Secondly, Gary will have to come back to Shepherd or go somewhere else to learn how to drive a van with hand controls. (Shepherd has a driving school, where first the clients are extensively tested to make sure their SCI hasn't rendered them unsafe to drive, as might be the case if they've aquired attention difficulties due to brain changes that might not be readily apparent; then the clients start out in simulators.) Then Gary will have to be re-licensed to drive (legally his old license is no longer valid – if he were to use it and get in an accident, the other person could claim that Gary had physical limitations not noted on the license, that these had contributed to the accident, and that therefore Gary shouldn't have been driving).

Soon after, the casting person came (I suppose I should have learned what her title is). "Your clamshells are here," I told Gary. "They're called 'bivalves,'" the casting person corrected.

Well, I was close.

She and the PT taught me – or rather, tried to teach me – how to put the bivalves on, since unless Gary gets really, really flexible I am going to have to put them on him each night. They put Gary on his back (temporarily, as for the flap he still needs to lie on his side), and then the casting person put the left bivalve on. When she was through I tried putting the other one on Gary's right foot. It had looked highly nontrivial ;-) when she'd done it, and I found it downright hard, not having the eight arms I apparently needed. First there is the matter of bending his leg up at the knee and getting his foot resting on the bed. Well, he can't hold his knee up with his leg muscles, and though he tried to help by holding his leg underneath his thigh, it was still a lot of weight for me to hold. I ended up hooking my left arm under his right knee and letting his knee rest on my shoulder (all the while wondering what this was doing to my back). Then I had to stuff his heel into the lower half of the cast and try to get the cast molded against his lower leg. Again, since he can't hold his leg up, this wasn't as easy as it may sound. ("You're doing great," the casting person told me, as she re-adjusted everything I'd done. Uh huh.) Now it was time to put the top half of the cast on – oops, it was on the table behind me, not good advanced planning. The PT handed it to me, and I fitted it over the bottom half. Next came the one-handed wrapping and tightening of the velcro straps that go around the two halves of the cast. First came the middle strap that goes around the calf, then the bottom one that goes around the top of the foot, then the top strap that goes around the top of the shin – except, before tightening that one I needed to pull (using my eighth hand) the top of Gary's calf muscle (what is left of it – things have noticeably atrophied down there) out and up so that it doesn't get pinched between the "valves." Then all the straps had to be re-tightened so that there was no space between the two valves (even the casting person had to do this – it is part of the procedure). And then one final check is made to make sure there is a seamless fit and that no skin is pinched between the valves.

I then collapsed onto the bed in exhaustion.

Okay, that was an exaggeration, but putting that bivalve on was work. The casting person told me to practice putting them on each day and claimed I'd get it down with practice. She'd better be right.

I left to grocery shop, take a walk, make dinner, and meditate. Just as I got in the door from my walk, Gary called. His dinner had been terrible, he said. I told him that, coincidentally, I had just checked out the deli section of the Fresh Market and told him what I'd seen. He asked me to bring him some salmon, as well as the Hagen Daz I told him I'd already picked up. I had already put some mixed baby greens from that market in the hospital fridge for him, so all this would make a nice meal.

So, later, on my return trip to Shepherd, I stopped in at the market and got the salmon. At the hospital I set up his meal (except for putting the ice cream in the hospital freezer – in a brown paper bag with his name on it so it would still be there when he finished his meal). Shortly after he commenced his second dinner, his cousin Helen arrived. She had called earlier in the day to say she was coming. She asked if I wanted to use her condo from the 16th to the 24th – at which time her remodeller would commence working on it. Since I'd gotten such a good deal from the Residence Inn, I decided it would be easier not to move twice, so I declined her kind offer. She then offered to let Gary's family use it while they are here, so we called Norma and had a four-way conversation about it. Hopefully mine and Helen's directions to Helen's condo won't result in the Gruenhage family getting too lost. ;-)

Close to the end of the conversation Norma said, "See you in a week." For some reason it hadn't connected in my brain that their visit was only a week away. Which, significantly, meant my "kick-out" date at the apartment is only 9 days away (Friday the 16th). Which means I have to start moving things out to my car starting tomorrow, because Shepherd housing gave me a check-out deadline of 9am, and I am supposed to have the apartment cleaned and sheets and towels washed and folded by then. Since I have no intention of getting up at six to do this, especially on a day when Gary's family will be here, my plan is as follows: clear as much of my stuff as possible out of the apartment ahead of time; clean no later than Wednesday and then try to be really really neat so all I have to do is give things a last swipe; and wash the sheets and towels on Thursday and then "borrow" a towel from Shepherd to use overnight (I know where the linen is kept, since I get towels for Gary to use as "bibs" during these lay-down meals of his). I was stumped on the bedsheet issue, but I thought to ask Helen if I could borrow some from her for that one night I'll need them, and she agreed.

Helen left soon after the end of the phone conversation, saying she would show me the ins and outs of her condo tomorrow, in case there's any info I need to pass onto the Gruenhages. After she left Gary remembered his Hagen Daz, thus not having to share any with her (if he ever hears I wrote this, he'll protest, saying he hadn't done this intentionally), so I scooped him out some and then left for the night after he made suitable noises of approval of the ice cream.

Before signing off on this entry, let me thank Michel for reiterating in an email that he saw no problem with arranging a suitable teaching schedule for Gary this coming year, starting in the fall. Because that is the case, and because Gary could, as might be necessary or wise at the beginning, come home after teaching rather than staying on campus all day long as he used to, we're as confident as we can be at this point that this would overcome the doc's concern that Gary won't know his body well enough to be at work so soon.

Oh, and in response to an email, no, I don't swim anymore. During my first years of CFS, before I was diagnosed and had no idea what the problem was and how it could cycle, I used to try to start up on my swimming whenever I seemed to be going through a reprieve – I had been a competitive Masters swimmer, even ranking first in the Southeast in an event in my age-group (30-35 year olds) the summer before I got ill, and I was quite the fanatic (right, Connie? :-)). But I kept getting ill soon after I would start getting into the pool again, even though I started off easy. I don't know if it was that the exercise was too much for me, or if I was reacting to the chlorine. Anyway, that discouraged me from attempting it much, and after my big crash in '95, I've never swum again. I have no desire to – I don't want to have that stark reminder of what I can no longer do in that regard. I suspect it's like Gary telling the TR that he has no interest in re-learning how to play golf under his current circumstances. I asked him why, and he told me it wouldn't be fun anymore, and I completely understand – it was something he really really enjoyed, and now he's not going to be able to do it as he could, so rather than be reminded of that, it's better to try something different, something that didn't mean as much as it did before the disability struck – that's my interpretation of why he doesn't want to do it, but that might simply be my explanation of why I don't want to swim anymore.

All for now.

June 8, 2006 (7:30pm)

Gary had another class this afternoon – the second of the "Wellness and Leisure" classes. Unfortunately it was just as boring and lacking in useful information as the first one; again, the person could've said what she'd had to say in about five minutes. Fortunately I haven't had this reaction to anything else that has gone on here.

This time the presentation listed (and little more than listed, rather than going into details) what areas the ADA (Americans with Disabilities Act) covers: public places, government places, employment, public transportation, telecommunications. Then people were asked what accessibility issues they thought they might run into when they leave the hospital (door widths, bathrooms, etc.). And the above is just about all that was accomplished in the hour, except to tell us that Shepherd has an Advocacy Department should we need to get in contact with them.

After getting Gary re-settled in his room, I realized I had once again forgotten about the orientation meeting that family members are encouraged to attend soon after their loved one comes here. It is offered every Thursday, and each time I'd missed it – the first time because I didn't notice the message about it up on the case manager's door until some days after (I'm lucky I noticed it at all), the second time because I forgot and was in a class with Gary. I decided to go this time, even though I was about twenty minutes late. Turned out I hadn't missed that much, and at the end the SCI Program Director, who was giving the presentation, filled me in on what I'd missed.

This was a very good meeting. First we were given a sheet of paper listing all the important contact information – the numbers for the nursing manager on our floor, for the charge nurses, the TR manager, the recreation supervisors, the case managers, the patient/nurse educators, the post-Shepherd program managers, the director of SCI research. Next we got a list of all the Shepherd physicians and their areas, as our loved one may see more than one kind of doctor (for instance, Gary seeing not only his rehab doctor, but the plastic surgeon). Next we were given a general time frame for what happens when during our loved one's stay. Here is some of it:

• Admission day: meet primary doc, start going through an assessment (taking up to three days)

• Within the next couple of weeks: have medical conference, have goal-setting conference, get schedule of family training dates, receive tentative discharge date

• Two weeks before discharge: The final seating clinic (finalizing the choice of custom-made wheelchair), post-inpatient recommendations for further rehab, etc.

• Last week: Discharge training for family member (though since I am here all the time, they are spreading out my training – the full day of lectures (which I've already had), and the two days of hands-on learning – throughout my stay), family outing to a dinner (read, "Gary and I go out to eat"), one night "on our own" simulation (we behave as if at we're home – we are left to ourselves in a special room in the hospital and we simulate being at home by ourselves, running through a 24-hour period of Gary's routine – the staff is available to us if we run into trouble), loaner wheelchair obtained for use until custom-made one can be delivered (it takes up to six weeks), prescriptions for day program/outpatient services completed, medication prescriptions obtained and filled, discharge supplies obtained, family attends discharge conference with patient and all the members of patient's team (the primary doc, case worker, and all one's therapists).

• Day of discharge: nurse reviews discharge instructions.

The last thing covered was the kinds of passes we can apply for: push pass, which will let us take our loved one off of Shepherd property but not by car (a little stroll down Peachtree Street ;-)); and day pass, which lets us drive our loved one off Shepherd property. As you can guess, quite a lot of training, for both Gary and me, has to be accomplished before such passes are given out – I'd hate to have him go zooming down the steep hills of Peachtree on his wheelchair, for instance. He and I would have to be able to satisfactorily show that we can take care of all his bodily needs, that we can handle the architectural structures we might encounter (for instance, curbs), that we can do the appropriate transfers, that we know how to handle dysreflexia – in short, that we pass the course on the classes we are taking here. In additon, we will have to have already gone on one of the TR supervised outings so our safety/judgement/problem-solving abilities can be assessed. This sounds like a lot to learn in a short time, but I suppose if 315 patients per year go through this place, they must feel confident that people can become proficient enough to handle such things in such a short time.

After I told Gary what I'd learned, we checked out our heap of mail. Another avalanche today! (Gary got to look at the cards, I got to look at the bills ;-)) Thanks to Thelma West, Dimitrina Stavrova, Juanita Meschke, Dave Sieh, Mom Gruenhage of course ;-), Rod Becher, Jerry and Theresa Vaughan and their latest supply of tapes ;-), Bruce Noda, and Stew Schneller.

One of the things we got in the mail was a satisfaction survey from UAB Hospital. You can bet

Gary will be filling it out, and not with glowing praise all around.

In the evening we started “Capote.” I found it interesting to watch the character; Gary wondered what Capote had seen in the murderers about which he wrote “In Cold Blood.” Neither of us have read that book or seen that movie.

And that’s today’s report ;-)

Blog at http://drpeg2003.blogspot.com/

June 9, 2006 (3:50pm)

Gary has been able to prone for five and a half hours each of the past two nights, encouraging news for his home bedtime routine – hopefully he can get it up to eight hours prone so he won’t have to set an alarm after at most six hours to remind himself to turn off his side or back.

He had two classes today. The first, “Been there, done that,” was led by two former Shepherd patients. One ,a young man – late twenties, early thirties, I think – was a T12 whose injury had occurred two years ago. The other was an older woman, maybe sixty-ish (I’m really not any good at guessing ages) whose C 6-7-8 injury occurred eleven years ago. The guy was very vigorous – I told Gary he needed to look like him in a few weeks, referring to the guy’s bulging muscles – and very inspirational. They both were, having obviously adjusted well to their new lives. They talked about how when people first leave here, their lives will be filled with new challenges, new complications, but each accomplishment will make the next one easier. They emphasized being innovative “as the rubber hit the road,” (meaning that time when one leaves the hospital and using, I assume, the rubber of the wheel of the wheelchair in the symbology) and thinking outside the box as one finds one’s new normal. “Life is the same,” the young man said, “but the approach is different.”

There were some questions asked by the patients, some concerns briefly covered, but the main value of the time was that, as Gary put it, “it’s great to see someone who’s adjusted so well,” though we also found it interesting that when the guy was here after his injury, he had absolutely no feeling or movement in his legs, and now after two years he can lift them and feel some sensation in them, and he feels like he may still get more back. He talked about his exercising a bit, bringing up that he exercises on a special bike. At that point I asked if there would be any benefit in Gary doing so (I know I asked someone else about this, but I wasn’t clear about the answer). The guy thought it would absolutely be of benefit, not only to maintain muscle mass and all those good things that come from exercise, but to possibly form reconnections. He said he didn’t know for sure it had helped him regain his functioning, but always when he exercises he concentrates on the muscle being exercised, with the hope that the brain signals he sends by such intentions (a nonverbal “quad muscle, move!”) will somehow form a connection with the signals being sent by his muscles that are being forced to move by the machine. (I suspect that’s the closest Gary would get to adopting a “New Age” technique ;-))

I gathered it is the case that later on in his rehab Gary will be taken to another gym here where they have such special equipment, and Gary can try it out.

After the class Gary and I stayed in the room – there was a half-hour break before his next class, so by staying there we saved the nurses the effort of hauling Gary's bed up and down the elevator another time – and the male class leader stayed to chat for a while. We found out that he gets money from a brain and spine foundation in Georgia to buy adaptive equipment (such as the special bike mentioned above, or a special stepper); he thought there was such a foundation in Alabama and said he'd look into it for us.

I took a quick potty break, and when I came back it was almost time for the bladder class (good timing). The class leader was the guy who'd given my afternoon series of lectures, and I liked him a lot – he comes off as a very caring, sensitive individual.

He'd come to Gary's room and introduced himself sometime when I wasn't there, and Gary and he had gotten around to math – Gary had told him about how a topologist couldn't tell the difference between a coffee cup and a doughnut. Today when the guy saw Gary, he rushed up to him and told him how he'd just recently seen on the news some story where they mentioned something about topology and how a topologist couldn't tell the difference between a coffee cup and a doughnut! The guy was quite pleased that he'd already known that, because of his discussion with Gary :-)

Neither Gary nor I picked up any new information from the lecture, since I'd already heard it and then described it in excruciating detail to Gary ;-), but we both realized we still had the part where we have to apply that knowledge ahead of us.

Next came lunch, which Gary proclaimed half-decent (as opposed to yesterday when his reaction to every meal was, "Oh, god, is it time to eat again?"). When he finished he said, " You know what would hit the spot?" I raised an eyebrow, knowing full well what he was intimating. "Hagen Daz chocolate chip ice cream?" I hazarded. He smiled blissfully. "And this time I have a metal spoon," he trumpeted, waving his lunch spoon at me. Last night it had been a struggle using plastic utensils to get the well-frozen ice cream out of its container into a cup.

After I returned from the snack room with his treat, we went into hysterics as he told me about his unsuccessful attempt to steal hospital silverware. Apparently, on Wednesday, when he'd first made the request for the ice cream and knew I was bringing it that night, he'd tried to secrete the metal spoon from his dinner in the towel the nurse had put over him to use as a bib, so he could later use the spoon for his ice cream. Unfortunately, the nurse whipped the towel away immediately after Gary finished dinner because it was time to turn him to his other side. The contraband clattered to the floor. You know the phrase, "You can run, but you can't hide"? Well, Gary couldn't run, either.

In the afternoon they started Gary on the next phase of recovery from his flap surgery – someone came in and put his hips at a ninety degree angle, at which they stayed for two hours. Each day they'll increase the angle by five degrees, and after he's at one hundered and ten degrees, they'll start the next phase where he gets to start sitting up, starting with a half hour and increasing to eight. The person who adjusted Gary's legs also did cross-fiber massage on his scar tissue to break up the adhesions. Things seem to be healing well, though there is one place we need to keep a special eye on because it will be naturally weaker – the place where two incisions met.

In the later afternoon, cousin-in-law Helen picked me up at my apartment to show me her condo in case anything about it needed explaining to the Gruenhages when they come and stay in it. It is too bad I cannot retain visual impressions without focused concentration (I couldn't focus on my surroundings because I was trying to focus on what Helen was saying about what was where and how things operated) – or maybe, since I know Helen has read in this blog, Helen will be thankful of the fact my visual memory stinks, because this way she won't see my description of her condo here ;-) Let me just say it is very nice, and the Gruenhages staying there will probably feel like royalty ;-) (Let's see, if you want to swim, you go through the center atrium and out the rear doors, pass through the English maze garden with all its statuary and somewhere out there is hidden a pool).

I tried my best to retain what she said, but I hope you guys don't plan on doing a lot of fancy cooking so I have to remember how the convection oven works. I think I remember the directions about the microwave, as they seemed standard. The oven might be a little trickier, as there are digital controls ("It's all self-explanatory," Helen said airily, waving her hand at the digital controls, the same thing she had said about the digital washer and the digital dishwasher; meanwhile, my eyes are glazing over.) I probably should've taken notes, but couldn't bear coming off as that much of an idiot ;-) The stove is gas and seems to work like other gas ones do (I've operated such a couple times), except apparently the left front burner is a little tricky so my advice to the Gruenhages is just don't use the left front burner and we'll all be much happier.

Helen plans to leave little notes, but if need be, I believe I can remember how to get you to where to empty your trash when you leave, and if absolutely necessary I can probably recall how to adjust the temperature of the condo (the little trick there is after you push the button on the outside of the thermostat control and get the temperature at the number you want, you have to flip down the front of the control box and push the button that says "hold," and you have to hold it for a minute. I think it was a minute. Well, I'm sure a minute will suffice.)

Oh, well, I'm sure we'll muddle through. I *am* confident you'll spot the bedrooms and bathrooms. And the actual getting into the place starting at street level seems straightforward enough – yes, I practiced, to make sure there weren't any tricks with the elevator, for instance.

In the evening Gary and I watched more Capote. I find the movie character a little ghoulish – wanting to keep the murderers alive so he can write a good story, insinuating himself into the lives of other people that he wants to use for research purposes. I get the impression he says what he says to them simply in order to use them for the benefit of his book. The movie makes me wonder if they were wise to trust him (I don't know; I'd have to read "In Cold Blood" and maybe find out what the featured people's reactions to it were).

I cracked up at Norma's email remark, "Have you considered cheerier movies?" When at home we watch an hour of entertainment a night and do go through more of a mix – TV shows like 24 and CSI and Without a Trace, old Columbos (I think we've seen them all, but we almost always remember each scene AFTER it happens), movies we tape from the TV. We like comedy, romance, mystery, and some nonfiction, but the high proportion of the latter these days is somewhat coincidental – these happen to be recent movies with good reviews and people have happened to offer to send or loan them to us. Also, I think I mentioned Gary prefers nonfiction to fiction, and perhaps that played a role (though that applies more to reading material). Me, I tend not to like the more reality-based movies, but it depends on the subject matter. I prefer movies with happy endings, but there are the exceptions. It's safe to say I don't like "downers."

All for now.

START OF CHRONOLOGICAL ORDER KEEPING – MAY WANT TO CHECK THAT GOT ALL FROM GARY2.WPD TRANSFERRED TO THIS ONE.

June 10, 2006 (3:46pm)

No classes attended, not many things to note in Gary's usual routine today. I did wake up with a curious dream: it was time to go home from here, and I was out shopping getting some discharge supplies for Gary. For some reason, I was in a gardening store doing this. I woke up before I could discover just exactly what it was I was getting there (I thought of some possibilities, but I think I'll spare you and let you use your imaginations ;-)). When I told the dream to Gary, he said, smiling, "You really want me to learn how to mow the lawn while I'm here, don't you?" (No, I could care less.)

I almost got in a zucchini fight today. At the Fresh Market there was only enough zucchini for about a day and a half's meals (I go through about two and half pounds of zukes per day). Just as I was shoveling the last of it into a plastic bag, I saw out of the corner of my eye a man approach. He stopped just to the side and behind me, put his hands on his hips, and heaved a sigh. I knew what that was about but ignored him and asked the produce man who was stocking items a short distance away, "Do you have any more zucchini?" He said he'd check and left to do so. I continued to stand there, still ignoring the guy behind me. If the produce man came back saying he didn't have any more zukes, I figured I'd probably feel guilty enough about taking the last of the zukes to offer the waiting guy a few – but just a few. It depended on his expression – maybe I'd decide, "tough luck, mister – first come, first serve." ;-)

The produce man came back with more than half a box and offered them to me. I proceeded to shovel more into another bag. As I did so, he said, "I usually sell a lot of yellow squash, but I've never sold so much zucchini as I have since you've been coming in." I told him I had weird allergies, that this was the only vegetable I could have, and that I usually cleaned stores out of it – all of this said knowing the waiting guy would overhear, though why I should feel the need to explain myself I don't know. The produce guy said, "That's all right," and after I finished taking what I wanted, he proffered the box to the other man. I turned and saw the other guy now had a big smile on his face. "I just want one," he said. "Oh, go on, take two," the produce man said. "Yeah, I left you two," I encouraged. So we all had a good laugh over that.

Hmm, what else? Oh. When Gary did weights in the afternoon, I complimented him on the cuts he is developing in his forearms. Look out, Ahnold.

Dinner turned out to be another bust: Gary's pepperoni pizza turned out to be a bagel (!) topped with cheese and ham slices. He doesn't even remember if there was tomato sauce, but I told him there must have been – otherwise those ordering the cheese pizza would have just gotten a bagel with melted cheese on top ;-).

So Gary has warned me, he intends to send me out for pizza sometime. He filled out tonight's dinner, thanks to the Fresh Market (and me ;-)), with nuts and baby greens and a fresh berry cup. Oh, and Hagen Daz, of course.

I got in some practice with Gary's bivalves today. When it was time to turn him in the evening, we asked the nurse to leave him on his back a few minutes so I could practice putting his bivalves on. I had intended just to put them on then take them off, thinking that later the nurse would put them on for the night. Gary thought I should put them on for the night myself, but that made me nervous – this was only the second time I was doing it, and there wasn't anyone supervising me – what if I didn't get them on quite right and he got the first stage of a pressure sore? We finally decided that after I put them on we would have the nurse check the fit and re-do them if she thought that necessary.

I don't know why, but it was a LOT easier this time – which made me nervous, wondering if that meant I was doing it wrong. But the nurse checked them and said they were fine. I hope she is right – I don't want the guilt of causing him the start of a pressure sore.

To finish the day, we watched more of "Capote," and I still wondered if Capote felt for the one murderer or just behaved that way toward him in order to get what he wanted from him, which was more the feeling I got, though I felt some ambiguity about that (and maybe so did Capote). As the movie went on I surmised that what was really going on in Capote's mind was, in fact, a theme of the movie. (I am not very confident of my movie critiques, which is why I am not stating this more strongly.) Unfortunately, at what seems to be almost the end of the movie, we are running into glitches with the DVD – something wonky with the sound. It was about time to quit watching, so we just stopped the DVD. Tomorrow night we'll put the DVD in the other laptop or in the portable DVD player and see if we have any better luck than when playing it in the laptop we did. I suppose we can always rent the DVD from the local Blockbuster if none of this works – I think we're too far along in the movie to want to return the DVD to Amazon for a replacement before finishing the movie.

And thus ended the night.

June 11, 2006 (8:13pm)

This morning I learned how to give Gary a bath. He will eventually be able to do this himself but will need assistance with it until he is healed up from the flap surgery. The process was straightforward enough :-), though since I've never given anyone other than myself a bath, I was glad of the instruction since I am always concerned about "doing things right." ("Over-concerned," I hear you say?)

Speaking of which, I briefly worried I had put Gary's bivalves on wrong, because this morning he did end up with a reddened area on his foot that didn't resolve. But the nurse assured me it wasn't anything I had done but rather that the bivalves needed refitting. Gary will not be wearing the bivalves tonight – we want the people "in charge" of the matter to do what needs to be done so Gary doesn't have a problem with them.

My brother called mid-morning to tell us he'd made it to our home at midnight last night. He pointed out that all the street signs out where we live are short stone posts in the ground and therefore hard to see – especially in the dark. This was a factor in his trip because it caused him to miss the turns to our place. As he needed a map of the town anyway, his fortuitous ending up in an area of town with stores and gas stations provided him with the opportunity to get one ;-).

Aside: Do smileys and other emoticons drive you nuts? There is a Dave Barry article about them. He thinks all the classics should be rewritten incorporating them, as they add so much to the text. It was the best of time :-), it was the worst of times :-(

Tigger was on hand to greet my brother (poor kitty – he must be truly desperate for affection if he greets a dog person); Blackjack, unsurprisingly, was nowhere in sight. In fact Tigger was so glad to see Joe he jumped on the bed and woke Joe up this morning just to tell him so (or maybe it was in hopes of getting an early start on breakfast).

The cats must have been preparing for Joe's visit for quite some time, because in the house Joe found a bird and a ground squirrel, both aged to perfection – Joe took note of the fine bouquet. (Actually, at first Joe thought the ground squirrel was a toy, until he noted the smell and saw the maggots – thank you, Joe, for sharing those details with me. I just knew my readers would want to hear them too.)

Joe is going to spend the day recovering from his trip and checking out the house to see how well the recommendations of the OT and PT match up with the realities of a home remodeller. Tomorrow he will come to Atlanta to visit with us and go over his thoughts on the matter.

After Joe's call, I removed Gary's lunch tray (I had waited until he finished lunch before passing the phone to him, suspecting Joe would want to share his cat experiences, which he did). As I moved into the outer room where the sink area is and where the food trays are left, I heard someone say "hi." Not to be rude, I gave a quick glance back and said "hi," thinking it was someone leaving the curtained area of one of Gary's roommates. I did a double take. "Stu!"

So we had a surprise visitor, Stu Baldwin. Gary and he talked math, math department, politics, and general chit-chat for about an hour and a half. As Stu left, he asked Gary if he had any message for the department. Gary told him to tell everyone thanks for their concern and caring.

In the evening Helen dropped by. She told us about some good restaurants near here (both for the times when Gary wants to order out and as places for his family to go when they are here). She also told more stories about her nephew who has been paraplegic for years, about how full his life is. Gary said that's what he liked to hear. After that, he called his mom – he is so excited about his family coming at the end of the week. I noted he mentioned to her about Helen's nephew and about the "Been there, done that" guy he'd met, about how great it'd been to meet someone who'd had an SCI who was so fully engaged in life, fully involved with his wife, his little boy, his job.

So, I was thinking, if any of you out there knows of someone who had an SCI and adjusted well to life after it, please, if possible, share their story with Gary, through email, a letter, or by telling Gary the story when you see him.

All for today.

June 12, 2006 (9:25pm)

The last of Gary's drains for his flap surgery was removed from his back this morning. When the nurse pulled the drain out, she let me see it; I told her to show it to Gary too. "I'm glad that's out of me," was his comment.

While they were removing the drain and some of the dissolving sutures that were still along his incision line, I attempted to open a big box sent from Japan by Kohzo Yamada. I got it open and pulled out something that at first I couldn't fathom. Then I saw it was chains of hundreds of folded papers – identical origimi figures – all the paper chains connected to one point at the top so they hung in a circle. "Did he make this?" I asked in amazement. Gary opened the beautiful paper card that accompanied the gift. In it, Kohzo explained that in Japan they had the tradition of making a thousand origami cranes (the entire creation called a "senbazuru") for prayers for cure of sickness or injury. Kozho and his family began making the senbazuru when they heard of Gary's accident through Haruto Ohta (who heard it from me – his was the only email address of Gary's Japanese math friends that I could find offhand – he is the one who in the past has sent me seeds for Japanese pickling melons and other oriental squash family members). Haruto Ohta had also folded some of the cranes. The majority of them – over seven hundred of them – were folded by Kozho's wife, Kazuko! They sent it with the strong hope that Gary would be getting better as soon as possible.

One of the nurse's stood on a chair and hung the senbazuru from the ceiling. In this way we will have the constant reminder of the friendship, concern, and care that the Yamadas have shown us, and not only that, we hope the Yamadas won't mind if we use the senbazuru as a symbol of the friendship, concern, and care that all of you have shown in this time.

Little Laura's chocolates and candies straight from France were another welcome surprise of the day! Gary pronounced them exquisite and thanks you so very much, Laura.

And there was also a group card from an aunt and cousins (the Meinzens) of Gary's.

My brother Joe came to visit and to discuss the house. The changes to the bathrooms appear to be doable. He had some good suggestions for moving things around in the master bedroom in order to free up more space (it being a given that the big bed has got to go; pieces of furniture in the family room will have to go for a similar reason). And he had the good suggestion of clearing off the back patio so that is more livable – it is currently covered with the remains of my gardening passion (I can only handle one passion at a time, and when I took up writing, gardening fell by the wayside, except for a few herb plants that have put up with my neglect); as well, there is an ancient spa (aka jacuzzi) out there that I haven't used since my early CFS days (either the heat of the water or the chlorine making me sick). So, if anyone wants a spa, it is free for the taking, as is – it hasn't been turned on in years nor have we opened the top, and the redwood near the motor is rotted, but if you're interested . . . :-)

One problem not yet solved is that of the cat barrier. The doors from the kitchen area into the family room area make that entranceway too narrow for a wheelchair, and so the doors need to be removed. But, those are the doors we chain closed at night in order to keep the cats in the kitchen area – in particular, to keep them as far away from the bedrooms as possible. Joe saw the wisdom in this. He didn't chain the doors, plus he left his bedroom door open, and Tigger decided to spend the night with him. Tigger made sure Joe knew he was there, giving Joe's eyebrows a good licking about once an hour throughout the night. Actually, it wouldn't have done any good had Joe shut the bedroom door – Tigger (or Blackjack, if Joe was someone he was friendly with) would have scratched on the door furiously and howled until let in (or put out) – we've discovered this the few times we've accidently forgot to chain the cat barrier. (Don't you hate it when people go on and on about their pets?)

Joe wasn't sure the kitchen was going to be accessible to Gary, thinking the sink was going to be too high and the area too small for Gary to be able to maneuver into it and open the fridge or the dishwasher. When Joe returns to our home, he'll do some measuring and sit in a chair in the kitchen to see what he'd be able to do.

During our visit, the bivalve person came in – unfortunately she claimed Gary had gotten those red spots on his foot because I had put those contraptions on wrong (Gary claims that the bivalve person is the only one who can put them on right – the nurses have trouble with it too). So she was there to watch me put them on and offer tips. I did the right one without her offering comment (well, except that I started off putting the left bivalve on his right foot, but that was her fault – that was the one she handed me). On the left one she said I hadn't shoved his heel in far enough. So I did it over from the start, this time doing it right, but I'm paranoid about not being able to figure out I've got it in far enough.

Fortunately we seem to have misunderstood how long he needs to wear them for. Once he is sitting up all day, he shouldn't need to wear them at night: the angle his foot will be kept in while sitting, along with the stretching exercises he'll do on his ankles during the day, should be enough to keep his ankles from going into contracture. But if he notices any loss of range of motion, something will have to be done about that – more stretching, changing the angle his feet are kept in when he sits, or the dreaded bivalves (or possibly another type of boot if we can find some that fit). I really hope we don't ever have to use the bivalves after this – when I woke up on Tuesday, I discovered I had pulled a muscle in my back. Could be from the strain of getting the bivalve on, could be from the vacuuming I did in the apartment (the vacuum is very light, but still, I'm afraid it doesn't take much to throw me off kilter physically . . .).

All for this entry.

June 13, 2006 (9:54pm)

This morning Gary had the skin class. I got to miss most of the gross pictures this time around cuz I had to leave for my orthopedic doctor appointment. Gary said later that he was sure the reason for the pics was to indelibly print on people's minds the horrors of pressure sores, but that he had other reasons for never forgetting what could happen from the simple act of not being turned frequently (or turning oneself frequently) off one's pressure areas.

My doc appointment was a bummer. And I don't want to believe the guy. He claimed that there was nothing I could do for myself by way of physical therapy (or surgery – not that I would be interested in that) to be free of back pain; he reiterated that point later, saying there was no way I was going to be able to handle Gary's care without having back pain as a result. I had been hoping that he would set me up with some physical therapy, but what he did was write me a prescription so I could get membership to the open-to-the-public gym at Shepherd. But this prescription did not include any sort of exercise guidance. What he gave me for that was a little booklet. I noticed the exercise that had caused me a huge setback (back arches, aka, "the cobra") was one of the recommended exercises. So much for that.

I will check out that gym anyway. I'm not extremely hopeful I'll get any help, but I will try to weasle some from the staff.

While I was in the doctor's waiting room, my brother, Joe, called. He had sat in a chair in the kitchen and decided that Gary would be able to reach the faucets – good news, since at first he thought the counter might be so high that all Gary would be able to do is heave the dishes over the counter and into the sink (we might have gone through a lot of dishes that way). We will ask Joe about a roll-under kitchen sink to make the task of dishwashing easier for Gary – hey, I still want chief bottle washer to remain chief bottle washer (I am best at dirtying up the pots and pans) ;-). Joe thinks Gary can get into the fridge all right, but opening the dishwasher may not be possible.

I asked Joe about the kitties (which is dangerous – I have been missing them much more intensely after hearing Joe talk about them). He said Blackjack is mostly unseen, but Tigger seeks out Joe hourly to get a petting. Tigger was always the more demanding of the two for petting, usually wanting it at the most inopportune times, as cats do, but he normally only insisted upon it a few times a day – he seems to be making up for all the time he hasn't had companionship. Hope Joe can tolerate it!

The Browns dropped in for a scheduled visit soon after I returned to Gary's room from the doc's. We had a nice chat, and then they continued on their way to a Real Analysis symposium (that's math, not psychiatry, for the nonmathemticians out there ;-)). They plan to return for a visit this coming Saturday afternoon, and so will no doubt meet some of Gary's family.

After lunch someone came in and asked Gary if he was ready to go to his 1pm class. There wasn't one on his schedule, we told her, but Gary would be glad to go to one. We might not have said that had we known it was the third of the Wellness and Leisure classes – fortunately the last one. Gary asked me afterwards if I had the same opinion of it as the other two. I rolled my eyes. "Me too," he said.

At least those are over now.

In the afternoon we went through some of the mail Joe brought up from home. We discovered a bill for the ambulance that had taken Gary from Birmingham to Atlanta. Insurance had paid only a third of it. Gary looked at what we owed. He looked at me. "If I'd known it was going to cost us that much, I would've had you take me," he said. "Yeah, I would've loaded you in the back of the Escort with all my stuff," I replied.

Looking through the mail, I also discovered I had completely forgotten about the paperback book club I belong to (and haven't actually bought anything from in years, ever since I discovered half.com and the used section of amazon.com). By default I had ordered $65 dollars of books I didn't want. I called the customer service number, explained the situation, and to my surprise, they put an "order only" status on my membership, so I don't have to reply to any further mailings, and as well they said that when we got home we could just send back the unwanted books and the charges would be removed from our account. Pretty great.

There was also mail delivered from Shepherd. Thanks to Ferenc Fodor, to my mom for the cute shorts set, and to Chayna (I never knew you had another name!).

In the late afternoon, I left for the chiropractor. I was not surprised to see Alex (Sasha) Shibakov drive into Shepherd just as I was driving out – I think we have some kind of car karma. He was stopping in for a visit before continuing on his way to our house to help out Joe. I am sorry I didn't get a chance to say hi to him this time – he is probably sorry too, since this meant I didn't pay him for the stainless steel three-piece Chinese steamer he picked up for me at an Oriental store near the DeKalb Farmers Market (the check's in the mail, Sasha ;-)). I noted upon my return that he had brought Gary more chocolate! Soon we are going to need a drawer just for chocolate, I think ;-)

And upon that return, I brought Gary a Mellow Mushroom (name of the chain) pizza served with some Fresh Market baby greens – Gary had known ahead of time that the dinner choices tonight were uninspiring, so had placed the request. He very much enjoyed the food.

I gave him a toe-to-head application of skin cream – some areas were looking dry – and then we finished "Capote" – it worked in the DVD player. We both thought it a very good movie. Now, let's see, what movie's next . . . Maybe "Crumb."

To finish the evening, the tech came in to watch me struggle with Gary's bivalves. She commented to Gary, "Your wife is strong." Hah, not strong, just determined to get his damn heel in there right. She claimed I did everything perfectly, so if there is a red spot tomorrow, I'm going to blame her ;-). She then rolled Gary to his other side (I don't know if I ever put this – he is getting turned every three hours these days), and it seemed to me that on the side now exposed, his incision line looked different – opened up more, and a yellowish color. This set off alarm bells in my head, and the tech went and got the nurse for me. The nurse hadn't seen the area since the staples had come out, so wasn't sure what it had been looking like, but since I said it was different, she made a note of it and said she would have the skin team told of it tomorrow morning so they can come and check it. Hopefully it is nothing to worry about. I hadn't noticed it looking this way before, and it had been all right when the person came to put Gary in his final stretch – the one hundred and ten degree stretch – that is to precede his beginning to sit up (hopefully tomorrow, for thirty minutes). So maybe the opening up is due to that last stretch. Maybe it was expected. But I am extra cautious of such things these days – best to err on the side of caution.

So, I will find out about that tomorrow.

All for tonight.

June 14, 2006 (12:07pm)

Mail call: more tapes from the Vaughans!

I got a little hurried the other day and didn't put down who the group card from Gary's relatives was from. So I'll do that now: the card was from Faith and Steve, Seth, Claire, Luke, and Chris, and Jo, and Aunt Dorothy.

When I got to Gary's this morning, I found there had been a conference around his bed, the attendees being the bivalve person and various and sundry nurses and techs. The conference concerned Gary's feet – when his bivalves had been taken off in the morning, there were red areas again. They've decided that it's not a problem with the bivalves or how they're being put on – he just has sensitive feet. So they're hoping the other methods of keeping his ankles stretched out will avoid any problems of contracture.

His flap was doublechecked, and apparently it is fine – the changes I saw were due to the scabs falling off along the one side that hasn't healed as seamlessly as the others; their falling off revealed the heretofore hidden tissue underneath.

Gary's other bit of news for the morning was that they've finally removed the peg tube. Even though he hasn't been fed through it since Birmingham, they said they were keeping it in "just in case." We noticed that they decided to remove it a day after one of the nurses we hadn't had before came in to flush it, saying that it was supposed to be flushed twice a day; we pointed out that this was the very first time it'd been flushed since we've been here, and she said "I'm going to pretend I didn't hear that." Evidently the twice a day flushing was then entered as an order into Gary's chart. If I were more cynical (who, me?) I'd say the fact that removing it means they don't have to flush it has something to do with why it came out now.

I left Gary for a bit to go down to the gym to see about the membership the doctor had said I could get. I told the person at the desk the situation (Gary is a patient here, a paraplegic; I have back problems and want to do whatever can be done to minimize them in order to be able to give him the help he's going to need), and she said that although they were not supposed to give advice to nonpatients, that if I came tomorrow afternoon, she would give me suggestions for exercises to do for my back. She then happily took my money; I hope it's not a waste.

Joe called during lunch, and we talked about flooring and then about getting rid of clutter and debris. Along that line, if anyone is interested in having one or more 5 gallon glass bottles, we have some free for the taking (I've given up on the ex-distributor of Mountain Valley Water ever coming to pick them up and on anyone else ever taking on the distributorship in our area). Just leave two bottles, as Gary's roommate wants them.

After lunch, they wheeled Gary down to a counseling class. The counselors need further training, IMNSHO (you remember IMHO, don't you?). They just let the conversation drift, whereas I thought they should have been at least a bit more directive. Several times they passed up opportunities to explore emotions that had been brought up, instead letting people turn the conversation to what pieces of gym equipment they'd tried out.

After that class, for the first time in several weeks the nurses started to change Gary out of his hospital gown into some clothes, in preparation for his "big event" of getting to sit in his wheelchair again. While they did this, I went down the hall to talk to our case manager, who had poked her head out of her office as we'd passed by on the way to class and told me she wanted to talk to me. It turned out she had information about Gary's discharge. While not set in stone, it is scheduled for July 14th! That's much sooner than we expected. They have him enrolled in the day program for the two weeks after that, but that may not be necessary. (The day program is essentially the same as the inpatient rehab program, except instead of going back to his hospital room at 4pm, he is bussed to some nearby apartments of Shepherd's. Insurance usually covers the day program.)

She also said my two remaining family training days are scheduled for July 6 and 7, but that since I am always here, I can talk to his principal nurse and to his OT and PT therapists to ask them to spread out the training instead of trying to do a two day marathon. His principal nurse was the one getting him into his clothes, and when I went back and talked to her, she agreed to set up convenient times to do the bowel and bladder training with us.

Next came the big event. Gary was hoisted through the air and put into his chair. He had expected that the first time he wouldn't feel so great – that had certainly been the case in Birmingham – but other than a brief spell of dizziness that was relieved by doing his side weight shifts, he felt reasonably good. Not as good as just before the flap surgery, when he'd been regularly up, but all in all, pretty good. He thinks the binder they put around his middle really helps – they never used that in Birmingham, and there he always felt "weird" for at least the first half hour of his sitting, because of changes in blood pressure.

He wheeled himself partway down the hall and back but the rest of the time just sat in the chair – that was enough for a start. But this was better than he expected, so he was really pleased.

He is also being allowed to lay on his back for two hours as part of his turning schedule (so it goes: left side 3 hours, back 2 hours, right side 3 hours, then repeat). He is really happy to be on his back some – it makes a big difference when you haven't been able to lie on it for so long! But he is getting muscle spasms that start in his abdomen and run down his legs. He can't feel the actual twitching, being below the level where his feeling stops, but he knows his whole lower body is jerking, and I can see it doing that. As this has never happened before, we're hoping it is a temporary thing until he gets used to lying on his back again. We noted it stopped as soon as he was turned to his side.

For his reward for successfully sitting in his chair ;-) I got him some Ben and Jerry's Cherry Garcia ice cream as an after dinner treat (I also got him a baby greens and herb salad, some mixed berries, and some mixed nuts to make up for a dinner they claimed was salisbury steak but Gary claimed was a hamburger they'd done something unexciting to).

All for today.

June 15, 2006 (3:09pm)

Mail call: Thanks to Lois Stavig and Beth Fletcher.

This morning I walked in just as the nurse was about to give Gary his bath, so I asked if they wanted me to do it. They said sure, and then the nurse abdicated a bit more than I expected – she told me to put his clothes on him too. This probably sounds like no big deal, but there were things to contend with – like his Foley catheter and (since he was going to soon be sitting up) his (mid-section) binder and his ted hose, which fit like very very tight thigh-high stockings (I'd never put the binder or the hose on him before) – not to mention how exactly to get those clothes on him and the binder around him when he is mostly deadweight and can't be pushing himself up in bed to help because of the flap. It took me forty-five minutes to complete the process. I had the nurse check the results. Ted hose perfect, binder needed tightening but was positioned fine, pants needed a little straightening (I couldn't lift him up at the booty to get them to fit over him quite right and I didn't want to be scraping the pants over his flap).

We talked to Joe shortly after this, and he told us of his idea to remove the bathtub in the master bathroom and replace it with a roll-in shower. We had known of the existence of such, and Joe convinced us this would be a good thing. He also told us that Jo Heath had popped in, and was going to try to find out about debris removal – Joe had only been able to find a place that would rent him a 20-yard dumpster for a price that sounded pretty outrageous.

Jo and Bob Heath, and Janet Rogers, are helping with yard work, I hear. We are so grateful to them, and to the others who responded to the math dept. email asking if anyone could help Joe out while he was there. (A little later today I got an email from Janet which made me laugh. She said she had tried to take digital pictures of the kitties to send. She only got a glimpse of Blackjack, and Tigger kept trying to be friendly and wouldn't stay far enough away for Janet's flash to work properly. Tigger has definitely had a personality change – he never before let other people get this close to him on such short acquaintance).

Today Gary sat up for an hour. They brought a new chair for him, one that was narrower, but it turned out to have other features that made it less comfortable than Gary's previous one – the back was lower, cushiony instead of hard, and it didn't have the "side wings" that curve around Gary's mid-section and give him side support (needed since he doesn't have the use of the abdominal muscles that would prevent him from sliding to one side or the other). So for now he is back in the one that is too wide in the seat and is "tippy" (tho not dangerously so, since it has tip bars in the back – the problem is it takes little hops when he rolls it along). After the discussions about the chair with one of the staff, and after eating his lunch sitting, he had only ten minutes to go anywhere in the chair. That got us down to the garden – but we had to immediately go back. At least he got outside for the first time in weeks. And, he got up the ramp completely by himself this time, whereas last time I had to stand behind his chair and prevent it from going backwards – so, his weight work is paying off, he is stronger! He also got down the ramp without me hanging onto the handrails on the back of his chair as I did last time, though he scared me a little cuz he got going a little fast. I told him to yell if he needed me, but since he didn't, I let him go zooming down it, me right behind with my hands poised just in case. He admitted he'd gotten a little nervous there at the end. But he pointed out the worst that would have happened is he would have ended up in the bushes. I told him, half-joking, that I didn't that would've been too great a reflection on me, but he said he'd take the blame.

When they got him back in bed, he said the time had gone by much too quick. So he must be feeling pretty good with the sitting.

The wife of one of Gary's roommates then stopped by to tell us about a phone call she'd just had. The person had asked her why there were three patients sharing the room. She had replied, "So they can see that other people are in the same situation" (I doubt that's the reason but didn't contradict her). Her friend then asked, "Do they have anything in common?" and she replied, "Well, there's redneck Greg, the brother Thomas, and Professor Gary. . . No, I don't think so." We laughed, and she went on in a serious vein, "It just goes to show you that this could happen to anyone."

Soon after that, Gary conked out for a nap. After a short time, two nurses came billowing through the curtain, and even though it was obvious Gary was fast asleep one called his name out in a loud voice. I was standing next to his bed working on the blog, and I immediately put my finger to my lips. This succeeded only in turning her attention away from him to me. "We just came to see if he wants anything," she said in a just-as-loud voice. I smiled politely and shook my head, still trying to get across the message with my body language that they should be quiet, not voicing the thought that had come to mind at her statement. I didn't voice it for two reasons – one, because I was trying to be quiet, two, because the thought was a sarcastic, "What he wants is to sleep." This type of behavior seems to be a universal nursing failing – for example, a couple times Gary had a nurse who would come in at 5am, roust him from his sound sleep for his bowel program, and expect him to be chipper and laugh at her jokes. I can think of several reasons why I would find little to be amusing under those circumstances. And we heard a story which we think is the ultimate of this type: a patient was awakened from a sound sleep only to be asked if he wanted a sleeping pill.

Since today's meals had been ordered yesterday, Gary already knew tonight's dinner choices didn't appeal to him; I had told him some more things that were available at the Fresh Market, and he had placed his order. So I picked him up some BBQ rotisserie chicken drummettes, throwing in a few that were Buffalo-style, which evidently means they are very hot. I also got him some smokehouse BBQ beans, and he rounded out the meal with baby greens and berries.

After dinner we got him spruced up for his family tomorrow – since the accident he seems to think he can indulge in a behavior he used to reserve for weekends: going around without shaving and looking like a bum. Oh, excuse me – he claims he looks very chic that way. So I guess he won't look chic tomorrow cuz I used the Schick on him tonight. He needs a haircut, but he had to forgo that – lying in bed is not the best position to be in while cutting your hair or having it cut. We found out from his roommate that the way to do it is to be sitting in your wheelchair which you've rolled over a sheet, and to have another sheet wrapped around you. This roommate's wife has volunteered to cut Gary's hair – I won't touch it because I don't want to be blamed for the result ;-) He would normally cut it himself, but there isn't a mirror in there for him to look into.

After giving him a bit of a lotioning up, I left early. There were a few more things I could pack up now that my own dinner was over. I'll still have some kitchen stuff and bedroom stuff to go out to the car in the morning (this is the last night in this apartment), but I won't have to do it myself – the Gruenhage family said they'd come over and help me. Good timing of their visit ;-)

All for tonight.

I lied. One more thing. It may be all to the good that I am moving out of this apartment. Elephants who never sleep have moved in next door.

June 16, 2006 (8:43am)

I called over to the Residence Inn to make sure they had listed my preference (back row facing the woods, upstairs, nonsmoking) and also to ask them the best time to check in – too early, and the rooms wouldn't be ready, too late, and the best choices would be taken. They said they had a room that met my requirements available now. "What number?" I asked. "1623," was the reply. "Uh, that's right upstairs from 1613, right?" I asked. It was. This could be a problem. A couple weeks ago I had told another woman who was being kicked out of the Shepherd apartments about the great deal I'd gotten at the Residence Inn, and she was in 1613. She had told me she loved the place. She also told me there was somebody with dogs who lived upstairs from her, but that she didn't mind. As you can probably guess by now, I would mind, so I wanted to make sure I wouldn't be near them. So I told the Residence Inn guy my friend had told me their were dogs up there. "Yes," he replied, "They're right next to 1623." Can you believe that? What are the odds that out of all the rooms in the place they were going to stick me in the one next to the dogs? I asked for a different room; he told me one the building over would be ready at noontime. I took it. Keep your fingers crossed.

I finished packing up and lined everything along the hallway of the apartment for the Gruenhages to help me haul out. Norma called, and they came over. I went out of the apartment and waved Gary's brothers Bob and Donne and Donne's son Justin up the stairs. Donne then told me his mom had fallen in getting out of their rented van. When I went over to the van to say "hi," she was clutching her arm. "What a drag," I told her. "What a drag," she agreed. They wondered where to take her for a doc to look at her arm. I thought of Piedmont Hospital, right next door to Shepherd, said maybe they had an emergency room. They left to grab a takeout breakfast and find a doc, and I went to Shepherd. I dropped off my housing key at the security desk at Shepherd per instructions. Good timing, since just as I did so the housing guy called to see if I was out of my apartment yet. I really hadn't expect them to be such sticklers for a 9am departure time, but evidently they are.

I got to Gary’s room and told him about his mom. “What a drag,” he said. We were all in agreement. I found out from a nurse that Piedmont did have an emergency room. I called Norma to tell her (or did she call me just then? I forget). It turned out they were just entering Shepherd’s parking garage. I told her there was a tunnel that led from Shepherd to Piedmont (Gary had been rolled through it on his way to Piedmont, which is where he had his flap surgery). I thought of meeting them at the elevators and taking them through the tunnel after getting the directions to the ER myself, but they decided to come up and see Gary first. Just then the tech came into Gary’s room and hoisted him into his wheelchair. His hair was a little wild from being in bed (and from it being too long), so he wheeled over to the mirror in the outer room and did his best to tame it before his family came.

It was a happy reunion, though Mom Gruenhage got teased for trying to take the attention away from Gary. We talked a bit, then I suggested we figure out how to get to the ER. We asked at the nurses’ station and it turned out someone was headed that way. At first only Mom G and Donne were going to go, I believe, but I asked Gary if he wanted to go too (to get a little change of scenery). He decided he would, so we had a little caravan. This was Gary’s first trip through the tunnel by chair, and we discovered that in some parts it sloped downhill and in other parts definitely up. Gary had to make a stop for a weight shift, and a few more brief ones to rest, so he and I and Bob fell behind the others. I asked Gary how he was doing, and he said he was getting a good aerobic workout. We made it to the ER, possibly doing something “illegal,” as to get there we had to briefly go outside off of Shepherd property and I don’t know if we were supposed to do that yet (not having had certain training).

Amazingly, it didn’t take long before a nurse came to take Mom G back to have her vitals taken. Gary needed to head back to the room, as he was only allowed to sit for an hour and a half today. Norma stayed with Mom G, and the rest of us headed back. At one point in the tunnel Gary zoomed off, due to the slope, and I ended up at a near-run trying to keep up – just in case. We had to stop for another of his weight shifts (right now he is to do them every fifteen minutes, though soon that will go back up to the standard half hour), then we headed up the elevator and toward his room. His PT saw us go by and said his TR (who Gary calls “the definition lady” (“ I am a recreational therapist. What do you think I do?”)) had come by for her scheduled visit at 11. We told her our sheet had said 10 and we’d wondered why she’d never shown up. Turns out there were two schedules in Gary’s room – the old one, which had been on Gary’s table and was the one we’d gone by had the RT coming at 10, and the revised schedule, hanging from the arm of the TV, which had her coming at 11. Oops.

I left to check in at the Residence Inn. I have a suite with a queen-sized bed, and I did get in back facing the woods. As long as my neighbors are quiet, this should be good. I unloaded enough from the car to have available the things I would need to cook dinner, then headed back to Shepherd. I certainly got spoiled with the convenience of the Shepherd apartments: it took me twenty minutes to get to Shepherd, as opposed to the two minutes from the apartments. It probably took longer than it normally will, though, since I had to deal with lunchtime traffic in Buckhead.

As I got about halfway through the hallway from the parking garage to the Shepherd building, I saw the Gruenhages in front of me, heading into the pharmacy. “What’s the verdict?” I called, seeing Mom G with her arm in a sling.

Broken arm!

At least it was only a hairline fracture. She will have to wear the sling, but that is better than having to wear a cast. The Gruenhages were filling a prescription for pain pills for her, and then they were taking her back to Helen’s condo to rest.

I went up to Gary’s, and he was ready for a rest, too. While he napped, I called my brother to see what was up with the house. We talked more about the roll-in shower, about the flooring (trying to decide whether to have ceramic tile throughout the entire master bathroom and bedroom so there is no break in surface or to have the tile only in the bathroom and have the floor in the bedroom be wood or vinyl sheet goods or low-pile rug (I preferred one of the first two choices but wanted to check with Gary)), and we also talked about the cabinetry in the bathroom – specifically, what to replace the existing cabinetry with, as the existing counter sink is being replaced with a pedestal sink.

Joe also talked about how much help he had gotten from Alex, and how much of a resource Jo Heath is for him. I can’t tell you how wonderful it is having this being handled for us. It would be overwhelming to have to deal now with all that has to be done in order to make our house wheelchair friendly – I don’t think I could do it.

I checked my email and opened the one from Janet Rogers – two cute pics of Tigger! Janet even went to the trouble of photoshopping out (don’t you love the practice of turning nouns into verbs?) the toilet plunger that had also made it into the picture.

Gary woke, and I showed him the cat pics – he thought they were great, too. I started telling him my conversation with Joe, and the Gruenhages walked in. So we gathered opinions from them as well (and they wanted me to be sure to convey their appreciation to Joe and crew for doing all this for Gary and me). We all liked the idea of a wood floor in the master bedroom best. For the cabinetry ideas kicked around, Norma pointed out that even if Gary couldn’t reach all the shelves in an overhead cabinet, they could be used for storage. So we are leaning toward a lower-drawers-and-overhead-cabinet system. While we were talking an email from my sister Janet arrived, saying “hi” to the Gruenhage family and wishing them a good visit with us (fortunately this email was immediately delivered). They say “hi” and “thank you” back.

The TR popped in and said Gary will have a couple table tennis classes next week. Now this is the type of rehab he can really appreciate! ;-)

Shortly before I was going to leave to do my usual early evening routine, Norma showed us some presents she'd brought: a large selection of paperbacks from various genres; since we like CSI and 24 and she does too, a lot of the ones she picked out had what she thinks is a similar flavor. But Gary is going to start with "Into Thin Air"; we've seen the movie based on it (on Donne's recommendation, actually) and liked it very much (though we thought those climbers were a little nuts to have enjoyed the kind of climbing they did ;-)).

I left for my hotel, and shortly after the Gruenhages came over to help me with the rest of my stuff. It took less than two trips for the four of us, but that meant it saved me an extra four trips. Unfortunately my leg had started acting up as a result of the trips to the car the previous night, but I'm sure it would have gotten much worse if I'd had to do all the trips the Gruenhages saved me.

Later on, I brought my dinner back to Gary's to eat, as usual. I suppose it had to happen sooner or later – somehow I knocked my food container of zukes and rice off the stand in his room and it went sailing. Food covered about a third of the floor, the dresser drawers, and part of my clothing. Gary said I couldn't have covered more area with it if I'd tried. I got it cleaned up, and a nurse who had come in to check on Gary called an environmental service technician ;-) to go over it with a mop.

The Gruenhages phoned – they'd gone out to eat at the nearby Ted's Montana Grill (owned by Atlanta's Ted Turner) – and wanted to know if Gary had had dessert (good timing – he'd been planning on having some ice cream). They said they were bringing over a surprise. Boy, did they. Ice cream and chocolate brownie and chocolate sauce from Ted's. Gary's mom, who was up and about again after having spent the afternoon resting and said she was in no pain, wanted to know if the dessert was tasty. Gary said that wasn't the word for it. The Gruenhages exhibited remarkable self-control, turning down Gary's offer to share it (they claimed they were stuffed from the excellent meal they'd had, but still . . .); me, I silently endured the torture (when I'm about to die and allergic reactions don't matter any more, give me this dessert; you can precede it with baked beans and crispy baked potatoes, both with a generous amount of catsup on top).

The Gruenhages said their goodnights, and shortly after I did too. I left a little earlier than usual because I live much farther away now. The room seems nice and quiet so far (I did hear those dogs outside about tennish, but that didn't continue) but I still slept lousy – my leg was bothering me some, but I think it was mostly because it is a new environment to get used to. I'm not very adaptable that way.

All for now.

June 17, 2006

A few odds and ends to start. 1)Evidently we got "Into Thin Air" confused with "Into the Void." The latter is the movie we've seen; Gary has started the book with the former's title, says it's about a disastrous Everest climb and says he's really enjoying it. 2) Jo Heath called my attention to the fact that tho she knows who to call, the people who gave her the information are John Hinrichsen, Eric Ford, and Donna Bennett. So, our thanks to them!

This morning as Gary's tech went to hoist him through the air and into his chair, she seemed surprised I hadn't learned how to get him settled into his chair yet and gave this speech about how they like family members to get involved in the care of the patients. I felt myself bristling, but tried to restrain myself – she was, after all, someone we hadn't had before. Gary explained to her that I had been being involved but hadn't been taught how to do this (the PT had shown me, but hadn't had me do it because of my back). The tech showed how to lay him onto his sling by having him turn in the bed first to one side and positioning half of the sling so that when he turned onto his back he'd be on it right, then tucking the other half under him, then having him roll to the other side and pulling the tucked part out from under him and laying it flat, then finally having him lay on his back with the sling now perfectly (hopefully) under him. Then we hooked the sling onto the hoyer (this part I'd done before) with chains. As Gary used the control button to lift the sling up, the tech had me hold Gary's legs and guide him over to the chair (this is one of the parts I've been worried about, since I am supporting the weight of his legs). Finally she showed me how she guided him into the chair as he operated the controls to lower the sling. The important part is to make sure his butt is as far back in the chair as possible and that his hips are even – he sometimes can't tell, at least at this stage; in fact, several times the techs have asked him if he felt straight in the chair and he's said yes, whereas when we look at him we can clearly see one hip jutted to the side. He decided the trick is to check the position of his knees, make sure one isn't forward of the other.

Tomorrow I'm supposed to so this entirely myself (with the tech watching).

Just when he got settled into the chair, his siblings and nephew entered the room – his mom was still resting back at the condo. We headed to the garden. We took a spin around the small area, finding the weather pleasant, though Gary was not in complete agreement – he was the one working to move the chair around, and on top of that he was wearing a long sleeved T-shirt (the inside of Shepherd tends to be on the cool side). So he was ready for the cooler air of indoors. We exited the garden into the rec room where they have a pool table, table tennis table, and large TV set up (plasma, maybe – I don't know my TVs). Gary and Justin decided to play pool. Now, it's been many many years since I've seen Gary play pool, but still it was obvious to me that he was definitely nowhere near his former level of performance. He remarked that if you've never tried to play pool sitting down, it is quite an experience (and by the way he said it, you knew he wasn't recommending it). He said it was the longest game of pool he's ever played, and he gave a heartfelt thanks to Justin when Justin had gotten the last of the solids in and also the eight ball. I think Gary only managed to get two stripes in.

Continuing our little tour of the facilities, we next went to the Marcus building (part of the Shepherd center and where rehab is offered for those with brain injuries). We went down to the gym level to view the pool and to see the ProMotion gym (has special rehab equipment and is the gym open to the public). We then headed back to Gary's room; it was obvious Gary was eager to get back there, having had enough activity for a while, tho he did briefly show the family the gym on his floor – that's where he does his rehab.

The others left to check on Mom G, and Gary started in on his lunch. The tech came to put him back into the bed before he finished, and he was ready – definitely ready – for it. A scale was set up on the hoyer, and the tech took Gary's weight. 127, about the same as they'd weighed him before the flap surgery. So even tho he's been "packing it in," he hasn't gained anything. But at least he hasn't lost anything, either, which is what the doctor thought might happen after the flap surgery (before the accident Gary consistently weighed 140, though I thought he looked best a bit lighter than that, say 132-5; he was at 132 in that photo from '79).

He finished lunch, then we called my brother to talk about the house, including discussing a possible solution to what to use as a cat barrier – replacing the slatted double doors now functioning as a barrier with a single door having a recessed hinge. After that Gary took a nap and I answered some emails. His family rejoined us, including his mom, and we shot the breeze. One topic that came up was how Gary and I will be celebrating our 25th wedding anniversary in August. This reminded Mom G of how my dad and mom had taken her and Fred (Dad G) and Bob out for a little tour of Chicago (I think this was the day after our wedding ceremony; Gary and I were on our honeymoon). I'm not sure if I got the story exactly right, but it's something like this. My mom didn't want to go if it involved a lot of walking. My dad assured her it wouldn't. Mom G said it turned out practically all they did was walk, and they saw parts of Chicago they'd rather they hadn't. "Bums and prostitutes," Mom G said. At dinnertime, my dad was trying to find a nice place to eat, and I think the story is he couldn't find the one he had in mind. At any rate, they asked a cop, and he directed them to a place. Mom G said the place was filled with cigarette smoke, and when they sat to eat, my dad and Dad G were approached by ladies who, well, er, ignored my mom and Mom G and lavished attention on the men. My dad told these nice ladies that he and the rest of his party had just come from a school board meeting, and then they left. Mom G went out on the steps, sat down, and roared with laughter.

They never did find a place to eat until they came all the way back to my parent's town. There, they stopped in a restaurant that was closing up. My dad persuaded the restaurant folks to take the chairs down from a table and serve them.

Yup, that's my dad, from start to finish.

Jack and Jane Brown stopped in while Gary's family was there, bringing with them a card for Gary signed by attendees of the 30th Summer Symposium in Real Analysis. The Browns told us about the Carl Sandburg house in North Carolina they'd just come from visiting, saying they really enjoyed it (I hadn't realized Sandburg had lived anywhere but Illinois). The talk turned to baseball – Jack and Gary are real Braves fans and have gone to a game together for each of the last several years; Norma roots for Houston; Bob for the Cardinals; and Donne for San Diego (the fact I'm not a baseball fan is probably obvious from the fact that I don't name the Houston or S.D. teams. I'd say "Oilers" and "Padres," but I'm thinking "Oilers" are football – I'm sure Houston fans are ready to shoot me – you know how they are with those guns in Texas ;-)).

Later that afternoon I had to do some errands. First was a stop at Fresh Market to pick up zukes. I got the usual question, both from the produce man (a different one this time) and from the checkout woman, namely, “What are you going to do with all that zuchinni?” “Eat it,” never seems to be an appropriate reply, so I tell them I have weird allergies and this is one of the few veggies I can eat.

I then stopped at a Publix to get some bottled water – much cheaper to get it there than to get the same stuff at the yuppie Fresh Market (tho their zukes are usually much better quality and therefore it’s worth the other stop). Next came a stop for gas. I decided to get a car wash as well. This was my first time in a car wash, which you would know if you ever saw my car. It was so dirty even I noticed that fact. I had the odd sensation while in the wash that it was my car that was moving, not the brushes and soaping and rinsing equipment. I experienced vertigo during it, but it was not unpleasant – kinda fun, actually. After that I had to make another stop at a different Publix because I remembered something I’d forgotten to get (this was a way I could tell I was tired out – there were only three things on my list). As I got out of the car, I noted that it didn’t look much better than before the wash – some of that dirt must be ground in.

When I later returned to Gary’s, he asked for fruit and baby greens to complete the dinner he’d finished an hour previously. He said it had been a good one – catfish and green beans – but that was all he’d ordered and it was not enough. After all this good-for-you stuff, he said, “Now how ’bout that dessert?” So I went to the patients’ fridge and got him the ice cream and brownie and chocolate sauce left over from last night’s treats from Ted’s. Just then the Gruenhage clan came, except for Mom G – she was back at Helen’s resting. I feel so sorry for her – coming all this way to see her son and then breaking her arm and having to spend so much of the time resting instead.

At one point Norma told Gary the story of how all her class knew of his accident and how they had all sent her a large bouquet of flowers after learning of the news. She mentioned that when the kids found out about it at chapel (Norma teaches at a Lutheran school; her husband Wayne became the principal there years ago), the first thing they asked her was if this was the brother of hers that they “knew.” That, we needed an explanation of. She started the explanation by making sure we understood that she always builds Gary up and the kids know he is very smart. But, she uses Gary to illustrate a point in her science class every year, the point being that even though you can be a very smart person, you still need to use sense (the way she put this had me nearly falling down with laughter, especially as I think of Gary as someone eminently commonsensical, whereas I am not). The illustrative story is the one where Gary found a container of unknown chemical in the basement and put some into a spoon and tried to light it. It didn’t light, so he blew on it. And it blew up in his face. Rocket fuel. He still has a tiny scar above his lip from it. (He is lucky that that is the only visible reminder of it; had he not been wearing glasses (which blackened during the explosion and he threw them off) or had his mom not put his face under running water then whisked him off to the doctor, the results might have been far worse.)

The rocket fuel story led the Gruenhage siblings to reminisce about the farm they grew up on and about all the wild or mischievous things they had done as kids – the story where a very young Gary suggested an even younger Bob hide under the farm porch until he dried out after getting completely soaked from head to toe after falling into a creek none of them were supposed to be near had us all in hysterics. Bob followed Gary's suggestion, but this brilliant cover-up attempt didn't work out. Their mom wanted to know where Bob was, since Donne and Gary were in the house carrying on as usual and little Bob was nowhere to be found.

Back in my hotel room I noticed the quietness of the surroundings. I went to bed, hopeful. At midnight, I was shot awake by a horrific racket – it took me a moment to identify the noises as those made by the hounds of hell, which apparently belong to my next door neighbor, aka Satan. The hounds barked and carried on while the demonic one took his sweet time getting into his room (that, of course, was part of my eternal punishment).

I can't believe it – here I ask them not to put me in a particular room because there are dogs next door, and I get put in a different room with dogs next door. And I know Beelzebub has been here since before the day I checked in, because he had a "no service today" sign on his door when I was first moving in.

I finally fell back asleep, and some time later was ripped awake again. I then heard a door slam, from where, I don't know. I'm not sure what originally woke me. After a while my heart stopped pounding, and I dozed off, but I don't think I slept long. At four-thirty I woke again, shaking – having what I call the CFS shakes, since I never had them before I had the illness. I continued to shake for about two hours, feeling absolutely horrible. I meditated throughout that time, but what I needed was sleep. I finally got relaxed enough to doze off until close to eight. I got up feeling very dragged out, and when I got to Gary's I started crying. I don't want to go through all the tiredness I experienced that first month again. So I'm not sure what to do – hope it was a weekend fluke and stay where I am, ask for a different room, try the other Residence Inn that is further away, or go to Holiday Inn Express which would cost over twice as much (assuming I can get in at all) but where we've stayed before and had pretty good luck with in terms of quietness. All but the first option would, of course, mean I have to pack everthing up again and move myself, this time with no help at all.

One problem with being tired is it makes thinking and decision-making much harder.

All for now.

June 18, 2006

After I got over my crying jag (see last of previous entry), Gary called the tech to oversee me putting him in the chair. Over the intercom, she told me to get the sling around him. I don't know if I remembered the technique correctly, but the sling ended up properly positioned. So, as long as it worked . . . I then started bringing the hoyer over (it runs along a track in the ceiling), and at this point the Gruenhage clan walked in. I got the sling chained to the hoyer, and brought Gary's wheelchair in from the bathroom. Mom G nervously asked at this point if I intended to now move Gary to the chair. I assured her I had no intention of doing so without the tech present – wouldn't want to dump Gary on the floor.

The tech came, said the sling was A-OK, and had me bring Gary over to the chair. I couldn't remember how to get him seated (I knew I had to let go of his legs, but what did I hang onto instead?), so she did it and told me I could do that part tomorrow. I told her, no, I wanted to do it now. So Gary operated the controls to lift the sling up a little, and then we redid that part. Gary tightened his binder, put on his seatbelt and his chest strap (like a seatbelt but goes around him at chest height), and then we took off for the garden. We went around a bit, then stopped for a pleasant chat with Gary's roommate Greg and his family, who also had come to visit this weekend and were out in the garden.

Then it was time for the rec room. Gary started out with table tennis this time, playing Bob. That seemed to go better than pool, but still, if a shot went wide or too shallow, he couldn't reach it, and we wondered how two people in wheelchairs could play if they didn't have a ball boy or girl. Bob asked me if I wanted to play, and thinking he meant play him, I said no – Gary had told me how Bob had won all these trophies in table tennis in his high school and college days. But they had meant Gary. I said, well, you realize I've never played this game before and the ball will probably be all over this room. He said I'd probably be just his speed. It was kind of funny – I made a number of lucky shots – the ones where the ball hits the very edge of the table. He said he didn't believe I've never played before, but I swear at best I was just trying to hit the ball back and keep up a volley and at worst I was trying to defend myself from getting hit with the ball. Justin asked Gary for a replay at pool, and Norma took Gary's place and played with me. She had the kind of philosophy I like – the goal was to see how long we could keep a volley going, not score points. She turned the paddle over to Donne, and it got harder, cuz he hit the ball harder. He also said he couldn't believe I hadn't played before (these people are kind), and he turned his paddle over to Bob – I thought it was about time someone walked over to my side of the table so I could turn my paddle over to them.

Meanwhile Gary was doing much better at pool than he had yesterday – in fact, he was winning!

Back to the table tennis. Bob is a highly skilled table tennis player, but fortunately he was kind. At least relatively so – he decided I needed some practice in moving about the table. Actually, I didn't want to do that all that much for several reasons: my leg, which has been acting up since the moving, my general unfitness level which guaranteed I'd be sore, and the fact that I was tired out. So I played a little more (it's hard to quit when I'm enjoying myself at something, even though I know I'm going to pay for it later), but turned my paddle over to Justin the moment he asked if I wanted to watch him play his dad. I then learned Gary had won his game! But he was heading back to his room, so I figured he was a bit tired. I was too, so I headed back with him, as did his mom (and Norma too? I forget). As we got in the elevator, my brother called – our ad in the paper for the free spa and free 5-gallon glass bottles was a success – a person came and took not only the spa but all fifteen or so bottles! Joe said he had a feeling the guy was going to use the bottles to make moonshine. In which case, perhaps he's going to stomp muscadines in the spa for wine. Joe said the guy also took the "cat barrier" doors Joe had just removed. I told Gary all this and Gary said we should have told Joe to tell the guy to go around to the side of our house and take all the garden pots and other gardening-related items we have laying over there.

Soon after we got back to Gary's room, the others rejoined us, and then all too soon after that, it was time for the Gruenhage clan to leave for the airport. Gary said goodbye to his mom first, thanking her for coming. He started to cry, with the result that his sister and his brothers and I immmediately had tears spring to our eyes too. His mom told him she hadn't expected him to look as good as he did. The goodbyes to the others were made, and after they left Gary and I shared an extra long hug.

After lunch, under the tech's supervision, I got Gary got back into bed and turned on his side – I still need help there, because I'm too afraid of hurting my back to tug him over in the bed by the sheet. But once he is far enough on one side of the bed, I can do the actual turning of him with his help (the key is to bend his leg at the knee and fold it over his body, since that helps turn his entire lower body; he can grab onto the rail and turn his upper body at the same time). And I've pretty well got down the placement of the pillows for padding the points of pressure, except when he is in the prone position – haven't done that one with him yet.

Once he was settled in, I read some emails to him, and then he was ready for a nap. I worked on the blog while he slept. After he woke, he did his weights. I left earlier than usual because fatigue suddenly hit me hard and I hurt like hell. At the motel I went to the front desk and asked how long my neighbor was checked in for. They said he was long term. I said his dogs had disturbed me last night, and they said they would try to find a room that didn't have dogs near to it – personally, I think they should make it a policy they require those with pets to at least register that fact.

I decided to talk to this neighbor. He answered the door when I knocked. I said I didn't mean to be antagonistic, but I was under a lot of stress because my husband had been in a bad accident and was in the hospital. I said I had to live in a hotel the next thirty days, and that last night I hadn't been able to return to sleep after his dogs had woken me, that I'd felt horrible all day because of that (not too much of an exaggeration), and that I couldn't take that. I wanted to know if last night's events were typical, in which case I would move to another room.

The divil turned out not to be such a bad fella after all.

Or rather, this guy claimed not to be the evil one. True, he had one dog. What had happened was that he'd been out walking his dog in the back here, and two unleashed dogs had attacked his – that had been the horrible racket I'd heard. The attacking dogs had turned out to belong to someone else staying here, and the two men had gotten into an argument, the one telling the other to leash his dogs, the other saying he didn't have to – that'd been all the raised voices I'd heard.

My neighbor said he'd complained to the management about the unleashed dogs, and they'd said they'd take care of it. My neighbor was sympathetic to my situation and assured me I wouldn't have trouble with noise from their side. So I'm cautiously optimistic.

My body stopped hurting so much after I meditated. When I returned to the hospital Gary told me I had missed a visit by Michel Smith (head of Auburn's math dept. and supremely supportive of getting Gary back to work this fall, as well as of our situation in general). Michel had been on his way to the airport and had stopped in to see us on the way.

Gary's dinner had been something he hadn't even ordered (catfish fingers – "fingers" meaning it's going to be heavily breaded and deeply fried). Gary had pulled off as much breading as he could and eaten the catfish, forgetting that he still had some of those chicken drummettes left over from the other day. When I reminded him, he said he'd take some now, so I warmed them up in the microwave they have in the gym (odd place for it!), and brought him some of the leftover BBQ beans and some salad greens. Later, he had some Ben and Jerry's.

To finish the night we did some grooming tasks. Gary forgot to brush his teeth when he'd been sitting up earlier in the day, so he had to do it in bed, spitting into the suctioning device (sort of like that thing at the dentist's) that is standard equipment above everyone's bed – thank God the days are over when that device was used to suction out his trache hole (which has closed, but you can still see where it was). I lotioned his feet, which have been very dry lately – maybe as a result of the ted hose and/or bivalves and/or those other boots he'd worn (we're not sure what happened to the bivalve experiment – the person who made them had said she would be the one to put them on him, but she hasn't done so since Thursday; either she doesn't work on weekends or she's decided this is a failed experiment). Then I stretched his ankles. We do that three times a day – when they get his chain loops made, he'll be able to do it himself. Again, he'll eventually be fully independent in his personal care and so forth, though for a while there will be some restrictions until his flap is fully healed, which worse-case scenario is generally a year. We haven't figured out how he'll be able to turn and pad himself in bed every so many hours during the night, but we're both hoping he can – neither of us wants to wake me regularly during the night to turn him ;-). He said he saw a video on the hospital's channel showing some guy turning himself, but this guy had a lower injury than Gary does and so had the use of his abdominal muscles. But since they said he would be independent, we're thinking this must mean he'll be able to do that too.

The hotel again seemed quiet when I returned to it, and I hoped it wouldn't prove to be a deception. It wasn't – I got a good night's sleep. Thank God.

June 19, 2006

Today critique group friend Jamie came to visit me again (okay, she had to take her family to the airport but I'm sure the primary reason she came to Atlanta was to visit me ;-)). She visited with Gary for a short time, and then I "played hooky." We weren't sure how to spend the time – a tech had suggested we go see the human body exhibition at the Civic Center, but Jamie hadn't look utterly thrilled at the suggestion (it wasn't how I wanted to spend the time, either, though I'd be interested in seeing it with Gary when he is at the point in his rehab that he can take such a trip). I wasn't really up for anything involving a lot of movement, particularly seeing that I am still recovering from the lack of sleep the night of the dog fight as well as from ponging when I should gave been pinging the other day with the Gruenhage clan. We decided to go to the Blockbuster that was a couple of blocks from Shepherd and rent a DVD.

I wandered through the stacks and worried that this was going to be a very short visit. I couldn't find anything I wanted to watch. So what would we do? I'm not much of a conversationalist. (The vast majority of the time I've spent with Jamie has involved critiquing her fabulous 1200 page novel, which is in its last revision before being sent to publishers, and I haven't been doing my homework of reading this version and critiquing it, so we couldn't talk about that. My mystery story isn't anywhere near the point where I want to talk about it to her, so that was out. She reads my blog, so there wasn't any current news to give her. I was at a loss.)

She came over from where she'd been perusing DVDs and asked if I still had any RS DVDs here. I had almost suggested that earlier but had held off, figuring she'd agree just to be polite, even though I knew she'd been a fan of the show.

But since she'd brought it up . . . :-)

So we went to my hotel room and watched an episode. After that she asked if I wanted to watch another one ("Unless you need to get back to Gary?" she asked. "Nah," I replied, selecting the next episode. Gary? Who is Gary?). After that episode it was lunchtime and she was too hungry to watch a third episode ;-) so we decided to go to a Thai restaurant in the same shopping complex as the Blockbuster was.

We first stopped at Shepherd to pick up my lunch, as I'd left it in Gary's room (I finally remembered I was married to a guy named Gary). Gary was there, so I asked him what he'd done with his PT this morning – this was his first day back at rehab, and I had felt a little torn about missing out on that. He said the PT had first wanted to see if he could do a depression weight shift, the kind where he lifts himself straight up by pushing down on the wheels of his chair with his arms. He'd practiced it over the weekend, and we knew he could stay up on his arms for a minute (which he couldn't do before the flap surgery, so this was a result of the weight training), and in putting my hand under him it had felt to me that he had his weight off the chair, but I hadn't been absolutely sure if he was getting his butt high enough off the chair that it would count as a weight shift. So he showed her what he could do and she said he was doing it perfectly – and that she was impressed! She had then got out the transfer board, and he had been excited – this is what he'd been hoping to learn for so long. They practiced the kind of transfer we're hoping he can do when he gets home. It is not the sliding transfer, which he won't be able to do for maybe a year because of the flap surgery, but a transfer of little "hops," starting by picking his body up with his arms like in the depression weight shift and then hopping it over a bit to the side, and then repeating that until he's transferred over to other surface. With the PT's help, he practiced "hopping" along the board from his chair to the exercise platform, then from the platform back to the chair. He needed a lot of help from the PT to do this, however, because it involves a lot of balance. Remember, he has no abdominal muscles to help him, so right now, because he doesn't have the balancing technique down (which relies mainly upon head placement), it would be very easy for him to fall forward or backward off the transfer board (I haven't measured it, but at a guess I'd say the transfer board is about 2 feet long and maybe a foot wide).

After that he had practiced rolling from back to side, and then from back to side to getting up into a sitting position. You might remember he was doing this before the flap surgery. He said he could do the rolling easily, which was good to hear because, if you recall, the very last day before his flap surgery he had been having trouble with it.

For getting into a sitting position once he had rolled onto his side, he still needed a lot of help from the PT. You may recall this involves both a lot of technique (placement of arms and also of head) and a lot of balance.

After his lunch he was supposed to meet with the Recreational Therapist. She had said they were going to do table tennis, but when they got to the rec room, it turned out there was another group of patients in there playing a scheduled game of jeopardy. So they went back to his room and she ran him through a series of situational questions, which he said was good. (The one he remembered off the top of his head was, "What would you do if you were in a movie theater and they told you you couldn't have your wheelchair in the aisle?")

He said he didn't mind if I went off with Jamie for a while longer (no, I don't intend to remain attached to him by an umbilical cord for all the future – but these days it is still a little hard to let him out of my sight. I remember at one of the counseling classes some people complained about their family members smothering them, trying to do too much for them. I didn't think that was me because my intention is only to do what he asks me to do (and he wouldn't ask me to do something he should be doing for himself, as he's not that type) or to do stuff that should be done but he is not aware of and can't do for himself and the hospital staff don't seem to do (like lotioning his dry-skinned feet) or to get him things that will make his hospital stay more tolerable (like DVD players) or more pleasurable (like decent food when he finds the hospital stuff unappetizing, or ice cream treats). But I later asked Gary if he felt the way the others had said they did, just to be sure. He said no, he felt cared for. And then he said more mushy stuff ;-)).

So Jamie and I slipped off to Thai Basil. She had cashew chicken, I think it was, and I ate my rice. The guy who I suspect is the owner and who was our waiter came over at some point to fill Jamie's water glass (I had even brought my own water in, because I can't drink ice water) and he asked what kind of rice it was (basmati). He seemed friendly about it, whereas I had been worried he would at least be disapproving of my bringing food into his restaurant. I resisted the urge to go into a big explanation of how different rices affected my guts differently and I hadn't wanted to take a chance on whatever rice he might serve here. Come to think of it, that was probably good I didn't launch into such a detailed description of the relevant circumstances – he probably would have found that even more insulting :-).

Joe called, and I became one of those obnoxious people who not only talks on their cell phone in public but talks on the phone instead of to their companion – but Jamie said she didn't mind. There were some questions about house furnishings (window coverings, bathroom cabinets) that I had spaced out on and forgotten to answer by email; the window coverings take three weeks to be delivered, so had to be picked out now. Joe had also called earlier in the day to let us know, among other things, where he was in the process of getting bids for a garage.

After lunch, Jamie had to get back to Auburn. She will be picking up her family at the airport later on in the month and will come before the flight to visit with me again. I'll have to pick out the best of the remaining RS episodes for us to watch ;-) I'd suggest we watch Pierce Brosnan's "The Matador," which Gary and I really enjoyed when it came out around Christmas time (and is not what you would probably expect a PB movie to be like – it is a black comedy where he plays a degenerate assassin who is having a nervous breakdown and befriends a straight-arrow struggling businessman), but that DVD doesn't come out until July 4th.

No, really, Jamie, we can do something else ;-)

When I got back to Gary's the OT was working with him. She had upped his weights on his exercises and told him she could see he'd put on muscle and asked if I'd noticed. I told her I had already commented on the cuts he'd developed on his forearms. We're not talking Ahnald yet, but we're close ;-)

After the OT left he called his mom to see how she was doing from the flight and with the broken arm. She's doing fine, she says. She asked if they'd tired him out when they'd all been there, but Gary assured her that they'd lifted his spirits, that it'd been fun.

The PT brought Gary's new chair – which was the latest chair they'd brought but they'd put a different back on it. So we'll see tomorrow how that one works.

Gary got some mail – his math department mail, and a card from Al Wehrly, who had Carlos Borges as his Ph.D. advisor around the same time Gary did.

The nurse came in and took out Gary's foley, so he'll be back to doing I.C.s (bladder program) starting tonight. The nurses will take care of it tonight, but tomorrow (Tuesday) morning his primary nurse will run through the process with him again, and he'll start doing it to himself. At noontime she'll go through it with me, and then some of the time I'll practice on him instead of him doing it to himself. This is just a precaution – in case he is ever to sick to do it for himself, I'll know how to do it.

When I left I went down to the public gym – the person who was supposed to show me the ropes last Thursday but had gotten sick had never called back. She was there, and we set something up for Tuesday 4 pm.

When I returned to Shepherd in the evening we had some business of Gary's to attend to. An email from Krystyna Kuperberg reminded him he hadn't told the people at the Prague conference that he wouldn't be attending and giving a talk there in August, so he dictated an email to me telling them that. Krystyna had offered to help Gary put his talk up on a computer, and then someone at the conference could help with the delivery of the talk, but Gary decided not to do that, though he so appreciates the offer. There doesn't seem to be the time he needs to do justice to a talk. He is going to be kept quite busy with the rehab then the day program here (which is as intense as the rehab, only we'll live together off hospital grounds in an apartment) until July 28th if all goes according to plan, and when he gets back home he feels there won't be enough time before the conference to properly prepare a talk while trying to adjust to his new living circumstances.

Back at the motel, I had another restful night. Yea.

I will finish this entry by including something my sister-in-law Dolores sent me in an email, on the chance it will amuse you as much as it did me:

HELL EXPLAINED BY CHEMISTRY STUDENT

The following is an actual question given on a University of Washington chemistry mid-term.

The answer by one student was so "profound" that the professor shared it with colleagues, via the Internet, which is, of course, why we now have the pleasure of enjoying it as well :

Bonus Question: Is Hell exothermic (gives off heat) or endothermic, (absorbs heat)?
Most of the students wrote proofs of their beliefs using Boyle's Law
(gas cools when it expands and heats when it is compressed) or some variant.
One student, however, wrote the following:

First, we need to know how the mass of Hell is changing in time. So we need to know the rate at which souls are moving into Hell and the rate at which they are leaving. I think that we can safely assume that once a soul gets to Hell, it will not leave. Therefore, no souls are leaving. As for how many souls are entering Hell, let's look at the different religions that exist in the world today. Most of these religions state that if you are not a member of their religion, you will go to Hell. Since there is more than one of these religions and since people do not belong to more than one religion,we can project that all souls go to Hell. With birth and death rates as they are, we can expect the number of souls in Hell to increase exponentially.

Now, we look at the rate of change of the volume in Hell because Boyle's
Law states that in order for the temperature and pressure in Hell to stay
the same, the volume of Hell has to expand proportionately as souls are added.

This gives two possibilities:

1. If Hell is expanding at a slower rate than the rate at which souls enter Hell, then the temperature and pressure in Hell will increase until all Hell breaks loose.
2. If Hell is expanding at a rate faster than the increase of souls in Hell, then the temperature and pressure will drop until Hell freezes over.

So which is it?
If we accept the postulate given to me by Teresa during my Freshman year that, "It will be a cold day in Hell before I sleep with you," and take into account the fact that I slept with her last night, then number two must be true, and thus I am sure that Hell is exothermic and has already frozen over. The corollary of this theory is that since Hell has frozen over, it follows that it is not accepting any more souls and is therefore, extinct......leaving only Heaven, thereby proving the existence of a divine being which explains why, last night, Teresa kept shouting "Oh my God."

THIS STUDENT RECEIVED THE ONLY "A"

June 20, 2006

When I got on the elevator this morning, another guy managed to get on just before the doors closed. He pushed “1." The elevator doors opened wide. “Uh, we’re on 1,” I told him. “If that’s the floor you want, you just step off here.” He laughed and pushed “B.” The up arrow had been lit all this time, and I had already pushed “3.” “I guess you’re taking the scenic route,” I told him. He laughed again, embarrassedly but with good humor, kind of shuffling and mumbling – I got the strong impression he didn’t know what floor he wanted to go to. “Too early in the morning, huh?” I said. He agreed.

The OT arrived at Gary’s the same time I did, and she put Gary on his stomach to do some exercises for his back – his back muscles are obviously his weakest ones (and not just because of the accident). So she had him doing rowing motions, lifts out to the side and to the rear, all without weights, making sure to shrug his shoulder blades together. While he was exercising, she left for a moment to get a mirror, as he was going to practice skin checks next. She had me stay next to the bed to make sure he didn’t fall out, as he was way over on the edge. As I watched him exercise, I could see he definitely had more muscles in his arms, and I told him I could see tricep development. Coincidentally, when the OT returned, she also commented on his muscle development. “Yeah, I’ve got triceps now,” Gary said. “I never had them before.”

To do the skin check she gave him a mirror attached to long arm – think of one of those mirrors the dentist sticks in your mouth to look around in there, only this one made for a giant dentist (for use on a client with a giant-sized mouth, one would hope). For Gary to try to see his backside, he had to lay on his side, fold his body up a bit (though he is not allowed to fold too far because of the skin flap) and get up on one elbow and use the other arm to hold the mirror. Again, balance came in to play, but so did his flexibility – or rather, his lack of it in his neck, shoulders, and hips (he's never had much physical flexibility – he said even when he was a kid he could never touch his toes with his legs straight). The OT said she could see that I was going to have to do the skin checks "back there" and probably also on his feet.

Next Gary practiced getting his pants up – nontrivial when laying down and without being able to move or have the use of anything below your chest. He did that successfully, with a lot of turning from side to side. I'll probably have to put on his socks and shoes for him, though, not only because he won't be allowed to bend over far enough to do it himself for six months to a year after the flap surgery but also because he may not have the flexibility – I'm going to encourage him to work on his stretching ;-) This discussion brought up a major concern. Gary asked if he was going to be able to turn himself and pad himself during the night, saying he didn't want to have to wake me once a night to do this as I had enough trouble getting a good night's sleep as it was. Whether he'll be able to do this is still up in the air. He can prone for about five hours, but he feels he may not be able to extend that because it gets uncomfortable after a point. So he would have to turn onto a side, which should be no problem, but the problem comes in getting the pillows placed properly for that position. One would go between his thighs, and that should be doable for him, but others are supposed to under and between his ankles, and he may not be allowed to bend enough for him to do that (because of the flap), even assuming he is flexible enough. I wonder if we can train the cats to position the pillows for him.

After the OT left, the PT dropped by bearing gifts – elbow pads, for when he is doing stuff on the exercise mat; a gait belt, for when he is practicing transfers – she said should he lose his balance, it will be better to grab him by this belt rather than grab him by his pants and give him a wedgie; a gel pad, for putting over the wheel of his chair when he transfers out of it, so he doesn't scrape himself along the wheel; and a couple of transfer boards, the shorter one for most transfers, the longer one for transferring in and out of cars. She told him she'd sign him up for the class where he'll learn about vans and practice getting in and out of them. She said she didn't recommend he get a car or van where he would have to pick up his chair and get it in and out, that that was okay for a twenty-something, but with his arthritic shoulder, he needed to be thinking of preserving the strength of his shoulders for as long as possible. He told her we'd already decided we'd get a van with a lift or one where he can wheel into it and lock the chair into the driver's position. She said if we wanted the latter, to be sure they knew that at his wheelchair clinics, because not all chairs had that EZ lock feature. She said he also should think if he wanted any power features on his chair. If he intends to do a lot of movement around campus or out in the community, he might want a chair that, while not a fully powered chair, had wheels that had some power features, easier to push than a purely manual chair. The PT left, and I asked Gary what he'd thought about what she said about the chair. He said he'd decide more about that when he got further into the rehab and got more of a feel for what it would be like to push himself around on a daily basis.

This reminded him to tell me that he had talked to his (rehab) doctor (the one primarily responsible for his care here), explaining things to the doctor along the lines that I'd told him I thought he should. Gary had started out their conversation by saying that he knew the doctor had some reservations about him returning to his job so early, but . . . Then he explained how supportive the math department was being, what his job in the fall would entail. The doctor stopped him at one point and said he was convinced. Gary said the doctor then became encouraging, saying there was no medical reason Gary couldn't return to work this fall. This was a great relief to Gary, since he'd found it disheartening when his doctor, someone with a similar injury to his, had been so negative about him being able to return to work that quickly.

His primary nurse came, and I hoisted Gary into his chair. Then it was my turn to do an I.C. on him. The nurse said I did great.

Later in the afternoon, when I passed by the case manager's office, she yelled out, "Peg, congratulations!" "For what?" I asked. "You got the I.C. checked off," she explained. "Yeah, one down, fifty more things to go," I joked. I joined Gary in front of the elevators, where he was supposed to meet for push group, where he and a bunch of other people would practice pushing their wheelchairs over different surfaces. No one else was there. I looked at the schedule, and checked in the gym, and he was where he was supposed to be; they said the previous group might be running late. Ten minutes later, we were still alone. The leader finally showed up and said they were waiting on another person – evidently it was a group of two; she went off to find the other guy. Gary thought maybe he should get a start on his protein drink of the afternoon – he is having to adjust his liquid intake so that the ICs stay in the right range – so I went back to his room to mix it. While there, my cell phone rang, and it was his family physician's office. He'd called her office earlier today because Shepherd requires that before he leave here he name a hometown primary physician willing to work with him now that he has an SCI. The only doctor he's regularly seen n the past thirty years is close to retirement, so he didn't know if she would think it better in the long run to now turn him over to someone else, and if so, who, and that is what he wanted to talk to her about.

So, with his protein powder and three paper cups in hand, I ran back down the hall to the elevators and gave him the phone. Then I went into the nearby bathroom to mix his drink. I came out with one of the cups; Gary said he was keeping the cell phone because the doctor was going to call back (she did, but somehow he didn't hear it, and when I told him later when he handed the phone back that there was a voice message on it from her and he called her back, he didn't get her; he left a message, but they never connected the rest of the day). He then said he didn't want the drink now because he had to go on his "push group" right then (it was a group of one – him – I never found out what happened to the other guy). I said I was coming with, to let me put his drinks back in his room, but the leader, who we hadn't met before, said I couldn't come because I'd be a distraction. Frankly, this p'd me off. He rolled away; I went into the bathroom, collected the other two cups of the protein drink I'd just made up, went back to his room, and worked on the blog. About an hour later, I left for my gym appointment.

The person showed me how to operate a few of the cardio machines – she didn't think the treadmill would be good for my back, but suggested I use the bike or the Nu Step, which you operate with hands and feet. She had me try them; I did, and she told me to peddle faster. I turned the resistance down from where she had it and complied briefly, but I didn't want to do a lot. Even though she knows I have CFS, I don't trust that she really knows what that means in terms of how exercise affects me. (The last time someone claiming to know about CFS tried to set me up with an exercise program at a gym, I did one day of it, a program that had seemed easy, went home, and crashed for a week; I didn't return.) She then showed me a few weight exercises she thought would be good – lat pulldowns, flies, and reverse flies (but if I do them, the latter two I'll do with free weights, not on the machines as she showed me – most exercise machines aren't made for small bodies). Again, I kept telling her to put less weight on the machines than she had on there, and I only did a few reps.

She repeatedly told me what she really thought would be good for me would be the swimming pool. She may be right, but you already know I am not eager to get back into the pool. Sigh. Maybe I should, if that's what would help my back. Shoot. That would mean I would have to see myself in a swimsuit. Maybe I can avoid looking in a mirror or at my reflection. I weigh about the same as I did in my swimming days, but all that swimming and weight-training muscle has turned into excess thighs and butt. One more thing I'd rather leave behind me.

(Yes, that was intentional, as well as true, though I know that would be a silly reason not to get into the pool again.)

Anyway, the afternoon's events left me in a not-so-good mood, not helped by the fact that I was on the tired side. Even though the motel seems all right now, I don't sleep as well there as I did at the apartment. Maybe I should try a different motel. Maybe the results would be the same. I want my own home and my own bed! Five more weeks to go, if all goes according to plan.

I got to Gary's room and I'm afraid I let him see my bad mood and told him the reasons for it. Later I resolved not to let this kind of stuff get me down so or at least not to lay it on him – it's rather trivial in light of his circumstances.

He said he hadn't heard the push group leader say I would be a distraction. He said he didn't see why I couldn't have come, so maybe if he does it again I will protest if they say I can't come. What he did was practice pushing over different surfaces. First they went down to the carpeted tunnel I had taken from the Shepherd Center to the Peachtree Orthopedic clinic. I told him I remembered thinking as I walked back from that clinic that it was surprising they had such a steep incline on that tunnel, that it must be hard for someone to get up it in a wheelchair, especially with the carpeting. Gary said he did it, though he had to stop and take a few rest breaks.

They then went outside and he practiced wheeling over grass, which he said was harder than the carpeting. Then they went to the parking garage, and first he practiced opening the heavy door there, and then they went up and down parking ramps. He said he could do it all, but that it was a very good workout!

Towards the end of my evening visit with Gary, Joe called and filled us in on how the house is coming along. Sounds good!

To finish this entry, I will tell you a new expression I learned tonight. Gary's roommate wheeled by our section of the room and called out, "How are you doing, Peg?" "Fine," I lied (this was when I'd first come into Gary's room). "How are you?" I asked. "Fine as frog hair," he told me.

June 21, 2006

Mail call: thanks to Corinne Wurdeman.

Latest freebie: if anyone wants approximately a quarter of a cord of hardwood, it is free for the taking – just give Joe a call first to let him know you are coming (use our home phone number).

This morning Gary's longtime physician called, and she said she was willing to keep him on as a patient; not only that, she exhibited some knowledge of the special problems of those with SCIs, bringing up the increased risk of pneumonia and bladder infections, for instance. Another unexpected plus – she said she has a partner who is a rehab doc, and she thought the two of them would make a good team for Gary!

On our way to the therapy gym, our case manager came out of her office and told Gary she wanted to shake his hand. The first thing that went through my mind was this was going a little overboard in enthusiasm for him having done his own IC :-) but she said it was on account of what had happened at their team meeting (ie, the weekly meeting of his team) this morning. They were all impressed with him, how he'd gone straight from bedridden to full participation in the rehab program, starting off at a higher level than he'd left off at (cuz of all that weight training in bed!).

First Gary had the OT, and he started by asking her questions. They had recommended we get an overhang from a garage to our house so he wouldn't get soaked in rainy weather, but what was he supposed to do at work, where there wasn't such an overhang? He's not supposed to sit in wet clothes. And somehow erecting a big umbrella over his wheelchair didn't seem practicable or even effective – rains aren't always cooperatively coming straight down. The best solution the OT came up with was to wear a big poncho.

Another question he had involved transferring to our futon couch. This is what we sit together on to watch TV at night. It's like a cross between a bed (since we can stretch our legs straight out in front of us on it) and a couch, since it has a back. Problem is, the top of it is only 11 inches up from the ground. Gary's OT – and his PT, who just happened to wander by at that moment – thought it would be too difficult for him to not only transfer from his chair to something that low, given his flap restrictions on his types of transfers allowed, but to transfer back up from it to his chair – it would turn a leisure activity into a chore (and that might be true no matter what transfer he eventually does). They suggested replacing it with a couch, but in all my years I have never found a couch I am comfortable on, and believe me we have looked – they just don't make them for short people. So I am hoping we (Joe? :-)) can figure out a way to lift the futon couch up – on blocks, or some kind of frame or something.

After we talked about such things, the OT said she was going to give him more IC training, so we went back to the room to do that. Tomorrow he will do it in the bathroom, in preparation for a real-life situation.

After that came lunch, and then it was time to see the PT. In the gym his PT started off by telling us she'd talked to his skin nurse, and he will be allowed brief periods of bending down to reach his ankles, so as long as he doesn't have to get in an extreme stretch to position pillows down there when he turns in bed, he should be able to do this himself. Great news to both our ears! (Of course, he still has to practice and see if he can physically do it.) She then explained about the power-assist wheels option for his wheelchair, about how such wheels require half the energy expenditure of manual wheels – when you give them a push, they add an extra push of their own, giving you twice the distance. Gary told her his doc had already talked to him about them this morning, and Gary was going to get some for when he had to travel long distances or get somewhere fast (like if he has to teach his class in one building and to be at a meeting in another building immediately after the class). But he will not use them all the time – there is a weight disadvantage, as they are heavier than the manual wheels, and it is best to have as light a chair as one can operate; and also, he would not need the extra boost they give when he's just tooling around the house or around the math building.

Next she had him transfer from his chair to a seated position on the exercise mat, using the transfer board, so this is the first time I got to see him do this. She still gives him help to make sure he doesn't slide on his flap along the board or lose his balance off it, but she told him she was doing much less for him this time than she had Monday. It was neat to see these beginning steps – I'm sure he'll be an old hand at it soon.

We then watched a video of paraplegics doing various skills that Gary will be learning or is already practicing. The video showed people sitting and doing balance exercises – the PT pointed out how they were using their heads (literally) to control their balance point. Next the video showed people dressing in bed. (The PT said when Gary does this I may have to give him a start with his pants, getting them up over his knees – it depends on the flap restrictions and on his flexibility, the former restricting how much he's allowed to bend up his knee toward him (using his hands to bring the knees up), the latter determining how much he needs to bend his knees to get his pants over his ankles and up his legs.)

I tell you, while watching the people twisting around to dress themselves in bed or while in their chair, the thought kept going through my mind of what a production it was, how complicated the “simple” act of pulling up your pants or getting your pullover shirt down over your torso becomes. No wonder they say maintenance eats up a huge chunk of the time of those with SCIs, especially in the beginning days.

Next the video showed people doing transfers out of bed into their chairs, and from their chairs to a car, and it also showed the reversal of these transfers. It also showed more advanced skills that Gary can’t learn until the flap restrictions are lifted – such things as how to get back into your chair if you’ve fallen out. (It seems a hell of a lot simpler to call for help than to go through what has to be done, but the goal is independence – although if Gary falls out (and they say it always happens sooner or later), the PT said we would have to get two strong people to get him back in his chair, because on account of the flap he isn’t allowed for x amount of time (x to be determined by his doctor some time in the future) to make the movements required to get back in the chair). Less traumatically, similar skills as those needed to get back in the chair after a tumble are used in going from sitting on the floor to sitting back in the wheelchair.

Finally the video showed people doing wheelies up over step-ups, and going up and down ramps (going down ramps many people raise the front tires of their wheelchairs up, because some ramps have a lip at the end, and if the front tires thud down, the whole chair could tip over forward).

So far, neither the OT or PT had Gary doing much physical stuff, a change from the usual routine, but the PT finished by having Gary work on his balance. He would do things like slowly raise both hands from his knees while sitting with no back support and with his legs over the edge of the raised mat. Once he’d gotten his balance (again, something we take for granted, but watching him work at trying not to fall over, really brings home what all is involved in doing such a “simple” thing – I never appreciated my abdominal muscles so much before!), she would have him reach out to her hand – in front of him, upward, to the side, to the back – always using head position as a counterbalance (but of course it is a delicate thing – can’t compensate too much or you fall in the direction your head is leaning). She had him practice shifting back and forth between a sitting forward position (hands to the front) and a sitting backward position (hands behind you). Finally she told him he had to sit upright with both hands raised (in front of him, above his knees) for a minute.

She cheated! After thirty seconds, she gave him a little push! He wasn’t prepared for that, and he had to drop his hands to the mat and save himself from falling over. She had him start again, but this time she gave him little pushes throughout while he tried to compensate. He wasn’t always successful, but I thought he did pretty good.

To end the session he transferred back to the chair, and she told him she’d given him the least amount of help with that yet.

Shortly after, Gary was hoisted back into bed. The PT came again, saying they had to go through the ASIA test again – that is the test they did toward the beginning of his stay here. They touched him with a cotton swab to see how well he could detect a light touch, then touched him with the sharp and dull ends of a safety pin (he didn't seem to be able to feel anything he couldn't before), then they finished up with some muscle strength testing.

I stepped out after this to talk with someone I'd met at the chiropractor's; she'd come up to Gary's room, as I'd arranged with her. She is a yoga teacher and a nurse here at Shepherd (in the MS section, I believe). We went to the gym and she suggested some exercises she thought I'd find helpful for my back – including for stretching my hamstrings and strengthening my abs.

Right after that I left to indulge in a massage (ahhhh!). Tomorrow, the chiropractor returns from his visit to his parents, and I will see him then and again on Friday.

All for today, except to report I found out the guy with the unleashed dogs has been living at the motel for four years! Even if he pays the rate I do, that's a rent of about $1600 a month. I thought surely he could find some place cheaper, but Gary said maybe not in Buckhead. Then Gary added, maybe the guy likes the linen service.

June 22, 2006

Today (Thursday) with the PT Gary practiced skills related to his "hop" transfers. With the PT's help, he transferred from his chair to the exercise mat (which is of the same approximate height). Then from a sitting position, his legs dangling over the side of the mat, he practiced maneuvering himself backward on the mat until his legs and feet were out in front of him on the mat. Next he practiced backward "hop ups," throwing his head down and pressing down on the matt with his arms to hoist his butt onto a mat that was behind him and folded so it was a couple inches higher. Then he would throw his head back and press down with his arms to hop back to where he started. Then he transferred back into his chair with her help, and we went back to his room where he practiced transferring from his wheelchair to his bed. This was significantly harder, firstly because the bed is significantly higher than the chair, secondly because the bed is soft. The PT was definitely giving him more help with that transfer. He ended up angled in the bed, his legs over the side, just as he should have been, but then he was supposed to pick his legs up with one arm and get them onto the bed, then straighten himself lengthwise in the bed, still in a seated position. At one point, he completely lost his balance, but this only meant he fell backward onto the nice soft bed (don't worry, the PT is always is right there with him). He got back into a seated position and used his "grabber" to get his tennies off. It was here we discovered the value of shoes a size too big with velcro straps. He undid the velcro of one shoe with the grabber, but eventually gave up on the other and used the grabber as a pusher to just push the shoe off. Next came some practice in dressing. He got his pants off as far as he could (mid-thigh), and I took them off the rest of the way. I put them in the dirty laundry as I planned to do a load for him today (such a sacrifice on my part – insert dramatic sigh here ;-)), and got out another pair. The OT came into the room, and the PT turned the session over to her. I put Gary's pants on him up to over his knees, since he isn't allowed to bend to do that, then let him do the rest. The OT told him the key to getting into pants while laying down is that when they are at about mid-thigh to put your hand between your legs and grab the pants by the back of them and pull – it's the back of the pants that is the part that gets stuck. He did that, and then with a couple of turns to both sides, he wriggled into his pants the rest of the way. The OT was impressed with how well he has already learned to turn himself in bed – he hasn't been able to practice this before, because of the state of healing of the flap.

Next came the nontrivial process of sitting back up in bed, then the getting of the legs over the side of the bed (in preparation for a transfer back into the wheelchair). The OT was also impressed with this – Gary just went ahead and figured out a way to do this without being given any directions. Transferring from the bed to the chair was something he needed a lot of help with (to prevent him from tumbling off the transfer board due to lack of balance).

The next project was to do an IC, starting with gathering together all the needed supplies, then doing the IC, then finishing by taking care of these supplies, all as if it were a "school day" and he was going to have to do his IC in a public bathroom.

At one point the OT stepped out of the bathroom for a moment to replace a necessary supply that Gary had dropped on the floor. Gary looked at me. "Everything takes so much longer," he said. I nodded sympathetically. Gary went on to recall that the guy who had been so inspirational at the "Been there, done that," class had said it takes him an hour to get ready in the morning but that he himself suspected it would take him two hours, at least at the beginning.

After lunch, a therapist substituting for one of Gary's own brought him a wheelchair with power-assisted wheels. There is a battery pack on the chair which supplies the extra push to the chair – Gary gives a push as normal and the wheels extend it with a push of their own. The chair was claimed to have three gears, but we never found third. Supposedly by pushing in on a circular area on each wheel the gears changed, and the change of gears was indicated by beeps – one beep for first gear, two for second, three for third – but none of us could get it to beep three times. Worse, sometimes it would beep two times but seem to stay in first gear. To top it off, Gary couldn't hear the beeps (I suspect he is not going to regain all his hearing; we are still mystified as to what caused the hearing loss that showed up after that second back surgery).

Maybe I shouldn't have said "to top it off" there. The topper was that the chair was a disappointment to Gary. First gear assisted his movements a little, but not enough for the wheels to be worth their $5000 price tag. When he put it in second gear, he found it hard to steer (if you don't push with equal strength in both hands, you're going to travel to one side), but he got the hang of it more with practice. BUT it turned out to be just as much – if not more – work to use the chair to go up the steep ramp of the Blue Carpet tunnel. The chair kept popping wheelies the entire time, meaning Gary was always back on the tip bars behind the chair, stuck in place. The therapist told him to lean his weight forward and not push as hard, as when one pushed hard the wheels' response was exactly that of doing a wheelie. But if he pushed slowly, it was as much work as when in his manual chair. More work, in fact – he couldn't lean as far forward as seemed necessary, and unless the therapist held his back forward with her arm, the front tires still had the tendency to rise. Since she wasn't going to be following him around holding his back for the rest of his life (and neither am I ;-)), the chair didn't seem worth it. He will try it again to see if further practice makes a difference. Or maybe tomorrow his regular therapists will have some tips.

There are other options. He could get a chair that has a motor on it and can be driven by a joystick.With the motor turned off it would work like a manual chair. But such a chair weighs three hundred pounds, so is definitely less portable. I doubt many people would consent to have him as a passenger in their car, knowing that meant they were going to have to lift that chair into their car ;-) – assuming the chair would even fit, because it doesn't fold up to a nice compact size like the manual chairs do. Another option is a power chair – it has no manual option and again is one of these heavy things that doesn't fold up nicely. He doubts he would go with that option until he is eighty years old or so.

Well, he's still got some time before he needs to decide what kind of chair he is going to get. He could get more than one, of course, but insurance would almost surely only pay for one.

Gary was pooped out after that little excursion – we joked about how much "help" the power wheels had been, giving him more of a workout than his manual chair had. He took a nap to recover from all that help, and I soon left to go to the chiropractor. The chiropractor is good; I'm glad I found him.

In the evening Gary brought up a few things he'd talked about some time back. Watching me rearrange his legs in the bed, he said he was now used to feeling his legs with his hands and understanding that this was his body; at first his legs hadn't seemed connected with him, as if they belonged to someone else. He also talked about the "line" that goes across his chest and back, where sensation ceases. When he'd talked about it before I hadn't understood that the reason he doesn't like to be touched there isn't anything psychological but is entirely physical – he said it is hypersensitive there and it doesn't feel good to be touched there. I think I mentioned long ago that he had had the sensation of a rod running crosswise in his back. At one time he'd thought that was the rod stabilizing his spine, and I had explained that his rod went lengthwise – I even had gotten the nurse in to show him, using my back to illustrate, just how and where his rod was placed. He said he had only recently realized that that rod feeling was again that "line" of hypersensitivity, though it isn't quite as sensitive as it was. He is going to ask his doctor if there is an explanation for what he feels.

I had been thinking as I left him in the afternoon that he was now almost done with his first week of rehab. Watching the effort he makes to try to learn the new skills and seeing where he is now and knowing what the desired outcome is supposed to be, it seems nearly unimaginable that he is going to learn all he needs to know by July 28th, though I would never say that to him. Coincidentally, in the evening he brought up the same thing. He said he was now confident he could learn how to transfer from his chair to the exercise mat before the 28th but asked with an ironic smile, how often was that particular skill going to come into play? He realizes that should extend to the skill in transferring between surfaces of the same height, but the transferring between two surfaces of unequal height, such as getting from his chair to his hospital bed by himself seems a daunting task.

But we know they are not going to let him go home until he has the skills he needs. If they thought the 28th was a reasonable date for all that to happen by, they must have a reason for saying that, with all their experience here. I pointed out that he has only been doing two hours of therapy a day this week and that they had said he would get up to four (he hung his tongue out at that :-)).

Well, it's going to be interesting to watch his progress.

We talked to Joe toward the end of my evening hospital visit; he filled us in on the progress being made. The dumpster he ordered to put waste in didn't arrive as it was supposed to today. Joe called the company, and they told him if he turned on the news on the TV he would find them in it – evidently they were having a big fire on their property today. Joe told them they'd better have the dumpster at our house tomorrow. Go Joe.

He said a a crew of math people had come today to help him tear down the master bathroom ceiling. Janet Rogers was there tearing down wallpaper in the other bathroom. Janet wrote me an email and told me that Wlodek Kuperberg, Jack Brown, and Pat Goeters were there when she was, working on the other bathroom. So thanks to you all. I hope I haven't missed naming anyone there – let me know. Joe told me the names, too, but I forgot to write them down.

Oh, and Wlodek, Gary really regrets not taking your advice and working out like you have been doing these past years.

I asked Joe about the cats, and Joe said they are friendly and comfortable with him. I nearly fell to the floor when he said Blackjack sits in his lap in the evening (I should have asked him if he's experienced Tigger's terrible jealousy yet – Tigger, thirteen pounds to Blackjack's seventeen, will run Blackjack off if he thinks his brother is getting any attention; Blackjack has never realized that all it would take is one big swat with his paw to put his brother in his place).

But I think I may have discovered why "the boys" have taken a shine to Joe – he's been feeding them a can of Fancy Feast each evening, ever since the night they started whining at him, seemingly still hungry but turning up their little cat noses when he offered them more of their vet-advised-weight-control dry food. (The only times we've fed them the wet food is when they were sick enough to be on drugs and the only thing that would coax them to eat was Fancy Feast, so I'm sure they think Joe is the cat's meow for giving it to them every night. They'll probably run away from home to try to find him after he leaves and they only get the dry stuff from us.)

But I can understand Joe doing anything to shut them up. I told him that we thought Blackjack in particular had to have been a member of Saturday Night Live's Whiner Family before we got him. He is an absolutely beautiful cat – built big, having glossy black fur (my older sister when she first saw him thought we must give him egg shampoos) – but I often want to rip his vocal cords out.

There are disadvantages to Blackjack getting comfortable enough with you to turn friendly.

All for now.

June 23, 2006

Oops! I did miss naming a person to thank: Narendra Govil also came out to the house to help with the master bathroom. Janet Rogers is sending pictorial updates on the progress being made.

The OT was up first this morning. Gary's task: to learn to position pillows the way he'll need to after turning from a prone position (lying on his stomach) to a side position during the night. First he pretended that the exercise mat was his bed and did a transfer onto it from his wheelchair (still helped by the OT, though she mainly helped him maintain his balance, not actually having to do any lifting of him). Next he pretended he was going to go to sleep so had to get himself into a prone position from the seated position he was now in. First he had to get his legs up and get into a side lying position. No problem. Then he was to turn from that position onto his stomach. Now he had a problem. The pillows. He could've done this turn if they weren't there, but they were set up as they would have to be for a proning position (to end up under his chest, above each knee, below each knee extending to above the ankle), and they seemed to get in his way – he couldn't roll over them. After watching him attempt to heave himself over the pillows several times without success and standing there thinking that going through such a process at bedtime would certainly not be relaxing, I said, well, if this is the position he's going to start in at night, can't we "cheat" and have me help him get into this position without him having to do everything himself? The OT said she'd been about to suggest that. So I bent his leg up at the knee, laid that leg over the other straight one, and then gave his hip a little push on the count of three as he swung his arms and raised and followed through with his head to give himself momentum as he turned to the side. Success. Now he pretended it was five, six hours later and he wanted to turn onto his side without my help. Getting onto his side was no problem, but once again the pillows proved to be a stumbling block. He needed to get a pillow or pillows down by his ankles so that they would "float" above the mattress, and when he turned his legs had ended up positioned in such a way that the pillows already down there for the prone position were not in the proper place for side lying. He tried to fold his body over and use a grabber to move the pillows. He tried using a chain loop (a chain of loops of cloth) to hook his foot and thereby move his leg to the proper position. He just wasn't flexible enough in the legs and hips and shoulders (and, and, and) to be able to do it anyway he tried. The OT decided we needed to work on his flexibility, so she gave us a bunch of stretching exercises to be done twice a day – I say "us," because I am the one holding his leg in position for the stretch. When he gets his own chain loop to use, he may be able to hold at least some of the stretches on his own, but maybe not all of them, but still he can't get his leg in the proper position on some of them – at least he hasn't figured out a way to do so yet. So, we'll see on that (and we'll also see if my back can take holding his legs in position).

However, this still left us with the problem of what to do until he gets more flexible (and I have my doubts he'll ever get much more flexible). We were surprised to find the OT didn't have any more suggestions for what Gary could do (we thought surely Gary hadn't been the first to ever have this problem). I had a thought, and told the OT that this was just off the top of my head, but what about little “ankle band pillows” – little pillows or pieces of foam that would wrap just above his ankles, but wouldn’t be tight enough to cause any pressure, and would keep his feet from touching the mattress. Both she and Gary liked the idea, but she said she’d have to check with the skin nurse to see if there was any problem with that.

Gary returned to his room, thirsty and hungry after all this activity. I went to the patient kitchen to get some cups in which to mix his protein drink and on my way back happened to see the skin nurse. I asked her about my idea of ankle band pillows. She said there were such things but they had a tendency to slide out of position. She also said there were such things as waffle boots (I found a pic at http://www.ehob.com/products/foot.html) , but that they were for “old men” and Gary should work on his flexibility and not rely on these other products. I returned to Gary’s room and told him this, but he objectd to her reasoning. He wasn’t convinced that ankle pillows would slip, and if waffle boots would work and there was no medical contraindication to using them, he saw no reason not to use them just because she thought they were a last resort. I said maybe she was afraid if she approved of them then he wouldn’t work on his flexibility and he needs to do that to help in other matters, such as dressing. He said he’d still work on that, but if there was a simple solution to the turning in bed problem it seemed better to take it than to spend a lot of time trying doing it a harder way. “Whatever works,” he said. “Would you rather I wake you up every night to put pillows under me?” he continued.

I saw his point.

The skin nurse came in later to schedule showing me what she wanted me to do for Gary’s flap care over the weekend. She again mentioned that in order to solve the pillow placement problem Gary should work on his flexibility or work at getting his proning up to eight hours so he didn’t have to turn at all. Gary didn’t say anything, but I know she didn’t convince him. ;-)

For an hour in the early afternoon Gary met with another substitute PT, his own PT having taken a long weekend. He was supposed to try out the power-assisted wheels again, but one wheel refused to turn on. So instead, Gary started to learn how to do wheelies. This isn’t for fun (well, I’m sure it can be) but to get over obstructions on the ground – like garden hoses, small tree limbs – or for getting up small stepups to doorways, or for getting out of crevices if the front wheels get stuck in such.

First the PT took his tip bars off of his chair, then she stood behind him with a gait belt attached around his rear axle and tipped him backwards to the balance point (further back than he’d thought it would be and far enough back that I winced and had to restrain the urge to run over and put him upright ;-)). To keep the chair in that wheelie position (front wheels in the air) one must use one’s hands to constantly move the rear wheels a short distance back and forth. He practiced this a number of times. Then she had him practice popping himself up into the wheelie (give a strong pull on the wheels) and trying to balance there. He definitely improved – she said he was a quick learner and another therapist walking by said, yeah, he picks up everything very quickly, which made me puff up with pride (though it has nothing to do with me ;-)) – but neither he nor I could tell how much help she was giving him. Let's just say he won't be practicing tip-bar-free wheelies without a therapist behind him, at least for a while ;-)

Finally she showed him how to take his tip bars off and on or how to simply swing them away (he will need to this if there are obstructions he needs to get over but the tip bars don't allow him enough clearance). Then it was time to go back to the room and soon after that, time to get back into bed. He was ready for it.

The tech hoisted him into bed (I was being lazy ;-)), and then I got him ready so the skin nurse could check his flap. He started laughing and said maybe he should take his gloves (to protect his hands while he does all that turning of the wheels of his chair) and his elbow pads off. He did look a rather funny sight leaving them on in his current state of undress ;-).

Between the two of us we got him on his side and properly pillowed – he can do enough turning and maneuvering around in the bed now that I don't have to exert a lot of strength to help. The skin nurse came and checked him out. What she is "working on" is the third side of his flap, which didn't close in a nice seam like the other two sides but rather stayed slightly open and scabbed over. The scabs have dropped off, so that third side looks like a "channel," with definite "walls" on each side. She wants to get rid of the walls so the skin heals over smoothly. To do that she uses silver nitrate (brushed on with a little stick) to burn the top inner edge of the wall. The result is supposed to be that the skin breaks down and then heals back up smoothly. Then she uses the cadillac version of neosporin, xenaderm, on the skin around the wound. Finally she uses something called acuzyme (I read an ingredient of papain, so think meat tenderizer ;-)), which she sprays on a topical wound dressing and then sticks it on a couple parts of the wound that still need debriding. Finally she tapes on gauze over the wound.

She doesn't work on the weekends, and she thought that rather than having to round up and explain the process to each different day nurse Gary would have over the weekend, I could do it once a day (under nurse's supervision) if I'd agree to that, which I did. (She'd let me finish each part of the task after she had shown me what to do, so I was sure I could do it. And I had her write out the steps so I'd be sure to do the things in the proper order.)

A little later Joe called with an update on the house, but I had to dash off to the chiropractor so I gave the phone to Gary. I'm sure I don't remember everything Gary told me later about the conversation, but I do know progress was being held up because the dumpster wasn't delivered, that the plumber will be coming out to move the drain in the shower from the front to the middle, that new window coverings have been ordered for all downstairs rooms except the kitchen, and and that we put in an order to have a detached garage built for us. I probably won't recognize the house when we return. Or maybe I won't notice the difference ;-)

During the evening visit I stretched Gary. It wasn't easy in the bed – I sunk into that air mattress – and I worried about my back. Then Gary remembered the bed could be made firmer, so we pumped it up to maximum level. Then it was more comfortable for me, but not for him. He only had to stand it for about ten minutes, though. If he can't do all these stretches himself at home, we are going to have to do them on a firm surface, like maybe that futon couch.

So, all in all, we are gradually taking over more and more of the nurses' and therapists' tasks, becoming slightly less dependent of them. But it's good to know they are there!

All for now.

[also did IC]

June 24, 2006

Mail call: thanks to Ron Becher

When I walked in this morning, Gary made a face. He said that on account of him not being in his room yesterday when "dietary" had come and taken the orders for today's meals, they'd chosen his meals for him. He'd really disliked the breakfast he was served and feared all the meals today were going to be terrible. I reminded him that if he wanted, I would go and get him something else to eat. That cheered him up.

We started with a stretching session, me climbing up on the firmed-up bed with him. I had had the idea of looping two gait belts together (imitating Shepherd's chain loop devices, which supposedly had been ordered for Gary before the flap surgery but have never shown up), so we tried it, and it made things easier – once I got Gary's leg in the proper position and looped a belt over the arch of his foot, he pulled on the other belt looped through the first one, and that helped support his weight while I held his leg in position. After the stretch session, we got his net (sling) in position under him. We weren't absolutely sure if we were allowed to do a hoist without a tech or nurse present. I'd done it often enough under supervision that Gary trusted me to do it without being watched, but it turned out that his nurse walked in just as I got the hoyer. The nurse stayed during the maneuver (he said Gary and I made a good team :-)).

Gary may not have had his binder on tight enough, though. Later, when he was doing a depression weight shift, he felt a little dizzy. He tightened his binder, and that helped a little, but at the next weight shift he again had a problem with dizziness, so I tightened the binder even further around his abdomen, as it was hard for him to get it tighter himself. Apparently that solved the problem – he didn't have another episode of dizziness the rest of the day.

When lunch came, Gary pronounced it acceptable (grilled cheese sandwich), but when "dietary" came around a shortly after that Gary found out they planned to give him meatloaf with brown gravy for dinner. No way was he going to chance that ;-). He asked if he could change it. The woman said yes and that his other choice was a tuna melt. He decided this was a good day for his wife to bring him dinner ;-).

After lunch it was time for another weight shift. He didn't want to do another depression lift, because those were the kind that had made him dizzy. I offered to clear the pillows and blankets off the chair in the room so he could rest his arm on that as he leaned over to the side for a side weight shift. He said he'd find another chair, and wheeled off. I was trying to upload a blog entry, so my attention wandered from him. A short time later, Piotr Minc walked in and said hi – we were expecting him for a visit. "Didn't you just walk by Gary?" I asked Piotr, thinking that since Gary wasn't in the room he must be in the outer room washing his hands or something. Piotr said he hadn't, and I said I had no idea where Gary had gone off to or what he was up to (such a good short term memory I have). Piotr said that that was good, meaning that the last time he'd seen Gary, Gary had been a far cry from being able to toodle off by himself somewhere. At that time, Gary had just been moved from the B'ham NICU to its nursing unit; he hadn't been able to talk, still on the trache tube; he hadn't sat up yet; we were just starting to think about rehab; I had just pulled out the information my older sister had given me about the best places to go.

As Piotr said later, what a difference six weeks has made. He thought Shepherd was a great place, with its intensive approach. We agree.

Anyway, Gary came back a few minutes later; he said he'd gone all the way to the gym to find a chair for his weight shift. Don't ask me why he didn't simply ask me to take the pillows and things off the chair in the room – I don't know. Must be one of those "man things," like not asking for directions ;-) (Gary definitely doesn't display many stereotypical male behaviors – otherwise I wouldn't have married him – but that is one he does.)

Piotr brought up some Topology Proceedings stuff; Gary said he was now at the point where he felt he could take over his duties on that, rather than filtering it first through Jo and Piotr – but of course he is so grateful that they did that for him when he wasn't up to it.

Piotr had done some shopping for me (I had felt a little hesitant about asking him to do such a thing, since my reluctance to do the shopping myself is only due to hating to shop and the fact that taking the time to shop means having a little less time to spend with Gary. But Piotr had said he loves to shop, a consequence of having grown up in a socialist country, so I took advantage of that ;-)). Piotr got Gary some more of the skin cream I've been putting on him and three more pairs of the sleep pants he's been wearing during the day (though called sleep pants, they look like lightweight sweat pants, at least for the most part – for some reason Gary is averse to wearing the red plaid pair (hey, they'd said to get him six pairs of sweatsuit-like pants, and in his size Walmart had had only three in solid colors; believe me, there were far worse options than the plaids ;-)). Piotr also brought some stuff up from home I'd asked for (including enough Basmati rice that I won't have to shop for any more while here, and the only swim suit of mine that Joe could find – a suit which I unfortunately immediately knew was one that I'd looked great in fourteen years ago but wouldn't dare put on now ;-)).

There was some talk about vans and chairs, during which I remembered Phil Zenor had sent an email reminding us that he had an electric wheelchair that Gary could borrow and telling us that the community bus in our town has a service where after getting a doctor's statement, they will come to a wheelchair-bound person's home, use a lift to get the person into the bus, and take the person to his destination, for $3 per trip (fantastic news, Gary thought!). Then Gary took Piotr on a little tour. The rec room was full, so we were all spared from playing pool or ping pong. We went to the garden instead. Gary had felt on the cool side up in his room, so had put on a long-sleeve T-shirt. He definitely didn't need it out in the garden. In trying to get it off he lost his balance and went sideways. Not that there was any disastrous result – he had his seat belt on – but it brought home to me that there are still "basic" skills to be mastered. He also kept popping wheelies in trying to get back up the ramp – every time before he's done that smoothly. We thought his net had gotten caught in his wheel, so we corrected that and he tried again. It went better, but still some wheelies. We didn't figure out why this should be so.

Somehow time had escaped us, and Gary needed to go to a therapy session. I walked back to the parking garage with Piotr to transfer the bags of rice to my car. Piotr again remarked that Gary certainly seemed to already have all the physical skills he needed to get right back into teaching this fall (Gary had agreed with him about this earlier) and noted that it would be good on the psychological level as well. Gary has had getting back to work on his mind since the beginning, so I know that is true.

I found Gary's substitute PT stretching him in the gym, which meant I wouldn't have to do it during the evening visit (lately that time has been eaten up by the personal care tasks that we have taken over from the nurses, so we haven't watched a DVD since finishing Capote). After the stretching came weights. I think the PT liked Gary cuz he would tell her if he needed to use a heavier weight – she said some of her patients try to "get away" with stuff, not working up to their capacity. But Gary is highly motivated to get as much as he can from his time here, so is no slacker. They finished up with practicing transfers back and forth between the exercise mat and his chair, including a couple where he didn't use the board at all, just popped right over from mat to chair or vice versa. The PT still supplied help, but mostly in balance, not in lifting his weight. I could tell he was really pleased at doing the transfers without the board, and I gave him the thumbs up. On our way out of the gym I asked in what situations would he do transfers without a board. He said it would depend on the distance he needed to transfer and on his strength.

We had a half hour to go before we needed to get back to his room. We went down to the rec room. The pool table was still occupied by some able-bodied players, no patient in sight. Personally I think the people should have turned the table over to Gary. But as they didn't, we went to the ping pong table. During play, Gary lost his balance when reaching too far to the side, so decided he needed to wear his chest strap. Later he felt a twinge in the shoulder as he reached out for a wide ball. I had felt a wrench in the leg chasing the ball. We decided maybe this wasn't such a good game for us ;-).

When it was time to get Gary back in the bed, the nurse came and watched us do it. I should have asked if there was some official clearance to doing it on our own, but I forgot. While Gary called Mellow Mushroom to order himself a pizza, I got him situated to do the care of his flap as the skin nurse had taught me. I thought it best to have Gary's nurse watch while I did it, so we called him back. He said I did it just fine. I did notice my final taping of the edges of the gauze wasn't as neatly done as the nurses do it, but the nurse didn't take points off for it not being symmetrical ;-)

I picked up Gary's pizza, and after delivering it headed back to the hotel. Unfortunately I then remembered we had forgotten to give Piotr a check to give to Joe for a down payment on the garage. I called Gary and finally got through to him – since he was back in bed a nurse had had to go in and put the phone near him. We couldn't think of a good way to get the money to Joe quickly, though later at the hotel I thought of Paypal and called Gary again. We weren't sure what Joe would have to do to get the money from his side, assuming he didn't have a Paypal account, so I sent Joe a "test" dollar. The Paypal instructions then said Joe would be emailed that this money had been sent to him and tell him how to open an account so he could receive it. We had our doubts that Joe would want to open an account. Gary had already called Joe and left the message that we'd forgotten about sending that check with Piotr, so the only thing to do was to wait and see what he suggested we do (fearing it would be along the lines of "go jump in a lake" ;-)). When Joe called later in the evening, he started off with, "Oh, you mathematicians," but said in a joking way. I was relieved, as I thought he'd be exasperated with us – here he's been working his tail off fixing our house, and we can't even remember to write a check.

He said to just put the check in the mail sometime tomorrow (Sunday), that if I did it at a post office it might even be picked up then. I knew there was a post office right on the corner near my hotel, so on my way home I did send off the check – and at the same time mailed Janet Rogers a check that we'd also forgotten to send off with Piotr. But the box didn't list Sunday as a collection day. Oh well, nothing more that can be done about that.

Gary had finished "Into Thin Air" already (he said it was a really good book), and I asked him how he liked the new book he'd just started. (Judy Roitman had told us about a book that was supposed to be good, called "Still Lives," about people with spinal cord injuries. I had read the amazon blurb to Gary, and he thought it had sounded good so we'd ordered it. Piotr brought it up with him, it having already arrived at our home (which confused me – I thought I had had it mailed to Shepherd, though I was happy to see it had come so quickly)).

Gary said he liked the book so far. He said it was mostly about quadraplegics, though, which we both feel would be quite a tougher situation, and he'd like to find a book that included more paraplegics (we'll have to check amazon recommendations). Gary said it was amazing how much the people in the book had been able to do with their lives. "No million dollar babies there, huh?" I said. He said that at the time we'd seen the movie he'd thought it was one-sided, but reading this book made him realize just how one-sided the movie was.

I had had a much stronger negative reaction to that movie when we'd seen it – I hadn't liked the ending at all and had left the theater mad, railing, "What kind of message does that movie give to disabled people – that just because they can't do what they could before or because they can't do what able-bodied people do, their lives are worthless, might as well end it?" I freely admitted the movie hit a nerve because of the way CFS disabled me. Those first years after I'd come down with it, when it was such a struggle to do any math and I'd finally given up on it, when things had gotten worse and I couldn't do much of anything, let alone anything "productive," (set-theoretic topologists perform a valuable service to the world, don't they? ;-) Or at least math teachers do. . . . Hmm, many students would beg to differ) I had felt my life was a waste.

But I digress (again ;-)). After seeing that movie I had gone on and talked about what Christopher Reeve had accomplished, about how this young woman in the movie was understandably suffering from depression just after an accident that had made it impossible to do the one thing she thought she had been born to do, but that that was not the time for someone to assist her in ending her life. She hadn't had the opportunity to explore other options – the movie had made it seem like there weren't other options, like there was nothing more she could do with her life. (When I brought this up again now to Gary, he pointed out that that might have been true many years ago – from the book he learned that until the beginning of the twentieth century, quadriplegics only lived a few months, dying of pressure sores and infection.) If the movie was supposed to be about how it was sometimes kinder to let someone end their life, then there should have been another reason for it, say that she was suffering from intense pain that had no chance of being relieved.

And that brings up another thing Gary learned from the book, that 60-65% of those with spinal cord injury have chronic pain; for 20-25% of them it is severe. I told Gary that one of the first things I had read about spinal cord injury was the possibility of having to live with chronic pain, and that I had had to stop reading the material, at the time not in the psychological position to be able to handle reading more along those lines. I had simply hoped that that wasn't going to be his experience. So far it hasn't been; that "demarcation line" around his chest that can cause him discomfort but has never gotten to the point of being actually painful.

Thank God for that.

June 25, 2006

From an email sent to me:

> I'm curious, how do you
> cook these zukes?

LOL. That is usually the follow up question to "what are you going to do with all those zukes?"

I steam them, then puree them, so it's like a soup. That's about the only way to get down over two pounds of zukes a day ;-). (Fortunately, I really like them that way.)

Gary and I started our day together with stretches of Gary's legs, then I put his net under him and got him ready for the hoyer. I mentioned to him I wasn't sure if we were cleared to have put me in his chair with no supervision; he told me to go ahead and do it. So we may have broken the law again ;-), don't tell. Fortunately Gary ended up in the chair and not dumped onto the floor ;-) (I have to put that little wink in there – otherwise I'm afraid his mom will read that and start to worry him ending up on the floor was at all likely.)

Lunch arrived a little while later. I think Gary will be awfully glad when he doesn't have to put up with the cooking here. Chicken breasts are definitely not their forte, never failing to be dry and tough. He said the best thing about the one they served for his lunch was that it gave him practice balancing, because he needed two hands to saw away at it (sitting with both hands raised is a challenge; in fact, you probably recall that it is one of his therapy exercises. I didn't push him while he tried to cut his meat, though – I'll leave such dirty tricks to his therapists ;-)).

He had nothing scheduled for the day, and I wasn't sure how we were going to fill the time – he was going to be up in his chair for six hours, and one thing I knew was it didn't sound appealing to hang out in the same room he's stuck in when he has to be in bed. Days ago we had talked about how he was going to get home when the time came, and I had said that I didn't know how I would get him and his wheelchair in my car because the car was stuffed to the gills with things I had brought up from home or had acquired here in Atlanta or in Birmingham. With that it mind, I suggested we go out to the car and see if there was anything in it we could send back to our home with any visitors who came. So this became our project. First came the trip to the parking garage. This is where he'd gone for his push group (the group of one) and he showed me how he'd learned to open the heavy door by himself (the trick is to judge the path that the opening door will take and to be just outside that arc in order to get the chair inside it before the door starts to swing closed). He then took off down the ramp. I gave up running after him. When he stopped, I asked if I was supposed to keep up with him in case something happened. He said, no, there wasn't anything I'd be able to do if the chair tipped over anyway. "Except to say, 'uh-oh,'" I said. We laughed. He then went down the next ramp, and I told him that, actually, it looked like fun. He said it was, but that it wasn't fun to go up it.

We sorted through the stuff and filled three small boxes with things that could be sent back. (I'm not sure that would give us enough room, but if not, Krystyna Kuperberg has already offered to help us get home.) One of the last boxes I grabbed to sort through was filled with all the stuff I'd salvaged from his wrecked car; for one thing, it contained all his material related to his now-cancelled Alaska cruise ("Alaska for Dummies," among other things – do they have books for everything?). I had set the box down in front of him before realizing what it was, but thought he'd find it weird if I suddenly snatched that box back up. So I started handing him the stuff in it, as I had the stuff from the other boxes, so he could decide if there was anything in it he wanted to keep up here in Atlanta. I had wondered how he would feel about going through the box, but it didn't noticeably affect him – I think it was much more disturbing for me, as it reminded me of the sight of his wrecked car.

We ended up with a few things to take back to his hospital room – the R.L. Moore biography, the DVD "Ghost World" (I have no idea what that is, but Gary said it looked fun), a Prairie Home Companion cassette. I started to stick the things in the backpack that is on the back of his chair.

“Oh, sure,” he kidded me, “make your crippled husband carry the stuff.”

He decided not to show me how he could go up the parking ramp (Sunday is a day of rest, he declared), so we went to the parking garage elevators. That involved going up a small ramp, but it was pretty steep and his tip bars kept catching on it and it seemed harder than it should have been– probably another thing to ask his therapists what he should have done there.

Later in the afternoon he called his mom (she is having to cancel the cruise too, because of her broken arm, and Gary needed to tell her about the procedure for using the flight insurance he bought for them, so that she can get a refund of her ticket). I heard him tell her he was a little nervous about them discharging him from here in only three weeks – there was still so much to learn. But, he told her, he knew they wouldn’t discharge him if he wasn’t ready, and he’d still have two weeks of the transitional day program to attend after the hospital discharge. (We also plan to come back for another two-week session of day program later on, once he’s cleared to do the activities he is currently restricted from because of his flap. Once he’s cleared, he would be allowed to learn some of the more advanced skills. We’re hoping he’ll be cleared in time for him to come back here during the break after fall semester; otherwise we’d have to wait until next summer. Insurance probably won’t pay for the second session, and if they don’t, Shepherd told us the day program would cost $100 per day. It’ll be worth it.)

Gary also told his mom how great Joe has been to us, doing all this extra stuff we never expected – organizing yard clean-up and painting, etc. And he told his mom how all these math department people have volunteered their time and skills to help Joe – and therefore us – out. The response has truly been tremendous. We are so blessed.

(Oh, and the neighbors and Joe have been watering Gary’s pepper plants – Piotr brought up some peppers and Gary said they were great! In fact, I should mention again here that our neighbor Sylvia has been taking care of our mail and feeding our cats, and that other neighbors – the Rodgers, and I’m not sure who all else – have been taking care of mowing the lawn.)

The nursing staff occasionally checked in on us throughout the day to see how Gary was doing and if he needed anything, but they mostly left us to ourselves. We did pretty well on our own until after I had gotten him back in bed and had taken care of his skin wound, when we were trying to get him settled on his side. For some reason it took us quite some time to get him situated in a way he thought reasonably comfortable. But he told me upon my nightly return that he’d still kept slipping sideways. He thinks he figured out that it was because he didn’t use an extra pillow to help support his head in the way he normally had, but he wasn’t sure that was it. This is the kind of thing that makes me nervous, because I have visions of us going home and something similar happening, where we don’t know quite what to do to set things right. Thank God there are still these five weeks of practice.

At the end of the day, while we did his stretching, Gary remarked that today had almost been like being at home – we’d done a lot of his care ourselves, and the nurses hadn’t been around very much. True, we hadn't had an active day, filling the time with little things (the things I already mentioned, plus talking to his roommate, being on the computers awhile – fighting over who got to use the ethernet cord to connect to the internet ;-) – etc.), but he thought it had been a very nice day.

I agreed.

I gave him a big fat hug and we said mushy stuff, and then I left.

All for now.

June 26, 2006

The skin nurse came in this morning from her weekend off and checked Gary's flap. She told him I'd done a great job with the silver nitrate and such. That was a huge relief, as it had made me a little nervous to be "in charge" of the various procedures involved in his flap care.

This morning after the OT helped Gary transfer from his chair to the mat and put him in a stretch, she said she had something for him to sign. She left to get it, and as Gary laid there flat on his back with his left foot crossed his right thigh, I joked that he was in no position to refuse to sign anything. "Ve haf our vays," Gary said. I said her way would only have to be to leave him there on the mat until he signed, as at this point it would be impossible for him and me to get him back in his chair.

Fortunately all she wanted him to sign was his therapy goal sheet, and she ran down the list with us. Among the items: assisted coughing (him learning how to tell someone else how to help him cough if he ever needs it); bed mobility (rolling and turning in bed); wheelchair management (learning how to take the wheels off and put them on; where to take the chair if it breaks); range of motion (doing as many of the stretches on his own as he can); eight hours of proning; skin care (him checking everything he can see, me checking the rest); special instructions related to the care of his flap; depression weight shift for one minute (which he can do, but it takes its toll so he needs to work on his endurance); side to side weight shift without leaning on something (at this point he needs to lean his arm on something like a chair); depression transfer to/from chair, mat, car, bed, bathroom equipment; activities of daily living (bathing, drying what he can reach (I'll do the rest), dressing what he can reach (I'll do the rest)); balance training, which will assist with the attainment of many of these other goals; bladder training; bowel training; equipment knowledge (what he's getting, who the vendors are, who to contact if there are any problems (there will be one person at United Seated Mobility who is responsible for coordinating the purchase of all of Gary's equipment, and he will be the person Gary would contact if there are any problems)); strengthening the upper body; family training (i.e., my training, and that is ongoing); van evaluation.

After taking care of that paperwork, Gary then practiced skills needed for turning in bed and placing a pillow between his knees. The OT had him balance up on an elbow while in a side-lying position. From that position she had him reach to the front and back while holding a dumbbell at arm's length. Then she had him practice moving his legs around while in that position, then sticking a pillow between his knees (we're still not sure what is to be done about padding the ankles). For some reason he was much better at all of this than he was last Friday. The OT asked him what the difference was. He said it was because he'd had the weekend to rest. We laughed.

The PT took over and had him maneuver around the mat – moving his legs, sitting up. Again, he did much better than last Friday. They then went through his stretches, the goal being for him to do as many as possible with only the assistance of the chain loops, not another human. She thought it might be possible that he'll get flexible enough that he can eventually do all the stretches on his own.

Next he practiced opening various doors by himself – he did great. Since we'd told her that he had trouble with the ramps last weekend, we went to the garden ramp. She watched him attempt going up the ramp and gave him tips. It turned out that by leaning farther forward in his seat (his chest strap firmly in place), he accomplished the feat much more smoothly – no wheelies.

Therapy sessions over, we went back to his room. He pointed out how some nurse had written "G. Man Gruenhage" on one of his supplies. As you might suspect, everyone who's been involved in his care has mispronounced his last name when they come in and introduced themselves. He'd then always told them to call him "Gary." Some of them call him "Mr. G." But he rather liked this new designation of "G. Man Gruenhage," so when a new supply item came in a short time later, I wrote that on it in magic marker to make him laugh.

I'm not sure what he'd think if people in the math department started calling him that, though ;-)

After lunch he had another therapy session, this time with his tech. They started out with "the rickshaw exerciser" (see http://www.wisdomking.com/product17194c90020.html for a picture) which "develops the specific arm and shoulder muscle groups used for transfer in and out of a wheelchair." Then she helped him transfer to the mat and they went through his stretches again. For some reason everything is much more awkward with this tech. She makes me neurotic – I always have the urge to question her about every little thing.

Maybe I should have questioned her about one thing though – at one point she moved Gary's legs for him in such a way that he fell back onto the mat and hit his head hard. I could see it in his face that that had hurt, and once again I felt like bursting out with "Just leave him alone." Gary told me later these things were bound to happen; I told him I just didn't like seeing them happen to him. He said be prepared, because there will no doubt come the time when we have to call 911 to get him back in his chair, since he won't be allowed to even attempt such a skill until his flap is healed and I certainly can't lift him back into his chair.

Anyway, back to the session. He was supposed to practice wheelies with her, but fortunately we ran out of time – I don't think I could have taken having her balance him backwards on his chair without his tip bars in place ;-)

We made our escape, going back to his room so he could have some of his protein drink, and then we went back out to the parking garage so I could get some bottled water from the car. He practiced his door opening, then said, “See ya,” and zoomed down the ramp. We met down by the car. On the way back to his room he practiced going up the ramp that had given him particular problems yesterday. He still couldn’t get up it by himself, even with leaning over, so I had to help. I asked him what he thought the solution for that problem was. He said, “To get stronger.”

Back in the room, we prepared to give him a haircut. I laid a sheet down in the bathroom connected to his four-man room, he wheeled over that sheet, and then I put another sheet around him. I then discovered he wanted **me* to cut his hair. I thought he was crazy, and told him I couldn’t – he should do it. He insisted I could do it. So I used the trimmer on his electric razor, and after he showed me a little of how he did it, I attempted it and thought I did the sides fairly decently. I started on the back and had it going pretty good, but when I was nearly finished he decided to take some scissors and do more with the front of his hair. This was a mistake because he moved his head just as I was finishing shaping the back of his hair, and because of that movement I removed about an inch of hair at the bottom of the very back of his head (it could have been worse, I suppose – I could have cut a hunk from the middle). Of course, that meant I had to trim the rest of it to that length, and I don’t think it looks that great now – it looked much better before that little disaster. Fortunately, he can’t see it ;-), and more fortunately, it’ll grow back. The PT came around later, and looking at him from behind, told him “Great haircut.” I scrutinized her to see if she was being sarcastic, but she didn’t seem to be. However, I suspect she was being kind.

Anyway, if you see him and think the back of his hair looks strange, you now know the reason.

The reason the PT had come was to ask if Gary had any pain. He told her he had that “line of discomfort,” but that it was never really painful. He told her he’d asked his doctor about it, and his doctor had said it was common – in fact, he said he himself had experienced the same sort of thing for several months after his own accident, but that it had gone away. The doctor also said that if it did become painful, that there were medicines for it, but that it was best to avoid taking them if possible because of the side effects.

Mail call. Thanks to Michel Smith, Norma Kramer, Mark and Dottie Meschke, and Bruce Noda. As always, each piece of mail and email we get means so much to us. Just taking today as an example, getting mail from Michel reminds us of how supportive he and the math department have been; the letter from Norma reminds us of the love of our families; Mark is a childhood friend of Gary’s, Bruce is a friend of Gary’s from his graduate school day, and their letters bring home to me how many people Gary’s life has touched.

And also how many other lives have touched Gary’s. Bruce mentioned in his letter that another memorial for Gary’s good friend Ward will be held at the end of July and said if Gary liked, he could compose something to be read during it. Ward died a couple of weeks after Gary's accident. When I'd first learned of it, I hadn't been sure whether or not to pass the news on to Gary – he wasn't in such great shape himself, and as he couldn't speak, I wasn't sure how fragile his psychology was. But since Gary had asked me several times if I'd heard any news of Ward, I decided to pass the news on, telling him I wasn't sure I should be doing so. The news of Ward deeply affected him – it still does – but he said he preferred to know.

He is going to compose something for that memorial. And he is now at the point where he feels up to getting on the internet and looking at some of his email for a short time. I'm sure he'll be talking some math with people in the near future. We take these as further signs of his progress in healing.

Norma, to reply to your letter, I have no idea if "Hell Explained By Chemistry Student" really happened or if it is an urban legend. At the least, it gave some of us a big laugh. If the story is true, it is amazing the person could come up with it during the heat of an exam – I wish I were clever enough to come up with something like that at all!

My subconscious has it's own definition of hell – or maybe it's not so subconscious. I had a dream the other night, in which I couldn't get checked out of a hotel, though I'd been trying to do so for several days. The desk clerk finally told me that no one ever left the hotel; once you came, you were executed shortly thereafter. Reminded me of the roach motel commercials. Or Hotel California. Or the fact that I've been living in hotels/apartments for over ten weeks now, and maybe sometimes it seems like that will never end!

All for now.

June 27, 2006 (revised)

Today's therapy started out with the tech holding theback of Gary's chair while he practiced wheelies. The session seemed worthless. Her idea of where the balance point was was quite a bit forward of where the substitute PT has said it was, and she hung on so tightly with the gait belt he got no feeling himself for where that point might really be. On the other hand, by her holding onto him so tightly, I didn't have to worry she'd drop him (well, I almost didn't have to worry – she wasn't ready for him one time when he went up into a wheelie).

Next they went into the gym and he was first to transfer to the exercise mat from his chair. He wanted to try it without the board, and his PT happened to walk by at that time and she stayed and lended a few comments and a little aid. He did his best transfer yet, with the least amount of help, so we are thinking he won't need the board for similar transfers, though for transfers of longer distances – like to the car – he will.

His next task was to put on a long-sleeved shirt while sitting on the edge of the mat with his legs dangling over it. Before he started, his nurse for the day shift came in with some Tylenol. He had had me ask her to get him some – he had a headache, he thought from falling on the back of his head yesterday and all the jerking around from the wheelies; we are going to have to keep an eye on that and make sure there is not a serious reason for the headache. He used getting the Tylenol down as preliminary balancing practice for getting the shirt on, since he put the pill in his mouth with one hand while holding a cup of water for washing the pill down in his other hand, so neither hand was being used to support himself upright.

Then he tackled the shirt. The tech offered no advice, just had him do it. It was quite a struggle to get the shirt on, but he did it, then got it off. She had him put it on again, as she said he'd cheated by leaning sideways onto the mat to do it (she hadn't told him that wasn't allowed); as he attempted to get the shirt on while staying completely upright, his OT walked by and offered a couple pointers – this made the task FAR easier for him. Afterwards, he confided he had been certain he wasn't going to be able to get the shirt on, so he was really pleased.

The OT then took over, and the first task was to try to get an ankle over the opposite knee while sitting with his legs over the edge of the mat. For this task she had him use something she called a leg reacher (like a stiff lasso – the noose stiff as well). He couldn't quite get his foot up on his own, and in fact at one point he went over backwards and hit his head on the mat again, though not as hard as the last time. I cringed. I thought of sitting behind him, but he goes down so fast I think the result would be that he'd hit me hard, and that might be worse (for both of us) than hitting the mat.

Once he got in the proper position, she had him remove his shoes. This he did easily. Next he was to pretend that the mat was his bed, that he'd just transferred to it from his wheelchair, and that he was to get his legs from over the side of his "bed" into it. This he eventually did, though she is afraid he ends up needing to bend himself more than is allowed by his flap. Next he attempted to get a pillow between his ankles, but nothing worked. We are going to have to experiment with making ankle pillows (I talked to Joe later, and when he comes to visit this Sunday, he is going to bring up a piece of foam from our house to experiment with. My idea is to encase a thick piece of foam in cloth, and use velcro to wrap the cloth around his ankle. If it seems like this might work, are there any sewers out there who could easily sew such a thing? I could probably figure out how to do it, but if this would be easy for anyone . . . ;-))

Next he got into a prone position and did some strengthening exercises for his back – he needs those the most, his back muscles being his weakest.

After that we went back to his room. His case manager came by and gave us some bad news. She has been great, but this time she had messed up. She had forgotten to get him into Day Program when we wanted – right after his discharge on the 14th – and she couldn't get him in until at earliest August 7th. This was a drag for a number of reasons. First of all, Gary feels that no way is he going to have learned by the 14th all he needs to know in order to be able to function at home. Second of all, *I* am not confident *I* will be able to handle being thrown into the home situation without any transitional period. We had been counting on having that two week period immediately following his hospital discharge during which time he would be at day program from 9 to 4 and then we'd be alone in the apartment just a couple blocks away from Shepherd until 9 am the next day. If any difficulties arose or we realized we needed to know something we hadn't learned yet in order to function on a day-to-day basis, Shepherd would be practically right next door to help. And third of all, if he doesn't get into the program until the 7th of August (and even that wasn't a given), that will run into the beginning of fall classes.

We pled our case to the day program manager, but couldn't get into the day program on the 14th – it's all full (not just of Shepherd referrals, but of people from everywhere). The best that they could come up with is to extend Gary's inpatient stay to July 28th and to try to get him in a private room in the hospital for that last week (not a given). I would live with him in that room 24-7, and we would be totally responsible for his care. (Oh, boy – living in a hospital is even higher than living in a hotel room on my list of things I want to do.) What we would do after the 28th isn't clear. Possibly live somewhere in Atlanta until the 7th of August and then have him do the day program for one week. Or maybe we'll decide he doesn't need the day program at that time.

Sigh. We are bummed out that it isn't going to work out as we'd originally thought.

In the early afternoon Joe called with an update on the house. Our first choice for the color of wood ("natural"), which we think is the color of wood we already have on the living room floor, wasn't available, so we went with "desert natural," a darker color but since it will be back in the bedrooms and not right next to the living room, it shouldn't be noticeable that they don't match. The plumbers weren't prepared for the job they were supposed to do, even though Joe had clearly explained to them beforehand what needed to be done, so they will have to come back again.

After lunch Gary met with a recreational therapist down in the ProMotion Gym. She showed him a single-rider golf cart that those with SCIs use on the course – including the greens, because the weight of the cart is so evenly distributed. Some of these carts actually have a hydraulic seat that lifts the golfer up into somewhat of a standing position and then they can use two hands to swing the club. But she actually preferred the kind of cart where one golfs from a seated position; one is strapped in by a harness and sits way forward in the seat to swing. Those with injuries at a lower level than Gary, having the use of their abs, can rely on the harness and do the traditional two-arm swing, but many of those with SCIs do one-armed swings; she claimed it gave one greater accuracy though less power, and also that one might have better balance with a one-handed swing because one could grab the chair with one hand, lean forward, and swing with the other. (She mentioned this is the way Don Shapiro golfs – he is supposed to be quite well-known here; he is a T1 who gives golfing clinics.) She cautioned that playing golf this way can be frustrating – one's swing is totally different – but one can get back into the game.

There is also the matter of getting the cart. Some golf courses have them – she is going to get Gary a list of the courses in Alabama that have them. As a new such cart costs around $8000 dollars, if no course close to where we live has one and Gary wants them to, he would have to "lobby" them for it, saying how it could bring in more business from those who would make use of it (disabled people, elderly people); the course could charge a rental fee. Gary was skeptical if the courses around home would think it cost effective.

His other alternative if he wants to do any golf would be to just go to the driving range and swing from his chair. She showed him a couple adaptive clubs – not being familiar with golf equipment, the only difference I could see was that they were shorter. She put a big "body brace" (like a giant version of his chest strap) on him and had him swing the clubs. He could see that he would definitely need to use a one-handed swing because of balance issues, and in fact he said he could see that even with the one-handed swing it would take a lot of balance.

She also showed us hand cycles while we were there – like bicycles but "pedaled" by hand.

I asked him if seeing that equipment and giving it a try had made him think he might take up golf again. He said he wasn't sure he could see him doing it – it would be a completely different game.

We went back to his room, and a few minutes later Jamie from critique group came up and spirited me away for a while. First we went to Casa Grande and she got a tasty-looking vegetable fajita with a side order of black beans. She said the food was excellent, so I'm sure Gary will want to go there when he is cleared for that sort of activity, as he loves Mexican food. Next Jamie and I went to the Fernbank Museum of Natural History to see an IMAX film. They were showing "Wild Safari" and "Dolphins." Since Pierce Brosnan was the narrator of "Dolphins," the choice was clear ;-). We both enjoyed the movie. I learned some new things, like that dolphins call each other by name (the name defined by a specific series of vocalizations) and that they sleep with one eye close, only one half of their brain sleeping at a time! (With the other eye, they look for predators. Another reason they can't be totally unconscious during sleep as we are is because they need to be conscious in order to decide when to breathe.) After the movie, we decided to go back to my hotel room – for one thing, I needed to get my dinner started. Naturally, we got a little lost during the drive, but Jamie knew how to get back to Shepherd from I-75-85, so we did that. I needed zukes, so we made a stop at the Fresh Market. Jamie thought the place was cool and declared we needed one like it in our town. Of course, in our town it would probably go out of business (Peg says cynically). After I got my dinner started we watched another episode of Remington Steele. You could probably have guessed that, as we had spent the time on her previous visit watching two episodes.

After that, Jamie had to dash of to the airport to pick up her family. She dropped me off at Shepherd, and I went back to Gary's room. I told Gary how we'd spent the day. "Pierce Brosnan narrating a film and then an episode of Remington Steele. It can't get any better than that – a perfect day," he teased me.

He told me what I'd missed of his day, and I felt a little twinge at missing it, though I'd had a really fun time with Jamie. He said his PT had taken him outside for practice with wheelies to get up curbs. It turns out she'd expected me to be there ("What do you mean she isn't here – Peg's always here," the PT had said to him), as she had wanted to "check me off" on that skill, as it is one I need to be checked off on before the two of us are allowed off Shepherd property by ourselves. So I will have to do that another time. (Basically it involves helping him up and down curbs, if that becomes necessary, and it should be done in a particular way for safety -- and also not to strain myself unnecessarily.)

He'd also had his first "seating clinic." This was where he went and discussed what kind of chair he wanted. The person he spoke to about it advised him not to get the power-assisted wheels. They weigh 25 pounds each and would be a lot of hassle, the man claimed, to cart around and get on and off (and getting them on and off would also involve a number of transfers on Gary's part as he couldn't be sitting in the chair while changing the wheels on it). So if Gary gets a second chair, it will be a power chair. He remembered after the clinic that Phil had offered the use of such a chair, and the PT said that using Phil's chair was an option and that if the chair was brought up to Shepherd they could try to modify it to fit Gary better.

Since Gary will definitely be getting a manual chair -- that will be the one he mostly uses -- the clinic guy went through the various features of manual chairs so Gary could make preliminary decisions about the one he wants for his own. Among other things he decided on were the dimensions, the color (Gary chose a bright blue but may now be chickening out on it), and the addition of side flaps to the chair to help keep him from sliding to the side of the chair as he tends to do in the one he currently uses.

The guy also recommended Gary not get a van in which his chair would be locked down in the driver's side – he thought that too dangerous. So now Gary is thinking he may get a van with a lift or a ramp so he can get his wheelchair into the van, and then he would transfer from the wheelchair into a regular driver's seat (well, not quite regular: it would swivel around to face the back so Gary could transfer into it).

And that summarizes Tuesday!

Oh, except to mention Gary has a new roommate. With a speaker phone. Turned very, VERY loud.

Sigh

June 28, 2006

Today's therapy started out with transfer from his chair to a shower bench (like the one at http://www.medicalproductsdirect.com/tranben1.html). I didn't notice it being any more difficult for him than the transfer to the exercise mat, but they cautioned him it would be harder tomorrow: at eight in the morning we (yes, "we" – whose bright idea was it that I needed to be there at eight am? ;-)) are going to practice showering for real. So Gary will be transfering to the shower bench, giving himself a shower, drying what he can reach (I will dry the rest, thus getting to mark off another of the family training skills), and then transfering back to his wheelchair.

After Gary practiced this transfer several times, the OT wanted to check on Gary's ability to maneuver himself in a real bed, so we killed two birds with one stone by having her observe me use the hoyer to transfer him to the bed. She then officially cleared me to do that without supervision.

After his OT session, his psychologist came in for her weekly visit (evidently she is not the probing type: her sessions with Gary usually last about two minutes – she asks if there is anything he wants to talk about, he says no, she says "good" and leaves – which is just fine with Gary :-)). Gary was on the phone with his mom at the time, so the psychologist talked to me a little while – this is the first conversation I've had with her. She said that they'd had their weekly team meeting, and they all agreed the two of us were doing great, BUT, their concern was that we don't seem to know we're doing great, that we don't seem to have the confidence we should be having. I told her that for my part, that was my personality – that I am a perfectionist ("No," you gasp in disbelief), that I like having things laid out for me so I know exactly what I am supposed to do so I can do it right. And the kind of precision I like is not possible in this situation. For instance, the thing that scares me most is sharing responsibility for his skin care, as he'll be counting on me to check the parts of his body he can't see. I know that what I'm supposed to do is look for changes in his skin, but with my somewhat lacking visual memory, I'm afraid I'll miss some sign I should be aware of and therefore be responsible for him getting a pressure sore. Or that somehow I'll do something else wrong in his care and he'll suffer for it. She assured me that they all had confidence in me, that if they ever didn't in some area, they would definitely let me know. Being me, that doesn't take away my worries ;-)

When Gary got off the phone she said similar things to him about lacking confidence, and he said he was confident he would learn what he needed by the 28th, but he was not confident he would learn it by the 14th. She told him the team had agreed he would not meet all his goals by the 14th and had gotten him extended to the 28th. Gary said that in that case, he had no confidence issues.

Next Gary met with his tech. His first task was to make the bed set up for that purpose in the gym. "You realize I was never that great at this," he joked to the tech. He then told her that even though he was in the hospital, he wasn't going to make hospital corners.

As he made the bed (doing a better job than I ever would ;-)) I joked that next he should tackle the laundry – I had a load of his clothes in the third floor dryer that were probably dry by now. The tech thought this was a good idea (I'm not sure what Gary thought ;-)), and we next went to the laundry. The front-loading dryer wasn't that much of a problem for him to work – he used his grabber to remove the dried clothes. It did take time and effort for him to manipulate the cycle control with his grabber, though. The washer, top-loading, as ours at home is, was being used, so he couldn't try to work it. We considered the problems it would pose, and while we could see him being able to load his clothes into it, we couldn't see how even with the grabber he would be able to remove the heavy wet clothes from it without taking an inordinate amount of time to do so (and we also couldn't see how he would know all the clothes were out). So rather than him having to regularly call the math department to say he wasn't going to be able to make his class that day because he was still fishing out clothes from the washer ;-), I have made the supreme sacrifice of consenting to remove his clothes from the washer.

Or maybe I'll break our washing machine so we have to get a front-loading washer ;-)

That particular session ended with stretching. After lunch, Gary and I had a "supervised outing" with a rec therapist, this being part of the requirement for us to get a "push pass" so we could go off Shepherd property without supervision (not in a car – me walking, him in his wheelchair). To start the outing, I had to be "checked off" on handling curbs with him. This was pretty much commonsense (so much so that even I had guessed what should be done before I was told ;-)) – to go down a curb, you make sure his chair is locked, remove his tip bars (or the evidently more politically correct term, "wheelie bars"), take everything slow, press a hip against the back of his chair, have him unlock his chair, tip his chair back slightly against your hip, and go down the curb. You essentially reverse the procedure to go up a curb. There will come a time (presumably before we leave) that he won't need any supervision whatsoever to take curbs, and he'll do them by performing a little wheelie (after taking off his tip bars, which would prevent his chair from going back far enough to clear the curb).

After I was cleared on that, we took off down the road. It was downhill all the way for the two blocks to Fresh Market. Their parking entrance sloped sharply downhill.

Having observed all that, I knew getting back to Shepherd was going to be . . . interesting.

Gary liked Fresh Market, saying it reminded him of Whole Foods, a store he also really likes. I showed him the fresh and prepared foods I thought he'd find interesting (he has decided on their sushi the next time he has a dinner emergency ;-)).

Next he tackled the ice cream case (he "needed" ice cream). He got the door open fine but couldn't reach the strawberry Hagen Daz. His gripper wasn't a trustworthy tool for this (though later we found out there are a number of different kinds of grippers – maybe another kind would have worked). Rather than make him settle for a different flavor ;-) I got it off the shelf for him.

His final task at the market was to open their bathroom door – the PT had warned him that it was a heavy one, as past expeditions had found out. Gary got it open both on entering and exiting but noted it was indeed the hardest door he'd attempted.

Next came the return to Shepherd. Getting out of Fresh Market's parking lot was a huge challenge, given the steepness of its slope. In fact, in the interest of time (since we didn't have infinity), I had to push him up the last half of it (we later joked about how he'd have to live in the parking lot if he had to do his marketing by himself here). He made the first block back to Shepherd by himself, taking frequent rests (I kept thinking that all the people in the cars whizzing by us must have thought the therapist and I were cruel people, walking next to but lending no aid to this crippled guy huffing and puffing his way up Peachtree in a wheelchair). But we were not going to make his next class if we had him get there on his own, so I pushed his chair for the next block and then up the upward sloping entrance to Shepherd. Had I known ahead of time I was going to have to do all this pushing, I would have vetoed this excursion – it did not do wonders for my back. Fortunately his chair is designed well enough that it was in no way like pushing a 130 pound man, but it was still more than I should have done. He thought it was more than he should have done too – he said a one block excursion would have been a better first trip. But all in all, he was glad to have made his first trip out of Shepherd, even though he was still tired from it by the end of the day.

Next came a group class, which his therapists said would be fun – Gary was dubious, because the last time he'd had this class was the time where everyone else got to play pictionary and he and another guy "got" to lift weights. This time it wasn't purely for fun, either, but it did have some enjoyment value to it. Gary and one of his roommates were paired together, and they alternated playing a computer game of table tennis. It was an interactive game, each one of them pitted against a computer figure. They used their hands as the "paddles" to swat at the ball onscreen – so the therapeutic value of the game was that it made them practice their balancing skills (each of Gary and his roommate fell over backwards onto the mat at least once – they're supposed to learn to throw back their hands to catch themselves when this happens). After a while of that game, the two of them played each other in checkers. I left them and went to work on the blog, then returned at the end of the class. Naturally the therapists hadn't let them finish the session with a fun game of checkers – they each had to do twenty depressions (lifting themselves off the mat with their arms).

(Speaking of the blog, you may have noticed an increased time lag in posting – the Shepherd people are keeping us hopping here, and it is more difficult to find the time to write. And I am WAY behind on emails again.)

Next we went to a "hot/cold" class, where the problem of having increased difficulty with regulating one's temperature was discussed (one may not sweat below the level of injury and blood vessels may not constrict as they should, for instance). It is typical that one gets cold easily (this is Gary's experience), but others find they get hot easily. Or one can swing back and forth between the two. "One never knows," the class leader told us.

Strategies for dealing with heat or cold were discussed, the strategies pretty much standard – dress appropriately (what that might entail was gone over), get out of the heat/cold, etc; signs of overheating were discussed; special clothing was discussed, like a vest that circulates cooled or heated water.

After that class I left for a massage.

In the evening Joe called. I overheard Gary tell him that it was amazing all Joe was doing on the house and that he was eager to see the results. After hanging up with Joe, Gary told me that at the beginning of every summer he makes a list of things to do for the upkeep of our house. By the end of the summer he usually has gotten two or three things done. He said that in these few weeks Joe has done everything Gary has had on his lists for the past five years – and more!

(Jumping ahead a day, when I told this to Joe on Thursday, he said the "secret" was to hire out for this kind of work, that it was not our area of talent or interest (astute observation ;-)) – just as writing or math was not his – so to get someone else to do it. I told this to Gary. He laughed, and then he said the problem was in finding someone as good (and reliable) as Joe to do the stuff.)

I noticed a package from Donne had come while I was gone – a couple classic DVDs ("Annie Hall," "Crimes and Misdeamenors") and a big thick book. Main Currents in Marxism. I am curious about this choice of reading material.

During my evening visit, Gary's new roommate's speaker phone was constantly in use, one call after another, and the guy spoke so loud and his phone was turned up so high it was like the guy and his conversation partners were yelling at each other. Gary and I literally couldn't hold a conversation unless it was between calls (if that keeps up, guess who is going to put in another complaint). We heard over and over the guy's explanation of his injury, etc., etc. Being driven crazy by the loud conversations, at one point when the guy told his caller that his injury was an incomplete injury and affected him from the neck down, I remarked to Gary that it was too bad it wasn't from the neck up. This sent us into a spate of laughter, as we joked about talking to the guy's doctor about reversing the direction of the guy's injuries so he wouldn't be able to talk.

Hey, I can be mean.

Just before I left for the evening, Gary asked me some questions about my "transfer." Earlier in the day I had told him that I still thought he could be bending down lower at the beginning of his transfers (one bends away from the direction that one wants to go in – head goes to the left if you want your butt to go to the right), and that he wasn't using his body to maximum advantage. I said I'd try to demonstrate and did a transfer, careful not to use my legs, though I probably wasn't able to help recruiting some abs. I wasn't sure I'd be able to do one at all, but he said he was envious – I'd done a good one. Importantly, he said he'd learned something by watching me. He realized that in going to the right, I'd pushed off with my left arm, mainly using the right arm for stabilization. He'd also noted that I'd pivoted on the left arm while pushing (one pivots because one is not going straight to the right, but twisting the butt from off the mat to the wheelchair that is in front of and to the right side of one). Finally he noted that by lowering my body toward the mat on my left arm, I could get a bigger push with that left tricep than he could get by staying nearly vertical. For some reason he finds he always wants to grab with his right hand to pull his body to the right rather than pushing off with his left hand and blindly aiming his butt in the direction he wants to go. So he thanked me and said he thought he understood more of the theory behind the transfer and he thought that understanding would help him do it better. We'll see if this theory transfers (sorry for the pun) to practice tomorrow.

To finish this entry: Janet Rogers was able to snap a picture of Blackjack! A great one – we're amazed she got such a closeup. See the blog for it, along with a picture she earlier took of Tigger.

June 29, 2006

Today must have been National Bad Driver Day. You may recall I had to be at Shepherd at 8am for what they call a "wet run," meaning Gary was going to go through the process of taking a shower, trying to do as much of what is involved on his own. I pulled out of my hotel parking space around 7:30. I turned a corner in the parking lot to get to the exit from the hotel to the street. I burst out with an "oh, crap!" at the sight that greeted me and slammed on my brakes. Nerve-wracking increments of time later, Mr. Not-Awake-Yet finally registered that he was about to hit my car – head on. At what seemed the last moment he swerved back into his own lane. Needless to say, I was rattled – that had been much too close. Later in the day, I sat in an intersection on Peachtree to make the left turn into the street that led to Fresh Market's driveway. The light turned yellow; I couldn't make my turn until it turned red. Just then, the guy in the right lane on Peachtree traveling the opposite direction decided to make a right-on-red. We both hit the brakes; he finally let me go first. Then he followed right behind me and honked his horn at me until I turned into Fresh Market. Someone needs to tell the guy that right-on-red is only allowed if cross traffic is clear, and I had the right of way – what did he expect me to do, hang out in the middle of the intersection until everyone who'd wanted to make a right-on-red had done so? Later, when I pulled out of my parking space to leave Fresh Market, when I was nearly out, the SUV parked behind me decided to leave without checking behind him. He didn't stop coming and I had to throw my car in forward and get back in my parking space. When the guy was half way out, he threw his car in forward, and went out that way. ???? Finally, when I went home that night from the hospital a number of trucks drag-raced past me on Peachtree. Then came three motorcyclists zooming around, cutting lanes, performing various antics. They finally pulled off the road into some eatery, but just as I was about to pass by, one of them zoomed out right in front of me doing a wheelie and causing me to have to slam on my brakes. I was ever so glad when I was finally able to get off the road that night.

Back to the day's activities. Naturally (she says sarcastically) I had slept lousy, worrying that the three alarm clocks I had set wouldn't go off. (They did, of course.) I got to Gary's room about ten to eight, having to lug my stuff (including my laptop) up four short (but not short enough) flights of stairs because the parking garage elevator wasn't working. Gary was finishing his breakfast, and I started in on the rice I had brought. I told him I hoped the PT and OT weren't going to be late if they were making me be there that early. At ten after eight they hadn't arrived, and I told him we should get him hoyered into his chair and go look for them. "But I'm naked," he said. I told him I knew that, and that I thought it would be very effective for him to go wheeling down the hall in his current state of undress – they would find his OT and PT very quickly for him.

The therapists showed up just after that – they had been trying to figure out the best way to align the shower chair in the shower for him. We got a gown on him, and he did a bed (depression) transfer with their help– an advanced skill, as the bed is such a soft surface. He wheeled into the bathroom, and they guided his transfer to the shower bench. In the shower he soaped and rinsed everything but his lower legs and feet, which I did. In the course of the shower, he managed to get all three of us "aides" wet, he being in control of the hand shower fixture. He claimed it was an accident, due to his problems with balance. We suspected maliciousness ;-). He dried most of himself, me doing his lower extremities again, and then his therapists helped guide him back into his chair. The PT commented he was doing his transfers much better than even the previous day. He told her watching me do one yesterday had helped (I puffed up with pride), “And besides,” he told her, “if she can do one . . .” I gave him the evil eye.

He did a transfer back into the bed. Since his dressing had gotten wet, it had to be changed. Also, his skin wound had to be checked to make sure there hadn’t been any change in it from the shower (mainly, from the transferring to and from and sitting on the wooden surface of the shower bench while unclothed). While changing his dressing, I noticed a round red spot to one side of the wound that I hadn’t seen before. Also, the one seam that hasn’t healed nicely looked like it might have opened up a bit more. Gary also informed me that the skin PT (I’ve been calling her “the skin nurse,” having gotten mixed up on which person held which title) had found another hole in his wound, on the side opposite where things hadn’t been healing up as well as we’d like. (I hadn’t noticed that hole because the nurses had taken over from me the care of the wound after last weekend.) It turned out that that area had abscessed because of the sutures the skin doc had used – apparently the company that supplied Shepherd with their dissolving sutures had changed their sutures and hadn’t informed Shepherd of that. For months Shepherd has been having trouble with patients suddenly having abscesses of their skin flaps, caused by their dissolving sutures not dissolving. Unfortunately Shepherd didn’t figure out until after Gary’s surgery that it wasn’t that these patients were unusually sensitive to the same sutures Shepherd has been using all along, but that the sutures themselves were different.

With my cell phone camera I took a picture of the main wound since it looked different after the shower, as I didn’t trust my visual memory to keep track of any further changes (I decided not to publish that picture to the blog ;-)). We called in his nurse in order to make her aware of these changes. This pressure sore stuff is so frustrating. I’d hoped with the surgery the troubles would be over, but the area is still so fragile.

After lunch we met with a rec therapist. This one went over gardening strategies with him. She said she’d heard he liked to garden. He said it was more a matter of liking to eat the results (he’s a tomato and pepper grower). She took him out to the garden here and showed him the in-ground raised beds they’d made, as well as container “beds” raised up on legs so they can be wheeled under. She talked about using containers, either raised up high enough off the ground (on bricks or whatever) or hanging from poles. At home he often grows his plants in containers (and I did some of that as well), so we are familiar that. And I am familiar with books on container and accessible gardening, on account of my CFS, so this wasn’t new to me and I know where to find more ideas. One neat thing she showed us were adaptive tools – telescoping trowels and forks suitable for small plot/container gardening. She also suggested looking into kids’ tools, as they were light. She mentioned that Fiskar’s tools have the approval of arthritics, as the tools are lightweight and operate on a ratcheting system for ease of use. She also mentioned that there are vegetables bred for containers, which I was aware of but I’m thinking might not be necessary. Tomato and pepper care aren’t all that involved, and if he wants to still grow his indeterminate tomato plants, we can probably find someone who’d be willing to stake them up for him when they reach the proper stage (he uses these big circular wire cages, so I’m not sure I could do that for him).

After that we went back to his room so the skin PT could check on what was going on with his wound. She told me I could do another silver nitrate application over the weekend, and that the accuzyme for debriding should be used twice a day, either by me or the nurses. She wasn't sure what that new circular red area is about. An observing nurse said maybe it was a rash, perhaps an allergic reaction to the tape that has been being used on him. All we can do is keep an eye on it and hope it resolves or at least that it becomes more clear what the cause of it is.

The nurse stayed after the others had left and went over with us the signs and treatment of dysreflexia, which I already knew from my class. She also went over assisted coughing, which I'd done a little bit on him in Birmingham (the nurses and techs doing most of that). With that, she cleared us for a push pass from the nursing team. The OT had cleared us from her perspective, the PT from hers, but that hadn't been put in the computer yet. The final step would be getting the doctor's okay. Then Gary will be free to go anywhere out of Shepherd he or I can push his chair to.

Next Gary had a session with his tech. She started him on the tabletop "hand cycle," which you operate by rotating your arms (see http://www.rehaboutlet.com/stationary_bikes.htm, for instance – the Endorphin is the one he used), giving you a workout and exercising your back and arm muscles. This was obviously work. After a couple of minutes he stopped and looked at the tech plaintively. "Are we there yet?" he asked.

We weren't.

Every couple of minutes he would stop and let out a big sigh. I couldn't help but laugh, even though I knew he wasn't doing it to be melodramatic. "I'm just letting you know how hard I'm working," he joked. I assured him I knew very well it was hard work for him.

After that he went on the rickshaw exerciser for three sets of fifteen. Next he got onto the mat in order to finish the session with stretching. I think he did an illegal move in getting into position. He was supposed to roll over so the tech and I could get pillows under him to cushion his flap. I was kneeling next to him on the mat, and as he rolled he grabbed onto my butt to help himself over. "Whatever works," he joked.

After that session his PT came with a new set of power-assist wheels. She demonstrated how the equipment worked, how to get the wheels on and off, then let him try them. We went to "The Blue Carpet" that had given him quite a workout before. "Hey, all right!" he exclaimed as he took off up the sloping tunnel, doing it with relative ease. We next went to the parking garage where he tried the ramp that's given him fits. He did it better with these wheels, but it still wasn't an easy maneuver.

When we went back to his room, we found mail – from Marilyn Foreman, Norman and Margaret Groteluschen, and my sister Janet. As always I feel amazed and humbled when people express their reactions to the blog in their letters.

I also found they'd left my schedule for family training, to take place on July 6th and 7th. We'll have to get through the shower routine by ourselves, with the therapists only observing (actually, I'm surprised they have this down for the 6th already, as I haven't yet been allowed to assist him with a depression transfer from even the easiest surfaces – chair to exercise mat – and it seems to me the shower transfers will be harder – done in the confined space of the bathroom, the final transfer taking place after the shower when the surfaces have been wetted down (I will have to make sure both he and the floor, etc., are as dry as possible). After that I'll have a "Therapeutic Rec Lecture." Since I've already suffered through three of those with Gary, I figure if it's on the same stuff I'll just pull out my notes and answer all the questions the TR asks. Since the majority of the time of these lectures was wasted on needlessly asking questions and making the audience guess the answers (like, "What areas do you think the ADA covers?" Why make us guess that????), I figure that if I just answer the questions, using my notes, I can reduce the lecture from an hour to about five minutes ;-) (Gary laughed, then said, "That would be mean."). Next on the schedule is a lunch break, then a "Wheelchair repair and maintenance" lecture. Finally, for two and a half hours (!!!!) there is an "Emotional Adjustment" meeting. (Seems to me that is coming a little late in this process.) The next day is also filled with family training, but what it entails is mostly unspecified on the sheet I was given. The day will finish with a family outing – we will be going to a sporting goods store near the Target I went to.

Just before I left for the chiropractor's, Joe called. He told us the plumbers had come and were done for now. Next on the agenda is the putting in of new floors and the power washing of the walks, the driveway, and the exterior of the house. Painting is on-going (I didn't realize the master bedroom was being painted too – "Well, you can't put in new floors and keep your dirty old walls," Joe said. After a pause, he added, "At least, I won't let you." Good ol' Joe, keep us in line.) Later in the evening, Joe gave us the final price of what the new garage is going to cost.

I felt so sorry for one of Gary's roommates today, the one we have been friendliest with (the one his wife labeled as "The Redneck"). He was in a lot of pain, and it was really dragging his spirits down. As I said before, I am so thankful Gary doesn't have pain like that.

All for now, except to pass on an email Mary Ellen Rudin sent me:

I thought I might
add for the topologists that Madeleine Jones, Burton's wife of almost
60 years and a close friend of most of his mathematical friends died
at age 88 in California near their daughter Marian and her ashes
will be scattered near Burtons and their two other daughters in
La Grange Texas the small town where Madeleine was born.
It was time in this case for she had been ill for many years.
My best to all. Mary Ellen Rudin

June 30, 2006

First up today was the OT, and first task was for Gary to transfer from his wheelchair to the mat. As I watched him take so much time to get his feet off the footrest of his chair in preparation for the transfer, and as I watched him a short time later try and try but remain unsuccessful in getting himself rolled over from his back to his side on the mat, I couldn't help thinking that he's got so far to go to get this basic stuff down second-nature; I can't imagine he'll have it down smoothly in a month. But he is confident he will.

In any case, I certainly don't share such thoughts with him. After all, in his beginning days here sitting himself upright on the mat from a side position seemed such a daunting task for him – now he can do it every time he needs to, though not without effort.

The main thing the OT had him do was practice arm circles with weights while on his side, to increase the endurance of his shoulder muscles. After his session with her, he supposedly had an hour's break. "Do you want to stay on the mat and work by yourselves?" she asked when her hour with him was through. "Sure," we said. She gave some suggestions for what to do, but Gary asked her if he could sit on the edge of the mat and practice little hops along the mat – after watching me do my transfer, he'd come up with some ideas for improving his own transfer and wanted to try them out and get more practice at the skills involved. At first she wasn't going to let him do it because he still loses his balance and it would just be us on our own with no supervision, but after he showed her what he wanted to do, she gave her okay under three conditions. First of all, I had to sit right in front of him on a stool. Second of all, he couldn't sit too far forward on the mat (and she showed him how far he was allowed to go). Third of all, if I left for any reason, he couldn't do anything that might lead to something bad happening (she gave the example that if he was sitting on the edge of mat, he couldn't move at all until I got back).

She left, and he stayed sitting without moving until I brought from his room the protein drink he'd requested. I automatically started to hand it to him, but of course he didn't automatically take it – doing so required balance. So this simple act became our first practice task. He figured out where to put his left hand on the mat for best balance and took the cup with his right. I had kneeled in front of him before passing him the drink and when he took it, I held my hands just below the cup in case he lost his balance. If he went forward, I would save him; if he went backwards onto the mat, I wouldn't be able to get him in time anyway, so I would save the cup. Fortunately, neither of those happened. He gave me the cup, took a breather, then took the cup for another drink. That accomplished, he practiced sideways hops down one side of the mat then back. He said he could definitely do them better now that he'd incorporated the ideas he'd gotten after watching me :-) After a while his arms were too tired to get him any height, so he stopped this skill practice, not wanting to be sliding on his flap instead of hopping. Since he had another session coming up that was going to involve strength exercises, he decided to stretch. So his next task was to get himself in the middle of the mat. Since he's not allowed to go into a deep bending position, he laid down on his side and I got his legs up on the mat. He again tried to roll from his back to his side with the goal of getting to the middle of the mat, but for some reason he couldn't get himself rolled over. It still remains a mystery why sometimes he does it so easily and sometimes he can't do it at all. We'd noticed some things that he sometimes forgets to do. Sometimes his movements in swinging his arms from side to side are not big and fast enough. Sometimes he doesn't lift his head and swing it along with his arms. Sometimes he doesn't remember to punch forward with his top arm at the end. But sometimes it seems like he’s doing all that but still can’t get over.

So after he gave up on getting over himself, I lifted and bent one of his knees toward the other leg and gave his hip a little push as he swung with his arms. This got him over. I gave him his chain loops, which the OT had just given him this morning (one person at Shepherd sews them for all the patients and she somehow had never received the email from the OT placing the order for Gary’s), and he went through his series of stretches while I went to the car and got our hometown phone book. When I got back, Gary had finished stretching one leg. Before starting to stretch the other, he used the phone book and my cell phone to call our bank to make sure there was enough money in our account to cover the check we were about to send off – the required 50% down payment for the garage.

After the call and after he finished stretching, Gary asked the tech, who was working with someone nearby, what she was going to have him do. She told him, and since he would have to be in the chair for it, his final task with me was to get to the edge of the mat and sit up. Somehow in trying to figure out how to do this (again, limited by what he is allowed to do because of his flap) we ended up with him having his head curled up against the wall at the top of the mat. He was stuck there. Because of my back I didn’t dare chance lifting him to an upright position; fortunately it was time for the tech to have her session with him. She came over, saying, “Gary, what are you doing way up there?” We gave ironic laughs and briefly explained. She grabbed onto trunk on one side and I helped push on the other and we got him upright. (And we’re going to be ready to go home in one more month? The therapists claim he’ll see more and more rapid improvement as the weeks go on. They’d better be right!)

She had him work on the rickshaw first. Then came his most difficult strengthening exercise yet. At the parallel bars, he was supposed to press himself straight up, hold for five seconds, then lower himself (no plopping down allowed) – fifty times! He was to do it in five sets of ten. After the third set, it was time for him to do a weight shift, so he used the parallel bars for a depression weight shift, holding himself up for a minute. He said that was the longest minute he’d ever experienced. He and I thought that would count for at least one set of the “dips” but the tech would have none of that. He forged ahead and triumphantly finished all fifty dips, noting that when he’d first come here he wouldn’t have been able to do even one dip. I told him that his upper arms were about twice the size around as they were back then, and it’s true.

The tech wasn’t through with him yet – he did ten minutes on the hand cycle, stopping for rests as he did last time. He was very glad when the clock struck noon and after lunch said that since he’d had three tough sessions with his therapists – the OT, the tech and me :-) – he deserved some ice cream as a reward. I gave him the eye ;-) but brought him some Hagen Daz.

After that we went back out to the gym for his PT session. She wanted to take him outside to try out these other power-assisted wheels (again, they don't do all the work, but provide an assist so he only has to push the wheels about half as much as he would with a completely manual chair). She suggested we go to Chick Filet, which was in the opposite direction as Fresh Market and not quite as far. I thought maybe we should go to Fresh Market so he could really compare the difference between using these wheels and his regular chair. He said he'd prefer to go somewhere different. I suspect that the fact that the trip to Chick Filet would be uphill on the way there, and therefore down on the way back (the opposite of Fresh Market), played a role in his decision.

He liked the wheels a lot; they have only one speed, not the two the other power-assisted wheels he'd tried had had, but he found the chair much more controllable. Strangely, though, a couple of times when he turned the power off, like to go down curbs, it didn't always turn back on right away after he pressed the power button. The PT would jiggle the cord from the battery to the wheels and press the power button several times and eventually the wheels would turn back on, but we never figured out just what the problem was. Unfortunately one time they wouldn't work was when we were crossing an intersection, and the PT had me wheel him across it because we were in danger of the light changing on us. I was already sore from wheeling him back from Fresh Market, and this didn't improve that state.

At Chick Filet, Gary negotiated the door (we had to tell the customer who came and opened the door for him that we didn't want help, that Gary was practicing opening doors by himself). Then he got himself a lemonade, remembering to ask for a lid for it since he was going to have to carry it between his legs (though that isn't allowed with hot drinks). Even with this precaution, he spilled some on him when he flicked the straw. Fortunately it was only a little bit, so we didn't need to head back so he could put on other pants (he is not supposed to ever be in wet clothing for any length of time). This incident taught us the value of him carrying along a change of clothes on any excursion.

We checked out the heights of the tables, and they were high enough that he could roll his chair under them. We went to a booth, and the PT told him that when he had his transfers down, if he wanted to when he was in restaurants, he could transfer from his chair to the booth and vice versa; some people did that, others preferred to remain in their wheelchairs.

On the way back to Shepherd, since we were now on the opposite side of the street from it, the PT showed us how to get to the tunnel that goes under Peachtree and leads to Shepherd. She pointed out that we can use the tunnel on a trip to Fresh Market, for instance, in order to avoid crossing Peachtree, as it is a very busy – and narrow – street (on our way to Fresh Market I had made Gary travel on the inside of the sidewalk, to try to avoid any mishap of his chair veering into the street, hoping that he wouldn't veer and knock **me** into the street).

Upon our return to Shepherd, Gary told the PT he really liked these power-assisted wheels, so now is thinking of getting them for use in getting about campus (but not at home or in the math building). He'll have another week to try them before making a decision. One thing of which I want to make sure is that he is going to be able to lift the wheels and get them on and off his chair without much difficulty – they weigh twenty pounds apiece.

Back in the gym, the PT helped him transfer to the mat. Then she had him practice moving his seat cushion from the chair with the power wheels to the chair he's been using – once again this was a reminder of how every little thing he has to do has now become something that has to be thought through. He got the cushion over to the other chair, but since he'd used a "fling it and hope it lands in the right place" technique, she had him do it again, giving him tips of how to balance to get the cushion where he wanted. He wasn't quite successful, falling backwards onto the mat in the process. The PT pointed out that once again he hadn't flung his hands backwards to stop his fall, but rather he'd tried to reach forward and grab at the mat, which hadn't worked yet. She warned him that on Monday they were going to go through an exercise where he would sit on the mat and she would push him backwards, trying to make him fall over. She said it had to become second-nature for him to fling his hands backwards.

As he and I went back to his room after that session, a nurse stopped us and told us that our team nurse, OT, and PT had cleared us for a push pass, and all was needed now was the okay of Gary's doctor or the resident who worked with the doctor. We asked when we could get that, and she said she would put in a call to the resident. She did so, and before we'd even gotten to his room she yelled that she'd gotten the resident's okay and we were now all clear for a push pass! So we can now take any little trips around here that Gary feels up to (as "pedestrians," I mean). Gary said he wants to go to the nearby Mexican restaurant soon. This caused him to recall that only a relatively short time ago, he'd somehow gotten it into his mind that he was going to have to "eat" through that tube in his stomach forever. More dismaying, he'd thought he was going to have to be on the ventilator for the rest of his life, that perhaps there were people with his level of injury who couldn't be weaned off it. Progress had seemed so slow at the beginning of his recovery.

So I guess when I'm thinking how slow things are proceeding now, I should recall what things were like just two months ago.

We went back to his room, and I planned to leave for my walk/meditation/cooking dinner break about a half-hour early. It was not to be. Earlier I had overheard Gary's new roommate talking on the phone with his sister (as I indicated, it is impossible not to hear every word of both ends of the guy's conversations), her saying how she was having difficulty in finding a place to stay here, so I'd gone to his part of the room and told him I had done some investigating of the possibilities, that I'd checked out the hotels on the list Shepherd had given me and had also found some promising hotels via the internet. Evidently he'd passed that information on to his sister when she'd arrived in his room (in his quarter of the shared room, that is), because she stopped me as I was leaving and asked to know what I'd found out. Then I headed to the elevators, only to find they weren't working because Shepherd was having a fire drill. Even after the drill ended, the elevators didn't work. A nurse walked by and told me and the other person who was waiting for the elevator that they were broken and that we needed to walk down the passageway to the Marcus building and take those elevators. I headed that way. I had a brief twinge of conscience as I tried to leave the other person in the dust, rationalizing that Shepherd wanted their patients to be as independent as possible. This patient was lying on her stomach in a bed and the way she was getting around was to push the big wheels at the front of the bed – a wheelchair bed. I had done enough pushing lately and I feared for my back if I tried to push an occupied big bed. But when I was about half a hallway ahead of her, I heard her calling me. Sure enough, she wanted me to push her. How could I refuse? So I pushed her to the Marcus elevator, dragging my rolling suitcase behind me, and then we went down to first floor. It turned out she wanted to go all the way back to where the Shepherd elevators were, make a left, and go out the door there to the outside. So I began pushing her in that direction. As we approached our destination, she told me that the purpose of this trip was so she could have a smoke. I felt like pushing her bed, her in it, out the nearest window ;-).

I had to go to the grocery store after that, and upon my return to the hotel, I balanced my bag of zucchini on my roller suitcase. As I got to my stairs, a worker at the hotel asked me if I wanted assistance. I said sure, and he took the suitcase. I started up the stairs then turned to tell him the handle on the suitcase could be pushed down and it might be easier to carry that way. “It would be,” he said, continuing to carry it with the handle fully extended, “but you know us men, always having to do things the hard way.” We had a good laugh at that.

While driving back to Shepherd in the evening, I stopped at a red light behind a car that had a dog in the back seat. The dog had a little routine. He would run to the passenger side, make a U-turn, run to the driver’s side, stick his head out the window and look all around, the repeat this procedure again and again, all at dizzying speed. Why do dogs do things like that?

Back at Shepherd it was obvious that Gary’s roommate had been given his pain pill again – they’d evidently tried to make him go cold turkey, which IMHO seemed rather extreme, going from a pill every four hours to nothing. All evening he was in a really good, talky mood, calling various people on the phone or talking through the curtain to Gary – basically, the man was flying. I’m not sure what he and/or his medical team have decided to do about his pain. He and his wife had told us that they’d talked to his doctor about it, his doctor being the same as Gary’s. His doctor had said that he himself still has pain (and I think it’s been at least fifteen years since his accident), and that in fact right then as they spoke he was having strong burning pain (which was situated nowhere near where his injury was – the pain can be anywhere). But, the doctor had continued, rather than live on medication he chose to not take any and to just cope with the pain.

Back to us. Gary and I went through our nighttime routine – personal care stuff, stretching him, and once again me taking care of his skin wound. I cleaned it, put the various medications on it, and covered it; when I was nearly through he asked how much longer it would be. I said I was almost done and asked why he’d wanted to know. He said because it took the nurses about two minutes to do it, and it had taken me over twenty. I said they’d had a lot more practice and if he preferred the nurses to do it, then that was fine with me. He said he trusted me to do it right more than he trusted the nurses. I sure hope that trust is well-placed.

We again had a hard time carrying on a conversation during the evening visit because of you-know-who’s speaker phone. Gary joked that the two of us should get megaphones, maybe give the guy a taste of his own medicine, with the added benefit that Gary and I would be able to hear each other ;-)

All for now.

July 1, 2006

No rest for the weary: Gary had a therapy session scheduled for today (Sat), from 10-11am. His regularly scheduled therapists take off each weekend, but the therapist assigned to him for today had worked with him before, so was familiar with his case. She is one of the few therapists here, it seems to us, who has long-time experience – over twenty years. Most, if not all, of the other therapists we see in the gyms seem pretty young; Gary's PT, for instance, has only been working as a therapist a little over two years. We were amazed at that, because she seems very good, as is his OT, of a similar age. But today's person's greater experience was very evident. (I suppose there aren't many long-time PTs because the pay probably isn't that great. This person told us she only works on weekends so I would assume she is not dependent on this job for her main source of income.)

Maybe because of it being so close to July 4th and staff taking off for the holiday, there was an over-scheduling of patients to therapists. Consequently, during the hour the therapist was supposed to be working with Gary, she would give him a task and then go off to help other patients, coming by occasionally to ask us how things were going. She started Gary off on the rickshaw. After that, she helped him with his transfer to the mat and then brought him dumbbells and told him which exercises she wanted him to do. I mostly oversaw him, making sure he didn't cheat ;-) (by the way, mom, since you are new at email, that symbol I just typed, the colon followed by a dash then a parenthesis (here it is again ;-)   ) is a wink (look at it sideways – the semicolon is the eyes, one eye winking; the dash is the nose; the parenthesis is the mouth, smiling. The symbol :-) is a smile (again, look at it sideways)). At one point, though, since Gary was safely in the center of the mat, I stopped my overseeing of his weight program and went over to another mat to practice the rolling from back to side that he has so much trouble with. I'd never tried such a roll before, and I was hoping that in doing it myself I could figure out something about it that might help him. I kept my body "dead" from chest down and tried to roll from my back to my side in the way they taught. I noticed one thing immediately. If I wanted to roll to the left from a supine position I first swung my arms to the right (chest and head following) as he did, but then I automatically arced them up to the left over my head. If my memory was correct, he always swung straight across. I tried it that way and found that my arms essentially got in my way and stopped me from being able to roll over. I went to his mat, told him my findings, and after he finished the set he was on, he watched me do a roll swinging my arms upward. "But that's the opposite of what they told me to do," he said. I told him no, it wasn't – his OT had told him he could swing his arms upward if he found that easier. He told me he didn't remember that, and in fact had been swinging his arms downward. So, as he watched me, I tried it that way. I stated the obvious result: "Well, that completely stops me – I can't get over at all. My arms get in the way." He gave an ironic laugh and said maybe that was why he couldn't get over, that maybe the times he'd successfully gotten over were the times he'd forgotten to swing down. He decided to try my way before the end of this therapy session. He finished his weights and then went into his stretching routine. I helped, supplying a tiny bit more of a stretch than he can get on his own, as his OT had suggested I do – Gary's flexibility is so poor and it's so important now that he get as flexible as possible, I figure he needs all the help in developing greater flexibility that he can get. After we finished the stretching, he tried my rolling tip, and he got right over (well, on the count of three swings, I mean). He tried the roll a couple more times, and each time he got over. I felt proud that I was able to contribute something to help him in another area he'd been having a bit of trouble with.

We had already run over our hour (the most recent time the therapist had walked by she'd told me that she was glad I was there and that I should get a pay raise; I asked her what kind of raise I would get from $0; she said she'd double it; I told her that having a Ph. D in math, I knew what that was), and Gary was ready – a bit eager, actually – to leave. But the therapist came over, her other patients now gone. She said they needed to work on his rolling. She said she'd noted when he first got on the mat and did a roll that he needed to swing his arms up at the end of his swing. I felt validated. Then she told him he needed to tuck his head and chin more as he swung over, and to punch hard at the end. All this he had been told before, but then she did something that really brought this home. After he got himself rolled over by using the arms swinging upward technique, she had him stay on his side and told him "Don't let me push you back." She then pushed him at the hip as if to roll him onto his back while he fought to stay on his side. Sure enough, his natural reaction was to strain upward with his top arm (there being nothing to grab onto – I'm sure he wouldn't have tried for HER butt, as he had mine) and to tuck his head and chin in. That little practical demonstration made a world of difference to him. He practiced a few more rolls and they were done so much more easily. I'd venture that if he does a few more practice sessions at it, they will be completely automatic.

She then gave him tips on how to get his legs onto and off the mat after and before a transfer – another skill no one else had broken down into steps for him so that he knew precisely what he should do (I just hope that between the two of us we remember how to do it). Then she gave him some tips for getting into a sitting position from his side (on his side is where he ends up after transferring to, and getting his legs on, the mat) – he has always resorted to getting in a prone position and working from there, saying he isn't strong enough and his shoulders aren't flexible enough to do it from the side position. She then showed him a way to get to the sitting position from a lying-on-the-back position, but he had similar strength and flexibility issues there. She said she thought he should work on those issues, rather than abandon completely these more efficient ways of getting to a sitting position. One of the first things he needed to do in order to use these more efficient techniques, she said, was strengthen his neck muscles. (We've noticed this for a long time, actually – when he is hoyered with the net (which supports him on his backside from mid-thigh to shoulder and lifts him from his bed into the air), he has a hard time holding his head up without using his hand.) She told him that when she saw him again – in two weeks – she wanted to see improvement in his neck strength. She gave her thoughts on what progress she thought he could expect to see by then: that he should pretty well have the rolling down pat, and that the getting into a sitting position using the method he had been using would be easier. She hoped that he could also make some progress in the other methods of getting into a sitting position, but that he would just have to see if his arthritic shoulder prevented him from doing so (so far, nothing he's been doing has affected that shoulder negatively).

The rest of the day was ours, and we hung out in his room for a while, doing some personal care tasks, having lunch, being on the computer and on the phone. After he talked to his mom about the Alaska flight cancellation, we decided to go out to the garden a while, since he was feeling a little cold. No problem with cold in the garden – we didn't want to get out of the shade (it was about ninety degrees at the time). In front of where we sat was a thigh-high curved sculpture of a human. The figure was kneeling on its legs, bent forward, head down. "What do you think that sculpture is about?" Gary asked me. I thought only a moment and then titled it: "'It's been a tough day at Rehab.'" Gary laughed and said he thought that fit. He said it'd be funny if we taped to the sculpture a sign with that title– he was sure every patient would get a kick out of it. So maybe I will put up a sign ;-)

We left the garden and entered the rec room. I asked if he wanted to shoot some pool. So we played a game where we got whatever balls we could in, no division into solids and stripes. Gary creamed me – I got only two balls in. This is no doubt due to all the helpful techniques he discovered while playing his nephew Justin in pool that second time – and not a reflection on my skill at this game ;-)

Joe called during the game, giving me a brief respite from my humiliation. He gave us another update on the house. He has rethought the pedestal sink scenario and now plans to get wall-hanging sinks. Just before he hung up, I remembered something else we might want done: having a mirror hung over the bed in the master bedroom. "After twenty-five years of marriage you want a mirror over your bed?" Joe asked insinuatingly. "So Gary can see himself when he's stretching, so he can make sure he's thrown his chain loop over his foot and so on," I hastened to clarify. I am not sure Joe was convinced that is the reason.

During my evening visit with Gary we talked to my mom by phone. At one point, when Gary was on the phone with her, he started crying and said, "That's what my family says too." He couldn't talk any more, and he handed me the phone. I had no idea what that was all about but I thought he needed a good hug so I supplied it. After the call was over Gary told me that what she had said was that the whole family was proud of my devotion to his care. He started crying again, and I gave him another hug, saying, "Goodness, every time you tell me something like that you start crying." He said, as he's said before, that it was because he was so grateful to me. It feels a bit odd to hear him put it this way, because of the following: my reactions to this situation and how I deal with it have not been thought out, and it seems to me that gratitude implies thanking someone for something they wouldn't have otherwise done. However, I know that if our situations were reversed, gratitude is what I'd be feeling too.

I know he sometimes feels badly that I have to deal with this. When I told him my dream about not being able to check out of a hotel and that it turned out that everyone who checked in was soon executed, he said he had a possible interpretation: that the situation we now find ourselves in is the hotel I've checked into and I'm feeling trapped into it, like it is ending my life.

After he said this, he started crying. I hugged him and said that I didn't like that interpretation and that it would have never occurred to me – sure, the situation was one I'd prefer not to be in, but I wasn't feeling that beleaguered. After he calmed a bit, he said he'd like to check out of this situation, too, and go back to the way things were.

I know that he doesn't long entertain such thoughts – in fact, I think he is remarkable in how well he has accepted the situation and makes the best of it – but I don't think he would be human if he didn't have such thoughts at all.

Well, I sort of wandered off track there . . . Back to my mom's call. Something she said reminded me of another person I should thank – my sister-in-law Dolores, for letting Joe stay away from home for this length of time and delaying their own clients so he can work at our home. So, thanks, Dolores! (When my mom talked to Joe recently and said to him, "Poor Dolores," having not yet explained that she meant it must be hard on Dolores to have Joe gone all this time and that it was so good of her to let him do this, my mom said Joe exclaimed something along the lines of, "What do you mean, 'Poor Dolores'? She's got our dogs. What do I have here? Cats! When they even deign to turn up."

Well, I can certainly sympathize with Joe missing his wife and his dogs. We miss our kitties, and I always hated it when Gary would go off for a semester on sabbatical. Nighttime was the worst.

And I know Joe is making a great substitute "papa" for our "boys." He still hasn't put up a cat barrier to keep the cats out of his sleeping room, thus letting Tigger wake him at 5:15 am to demand breakfast. He's been something of a pushover with them ;-), as he knows they have not been getting their usual quota of attention – they are used to me being constantly around the house.

But, when Gary and I get home, we are definitely erecting that cat barrier, and there will be no giving in to whining for Fancy Feast.

I think.)

All for now.

July 2, 2006

When I came into Gary's room this (Sunday) morning, I found him leaned way over to the side in his chair. I thought he was doing a weight shift, but it turned out he'd dropped his grooming stuff and was trying to pick it up off the floor. He laughed and asked if I'd get it for him rather than have him get "practice" for a half hour at retrieving the stuff. I retrieved the comb and some other things from the floor. The chapstick, he informed me, he'd caught between his feet. His toothbrush had apparently gone AWOL. I looked all around the floor but couldn't find it. He had the thought that maybe it had fallen between his feet, too. Sure enough, it was wedged farther down between his shoes. And even farther down, at the bottom of his foot plate, was his bar of soap. Gary started laughing. "I'm pretty good at catching things there, aren't I?" he joshed.

That taken care of, I showed him the little "It's been a tough day at Rehab" sign I'd made, in case we dared to put it on the garden sculpture. "Let's go for it," he said. The coast was clear in the garden, so I scotch-taped the 4"x4" sign to the bottom right-hand corner of the sculpture, thinking it wouldn't draw too much attention to itself there. We made a quick get-away to the other side of the garden and checked out the various planters. One was full of herbs. A few of the herbs we didn't recognize; we were able to identify the lavender only because of the sign next to it, but not all the plants had signs. And at least one sign was misplaced. We found the "oregano" sign in another planter next to something obviously not oregano, so I put that sign where it belonged. Gary then said since we'd now become graffiti artists, we might as well go further with our pranks and re-arrange the signs – for instance, putting the "donkey-tailed fern" sign on the elephant's ear. I'm not sure if I should be worried about his new criminal tendencies ;-) (And no, we didn't rearrange the signs.)

After hanging out in the garden a while, we went back to Gary's room so he could eat his lunch as soon as they brought it, the urgency due to wanting to have a full hour of "pet therapy," which was taking place from 12:30 to 1:30. We hadn't been to pet therapy before and we were hoping to be able to pet some kitties. But when we found out the therapy was in the garden, we figured they probably hadn't brought cats. Sure enough, the only pets were two dogs. Okay, they were cute, but they were dogs. We petted them for a while, and before leaving we told the therapists to bring cats next time. I'm not sure they're going to listen to us ;-)

On our way back to Gary's room, I told him I'd had a creepy thing happen to me last night. As I'd gotten into bed in my darkened room without my glasses on, I saw a tiny flash of light that must have been reflected off the mirror in the bathroom sink area. Worried it could be something electrical, I turned the light on and checked. Nothing. I took my glasses off, turned off the light, and got into bed again. The tiny light flashed up on the ceiling. Then again further along. Irrationally, this made me afraid (little devas in my room?). I turned the light on. And discovered a lightning bug on the ceiling. Gary got a good laugh at that.

He mentioned to me that they'd weighed him again, and he's up to 128.9, which means he's gained 3 pounds in a week. I told him I thought it all went to his arm muscles. He thought it was muscular weight too, as he hadn't noticed any weight gain about his middle, which would probably be the only other possibility. He was happy to have gained the weight – I think he worried some when it kept slowly going down, probably due to continued muscle wasting in his legs.

In the afternoon Gary called his brother Donne to thank him for the gifts and to ask him how he knew "Main Currents in Marxism" was just the book Gary had always wanted. Gary said he is going to have to get a lot stronger to read it, however – the book is a huge hardback, about four inches thick.

During the course of their conversation I overheard Gary mention something I had wondered about. In writing in the blog about Friday, when I got to the part where I told about us volunteering to do the extra therapy session, it occurred to me that maybe **I** had been the one to volunteer Gary for the extra work, but I couldn't remember. Turned out that was the case. Gary told Donne that one of the reasons the therapy had been so tiring on Friday was that when the OT had asked if we wanted to do that extra session, I had said "Sure," before he himself could open his mouth, and he hadn't felt like he could back out and say, no, he'd rather return to his room and browse the internet to rest up for his next session.

Oops.

Gary also talked to Donne about why he hadn't felt confident about leaving here on the 14th. The main things he needs to get down before going home are doing transfers by himself and to be able to turn himself in bed during the night and get himself properly padded at the ankles. As far as transfers go, as of now he can't do even the easiest transfer, the one from wheelchair to mat. And we haven't yet solved the problem about what to do about padding between his ankles when he turns in bed from the prone position to the side position. We are going to make ankle pillows from foam, and if they don't solve the problem, we'll buy some waffle boots to try. And if they don't work we'll have to brainstorm for some other way to get a pillow down between his ankles or for some equivalent solution.

I talked to Donne while Gary went to do a weight shift (Donne blamed the choice of book on me, since I'd said Gary liked non-fiction; I thought that was a rather large leap). Donne mentioned that one of his in-laws had recently started reading my blog and had asked Donne if I was going to publish it in book form. I told Donne that other people have suggested I do that and that I would like to look into it after we return home and our lives become more settled. What I really need is for a publisher to stumble across the blog and say the same thing ;-), since I have no idea how to go about getting something like this published. Jamie of critique group has said we can discuss ideas for turning the blog into book form, if that's what I want to do when I return to the group (hopefully I'll rejoin you in about a month, Jamie). And I was recently sent an Amazon recommendation for a book about writing niche books – surely this would certainly qualify as a niche book – so maybe that would give me someplace to start.

Anyway, it's great to hear that people have that reaction to the blog – I like to be read :-), just as I liked to have publishable results in math. Donne mentioned in our conversation that maybe it was a good thing I'd changed from math to writing. That change wasn't exactly voluntary, as he knows, and getting into writing was not actually a conscious choice – I fell into the writing by accident a few years ago (thanks to discovering Remington Steele fanfiction <grin>). But I am very glad I found something I can be as passionate about – I like to have passions. One advantage to doing math, however, was that I could check that my proofs were right by myself, just by going through the logical steps. I find it hard to know when my writing is “right” (i.e., “good”) – no checklist for me to go through ;-). So it’s great to hear that the blog is holding other people’s interest (or at least, that that is true so far ;-)).

Back to Sunday. Later in the afternoon my brother, Joe, came for a visit. Gary and I planned to take him to dinner at the Mexican restaurant, Casa Grande, a couple blocks away. This was to be our first outing on our own, and we figured it would be good thing to have someone like Joe along if we were going to attempt that particular restaurant: if the uphill traveling got to be too much for Gary, we could foist off any needed external pushing of his wheelchair on someone else besides me ;-). Joe was game (I hope he isn’t cursing us now that the excursion is over). The nurses prepared an IC (intermittent catheterization) kit for Gary to take, letting Gary off a little easier than his therapists probably would have. Then we took off on our adventure. We cut off one block of upwardly inclined traveling by using the underground tunnel going from Shepherd to a building up the street. But the trip still wasn’t easy. The sidewalks around here are practically obstacle courses – they’re broken, full of cracks and crevices, etc. Joe pointed out that even though Georgia is supposed to be a leading state in terms of the ADA, any benefit of the cutaway curbs on Peachtree is negated by the condition of the sidewalks along the street.

At the restaurant, we made things a little harder than they would have had to have been, as we didn’t see the ramp entrance until too late (it led from the parking lot in the rear). Consequently, Joe “backed” Gary up the couple of steps to the restaurant entrance, following a suggestion Gary had received from a rec therapist for what to do at a restaurant without a ramp. When we got to the door of the restaurant, Gary said he felt like the back of his chair was giving way and that he was going to fall out. He was right about the back of the chair. Fortunately my mechanically minded brother fixed it. Gary said he’d had a vague feeling a few days ago that the back felt different, slanting him too far forward. So we figured something had slipped out of place a few days ago, and when Joe had lifted the chair, that had been “the last straw” (or, “the next to the last” – thankfully, there was no big disaster).

We took a table, and the guys ordered their fajitas – I had forgotten to bring along the dinner I had purposely prepared ahead of time <peg rolls her eyes>. After they ordered, next on the agenda was Gary’s IC (bladder program procedure) – Gary had to stay on schedule, so it couldn’t be delayed. Since he hadn’t done one in a public place before, and since he was going to do a slightly different routine than he had been using at Shepherd, I asked if he wanted to see if he and I could go in the handicapped stall in the women’s room. But Joe said he would accompany Gary in the men’s room.

So off they went, and about fifteen minutes later, they returned. I asked if things had gone okay. Gary said there’d been a few minor glitches, but basically things had gone fine. (It turned out he’d forgotten he could lay his transfer board across the toilet seat and use that as a shelf for his needed items, so instead he’d put the stuff on the back of the toilet seat, which wasn’t as convenient; also, since he normally uses a reusable bag for collecting the urine, he wasn’t familiar with the disposable kit bag, and he didn’t know how to empty it. So he rolled out of the stall with it on his lap, thankful that only Joe was in the room to see it, and threw the whole thing in the trash. We later learned that the kit bags can supposedly be torn open at the top and the urine emptied into the toilet, but the OT said that she herself had trouble doing that).

The guys dug into their food and thought it was excellent (the one problem with the dining experience at this place is that they play music too loud – which is why the Gruenhage clan hadn't stayed there to eat after checking the place out). After Joe and Gary finished eating, I pulled out my credit card to pay for the food. I then had to have Gary and Joe tell me how to handle the bill (which of those slips of paper were mine to keep?). After I put down the tip, Gary commented to Joe that I hadn't been out to a restaurant a long time. Evidently a 20% tip was too high.

We exited the restaurant, using the back ramp this time. We noted that we would first have to go down the long slope of the restaurant's driveway, which exited onto busy Peachtree. "I can handle it," Gary said. "Well, I'm not going to let you," I replied, keeping my hands on his chair to act as brakes if necessary. That negotiated, we jounced along the sidewalk to Shepherd (well, Gary did most of the jouncing; Joe and I kept surreptitious hands on his wheelchair). Gary needed some help on some inclines, and on some cutaway curbs, and over some parts of the broken sidewalk, and Joe also gave him some extra breaks by pushing his chair when it wasn't absolutely necessary (but gratefully accepted), but all in all we thought our trip a success. Rather than finish by going up an incline into the entrance of Shepherd, we went in through the garden gate. While there, we checked out the sculpture to see if our graffiti was still in place. It was. Joe laughed at it and said of the sculpture, "Definitely not a person who has been using a power chair." He ranked our graffiti right up there with the "Who would Jesus bomb?" bumper sticker he'd seen on a van as he was driving into Atlanta. I'll let you figure that one out yourselves ;-)

The van he'd seen, by the way, was one of the models that is used as an adaptive van (Toyota Sienna, I think it was). Joe looked through the catalog of vans that we'd been given, and in his opinion that particular one would be on the small side for Gary's needs, having the same size interior as his own van, so he was a good judge. (We haven't gotten far enogh along in the process to seriously be picking out a van, actually. At some point, Gary will have a class about vans.)

Joe stayed for about another hour after we got back to Gary's room. We went through the mail he'd brought, talked more about the house, about his dogs. He explained that Dolores would unfortunately not be able to come to visit because one of their dogs has Addison's disease and given that dog's personality they are afraid the stress of both Joe and her being gone at the same time for even for a short visit would be very detrimental to their pet; Gary and I completely understand their devotion to their pet's well-being, of course.

And speaking of pets, Gary and I asked about our cats. Joe told us we'd gotten a free bag of cat food from our vet – he'd walked into the vet clinic and told them he needed to buy some cat food for his sister and brother-in-law, and they immediately knew who he was and gave him the free bag (I'd guess the vet staff had heard of Gary's accident through our neighbor who has been getting the cat food for us, and they probably figured Joe had to be my brother – of all of us in the family, I'd say he and I share the closest resemblance). Joe also told us Tigger had a tail-chasing problem, which set us all laughing, Gary and I knowing exactly what he meant. Joe said he was afraid Tigger would one day catch his tail and kill it. He said that the first time he'd caught Tigger at this activity, he'd had no idea what was going on. He was in another room and heard this horrible banging-against-the-walls noise. He investigated and found Tigger madly chasing his tail. This cat likes to do that while in a corner, evidently to make the most noise out of it. Or he'll do it in the confined space under the microwave stand, again so he can hit as many walls as possible while doing it, apparently. I forgot to ask Joe if he's caught Tigger scratching madly at the windows or at a mirror or on the bottom of the bathtub, other activities he's been known to engage in. I don't think Blackjack does that kind of scratching as much (and never chases his tail, being a very lazy cat), but for him, a closed door is an invitation to scratch. And scratch. And scratch. He can endure at that activity for far longer than any human can take it, another reason Joe doesn't close his bedroom door at night – and another reason why our "cat barrier" was the door way out between the kitchen and living room areas and not the door between the living room and the bedroom areas.

During the course of the day's conversations, Joe mentioned the math department people who'd been at our house to help this week: Jack Brown, who broiled in the Alabama heat, weed-whacking while Joe waved at him from a window in the air-conditioned house (this is how Joe put it, and of course, it is not literally true, as anyone who's met Joe can attest to: while he hates the hot summers of the south, he is too busy working to idly stand by waving at someone else who is working); John Hinrichsen, an expert home builder himself, who helped Joe with "mudding" the bathrooms and contributed the use of his power washer (much to our cats' dismay, as it is noisy), to be used to clean the bricks of our house and the surrounding concrete areas (patio, porch, and sidewalks, I believe); and Janet Rogers, who Joe says deserves the whirling dervish award, seemingly everywhere at once, pitching in at any task, painting all day without tiring, etc. Joe said at one point he went outside, figuring to help her with the power washer, but found her out there handling it like she was born to the job. (Good Lord, Janet, can I have some of your energy?).

Of course, I'm sure everyone who works with Joe holds his work capacity in similar awe. Jumping ahead, I got an email from Janet on Monday with pictorial updates of the work on our house, and she mentioned that Joe is, of course, the hardest-working person of all. She said she didn't know what time he started or when he quit for the day, but he was always working, no matter when any of the rest of the people showed up. That is definitely Joe. We are so incredibly lucky to have him doing all this for us. We can't thank him enough.

Right before Joe left us, I got him to take a few boxes of stuff from my car back with him – I'm still hoping to make enough room in the car that Gary and his wheelchair and his various paraphernalia can get in it, but don't know yet if I've succeeded.

After saying goodbye to Joe, I went back to Gary's room and helped stretch Gary. Then I did some personal care stuff, including changing his skin wound dressing. Then I got him properly positioned in bed. Norma called at one point, and Gary had a short conversation with her – she and his brothers and their families will be leaving for the Alaska cruise at the end of this week (yes, those Birmingham people had been a little over-optimistic that Gary would be ready for that cruise – even not taking into account the delay caused by the bed sore).

I was pooped by the end of the day. As I dragged my roller suitcase down the hall from Gary's room to the elevators in the Shepherd building, I passed by the nurses' station. A nurse stopped me and had me fill out a push pass form – evidently we were supposed to have filled part of it in when we left on our excursion and part of it when we returned, but no one had told us about these forms. After she and I had both signed it, she looked at me, obviously a little weary herself, and said, "Have a good weekend – I mean – "

"Yeah, whatever," I broke in. She and the other nurse at the station and I all laughed, knowing that she hadn't said what she'd meant, since the weekend was essentially over (no doubt she'd meant to say "Fourth of July" holiday).

I got into the elevator and got out when it opened; another person stepped into it. I turned around to get back on the elevator, realizing it had opened on the second floor. "Oops," I said, "I'm going down." She stepped out of the elevator, saying, "Oops, I'm going up."

Days can get long around here!

Okay, this is the second entry being uploaded today, so you may not yet have read the one that appears below it (if you're on the blog). In which case, if you want to stay chronological, you need to read the entry below this one, concerning July 2nd.

July 3, 2006

We had a triumph today, as you will see later in this entry. But I'll start off chronologically (keep you in suspense awhile longer ;-))

When I went to leave for Gary's this (Monday) morning, I couldn't find my car key – it was not in the same place I always laid it. I checked all my pants' pockets. Not there. Fortunately I had worried that something like this might happen and had had a spare key made when I was in Birmingham. I went out to the parking lot with that one, afraid my car wouldn't still be there. But it was, no key in the ignition. I figured I'd either dropped the key on the way to my hotel room or absently laid it down somewhere in the room.

First on Gary's schedule was the PT. She brought him a power chair to try out. We told her this was good timing, because Gary's chair back had started to fall through on our outing last night. She said that she would take his chair down to maintenance to have it fixed, and that Gary could use the power chair for the entire day, since his own chair would most likely not be ready until sometime on Tuesday.

The two hundred pound power chair was controlled by a joystick, and Gary was like a little R2D2 run amuck (well, maybe that's a tiny bit of an exaggeration, but . . .). I'm sure he'd get better with practice, but he kept toggling it too hard (or maybe the gears needed to be adjusted) and the chair would jerk in one direction then another. One had to be very careful around him, as he didn't always let you know what direction he was about to head. Fortunately he ran over the toes of my shoes only once. Much more fortunately my own toes didn't extend far enough out in the shoes to have gotten mashed. All day long we had to warn other people to give him space – I joked that we needed to put the sign "Student Driver" on the back of his chair.

He didn't like the chair much. It sloped his feet too far forward, and as a result he couldn't get very close to things. A consideration for later on was the fact that only way it could be transported would be by using a lift, so it wouldn't be nearly as convenient as the power-assist wheels. And of immediate importance, it was harder to do weight shifts in it. The arms of the chair did not easily lift away, which made a side weight shift inconvenient. And the only place to hold onto the chair to do a depression shift were its arms, which were much higher than those on his manual chair, thus turning the weight shift into an exercise that rivaled doing dips (keeping his balance was the major problem).

After letting him get a little practice with the chair, the PT had him go out to the gym to practice transfers. I mentioned to her that Gary and I were scheduled for a "wet run" on Thursday, and that my understanding was we'd be doing it entirely on our own, with the PT and OT watching but not helping unless absolutely necessary, which meant that I would have to be the one helping him with the transfers. I asked her if I could practice doing transfers with him before then, rather than the first time being in the shower. She said we could practice right now. I had some idea of what to do – not only have I been watching the therapists aid in his transfers since the start of his therapy, but I'd actually helped with one of his transfers before – unofficially. One of the first times he'd tried doing a transfer from the exercise mat to his wheelchair without his board, he had come down way too short of his destination, and, fearful that he was going to land on the wheel or in the gap between his chair and the mat and thus harm his flap, I'd reflexively stuck my hands under his butt like I'd seen the therapists do and lifted him over. The PT, who'd been in front of him to lend aid, had looked at me in surprise, and I was surprised too – I'm sure my being able to lift him that way was due to an adrenalin rush, not something I would normally be capable of, comparable to those incidences of people lifting cars off of injured people.

She explained the proper procedure to me. When he is going downhill (like from the wheelchair to the gym's exercise mat), I don't need to supply any lift. I would be behind him (in the case of the exercise mat, I would be kneeling on the mat), and I would keep my hands on his rib cage to aid his balance, so he doesn't fall over backwards – based on the therapists' observation of him, there wasn't much danger of him falling forward uncontrollably, as there is his chair to grab onto and he's always done that successfully.

On uphill transfers, however, he needs actual help, sometimes just a little (maybe 20%), but other times a lot, depending on how tired he is or if his technique is off. So the technique for helping him uphill is different than that of aiding him downhill. She had me try doing the upward transfers both from a position of being crouched down in front of him and from a crouched (or sitting) position to his rear, to see if I preferred one position over the other. Because of my small stature, I seemed to be less in his way if I was to his rear. Neither position was kind to my back, so I hope he'll soon have the transferring on his own down pat!

The technique for the upward transfers was to get my hands under his two "sit bones" (as I'm sure you can guess, these are the bones you sit on, located under the flesh of your butt), and then to provide any lift he needed. I wasn't exactly sure how much help to provide, and because the goal is to provide the least amount of help that allows him to make the transfer, sometimes it turned out that I provided less help than the therapists would have done – which I knew immediately, because he wouldn't make it square into the chair in one movement, as he always did with them, instead having to take two hops instead of one to finish the transfer. But even those times the PT said that I had helped enough – she said all I needed to do was to make sure he landed securely, that the great majority of his weight was in the chair, that he wasn't on the wheel or stuck in the gap, things like that. If he needed to take two hops to get himself situated properly, no big deal. I told them I could provide him more help, and did so a few times, but they said that really wasn't necessary.

So, I'm pretty comfortable with helping him with a transfer now, though I'm sure they'll give me lots more practice, maybe having me do it from now on, which I think would be a good idea (though I'm not sure my back will). Gary said he was impressed with my being able to do a transfer with him the very first time I tried (not counting that adrenalin-driven heave through the air).

After his hour with the PT came an hour with the tech, who wanted him to start the session with his stretching exercises. First he needed to roll himself to get into position. He had just told me a couple hours earlier that between the tip I had given him about swinging his arms upwards and the tips his Saturday PT had given him, his rolls had really improved. Now he couldn't do one again. We realized it was because he was wearing his shoes while on the mat, and on Saturday he hadn't been – the friction of the shoes was stopping his roll. After I took them off, he got right over.

The tech had him go through his stretches, trying to get him to do them as independently as possible, more so than he and I had been doing. But neither Gary nor I really saw the point of having him take five minutes to try to get his leg in a certain initial position when I was going to have to be standing right there anyway because he wouldn't be able to lift his leg up into the stretch. When he is a bit stronger and a bit more flexible, he should not only be able to able to lift his leg up into the final position but also be able to get into that initial position in a much less laborious fashion than she was trying to make him do for now.

Whatever!

After the stretching she told him to do twenty-five pushups. I wasn't sure he was going to make it there at the end, but he did, collapsing to the mat afterward. “You did that easy, Gary,” the tech told him. “Next time we’ll have you do fifty.” He looked at her like she was insane, but he didn’t have the energy to mount a protest.

Next came a triumphant moment: in preparation to transfer to his chair, he rolled over, got himself up on his side, got himself moved over from the middle of the mat to the end, got his legs off the mat, and got himself sat up. ALL BY HIMSELF! The tech and I gave him big applause. This was the first time he’d done all that without any help at all, and we couldn’t stop talking about it all day. And for the rest of the day, anytime someone asked him how he was doing, he told them about this accomplishment.

He got out of doing dips, not as a reward, but because we’d run out of time.

In the afternoon he had a session with the OT, and she went over with him what her goals for him this week were. One was laundry, which they would do today. Another was to start him doing his own bowel program. You may want to skip reading this next little part, if you don’t care to know the graphic details of it, but since somebody asked . . .

Here it is in layman terms. Normally, when the bowel is full it sends a message to the spinal cord giving it that information, and the spinal cord send a message back for the bowels to empty. And at the same time that message is going from the bowel to the spinal cord, a message is sent to brain saying “I have to go.” The brain can then decide to allow the bowel to empty right then or it can override that message from the spinal cord to the bowels, instead telling the bowel to hold off (because you have to find a toilet first, or whatever).

With a spinal cord injury, the message goes to from the bowel to the spinal cord (“I’m full”) and maybe the message from the spinal cord to the bowel is sent back (“Empty yourself”) (this is called the “BCR reflex,” a reflex action because it doesn’t involve the brain), BUT the message sent to the brain telling it you have to go never gets there because of the SCI. So there is no conscious decision to be made – the bowels are going to move whether it is convenient for you or not.

To deal with this, that BCR reflex is made use of – if it works! Not all those with spinal cord injury retain that reflex, but Gary has, so I will not go into what has to be done for someone without that reflex.

To use the reflex, one sticks a finger into the rectum and rotates the finger around and around in circles. For twenty minutes! (Yes, your hand is probably going to cramp until you build up endurance.) Amazingly, this action tricks the bowel into thinking it is full, and that triggers the BCR reflex and the colon empties. So the idea is to do this technique at the same time each day, emptying the bowel on a schedule, so that the reflex isn’t triggered at other times of the day because you’ve let your bowel get full (resulting in an “accident,” or as they’re termed at Shepherd, an “involuntary”; inevitably though, involuntaries will occur, because if you have an SCI, you have no way of knowing when your bowel is full, just as you have no way of knowing when your bladder is full; one purpose of the scheduling of the bowel and bladder programs is to reduce the likelihood of "accidents").

Okay, that's probably enough of that. I'm sure if you think about it, you'll come up with questions you could ask about it. But you may not want to think about it ;-)

Back to the therapy session. Another goal of the OT's for this week was to do a "community IC" (no, not doing it with others, but in a public facility at Shepherd). Gary told her that he'd done one at the restaurant. She asked him how it had gone. He told her. She said they'd do the community IC on Thursday. "But I did one at the restaurant," he protested. "Do you really think I need to do another one?" "After that story?" she replied.

I guess her question was meant to be rhetorical.

Next she had him do laundry. He started in his room, collecting his dirty clothes. She had him talk through how he would get the laundry from his bedroom to the washer. We went to the third floor washer. I had just put a load in a short time before this, and it had finished its cycle. He used his grabber to open the top of the washer, and then she had him use his skin check mirror to see if there was any laundry in the machine (which of course there was). Then he tried to use his grabber to set the controls, just to see if he could (this grabber, at least, wasn't adequate to pull out the control to start the machine). She left to get a different grabber to try (which also didn't work), and while she was gone Gary used the grabber to see if he could get the wet clothes out. But as even I know ;-), wet clothes in the washer tend to wrap around each other. Gary figured that at the rate he was going, it would take him an hour to get a load of his laundry out. So I think we'll just stick with me having to do that for him, at least until we get a front-loading washer ;-). (Gary commented later that though they'd said that when he first returns home half his day would be taken up with maintenance tasks, he thinks that is an underestimate.)

(And before leaving the subject of laundry completely, let me share Gary's discovery with you: it is not a good idea to use the grabber to prevent the lid of the washer from falling down; doing so will break the grabber.)

After the laundry task, the OT put Gary on the rickshaw, while she and I took the piece of foam Joe had brought up from our house so that we could try to make ankle pillows out of it. Unfortunately she couldn't find a tool to cut it, so we decided to put that off until the next time we met. BUT, a short time later Gary's team nurse saw me with the foam and asked what I was doing with it. I explained, and she said why not try making the ankle pillows out the foam quad pillows they use at Shepherd. For some reason I had thought the quad pillows wouldn't be long enough, but when I wrapped one around Gary's ankle it seemed perfect. We showed this to the OT; she'd already made velcro straps for us to keep the "pillows" on, so the plan is for me to wrap the ankle pillows around Gary's ankles before I leave for the night (Gary will be lying on his side), and to have the nurse take them off him at midnight when she turns him into a prone position, at that time her checking his ankles for any negative consequences of wearing the ankle pillows.

Back to Gary in the gym. After the rickshaw, there wasn't much time left (about five minutes), and the OT told Gary he could go if he wanted. To my surprise, he asked if he could do the hand cycle (maybe with his bad hearing he hadn't heard her say he could leave :-) ?). He told her he could feel that the hand cycle really worked his back muscles and that he knew his back muscles were very weak.

I know the therapists are impressed with how hard he works – today, the tech referred to him as "the energizer bunny. He keeps going, and going . . ."

He got on the hand cycle. Every minute or so he would have to quit pedaling it in order to take a rest break. He again commented to me that the hand cycle was tough, but good for his back. One time after he collapsed face down onto the table for his rest break, the alarm for a weight shift went off, and since he was still in that power chair, it was going to have to be that more-difficult-than-usual depression weight shift. "Oh, shit," Gary moaned to the table.

But he did it.

He so hated that chair by now that we went off to find the PT. No one had yet taken his regular chair from his room, and he was worried he was going to be stuck with the power chair for another day. After he pled with the PT, she took his other chair to see if she could find someone to fix it. She was successful and brought it back later. She tried to explain what had been wrong with it, but I wouldn't be able to repeat what she said. Something about loose brackets and stripped bolts ;-). Anyway, she was certain it was secure now, but just in case told us to keep watch on certain latches that were supposed to be pointed in a certain direction.

In the late afternoon I went off to see the chiropractor. Today he planned to again run through those tests he'd done on me when I'd first seen him, in order to check my progress. I figured he would find I'd gone backward. I knew that at the moment my back felt worse than ever – lower back painful, upper back sore, no doubt due to all the pushing of Gary's wheelchair the past few days, doing the transfers with him, practicing rolling, and so on.

These past few days I'd also been having another symptom which I figured (and hoped, actually, because alternative explanations could be scarier) were due to misaligned vertebrae: I've been constantly feeling like I'm walking on a rolling and dipping ship. I know that when I've knocked my neck vertebrae out of place, I get vertigo – I get up intending to go one way, and my body goes another. So I'm hoping this is a variation on that (and after telling the chiropractor about the symptom, he thought that was most likely the case, telling me he thought I could hold off until we got the current misalignment problem corrected before considering other possibilities).

Anyway, at the chiropractor, sure enough, my tests came out worse than the first time I had seen him. He told me that the results would have no doubt been even worse than they were now had I not been seeing him. And I believe him – I've been to enough chiropractors to know a good one, and I really think he is good. He asked me if I wanted to continue seeing him this month, and I said yes. He then said he would “bend the rules” and let me come in three times a week for the price of two, saying obviously twice a week just wasn’t good enough for the stress I was under. So I agreed to his offer, telling him I really appreciated this offer and his help.

After seeing the chiropractor I went to Ace Hardware to have another car key made. While there I happened to think about grabbers and bought Gary another one – this one seems much sturdier, though it doesn’t fold. Other nice features it has are that the “grabbers” can be rotated to any direction, and that after picking something up, the grabber can be locked in place.

When I got to my hotel room, I reached into my shirt pocket to get my hotel key. I pulled it out. I also pulled out my car key, the one I’d “misplaced.” It was then that I remembered that I’d thought last night that my shirt pocket would be a much “safer” place to keep my key so I didn’t absent mindedly put it down somewhere in the hotel room and then not be able to find it.

Oh well.

In the evening back at Shepherd, I went through my usual routine with Gary, and just before I left, velcroed the ankle pillows to him. Keep your fingers crosse.

To finish this entry, I will put on the blog at http://drpeg2003.blogspot.com/
an image of the sculpture I named “It’s been a tough day at Rehab,” and a closeup of the sign I taped to the sculpture at its lower right hand corner. At Gary’s instigation, of course ;-)

If you are getting to the blog from an email, you will have to scroll down the blog page to get to the image.

All for now.

July 4, 2006

First some mail.

Thanks to Steve and Karen and Oren Watson for the nice card (boy, is Canadian mail slow! Oh, and by the way, Steve, I thought of you when someone mentioned that I was rather talkative in my blog; I recalled that you were the referee of my very first math paper submitted for publication; on your report, you wrote “Too verbose” :-)).

Also, thanks to the over sixty mathematicians at the Aegean Conference who sent Gary a group card!

On the 4th I uploaded the July 3rd journal entry a bit too quickly and it was fully of typos. I cleaned it up and reloaded it later in the day. So, if you read it before I had the chance to revise it, sorry about that! You can check out the corrected version below this one (the email that went out that night was the corrected version, in case you are getting that instead of going to the blog).

Today, July 4th, was the annual Peachtree Road Race, with contestants from all over the world. 80,000 runners, I heard. But before the running event came the Wheelchair Division – Shepherd is the official founding sponsor of that event. The Shepherd patients who wanted to witness the race were gotten up about 6 am, and were lining the street by about 7. I was told that if I wanted to attend this fun event I would have to be at Shepherd around 6, because the race goes right past Shepherd and so the road would be closed to traffic.

A fun event that would occur at 7 am and that I would have to be there by six for? Now there's a contradiction in terms. I decided to skip it – under other circumstances I'm sure I would have found it very interesting, but I've been feeling more tired out than usual these past few days and wanted to take a little extra rest. I had hoped to sleep in late, in fact, but my hotel neighbors must have been planning a big day for the Fourth of July because they were up at six making a commotion. I have to say, though, that the hotel has been quite good noise-wise except for that first night with the dog fight – and now, with waking me up too early on the fourth!

Gary said the leading wheelchair racers were very impressive – especially the woman who raced using only one hand to wheel her chair – but that he was actually more interested in the stragglers. He said that they didn't move any faster up Peachtree than he did, but that unlike him they didn't have to rest every twenty seconds. He wished he could see these people go down one of Peachtree's hills, to see how fast they went and how they handled it – he said that his personal experience in going downhill was that it was not the piece of cake he'd once thought it would be, because he had to constantly have the palm of his hands against the rim of his wheels to act as brakes.

Here is some info I found about the Wheelchair Division from the web:

General Course and Race Information
The Wheelchair Division starts at 6:55 a.m. and follows the same course set for the foot racers: 6.2 miles down Peachtree Road, starting at Lenox Road and ending on 10th Street at Piedmont Park. The course challenges racers with quick-turning curves, steep upgrades and fast-paced downhills.
Athletes often find the most difficult part of the race to be "cardiac hill," in front of Shepherd Center at 2020 Peachtree Road, where patients and staff gather to cheer on the racers.
Wheelchair racers use specially-designed wheelchairs with a lower center of gravity and tires similar to bicycle wheels with a steering handle in front. Lighter, high-tech racing chairs, along with rigorous athlete training schedules have contributed to faster speeds and new records over recent years.
Numerous Shepherd Center volunteers and staff members work before, during and after the race to make the Wheelchair Division possible. Since 1981, as the official founding sponsor, Shepherd Center's Junior Committee has raised funds to provide pre-and post-race brunches, defray travel and lodging expenses for racers and offer a purse of over $35,000 for winners.

Shepherd Center's 20-member therapeutic recreation staff coordinates all race logistics, including reviewing applications, orchestrating the start and finish, monitoring the times and overseeing the needs of the athletes.
Providing opportunities for athletes with disabilities is not unusual for Shepherd Center. As Founding Sponsor of the 1996 Atlanta Paralympic Games, Shepherd paved the way for more than 3,000 athletes from 104 countries to participate in international competition. Shepherd Center, which is home to 11 wheelchair sports teams, is proud to one again sponsor the Wheelchair Division of the Peachtree Road Race.

You can find more info at http://www.atlantatrackclub.org/prr-wheelchair.pdf

After the race, there was an awards ceremony and brunch in the auditorium at Shepherd. Gary went to it, but the road was still closed to traffic, so I didn't make it. Gary said one reason that gathering was interesting was because the room was full of people very experienced in handling their chairs, unlike the newly-disabled patients of Shepherd (after the race, the entrants transferred to their regular wheelchairs rather than stay in their racing chairs). Gary said he sat next to a man who was not disabled but had entered the Wheelchair Division. Evidently he likes working out in a wheelchair because of the exercise it gives to his upper body. But, he said, he can't keep up with his wife, who has an SCI.

Strachimir Popvassilev ("Mirko"), a former student of Gary's who teaches at Southwest Louisiana University, had arrived in Atlanta by bus in the very early morning and had walked his way (about 2 miles) to Shepherd and found Gary sitting watching the race (Later, I heard Gary describe their meeting as follows: he said he was watching the race and all of a sudden amongst the runners he saw a guy in long pants, walking along, wearing a backpack; he looked closer and saw that it was his former student). Gary's team nurse took a picture of Gary and Mirko (she was taking pictures of all the patients), and I am trying to get her to send me it by email so I can upload it to the blog.

Gary called me when Peachtree was again open to traffic, and I got over to Shepherd around 11:30. I confess that instead of joining in on Gary and Mirko's conversation, I stood by them in Gary's room and worked on blog entries covering the events of July 2 and 3. I keep little notes to help me compose my entries, but I need to transform the notes into entries fairly quickly, because with my memory they soon become incomprehensible, and I had gotten way behind in the blog.

I did go out to the garden with them (we noted my little sign was still on the sculpture). Gary had to do a weight shift while we were there, and Mirko joked that he should make all his students do one with him when he taught class (since he has to do one every half hour, he will have to do one during class; by the time he is actually teaching a class of undergrads he might be able to do the depression weight shift while lecturing, but he is thinking it might be better to let them know what he was doing rather than suddenly press up from his wheelchair and stay in that position for a minute. He told Mirko that he's been wondering what he would tell his first such class about his disability, as teaching with it will be new to him. He thought he might say something along the lines of, "You've probably never been taught by a paraplegic. Well, I've never taught as one." He then commented to Mirko that when you have a spinal cord injury, you learn a lot about your body. Mirko said that that must be where the term “blissfully unaware” comes from, meaning that that is the state of the rest of us. Gary said you simply couldn’t afford to be unaware if you had an SCI, not if you wanted to stay healthy).

Gary had to go back to bed at 2, because he had already been sitting in his chair for 8 hours, and at this time, 8 hours is all he is allowed of consecutive sitting. However, he is now allowed to get in the chair again, if he wants, after going back to bed for three and a half hours in between the sitting sessions. And today he was definitely ready to get back to bed – time for a nap! The morning events had worn him out, since the nurses had come earlier than usual for the already early morning routine of doing his bowel program, giving him a bath, and so forth, as well as to get in the regularly scheduled 6am IC.

Actually, everyone in the shared room conked out. As I stood next to Gary’s bed and typed the blog, I noted that the room had never been so quiet while I’ve been it it.

Mirko had left after Gary was gotten back in bed. Mirko had said he would show people at the Summer Topology Conference the picture that had been taken of him and Gary (the nurse had given him a copy). Gary told him to tell those at the conference he would see them at a future one, though he doesn’t know at this point when he’ll be ready to take on the challenge of travel.

I left much earlier in the afternoon than usual to make my dinner and so forth, because Gary was going to get up to go to the ice cream social at 8 and the fireworks display at about 9, which meant we had to go through the stretching routine and his wound care starting at about 6:30, after his IC. The ice cream social was down in the garden, and we noted that our graffiti was still up. We saw someone pass it, read it, and move on. It then occurred to me that maybe they really thought that was the title of the piece, and Gary agreed that might be the case – to us that title seems so appropriate.

At the social, the father of a young man with a T6 injury, fairly equivalent to Gary’s, came over to talk to Gary. His son, who has a job accreditating business colleges, had told his father Gary was a professor and was going to teach in the fall, and the man wanted to know how it was possible that Gary would be returning to work so soon, when that seemed so far out of reach for his son. Gary explained that the math department was being very accommodating and what his teaching would involve, etc. The man said there would be no way his son could return to work at this point, and that they had no idea when he would be ready to do so. The man remarked that people just didn’t understand what it is like to have a spinal cord injury, that it’s not simply matter of things being the way they had always been only now the person is in a wheelchair – so much more is involved. He told us that friends and relatives kept asking when his son would go back to living on his own and/or going back to work, and couldn’t comprehend why the answer was, “We just don’t know, probably no sooner than a year from now.” Not that the man was blaming these other people for their lack of comprehension – as he said, no one really knows what it’s like to live with an SCI until it happens to them or to someone whose care they are responsible for. (Of course, you guys now have a better idea than most of what it is like ;-))

We headed for the parking deck about nine, about the same time Mother Nature let loose with fireworks of her own. Her lightning display was much more impressive than the Atlanta fireworks we could see from the protected second level of the garage, so we didn't stay there all that long. Which was good, because I still had to get Gary hoyered back into bed, undress him, get him positioned properly, and attach the ankle pillows (we did have some comic relief during that routine. I pressed the button that would make his bed rise. "I feel like I'm in "The Exorcist," Gary said, then continued, "Hopefully I won't spit out green soup and my head won't spin around." "Well, if it does," I replied, "we can show the therapists how well those neck flexibility exercises have worked"). I didn't get out of his room until about ten-thirty, a little later than I've been getting out of there ever since I've been doing his wound care. I'll be glad when his flap is healed sufficiently that all these extra medications on it are no longer necessary so I can go home closer to nine, as I used to do.

By the way, the ankle pillows seemed to have worked fine for those two hours last night (hah! Peg came up with another helpful idea!), so tonight he will keep them on the entire time.

I didn't yet get the pictures from the nurse, but Jack Brown scanned the one Mirko had, so on the blog it will appear below this. From email, go to http://drpeg2003.blogspot.com/ and scroll down.

July 5, 2006

Gary's first scheduled activity was to learn how to do the bowel program on himself. As this took place at 7am, I did not attend ;-) (I will have to do it on him a week from tomorrow – I need to learn how to do it in case he ever is too sick to do it on himself). The good news was he lasted the twenty minutes; the bad news is he wasn't able to do on his own everything he needs to. He will have another attempt at it next Tuesday.

When I got to his room later in the morning, he told me the OT thought the ankle pillows would work (I think I should get paid for this idea ;-), as I'm sure they'll use it in the future on patients here). The next step is for him to sleep with them on as he would at home, starting from the prone position and then turning onto his side.

We went to the gym for the PT session. While we waited for his therapist, I noticed that Gary's roommate, sitting nearby, was wearing sandals, not the ubiquitous velcro tennies. Gary looked at his own shoes and said that though they were fine for here, he wanted something less dorky when he went home. I asked him what he had in mind. He still wanted the velcro, and thought he might find something at Target or Wal-Mart. I told him to forget Target – I had looked at every single men's shoe they had and they had nothing with velcro (except for one pair of a similar style). Maybe he can find something on the internet.

When the PT came, she said that the first activity would be to do a car transfer, which is more difficult than the transfers he's been doing. Today he would do one using Shepherd's Saturn ("Twin Cam"), next Tuesday we'll use my car (Note to self: clean out front of car). We had to go to his room to get his long transfer board, and on our way we ran into his doctor. Gary asked him about the two kinds of power-assist wheels, because while Gary had liked the second kind, the doctor had been encouraging him to get the first kind. The reason for this became clear when we learned that with the first kind, you lift a battery out of each wheel in order to make the chair into a manual chair, with the result that the chair immediately becomes about thirty pounds lighter while keeping the same tires (he could keep the batteries at the office); whereas with the second type of chair, to make it into a manual chair, you have to go through the rigamarole of exchanging the tires for a different set.

Gary agreed with the doctor that in theory the first kind of wheels sounded better but said that he hadn't had a good experience with them – he'd had trouble "steering" the chair (which could be a matter of practice), and even worse, the wheels didn't work as they should most of the time. His doctor told him not to let a defective demo model deter him and that in his opinion the first kind would better suit Gary's needs. I remarked to Gary later that it is hard not to let a defective model deter you when that's all you have to go by; Gary agreed, so while he is now leaning toward the first model, he wished he could try out a demo that worked as it should; his PT is going to try to get such a demo.

We next went off to the parking garage, and the PT talked him through the transfer. Again, it is a matter of balance and position and technique – and again it struck me how time-consuming something like just getting his own legs in and out of the car becomes.

On the first transfer into the car there was a lot of head banging (on his part, I mean ;-)), so I kept my hand placed where he would hit it instead of the door frame. After he'd transferred back out, she had him transfer back in again. That time went much, much more smoothly, and we were all pleased. The PT said I would have to help him, as she was doing, from behind him – as small as I was, there was no room for me to get between his chair and the front of the opened car door and be able to help lift him.

After this, it was time for a session with the tech. As at some point she was going to have him do his stretches and he'd forgotten his chain loops, I went off to get them and to bring him his protein drink. When I came back he was on the edge of the mat practicing throwbacks – throwing his arms behind him as if to catch himself should he fall backwards. But what he was doing – starting with his hands placed in front of him to the side of his thighs and then throwing them behind him – didn't seem like it recreated a falling backwards experience and, in my opinion, it wasn't going to ingrain the proper reaction in him. I said this to him, and as if to prove my point, he went to move his arms forward, really did lose his balance, and started to go backwards; instead of throwing his arms backwards, which was what he was supposed to do and what this exercise had been meant to teach him, he grabbed forward at the mat, as he always automatically does, and which had never before been successful. And even though it was successful this time at preventing him from falling backwards, he saw my point. I suggested he sit and purposely lose his balance backwards and then do the throwback to prevent himself from falling over. He refined that idea: he practiced balancing sitting with both hands up; at some point he loses his balance while doing that, generally going backwards. When that happened, he did the throwback. We both agreed that this was a more effective way for him to practice what he was supposed to do in the situation of him losing his balance backwards. After he did over twenty of these, one time he balanced way too long ;-), and taking a cue from the PT, I gave him a tiny push. He went backwards but caught himself with just the kind of throwback he was supposed to be learning. He gave me the eye. “You really would have felt bad if I’d fallen backwards onto the mat,” he said. He was right, I would have, but as I told him, “I was confident you weren’t going to, based on what you’ve been doing.”

I have to admit I am pleased when I come up with these little ideas that aid him in his therapy and in other matters.

After the throwbacks he did stretching. Then came pushups – fifty! But he did them in five sets of ten. This turned out to be easier than the twenty-five straight he’d done last time, I believe, basing my opinion on the fact that he didn’t collapse purple-faced onto the mat when they were over. He got himself to the end of the mat by himself again, and then I helped him transfer into his chair. I needed to give him more lift than I had before – we think his muscles were tired out from the pushups.

He was next to do five sets of ten of those “dips” where he holds the extended position for five seconds. But he got to five on the second set and literally couldn’t get up on the sixth one.

Well, it was past quitting time, anyway.

He realized later that what he should have done was change the order of his exercises: first do the pushups, then the stretching, then the dips. Trying to do the dips right after the pushups was too much for his muscles (makes me proud, Gary trying to figure out how he could have done more work).

After lunch he had a session with the gardening rec therapist (the graffiti sign was still up in the garden). We are still trying to figure out who this therapist reminds us of, some TV character. She has a fairly strong Minnesotan accent, kind of reminds us of the Dakotan accent in “Fargo,” but not quite that strong.

Anyway, she gave us a half-inch-thick stack of printed material on adaptive gardening and some tool catalogs she has found useful. She showed us a “J-pad,” which is a pad that Gary can sit on that straps to his legs – so if he moves, it moves with him. He would only be able to use it for maybe a couple hours at a time, if that, because it is not nearly as thick as his wheelchair pad. But if he wants to grow his in-ground tomatoes, this could be useful. We’re thinking we might have to make the raised beds in the backyard shorter (or rather, we’d have to hire someone to do this), and probably eliminate the middle beds (there are six) and use wood planks between the beds, all in order that he can wheel his chair between the beds. By next summer, we’re hoping he’ll be able to either transfer to ground level or onto some kind of rolling cart lower than his chair (now he can't possibly do either of those on account of the flap), so he do his gardening from there rather than from his chair.

The rec therapist asked him if he wanted to do a class on transplanting, and he said sure (adding, perhaps unwisely ;-), that it would be easier than another PT or OT session). She asked him what he would like to transplant. Turns out she has a small tomato plant that needs transplanting, and she said he could do that – and that for the rest of his stay he would be responsible for its care and it would be his to take home (meanwhile I'm sitting there wondering how I'm going to get it home – let's see, do I want to fit the tomato plant in the car or him?).

She kept on saying throughout this session that she wanted to show him the adapted hand-controlled power mower, and he kept saying he wasn't interested in mowing. At the end of the session, she ran off to get it ("just in case you ever changed your mind about wanting to mow the lawn"). She came riding over on this big, noisy machine. She obviously loved the thing, running through all its features with Gary. We laughed about that afterwards.

As we left the garden, Gary commented that that class had actually been useful (not referring to the mower, of course), not only because of the information but because she was going to get a J-pad ordered for him and, best of all, he was going to get a tomato plant out of it, assuming he didn't kill it in trying to transplant it (I'm not sure why he's worried about that – he's transplanted his own tomatoes before, and I can't see why the technique would be all that different now – next week I'll let you know how it goes).

Next on the day's schedule was a scavenger hunt in "group." We knew by now that "group" was not all fun and games like the therapists seemed to like to pretend it was. We wondered what the scavenger hunt would entail.

Turned out to be nothing like a traditional scavenger hunt, of course, but it turned out fine. As Gary said afterwards, "I finally had fun on one of these things (meaning "group")." There was a list of tasks to be done. First was to find the Bridge office and find out about the peer support program (you may recall that the purpose of Shepherd's Bridge Program is to help "bridge" one back into the community after being a patient here). Gary took off at top speed in order to be the first to find the office, which cracked me up – I thought that was more my personality, not his. He found the office, but because he wanted his protein drink after being out in the hot garden, I went off to make up the drink for him rather than stay to hear the conversation he was having with the (paraplegic) woman who ran the office. When I returned with the drink, all the other scavenger hunt participants and therapists were there, and the woman Gary had been talking to had moved out into the hall to explain to all of them about the peer support group. I had missed most of what she'd said to them, but I did hear her say that her office could help with any problem that came up any time after they were discharged from Shepherd, assuring them that no matter what the problem was, someone had no doubt already experienced it, and Shepherd could help find the answers; I also heard her say it usually took about two years to adjust emotionally to having an SCI, and that

that was where the peer support group came in. She said she knew firsthand just how important such support could be - when people she meets tell her now how well she was doing, she tells them that for the first two years after her injury she was suicidal.

When that task was accomplished, Gary asked what his prize was for getting there first. He seemed disappointed to learn that there was to be no prizes on this hunt (again cracking me up). "What is a scavenger hunt without prizes?" he asked, not entirely joking. But it turned out the Bridge person did have some ponchos she could give away, and since this was something he'd really wanted, he thought that was great.

I asked him what else had gone on when I wasn't there, and he said she'd talked about the peer support group that meets twice a week at Shepherd. Since that wasn't something he'd be able to attend, he'd asked about an online group. I didn't get a chance to ask what she'd said about that, because he tore off to do the next thing on the list (he later told me there was an online chat group, though not run by Shepherd).

The next task was to find the pool and ask the requirements for using it. Gary was there first, of course. It became clearer that what we were doing was not going to have all that much relationship to a traditional scavenger hunt, as the participants were definitely not pitted against each other – indeed, after Gary found out the requirements for using the pool, the therapists made him tell the late-arriving participants what the requirements were (he forgot a couple, but I remembered those and added them to his list; the requirements were things like no skin sores, no open trache hole (I'm sure you can see why that would be a problem!), and so forth). Next task was to find out the gym hours, and Gary got there first again and made his report to the others. Next we were to go to the library and find out where the books on home modification were kept. Gary probably did that first too, but I went off to get another cup of his protein drink and they were coming out of the library by the time I got back. Next on the list was to go to the garden and count the fish in the pool (I'm not sure what the practical benefit of that was). While there, I beckoned Gary's roommate over to the sculpture and showed him our sign. He started laughing at it, and said to me, "I hear that" (maybe a Southern country expression for "I can relate"). Unfortunately a rec therapist got curious and came over and checked out what we'd been laughing at. She looked at me. I looked innocently up at the sky. Anyway, if it's not there tomorrow, we'll know why.

The final task on the list was to find the cafeteria (again, of no practical benefit to Gary ;-)). Gary was first again, by a long shot. As we waited for the others, he started laughing. "I'm an eager beaver at this today, aren't I?" he asked. I agreed and told him I thought he'd had a personality transplant – mine into his (not that I would like a scavenger hunt, but if I had to do it, I would strive my utmost to be first at it).

There was actually one more thing on the list for the hunt, but the rec therapist simply explained it to everyone. It was the Outpatient Program, which is the step after the day program. That program entails going to therapy two, three times a week. Since Gary can't come to Shepherd do that, we'll have to see if he can do it somewhere in our area; if not, another possibility is Home Health, where a therapist comes to the home and works with the person. That's not as good an option, though, since a therapy gym would have all kinds of specialized equipment.

Soon after that I left for the chiropractor. I was able to get back to Shepherd a bit earlier than usual in the evening, but I wanted to leave earlier as well – tomorrow is a long day of family training, starting with an 8 am wet (shower) run.

Mail call: Thanks to Mark Meschke.

All for now.

July 6, 2006

10 pm on the 8th: I edited this entry just a bit but not as much as I'd like. See next paragraph.

10 am on the 8th: I am behind again, so this is going up on the blog and out in the email unedited. If I get time, I will come back and spruce it up on the blog, so you may want to check the blog later and see if this paragraph has been removed, meaning I've edited the blog entry. If I don't get time to revise it, forgive all typos, awkward sentences, etc.– I warn you, it reads pretty rough (at least, to me).

I got the other picture of Gary from the nurse, so scroll down for it -- it appears after this entry, and is, I think, a particularly good picture. (If you're getting this by email, you will have to go to the blog for the picture at http://drpeg2003.blogspot.com/)

Since I had to be at Shepherd at 8, I'll let you guess how well I slept last night (even though this time I had added in a wake-up call request from the front desk to my three alarm clocks). We were to do a "wet run," where Gary took a shower with my aid, the PT and OT supposedly only observing. The therapists started out by throwing us (or at least, me) a curve ball – last time I'd hoyered him from his bed into his chair, whereas this time they wanted me to aid him in a depression transfer from his bed to his chair. This was a harder transfer than those between his chair and the exercise mat I'd been doing with him, plus it meant that he had to get himself sitting upright in the bed (with my help), which the two of us had never done together, instead of just my getting the net under him as he laid in bed (by him rolling from one side to the other) and hooking him to the hoyer.

So we winged our way through it. I helped him roll to his side in the bed, took his wound dressing off, and then I positioned his wheelchair next to the bed where I thought it should go but asking him if that was where he thought it should be. After we were satisfied with its position, I got his legs off the bed and he pushed himself upright. Then he took little depression hops along the bed, me with my hands on his ribcage for balance, to get himself in position for the transfer. The PT reminded us to put his shoes on (he should never transfer without them – he can't use his legs and feet for support, of course, but he uses his feet as pivots, and thus his weight is put on them). I don't think she needed to do that, though, because the next step was to position his feet on the floor and I'm sure I would have noticed then that he didn't have his shoes on. But she also caught that we hadn't checked that the bed was in a locked position, and I started to wonder if we were going to "pass" this time.

Though generally I prefer to help with the transfer from behind, it seemed to me that in this case helping from the front might be easier; the PT got behind him, just in case. Because the bed was higher that the chair, at least this direction would be the easier one to start with.

We did the transfer, which went fine except I got knocked in the glasses (as I mentioned in a previous entry, when I help from in front, I feel I am really too close to his body, on account of my short arms). We then went to the bathroom, and he maneuvered into the shower. After several false starts, he realized he should back into the shower instead of trying to get in position next to the shower bench from a direct approach.

Next we prepared for a transfer to the shower bench. I could do this one from behind and it went smoothly. I moved the chair out of the way, took his shoes off (though doing that himself is one of his therapy goals), and then he washed himself. Fortunately this time I had worn shorts and had taken my socks and shoes off, as he still got a little wild with the shower head ;-) (he did miss the therapists this time). I soaped his lower legs and feet, and then he rinsed off and dried, me doing his lower legs and feet.

I got his shoes back on, moved the chair over, and we prepared for the transfer back. That also went smoothly. The therapists commented how impressed they'd been his transfers lately, that it seemed that one day things had just clicked for him and he'd been doing so much better. He said it was because he'd watched me do one and had picked up tips from that :-). They responded that his transfers were awesome, that he them like a forty-year-old, that it was rare for someone on the "senior program" to do transfers as well as he did. (Of course all this praise confused me a little bit, as he isn't doing the transfers entirely on his own yet, but maybe they meant it for this stage of his rehab).

The therapists also commented that they liked how we constantly communicated with each other, him keeping up a running commentary of what he was up to (though I think part of that was just talking to himself – I don't think it was really necessary for me to hear him say, "Now I'm going to wash myself") and me letting him know what my status was (though I made my comments mostly out of the irrational fear that he would do something I wasn't prepared for; for example, "if you're about to make the transfer let me point out that I don't have my hands under your butt yet" :-))

Next we went back to his room and he put his shirt on. Then we had to do a transfer back into bed, since I needed to put a new dressing on his wound. This transfer was a hard one – uphill and onto a soft surface. He didn't do a great one (after all that praise), not making it the entire way and ending up with part of a butt cheek on the wheel – fortunately not the part with his skin flap. I worried again that this meant we hadn't passed. He did another "hop" with me aiding and got on the bed. I then started to change his dressing. The PT left for her next patient, the OT told us she would check back in a little while and if we were ready she would watch us do another transfer from bed to chair. Before leaving, she again told Gary how well he was doing (I wondered if the psychologist told everyone we needed more praise) and asked when his accident had been. He told her April 14th, and she said something along the lines of "Look how far you've come." Then she mused that he'd had that accident nearly three months ago, a quarter of a year. It was probably unfortunate that she put it that way. Gary said, "And I haven't been home in all that time," which set him off crying. It took me a moment to realize that had happened, because I was concentrating on putting some medicine on his wound. I went over to the other side of the bed and gave a needed long hug; meanwhile the OT stepped out of the room.

When he seemed okay, I finished dressing the wound and then got his pants up over his knees and his binder around him. The OT had said he should get his pants on the rest of the way, so he essentially did so with a lot of rolling from side-to-side; I helped him a little at the end, though, because I was afraid he was going to pull the gauze bandage off his wound. The OT hadn't returned yet, so we decided to get him upright again, in preparation for a transfer. The OT walked in just at that moment, and so watched us go through it again. She then said we could now do transfers out of bed under a nurse's supervision, instead of using the hoyer. She made to leave for her next appointment. I asked her if we'd passed the wet run, and she said we'd done great (so I guess that meant "yes").

We were a little late getting to the gym for his session with the tech. I helped him transfer to the mat, he got himself up on it, and then the tech had him do "the terrible threes" – lying on his stomach, lifting his arms to the rear, to the side, and to the front, with weights. Actually, because of his arthritis and lack of shoulder flexibility, he can't do the ones to the front ("superman lifts") so she had him substitute fifteen pushups.

Before he was done with that I had to leave for my first family training lecture of the day. It was to be the "Therapeutic Recreation Lecture," and I was not looking forward to it, having suffered through three of them (I've mentioned that these lectures were the only ones I haven't thought very useful). I found out the same material was to be covered, and I tried to get out of it, telling the lecturer (not the same one who'd I'd heard before) that I'd gone to all three rec lectures offered to the patients. But since that hadn't been documented, it didn't count.

But, it turned out not to be bad at all, and in fact the material actually seemed far more useful this time. In forty-five minutes she covered the three hours of material the other person had done – the difference was she didn't waste time (and thus irritate me ;-)) by trying to get the audience to guess things that it was highly unlikely we'd know. Mostly. She did do a little bit of that, so I confess I cheated and to spare myself from having to sit there any longer than necessary I answered some of the questions based on what I'd picked up at the other lectures. For some reason this impressed her, though I'd told her that I'd attended these lectures before. One statistic she gave that I think was new to me was that 60-80% of those with an SCI never return to work.

After that class I went to Gary's room to eat lunch. I looked at his schedule and saw he was doing a community IC with his OT. He came back, and I asked how it'd gone. He said he had to do it again with her next week, thus indirectly answering my question. I asked him why, and he said he hadn't done it smoothly enough for her – this was because he'd do it slightly differently in a public facility than he would at home, and he hadn't been practicing the "public version."

I had more family training lectures in the afternoon, so missed Gary's stuff. He told me that the PT had him practicing transfers to and from various surfaces, including a regular (i.e. non-hospital) bed in the gym. He also had a visitor, Tony Crumpton, from the Crisis Center where Gary has volunteered for decades (I can't remember exactly how long, sorry). Tony knew of the blog, said he heard it from Doug, another crisis center person – we're not sure how Doug knew of it!

Gary also had a class with the sports rec therapist, who showed him the various pieces of equipment in the ProMotion Gym. I had told him to be sure to find out about the NuStep, which the "Been There, Done That" guy had recommended – where he could strap his feet onto pedals and move them by using the arm pedals, thus giving some exercise to the leg muscles. Turns out the PT would have to test Gary to make sure that was something he should do (I think the concern is with how much pressure it would put on his flap).

In the meantime, I next went to my required "Wheelchair Maintenance and Repair" class. After twenty minutes of a bunch of us sitting around waiting for a lecturer, I left to find someone who could find the lecturer for us. She was located, and came about ten minutes later, apologizing for forgetting about us. She then rushed through the hour lecture in forty-five minutes. Between being tired from lack of sleep and the morning's activities and not being mechanically minded, all I can say is that after Gary has this class, he'd better have a firmer understanding than I do of what exactly he is supposed to do, and when, in order to maintain his wheelchair. Of course, I will most likely attend that class with him anyway, so I can pick more information up the second time.

Because that person was late, we had no break before the "Emotional Adjustment" lecture (I remarked, not entirely jokingly, to Gary's roommate's wife, who was also in attendance, that this lecture was coming weeks – or months – later than it should have). The lecturer was one of the counselors who'd led the counseling classes that I'd attended with Gary – classes which I'd also thought fairly useless (honest, those and the rec ones were the only classes I've felt that way about) – but again I was pleasantly surprised.

The first forty-five minutes were on sexuality after an SCI. Three people got up and left immediately. I could understand why two children did so, but I didn't quite understand why this woman who looked in her thirties and was the daughter of a patient here, also felt like she had to leave; her mother explained it was because the daughter couldn't handle thinking of her parents "in that way," which struck me funny, though maybe I would have felt the same way in her situation.

Anyway, this seemed to be pretty much the same lecture Gary had told me about, though it also covered the physical consequences of an SCI on female sexuality, which were far less complex (reminded me of that old joke, by Rita Rudner, I believe, that men envy women because women can do it when they're dead – excuse my seeming insensitivity).

If you don't want a sex lecture, you may skip ahead a few paragraphs ;-)

The lecturer explained that in men, the psychological reasons for an erection (seeing something arousing), which depend on the brain-spinal cord connection, are affected, but the reflex reasons for an erection (full bladder in the morning, etc.) were often unchanged and can possibly be made use of – friction may be all that is needed. But if it's not enough, help comes in the form of medications, vacuum pumps, and injections (there are also the implants, but these are discouraged because they could lead to skin sores – from the constant pressure of sitting on a hard object that would be surgically placed in the scrotum as part of the implant). If children are desired then one can go to an urologist and make use of one of a couple techniques they can help with to collect sperm and implant it.

In terms of orgasm, if one has a complete spinal injury, one will probably not have an orgasm, though apparently some may feel some sense of release in some other part of the body where sensation still exists.

The question might naturally come up, why would someone want to have sex when they can't feel it (outside of the desire to be a parent)? For some, it's not going to be important; for others it is very important for their self-esteem; for others there is the fear factor ("my partner is going to leave me and find someone else if I can no longer satisfy them this way"). In fact, the first reason those with an SCI usually give for wanting to have sex is, "for their partner." But if this is the only motivating reason, the lecturer said, it's not one that is likely going to be sustained – if they're not getting any enjoyment out of the act, then their partner is going to pick up on that and it won't be enjoyable for them either.

So how can it be made more enjoyable for the injured person? Well, certainly not by concentrating on what they can no longer feel. They and their partner need to think about what is fun in the areas they can feel in – discover new erogenous zones. They need to become creative. The lecturer mentioned that it is not uncommon for the injured person to have about an inch-wide band around the level of injury that becomes more sensitive, and he suggested a feather could be used on that area (I told the lecturer that my husband found that area hypersensitive and didn't like to be touched there, so I would save the feather for the times I wanted to torture him ;-)). He said it was common for couples to engage in more oral sex. He also told the story about one guy who had a harness hung from the ceiling. (I thought Joe would really love that if we made such a request (along with the mirror). Gary's comment was, "Boy, the guy really wanted to be on top, didn't he?") Evidently the guy liked how in this way his wife could move him above her and recreate the sex experience.

The lecturer brought up various other concerns, like one doesn't have to be afraid of hurting the other person physically unless a doctor has said so. And he covered the fear of hurting them psychologically too. When Gary first told me he had a class on male sexuality after an SCI, I evidently had a common reaction: why remind them of something else they can no longer do? Won't this just make them feel bad? The lecturer said that avoiding physical intimacy because of that is actually experienced by the injured person as rejection, not the intended concern for their psychological well-being. Their confidence level automatically drops as a result of the SCI – they have physical limitations they never had before, they may no longer be a provider, etc. They need to realize that they are the same person they always were, and this is one more way that their partner will help provide the reassurance that they are. (The lecturer also mentioned that rehab programs like Shepherd's also build confidence in those with SCI – with each achievement they make, with becoming as independent as they can, with taking as much control of the situation they can.)

The lecturer mentioned that in the sexual arena it would be useful as well to expand one's definition of intimacy. He said he was going to be sexist and say that women think of intimacy as more broad than what happens in bed, and men (especially those with SCIs) need to do this too. It would be good, he said, for it to expand to snuggling while watching TV or in bed or to having a heart-to-heart conversation, and so forth.

After this part of the lecture, the counselor turned to the matter of emotional adjustment. He first asked us what this experience has been like for us. We brought up that at times it had been petrifying, overwhelming, a time of loss of hopes and dreams, a time of uncertainty. (But we all agreed that our loved one was still the same person to us.) The lecturer mentioned that some people felt it was better not to talk to others about the situation, but that talk was good – for getting things off one's chest, for information, for emotional healing, for getting what one needed for oneself – whether that was practical help or emotional support – and for letting others know how things are, what is needed, what is going on.

The lecturer mentioned that often when patients go home, they and their families become isolated, and he went through strategies to avoid that. We don't expect this to be a problem for us, because Gary will be getting right back into the thick of things and I'll be returning to my normal routine as much as possible, and if we need help, there seem to be plenty of people offering to help us out.

One thing the lecturer said we caregivers need to do, as soon as possible, is to talk straightforwardly with our loved one about how we are doing (and I know I am guilty of not doing that, especially in the beginning days but even now, not telling Gary how tired I am sometimes, or how much pain I'm having, since I feel he has enough to cope with without burdening him with that; the lecturer claims that is a mistake, but I don't think I can change that behavior. Besides, the focus of his admonition was in not letting the injured person burn you out by demanding too much from you, whereas Gary always tells me to leave and take care of myself (Gary's roommate's wife laughed when I said this in the class, saying she knew this was true because she can hear our conversations through the curtain; she told everyone that she had often wanted to swap her husband for mine. No way!)).

The lecturer then turned to the process of grief, which he defined as the process by which we encounter change/loss and deal with it to create a new normal. He said in his experience with those with SCIs, it takes one to five years to create such a new normal. He also said that in his experience there were three main "hard times" in this process.

First, when "reality first sets in" – when you and your loved one realize s/he is never going to be the way s/he was before the accident, that your lives are permanently changed (not to imply you both realize this at the same time).

Second, when you go home. You know how to live with the facts of the injury in a hospital situation, but not at home, doing it on your own (I have thought from the beginning going home would be the harder part for me, at least – here the hospital staff have been responsible for his care, especially at the beginning, but even now when I'm doing more of it, it's not like living with it 24-7; but fortunately by the time we go home he'll be even more independent, and that should keep improving). The lecturer said that adjusting to the home situation would be a trial-and-error process and would probably take about a year.

Third, about one-and-a-half years into the process. The anniversary of the accident comes and goes, and a few months later one realizes that one has gotten back just about all they're ever going to get back. The permanence of the situation sets in. (He talked about a former patient at Shepherd who put it this way: "When I left Shepherd, I knew I wouldn't walk. One and a half years later, I KNEW I wouldn't walk.")At this point one moves away from physical recovery to just moving along with life.

The lecturer then covered his version of the stages of grief, pointing out that each family member could be at a different stage, and that the stages weren't necessarily linear or on a time-table, that you couldn't say, "Okay, now I'm done with shock, what's next?"

With that in mind, the first stage is shock, perhaps expressed as feeling like one is in a nightmare that one should wake up from (definitely the feeling that came over me a few times at the beginning, though not something that I was really stuck in), or one feels numb, or like one is watching the unfolding events like they were watching a movie (emotionally removed).

The second stage is "positive attitude": "we're going to beat this thing"; or, from others, "it's going to be all right, no big deal, just put up a few ramps." The lecturer pointed out this stage is a little short on reality. I don't know if either of Gary or I really exhibited this stage. I don't think I ever thought this was something we could beat – I just viewed it as something we could handle (that's about as positive as I can get ;-)). And maybe the doctor thought we might have been exhibiting this type of attitude when we talked about Gary being capable of going back to work in the fall, but hey, we were right and he was wrong :-)

The lecturer said a positive attitude wasn't necessarily a bad thing and asked us why we thought that might be the case. I said because it gives one hope. That was the answer he was looking for, and he said that hope was what got one through rehab and so forth. He pointed out that positive attitude could be viewed as kin to denial, which is just an emotional armor plating and can be useful, an emotional shock absorber, and can be a way to adjust to new conditions (one starts by saying their goal when they leave Shepherd is to walk; sometime later that becomes, well, maybe I can't do that but by the time I leave, I'm going to be able to (fill in the blank); and maybe that readjusting of goals continues).

The key is, does the denial help one move forward or stop them (for example, a person telling the therapists that he doesn't want to learn how to do transfers because he isn't going to need to do them – he's going to be able to walk by then).

The next stage is realistic thinking: this has happened, I don't like it, but what do we have to do to deal with it. It's a facing down of the situation and working with it. Maybe I'm kidding myself, but it seems to me that this is mostly how Gary and I have dealt with this situation. And as the lecturer pointed out, you don't have to give up hope to have realistic thinking.

I don't really know if I have hope as the lecturer seemed to define it. I don't really expect Gary to ever walk again, for instance, and I don't do what I do out of the hope that he someday will. Same for any other specific activity that his level of injury is said to preclude. But I think that what he is capable of is unknown by anyone, and I want him to develop whatever his potential is to the fullest by always challenging himself to exceed his current accomplishments.

The last stage, according to the lecturer, is accommodation, which happens down the line. This is when the injury doesn't dominate – it's part of one's life but not all of it.

It's interesting to me to look at these stages in light of my experience of CFS, to contrast my reaction to it with my reaction to this happening to Gary. I know I spent several years with shock coming and going (I had the disadvantage of coming down with a poorly understood illness and being undiagnosed for several years. It felt like a nightmare because I didn't know what in hell was going on. Why couldn't I function mentally or physically as I used to? Could this all be in my mind, even though I was doing all I could to live my life in the way I always had, yet couldn't? Why couldn't any of the doctors I was going to explain what was wrong?) I also had the positive attitude thing. When my family doctor told me he suspected I had CFS but that people did recover from it, my attitude was that I had been more health-conscious than 99% of the population – ate right, exercised, etc., etc. I was going to beat this, be one of those that recovered in at most a couple years. ("'Recovery' rates for CFIDS are unclear. According to one of the few published studies, the probability of significant improvement was about 30% during the first five years of illness and 48% during the first 10 years. However, even "recovered" patients stated that they still had some CFIDS symptoms, and one-third had relapsed six months later." – from http://www.cfids.org/about-cfids/research.asp). I don't know if I ever got far enough removed to ever have the realistic thinking stage. I kept hoping I would find something to make me better, and would try various things that seemed to me like they might help, and when they didn't I would "give up" on them after years, or maybe just weeks, and simply live with the symptoms, until something else sparked my hope and I would try that. As I mentioned the thing that helped me most (as Gary will corroborate), the provocative neutralization shots I give myself daily, obtained from the Environmental Health Center in Dallas, was one of things I pursued as a result of hope being rekindled, but only a faint spark of it – I never really expected those shots to work, it was a "last resort" kind of thing.

And accommodation? I think that sneaked in just within the past few years, when the illness let up enough that I could engage in mental pursuits – first, reading with comprehension, then writing.

The last thing the lecturer covered was titled "Take Care of Yourself," which he said was easy to say and hard to do. First, because it doesn't feel right, it feels selfish; secondly, because other family members, including the patient, contribute to that; and thirdly because of guilt – not guilt that one was the cause of the injury, but that this has happened to someone one loves and one can't do anything about it and so one goes overboard and sacrifices oneself for the other.

I know I have problems with overextending myself. As an example, putting Gary back to bed and turning him into position myself instead of letting the nurses do it when I am tired. Doing this for him may sound like a simple thing (well, maybe you know better because you've been reading the blog) but it involves using the hoyer or, now, helping him with a still-non-trivial transfer into a bed, then pulling him (by using the untucked sheet he lies on) to one side of the bed, helping him roll to one side then another so I can get his clothes and binder and t.e.d. hose off (and at this point he cannot be the one to remove his lower clothing), possibly changing his wound dressing, getting the pillows positioned under his bony parts correctly, making sure everything he'll want or need in the hours I'm gone is in reach, etc.

But I don't think I don't always take care of myself as I should because of any of the reasons the lecturer gave. I don't think I have any problem with being selfish ;-), and Gary isn't demanding of me, and no relatives have given any indication they don't think I'm doing all I could be doing for Gary – they've been nothing but full of praise. I thought it might be the third reason, but after reflection, I think that would still only explain a small part of this tendency to overdo. I think the reasons for it are as follows. I like learning what his rehab entails. I like being involved in it, and I am especially pleased when I come up with useful ideas. I like seeing his progress – or at least, his efforts – from day to day. So I attend almost all his classes – therapy or lecture – with him. I don't have to be doing that, and in fact I know I'm a rarity among the caregivers for doing that (of course, more may have done that under other circumstances – when we first met with his therapists, they had said that caregivers were only allowed to attend the sessions the first few times, and then they couldn't attend after that, the reasons given being that, firstly, the gym would be too crowded if everyone did that and secondly, because the patient needed to focus on their therapy without the distraction of the family member; since they never brought it up again, I simply acted as if I belonged there, and only one time was told I couldn't do a class with Gary, that time a "substitute" therapist said I couldn't come on their group-of-one push class (oh, and when I couldn't go to his male sexuality class, for understandable reasons). The tech probably has wished I wasn't there a few times when I contradicted what she was saying. But the only other words concerning the matter that have been said to me by the staff here have been along the lines of, “I’m glad you’re here.” Oops. That was another long parenthetical thought wasn’t it? Now, we need to return to the topic at hand ;-)). I do like taking over some of his personal care from the nurses just because I love him and it’s a way to show it (he has said a couple of times to me, “You should be a nurse,” and I say, “No way. Only to you. And the kitties.” Which is entirely true. I wouldn’t want to spend my time this way for anyone else). And there is some arrogance involved – more and more I feel I can do at least certain things for him better than his techs or nurses do (though I was a little discomfited when he told me he had told a tech that I wasn’t impressed with the way his skin nurse had dressed his wound one day; it was true, but I thought that might get me kicked out ;-)).

So I think the reason I sometimes overextend myself at the caregiving is mostly a mix of my empathy for his situation, which I have because of my experience of CFS, and the satisfaction I get from the activities. And there may be a tiny bit of martyr complex in me that is contributing to the overdoing as well. Could that be a reason for the blog? In small part (but just a small part ;-)) because I want you to read it and say, “Oh, what a nice person Peg is, see what she does for Gary”? It’s not simply a reportage of Gary’s rehab, after all (obviously! ;-)).

If you read the previous version of this entry, you may note that the above paragraph is the major change. I think the above is the more accurate reflection of current reality.

Well, back to that class! The others in the room who talked about having problems taking care of themselves all seemed to feel burdened by their injured loved one wanting them to do more for them than they felt up to, or more for them than they should. So the focus of the rest of the lecture was on that (show “tough love” – don’t do for the patient what they should be learning to do for themselves; or put your foot down – tell them you need to take time for yourself; or allow/get others to help – don’t be (or let the patient insist that you are) the only one who can do for them).

I stayed after the lecture and asked the guy whether he gave this same presentation on emotional adjustment to the patients (he certainly hadn’t in the three classes of his I’d attended, classes I thought were full of missed opportunities and largely wastes of time). He said he didn’t, but that he might go over some of the stuff with those he saw on an individual basis. I told him I thought he should go over it in a class with the patients, that I thought it would extremely helpful to them to hear it. He thanked me for the idea. Since I was on a roll and he hadn’t registered that I was trying to tell him how to do his job (notice that tendency in me? ;-)), I brought up how I had thought that he should be more directive in his classes, bringing up the instance where someone had expressed a statement of positive attitude/denial (“I’m not going to be one of those people in a chair for the rest of my life – I’m walking out of here’), and rather than pursue it, he had let the others in the room divert away from the topic by a discussion of gym equipment. He said he usually just waits and sees if anyone else is going to challenge the statements brought up, and if they don’t, he pretty much lets the participants take the conversation where they would. I said that in my (not-so-humble ;-)) opinion, it would have been better for him to be more directive. I told him that I had felt like saying to the person, “And what if you don’t walk out of here? How are you going to deal with that emotionally?" perhaps using my own experience of saying that I was going to be one of those who kicked this CFS thing in a couple years but it hadn't happened. (I'm sure I could have dealt with my anger about that better had I been wiser). Maybe the person wouldn't have wanted to hear that, just as maybe I would haven't faced that if someone had said something similar to me in those beginning years, but maybe at some time in the future the person would have thought back on those words and realized there were choices to make about how to deal with the reality of the disability (I could be wrong, but the person seemed to be the type who would be in danger of getting caught up in anger about the situation they found themselves in, and in anger at the person who had caused the accident). Anyway, the lecturer thanked me for those thoughts too, said he would consider them as well. Maybe I should sneak into another one of his classes to see if he follows up on my instructions ;-)

I went back to Gary's room, saw on his schedule he was in the ProMotion Gym, so went there and found him finishing up. We went back to his room and filled each other in on our day. I left, "did my thing" at the hotel, came back. Joe called and while they talked I stretched Gary instead of waiting for them to finish their conversation so he could help hold the poses – I was too tired to wait. I got him side-positioned and padded too, getting him to help when needed. I then discovered that by having him pushed a bit farther over in the bed than usual, I could squeeze in too, so I did that and it felt very nice to lay next to him for a short time. He soon finished the phone conversation, we had a little cuddle, and then I left. Tomorrow was to be another full day of family training :-p (that is the emoticon for someone sticking their tongue out).

July 7, 2006 (another minimally edited entry)

If you read the current version of the reportage in the blog of the happenings of July 6th, you may note that one paragraph – the one that summarizes why I think I sometimes overextend in caregiving – has undergone more-than-grammatical changes since it was originally posted on the morning of July 8th. I think the changes I made give a more accurate reflection of reality. If you get these updates by email and not by going to the blog, you would have to go to the blog and find the entry to see the differences. If you really, really want to ;-)

Well, it had seemed a good idea to make my third chiropractor appointment of the week on Friday, so it would be a MWF schedule, but as the chiropractor only works in the morning on Friday's, and Gary's first class was at 9, I had to take the 8:30 appt. Given my problem with having appointments scheduled for first thing in the morning, this added to my stress, not subtracted from it. From now on I will take late afternoon appts on MWTh, even if that's not the ideal schedule.

I got to Gary's and the first thing he said to me was, "Good news, my 9 o'clock class was cancelled"; I told him that would have been better news had I known of that beforehand so I could have slept in – not that he knew beforehand. He dozed a bit, and then we called a nurse to watch us do the bed transfer. Thinking I would find it easier to do it from behind him, as I did on the exercise mat, I tried that, but because of the difference in surfaces, I somehow torqued my back. So my chiropractic adjustment lasted less than an hour.

The nurse wasn't impressed with our transfer, saying it was "scratchy," that Gary came down too hard and that I should have been in front (which I agreed with, but not for the reason she gave). Gary commented when she left that he knew that the goal was for him to come down more controlled, but the important thing for now was to make sure he landed in the chair, not to concentrate on the finesse of the landing at the expense of missing his target. The greater control will come with practice and with getting stronger so that he can use his arm muscles to let himself down more slowly.

We toodled off to our first family training session of the day, this one with the rec therapist. She asked him how he'd enjoyed the various classes in rec therapy – gardening, weight room, golf equipment. She encouraged him to keep up with the various activities. She gave him lots of brochures. The first was on the Adventure Skills Outing, which takes place yearly in Jackson Gap, Al., near Lake Martin. We'd seen a video on that in one of the rec classes (one of the interesting parts of it ;-)), and it looked kind of like an "Outward Bound" for those with SCIs. Gary indicated some interest in doing that.

She next gave him a calender of the rec clinics held throughout the year here at Shepherd. Then came a brochure on the ADA, mainly contact information. Gary said that reminded him, he wanted to know how to find out about accessibility in Europe and Asia. I'm not sure if she exactly answered his question, but she said she would sign him up for the airport mobility class and the travel class – maybe they cover the pertinent information in this latter class. (He also then asked about the driving class, but she said she didn't handle that and he needed to talk to his case manager.)

Another brochure was on Accessibility in the Community, and seemed to mostly be a list of what to complain about if a place wasn't accessible. There was also a brochure on the National Spinal Cord Injury Association, and one geared toward me, on the National Family Caregivers Association, which I don't believe is specific for SCIs. This reminded Gary that Tony had told him that in our town there is a support group for those with SCIs and brain injuries, which Gary thinks he will check out.

Other brochures were on how to protect the skin during different activities (swimming, barbecuing, etc.); how to deal with hot/cold issues, which had been covered in a class we'd attended; useful information for water activities; what to ask about accessibility when calling ahead before going to a hotel or out to a restaurant; what to know about one's chair in order to ask the proper questions about whether a place is going to be accessible or not (height, width, etc.); problem solving techniques; common problems encountered in the community; how to be assertive in dealing with accessibility issues and how to be an advocate of the ADA; a community resource list for recreation information (including the phone numbers of the rec specialists at Shepherd – just in case Gary wants to call the gardening therapist and ask her where he can get that mower ;-)); a list of magazines and catalogs concerning Therapeutic Recreation resources and equipment (ponchos, backpacks, adaptive weight training equipment and machines, all-terrain wheelchairs, adaptive equipment for various sports).

That over, we headed toward our case manager's office, and Gary asked her about the driving class. Turned out she needed to consult with the OT about it, and, conveniently, the OT happened to walk by just then. It was decided to sign Gary up for the van evaluation class, at which time he would need to let them know that while he would first be only a passenger in the van, next December he would be returning here for the drivers evaluation, and if all went well, he would then want to be a driver of the van. I think I mentioned that during the driver evaluation they would make sure he was medically fit to be a driver. They also wait that long so that he will have time to build up his strength and to get his balance down pat (or at least far better than it is).

Next came a family training session with the OT. She had two issues to go over with us: the stretching routine and Gary's padding and positioning while in bed. The padding and positioning, as you probably know by now, involve keeping his bony parts off the surface of the bed so he doesn't develop bed sores. I've been having lots of practice when putting him back to bed of getting him into the side positions and placing the pillows where they belong, so I knew that routine pretty well (but would always take advantage of having the information gone over with me again). I'd helped get him padded off in a prone position for his exercises on the mat, but hadn't really done it enough to have the procedure down by heart. So we went over that. She had pictures of all of this for me to take home with me, which I am thankful for.

She also had pictures of the stretching routine she wants him to do at home, which adds in a few to the ones we've been doing every night (and she commented that she could tell we'd been working on his flexibility because it had definitely improved, though for some reason his legs still simply do not want to adduct – tight IT band; the therapist joked that we should tie his legs together at night – or maybe it wasn't a joke!).

We finished up the session with a transfer back into his chair – Gary did one of his best! – and the OT said we had successfully finished our family training with her. Next was a lunch break, and then a long family training session with the PT. New power-assist wheels of the first kind Gary had tried ("E-Motion" wheels) had arrived, and so we started with Gary and I transferring him from the chair he's been using into the chair with those wheels. First he did some traveling around the hallways to get a feel of the wheels, but despite his doctor's recommendation, he doesn't like them as well as the other kind ("Extender" wheels). While the Extenders have only one gear (which seems halfway between the two gears the E-Motion offers), the chair having these wheels was easy for Gary to operate, unlike the chairs having the E-Motions. The problem with the E-Motion wheels is that when he puts them in second gear, they respond too easily and he ends up spending most of his energy trying to correct his "steering." Another problem, a significant one for him, is that he can't hear the beeps that the wheels make when he pushes the gear buttons on them, so he doesn't know ahead of time if the wheels are turned on or what gear they're in (and since the wheels operate independently, whether both wheels are in the same gear). And although the doctor had said that the E-Motion wheels become significantly lighter when the battery packs are removed, this was not the case – they dropped a few pounds but were still at least twenty pounds apiece. Because the chair did not become significantly lighter, Gary would want to change the wheels out to turn the chair into a manual one, just has he would have to do with the Extender wheels. So either the doctor has his facts wrong about those wheels, or we are misunderstanding him. Gary says he'll talk to his doctor again about it on Monday, but as of now is still leaning toward the Extender wheels.

We next went to the parking garage, the purpose being for me to practice the car transfers with Gary. Not only were they really hard on my back, but we weren't anywhere close to being successful at them. So this is still a task for us. I just hope Gary gets stronger and a lot better at this by the time we leave (I think he will), because otherwise I think we're going to need help with this until we get a van – my back is not going to be able to take it.

The PT next went over the maintenance of Gary's chair with us – he will be getting one similar to the one he's been using at the hospital, so it was less confusing to hear her go over its specific maintenance than to listen to that person yesterday give a general lecture covering different kinds of chairs. The PT also covered maintenance of his seat cushion and how to test if it was properly inflated (important to prevent skin sores). She showed me how to inflate it, and I did that, then Gary sat on it and I did the test (get my hand between his sitting bones and the seat cushion and wiggle my fingers to make sure I could get a half inch to an inch of wiggle). It seemed on the low side of acceptable, and she agreed with me but said we could reinflate it tomorrow instead of taking the time to do so now.

She then gave us sheets of paper with information about the various pieces of equipment Gary will be getting – wheelchair, special bed mattress, hospital bed (these latter two for six months), shower bench. Fortunately, we have one person who coordinates all Gary's equipment and he will be the person we contact should we have any problems

Next the PT illustrated a two-man lift of Gary from where he lay on the exercise mat. Fortunately she didn't make me be one of the person's lifting him. But she wanted to show it to me in case I ever needed to direct anyone else how to do it. She and another PT did the lift, she reaching her arms around Gary's chest from behind and locking her arms, the other person reaching under Gary's legs above the knees and locking her arms as well, and then the two of them lifting him from the exercise mat onto his chair.

Next I had to do curbs with her. First she let me watch how Gary was practicing doing them on his own (flip the tip bars out of the way, approach the curb at good speed, pull hard on the wheel to do a wheelie to get the small front wheels up over the curb, then without a break get those front wheels down, lean forward and use good strength to get the back wheels up the curb). He can do two inch curbs with no problem but hasn't consistently done the four-inchers (and even on the more successful attempts at the four-inchers, he didn't do those without the PT's help).

So now I had to do four-inch curbs with Gary. I have described the procedure to you earlier, on the blog entry about our excursion to Fresh Market. But at that time I'd had to do it on a smaller curb, maybe a two-inch one. I looked at the four-inch one warily. Sure enough, even though the PT said I did it correctly and Gary had helped by pulling on his wheels, my body did not appreciate that at all and my right leg let me know it. The chiropractor is definitely going to find I've gone backwards when I see him on Monday.

We were then supposed to have family training with the nurse, but the only thing I have left with her was Gary's bowel program, and we have that scheduled for next Thursday. So I left for a two-hour break after hoyering Gary back into bed – he had to be up again in the evening, so needed to go back to bed now. The reason he would be up was to finish our family training with a group outing to Dick's sporting good store (oh, yippee, said I; or as Gary's roommate's wife said, "Screw Dick's – we want to go to the Target next door." Actually, Gary and I would have much preferred the Borders bookstore across the street).

We were late for the departure time of 5:45. Gary is on a 6-hour IC schedule, and according to this schedule he was supposed to do it at 6pm. It is okay to vary that by half an hour (so, it could be done any time between 5:30 and 6:30) but by no more. Now, you and I can take a pee in moments. But each IC can take a half hour or more, and probably at least fifteen minutes, as one makes the needed preparations and then sits there waiting for the urine to drain out of the bladder, through the re-usable (not permanently inserted) catheter, and into the re-usable bag. Nature couldn't be rushed, and Gary wasn't ready to leave until 6. We got down to the bus and discovered that at least we weren't the last ones to make it.

When the last person had arrived, next came the loading into the bus. Each of the five wheelchairs with their occupants was placed on the lift and brought into the bus. Next came the strapping down of each wheelchair into place and the seatbelting of each occupant – this took several minutes per person.

Then we were off. We arrived at Dick's in the overairconditioned bus in about fifteen minutes and were let out at the curb. We then had to negotiate the long up-sloping sidewalk to the parking garage. The other guys (the wheelchair occupants were all men), all younger than Gary by probably fifteen to forty years, were evidently stronger than Gary (well, except for the one in the power chair, but he had a motor to help) because they left us in the dust. But Gary made it up the slope on his own, the rec therapist coming back to check on our progress. We went through the parking garage, joined the others at the elevators, and took the elevator up to the second floor to the entrance of Dick's. The rec guy told us we could go through the store on our own, and he would go around and check on us throughout our stay. He said that when we were done looking around, we could go to the entrance, and when everyone was ready we would leave. He said we could stay until eight-thirty but if everyone was ready by eight we could leave then.

It was now 6:40. Gary and I told the guy we'd be through by 7. He was not amused (well, actually, he was).

So everyone wandered off. Gary had the idea of seeing if he could find "cool shoes" with velcro. We didn't find any, but I did manage to tip over a display of shoes by trying to reach the ones at the top – sheesh, the things weren't accessible to me, let alone to a guy in a wheelchair. The rec leader found us amongst the shoes and suggested Gary might like these "popular shoes," "Crocks," that look something like gardening shoes I have seen – rubberized, slip on easily, these particular ones with holes throughout them. As they came in only the most garish colors, I couldn't imagine Gary liking them. Gary just said dryly, "I can't see myself teaching in those." The only other possibility I spotted for him for shoes were sandals, but Gary doesn't like sandals.

The rec guy left us to ourselves after telling us we'd all meet at eight, and shortly after that Gary started to feel a little off. He decided it was because his binder wasn't tight enough. So we tightened it around his middle, right there in the middle of the store because there were no onlookers. Fortunately that did the trick.

After that, Gary did some of the tasks he was supposed to do while there – check out the bathroom to see how accessible it was, and just see how accessible the place was in general. The bathroom he thought was nice and roomy, but the door was on the heavy side. He did like the fact that he could roll under the lowest drinking fountain and get himself a drink.

We decided to wander around some more, so we went up to the third floor. I spotted some backpacks, and Gary checked them out for something to hang on the back of his wheelchair that he can get into easily – the Shepherd bag he was given is completely open and it seems to me that in "real life" things could fall out of it. There was one backpack that interested him – not too many pockets, which would make it hard to keep straight where he'd put what, since he'd be just reaching backwards into the hanging pack and finding things by feel, not sight. But I told him to first check out the pack I had gotten in Birmingham, which was similar and about twenty-five dollars cheaper.

We next went to another floor, and Gary looked at golf stuff. We wandered around a bit more, and I saw some long-sleeved pullover shirts, comfy-looking and a step up from T-shirts, but not fancy. I showed them to him, but then said maybe he didn't want one because he'd told me he didn't need any more long-sleeved shirts in the hospital. He liked them, though, and said maybe he would get one because he needed one for the cold bus. I gave him the eye, because I had suggested he bring a long-sleeved shirt with him in case Dick's was an air-conditioned building, particularly given that since the accident he can suddenly become cool. He had pooh-poohed the idea.

Sometimes (rarely) he can be such a man ;-)

I put the shirts back on the rack so he could see if he could get them off himself. He could. His next task was to negotiate the dressing room. Getting in was fine – there was plenty of room for the two of us – but getting the door closed was a challenge. Given how he was forced to position the chair, the door handle was too far for comfortable reach. Since the door was light, he ended up pushing it near the hinge to swing the door closed. When he had it halfway closed, a helpful salesperson came and opened the door for him, thinking he was trying to get out (and probably wondering what my problem was). We explained that he was practicing. Thanks to the guy's help, Gary had to start all over again with closing the door (which was all right with him – gave him practice).

Gary then looked at his watch. Twenty to eight, and we were all supposed to meet at eight. “Well, it’ll take twenty minutes for me to get the shirt on and off,” he said with humor. “Yeah,” I said, “and that’s after taking ten minutes to get into the dressing room.” We started to laugh, and he said, “It’s a new life we’ve got.”

I hope we always keep our humor about it.

He got the shirt on about halfway (at least he found putting it on easier in the chair than doing it balanced on the edge of the exercise mat), then he looked in the mirror and declared he liked it and would get it. I asked him if he wanted me to straighten it on him so he could really get a good look at it. He said yeah. We both knew he was supposed to do as much as possible for himself, but we allowed this one cheat. The shirt did look really nice on him – a soft, gray shirt.

Then he said he supposed he had to take it off to buy it, and proceeded to take it off. He can definitely do this sort of thing a bit better than the first time he tried, though there is still wobbling going on.

We went to the checkout counter. I gave him my credit card so he could pay. He could swipe the card through the reader but at first we thought he wouldn’t be able to read the display. BUT, it turned out that the card reader could be tilted downward and he could read it fine. After he made his purchase, we went downstairs to where we were all supposed to meet. The others, minus one, were outside. Gary put his new shirt on again (over his T-shirt) and then we went outside and joined the others. Turned out we had to wait out there a half hour for the remaining guy – I don’t know what he was doing, as he didn’t come out with any packages.

While waiting for this guy, the rec therapist had me do a curb with Gary. This was one of the things he was supposed to check me off on, the other thing being he was supposed to determine whether I was a responsible enough person to take Gary on an outing (though since I’d already been cleared for a push pass, this seemed a little redundant). When I saw the curb he wanted me to do, I nearly cried. It was a six-inch-high curb, and my leg and back were already paying for all the transferring and curb work I’d done with the other therapists today. Had I not been in fear that if I didn’t do this we wouldn’t pass our family training, I would have told him I couldn’t do this curb. So I did it, first up the curb, which I could tell my leg didn’t like, then down the curb. Because of the greater height of the curb and because it actually angled downward to the side, Gary’s chair started tipping to the side. I corrected it reflexively, so he didn’t tip over, but my leg felt like someone had suddenly twisted it around 360 degrees. Something must have shown in my face because the rec guy asked if I was all right. Still fearing that if I admitted I wasn’t ,we would fail, I said I was fine, inwardly hating his guts. He said most curbs weren’t this high, and asked me what I’d do if Gary and I were out and there was a curb like this or even higher that Gary wasn’t able to handle on his own. I said I’d find a big strong person to get Gary up it, telling the person what the procedure was. With this, we passed. I stayed inwardly mad that he had made me do that curb. I was really afraid that by the time I got back to the hotel for the night I was going to be in agony. Miraculously I wasn't. Maybe I killed off all the nerve cells.

We next returned to the bus. Again, Gary and I were stragglers, because Gary had trouble with a ramp that posed no difficulty to the others. The rec guy came back for us and asked if I'd helped Gary up it. I said no. This met with approval, the guy saying tough love was the best.

When we got back to Gary's room, I asked him if he wanted to have a nurse help him do a transfer into bed, or if I should hoyer him (we're not cleared to do the transfers in the harder, uphill direction of chair to bed). He said he didn't trust any of the nurses to transfer him. He had told me when I'd gotten there at about five-twenty that evening that the nurse who had helped him transfer out of the bed in preparation for the outing had been the same one who had said our own transfer was "scratchy," and that hers was far worse – in fact, he'd ended up landing on the tire with his butt, which had never happened before and was the main thing the PT and OT had been guarding against because of his flap (I had checked him out before we'd left on the outing but didn't see any damage – assuming he was right that he'd hit the tire on his sitting bones, the flap had not been in danger).

So I got him hoyered into bed, undressed and positioned, and then left – planning to sleep in to help recover from the past week!

July 8, 2006

Mail call: thanks to Ron Becher.

I worked on the blog in the morning, trying to catch up. I got to Gary's shortly before his 11:30 therapy session. I asked him if a nurse had transferred him into the chair. He said he didn't trust her to do it, so had her hoyer him into it.

The session turned out to be one with his regular PT. He joked that he thought she should take the day off. Perhaps in retaliation, she started him off with doing dips on the mat, where he was to use pushup blocks to give him elevation and then hold the extended position for a second. He did twenty-five, then rested, then continued. I thought he was going to have to take another rest after the next fifteen, but he made it to twenty-five. Barely ;-)

Next she had him get in the "model pose" – lying on one side pushed up on one elbow. She wanted him to hold a weight in the other hand, lift it straight out in front of him, then bring it toward his head while keeping his arm at the same height, then bring it toward his feet – a balance as well as a strength exercise. She set an eight-pound weight in front of him. "Now, lift it straight out in front," she said. He made to pick up the weight. "Yeah, right," he said, failing to get it off the mat. We all started laughing at the way he'd said that. She went off and came back with a selection of weights, and handed the tiniest one to him. He looked at the one-pound weight. "And it would be pink," he joked. He did a couple repetitions of the exercise, then said he could do it with the two-pound weight. He probably was highly motivated not to be using a pink weight ;-)

He did his twenty-five repetitions and collapsed onto his back on the mat, moaning. But when he did the exercise on his other side, he found he could do them with a three-pound weight, and though they weren't easy, they weren't such a struggle – he said he hadn't been sure he was even going to be able to complete the exercise on the other side. We thought maybe the difference was a balance issue – it might have been easier for him to balance when propped up on his left, nonarthritic shoulder.

She asked him what he wanted to do next while she worked with another patient, and he said the hand cycle. She set it up. Since she wants him to build endurance, she lowered the resistance so he could do it for more than a few minutes without needing a rest.

Next came a balance exercise, with him sitting on the edge of the mat. I forget the name of the ball she used with him – a typical exercise ball, sort of like a beach ball (not a heavy medicine ball). First, she wanted him to pick up the ball with both hands and lightly touch it to the mat to both sides of his legs. He couldn't do it, not having the balance for it. So instead, she had him roll it one-handed over his legs. This he could do. Next he was to do a Harlem globetrotter, rolling the ball behind him on the mat, hands always in contact with it. He tried awhile, but he couldn't do it – shoulder flexibility got in the way with this, in addition to balance. Next she stood in front of him some distance away and tossed the ball toward him – straight at him or to a side – and he was to hit it back. The first thing that happened was she hit him in the head with it. She told me not to put that in my notes. Of course, I did ;-). He was having trouble with this exercise too, so she had me be the one to toss the ball to him (or maybe that was to prevent me from keeping a record of every time she bonked him;-)) while she lent a little assistance with his balance. We made a great pair, him and me, he wobbling around hitting the ball with an intense look of concentration on his face, me running around chasing after the ball like some klutz. I don't think we're ready for beach volleyball yet.

He and I did a transfer of him back into his chair so she could finished up the session by practicing wheelies with him. We talked about transfers again, me bringing up how the nurse hadn't liked me doing it from the rear because his chair might somehow slip. The PT said there wasn't any danger of that (assuming the brakes were on!), that the way Gary was doing his transfers, he wasn't pushing away at the chair, but pushing down with both hands (one on the chair, the other on the surface he was transferring from). She also said that when he got more advanced, and stronger, he would actually be using one hand to pull the chair, as if to move it toward him (though it wouldn't actually move, because of the brakes) – which would help guide his butt – and using the other arm to provide all his lift. (She also told us that his doctor doesn't even have brakes on his chair (we wondered about that – how could he keep his balance if he wanted to have both hands in the air while on an uneven surface?).) Gary could see how the pulling at the chair would be useful for aiming his butt. With the way he transfers now, he always has the uncertainty of where his butt is going to land – he can't feel where it is, he's not supposed to look at it because that puts his head in exactly the wrong angle for making sure his butt goes to where it's supposed to go, so he just has to do the technique as taught and hope his butt lands in the right place. “A leap of faith,” I told him, and he laughed at that, saying that was truly what it was.

(Well, with a little help from physics ;-))

After this session, Gary did an IC, then had lunch. The PT had forgotten to reinflate his cushion, so we went back to the gym to find a pump. Another PT found it for us, and we went through the procedure ourselves – first transferring him to the mat, inflating the cushion, transferring him back to the chair, testing the cushion. Another PT walked by and commented, “Boy, give Peg a task and she does it.” “Yes, she does,” Gary said proudly. I puffed up – I like getting strokes ;-)

The cushion seemed fine, and Gary was glad of that, so he wouldn’t have to transfer in and out of the chair again (the cushion can’t be inflated with him sitting on it).

The rest of the day was ours. We did his routine stuff, I worked on the blog, we talked to Joe about the house, and Gary made phone calls concerning it. Since Joe is leaving soon, we have to arrange for others to “cover” for him (he is not replaceable). The main things are to have someone who will let the workers into the house and someone who knows what the tasks are and to check that they are getting done. Sue Rodger has agreed to let workers into the house; Jo Heath has taken over the job of foreman ;-). They have our unbounded appreciation.

I only paid half-attention to the conversations because I was trying to use the time to catch up on the blog, but naturally ;-) I did manage to overhear Gary tell someone, “Peg has devoted herself to helping me with my rehab these past few months, and that’s been so great.” Ahhh, more strokes, and from the person who means the most to me – I love hearing him say things like this. Did I mention this as being a primary reason for why I sometimes overextend myself on the caregiving? I certainly should have, but I don’t think I put it quite this way.

Jumping ahead a day, I had a chance to again look at some of the emails I received this week. Janet Rogers is doing her usual bang-up job of keeping us pictorially informed of the progress on our house (she also mentioned that the kitties are getting used to her now, both of them deigning to let her pet them a little). Work on the bathrooms and the master bedroom continues. Work on the floors is supposed to start this coming week. Janet sent pictures of her and Jo Heath and Donna Bennett painting the master bedroom, which I intend to post. She told us Bob Heath had been at the house, mostly doing some sanding. Jack Rogers set up a wireless network so that Joe can take advantage of our high-speed internet connection. (The modem had been taken out of the master bedroom for the remodeling, so he’d been unable to use an ethernet cord. He’d apparently just been using a dial-up connection, which at least at our house is soooo sloooow.)

Now a jump to a new topic, since I’ve caught pretty well caught up on the accounting of the therapy-related events of this week and so have a little time to write about other things (I’m writing this on Sunday, and so far the day has pretty much consisted of me writing the blog; Gary watching Wimbledon; routine stuff; and a trip out to the car to put in it a load of things from

Gary's room that he won't be needing/using for the rest of his stay here. Soon we will take a little excursion to the pharmacy up the block to buy a few needed items – and so Gary can get a little exercise. Wouldn't want him to get lazy, after all ;-)).

I've gotten several emails referring to the pictures of Gary I put up on the blog. The most common reaction was that he looked terrific, which of course, he does :-). Mark Meschke, a childhood friend, wrote (and I hope he doesn't mind if I quote him), " I went upstairs and looked at my trusty 1965 Columbus Discoverer Yearbook and Gary hasn't changed much at all. No added weight? no gray hair? still that sly smile! you've done very well. I'd probably recognize you if I met you on the street." (Well, we wouldn't say NO gray hair ;-))

Another person said Gary looked great, the same as always, and that as a result of some of the things I'd written she had thought he might look wasting away. (For a while there, he did).

My older sister's response was evocative (she saw him the first week after the accident when he was in intensive care): "The picture of him shows how his upper body has really developed, but for me it is healing as the last time I saw him, in critical care, he was so utterly helpless and fragile, as hanging between life and death. I think that image of him lying there with your scaredness (and mine, I might add) is the one that was still deep in me. The picture especially the one including his wheel chair, to me is Resurrection, not without the wounds, but including them and makes Resurrection seem more real and possible because of the included wounds."

To finish, a few pictures have been posted to the blog: Jo Heath and Janet Rogers toiling away in the master bedroom. Donna Bennett caught in an artistic pose as she paints the window in the master bedroom. Go to http://drpeg2003.blogspot.com/ to see the pics (scroll down).

July 9, 2006

I am posting three times today, so you may want to check the blog entries below this one to see if you have seen them.

Before I get to the main entry recounting today, let me state here, because someone asked for clarification, that the current plan is that we are leaving Shepherd for home on July 27th, and we do not plan to return for the day program until December. They had first changed the discharge date to the 28th, but then moved it to the 27th, because they don't discharge people on Fridays as a rule. By being discharged on Thursday, if something were to come up immediately upon arriving home, we could head right back to Shepherd and a full staff would be available; but if we were discharged on Friday, if something were to happen, there would only be the weekend skeleton crew to deal with it.

Back to Sunday. I already told you a little bit about today in the last entry. I left off just before we went on an outing to the CVS pharmacy up the block, so I will start with that. We began the outing by going to the first floor of Shepherd and then down the hallway to "The Blue Carpet" tunnel. Gary said, “See ya,” and took off. We played our version of the tortoise and the hare, me lagging far behind him on the long downhill slope of the first two-thirds of the tunnel (which would turn into a challenge on the way back), then easily catching up to him as he worked his way up the slope of the last third of the tunnel to the elevator – but he was pleased with his efforts as this was the first time he’d made that slope with no rests. Stepping out of the elevator, we were magically across the street from Shepherd and nearly a block away. CVS was across the next side street.

In the store, we picked up a few items – and talked on the phone to Joe, since he called while we were in there. Among his good news was that the cat barrier had been primed (I wouldn’t want to spend one night in the house without that being up! ;-)). At checkout, the credit card reader posed a little bit of a hassle, but Gary figured out that the best thing was to just pick it up and put it on his lap – it was so designed that this could be done. After that, we decided to check out the Tropical Smoothie Café down the block. Their idea of what was accessible left something to be desired. Right when you opened the door, there was a ramp. So to get into the café, first Gary had to get the heavy door open and then immediately try to go up the short and rather steep ramp. The workers tried to rush to Gary’s aid but we waved them off, telling them Gary was practicing. The two Latinos then turned into a cheering squad, urging Gary up the ramp (“You can do it, amigo”). He didn’t make it – I had to push him up it – but the workers continued in their friendly way, offering him encouragement, telling him he’d make it next month, that he just needed to get a little stronger, and so forth. Gary decided that after his efforts he needed a protein smoothie, so he got something called a “Power ‘Health Nut’ Smoothie,” with blueberries, mango, banana, almonds, and whey protein. The smoothie was huge, and when they brought it out, they gave me a cup of it too. They had been so friendly, I didn’t feel I could refuse to take it, so I had a little of it, hoping I wouldn’t have too bad a reaction to it. We turned from the counter with our goodies, and the workers thought we were heading out, so they rushed over to open the door for Gary. But he decided to pull up to a table for a while. They rushed over and cleared chairs out of his way. Now that was service.

Gary drank about half of his smoothie, and then we left, me carrying his drink (because him holding a large drink between his legs while going down the bumpy slope of Peachtree Rd did not seem to be a good idea). Oh – and on the way out he got the door open himself.

We strolled along the sidewalk on this same block, stopping outside of Mama Fu’s to read the large menu attached to the wall of the building. They have red Thai curry, so Gary thinks that sometime while he is here he’d like to come to Mama ;-).

After crossing the first side road, he couldn’t get up the curb cut – he backed up and tried a different approach (fortunately the light was still with us). He tried again, but his wheelchair again turned to the left when he didn’t want it to. He continued to pull at the wheels, trying to get up the slope, but he finally asked for my help and I gave him the last needed push. Just then I looked up to see a man tearing down the sidewalk toward us. “Is everything okay?” he asked. We assured him we were fine. It was nice that people were so willing to be helpful if we needed it. I wondered if it had anything to do with the location – people in this area must be used to seeing patients from

Shepherd making their first ventures out into “the real world.”

Back in the Blue Carpet tunnel, he now had that long slope to go up to get back into the Shepherd building. He did it with three rests, far fewer than the first times he’d attempted it. I told him we could come here every Sunday and test his progress by seeing how few rests he could do it in. “Great,” he said with mild sarcasm. I told him we didn’t have to, but he said, no, I was right, it would be a good test and give him some exercise at going up slopes.

Back in his room, it was time to put his feet up – he’s been having some problem regulating the volume of his ICs (too high sometimes, which is not good – review my bladder lecture ;-)), and this was a suggestion that had been made to us to try. Easier said than done. The man’s hamstrings are tighter than taut bowstrings, and it was a struggle for me to get his legs up on the chair. There was no hope of straightening them – his knees jutted up. So unintentionally this turned into a stretching exercise for his legs. After a half hour, I got his feet off the chair, and soon after that I left.

When I returned in the evening, we did the usual stuff. After stretching him, I positioned him, remembering to shove him far over to one side so I could climb in with him. We lay there and listened to one of his roommates snoring, another one on the speaker phone letting the whole ward know what was going on in his life (why would anyone think others would be interested in the details of their life? ;-)), and the other one talking to himself (this person is the newest one in the room, having been there about two weeks; at first I thought he was on the phone all the time, but Gary told me it was not that but that he talked to himself constantly – including all through the night).

“This is nice,” Gary said, meaning the snuggling, or as we term it, “hoodleing.” “Why didn’t we think of this before?” he continued. On account of his flap, I told him – we’d had to be so careful of his positioning. And before that I’d thought he was too delicate. We then said some mushy stuff, and then he asked what I wanted to do for our anniversary, which we should be home for. I said, “Spend all day in bed sleeping.” “Sounds good,” he replied.

And on that note, good night :-)

July 10, 2006

Was sleeping great until I had a nightmare about 6:30am. My little sister and I were lying on the deck of a big boat or ship, as were other people I believe. We were in some exotic place, surrounded by many fancy red boats, possibly houseboats, full of rich people. One such boat zoomed along the side of us in the dark, throwing up a gigantic wave. Our ship was inundated and sank like a rock. I could feel my sister’s terror. I struggled toward the water’s surface, made it. As I tried to catch my breath in preparation to call out my sister’s name, I had the thought that I should do this part over again, that I should keep hold of my sister as we swam toward the top, because while it wasn’t yet clear I was saved – I had no idea if someone would find me there in the water or where to swim to land – she might have drowned and I might be all alone. But then it occurred to me that if I re-did this and kept a hand on her, it could happen that she might panic at some point and grab onto me, causing me to drown, or maybe I might not be able to swim upwards to the surface in time if I held onto her, and again I might drown.

I woke up.

So, what do you think? Do you save yourself and risk being alone, or do you try to help the other person and risk them drowning you? I'll let you consider the broader implications of my dream on you own time ;-).

Mail call: thanks to Murat Tuncali. Also, thanks to mom – cute clothes for me and chocolates for Gary!

Gary was supposed to meet with the tech from 9-10, but she cancelled again. His PT said she would start meeting him at 9:30, so he had an hour-and-a-half session with her instead of an hour. To begin, she told Gary and me to transfer him onto the mat. She told me to put my hands on his hips, instead of under his butt, and only give him help if absolutely necessary.

It was absolutely necessary. His hand placement was off, and his hand slipped a little. He got no height (so I had to support his weight quite a lot), but even worse, upon landing he lost his balance and started going sideways off the mat. But between him catching himself on the chair and me grabbing him around chest (and the PT leaping forward just in case), there was no mishap. She made him do the transfer over again, and this time he did a great one.

It's all in the technique.

The mat he was now on abutted another mat about four inches higher. She had him do hops over to the center edge of the mat he was on, his back to the higher mat, his legs in a frog position out in front of him on the lower mat. The PT introduced him to something new, "bump-ups," which is something he'll be practicing more when he comes back for day program in December; he got only a taste of it now because his flap isn't sufficiently healed (and even now, he had to wear a J-pad, like the one we'd been show in gardening class, to protect his sacrum). To do the bump-ups, he was supposed to depress with his arms (pushing down with his hands) and at the same time throw his head forward to help him lift his butt up onto the mat behind him (for every action, there is an equal and opposite reaction ;-)). Problem was, he couldn't get any height when pushing down on the mat. She had him try it with putting his hands on the higher mat behind him, but his lack of shoulder flexibility wouldn't allow it. She brought over the pushup blocks, and using them he did the bump-ups like a pro. So we decided he needed to have that surgical procedure done to have his arm bones lengthened ;-).

He practiced that awhile, and then she had him do the bump-ups when slightly angled, so one hand was up on the higher mat, one on the lower. If he always did them this way, he would only need one arm lengthened ;-)

I had been wondering what the purpose of this was, but before I could ask, she explained. This is the technique he would use to get himself up stairs. I had also been wondering why she was having him do this now, when it wasn't something he could really practice for months (I said this to Gary later, and he said he'd been wondering the same thing) – I would have thought practicing something like car transfers would be more valuable – but I didn't ask why he was practicing this now, and she didn't say.

Next she had him workout on a weight machine called the "Uppertone," specifically designed for those in wheelchairs. On it he did rowing, presses, and side raises. Next we went out into a hallway, and the PT and Gary practiced wheelies. First he was to try to stay pretty much in place while in the wheelie, next he was supposed to travel down the hall in the wheelie position, next he was to do a three-sixty while in a wheelie (his were closer to one-eighties). She was always behind him to support his chair when he did this (as his tip bars had to be removed for these), so I was not sure how much help she gave him. I do know he commented to me that it would be a long time before he tried to wheelie up a curb unaided – if he should go backwards too far, he would tip back and hit his head on the street. That, we wouldn't want (understatement of the year; it'll be fine with me if he never attempts them.)

That was the end of that session, and we next went off to a travel class, given by a rec therapist. I was rather surprised by how the lecturer whipped through the information (now THIS would have been the time for those rec therapists to stretch out their lecture!) – I thought that there should have been handouts, as I can't imagine many people retaining the information given, and even with me madly taking notes I couldn't get everything down.

The lecturer covered

- Planning for the Trip (research your destination – various ways to do that were cited (check departments of tourism, internet resources, etc.));

- Know Your Rights (the Air Carriers Access Act);

- Packing for your trip (take carry-ons for medications, personal care supplies, and a list of emergency information (your physician's contact info, names of your medications, your medical diagnosis, etc.) – there is no limit to the number of carry-ons you can take onboard for these items);

- Making Airline Reservations (among the covered information: request a bulkhead seat – more room for weight shifts, greater privacy for ICs if they have to be done on flight); get a direct flight if possible, otherwise arrange for a "meet and assist" if you feel it necessary);

- Important Information to Explain to the Travel Agent or Airline (including telling them the type of equipment you use and the type of assistance you will require for transfers into the airline seat or for your luggage, and also, making sure they have an onboard "aisle" wheelchair available, as that is the only way you are going to get to your assigned seat);

- Arriving at the Airport (get there plenty early, check baggage as normal, DO NOT CHECK YOUR WHEELCHAIR until you are ready to board (you need your own comfy chair, which you know how to handle and is to your specifications to protect your skin, and so forth – you don't want to take the chance of being stuck in their chair if there is a delay in flight, for instance);

- Security Checkpoints (they will have you go through a manual security check, and you may want a doctor's letter to explain that it is the rod in your spine setting off the security alarm);

- Pre-Boarding (GATE Tag your chair; tag all removable parts of your chair or take them on the plane with you (preferable, to guard against loss); pre-board; remain in your own chair until you reach the plane door at the end of the jetway);

- Transfer to an Aisle Chair (they have a special chair for you to transfer into);

- Type of Transfers to do into the aisle chair and into the airplane seat (do a depression or sliding transfer – tell airline personnel how much help you need);

- Ready to Board (transfer into the aisle chair; make sure staff straps you into it; take your own seat cushion with you, being sure to let air out of it if is an air cushion (some are gel));

- Transferring to Plane Seat (put cushion on seat; raise armrest or put blanket over it to protect your skin; put seatbelt on immediately, asking personnel to stay until you have the belt on securely if you need them to make sure you are balanced (it's happened that they've transferred the person into the airplane seat and immediately turned away, and the person toppled over); make sure legs are at a ninety degree angle – don't want your legs dangling as that puts too much pressure on your bootie – you may need to bring something to prop your legs up;

- Balancing and Position (use chest binder for support – have someone wrap it under the tray in the seat behind you so you aren't preventing the person behind you from using their tray);

- During Flight (one half hour before arrival, have attendant call ahead to make sure your wheelchair is brought to the gate; be aware that attendants are not required to help you with personal needs);

- Getting Ready to Land;

- Departing the Plane (you will be last off);
- Inspect your Chair and other Equipment immediately (what to do if have a complaint);
- Travel Resources.

Whew!

She finished by showing us the aisle chair Delta uses. You are strapped into it, and then two trained airline personnel, one in the back, one in the front, back you down the aisle to your seat and assist you into your airline seat.

After the lecture, Gary went up to ask the lecturer a couple of questions. One was how he would transfer into the airline seat if he was still under "flap restrictions" – no way was he going to be able to depress OVER an arm rest. His own rec therapist was there and said that assuming the arm rest didn't swing out of the way, which typically they don't, he would have to be transferred by a two-man lift. Gary's other question was about ICs, if it so happened he was on the plane when he was scheduled for one. They told him no way was he going to be able to get into a bathroom on the plane to do it, so the only option was to do it while in his seat. They said that a traveling companion could hold up a sheet to give him privacy (and thus drawing the attention of everyone in the plane), or if he had no such companion, the flight attendants were required to hold up a sheet (ditto, on the attention attraction). Gary kind of blanched at that. As we left the room, he said that if I was with him I could hold a newspaper up, and he supposed he could take some other family member doing the same, but he would be too embarrassed to have anyone else do that. He opined that the best solution would be to arrange his flight so that he wouldn't be on the plane during a time he was to do an IC.

During the noon hour, Mirko Popvassilev showed up. He brought a great get-well card signed by fifty-four attendees of the 21st Summer Conference on Topology and its Applications (well, fifty-six attendees – according to the signatures on the card, Blackjack and Tigger had been there). Gary only had fifteen minutes to talk with Mirko before it was time for therapy, but Mirko said he could stay around a while longer and talk with Gary during his break from 2 to 3 (we always need to check his posted schedule – it varies from day to day).

So off Gary and I went to the afternoon session with the OT. On our way to it, the Day Program manager stopped us in the hall and said she thought she would be able to get Gary into the program a week earlier than she'd said. We were a little confused by that, as we'd thought all talk of Day Program before Dec. was off. The manager had someplace else to go, so she said she'd talk to us later in the week. As we went to the gym, Gary asked me what I thought about us staying for Day Program immediately after discharge from Shepherd. I said in my opinion the more therapy he could get before going home the better – for one thing, more chance to practice stuff, and also, this would give us the transition time of "being on our own without being on our own," as we'd be living in an apartment on our own while he was in the program. I said if he wanted a second opinion, to ask the therapists; he said he'd thought of that too, and asked the OT when she came. Once we assured her we'd be coming back later even if we had to pay for the second session out of pocket, she also thought it would be a good idea to stay for it, for the reasons I'd given; the PT walked by, and she agreed with the OT.

Gary's first task with the OT was laundry (I like this woman's thinking ;-)), and as we passed our case manager's office, I popped in to tell her what the Day Program manager had said to us. She went off to talk to the manager herself. Later, she came and told us that it still wasn't known if Gary could get in the program right after discharge, but it was looking like he could, in which case they would discharge him from being an inpatient around the 23rd or 24th, and then he would have Day Program for one or two weeks starting about the 26th.

So now that I've just put up a clarification of when we'd be home, it is up in the air again. Supposedly we'll know by the end of this week.

Anyway, back to the laundry. The shoulder flexibility exercises must be helping, because Gary was able to turn on controls just by reaching for them, rather than by trying to use a gripper on them. After he got the load started, the OT gave him the homework assignment of finishing up the laundry, and then gave him his final task of her session with him: to talk through the IC procedure with her while she stretched his legs. The oral exam wasn't sufficient for him to "pass" the IC aspect of his training, of course; they are still scheduled to do another community IC, on Thursday.

Shortly after that session, with Mirko as witness, Gary completed his homework assignment. It turned out that by using the new, sturdy gripper I had gotten him from Ace Hardware, along with using a long-handled mirror for checking where the laundry was located in the machine, he was able to remove his wet clothes from the washer with little problem. So, looks like I get out of doing any part of his laundry after all ;-) (A nurse walking by asked him how he was at unloading a dishwasher – she had one he could practice on . . .)

Back in his room, while he was talking to Mirko, some men came to replace his special air-flow mattress with a regular hospital mattress – a sign of progress! Gary had a little extra time to talk with Mirko than he thought he would, because the psychologist, scheduled to come to his room, never showed – maybe she knew he didn't have any issues ;-). But soon after that Mirko had to leave for the bus station, and Gary had to go to transplanting class – time to get his tomato plant! The plant had been started from seed in late April, but having been under artificial light ever since then, it was only about six inches high – and rather pale! Gary questioned why they should repot it into another small pot and keep it indoors rather than taking it out to the garden. The garden therapist enthusiastically agreed to transplant it to a big pot outdoors with him another time. So instead of the tomato plant, she gave him a eight-inch peace lily to transplant. He already pretty much knew how to transplant, so he did it with minimal direction from her; she spent her time with the other two people, one who also had a pretty good idea of what to do, the other a beginner. Anyway, Gary did a nice job, even adding some floral moss and polished pebbles to the pot at the therapist's suggestion. I left before he was through so I could collect my stuff from his room before taking off to the chiropractor. But before I could leave his room, he came in – carrying the plant. She had given it to him, and he hadn't felt like he could refuse, even though we have enough to take back in the car and we really don't need anything more to take care of. We're thinking of giving it away, but we can't do so until after tomorrow – that is when the gardening therapist is coming to his room for another session!

Later in the evening Gary told me he'd made his first transfer to the new bed, and the nurse hadn't helped him at all, just watched to make sure there was no mishap. He said it hadn't been a great transfer – he'd ended up closer to the edge of the bed than he'd liked – but he did make it. Accomplishment! He then asked me if I remembered the ramp leading down to the art/horticulture room where he'd done the transplanting. I sure did – it had surprised me they had such a long rather steep ramp in the building, a mini-version of the dreaded "Blue Carpet" (Gary joked that to do art here, you either have to be in a power chair or be very strong). Gary told me that when leaving the art room, he'd stuck his plant between his legs and started up the ramp. The therapist ran over to him and said, "Here, let me help you." Gary said, "No, let me try it." He then made it up the ramp himself. No way would he have been able to do that a couple weeks ago!

In the evening, before I was going to stretch him, I asked if it'd be okay if I looked at his flap to see how things were healing – I hadn't seen it in the past four days because they'd changed the nurse's order to having the wound dressed only once a day, and the most convenient time for changing it was in the morning after his bath, which I am not usually there for (and I think he was trying to save me some work by not having me do it in the evening when I came). I didn't like what I saw. First, whoever had dressed it had put tape on part of the area that was supposed to have medicine and gauze on it, meaning the tape was directly on an area that was still in need of healing. Secondly, there was a large, raw, red area below his flap that hadn't been there the last time I looked. We called the nurse, telling her that I at least wanted to put on new gauze and pointing out the new reddened area. She said to go ahead and change the dressing completely and to put some antifungal cream (which she gave me) on the new red area, saying it looked like the area had been kept moist and the skin was breaking down in reaction to that. So I dressed the wound, telling Gary I thought I should just go ahead and be the one to change his dressing from now on. He said good, because he no longer trusted anyone but me and maybe the skin PT to do it right, and that one of the problems was that the nurses changed from day to day, so they didn't know what the area had been looking like. (And another problem, IMNSHO, is that some of them are slapdash when they change the dressing, probably because they are in a hurry to get to the next patient who is beckoning them).

Joe had called just when I discovered this little problem with Gary's skin sore, so we delayed talking to him until I was through changing the dressing. Then Gary called him to receive today's update, while I stretched Gary's legs (oh, and sorry for the confusion, Joe, I misheard a previous phone conversation – it is Sylvia letting the workers in, not Sue. And thank you, Sylvia!) Gary finished his conversation at about the same time I finished stretching him, so we then got him in position, and I crawled in with him for a five-minute hoodle. A few minutes later, the nurse walked in with Gary's blood thinner medicine, which he takes in a shot in his belly because he can't feel there. Gary joked that the nurse could give it to me.

I was outta there. ;-)

July 11, 2006

When I entered Gary's room this morning, he did not look extremely happy. It looked like the tech had just helped him transfer into his chair, and when I asked him how it went, he said "scratchy," which I guess is our new code word "not so great." He told me later that the tech had held him by under his armpit, completely throwing his technique off. I told him he needed to tell her what he wanted her to do. He said he had thought that this was just her way of doing it and that it would be all right. I reminded him of what they had said in the travel class yesterday – that he was the one who knew his body, and he was the one who knew what assistance he needed in transferring, and he needed to be assertive in letting people know how to help him – which I know goes against his natural tendency.

We went off to a session with the PT. We worked on car transfers – boy, do we need work on that. She had him try doing it on the driver's side – not that he'll be needing that skill for a while! – but that was even harder than the passenger side because with the wheel he had even less room to work in. After that we went to our own car, and (after I threw the stuff into the back – I had forgotten about that note to myself!) he practiced transfers into the passenger seat. These were harder than the transfers into the passenger side of the Saturn had been – the distance from his chair to the car seat was farther. But we're thinking that if he uses the transfer board (which he wasn't) he might do all right as long as he has a little additional aid by a human until he gets the process down himself. (With the board he can do the transfer in little hops and not one big leap, which should also help with problems like the window frame getting in the way – he gave his head a pretty big bonk on it today.)

We headed back toward the gym, which meant Gary had to go up one level of the parking ramp. The PT remarked he was going up it very well, and he told her he was surprised (and obviously pleased) at how easy it was – he is definitely stronger! An even bigger surprise: he easily negotiated the short steep ramp from the parking garage to the entrance to the building – that was the ramp that had been giving him so much problems. That one he said was just a matter of getting the right technique (having good momentum, going up it at the correct angle). Unfortunately each curb cut has its own quirks, so it will be a matter of getting used to each one (unless they are well-designed) and not a matter of applying the same technique.

The PT then wanted him to practice transfers, and when she heard he'd gotten his new bed, she thought it'd be a good idea if we practiced them there. He did a good one (me aiding slightly), and she said she was going to "check us off" on bed transfers – no more hoyer!

Next we had a Van Modifications class, sponsored by the rec therapists. It was again a case of a lot of information being covered in too little time, IMHO. I felt like I got very little out of the presentation – a topic like this is just not within my bailiwick in the first place, but epecially when a lot of information is crammed into a short time and I'm tired (I'm still feeling the effects of last week's intensive family training and, to top it off, am having my period). I didn't understand what the steps were that we should go through to get such a van – the lecturers threw out the names of resource organizations like NMEDA (National MobilityEquipment Dealers Association), which is an organization that apparently connects you with an authorized mobility dealer so you can make sure your van is to your needs and properly outfitted; ADED (the Association for Driver Rehabilitation Specialists -don't ask me how they got that acronym), which evaluates and trains those with disabilities to return to driving safely; the Vehicle Manufacturers Mobility Programs, which offers rebates; the Vocational Rehab Department of State Governments. Anyway, it wasn't organized in a way I could grasp as to who we were supposed to contact when about what (or maybe my confusion was due to my frame of mind), though I did get a bit of clarification on that when I talked to one of the speakers at the end.

Besides covering these resource organizations, the lecture also covered the pros and cons of minivans and full vans, lifts versus ramps. The lecturers seemed to be suggesting that full vans were better than the minis, and lifts better than ramps, but Gary said that was only true for those needing power chairs, and that he's been planning on getting a minivan with a ramp. One thing we'll have to make sure of is that he can wheel his chair up such a ramp as I don't think I could handle pushing him up it – the angle will be twice as steep as the approved ADA angle.

A couple helpful things we learned are that it is possible to rent the various vans for a day or so (so if we want we can try some out before making our final decision) and that some local dealers are willing to come to Shepherd with their vans so that they can be test-ridden-and-driven. We plan to take advantage of that.

The presentation was mainly geared toward those who would only be passengers, not drivers, so we stayed after the lecture and asked some questions. Gary wanted to know if "turny chairs" can be installed in both the passenger side and the driver side (these are the chairs that turn 360 degrees, so that Gary could wheel into the van from a side or back ramp, wheel next to the chair, turn the chair in whatever direction is best for a transfer, transfer into the chair, secure his wheelchair to the floor of the van, then turn in his chair to face the front, either as passenger or driver). The lecturers didn't know the answer for certain and told Gary to ask the dealers. He is also to make certain that the dealers understand that though until at least December he will be a passenger in the van, after that the intention is that he will take and pass the driver's evaluation and class and so will then become a driver of the van. To drive, he will, of course, be using hand controls. I will use foot pedals, same as always (I still have a hard time picturing myself driving a van – I've never liked big vehicles).

I'm not sure how long it will take for us to decide on and get a van. We're assuming that for a while after he gets home he'll be transferring into a car and maybe using that LETA bus.

After that lecture we headed back to the room, me telling Gary he was going to have to be the one responsible for choosing the van. I told him that I felt overwhelmed by the lecture, confused by it all, and therefore frustrated – and that when I get frustrated I get very very crabby. Sweet Gary said he knew that and could tell I was tired and not to worry, he would handle the van decisions.

Before getting very far we were waylaid by another rec therapist, who informed us we will be having airport mobility class all day next Wednesday – for part of it we actually go to the airport and the Delta people let us practice transferring into a plane (I think they also serve a snack – oh boy, airplane food :-p).

Joe had tried contacting us a couple times when we were involved in the van lecture, so we called him back. "All hell was breaking loose" at our house, according to him. I was afraid that meant there'd been some disasters, but it "just" meant that a lot of things were happening all at once here at the end of Joe's tenure, plus that there was much that still could be done but there wasn't going to be enough time to do it all, turning things into a pressure situation. I was kind of spacey at the time of our conversation, so I don't know how much of it I retained, but I think the main hassles were such things as coordinating the various kinds of workers (tile, wood floor, plumber) and having to repaint something (I forget what right now) because the yellow color that Joe had thought would look good had not – he'd renamed it "Mustard Gas Yellow" (he said that the math dept. volunteers had stayed very quiet when they'd seen it, and after several hours, he'd finally said, "So, you really hate this color, don't you?" They'd agreed they did :-)). Thank God Gary and I don't have to directly deal with this. I'm sorry Joe does, but we are grateful he is shouldering this burden.

Because we'd stayed late to the Van Modification lecture and Gary had to get in lunch and an IC, we were late to the next class, but it turned out not to matter – it was one we'd already been to and was on his schedule accidently (thank God, because it was one of those first rec lectures ;-)). So we went to find the skin nurse, because I wanted to talk with her today. I wanted to take over the care of Gary's flap again, but I wanted to know exactly what was to be done. The skin nurse had seen him early in the morning and told him everything looked great, including that newly reddened area. I agreed that his flap looked much better, but I was dubious that the raw part I had seen last night now looked "great." (Gary had relayed the skin nurse's words to me while we were in the elevator with the PT on the way to the parking garage to practice transfers. The PT had said to me, “So, you agree with the skin nurse on one thing out of three.” (I forget now what the third thing was.) Gary smiled and said that in case she hadn’t noticed, I was a perfectionist, adding that that was a good thing when it came to his flap.)

We found the skin nurse in her office, and I questioned her about every little detail I could think of about his flap and the surrounding area. At the end she said the nurses could take care of it if I wanted, but I said no, I didn’t mind doing it, but I needed to know exactly what needed to be done. She gave a little smile and said, “I know how you are.”

People are getting to know me entirely too well ;-)

Since we no longer had that class, we had a big two hour break before the next therapy session. I tried to work on the blog a little, but I felt too tired to be very productive. I half-heartedly suggested to Gary we could work on some therapy stuff, maybe balance exercises or something, but he wasn’t in the mood for anything either, also feeling tired out (he said he hasn’t slept well since Sunday – too many interruptions to his sleep by nurses coming at inopportune times).

At three-thirty the garden rec specialist was supposed to come to his room. When she wasn’t there by three-forty-five, I called her number, got no answer, so went off to find someone to locate her. I got Gary’s OT to page her, and then I returned to Gary’s room. A person from Human Resources was there. Evidently she is going to pitch a story to our town’s newspaper, all about Gary and his rehab here at Shepherd. She wanted to take his picture tomorrow afternoon to send off to the paper. I told her that Gary’s nurse had taken some great pictures of him at the Peachtree Road Race and had sent the pictures to me by email. I said I would forward the email to her. She said that would be good but would still take his picture tomorrow – I told him he had to shave ;-)

It was time for me to leave for a massage (the garden rec therapist never came). Just before I left, I asked Gary if he still loved me even though I’d been crabby today. He said, “Yeah. You wouldn’t be you if you didn’t have days like that.”

I told him I wasn’t sure how I should take that ;-)

In the evening he had the thought that if he proned I could get at his skin wound more easily, so this was the first time the two of us attempted to get him in that position ourselves. We were successful, and he was right, that position enabled me to dress his wound in a fraction of the time it had taken me before (and I told him that though that newly reddened area looked better than last night, that one application of antifungal cream I’d made hadn’t completely healed it as the skin nurse had claimed). After that, we got him on his back and I helped him stretch. Then we put him on his side and I climbed in for a quick hoodle. As we lay there in the semi-dark, he noted that originally they had planned to discharge him just two days from now. We laughed – no way was he ready to go home. We joked that we would have had to throw a tent over him in the parking lot of Fresh Market, because we couldn’t even get him in a car on our own to take him out of this area.

He said that he was going to miss being fussed over by all the nurses and staff (except during the hours of 10pm to 8am ;-)) when it was time to go home, that while having the injury was not enjoyable (and at this he needed a hug), some of the consequences of having it, like the cards and the letters and the reconnecting with old acquaintances and the fussing, have been, and what would he have when he got home? Just Blackjack and Tigger and me.

Hmm.

All for now.

July 12, 2006

Okay, the latest "official" plan is that Gary will be discharged as an inpatient on July 28th and then will go into Day Program on July 31st for two weeks (there was an opening in the program). We will probably go home the weekend of August 5th just to test out the home situation, assuming we can arrange to have someone go to our home before then in order to be there for the people who are delivering Gary's equipment (in particular the hospital bed and mattress) so that the equipment can be ready for his arrival (I think the delivery people will set up the bed but am not sure).

Mail call: Thanks to Ferenc Fodor for the Hungarian chocolates. We're going to open a confectionary soon ;-)

To the events of the day. Gary and I got him transferred out of his bed into his wheelchair and then again from his chair to the exercise mat after we'd gotten into the gym. First up was the tech, first task was his stretching. While that was going on, first his case manager found us and told us about the new plan (which, come to think of it, was the first plan), then the PT found us and told us his wheelchair order had been put in, so he should have that in about a month, depending on how quickly the insurance company gets to it.

Next on the tech's list of things to do was for Gary to practice going backwards in his wheelchair down a long hallway. I had no idea what the purpose of that was, but realized when he attempted going up a ramp backwards that he was using different muscles than when in forward movement. This, in fact, turned out to be the reason for this exercise, as the PT explained when I later asked her about it – it was another way for him to exercise his back muscles, not only because they are a weak point with him but to try to keep those muscles in balance with the muscles he will normally be using while functioning from a wheelchair (though Gary told me later that except for going up the ramp that way, going backwards had been easy).

When the PT took over, we headed toward the parking ramp for more car transfer practice, using our car. On the way, she mentioned that we should start on the paperwork – obtained from the case manager – for getting handicapped parking stickers. Later, when we got the forms from the case manager, she said that after Gary filled them out, Shepherd would notarize them, and then we would take them to the DMV (oh boy). She claimed that we would get a placard that could be transferred from one car to another, so that no matter what vehicle Gary was in (including that of friends) he could always be in a handicapped parking space, thus giving him greater room for maneuvering his chair.

Back to the car transfers. This time Gary used his long transfer board, and though the transfers still weren't easy, he was confident that "he can get this." The PT showed me how she wanted me to place my hands (one above his waist, the other under his butt) until he can do them entirely on his own, but she didn't have me do it then, "saving" me until he was more proficient at the transfers.

On the way back to the gym, he again tackled that ramp leading to the elevators that previously had given him fits. He was again amazed at how easy it was for him now, saying that it was a matter of strength, technique – and confidence, the last required to get up the momentum needed to tackle the ramp. In the gym we practiced transfers to and from a hospital bed that had just been delivered to the gym for that purpose. The transfers went quite well, and in fact one was fantastic – he got tremendous "butt height" on it (in fact the thought went through my mind that what he'd done was the equivalent of a standing high jump), and the therapist and I looked at each other in surprise, each thinking the other must have supplied a lot of help. But we hadn't. I concluded that somehow his foot placement, along with the push of his arms, had allowed him to use his legs as pivots extremely effectively, getting him up and over as never before. He said he'd had the same thought and wished he could do that all the time, and that if he could, he could just do a depression lift into an airplane seat and not have to have two people lift him into it.

Hopefully some day soon!

After that session, we returned to his room. I called Joe – he had called when we were on our way to the parking garage but I had had to put him off until after the class. Joe told us that by this Friday, an entire wing of the house was scheduled to be done – both bathrooms finished, all floors put in, completed painting of the family room and master bedroom. This would "officially" leave only having the garage built, but Joe mentioned that this would be the perfect time to have the two other bedrooms painted as well, since everything would be out of those rooms for the laying of the wood floors. Fearing we would be taxing our volunteers beyond the breaking point if they were presented with this new project ;-) we decided it would be best to hire a professional painter to do those rooms. This left one not-so-little problem – what to do with all my stuff that was on the "bookcases" made out of wood planks and cinder blocks located in my "study" (aka "the computer room"; I'm sure Joe had other names for the room, given the state he found it in). We decided the best thing to do was to get rid of the cinder blocks, since neither Gary nor I are going to be able to lug them around (note: anyone who wants free cinder blocks, get them from Joe – otherwise they are going into the dumpster), and replace that shelving with metal shelving. I doubt Joe is going to have time to put all the books, etc., on the shelves before leaving, so I believe the plan is to leave that stuff out in the hall until I can get at it. Maybe that will be an incentive for me to reorganize and throw out some of the things I keep "just in case" ("just in case I again become a fanatical gardener," for instance). **Maybe** that will be an incentive. Knowing me, however . . .

After that I talked to Gary's nurse and told her I thought Gary should start doing his own bowel program now, with a nurse in attendance in case he wasn't successful at it – it seemed odd to me that with something so important he had only been scheduled to try it once a week last week, this week, and next week. She said that she would put a note to that effect in with his orders, and that he would start doing it on Friday – not tomorrow, as that is the day I "get" to have the hands-on experience of doing it on him (I should have been practicing finger pushups all this time). After the nurse left, Gary jokingly said thanks a lot for volunteering him to take on this responsibility. Okay, maybe he was only half-joking.

In the midafternoon came another "group" activity. They started off with volleyball, using a beach ball. The motto was "use what you've got," since one player was a quad but with some limited use of his arms, one guy had some use of his legs but not much of his arms, one woman could stand with aid, Gary and his roommate – "paras" – had the use of only their upper bodies, and so forth. One couldn't help but cheer them on as they attempted to hit the ball, but it wasn't exactly a fast-paced game. Before the game started, a Human Resource person came to take pictures of Gary for the news article pitch, and he also took pictures of Gary playing volleyball – he says he's going to email them to me, so hopefully I'll have some nice action shots of Gary to put up on the blog ;-)

After volleyball came an educational game. The entire group of people (maybe about fifteen people, as the quads who had been playing cards while the others played volleyball joined in on this activity) was divided into two teams. They picked cards on which were written questions about various topics ("skin care," "community," "miscl.") and answered the questions for points. A lot of the questions were "what if" questions, about what the people would do if faced with various situations out in the community. As time ran out, Gary wanted to know which team had won (has he developed a new competitive streak, or have I missed it all these years?). When he found out his team had lost by 200 points, he said he thought there should be a double or nothing round. The OT said okay, and then gave his team a question. Unfortunately it was on dysreflexia – what steps to take should you experience an instance of it – and most of his team, including him, hadn't been to that class yet. I had, but Gary said I shouldn't give hints. He remembered a couple things I'd told him, and some other people remembered a little more, but when his team had answered all they knew, the OT said that wasn't all and filled in some of the missing things. Only, she didn't mention everything I had learned in my class, and I couldn't help it – I burst out with the remaining steps to take. Gary later said he was impressed that I knew the material better than the OT, but I told him that the reason for that was that the condition had scared me so (since it could be life- threatening) that I wanted to make damn sure I knew what to do if it ever happened to him.

After "group" was over, Gary had another session with the exercise rec therapist. This time she had him try out one of the special golf carts. First, he did a depression lift to the seat of the cart – I think that was the highest transfer he'd ever done, but with the help of both the rec therapist and me he did very well. Next, she strapped him to the seat with both a seat belt and a trunk belt – loose enough so he could have movement, of course. She set up something I think might be called a "swing trainer (?)" (basically, a golf ball suspended from a string). She gave him a club, he swivelled the golf cart chair around to where he could hit the ball, and then he practiced some one-armed swings, hanging onto the seat with his other hand so he could lean. “At least I’m hitting the ball,” he said. He did that a while, and then we helped transfer him back down to his wheelchair seat. We were now going in the easier direction – he could use gravity to help him – but I was impressed that he didn’t just plop down onto his chair (which would have been terrible for his flap) but went down in a controlled manner, neither the therapist nor I having to control the rate of his descent. Another sign he is stronger and getting better at his balancing.

The therapist again mentioned that another option, instead of using a special golf cart, was to stay in his own wheelchair and go to the driving range to practice hitting balls. As he wheeled away, I asked him if he thought he might do that when he got home, or if he might use one of those swing trainers (or whatever it was), but he said he didn’t know; he was just doing it here because it was a new toy to play with.

I had to leave for the chiropractor and asked Gary what he was going to do next. He said he was going to stay in the gym and work on some of the weight equipment, because, he said, the volleyball had been useless as exercise. (I think the positive feedback he is getting by seeing the improvements he is making is fueling his motivation to get even stronger.) But when I returned in the evening, he said that exercise session hadn’t gone so well: one piece of equipment that had been recommended to him for strengthening his back was broken, and another one wasn’t set up right (but rather than ask for help, he just decided to do something else – typical! ;-)) What he did instead was tool around the facility, just getting exercise that way. He said one thing he’d done was to go to the same ramp he’d tried to go backwards up this morning. It is a rather steep ramp, and it leads to the stage the winners of the Peachtree Road Race (Wheelchair Division) had mounted in order to get their awards. Gary joshed that he’d thought he’d better practice it in case he had to go onstage next year to receive one of the awards (then noted that if he could win such an award, he would have no problem with the ramp). He said when he’d gotten to the top, he’d gone onstage, not realizing a meeting was taking place there. Someone had recognized him and said, “Hi, Gary.” I asked him if he’d told her he was practicing to receive his award next year, but that hadn’t occurred to him at the time.

In the evening I came laden with containers of Fresh Market mixed berries and Hagen Daz mango ice cream. He wanted both. As I dished them out, his nurse for the night shift came to introduce herself, as the nurses and techs always do. She said she just wanted to tell him who his nurse and his tech were for this evening, but she could see that he had his nurse and his tech right here (meaning me :-)). Gary said, “I sure do.”

We did our usual thing – stretching, wound care, then me climbing in with him for a short time. I told him I wondered if they’d let me participate in Day Program with him as I was doing now with his therapy sessions, or if they would at least let me observe the sessions. He said he didn’t see why not, and I reminded him that they had originally told me that after the first few days I wouldn’t be allowed to be with him during his therapy here, but that they’d never brought it up again – and I certainly hadn’t. He said he supposed whether or not they let family members stay depended on what the family members did – he said he sure wouldn’t want the parents or a spouse of a student being in his classroom when he was teaching – especially if they gave hints. He noted that I did the opposite, and then he mimicked me talking to the therapists and nurses: “Are you sure he doesn’t need more weight on the rickshaw?” “Yes, he can do another hour of therapy without a break.” “I think he should be practicing his bowel program every day now.” And the best one, according to him, was my answering for him the nurse’s question of “Are you in any pain?” by saying, “No, he’s not.” (Hey, he’d always said before that he wasn’t – I saw no reason for him to be in it then! ;-))

After I left his room for the night, I ran into his roommate’s wife in the restroom (she works at her job about half a week, then spends half a week up here). We talked a short time (they found a medication for her husband that is helping ease his pain, but he is sleeping a tremendous amount lately). As I left, I said, “See you tomorrow.” She rolled her eyes and said she had to be here at eight for a wet run (shower). I told her I “got to be here” at eight to do Gary’s bowel program. She said with relief that she’d already done that, and she’d told her husband, “That is the LAST time I am doing THIS!” The two of us started laughing, and then we laughed even more when I told her that when I’d just left Gary a moment ago, I’d said to him, “Just think. Next time I see you, I’ll have my finger up your – ” (You know what I said ;-))

Hey, we have to get our amusement where we find it here.

To finish, some pictures by Janet Rogers. See the blog, http://drpeg2003.blogspot.com/ (scroll down).

July 13, 2006

Doing the bowel program actually turns out to be quite simple. Maybe this means I’m weird (but you already know that ;-)), but I found it rather interesting to experience the mechanics of it, to feel the bowel muscles squeeze my finger in peristalsis, the BCR reflex provoked by the rotation of my finger.

However, I don’t find it interesting enough to be leaping at the chance to take over this duty on a permanent basis ;-) He needs to develop his endurance and shoulder flexibility quick!

After I’d finished with that (earning a “pass” from the nurse) and helped Gary with a bed bath and getting dress, we did a transfer to his chair and took off for the gym for a session with the tech (it just occurred to me there are two kinds of techs and I may have confused you – there is the therapy tech, with whom he does PT stuff, and then there is the nursing tech, who aids the nurse). The tech started him off on the Uppertone machine, on which he did side raises and rows (he joked that he needed less than no weight when he does raises with his left arm, as I had to even remove the pin on the machine for him to be able to lift the lever arm). After the side raises, he asked me to make up some of his protein drink, and he joked to the tech between the sets of the rows that he needed to drink some of this “muscle juice” to refuel him for the next set.

She next got him on the hand cycle, and when he started in with a little huffing and puffing, she told him he could breaks. He said he wanted to avoid doing so, because while there were lots of things he was strong enough to do now, he poops out and therefore needs to build his endurance.

Next came his stretching routine. Gary and I finished it up on our own because we ran out of time with the tech. While we were doing that, Gary's PT walked by, and I reminded her she was going to show Gary another hamstring stretch, one that he can do on his own rather than depend on me to lift his leg up straight while he is lying in bed (though after he gets more flexible and stronger, he should be able to do that one himself). This new stretch consisted of him having his legs out straight in front of him and sitting as upright as he can while keeping his knees straight (as opposed to his knees popping up). A more flexible person might even be able to lean forward and keep his knees straight, but Gary had to stay in a backward lean.

After the stretching, he lay back down and prepared to roll to his side so he could get closer to the edge of the mat, in preparation to sit up and get his legs over the edge so he could transfer to his chair. As he took a few preliminary swings with his arms, he commented his shoulders were stiff and sore. He stuck out his lower lip. "They're hurting me," he pretended to pout. We laughed, and I offered to help him stretch his shoulders. We did that for a few minutes, and then he rolled, sat up, and we did his transfer into the chair.

We had a half hour break, and then it was time for his session with the OT. Gary thought she was planning to do another community IC with him, and he was right. I wasn't sure I was invited, but I acted like I was and wasn't told otherwise. So there we were, three of us – two females and a male in a wheelchair – all in one of the stalls in the public men's room on the third floor of Shepherd (fortunately the stall was a large one). As Gary set out his equipment on the transfer board he'd set across the toilet and went through the steps of the IC, the OT kept up a running conversation – asking Gary if he would talk to another patient who was about to have flap surgery and was worried about it (yes, this guy too had gotten a bedsore while at another hospital), asking us about the van class we'd attended, and so forth. At one point I laughed, saying it seemed odd to be carrying on this conversation as we all waited around for Gary to finish with the job at hand. The OT said she'd thought it better to talk than to stand around in awkward silence during what is usually a private moment. I told her Gary had told the nurses, kiddingly, that he was going to have to watch it when he went home, so used was he now to so many people seeing him unclothed. He didn't think it would go over very well if he announced, "Sorry, class, it's time for my IC" and then proceeded to do it right then and there.

We all got very quiet as a man entered the restroom and went into the other stall. The OT and I held back snickers as, for some reason, the guy kept heaving sighs. The man gave no indication that he noticed all the feet in the next stall. After he left, I commented to the others how we'd all fallen silent, saying I had done that because I hadn't wanted to freak the other guy out, and they agreed with that motivation.

Gary passed this test successfully this time (asking the OT, "So, does this mean we don't need to spend any more time in the bathroom together?"), and as we were getting ready to leave the john, the OT commented that she wanted Gary to work on his method of propulsion in his wheelchair. After you push your wheels, you are supposed to drop your hands down and bring them toward the rear of the wheels, so they kind of describe a circle. Gary has the tendency to bring his hands straight back, which means he only gets them to the top of the wheel, and which, according to the therapists, is harder on the shoulders. The OT seemed ready to end the session, but I innocently ;-) said, "Is that all for today?" (Hey, there were another ten minutes to go – I want Gary to get his money's worth whether or not he likes it ;-)) She looked at her watch and decided she could set up a little obstacle course of chairs for Gary to weave in and out of and practice the proper push. So he did that, but I know it didn't break his habit: I pointed out shortly after his session, as we went back to his room, that he had already fallen into his old pattern. He isn't quite convinced that he needs to break that habit, I know. I found a rehab article on the 'net comparing the different techniques and saying that the method the therapists here recommended was the better one to prevent shoulder problems, so I will have to show that to him. Maybe he'll do some web research on it on his own.

By the way, speaking of bathrooms, Michel Smith emailed us that he is discussing with the university's ADA officer about refurbishing the men's room on the third floor of the math dept. building so it will be accessible to Gary, rather than him having to use the one on the second floor! Michel also wanted the measurements of Gary's wheelchair in order to make sure Gary would have a desk that would be a comfortable working surface :-)

A little non sequitur note (you remember those, don't you?): Gary no longer is restricted in how long he can sit in his chair, as of today! (Though a nurse confided to me that the patients were usually back in bed by 6pm anyway – they're still healing, after all, and there's all this therapy tiring them out.)

During a break after lunch, Gary found the other person who was going to have flap surgery and talked with him awhile about it. I wasn't there, but Gary said he spoke about how good the doctor is, that his own flap is healing slowly but surely, that the three weeks in bed afterwards wasn't all that bad – therapy is still done at bedside and your bed is rolled to classes so you can attend them.

In the afternoon, Gary had a wheelchair maintenance class. Between some combination of hearing the information again and not having the information rushed through, I didn't find it as confusing as it had been when I'd heard it during the family training class.

Next we went to "group chair class," whose stated purpose was to strengthen you for using your chair. I wasn't quite sure what that meant, but it turned out to be a group weight training session. Gary thought I'd be bored during it, but I wanted to at least see what they'd do, and it turned out to be a good thing I stayed. First they started with arm stretches, and Gary had problems with that for two reasons. First was his lack of shoulder flexibility, so to get anything out of the exercises he really needed someone to provide a little support and a little extra stretch. Secondly, they did the stretches while sitting up in their chairs, and as the exercises required both hands being used at the same time, Gary didn't have the balance to do them without me holding onto him at the shoulders so he wouldn't fall over. Same thing with the weight exercises. He can barely hold both hands up in front of him in "chipmunk" position, for example, without tending to fall forward in his chair, so holding weights in his hand while in a similar position just aggravated that propensity, and moving the weights forward or out caused him to topple. Even in doing the various exercises with just one arm at a time and trying to use the other to help provide support, with the weight in his hand he couldn't keep his balance on his own. So I held him by his shoulders the whole time as he did biceps curls, triceps extensions, rotations, side raises, punches, etc. I guess the other people in the group either had more abdominal control or their chairs gave them better support, as they didn't have this problem with their balance.

I did not like how the exercises were led. The therapist counted off the repetitions at a rapid rate, so the only way the exercisers could keep up was by slinging their dumbbells around, using momentum rather than muscle, not getting the full effect of the exercise. I muttered something to that effect to Gary, and when there was a break between sets I whispered in his ear, "Think I should tell her she needs to slow things down?" To my surprise, since I hadn't really been serious and he is usually the "don't make waves" type (or at least, that is my impression of him), he said, "Why don't you?" So I "asked" her if it wouldn't be better if they did the exercises at a slower rate, so that muscle rather than momentum would be used. She claimed they couldn't use momentum in the positions they were in, which made no sense to me, but I didn't push it. But when she started another set and it looked to me like Gary was feeling pressed to keep up the pace with the others, I burst out, loud enough for her to hear, "Slow down. You're going to hurt your shoulders." Since we had already told her he couldn't do the stretches like she wanted him to on account of his shoulders, I figured she would accept this as a reason for him not try to keep up with the others – and besides, it was true, he was more likely to hurt his shoulders if he didn't keep the weight under control, not to mention that the exercise would be more effective if done under control. I wasn't sure he'd listen to me, but he did, and it then became kind of funny in a tenderhearted way (at least to me): she wanted them all to participate in counting out the repetitions, so he would call out the same number as the rest of them, just to be part of the group, even though he was doing the exercises at about half their speed and therefore was way behind them on what repetition he actually was on. She did comment to him that his form was good and she liked how he went for quality, but why she didn't encourage that in the others, I don't know.

After that session was over, I told him anytime he wanted to work on balance exercises with me, to let me know. We are going to try to remember to ask his PT what would be good ones for the two of us to do – I don't want to do any where there is any danger of him falling forward off the exercise mat, for example. We are also going to ask if his chair needs any adjustment so that it is not so difficult for him to keep his balance when his hands are raised in front of him.

We talked to my brother Joe a few times throughout the afternoon. The main thing going on at the house right at the time was that the floors were being leveled in preparation for the wood floors being laid tomorrow. The pictures we've seen of the house look fantastic – I can hardly recognize the place. Joe is such a perfectionist in his work. I guess that shouldn't surprise me – we are related, after all ;-).

I went off to the chiropractor again so he could try to bend me back into my proper shape – I feel like I need to see him about every four hours. In the evening when I came back to Gary's, the man was fast asleep, so I worked on the blog awhile. After he woke, I got him some ice cream, then we went through the stretching routine. When we did his shoulders, he looked down at his forearm as I held it. "Wow, they really are bigger, aren't they?" he commented. I told him they were about twice as big as they had been when he'd first come here, that I could have practically wrapped my hand around them twice at that time (exaggerating a little ;-)) but that now I needed two hands to get around them; I said that when he'd first arrived, even the tops of his arms had looked like sticks. He then said that the Birmingham PTs and OTs certainly could have done better by him – he'd seen them maybe twice the entire time, they'd given him an exercise band to pull on, which he couldn't use because of it pulling on his IV needle, and that was it. I said it sure made a difference, coming to a place like Shepherd with such expertise. Then I added with a wink, "Of course, now I tell them how to do their jobs." He told me I'd make a good boss (no, I wouldn't – my employees would hate my perfectionism), that now I knew their jobs better than they did. "Or at least I think I do," I said in self-mockery. "I think you do too," Gary said.

I then did his wound care, and after that I gave him a little massage. He had complained after waking up from his evening nap that for the last two nights there has been a spot on the back of his shoulder that is bothering him, like a nerve is being pinched. It only bothers him when he lays in certain positions too long. I hope this resolves quickly, as he sure doesn't need this kind of problem along with everything else. I massaged him a bit on the tender part and reminded him that he could have the chiropractor come here, or a massage therapist, to see if they could help with the problem. Then we got him positioned on his side, and I climbed in for a little hoodle. Shortly thereafter, I gave him a kiss goodnight, and told him I loved him very much. "I know that," he said, "based on what you did for me this morning."

I laughed.

July 14, 2006

This morning while Gary and I were waiting for the tech, we stretched Gary's shoulders, did his transfer, and then he did a little balance exercising – sitting on the edge of the mat raising his hands and trying to stay upright. The tech soon joined us, bringing along pushup blocks. Gary's first task: forty depression lifts using the blocks (turning the lifts into dips). He told me to kneel right behind him to make sure he didn't fall backwards. (While he has gotten much better at "saving himself" by throwing his hands behind him when he falls backwards, this really isn't possible to do when he has pushed himself up on the blocks and then falls backwards – no time to release the blocks and then get his hands behind him). He did the forty lifts in four sets of ten. Next, the tech wanted him to do forty more, this time with his legs up on the mat, straight out in front of him, instead of them dangling over the edge of the mat. This turned the lifts into a much harder exercise. In fact, getting into the proper position was an exercise in itself, as he had to do depression lifts to hop backwards on the mat while the tech held his legs to give him a little help. Once he was in the proper position (and after taking a little rest break from getting into it), he tried this new exercise. No way could he do it unaided – he couldn't push up on the blocks without falling backwards (his already iffy balance made even worse by his inflexible hamstrings). So I held him upright by holding my hands against his shoulder blades while he did the lifts. With a little moaning and groaning in exertion, he got through those too.

The tech giggled as she read to herself the sheet of paper the PT had given her listing what was to come next, and we had a sense of foreboding. "Seventy-five pushups," she informed Gary. "Seventy-five pushups!" he exclaimed in disbelief. "This is a fifty-nine year old body!" She told him he'd do it easy, to take a little rest from his lifts before starting. He rolled onto his stomach and collapsed face-down onto the exercise mat. "Seventy-five pushups," he informed the mat in a "she's out of her mind" tone of voice. But he did them, five sets of fifteen, beet red at the end of each set. I told him I bet if someone had told him a year ago he could do seventy-five pushups, he wouldn't have believed he could. "You got that right," he informed me. For the rest of the day, whenever anyone asked how his day had gone, he told them in mock indignance how his therapists had made him start if off with eighty depression lifts followed by seventy-five pushups. But I suspect he is proud of his accomplishment.

He was grateful that the final task on the tech's list was his stretching routine. We went a little over time again, and ended up with a half hour break before his next session instead of an hour. I asked him if he wanted to practice anything else before the next session, but he wanted to rest, as next up was an hour in the gym with the exercise rec therapist, and he feared the torture she planned to inflict on him. So we did a transfer back into this chair, intending to return to his room for a short while. After the transfer, he asked if I'd given him much help. I said I'd helped a little, both because it hadn't felt like he was getting a major leap and because I thought he might be a little tired out from all the lifts and pushups. I admitted that when the therapists weren't around I probably tended to help him with the transfers more than I had to, that I couldn't stop myself from doing that – I didn't want him to get hurt so I wanted to make damn sure he landed square in the chair. He said he understood, that "better safe than sorry."

On our way to the exercise rec therapist, Gary again said he was worried about the session, that he was still feeling the effect of those lifts and pushups. I told him that those exercises worked his triceps and chest muscles, and if he told her what he'd done, she would probably work his back. He started off the session by making sure the therapist knew about all the lifts and pushups. She thanked him for informing her and told him that they would therefore work his back muscles :-)

She started him off on the NuStep machine (see http://www.nustep.com/ for a picture), which is the machine the "been there done that" guy had advocated, and Gary really liked it. He transferred onto the seat of the machine, then the therapist strapped his feet onto the pedals and put another strap around his thighs so his legs wouldn't splay out. He exercised on it for ten minutes, pulling on the hand levers, which caused his legs and feet to move as well. As the website mentioned above states, "NuStep® Recumbent Cross Trainer's unique design lets you move arms and legs in a fluid motion that simulates walking with the added benefits of resistance training." The therapist told him that among other benefits, it was a really good way to get the circulation going in his legs. I opined that one of those benefits would be that it would help disperse the fluid accumulation Gary has in his feet (which is a common problem for those with SCIs, due to sitting in the wheelchair all day without the use of the legs), and she agreed.

One thing that she noted during the session was that Gary now has one shoulder hiked up way higher than the other, something we never noticed before the accident (and in fact didn't notice until he'd gotten to the point where he could sit in the wheelchair and do rehab). She told him to consciously try to keep his shoulder down so the muscle wouldn't stay in a contracted state, and also to stretch his neck muscles. A little later, when the OT was working with Gary on his balance, she too commented on his uneven shoulders, and, lifting the back of his shirt and feeling his ribs, she noted that he had one of the ribs really sticking out (she had us feel it too). She thought maybe this was a result of how his broken ribs had healed after the accident. She wondered if he should get lateral supports on the back of his wheelchair to keep him more even in the chair and in that way help with his balance. I don't think Gary wants that though – that would mean he'd have to have a solid back on his chair, and he likes the canvas one better as it gives him more mobility.

Back to the gym. The rec therapist showed him the cable tower and had him do rows and internal and external rotations on it. She told him he could do all the exercises on it that she'd shown him last time on the Bowflex. She also pointed out the exercise tubes ("stretch cords," we used to call them in my swimming days; see, for example, http://www.exercisetubes.com/), telling him that using them was a nice portable way to do a lot of these exercises.

She finished by showing him the "Easystand machine." (See http://www.easystand.com/products/6000.html) He isn't ready for this machine yet, but when he is, the first step is to get him standing upright in it, as in the bottom picture on that website. She warned him that many paraplegics got lightheaded, could even faint, when first brought upright, on account of the blood rushing down into their legs. So, it is a gradual process. Once he can stand upright in it (for half an hour, I believe she said), he can try to pull on the upper levers, which will move his legs in a cross-country type of motion. But even the standing would be good weight-bearing exercise for his leg bones, she said.

So, it turned out he hadn't had to fear that exercise session – the therapist did a lot of talking and he did hardly any work. I notice he didn't complain about that ;-)

Next came the lunchtime routine. Brad Bailey, one of Gary's grad students, called during that time and informed Gary that he had cleaned out Gary's office (for some reason Hercules's task of cleaning out the Aegean stables came to my mind – not that I should talk ;-)). Gary was very grateful – as I said ealier, if you've ever seen Gary's office, you would know that with his papers piled everywhere, it was not wheelchair accessible (nor habitable by many humans ;-) – again, I should talk). Gary couldn't stay on the phone long, as it was time for the OT, so we toodled off to that session. The OT wasn't in sight when we arrived, so I asked Gary if he wanted to do one of the stretching exercises she recommended – crossing one leg over the other – or to just wait for her. I then asked him, “Why are you smiling like that?” He said, “Because I feel like there is a right answer and a wrong answer to your question.” He is lucky I didn’t smack him ;-). He escaped that because he then gave the right answer.

When the OT came and found him with his legs crossed, she said that this would be the perfect opportunity for him to work on getting his one foot up so its ankle is crossed over the other knee, working toward the goal of being to be able to get his own shoes on and off. So he attempted to get his foot up, using chain loops to help haul his foot up his leg, but he needed lots of help from the OT. Once they’d gotten his ankle up, the OT stretched his leg in that position, trying to get knee level with his ankle instead of pointing upward as it was. She couldn’t help laughing, saying she knew we’d been stretching him in that position, but that there hadn’t been a tremendous improvement. I pointed out to Gary how much of a stretch the OT was applying to his leg, telling him to note that I hadn’t been doing that any more than that. “Yeah, but she’s the expert,” he said. The OT said that I was getting to be an expert just from being there; then she said, “Don’t look too good, Peg. We’ll lose our jobs” (then she added, “Just kidding”).

Ah, another ego boost – good for keeping my enthusiasm up.

They then worked on Gary’s balance, Gary having mentioned to the OT how he hadn’t been able to do any of those weight exercises yesterday in group without me holding onto his shoulders. She named some exercises he could do while sitting in his chair or in his bed to help develop his sense of balance – such things as dressing; any activity involving two hands, like drinking from a cup; a weight exercise where he lies on his side and moves a light dumbbell in front of him and around to the back. Then she gave him a walking stick to hold and had him try various things with it: hold it by both hands out in front of him, touch the tips to one side or the other (trying to shift his head and therefore his weight to the opposite side), lift the cane straight up with both hands, bring it straight out (putting his head back to counterbalance), bring it in (bringing his head forward as well – all such moves to keep the center of gravity at “the balance point”). Then she gave him a large beach ball and had him try to roll it from side to side or touch it gently from side to side. All of this was clearly exhausting, his face carrying an intense look of concentration as he wobbled around like a bowl full of jelly. He was definitely ready for a break after that, and fortunately we had one before seeing the PT.

During that break, Gary and I ran through his stretching routine (first transferring him back into his bed). We wanted to do it then, because there was another scheduled outing in the evening, from 6 to 9 – a dinner outing – and I didn’t want to have to do the stretching after that. I noticed that after getting him into bed, he was having some muscle spasms in his legs and abdomen. He said he was having more spasms lately, and wondered if that was good or bad. I told him something that had been said in one of my classes: it could be either – good, in that the muscles were getting some activity, bad, if the spasms got to the point where they were causing pain or interfering with daily activity. I hope his don’t get “bad.”

The PT started out with “fun” activities, also with the goal of working on Gary’s balance. First she and Gary played something with “Koosh ball” raquets, though they didn’t have an official koosh ball. I don’t think any of us really knew what that game entailed, but she and Gary batted the ball back and forth in a manner similar to table tennis (and sometimes it got accidently swatted to me, and I became an involuntary participant). Next she had him practice quick turns in his chair – he was to face sideways, then do a quick turn at her command and hit the beach ball back to her that she’d toss him. She left us in order to help an OT for a while with something, so she had me be the one to toss the ball to him while he made these quick turns. Then he and I were supposed to play catch, me tossing it not just straight to him but to one side or the other. (I later regretted these activities – the jerky motions and running after the ball caused me to pull some things in my shoulder, back, and leg, not noticeable at the time, but definitely noticeable later). He finished up with the “fun stuff” by dribbling the ball to one side of the chair or the other. I thought he was pretty good at this.

We then went out to the parking garage, and she and he practiced car transfers. He only experienced one head clunking, and his last transfer was a really good one – he was pleased about it for the rest of the day. The PT thought the way she’d aided him during the last transfer he did would probably be the way I should help him – one arm under his arm and across his chest for balance, the other under his butt, mostly for guidance, not lift – she said she’d helped him about 20% on the way out of the car, but only guided him on the way in. I would have to be his eyes as well, to tell him where butt was in relation to the car seat so he didn’t end up on some of the hard rims of the door frame.

After he’d made his last transfer out of the car, the PT noted that this time he’d managed to keep his shoes on (for some reason, they kept coming off during many of his previous car transfers). Gary noted that not only had his shoes stayed on, he’d managed to land so that one of his feet had ended up on the footplate of the wheelchair. “Just the way I planned it,” he joked. He told the PT that he felt really good about this session, that he could almost do this “for real.” He brought that up several times the rest of the day, and I would add to that his lift and pushup accomplishments, so I think he felt really pleased with the progress he’s making.

On the way back into the building, at the PT’s direction, Gary “took the curb” instead of going up the curb cut. He approached the curb at speed and did one of his wheelies, the PT right behind him to make sure his wheelchair didn’t tip over. I asked her whether when we went home and Gary had to go up a curb (assuming he ever does), if I’d be doing that kind of thing with Gary, or if I’d be doing the other way, which is harder on me, the way where I put my hip against the chair and push. Of course the way that is easier on me carries a greater danger of Gary tipping backwards, so we wouldn’t want that! The PT said we would practice that after Gary got more proficient at doing those with her. Gary said the first few times he practiced it with me, he would wear a helmet. Good idea!

After that session, I took off for my hotel to cook up some rice and zukes to take on our outing, then rushed back to Shepherd and waited for Gary at the bus. The patients’ chairs were strapped down in the bus, and then we took off. It was a short journey – the Bear Rock Café was only about six lights away, in the same shopping center as the Publix I sometimes go to.

Gary was first off the bus (because he was last on, and therefore strapped down in the rear), and the rec therapist told him his task was to open the door to the café while the others were getting off the bus. It was a heavy door, and it took him several tries. A man and a woman seated outside looked on in puzzlement, no doubt wondering why I was making this poor man struggle with the door, so I made sure I said to Gary in a voice that would carry to them, “Good job,” when he finally got through the door – thus assuaging any of my own guilt ;-).

The café was similar to a Paneera’s – soups and sandwiches, in this café the bread all organic. Gary ordered a root beer, a cup of paella soup, and what I think was called a beef dip sandwich – beef and gorgonzola cheese and peppers, etc. We wandered into the seating area and for some reason took an inordinate amount in choosing a table. The couple who had been outside had come in, and they offered to move for us so we could have their table. I’m not sure why they did that – maybe to have the opportunity to ask what was going on, because when we declined their offer, the man said that he could tell by the door incident we were on some kind of training run, so we explained a little.

Right after we’d chosen our table and I’d set my food carrier down, Gary’s order was called, so he went over to pick it up. I trailed behind him. The patients were supposed to try to be as independent as possible, only calling on the aid of their helpers as a last resort. The pickup counter was extremely high. Gary asked me if his bowl of soup had a lid on it, as he couldn’t see into the basket the food was served in, and I said “no.” It took him a couple calls of “excuse me” to get the attention of a worker in order to get the lid. I almost grabbed the basket as he lifted it down to his lap but refrained – however, had the basket been any heavier I fear its contents would have been dumped out.

After setting his food down at the table, it was time for a drink ;-). The drink dispenser was set up in a corner, making it hard to maneuver a wheelchair near it, and the handles for dispensing the drinks were too high for easy access – Gary couldn’t see how much drink was in his cup without tilting his cup – which of course he couldn’t do while dispensing the drink, as that would have been a two-handed activity (as his Saturday PT said, he may never be able to do such two-handed activities, on account on not having the balance due to the height of his injury). He filled the cup about half way. He then placed the cup on the counter next to the drink dispenser and reached into a compartment to get a lid for the drink. Again, the compartment was too high for him, and he ended up just grabbing at it and snaring a couple of lids instead of trying to carefully get out just one. Getting a spoon for his soup presented a similar problem.

Back at the table, he realized he’d forgotten napkins, so he wheeled back to the same area for some. When he returned to the table, he told me that the woman in the wheelchair now at the drink dispenser must have had even more problems than him, because as he’d wheeled away, she’d said, “Oh, shit. Somebody help me,” and the rec therapist had come to her aid.

We sat at a table by ourselves, and while eating Gary decided to put his long-sleeved shirt on – he'd made sure to bring it, having learned his lesson on the Dick's outing ;-). I spaced out for a while, concentrating on my food. When I looked up, it seemed like quite some time had gone by and Gary only had his shirt on over his head. I looked at him. He looked at me. We both started laughing. He finally got the shirt down around his torso, me giving it only the final touches, both of us still laughing. "I don't know why it amuses me how long it takes me to get a shirt on," he said. "Better than 'frustrates you,'" I pointed out. "That's true," he agreed.

After finishing his meal, he went to the dessert counter – tonight was "free dessert" night (or maybe they just did this for our group, I don't know). Gary picked out a cake called "Chocolate Thunder," which he said was very rich. He had only a couple bites. Unfortunately, since the accident, his body strongly reacts to the diuretic effects of caffeine, and he therefore can't have much of it because he needs to keep his ICs under 500ml. So, he hasn't been having any coffee (a true sacrifice, for him), or caffeinated tea (a couple trials where he took a few sips indicated he needed to give that up), and he hasn't made much of a dent in all the chocolate sent to him.

After finishing the meal, Gary decided he wanted to get a paper, so he told the rec therapist he was going out to find one. Boy, was it muggy outside, like a sauna – particularly noticeable after the refrigerated air of the restaurant (why, in the South, do they keep the airconditioning on so cold??? I don't recall the buildings in the North being kept at such frigid temperatures when it was hot outside). We didn't find an outside paper box, but the drugstore in the shopping center carried papers. The employee behind the counter rushed over to open the door on our way out, but Gary told her he was practicing his wheelchair skills and not to help. On our way back to the restaurant, a woman at an outside table at another eatery said, "Looks like you're on an outing." It turned out that she was on the junior committee at Shepherd, a fund-raising and support group. We chatted awhile, Gary telling her to keep up the good work, that Shepherd was a great place. Then we returned to the café. It was time to go, and he and I waited outside while the others were loaded into the bus. He commented that he seemed to do more than the others on the outings – he was the only one to buy anything at Dick's, and here, he'd gone out to get a paper. I told him he was going to be more prepared for the "outside world" when he left Shepherd. In fact, his PT had said something similar today, that we were already more prepared than most people when they left Shepherd. I would hate to be in their shoes then – I don't feel ready to go.

We got back in his room about eight. We'd already done his stretching, and the nurse had changed his dressing in the morning, so we had all this "free time" we were no longer used to having. "What do you want to do?" Gary asked. "Get into bed and have a long hoodle," I replied. "Sounds good," he said. It took about a half hour to get him transferred into the bed, undressed, and positioned. Then I crawled in with him and we dozed together for about a half hour before I left for the night.

Mail call: Thanks to Todd Eisworth. I hope he doesn't mind my sharing this, but in his letter, he said, among other things, that he had been thinking about Gary, was wondering about how he was doing, wasn't sure how to find out, and that a Google search led him to my blog! Incredible. This reminded me that Jo Heath had told me in an email (and I hope that she doesn't mind if I share this as well) that when she and Bob were at the conference in Greece, a number of East European and African mathematicians mentioned that they read the journal (blog). Truly amazing. (I laughed when she said that when they asked her how Gary was doing, she couldn't tell them anything more about Gary's recovery than they already knew from reading the blog.)

Todd's and Jo's letters got me thinking again about the genesis of the blog, about how all alone I felt, how very afraid I was, after the accident – particularly that first week – and about how writing to others about what was going on, while it didn't relieve my anxiety, it eased it, a sense of shared burden, I think. The comments I get pertaining to the blog continue to make me feel like I'm not alone in this and keep my spirits up – good not only for me but for Gary, since we can give only from what we have, if you get my meaning. I'm certain things would be a lot harder on me if I hadn't found this outlet and didn't get the feedback. I admit I'm a little needy these days.

I had wondered how Todd had googled the blog, so I spent a couple minutes doing a search. I accidently used Yahoo! search instead of Google, filling in: "Gary Gruenhage" + accident. I didn't get any hits, though I later discovered that, for some strange reason, the blog will come up if I remove the quotes. Anyway, before discovering that, I decided to fill in his name plus mine into the search bar. I didn't get the blog, but I did come up with the following URL, which gives a photo (I assume taken by Ed Slaminka), of the math faculty and graduate students in 1982 (if I get permission from Ed, I'll put the photo directly on the blog).

Here's the URL: http://www.auburn.edu/~slamiee/NAMES.HTML

Aren't we a handsome group? ;-).

July 15, 2006

Ah, Saturday. Day of only one therapy session. This Saturday, Gary's session was run by the woman who'd said the next time she saw him she wanted to see that he could lift his head off the mat and that his rolls had improved. He was ready for her. But before he got to show this off, she set him other tasks. First came one of his favorite exercises ;-) : fifty depression lifts using the pushup blocks. At least they were the kind where his legs dangled off the edge of the mat. The therapist had to oversee other people at the same time as Gary (so I guess that's the standard Saturday situation), so she waited until I returned from his room with his grabber (for a later task) before starting him on the lifts. She went off, and I knelt behind Gary while he did the lifts to make sure he didn't fall backwards onto the mat and hurt his head.

After that, she gave him balancing exercises, me aiding him while she went to the mat next to us to help another person. For these exercises, I stood in front of Gary and he reached out and touched my hand with one of his hands, his other hand either behind him on the mat or on his knee. We first started with my hand directly in front of him, then to one side – eye height, higher, lower – then to the other side in various positions, so he had to cross his hand over his body, which was actually the easiest kind of touches. He started out very wobbly – which set off my vertigo, but I didn't tell him that; it was an interesting experience (not one I particularly recommend ;-)) watching him wobble around like a weighted chicken's egg while I myself felt like I was on a rolling ship. After we did it a while, he got smoother at it, able to slowly reach out his hand and touch mine in a controlled manner instead of starting to slowly reach out then batting at my hand hoping he'd hit it before he had to catch himself from falling. He said it was unbelievable how tiring these exercises were, due to how much concentration they demanded; he said he knew they looked simple, but they certainly were not. The PT came over and told him that the purpose of the exercises was for him to learn what he needed to do to keep his balance, to learn to reach as far as he could, but also to learn just how far he could reach, and where, before he would topple – everyone has such a maximum reach, but at the same time it wouldn't be good for him to limit himself unnecessarily.

After that, his task was to get his shoes off. But the new grabber was too heavy and big for him to manipulate it to get the velcro undone, and even after I'd undone the velcro for him, he couldn't push the grabber into his shoe and get it off. So, he will have to work on this problem, perhaps by using a lighter grabber while he's in the sitting position or by taking his shoes off when he is already lying in bed and not beforehand (unfortunately, taking his shoes off after he gets into bed presents the problem of getting his feet onto the bed with his shoes on – the friction of the shoes against the surface of the bed mattress makes it hard to get his feet up by himself). The PT had the excellent suggestion that he should think about what he wants his routine at home to be like, and then to try to go through the steps of the routine here and see if he runs into any problems that could be worked on these next weeks.

She next wanted us to run through his stretching exercises. That first involved him lying on the mat on his back, properly padded off with pillows. She asked to see him raise his head so she could put a pillow under it. He did so. She cheered because he hadn't been able to lift his head off the mat two weeks ago. She then taught him the routine she goes through with her four-year-old daughter when some goal is achieved: first they did a high five, then touched their fists together in a "rock" (as in the game "rock, paper, scissors"), then they raised their hands in inward-facing fists and pumped downward at the elbows, yelling, "Yes!" She told him she hated to tell him but her four-year-old looked much cuter when she did it.

She then had us do his stretches. She tsked at his lack of flexibility when we got to the last exercise, the hamstring stretch where I kneel next to him and raise his leg while he is on his back (he pulls on the chain loop wrapped around his foot in order to support some of his weight). She showed me another way to get more stretch on that exercise by kneeling next to him, keeping my arms straight – one at his heel, the other below his knee – and leaning forward. She did it on him first. Gary's eyes got round, and he asked if she should really be stretching him that far, saying that if he could feel, he was sure that would hurt. She assured him she wasn't over-stretching him, but I'm not sure he was convinced. She said he needed to work up to a 110 degree angle on the stretch, and he couldn't even do a 90 yet. Gary said we'd work up to it, but he didn't want to do that all in one day!

After that she wanted to see his rolls from his back to his side, and they went through another "Yes!" routine when he showed off how he could do them now. He told her that her tips had been in large part responsible for his improvement, but she refused to take the credit. She gave us both hugs when she found out that he wouldn't be an inpatient in two weeks, so that this was likely the last time she'd see him. She told him it was on account of people like him that she stayed at this job. She had been the person who had done his PT eval when he'd first come in on May 17th, those tests to see what and where he could and couldn't feel. She recalled that he'd been barely able to sit at the time, and now he was well on the road to independence.

After that came the lunchtime routine. Joe called and gave us an update on the house. He mentioned that he'd had time (or rather, made time) to modify the kitchen sink access so that there would be no obstruction to Gary rolling under it. Joe had lined the sides and the back edge under the sink with wood, so everything was "neatified." He was hoping the tile guy would come some time today and tile the floor under the sink to match the other tiles in the kitchen. Other updates were that the shades for the various rooms should be arriving next Thursday (on Jo Heath's watch ;-)), that Sylvia would feed the cats, and that he'd had to do a little conniving to get the dumpster people to do as they'd said they'd do and remove the dumpster today. Joe had also put a second coat of paint on both bathrooms and installed some of the fixtures.

He also mentioned that our poor kitties have been freaked out these past few days because of all the various workers – no surprise to us. He said he's spent time trying to calm them down at night, especially Blackjack. He observed that they would probably be very unhappy kitties after he left because they wouldn't be getting the day in and day out attention he'd been able to give them in our absence. :-(

I turned the phone over to Gary, as Joe might not be able to stop into Shepherd tomorrow to say goodbye. Gary told Joe that what he'd done had been truly amazing and that we'd be forever grateful. Tears came to Gary as he said that, but I doubt Joe noticed.

A little later in the afternoon, Gary decided he needed to do laundry. He asked me if I'd help by looking into the washer to see if there were any clothes in it and later by putting the clothes into the dryer, since it would take me two seconds to do something that it would take him ten minutes to do. I asked him if he was sure he didn't want to practice those skills. He said no, he was satisfied that a solution existed (which is what is important to a mathematician, after all ;-)). I pointed out that his back-up solution seemed to be that I do it. He just smiled.

Some time later, as we both worked at our laptops across from each other at a table in his room (me working on the blog, him working at the letter he is composing for Ward's memorial), Gary brought up the comment I'd made last night, that it was better that he was amused by it taking him so long to put his shirt on than to be frustrated by it. He said that it had never occurred to him to be frustrated by it, that "this is the way it is – it takes me fifteen minutes of wobbling around to get my shirt on." I told him that if I were in his situation my reaction would probably be to be frustrated a lot of the time, to get mad at myself because I couldn't accomplish "the goal" quickly.

I'd had the same thought today when watching him so patiently trying to touch my hand during the balance exercises – if our positions had been reversed, I'd probably have been screaming in frustration. I told him it was a good thing he didn't have my personality.

He let me read his letter for Ward's memorial, and it made me cry and laugh, it being about what Ward had meant to him and also relating an amusing anecdote about a camping trip they'd taken.

Though as of yesterday Gary is unrestricted in the time he can sit in his wheelchair, he said he now needed a nap, conveniently deciding this was the case at the time he should have been checking to see if his laundry could be put in the dryer ;-). So, we got him transferred into the bed and positioned. He fell asleep immediately. I put his laundry in the dryer and left until evening. When I returned, he was sitting in his wheelchair and said he'd managed to also get out of taking his laundry out of the dryer – someone else had done that for him (no doubt wanting to use the dryer), and had even neatly folded his laundry for him, leaving it on top of the dryer. I felt the teeniest tiniest smidgeon of guilt: I had taken someone else's laundry out of the dryer to make room for Gary's, and though I hadn't crumpled it into a ball, I had done a hasty folding job. Hey, it's bad enough to do Gary's laundry – I ain't doing some stranger's.

Joe called with an update. All the final major stuff was done: wood floors put in, tiles laid, most of the fixtures put in. Fantastic!

After Joe's call, I told Gary it was time for him to get into bed – we still had his stretching to do and his wound care. So we did that, and when I saw his wound, I regretted that he'd had the nurse change his dressing yesterday morning – again, tape had been put on a part that should have been protected with gauze, IMHO, and the area looked aggravated. I'm going to have to remember that if there are times when it seems necessary that the nurse or tech change the dressing, that at least I should check to see how they've bandaged it.

After getting him positioned, I climbed in with him for about ten minutes. When I made to get out, he said wistfully but not really serious, "Why don't you stay the night?"

I told him because I didn't want the nurses to accidently do his midnight and six a.m. ICs and his five-thirty a.m. bowel program on me.

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Well, wish me luck with the hotel situation. The long-term residents who had been living next to me moved out. They had turned out to be pretty good neighbors (I suppose they were about the best one could hope for in a hotel situation), and I'm a little anxious about who is going to be in there now. No one seems to have checked in so far, but I'm sure that luck won't hold ;-) I had thought of offering to pay the former neighbors to live there another two weeks until I leave this place to live with Gary in the Day Program apartment . . . ;-)

July 16, 2006

I spent some time trying to catch up on my sleep this morning. I slept until after eight, worked a little on the blog (yesterday's events), then went back to bed for another hour before heading over to Shepherd. When I got there, I told Gary I'd been thinking about what the PT had said about running through his routine and seeing if there was anything he thought he needed more work on. I told him there were a couple of things I'd like him to work on, as they were among the hardest on me: getting his legs up on the bed after he'd transferred into it and getting him positioned in the bed. Him getting more flexible and being allowed to bend more will help with the first – his hips and legs just don't want to bend as they "should," (like a person with normal flexibility's would, and he has never had normal flexibility) which makes it so much harder to get their deadweight up on the bed; and since he can't bend past a certain degree, he can't reach around his legs while on his side to help me lift them up. I don't know how much progress we can make on this particular problem, but I want to bring it up to the OT again. About the positioning, I told him it was hard on my back and shoulders to have to grab the top sheet he lies on (which is not tucked in) and pull it toward me in order to get him far enough to my side so that after he rolls I can get the pillows placed properly along his back to keep him up off his flap. He said he and I could work on this problem and he thought he might be able to help a little more on that than he sometimes had been.

Gary's cousin Jean and her husband Stuart came around noontime, and we soon headed out on our adventure to Mama Fu's, first taking the "Blue Carpet tunnel" under and up Peachtree street to cut off some uphill travel. Gary noted after the excursion that he could tell his endurance was improving – he'd made it to the restaurant without being tired out by the trip, though we did make a brief rest stop in the Atlanta heat. We spent over an hour eating (well, they did the eating – I'd again forgotten to bring my rice!) and having a really nice chat. One thing you don't have to worry about those Groteluschens is that they'll run out of topics of conversation ;-) – which is good, since Gary and I tend to be the quiet type when it comes to conversing. We talked about Gary's situation, Gary and his cousin exchanged news about various relatives, and so forth. After the meal, I asked Gary how his red curry had been. His restaurant review is that the place is good for a quick Thai meal, but if you really want Thai food there are much better restaurants in Atlanta.

We headed back to Shepherd, Stuart helping Gary up a curb cut that always gives him fits. We had intended to take the tunnel back to Shepherd, but the door to the building containing the elevator that leads to the tunnel was locked. Jean and Stuart checked out the other entrances to the building, but they were all locked too. Stuart offered to walk back to Shepherd, go through the tunnel, come up the elevator, and open the door for us :-) but Gary told him that was all right, we'd just go down Peachtree – it's not so bad on the stretch we had to cover, being downhill and the sidewalks in decent condition. So we did that, and entered Shepherd through the garden. We pointed out our graffiti sign to Jean and Stuart – maybe I should make a permanent plaque for that sculpture, as the paper sign is gradually deteriorating ;-). As Gary headed up the ramp into Shepherd, Jean asked me if I'd ever tended to try to do too much for Gary, probably asking me that because she'd noted I had let him try to open all the heavy doors on our way to and from the restaurant, had let him huff and puff his way up inclines without giving him any help (though I did help him down that nasty curb cut), and had let him get his own drink at the restaurant's drink dispenser, only offering to get a lid down for him to cover the drink with because there was no way in hell he could reach it ;-). I told her that the Shepherd people had told me right at the beginning to let him do as much on his own as he could. Gary added that I certainly followed that directive to the letter ;-). I told Jean that the only thing I may provide too much help on is the transfers. I suspect I'll tend to do that until they clear him on transferring on his own.

Stuart took a digital picture in the garden of Jean, Gary, and me, and said he would email it to me (and send you a picture through the mail, Mom G). I'll put that up on the blog when I get it (after possibly editing myself out of it ;-)).

After they had to go, I stretched Gary's legs in the chair, worked on the blog, finally got around to answering a couple emails (sorry about the ones I haven't responded to yet!). Gary did some balancing exercises and worked on some Topology Proceedings. He was ready for a nap at about four. We're thinking he might want to make that a regular routine, at least for a while, as taking a nap that early, rather than at about 6pm as he had been, seemed to help regulate his evening ICs. It is, of course, the getting his feet up that helps with the regulating, as it allows the fluid collected in his feet to start to resorb. We'd been putting his feet up in a chair during the afternoon but hadn't really noticed much benefit from that. Anyway, we'll see if this was just a coincidence or if the lying down that time in the afternoon really does help.

After he and I got him transferred into bed, I discovered the disadvantage of him dressing up for Jean and Stuart – Dockers. They don't slip off his legs as easily as those stretchy sleep pants do. Since this was the first time he'd worn them, I thought it best – recalling something we'd been told in one of my classes – to check his skin to see if there was any problem in him wearing the new type of pants. He'd cut the buttons off the back pockets so they wouldn't press against his skin (which is extra sensitive on account of the SCI), but the back pockets themselves were a new feature. So I got the pants inched off and checked his skin. No problem. I put a pair of sleep pants on him, and then we got him positioned on his side. We tried something new. He pulled and pushed himself over to one side of the bed instead of me pulling him over with the sheet. After he rolled to the side, since he was farther away from me than we'd normally had him, I used three more pillows than usual to prop him up on his side and hip. I'm not sure this new method was easier, as I have to tuck the pillows down under him then pull a sheet over the pillows and then tuck the sheet under the pillows in such a way that they won't slip, and this way there were more pillows that had to be fussed with (I don't think I can describe why this method seemed not much easier on my back and shoulder – you'll just have to trust me ;-)). The good news is that after the flap heals more, we won't have to be quite this precise about his positioning on his side – he'll just have to make sure he's on his side off his sacrum – at least, that is my understanding right now, though we will, of course, check on that before changing anything.

After he was "pillowed," I covered him, rolled his table around with his water bottle on it, put his call button in reach, turned off his light, and gave him a kiss. "Thank you, Pookie," he said. I think the extra gentleness in his voice was due to the battle I'd had with the Dockers ;-)

I stayed there a short time, working on the blog, and a resident (doctor, that is) came through the curtain. I played “Keeper of the Gate,” going on alert as the guy moved toward Gary, who appeared asleep. I’m sure the guy would have woken Gary up had I not been there – so he could check off on his report that he’d spoken to the patient, is my guess, whether or not the patient was in the state of consciousness to be spoken to at the moment. But as I was there, instead of waking Gary, the doc told me he was there to see how Gary was doing. Gary’s eyelids briefly fluttered open, and I think he registered the doctor’s presence, but he closed his eyes again without acknowledging the doc’s restatement to him that he was there looking in on him. “He looks exhausted,” the doc said to me. I should have said that was due to being woken up by staff at inopportune moments ;-), but I told him as quietly as I could that Gary always has a little nap in the afternoon, that we’d moved it up in order to see if that helped regulate the ICs, and that he might be a little more tired than usual because we’d gone on an outing. The doc asked if there were any more issues, and I said I didn’t think so. Fortunately the guy didn’t wake up Gary just to make sure <ironic grin>.

When I was certain the guy had gone ;-), I left for the hotel. In the evening when I returned, Gary told me that the IC had again been where we wanted it, and then we started on our usual routine, beginning with a transfer into bed. For some reason he slid backward on the wheelchair seat just before he made the transfer, which caused this transfer not to be one I’d want filmed. “Hey, I’m on the bed,” Gary said, meaning that this was the criteria for a successful transfer, even if it hadn’t been one we’d want his therapists to see.

Usually after he is on the bed, I get his legs up as he lays down, but in the position he’d landed, there was no way to get his legs up without him falling backward and hitting his head on the far rail of the bed. So I reclined behind him and helped him ease himself down onto me, so I could prevent him from hitting his head. I then laid him down on the bed and got up to get his legs. This was definitely a new position he was in – I joked that he’d have to sleep in the bed at a forty-five degree angle with his legs hanging out of the bed – but with a little judicious rolling on his part, we finally got him situated. Definitely some refinement of our technique is still needed. ;-)

We then did the stretching, then the wound care, then the repositioning for the night. I climbed in for a hoodle. After a few minutes of drifting, I felt him sort of pawing at my shoulder. This is the kind of thing he does unconsciously when we are in bed and he starts thinking about something (which tended to drive me nuts when I was about to fall asleep!). So I asked him what he was thinking of, and he said of how nice it had been to go out to eat with me, and we should do it when we go home (going out to eat together was something we’d given up when my CFS became so severe, and we’d never resumed the habit – one reason being, I still can’t eat anything out; but it’s been nice here just to sit with him and eat the food I’ve brought (or not) while he has his meal). Him bringing up home reminded me that I’d been wondering about his first days back on the job, whether I should be with him, “in case something happens.” He said he thought he’d be fine once he got in the math dept. building, so there was no need. I said it’ll be odd getting back into some semblance of our usual routines. He said I’d be able to start back with my story writing again, that he was glad I’d been able to continue writing during this time even though writing a blog is so different from the type of writing I'd been doing. He thought I should follow up on others' suggestions that I try to get the blog published in some form. I wondered how I'd be able to balance trying to work on two very different kinds of writing.

I suppose this is a sign of life moving on, this thinking about the future. I've had blinkers on for months now, just getting through day by day. Of course, I can't think too much about what's going to be going on a month or so from now – tomorrow's another full day of therapy!

Here are the latest pics, stealing some captions from Janet Rogers, who took the pictures (those of you getting this by email need to go to the blog at http://drpeg2003.blogspot.com/):

(Pictures inserted here.)

As Janet Rogers says, didn't Joe orchestrate a fantastic job! Thanks so much to everyone involved! (I had to laugh when Donna Bennett put in her email that everyone was looking forward to Gary's return, first because they really want him back with them, but secondly so that they can declare the house finished, at least for the time being. She said that the house is really looking good (so we see!) and that "all" that is needed is a little cleaning up, a lot of touch-up where the installers weren't so careful about the paint job done by Joe and the math department volunteers, and the completion of a long list of final touches. I would also like to share a little of what she said about Joe (paraphrasing a bit) – I hope she won't mind. She said that all of them really enjoyed working with Joe and hated to see him leave, that he was easy to work with, always willing to listen to their ideas and discuss what they were doing, and that he'd been full of great ideas – no doubt from his years of experience. She wished she had known some of the things he told them when she was redoing her house over the last two years.)

July 17, 2006

First let me say Gary seems to be all right. Second let me say I could have done without today's excitement. Before his afternoon session with the tech, Gary decided to practice wheelies like he'd been doing with the OT in the morning, only, doing it with the tip bars on instead of off as he had with her (as I've said, this skill is used for going up curbs, over uneven surfaces, down ramps). I felt uneasy, because I hated seeing him tip back even though the tip bars were supposed to prevent him from falling over backwards – I just didn't trust those tip bars. I decided to move behind his chair even though I figured he'd think I was being overprotective. I'm sure you can guess what happened. Just as I made my move, his chair tipped over backward. It was so awful, rushing over to him knowing there was absolutely no way I could stop what was going to happen, seeing the look of horror on his face, hearing the clunk as the back of his head smacked the floor, seeing the look of pain on his face. I fell to the floor next to him, afraid to move his head but wanting to cushion it from the floor, wanting to hold him. People came running. One of his first thoughts must have been about his flap, because he held his legs above the knees to keep his legs from falling toward his face (and thus preventing his body from bending too much). A PT told him she'd hold his legs in place for him. Two nurses arrived, and ran through various things one checks for with a head injury: whether he'd lost consciousness, if he felt nauseous, if he had a headache, if he had blurred vision; the only one he said "yes" to was the headache; he also said he had tingling in his fingers (that went away shortly afterwards). They said they'd bring some Tylenol and an ice pack and that the doctor was coming to check him out. They also took his temperature (normal) and his blood pressure (high). They asked him what happened, and he told them he'd just been trying to practice the wheelies. They first assumed he'd tried it without tip bars, but he said he'd had them on; then they said he must have done a particularly vigorous one, and he said no to that as well. They were perplexed, but the PT examining the tip bars said they were back too far. Turned out Gary's OT hadn't known the tip bars had two positions, and after the morning's session she hadn't put them back on what we'd been told was the correct position.

Various staff and fellow patients came by to ask how Gary was doing as he lay there on the floor. He said he was fine except for the headache. Me, I was more of a mess, trying not quite successfully to hold back tears, frightened that now he would have a brain injury, feeling guilty because I hadn't been behind him, hadn't acted on my intuition quickly enough. Once again I felt like turning him into "The Boy in the Plastic Bubble" so no harm would come to him. The resident doctor came and asked Gary the same questions the nurses had, then said he didn't think a head scan was necessary but that if any of those other symptoms should arise, to let the nurses know immediately and they'd get him scanned. The two nurses and two of the therapists lifted his chair up (him still strapped into it), and we discovered that he'd broken skin on the back of his head and it was bleeding a little. They shaved the area, then gave him ice (tied up in an examination glove) to put on it. They said the doctor said he was free to do whatever he wanted to do. He looked at the clock, saw there was half an hour left to his therapy session, and asked his tech, who was right there, what he was supposed to do during his session. She said "the terrible threes." He said he thought that would be all right to do, since he'd be prone and he was fine except for a headache. The tech and I looked at each other. We suggested to Gary that he go back to his room and rest – I tried to make light of it, saying I knew that I was always willing for him to do more in his therapy sessions, but today I thought I'd cut him a break. He agreed to go back to his room. The therapy tech and I got him into his bed and proned so that we could put ice on the back of his head. Other people came to check on him – his nursing tech, his OT and PT, the psychologist (Gary said he was fine, though admitted he'd been scared, especially when all the people had surrounded him in concern; he told the psychologist that maybe she should talk to me, since I was more traumatized by it than he was – he was right; I even felt guilty about that, since it took the attention away from him and put it on me. I told the psychologist I felt guilty for not having prevented the accident; she and Gary assured me it was in no way my fault; part of me didn't believe them.)

The ice on his head made him cold, so I brought him hot cocoa and later hot herbal tea. I told him I'd read the mail to him, as it had just arrived. One item was a card from my mom, and I started crying while reading it aloud and at one point I couldn't go on – the afternoon's stress had gotten to me. Gary tried to comfort me, again assured me he was all right and that it was in no way my fault. I said I intellectually understood that now, but overriding all that was the plain fact that I didn't like seeing him hurt. He smiled ironically and said that he didn't like being hurt, either. Janet and Jack Roger's package containing a couple "Clueless George" books (take-offs on "Curious

George," satirizing you-know-who) was the other item we'd gotten in today's mail, and I read the books to Gary – they were just what I needed to help calm me down.

After I read him the books, Gary took a nap for about two hours. I stayed right there, wanting to make sure no afteraffects from the fall arose. He wanted to change his head position a couple of times, so I would take the ice off his head then reapply it. I was glad he woke up these times, so I could make sure of there wasn't any disorientation or any other mental sign of concussion – had he not woken up, I would have woken him myself. After his nap, he wanted to get back in his chair. We "cheated," me giving him a lot more help than I normally would in getting him upright and in doing the actual transfer – he said he felt fine, but he would take the extra help just to be sure nothing weird happened. After he got into the chair, he told me to go to the hotel and take care of myself – I don't know how much of it he could see, but I felt really wiped out. As I collected my things to go, he wheeled outside the curtain. "Where are you going?" I said. I must have sounded anxious, because he said in an reassuring voice, "Just to open the curtain." As he did so, he joked, "Then I thought I'd practice some wheelies, then go outside and try some curbs. Would that be all right?" I gave him a look. He said, "Don't worry, I'll be a reluctant wheelie-er for the next while. I'd rather do a hundred pushups." I didn't tell him that the OT had come in while he was asleep and told me that the next time she saw him (which although she usually sees him everyday, this week won't be until Thursday), she would do wheelies with him, a "back in the saddle kind of thing." I'll probably be having an anxiety attack during the session – assuming she can convince Gary to do it.

As I left Shepherd, I remembered that I was supposed to have been at a chiropractor appointment over a half hour earlier. I stopped in, apologized, explained what had happened. He has been very understanding and compassionate this whole time, so my being late was no problem. He joked that maybe he should bring a helmet for Gary to wear. I felt like taking him up on it.

In the evening when I returned to Gary's floor, laden down with baby salad greens, mixed berries, and banana split ice cream, a nurse saw me coming down the hall and called out, "He looks good." I told her that's exactly what I'd wanted to hear. Gary was still sitting up in his chair, and said he felt fine, no headache. I had been planning on asking the nurses if they were going to wake him throughout the night to make sure of his neurological status by asking him questions (I knew that this is something that is done after head injuries), but it turned out I didn't have to – he said that they were going to do so every four hours throughout the night per doctor's orders. I told him I was sorry I'd gotten more traumatized than him by the situation. He said he understood why that should be, a "first a husband who is paraplegic, now this" feeling. He did hope that the OT wouldn't get in trouble, as other than this she's been great.

He had some fruit and then ice cream, and then we went through the evening routine. Before leaving I told him, "Do me a favor and don't hit your head ever again." He said he'd try not to. I told him that the chiropractor had said he could borrow his helmet. Gary joked that tomorrow he should go to his therapy sessions wearing it.

Not a bad idea.

Well, now that I started this entry with the middle of the day, I'll go back to the beginning. First up was the therapy session with the OT. They began with wheelie practice. He started off very jerky, and the OT told him to be zen, to be one with the wheelie. It isn't possible to stay in the wheelie position (at least, for long) without moving the rear wheels back and forth, but she told him to move his hands only as necessary, relaxed and reactive to the process; the PT who'd first worked with him on this had seemed to be indicating that it was a much more active process, and he did much much better with this new advice (and I think it was the great confidence boost that he got as a result of this session that later led him to practice the wheelies on his own). After having him stay in approximately the same spot, the OT had him do a little traveling while in the wheelie, and then to do 180s. They finished this portion of the session by having him practice "wheelies up a curb," except that because there wasn't time to set up the 4"-high wooden platforms they use as curbs, he was to pretend a particular line on the floor was the curb and do a wheelie when he got to it, and then immediately lean forward as he would in order to help the rear wheels get up the curb.

Next she took him to the practice kitchen they have set up for the patients. She pointed out how the kitchen sink had been modified in order to allow a wheelchair to roll under it, but we told her Joe had already taken care of that. She had Gary practice getting stuff out of cupboards with his grabber, pointing out the rather obvious thing that lighter stuff should go on the top shelves. He is scheduled to do a cooking session with her on Thursday, and she told him she'd placed his order for ingredients: spaghetti and garlic bread and broccoli. She also would have gotten him spaghetti sauce, but we'd said no thanks, we'd supply our own, and in fact I picked up some "Mothers" garlic and basil sauce and olive and caper sauce at Fresh Market in the evening.

She mentioned that he should now be starting to practice doing his bowel program on his own. He told her he already was. She said he was the first patient to ever do the bowel program on his own without being told. I held in a smile. Gary later said he should have told her that he was doing it because I'd suggested to the nurses that it was time for him to do so, and that I had an ulterior motive for making the suggestion – not that he blamed me!

Next he went to the ProMotion Gym for a session with the exercise rec therapist. This time she gave him a good work out. She started him on a Schwinn hand cycle for five minutes. Then he went to the Bowflex and did two sets of ten of chest presses, flies, internal and external rotation, one-arm rows, shoulder extensions, and tricep extensions. While he was doing this, I mentioned how he hadn't been able to do the group weight exercises with dumbbells because of his balance. She said she was going to show him some dumbbell exercises next and give him some tips. We went over to the dumbbell rack, and she told him to pick out his weights. He said he'd start out easy, and picked up some three's. She told him to put them back – that no way was she going to let him get away with that :-)! So he picked up some fives. She showed him one-armed (bent-armed) side extensions and a couple variations of one-armed biceps curls. She also showed him some more balance exercises he could do: raise his arms out to the side and lean in one direction, then the other; she explained another balance exercise, one where I would sit behind him and give him little pushes in different directions and he would have compensate. I gave an evil grin and said I liked that one (of course now that I write this after the head-bashing occurred, this doesn't seem very amusing).

During the half-hour break before the next class, I called the adaptive technology guy at Shepherd and asked if there was any way that both Gary and I could get on the internet in his room at the same time. The guy came to Gary's room later in the afternoon, and now Gary and I won't have to fight over who gets the ethernet cord.

The next class we attended was Airplane Mobility Class, where they went over what was going to happen at the airport when we go on Wednesday. It will be a long day, from 9-3. The participants will do ticketing, security, take the elevator to the train, take the train to the terminal, go to the gate, then do a transfer into the aisle chair (a big-boned woman asked at this point, "How long we gotta be in that itty bitty chair?", which made everyone laugh). Then they get rolled into the plane, then get transferred into the airplane seat. On the plane, there will be a presentation about airplane travel for those with SCIs. Next they'll deplane, and go off to do their ICs. Next comes lunch at the food court, then back to the train or the moving sidewalk, finishing up at baggage claim.

After that class came lunch, and then we went off to the tech session, right before which occurred Gary's fall. So now we've come to the events I've already described. It was a long, long time before I got to sleep last night (it is now Tuesday morning), and I shot awake too early. I kept seeing the image of him going down. :-(

July 18, 2006

Gary was his usual self this morning, except now with a bump on his head. He said the PT had come by this morning to see how he was doing. He joked to me that it was too late now, but if he had played his cards right, he could've gotten out of a couple of days of therapy.

First up was a Respiratory Class, which I'd already had. The lecturer spent a lot more time on the physiology of respiration than my lecturer had; I enjoyed the review of stuff I'd learned in science classes so long ago but can't say how many of the other people did ;-). She then went into how the different levels of injury affected breathing, coughing, and sneezing (I have certainly noticed that Gary sneezes differently now that he can't recruit his abs for the effort). The nerves for the diaphragm are located at levels C3,4, and 5. So those whose injury was at C1through C3 (hereinafter referred to as C1-3s, and similar for those with injuries at other levels) have no control over the diaphragm, no use of rib or abdominal muscles, can't breathe, cough, or sneeze without assistance (Christopher Reeve was a C1). C4-8s have partial use of the diaphragm, so can usually get off a ventilator; they will not be able to cough without assistance. T1-5s (Gary's category) have good use of the diaphragm so can get off the ventilator. Some rib muscles may work. Abdominal muscles don't. Thus coughing and sneezing are weakened and these people may need help to cough up secretions. T6-12s' diaphragm and rib muscles work well, abdominal muscles may be working; coughing and sneezing are weakened, and they too may need help with coughing.

Those whose injuries are in the lumbar region usually have no problems with breathing: all the muscles used in respiration work well.

Then the lecturer went into a discussion of pneumonia, which I have told you is the number one killer of those with SCIs. She covered its signs, treatment (including the "modified Heimlich maneuver" used in assisted coughing), and methods of prevention.

After that we went to a session with an OT – not our usual OT, as she was on jury duty. Before starting it, Gary and I decided to do one of the leg stretches he is supposed to work on, the one where he sits in his wheelchair with his ankle across the opposite knee, which will be useful in getting his socks and shoes off – assuming he ever gets flexible enough to get in this position himself. As I put his leg up, his chair tilted back a little, as it always does when we do this because his muscles are so stiff. Fear flashed in his eyes and I grabbed the chair. We both gave nervous laughs. Something like that wouldn't cause his chair to tip over, but I'm sure you'll understand why we were a little on edge about it. At least for the next while, we will make sure the back of his chair is against the edge of the exercise mat when we do this stretch.

In the OT session Gary did "the terrible threes" (described earlier), then the rickshaw, then he practiced learning how to sweep and use a (light) vacuum from his wheelchair. As the OT handed him the broom, she deadpanned, "Now, when you get this room all done . . ." Gary told her that at home we will be hiring this chore out.

On the way back to Gary's room after the session, the skin nurse stopped me and told me she had changed the protocol for Gary's sacral flap care. Now I'm to use just the xenaderm on the flap, and I'm to keep an eye out to make sure this change doesn't cause his wound to become too "wet" from drainage (she said to watch for it looking macerated or turning white).

After we got to his room, his case manager popped in and asked if we wanted to do an in-center pass this weekend. We said "yes." So this weekend, starting Saturday at 4pm and going to Sunday at 4pm, we will be in a private room in Shepherd, left to ourselves – like a dry run of being at home (it just occurred to me (maybe I'm a little slow) – I'll bet the reason they call a practice shower session a "wet run" is as a take-off on "dry run"). The nurses will still give Gary the pills he takes (stool softener and pepsin – the latter used as a prophylactic) and his blood thinner shot, but other than that, we are on our own (except in case of emergency). So, Debra, when you come this Sunday, we will be able to watch "The Matador" in relative privacy ;-)

In the early afternoon, the psychologist came by for her scheduled visit. She asked how we were doing after yesterday. Gary said he was fine, I said I was pretty much okay but still a little shaken by watching him get hurt. She said she was sure it had stirred up all kinds of unpleasant memories about his car accident, and she was right. She then asked how we felt about our preparation for being at home on our own. Gary said he felt good. I said I was a little nervous about it, about getting everything "right." Gary then said he also was a little nervous, but not much, and that as far as my being nervous about doing things right, he had confidence in me. She said our team continues to think we're doing great. She asked if we'd ever done an in-center pass, and we said we were going to do that this weekend. She thought that would give us (probably meaning me) more confidence that we would be able to handle things at home. But she cautioned that when we went home, our new routine would most likely tire us at the beginning, more so than we might think (though if it's more than I think, I might be in big trouble ;-)), so we should be careful not to try to do too much outside stuff, not to overextend ourselves socially or with work obligations – just settle into the home situation, keep things simple, and get used to the new routine. She and Gary talked about him returning to work in the fall, and she approved of how his schedule would give him flexibility should he need it (again, thanks, Michel!)

After the psychologist's visit, Gary had a session with the therapy tech. He did his stretching routine, and then he was supposed to do some exercises that were for both balancing and strength. One was the lying on his side on the exercise mat and lifting a weight out to the front, then bringing it down toward his legs, then up toward his head – he'd done this one before. The other was done from the same side-lying position and was a sawing motion. Unfortunately, pain in his shoulder prevented him from doing the first exercise while lying on his right side. He seems to have pulled something deep in his shoulder when he was stretching a few days ago, and now certain positions lying in bed and certain movements – like reaching forward – are bothering him. This is dismaying news, as he is so dependent on his shoulders now – I hope this is something that is going to resolve quickly.

After the OT session came a session with the PT. Joe called just before we started, and once again I felt a little bad because almost always when he calls something else is going on and I can't give him my full attention. The main thing he wanted us to know was that the garage people would be coming soon to start their work. (He also told us he'd managed to get to Madison, Wisc., to pick up his wife, Dolores, at the airport just five minutes before she landed – he'd been working at our home until the last possible minute (well, five minutes).)

Back to the PT session. This was a transfer session. Gary practiced transferring from his wheelchair to the type of chair typically found in a living room – "club chair," I think they're called, the kind that sink when you sit in them. It was a transfer to a much lower surface than he'd done before, and the PT said he did great, that it went much more smoothly than she expected, as she'd expected him to lose his balance on the soft surface. On the uphill direction she said she'd had to give him about 50% help, but that this was great for his first attempts. They did that transfer again, and then she had him transfer onto a cushioning pad (like memory foam wrapped in plastic) on a bench in the hallway. She is going to order him such a pad in case he doesn't always want to bother with having to move his ROHO cushion from his wheelchair to underneath him on the surface he's transferred onto. The ROHO cushion is supposed to be the best possible cushioning surface. Before he uses a different cushion, however, he needs to test it out, just as he will a new pair of shoes (and so forth): first try it for half an hour and then check his skin, then for an hour and then check the skin, and so forth, until he has tried it out without incident for the amount of time he plans to use it. If he ever finds red marks on his skin during these tests of the cushion (or of the new shoes, or of whatever he is testing), if after a half hour of taking pressure off that area, the red marks go away, then that is fine, but if the red marks stay that is a . . . red flag . . . to using that item or whatever (plus he will have to keep any pressure off that area of his skin until the red marks completely go away).

His final transfer was to a shower bench of the type he is getting, but with it set astride a regular bathtub instead of inside a roll-in shower, which is what we've been practicing in – he might need to do this kind of transfer if he is ever in a hotel room without a roll-in shower, for example. He couldn't do this transfer without quite a bit of aid because, for one thing, he couldn't get his legs into and out of the tub without violating his restriction on bending.

After that session, he and I got him transferred into bed. Sometimes I feel like we're getting worse at this without the therapists around to give us tips, but Gary doesn't seem concerned about it. Right after I got him settled, the phone rang. It was the housing person for Shepherd; Gary had left him a message for earlier. He informed us that we would be able to get internet access while we were in the apartments for Day Program (Gary started the conversation off by saying he knew that this was a bit silly in the scheme of things needed in accessible living quarters, but that the two of us were addicted to the internet and wondered about such access); the housing guy also told us that he wouldn't know which apartment building we were going to be put in, and all the units were full anyway, so as a consequence we couldn't check out the place beforehand. Well, as long as we can check our email, we should be set ;-)

After that conversation ended, the phone rang again. The publicity department at Shepherd was calling to say that our local paper is interested in doing a story on Gary – the paper will be calling him tomorrow for an interview! (Gary told me later this evening that he was a little nervous about it – what would they ask him? what would he say?)

I then took off for my usual evening hotel routine, then returned for what has become our evening Shepherd routine: getting Gary transferred into bed (after his ice cream treat); helping him with the stretches; helping him prone in order to change his dressing; getting him repositioned and pillowed on his side for the first part of his night. It seems almost unbelievable to me that this takes us an hour and a half to do, but it does. I reflected on that as I watched Gary crawl on his belly in the bed to help reposition himself. No doubt put into a particular frame of mind by seeing him fall the day before, I had a flash of the "shock" stage of grief (if you remember that from the Emotional Adjustment lecture I told you about). It was just hard to believe that this is the way it's always going to be now, that he's not going to get over this, that he is going to be dragging those dead legs around for the rest of his life, that simple daily tasks that "should" be easy are not. I hope he'll always be able to laugh, as he did today, at things like how long it takes him to get his foot off the footplate of his wheelchair to prepare for a transfer.

Actually, I'm sure he will. That's the kind of person he is. I hope **I* will always be able to stop and laugh with him – I am the one in whom the urge sometimes arises to just take his foot off the damn footplate for him so we can get on with things.

So far, I’ve resisted the urge ;-)

All for now.

July 19, 2006

Running behind (again ;-)) so this one is going up with minimal editing.

Today was the Airport Outing. We met at the Shepherd bus. The wheelchairs and their occupants were strapped in, family members took their seats, and off we went to Atlanta Hartsfield Airport. We took the elevator to ticketing and were met by David Martin, Sr. Specialist – Disabilities, Delta Airlines. He went around and introduced himself to each member of our group and talked with us individually as we waited for everyone to gather (the elevator could only hold two wheelchairs at a time, and there were six chairs). He told the group he was going to explain a little about traveling with disabilities and what Delta had to offer (and that he was so convinced that Delta was the best way for a person with disabilities to travel, he was going to give each one of us his business card with his phone, fax, and email, so that we could contact him about any future travel plans we might make). He said Delta has been doing the outreach program for customers with disabilities for fifteen years.

To begin the program, he said that if we took only one thing away with us today, he wanted it to be that if we ever had a problem concerning airplane travel, the person at every airport who could help us was the CRO, Complaint Resolution Official.

Next he covered the four ways a person could check in for a domestic flight: in our jammies at home by using the internet, even if we had bags to check – the only requirement to checking in online was to join the Frequent Flier Club, but that is free; by checking in with a skycap downstairs at Baggage Claim; by coming upstairs and using the terminals at the self-service kiosks; the old-fashioned way (and most time-consuming) of talking to a human at Domestic check-in.

He stated that once the person with a disability has a reservation, however they get it, they should call Reservations at the airline. They won’t be asked about their disability, but the more information they give, the better the service they will be provided with. So, for instance, people like Gary should let reservations know that they will be traveling with their own wheelchair and that they will need transfer assistance into the plane. They should give information about their chair so that the airline knows what to expect (useful info is the dimensions and weight of the chair, whether it is manual or power, whether it is collapsible). Also, this is the time to arrange for “Meet and Assist” if that service is desired, telling reservations exactly what kind of help is needed. This is a service mandated by Federal law for people with disabilities and carries a $25,000 fine if violated, so the airlines take it very seriously. This service provides you as a disabled person with any help you need, from pushing your wheelchair to walking with you to your gate to transporting your luggage (this last is something Gary would need). At reservations, one can also say a family member is going to help with assistance, and that person will be issued a gate pass if they aren’t actually going to take the flight.

Before David took us upstairs to the kiosks, all the patients did a weight shift. They had all “synced their watches,” so did them all together throughout the day. I wondered if anyone else in the airport noticed how every half an hour, this group of people in wheelchairs would suddenly bend forward, or bend from one side to the other, or depress upwards, holding their positions for a minute.

After showing us how the kiosks worked, David took us to Delta’s International Check-in. It had some kiosks, but they weren’t as “friendly” as the Domestic ones – you could book a flight directly from point A to point B, but no more than that; in more complicated situations, you needed to speak directly with an agent at the check-in counter.

Next we went to the Special Assistance Line. We showed our gate passes and IDs – at this point Gary decided it would be good to have something easy to get at that could be used to carry items such as these (he should no longer carry a wallet in his back pocket because of skin pressure issues, and it’s too hard to get things out of his front pocket); I told him I had a passport bag that is worn around the neck that he could try if he liked.

We were then admitted to the Security area. A member of the Transportation Security Administration (TSA) spoke to us about what the security procedure would be for PWDs (people with disabilities). Basically, everyone would be requested to remove their shoes (and if you couldn’t do it yourself, as Gary can’t as yet, and if you weren’t traveling with someone helping you, the security people would remove your shoes and then put them back on you at the end), all items that “normally” would go on the conveyor to be scanned are still treated that way, and the PWD goes off to a separate line for a pat-down (and if that person is uncomfortable with that being done in public, they can request a private screening). Their chair will be inspected, and they will be asked to lean forward so that their back and the back of their chair can be checked, and they will be asked to shift from side to side so that their seat and the seat of the chair can be checked. I didn’t think to ask what would happen if they couldn’t comply with this. I also forgot to ask Gary how thoroughly they checked his chair. As my chiropractor pointed out later, if the security people didn’t thoroughly inspect chairs, what was to stop a group of terrorists from posing as a quadriplegic basketball team and smuggling onboard some –

Okay, maybe the “quadriplegic basketball team” designation might have given them away, but you get the idea.

Anyway, the set-up at Atlanta made the process relatively easy for those with disabilities; that may differ at other places, but they all have provisions for security checks for PWDs.

David cautioned that at this point in the boarding process, the airport may become chaotic. People will be rushing to their flights and they only tend to see what is at eye level and may accidently run into PWDs (and some will just be rude and cut off PWDs). He said to be assertive and get up front to the doors of the trains – they don't bounce back like the elevator doors of Shepherd do, so you'll feel it if they hit you. Once you get in the train, you need to turn your chair around (which may not be the easiest thing if the train is crowded, but it is necessary to get out of the doors), face perpendicular to the direction of travel for safety, and lock your wheels or if you're in a power chair, turn it off. Finally, hold on, cuz you'll feel some g's in those trains! (At the command, "Please hold on," I grabbed one of the posts, Gary grabbed the handrails of his wheelchair – David was right – that train was jerky!)

We headed toward a gate on the international concourse. One of the wheelchair occupants entertained us by grabbing onto the back of the power chair occupied by another Shepherd patient and "waterskiing" behind it. I told Gary he should grab on and form a train.

At the gate, we were told it was a good idea to request to be pre-boarded. This is of convenience to the airline personnel, since it is easier to get you on first than last. If you pre-board, you will be last to get off, for safety reasons. Also at the gate, you "gate check" your chair – it will be the last thing put into baggage and it will be the first thing off, waiting for you at your arrival gate.

Each patient then wheeled themself down to the end of the jetway. Here they were each transferred onto the "aisle chair," a tall, skinny, high-backed wheelchair designed to fit down the narrow aisle of an aircraft. Delta has its own design for such a chair, which is hydraulic and so can be raised or lowered to the desired heights for transfer; it's not always available, though, in which case the other kind of "fixed" chair is. Gary did a depression transfer into the chair aided by two trained Delta personnel while I hovered nearby nervously and reminded him about the placement of his feet – for which he thanked me later, as foot position, as well as timing, is so important in a transfer. He was strapped into the chair and then wheeled backward into the plane – yes, a real plane. He forgot to take his cushion, so I grabbed that and followed him in. I took a window seat, and Gary was transferred onto his cushion in the aisle seat. He'd been thinking of doing a depression transfer to the airplane seat, but the airline personnel obviously wanted to do a two-man lift on him – maybe for the practice or maybe for speed because they had two more patients to get onto the plane. So Gary agreed to that. David noticed one patient wince as she was transferred by a two-man lift, and he reminded us that we needed to be assertive with the personnel: even though they are trained to do the transfers, they don't know your particular body, so you need to tell them if anything hurts, if they are going too fast, etc. He also cautioned that while Atlanta Delta personnel was highly trained in the transfers, this might not be true with other carriers of at other airports, so you may need to be more directive in telling them how to transfer you.

If it happens that the plane being boarded must be entered by going out on the tarmac, a mechanical lift is used for those in chairs. David cautioned the Shepherd patients to never let anyone carry them up the stairs; it is against the law.

We were in a wide-body plane, and David had airline personnel show how doors near the lavatories could be shut to enclose the entire lavatory area. So this would offer privacy if one needed to do an IC on the plane and couldn't transfer into the lavatory itself (which Gary couldn't, at least not easily, even using the on-craft wheelchair). I'm not sure if all wide-body planes built since '92 have this feature, but I believe David indicated Delta's did.

After a snack was offered (no special treatment here ;-)), the patients were deboarded. Gary did a depression transfer onto the aisle chair from his plane seat and declared it easy. He needed and got more help from the airline personnel with his transfer from the aisle chair to his own wheelchair. David came up to us and asked us if we'd thought the presentation useful, and we said very much so. It made it seem that airline travel was going to be very doable for Gary (at least as long as he sticks to Delta ;-)). David then gave us his card and told Gary to call him anytime he was going to travel by air, that even if it was to someplace not handled by Delta, he would make sure the flight went smoothly. We're not sure how he can handle making this offer to everyone – I believe Shepherd has these outings once a month!

After that, Gary and others went off to do their ICs in a restroom, and then it was off to the food court, where each patient got up to eight dollars to spend. (I ate my rice, which I'd at last remembered to bring with me ;-).) Gary and I got a table to ourselves, and he commented that when he'd first come to Shepherd, two months ago, he'd asked his doctor if he'd ever feel hungry again. He'd just recently stopped being fed intravenously, and he didn't have much of an appetite for "real food," plus he'd had trouble with nausea; he'd been packing down the meals and the Ensures and so forth only because the doctor had told him to. He'd worried that since he couldn't feel anything below nipple level, this meant he would never be hungry again, that it was always going to be the case that eating was a mechanical process only done to get nourishment into him and not a source of enjoyment. He said he was happy to say he now felt hungry. Then he dug into his quarter-pounder with cheese.

After everyone in the group had finished their meal, we got back onto the train to go to baggage check. While on the train, I commented to Gary that it would be a much harder test if they'd had to get off at one of the intermediary stops instead of the last stop, as the train was so crowded. This train was particularly jerky, and a friendly young woman who'd nearly fallen over said to Gary, "You're on wheels, how's that working for you?" Gary said his wheels were locked. "Chicken!" she teased him. She then watched our group get off the train, and she called it out as if it were a race, which we had to smile at. The woman "winning" said she had the "advantage" of being in a chair powered by a battery.

We didn't do anything at baggage claim, just went through it to the exit to get back onto the bus to go to Shepherd. The only complaint anyone had about the airport trip was that the paper towel dispensers in the restrooms were too high.

Back in Gary's room, we got him transferred into his bed. The call from the newspaper came shortly after that. I couldn't stay to hear it all because I was getting ready to go to the chiropractor. I know he was asked about the accident. He said he hoped they'd be putting a light at Grand National and 280; he said he'd always hated that intersection, and he still didn't understand how the accident happened, because he'd always been so cautious there; he told her that he remembers nothing of the actual accident, just that one moment he was at that intersection and the next moment he was being transported to the emergency room. He said he'd felt his legs, and it was like touching someone else's body, and he thinks he knew at that point he was paralyzed. But he also realized he still had his hands and his brain seemed okay – he could answer the questions of the transporting personnel. So he realized right away he would still be able to do most of what he loved – and he loved his work, he added. But it was scary, too, he said, because he didn't know what he was getting into, what it meant to be paralyzed.

He told the reporter a little about his hospital stay, how he was UAB Hospital for about a month, for three weeks of that in ICU on a ventilator. He told her how my sister had looked into spinal rehab places and discovered that Shepherd was one of the best places in the nation for it, and so he'd come here.

He also mentioned me :-), saying I'd been with him every day since the accident (okay, he forgot about April 17th when I'd dashed home to send in the tax stuff). He told her I'd started a blog to keep friends and family abreast of what was going on with him (I should have slipped him a piece of paper with the URL!). He told her a little about his typical day here, though he later told me he wished he'd gone more into that. He told her he'd be pretty much independent, though everything would take longer – for instance, that it would probably take him two to three hours to get up, get bathed, dressed, and have breakfast before heading to the university.

At that point he said he was really happy to be going back to work, that he loved his work. He said the people in the math department have been very helpful: he told her that my brother had come out all the way from Colorado to make our house more wheelchair friendly, and math department people had been with him nearly every day helping him do the job.

He told the reporter he never dreamed this would happen to him, but that he felt lucky to be alive, and that he was also lucky that unlike many others with spinal cord injuries, he would be able to return to his work. He said that somehow he'd never felt depressed about his situation. At this point I got mentioned again :-), him saying my being here all the time has been such a big help, that it would have been much harder to go through this alone. He told her he was confident that he would eventually be pretty independent, though it would take a few more months before he was as independent as he wanted to be (maybe he should have mentioned how the consequences of the bed sore he'd gotten at the UAB Hospital was holding him up on that account ;-)).

He told her he was being discharged from Shepherd on July 28th, and that he'd go into Day Program for two weeks until August 11th, then he'd be coming home – just in time for Fall Semester. He told her how the chair of the department was very supportive, arranging it so that this fall all Gary would have to teach was his graduate students. He said he also planned to lead the Topology seminar, to do his duties for the couple of journals that he was on the board of, and to continue his research, but that since he wouldn't have regularly scheduled undergraduate classes this fall, he could ease into things. He told her he planned on resuming a normal teaching schedule in the spring.

At that point I was out the door, so I didn't hear any more. When I asked him later what he'd talked about, he couldn't remember any more than this, so I guess you'll have to read the news article to find out. Just remember, you've probably heard most of it here, first ;-)

My cell phone rang when I was at the chiropractor, but I waited until I'd gotten back to the hotel to listen to the message. It was from Gary, saying the newspaper reporter wanted to talk to me too. Yikes! I'm no good at extemporaneous speaking. I'd like to tell her to just read the blog. Surely I've covered everything she could ask about, wouldn't you say? ;-)

Now for the home report, courtesy of Jo Heath. 1) John Hinrichsen plans to build a platform for our futon couch so that Gary can transfer onto it (right now, that transfer would be a major undertaking, as the futon is so low); the advantage to keeping the futon rather than getting another couch is that when the futon is flat, Gary can use it as an exercise surface (for his stretching program, for example). 2) Janet Rogers and Donna Bennett and Jo Heath went ahead and painted the other two bedrooms. 3) Wlodek Kuperberg is installing bathroom fixtures.

As Gary said when I read him Jo's email, we don't know how we can ever repay everyone who has been such a help. Actually, we know we can't, but if there's anything we can ever do for you (after we get our second wind ;-)) let us know.

To finish, the picture taken by Stuart (for those of you reading this by email, go to http://drpeg2003.blogspot.com/ and scroll down):

July 20, 2006

Mail call: thanks to Jim and Diane Barjenbruch and family.

Today started out with a Jeopardy-like quiz, led by Nurse Mark, who made the session a lot of fun. The six patients got to pick questions for points (100 to 500) from the categories "Respiratory," "Bowel," "Bladder," "Skin," and "Miscellaneous." I soon decided that you might as well always pick from 500, because Mark never allowed a patient to miss a question. He would engage in pantomime, ask leading questions, and so forth. Only a couple of times was a wrong answer still given, at which time Mark would suggest that they were only kidding and that they'd really meant to say . . . . One time he seemed to have exhausted all his hints, so I joined in and added my own pantomiming of the correct answer. The patient then got it and said he wanted me to be on his team. (I said I would be on everyone's team but would get into the action only if Mark's antics failed to elicit the correct answer).

The "Jeopardy quiz" a good review of things that had been presented in the classes. I picked up a couple of things I had missed before – but only a couple ;-). I couldn't figure out why Gary didn't always pick the 500 point questions (and for that matter, why only the young boy in the group – probably about fourteen or fifteen years old – did so), but he later told me he'd wanted to let the kid win and said with a wink that he'd been showing his maturity. I told him the hell with maturity, I would've wanted to beat the little –

ahem.

After that class, Gary's next task was to prepare a meal with the OT. He chose his speciality: spaghetti :-) He also decided on steamed broccoli, and the OT suggested garlic bread. The first half hour the therapy tech was with us, and like us she didn't know where anything in the kitchen was, so all Gary accomplished was to find a large pot for the pasta and a steamer for the broccoli, to get a start on setting the table for him and the OT, and to get out the salt from a cupboard and the pasta from another cupboard, using his grabber. When the OT came, he began the process of cooking. To get the rather large pot of water for the spaghetti from the sink to the stove, he used a rolling cart. At home, he will be able to slide such a pot from the sink along a counter to the stove, but we are thinking such a cart will come in useful to get things from the stove to the kitchen table. The OT cautioned him not to try to carry something like a large pot of hot water on a board on his lap – he of course has the sense to know he wouldn't put the hot pot directly on his lap, even if he can't feel it!

A nice feature of this kitchen was the cooktop – Gary could roll right under it with his wheelchair, and all controls were in the front. Gary really liked it and said maybe we'd get one. (Over the years, our usual division of labor has been that I get to do the cooking and dirty everything up and he has to clean up, but he did some of his own cooking several times a week, and even more often when I started to have back problems.) I'm not sure we could afford a cooktop like the one they have here, which lowers and raises at the touch of a button!

A few other nice "accessible" features of the kitchen were a lazy susan, a deep drawer that pulled out containing the garbage bag, and a shelf that lowered itself from an upper cabinet down to the counter at the touch of a button (it held spices).

The OT also showed Gary a tool that can be used to hook onto an oven rack for pulling it out or can be pushed against the rack to get it back in. This he used to remove the garlic bread (in the interest of time, the OT "made" the bread, i.e., buttered it and put garlic salt on it, wrapped it in foil, and put it in the oven). Again, the hot bread was put on the rolling cart to transport it to the table.

The OT and he enjoyed their lunch, Gary noting wryly that it had only taken him an hour and a half to make five-minute spaghetti. The OT pointed out that meal preparation could be speeded up with greater planning – setting the table after things got cooking and not beforehand, etc. The OT had to take off for a meeting, and Gary savored his meal. I got my rice (which I'd cooked overnight in a slow cooker in the hotel room) and joined him. At 12:20 he remarked that he had to do his IC before his 1pm session with the therapy tech, so guess who got to do most of the cleanup. He is definitely going to have to learn to organize better ;-).

On my way back to his room, I ran into Gary's roommate and wife. The roommate was completing his discharge, and we said our goodbyes. He was eager to go home, his wife was nervous about it. Sound familiar? ;-) I gave him a kiss and his wife a hug, and we wished each other luck. He told me to "Take good care of that bo'," meaning Gary. Gary asked me when I'd gotten back to his room if his roommate had said to take good care of him, and I said yes. He told me his roommate had told him to tell me to take good care of him, and he had replied that he knew I would. :-)

With the therapy tech, Gary's first task was to get on the "regular" (i.e., non-hospital) bed they have in the gym and practice rolling from his back to his side and then sitting up. The softer surface made the rolling very difficult, and the tech finally gave him a discreet push on the legs (which of course he couldn't feel), not willing to let him roll back after he'd come so close to making it a few times. He got himself sat up without help, though, and on a later attempt, he also did the rolling over all by himself.

After that, I assisted him in transferring back to his chair, then to the exercise mat. On the mat his task was to sit on the edge with his legs hanging over and do some weights – biceps curls and tricep extensions (start with arm bent in front, parallel to the floor, then extend the upper arm out to the side using the elbow as a hinge). Because the limiting factor for him was balance and not strength, he chose very light dumbbells. As all balance exercises do for him, these exercises required lots of concentration, particularly because the tech wanted him to sit up as straight as possible (for the weight-training aspect of the exercises to be effective) and not lean way over to counterbalance the weight. He started off very shaky but got smoother as the sets progressed. He was tired after that, more mentally pooped than physically, he said, and I went off to get him some of his "muscle juice," the Juven protein drink (they have cut him back from two packets to one packet per day, as the drink is more for wound healing than muscle building, so he's thinking of getting some kind of protein drink at a health food store to help him build muscle).

While assisting him back into his chair after his exercises, I noticed he had another abdominal muscle spasm (they're hard to miss, as they throw him backward in the chair). He told me he'd told his doctor that those had started up recently. The doctor had said the muscle spasms were a good thing, that they could help prevent the pot belly that those without the use of their abdominal muscles get, and that they could be a sign of "something returning," meaning some muscles possibly functioning again.

Next up was a session with a PT, but not his usual one. The task: wheelies and curbs. Yikes. She knew we were nervous about it (me even more than him, I suspect), so after she took off his tip bars, she not only used a gait belt around his axle while standing behind his chair, but kept one hand on his chair. She assured him not to worry, that there was no way he was going down – and that if he did, it would be on top of her. So he practiced balancing in the wheelie position, and then she had him travel for a short distance in that position; she told us that skill would be useful if he came to a patch of gravel or mud that his small front wheels could get stuck in (or he could go around it, I suggested ;-)). Next we were to go over to the section of the gym where the wooden platforms are set up to practice curbs. As she left to set them up, she handed me the belt still attached to his chair, and told him to put his breaks on and not to move (since his tip bars weren't on his chair). I stood right behind him, hands on his chair, the belt in one of my hands. She joked to Gary when she returned that I was probably going to keep one of those leashes on him when he was at home. Hey, there's an idea. We've already joked that he won't be able to get out of bed in the morning until I put down the rails of his hospital bed. Shades of "Misery."

He seemed less successful at the curb practice this time – he got his front wheels up it all right, but then couldn't get the back wheels up. She said it was all a matter of timing – two pushes, a stronger push to get the front wheels up in a wheelie, then without a break in momentum, a lean forward and continued pushing to get the front wheels down and the back ones up over the curb (obviously if you pop too high a wheelie or don't get the front wheels down, you are going to tip over backwards; Gary told her that the first few times he practiced curbs on his own (after being cleared to do so), he was going to wear a helmet).

After this, she had various other things on her list for Gary to do, but I mentioned that he hadn't gotten to try the tilt table yet, because the substitute OT we'd had the day he was supposed to do it hadn't been trained in using the table. (The exercise rec therapist had wanted him to do the tilt table so she could get him cleared to try the Easystand in the gym – that is the machine I told you about that would stand him upright and possibly even enable him to do cross-country type of motions, depending how his body reacted.) The PT agreed to do the tilt table with him. So we hoyered him onto the table – the table was too high for him to attempt a depression transfer onto it – and the PT strapped him onto the table at the chest, hips, and knees. The PT hit a switch, and the table starting tilting upward from its horizontal position. She stopped it after it was at a slight angle and then told me I could continue raising it toward vertical, stopping it along the way to make sure that Gary had no symptoms of light-headedness (it's not unusual for patients to faint from the unaccustomed rush of blood to the feet; as a point of possible interest to him, I told Gary that many people with CFS "fail" the tilt table test, displaying symptoms of Neurally Mediated Hypotension, and that maybe I should get on the table with him to see if this was the reason I've been having these episodes of light-headedness ever since a few weeks after his accident – my guess is that they're brought on by standing too long in one place).

I gradually brought Gary toward vertical, holding at intermediary positions for a minute before moving on. I kept asking how he felt, and he kept saying that while it felt different, he had no light-headedness. At last Gary said, "Hey, I'm up! I can see my feet!" The PT called over from the patient she was helping next to us, "And now you can hug your wife from an upright position." So we did that, and it was nice :-) I took him a little bit more vertical – the table goes only to eighty-five degrees. He noticed for the first time that the sign on the door across from him read "Quiet Treatment," and said he'd like that treatment some time – assuming that it meant they'd put him in that room and leave him alone, no pushups, no terrible threes. He was kidding, of course. Well, sort of ;-)

After a couple minutes in that position, he said he wasn't feeling quite as comfortable, so I backed him down a little. The PT said to hold him there for five minutes and then to slowly back him down to horizontal. But after about three minutes, he wanted to go as upright as the table would allow, so we did that, and he had no problem with it. After a couple of minutes, the PT told us to head toward horizontal – another patient was waiting to use the table. When I'd gotten him to horizontal, he said it made him almost feel like he was upside down. The PT came over to hoyer him back into his chair, and he told her the tilt table had been fun. She told him he'd done great, that most people don't go up that far that fast. But she told him not to be disappointed if he didn't get all the way up on the Easystand if he got to try it – it brings a person to vertical all at once, and the support is different.

After that session, he and I went back to his room to get him back in bed for awhile. Unfortunately, he hardly went anywhere on his transfer from his wheelchair to the bed. I was sitting behind him, on the bed, assisting him at the hips, and when I saw him land on the very edge of the bed, fearing he would slip over it, I pulled him back away from it. He lost his balance backwards and I moved my body so his back was against my chest and we both went down onto the bed together (I didn't want him to bump his head on the back rail of the bed – quite enough head-bumping lately, thank you very much. Note to self: keep that back rail lowered during transferring).

"Nice to know nothing bad will happen if I don't make a very good transfer," Gary said. "Easy for you to say," I mumbled from underneath him. "Are you all right?" he asked. "I think so." "Can you get out?" "Not quickly."

I then eased out from under him, telling him I was glad the therapists hadn't seen this transfer. He asked me if he'd really landed on the edge and had been in danger of sliding off the bed. I told him that it had looked that way to me, though I couldn't say for sure – but that I really really hadn't wanted wait around and see if that would happen. "Good thinking," he said. Our next task was to get the rest of his body onto the bed, as he was lying diagonally across it with his butt still hanging over the edge and his legs angling down toward the floor (I still had my grip on him, because I feared that if I let go, he would slip down the side of the bed). I kind of slid down onto my knees on the floor while holding onto his hips, and then I hoisted his legs up on the bed so that he was now on his back with one hip pointing toward the ceiling. This now became a problem-solving session: how to get him repositioned in the bed without doing either of ourselves bodily damage. I put up the remainder of the bed rails, and with a lot of pushing and pulling on both our parts, we got him into an acceptable position. Just then, our case manager breezed through the curtain of Gary's room to inform us that she had been able to get us the Transitional Living Apartment (TLA) in Shepherd's other building, the Marcus Building, to stay in for our in-center pass. She raved about it – we'd be off to ourselves, just like in a "real apartment," and we wouldn't feel like we were in the hospital at all; there was a queen-sized bed, a large accessible bathroom, a kitchen, a TV, and so forth. Gary and I responded enthusiastically, though actually my thoughts were a little occupied with something else at the time; I don't think she noticed anything amiss, though. After she left, I told Gary that it was a good thing she hadn't come through that curtain five minutes beforehand – she would have decided that we weren't ready to be on our own!

We then tried to figure out what had gone wrong with that transfer. Gary decided that his timing had been off and he hadn't twisted enough at his shoulders and therefore hadn't twisted enough at the hips.

I, on the other hand, had twisted too much at the hips in trying to make sure he didn't end up on the floor, and the additional pulling and pushing to get him onto the bed hadn't improved matters. After I got him padded off on the bed, I hobbled off to the chiropractor, who spent more time than usual trying to crunch me back into recognizably human form. (Okay, I exaggerate here. A little.)

I went back to the hotel to start dinner and tried not to get too nervous about the upcoming call – from the reporter who'd talked to Gary yesterday. Since I couldn't jot down notes when talking to her ;-) I don't know how accurately I recall our conversation, but here are some things we covered (I think ;-)). She started off by asking Gary's age and how long we'd been married (so now "everyone" will know we soon celebrate our 25th!). She asked me what my reaction had been to getting the news of his accident (so I told the story of going to Paneera's for my writers group meeting, getting the message to call the emergency room, and getting the news that Gary had been in a car accident and had a severe spinal cord injury and was paralyzed from nipple level down – at which point I found myself on the floor). She asked me things like what affect this situation had on my life, if any, and if I was bitter about having to take care of him (I thought that a little odd – if someone did feel bitter, would they admit it to a reporter?) or if I'd thought it my duty as his wife to take care of him. I told her "neither," that I've always thought Gary was the most wonderful person in the world, so what I did, I did because I love him. I said I hoped I never would feel bitter about it, but that I certainly didn't now. I told her that Gary would be independent in time and I would have to do less and less for him. Since Gary had said he wished he'd told her more about his rehab here, I picked a day (last Thursday) and told her about what he'd done that day. I also told her a little about the classes offered here, how they covered the various areas like respiratory, bowel, bladder, skin. I mentioned that pressure sores were a major concern because those with spinal cord injuries can't feel that they've had pressure on an area of the body for too long; so to prevent the sores they need to shift off the areas of pressure on a regular basis. I can't remember all I said about the various classes, but I'm sure I told her much more than she wanted to know ;-). But then, I've probably done the same with you ;-). (Actually, she thanked me for the information and said she realized such a disability involves a whole lifestyle change and that that was something you usually don't realize unless it happens to you or to someone you know.)

Anyway, I don't know how coherent I was or if I said what I'd meant to say. If anything in the article conflicts with what I've said in the blog, go by the blog!

Speaking of the blog, since Gary said that he regretted not telling her more about it, I went ahead and gave her the URL in case she wanted to look it over for more information. I told she could probably find the answer to any question she might later to think to ask us, as in the blog I covered everything from what Gary was doing in his therapy sessions to what we'd learned in the classes to what my thoughts had been on different days.

After that call ended, I checked a message on my cell phone from a person from Shepherd's publicity department. She said that a someone from the university's newspaper wanted to interview Gary, and she gave me the number to call to arrange for the interview. I don't know how the university paper heard of him.

As always, I returned to Shepherd in the evening. Gary's sister Norma called while Gary and I were doing his stretching routine. She told him a little about the Alaska trip and promised to tell more to him later. I know Gary was really pleased that the "flightseeing" tour he'd been pushing for everyone to go on had turned out to be a major highlight of the trip (they saw Mt. McKinley and its glaciers up close – even landing on a glacier).

To finish, a few notes from Jo Heath. First, Krystyna Kuperberg did a lot of the painting in the study. Second, "the big move" is Saturday the 22nd. Jo says that this is the day "when all of your furniture will be put back into the wrong room or at least in the wrong place." LOL!

July 21, 2006

Warning – no editing.

Uh-oh. Back was very sore and stiff when I woke up this morning – and it interrupted my sleeping during the night. I am worried about it, and I decided to help out physically as little as possible during the therapy sessions today, for example, letting the tech and therapists aid Gary in his transfers instead of me.

Gary's first session was with a PT, again, not his own. They started out with transfers into our car. Gary did his best one yet! Nice hops, good balance, not rough with his legs as he got them into and out of the car. No head bangs ;-)

This PT works in the day program, and she has been a therapist for fifteen years. She gave Gary a tip on his transfers – to lean forward and push through his shoulders and scapulae, not just through his arms. This will give him a little more height. You can try it yourself: sit on some surface where you can get your hands next to your legs, and push down with your arms to raise yourself up (no fair using your legs – "unfortunately," you will most likely not be able to not use your abdominal muscles to help, so you won't experience this like Gary does); now really push those shoulders down ("lengthen your neck"). She told him that if he did this, it would help save his from shoulder problems. She told him to practice doing dips and his weight shifts this way, really extending that scapula. And she told him to get prone and do the terrible threes regularly to strengthen his back.

Next came wheelies and curbs (Peg bites her fingernails). Of course, the PT used a gait belt on Gary's chair. She had him try to find his balance point in the wheelie and told him he was going too far back. After she said that, he was able to hand in the wheelie position all by himself – she kept her hands surrounding the handles on the back of his chair but wasn't actually holding onto them. He stayed in wheelie position (traveling a little down the hallway) for an entire minute! He came down and said he needed a rest. She told him to take the rest he needed, that she'd heard he busts his butt during his therapy sessions, so she would believe him if he said he needed rest – unlike some of her patients!

Next she took us to the outpatient gym and had him practice curbs on the 4" wooden platform. He took the curb again and again, working on momentum, timing, and technique. They went a little overtime, but the PT said he had to end on a good one. A couple more tries later he did one that was smooth and on which the PT said she hadn't had to help much, so that was a good stopping point.

We had about an hour's break, so we headed back to Gary's room, where he called the university newspaper reporter and answered her questions. He told her he'd been at the university for thirty-two years, and he told her about the accident, his injuries, his surgeries and stay at UAB Hospital, how it was my sister who had found out about Shepherd, and so he'd come here for the rehab program. Unlike the local paper interview, Gary mentioned getting the bed sore at Birmingham, and how he'd had to have surgery on it, delaying his rehab for about three weeks (I think I mentioned that to the other reporter, but am not sure), but that then he'd gotten into intensive rehab and was still doing it now, spending most of the day in one sort of rehab or another (don't you know it!).

The alarm for a weight shift went off, prompting Gary to tell her about the need for that, and how he was going to give the phone to me for a minute until he completed one. I can't remember what I babbled about. I know I said we expected him to be independent within a year, and she asked if that meant he'd be walking again. I said no, that it wasn't expected that he'd regain any movement or feeling below chest level. She asked what being independent meant. I should have told her that it meant he'd be able to take on all his personal care himself and able to function so well in all the activities of daily living that if need be, he could live by himself without any caretaker needed, but I blanked out, and since Gary had just finished his weight shift, I told her Gary could explain and handed the phone back to him. I was still flustered and forgot to take notes so I can't tell you what Gary said for the next little while. When I next resumed my note-taking he was telling her that part of the rehab entailed moving his body around, like getting it into the car (he should have included getting it in and out of the bed!), that such things involved a lot of strength and technique, so they spent a lot of time developing both. He also told her that they went through various activities of daily living and how he'd have to adapt to new ways of doing them – he gave the example that just today he'd spent time in a cooking session.

He told her he will get back to teaching Fall Semester, at which time he would have a flexible schedule of just working with his graduate students. He said he'd get back into a full schedule in the spring. He said Michel Smith was the one to thank for this. He then said everyone in the math department was being very supportive, and told the story of how my brother was leading the modifications of our home to make it wheelchair friendly but had had a crew of math people helping out every day – that everyone had been really wonderful. He said he's not a person who likes to ask for help, but now he's going to need some, and he again reiterated how people have been really wonderful.

He told her he was going into Day Program for the first two weeks and then would be home for good (maybe he hadn't wanted to get into how he would be returning to Day Program in December to pick up advanced skills he'll hopefully be ready for (like how to get down to and up from the floor) and to take drivers' training)).

It sounded like the interview was winding down, as I heard him apparently repeat her words that the article was coming out this coming Thursday (save us copies!). I think she must have expressed some sympathy toward him, as he next said that it was just one of those things, that it happened, he can't do anything about it, so he has to make the best of it and that was what he planned to do. He said that anything can happen at any time, that he never dreamed it would happen to him.

He then told her about the blog, saying that just a few days after his accident, I had started it to keep family and friends updated on his condition. He said I now used it tell everyone what he was doing every day. He said he was amazed at how many people read it, surprised that people would be interested in the details of what was going on with him (and you do get details, don't you ? ;-)) and he told the story about one of his colleagues being at a math conference in Greece and topologists from various parts of the world being there and asking her about him, but that she couldn't tell them anything they didn't already know because they were all reading the blog. He told her she should take a look at it, and gave her the URL.

The conversation ended about there, and soon it was time for his next therapy session, this one with the OT. I told her I was giving my back a break, so she assisted Gary with a transfer, this one to the bed in the gym. He did an, in her words, "awesome" transfer. He still needed her help getting his legs up on the bed; she said it was clear from his weeks of therapy that until he got the bending restrictions (due to his flap) removed, I would have to help him get his feet up and take off his shoes for him. She then had him prone and had him do the terrible threes, commenting that he's really bulked up since being here – and I agreed! Gary's student Brad Bailey called at this moment, so I tore myself away from Gary and found Brad directions to Shepherd from the north of Atlanta.

When I got back to the gym, Gary was finishing up his "threes," and she had him maneuver himself to the side of the bed and transfer back into his chair. She commented that he has done incredibly well in his rehab for not being athletic before his accident (golf doesn't count ;-)).

Gary and I went back to his room for the lunchtime routine. Gary pointed out that I had dropped a nickel on the floor. He said that before his accident, he hadn't thought it worth picking up pennies off the floor, now he didn't think nickels were worth it. I asked him what the smallest denomination was that he would now expend the time and effort to pick up. He said maybe a dollar.

Gary had a new roommate check in, and we were told this was someone else who had gotten a bed sore at another hospital (Grady). The nurse asked Gary to make him welcome, and almost immediately Gary wheeled off to say hello and chat awhile. (Fortunately, this guy's sore probably isn't bad enough to need surgery.) The case manager then came to the room, wanting to show us the Transitional Living Apartment we'll be staying in this weekend, so we went off to the Marcus building to do that. Gary and I had hoped there was going to be some kind of separate bed for me, as I really didn't want to be wakened at four in the morning by him shouting "One, two, three," and rolling himself on top of me to change positions (he joked that he wouldn't need any pillows to prone – he'd just use me), and it turned out that the couch has a fold-out bed. I'm trying to get resigned to not getting much sleep, as I'm sure that 4am "IC and turn" alarm is going to wake me and I'm not very good at falling back to sleep after I'm awakened. Gary told me if I could get resigned enough to the fact that I won't fall back to sleep that I probably will fall back to sleep <ironic grin>.

The apartment is very nice for being in the hospital – it is only one TLA at Shepherd right now, though with the expansion going on, they hope to build others. One long room had a kitchen at one end, an area with a couch and TV in the middle, and the queen bed at the other end. The large bathroom comes off the bedroom area. It has a shower bench, but has a regular tub, so I'm not sure if Gary will opt to try that or if we'll be doing the bed bath method (which is all he's gotten while here except for the couple of wet runs we've done with the therapists).

When we got back to Gary's room, Brad and his wife Elaine were there. They also brought their impossibly cute newborn daughter. They said it was fortunate she was asleep; apparently, she has quite a set of lungs. Brad told Gary he had rearranged Gary's office in order to to make it wheelchair accessible – removing one of the desks, re-stacking papers, moving the bookcase over. Gary is very grateful for that!

It was only a fifteen minute visit, as Gary had another therapy session scheduled. This one was with the therapy tech. She had him practice his hops along the edge of the exercise mat then do his stretches. After that, as he prepared for a transfer into his wheelchair in order to get on the rickshaw, he asked me for his glasses. Instead of just putting them on him, as I often do, I said we'd make it a balance exercise. He was game, and I stood in front of him and held them in my hand while he tried to get his balance and slowly reach for them. He was successful on the second try and put them on. "Everything becomes therapy," he noted.

After that session, we returned to his room, where a rec therapist was supposed to come and meet with him. We got on the subject of outings, and she asked him if he was interested in any of the ones coming up this week. Turned out there is a Braves game outing, and Gary said he'd like to do that. She thought it might be too late to get him/us tickets (you wouldn't have gotten me to a game before this, but I'd like to go with him), but she'd look into it.

She then said she was there to review with him what he had learned in his rec therapy classes, and that she would do more of this with him next week. She asked him various questions about accessibility issues: what problems did he think he might face in different situations and how he would solve them (at a store, in a public bathroom, at a restaurant); what details should he ask about a hotel he wanted to stay at (just because a room is claimed to be accessible, it doesn't mean it would be for him). At the conclusion of this part, which had lasted about forty-five minutes, she said she was happy to hear that he'd never said that one of his solutions to finding a place not quite accessible as is, was "I would leave." He said he wouldn't leave because he liked adventures.

She then asked him if he had any questions for her concerning accessibility, and he started talking about his family, saying that they lived all around the U.S. and got together each year at one place or another, and how he'd always loved to travel to their homes – and at this point he got emotional and I came over and gave him a hug. He apologized to the rec therapist, telling her that he was a little concerned about how that would work out now – whether he'd be able to get into their homes, and once in, would he be able to get into the various rooms. The therapist offered a number of ideas, telling him it just depended on what he was willing to do, what he was willing to put up with. For example, if there were a steps into their homes, maybe he'd have to bring along a portable ramp or rent one from some place, or ask someone to bump him up the stairs. If the door was too narrow for his wheelchair to go in, maybe someone would be willing to carry him in, and then he or someone else could "break down" his wheelchair (take the wheels off, fold the body), bring it in, then reassemble it. They would not have shower benches, so maybe he'd have to bring his own (shipping his equipment there ahead of time), or take bed baths if there was someone there he'd allow to help him with that (I may not always be up to such travels – I took one trip by airplane in Jan. 2004, the first one since coming down with CFS, and though I was pleased at how well I did, it was not something I wanted to make a regular practice of). The main thing, the therapist said, was that he would just have to think things through ahead of time. I know his family will help him any way they can.

After the therapist left, he told me he reminded himself of a person at one of the counseling classes who had said that she was much more emotional now. He said he felt the same way, that any little thing could set him off – moments ago, when talking about visiting his family, earlier, when the OT had mentioned that it had been a quarter of a year since his accident and he had said that he hadn't been home in all that time. I told him not to worry about it, that the same thing happens to me – that I could be set off by something I read in an email or card, or when I'm talking to someone (like a couple of times in talking to the city newspaper reporter). I told him I thought it due to fatigue and stress, that this was, after all, a life-changing experience – before, when he visited his family, he just walked through the door; now, he wasn't sure if he could even get through the door.

I left for the hotel and did my thing. I also arranged for a massage, though I couldn't get one scheduled until Sunday night, and it will be with a person I haven't tried before. But I don't think I should wait until next Tuesday, which is the earliest I can get in with the therapist I've usually been going to.

The only other thing I have jotted down about this day was that getting into the hospital bed and hoodling with Gary wasn't very relaxing that night – the speaker phone of one of Gary's roommates went off, a loud conversation ensued, and the other roommate who has been here awhile (or a member of his family) retaliated by turning up his boombox very very loud. Such mature behavior. I was going to complain to the staff, but the radio then got turned down. But the loud phone conversation kept going. I wished Gary good night and good luck.

July 22, 2006 (Bet you thought we hadn't survived the TLA experience. Well, we did. Barely. What follows has received little editing.)

I shot awake in the early morning, thinking I was hearing Gary screaming as he fell out of bed. Gee, I wonder where that dream came from. I got up to go to the bathroom – at least, that had been my intention. My back had stiffened up, and I could barely get out of the bed. I was very worried that I had really done something bad to my back, but in the morning I just found it very sore.

Gary's Saturday therapy session didn't begin until 11:30, so I stayed in the hotel room until close to then, icing my back and working on the blog until shortly before that time. The PT was one we've seen, but she has never led one of Gary's sessions. She was an "old-timer," having been at this job for fifteen years. Presently she works part-time because of her fifteen month old daughter. She said she'd work more – and her employers would like her to – but Shepherd didn't have a day care program, said they couldn't afford it. Wouldn't it be nice if such programs were mandatory?

The PT started him off on the rickshaw. She asked him if he wanted to try five sets of twenty. I couldn't help laughing, but Gary said "Okay, I'll try." She gave me a look indicating she was impressed with him, and then walked a short distance away to help another patient. A moment later, after he'd backed into the rickshaw, Gary looked at me, realization apparently having hit. "That's a bit more than 3 sets of 10 (his usual amount), isn't it?" I agreed it was. He churned them out, the last ones with effort. I made comments on his form. Helpful ones, of course ;-)

Next he got on the lat machine, which he hadn't been on before (there isn't one in the third floor gym where he does his therapy every day but Saturday). She had him do three sets of fifteen. Problem was, he couldn't get the bar down himself, and after a set he couldn't release it – well, he could, but they wouldn't have liked the weights slamming down on the stack. So I helped with that, trying to use my whole body in the effort and not just my arms.

Next she put him on the hand cycle, telling him to do it for fifteen minutes to twenty minutes. I knew he would need his muscle juice ;-), so I went off, got it, came back. Minutes later, he let out a "whoo!" and stopped for a break. The therapist smiled at him from the other side of the room and said, "Was that noise for my benefit?" He told her yeah, that he'd wanted her to know how hard he was working – and that she was torturing him. He continued with the exercise, going about eighteen minutes, taking maybe three breaks. I reminded him how far he'd come – just weeks ago, he hadn't been able to do more than a minute of the hand cycle without needing a break. (On Sunday, however, he said he regretted doing these exercises – his shoulder is now bothering him more than it had been, though the exercises had seemed fine at the time.)

It was then time for a weight shift, and as he did it, I reminded him to extend his scapula farther (as yesterday's PT had told him to). Today's PT walked over just as I said this, and Gary remarked to her, “She pushes me.” She laughed and said she knew that and thought it was great. Gary said he needed me to do that, because he was lazy.

I doubt they think that of him!

She then took us to the rec room for Gary to practice transferring on uneven surfaces – in this case, from his wheelchair to a low and soft chair. The downhill direction went well, but he couldn’t transfer in the upward direction, even with her help. She suggested he use his transfer board, got it out, and placed it so it went from his wheelchair down to sofa chair. The angle was very steep, and he looked at the board dubiously. But she told him not to worry, they’d be able to do it together. So he took one of his “hops.” She held him in place so he wouldn’t slide back down the board (dangerous for his flap, for one thing), and he took another hop and made it to his wheelchair. He told me afterward that if sometime he wanted to get into an SUV, he’d have to direct the person helping him to aid him in the way she had. The thought of that makes me nervous; at the least, I’d want to make sure the person helping him was strong!

Shortly after that session ended, I left for my appointment with a personal trainer. (Good thing I didn’t listen to Yahoo! because the supposedly seventeen minute trip took me thirty-five minutes – and this is without getting lost.) I can’t remember if I told you I was going to see one. I had told my massage therapist that even though I’d been to various doctors and physical therapists, I needed more guidance on what I should do to, first of all, help my back, and now, to be physically strong enough to help Gary. She had recommended her personal trainer. I had been reluctant to try that, but I finally made an appointment to see her.

I wish I had done this weeks ago – at least, based on this first session. I told her about what I was having to do for Gary that was physically difficult and causing some pain – helping with the transfers (in which I support some of his weight and have to twist with it to guide him to the next surface), pulling the draw sheet he lies on in order to move his body around the bed, pushing the pillows slightly under him while he’s lying on his side, lifting up various body parts to get pillows under them, helping him with his stretches by providing a little more force or supporting a body part (have you ever tried to hold someone’s leg straight up in the air for them while they’re lying on their back and they can’t give you a bit of help with it?), tugging those damn t.e.d. hose up his legs and pulling them down. (Come to think of it, I think Shepherd should expand their program and give PT and OT to the caretakers – teach us the ergonomic ways to move, give us programs to increase our strength, etc.)

The personal trainer said that based on what she was hearing, she thought we should work on the areas of muscular strength (she mentioned we’d do the traditional approach here – less reps and more weight, shooting for eight reps to exhaustion), endurance, posture, flexibility, and balance. (I admit I’m a little nervous about all this, afraid something is going to set of my CFS.)

We went through a mini-session. She said a warmup of at least 5 minutes was mandatory, and that it would be best if I got to the place early and did that on my own so it wouldn’t cut into our session. She put me on a recumbent bike, but it bothered my right leg, so we tried a “traditional” stationary bike, and that was better. She didn’t turn it on, though, because if the bike was on, it would “make” me pedal at a particular rate, and I am fearful of pushing myself (too many bad memories from these past fourteen years of trying to start an exercise program and crashing a short time after that).

She then had me do a type of squat – she placed a large exercise ball on my low back, and I leaned against it and and did the squats, rolling up and down along the ball. I did two sets of fifteen reps. (And this reminds me, because such a ball was in the package – did anyone come across a package containing my Gaia chair while they were putting our furniture back in place? It had arrived the day before the accident, and Gary was going to put it together for me over the weekend.) Next we went over to an inclined bench, and she handed me two ten-pound dumbbells and told me to do chest presses – two sets of eight – while she guided the weights. I looked at the dumbbells. “Ten pounds. Are you sure I should start with that? My shoulder has been bothering me.” (Such a wimp – at my best, fifteen years ago or so, I could bench press eighty-five pounds and squat one hundred and eighty-five pounds. But as I said, I now have these fears . . .) She told me to try them, and to ice my shoulder afterwards. I got through them fine, but I still wasn’t sure that had been all that great for a problematic shoulder.

Next came one-armed rows on a seated pulley machine. She had it set on one pound, and that was quite enough, particularly for that shoulder (if I forget to mention in the journal entry for Sunday, my shoulder doesn’t seem any worse for this – no better, but no worse).

We finished with stretching of the shoulders and back, all of which she assisted me with. I am going to try to be more assertive next time and tell her I really don’t want her to assist me – people assisting me in stretches have wrecked up my leg more than once, and I am afraid of a similar result when she does my shoulders (and I’m sure it doesn’t help when I am tensing them in fear).

Anyway, I have signed up for ten forty-five minute sessions, going three times a week. I have time for this, right? ;-)

After that session, I attempted to return to Shepherd. I was dismayed to see Lenox Square go by on my right – I had gotten back to Peachtree all right, but was now going the wrong direction on it. (Note to self: always print out a copy of the directions for getting from point B to point A. It never seems to work to just try to reverse the directions for getting from point A to point B – there is always a wormhole in that direction. At least, I’m pretty sure that is the problem.) Then I made the mistake of actually turning into Lenox Square to try to turn around. If someone knows a simple way this can be done, please publish your findings – I’m sure all of Atlanta would want to know.

So now I was all stressed out because I was supposed to be back at Shepherd by four so we could be checked into the TLA. I made it just before four, but there turned out to be another hitch. In the morning, I had called Gary and said I really didn’t think my back could handle carrying all I would need to do my cooking at the apartment down to my car from the hotel room then from the parking garage to the apartment (on the second floor of the Marcus building). I didn't know what to do – I asked him to ask if under the circumstances it would be all right if after we checked into the apartment I zipped back to the hotel and cooked my zukes for dinner, at the same time setting my rice cooker and crockpot to cook over night, and then zipped back to Shepherd with the finished zukes, then in the morning zipped back to the hotel to get my breakfast and lunch rice. He said he was sure that was okay, and I said I thought I wasn't supposed to leave him alone at all. He said it was supposed to be a trial run of being at home and I wasn't going to be with him every single minute of the day while at home.

Well, I was right – I wasn't supposed to leave him. Gary tried reasoning with the nurse, but she said it was official policy. So I went back to the hotel to get some supplies. Since there was no way I was going to carry all the stuff I would normally use in twenty-four hours (rice cooker, crockpot, steamer, zukes, rice, etc.), I just brought the rice cooker, some rice, a package of poha (flattened rice, kind of cooks up like oatmeal), and forewent any vegetables until the next evening. I had already packed my jammies, pillow, nightmask, earplugs, comforter, and two fans for white noise. Did I mention I am high maintenance?

To get us moved into the apartment, two nurses rolled Gary's hospital bed, on which lay his clothing and supplies – for ICs and bowel program, etc. (Now he has become high maintenance.) (Since he would be sleeping on a hospital bed at home, they had decided it was best he sleep on one in the apartment instead of him using the queen bed there.) Gary pushed along his rolling bed table with his feet while I pulled it on the other end – we were both trying to save my back a little (that table doesn't roll easily; it was needed to keep his supplies within his reach). So we formed a little caravan, going down the hall from the Shepherd building to the Marcus building, into the elevators (we needed two – the bed and a wheelchair could not fit in the same one), down to the second floor, over to the entry to the ABI (Aquired Brain Injury) unit, through that entry after a nurse buzzed us in, then into the TLA.

After getting the nurses to bring me some more blankets and to bring Gary more washclothes, they left and I "unpacked" the bed (taking the stuff off it and organizing it on the tables in the room). It was then that Gary realized he'd forgotten stuff like his grooming items and, more importantly, his plastic pan for his bed bath. So we made another trip back to his room. Then I needed to get all the stuff from my car. I was paranoid about him not accompanying me every step of the way (in case that got reported to the nurse), but he said he was going to stay in the hall on the first floor by the security desk, and I told him if we got in trouble, it was his fault! So then I made four trips out to my car, leaving the items near him each time. Then I carried them into the elevator while he prevented the elevator from closing. Then I carried them out of the elevator to the entrance to the ABI unit while he prevented the elevator from taking off with the remaining items. Then I got them inside the door to the unit while he prevented the door from closing (the door locks each time it closes, and you have to be buzzed in by a nurse at the desk). Then I finally got them into the room.

By this time – 7:30 – I was pooped, and he was tired too. So we got him transferred into the bed, we did his stretching (which first involves getting him in a straight position on his back), I changed his bandage (which first involves getting him into a prone position – and if you haven't picked this up by now, this turning business isn't easy for either of us), we got him undressed (first I pull off the long sleeve shirt over his head while he lifts up from his prone, then he turns from side to side so I could pull off his pants and those damned tight t.e.d. hose), then we got him turned onto his side. Now it was almost 9 pm. I got my bed ready, got into my jammies, set the alarm on my clock for 10 pm, set the clock on his bed table, and got in with him for a while. At 9:59 the nurse came in with his pills. At 10, the alarm went off, and he couldn't hear the buzzing. So after he took his pills I set the alarm on my cell phone. He could hear that, so I set it for 4am (ychh) and put it on a bed table.

At 10, he did an IC, and I lay in my bed waiting for him to finish. In previous weeks, the OT had worked with him on his trying to get into a prone position, and the conclusion was that I was going to have to help him prone at the "beginning" of every night at least until his flap restrictions are removed. So after he finished the IC, I helped him prone, stuffing three pillows under his chest while he rose up on his arms and putting pillows above and below his knees. I couldn't seem to get it right and I got frustrated. It was now 11pm. "I'm sorry you have to do all this for me," he said. He had tears in his voice, which melted my frustration. I told him I was sorry that I wasn't sure I was doing this right.

I slept pretty good – surprisingly so, under the circumstances – until that 4am alarm went off. I had been sleeping rather light at the time, so at least I wasn't jarred awake. I heard Gary move, and the alarm stopped. But then it went off again about a minute later (I can't figure out that stupid cell phone alarm – sometimes it turns off, sometimes it goes on snooze and sounds again one minute later, or ten minutes later, or seemingly whenever the hell it wants to). So I got up, took the cell phone out of Gary's hand, and shut the phone off. I didn't say anything, as I was hoping not to wake up too much. I was feeling sick, actually – I have learned from Dr. Rea at the Environmental Health Center that around four in the morning is the time when the body is cleaning itself, dumping all its toxins into the bloodstream, and so on, and that that is the time people with allergies of all sorts tend to feel their worst. No doubt making things worse was the fact that my body clock was saying this was not the time to be awake.

A minute later, I realized I was hearing absolutely no noise from Gary's bed. I got up again, went over to him, and whispered, "Gary?" He replied, "Yes?" "Aren't you supposed to be doing something? I don't hear anything." He then said he was thinking about what he was going to do next, how he was going to get out of the prone position to do his IC. I admit, I got unhappy – he was supposed to have been practicing this with the nurses. 4am is not the time to be thinking this through. I hope I didn't let my feelings show – I guess I didn't, as later, when I asked him about it, he said he hadn't noticed anything amiss. Of course, it was probably hard to register anything at 4am!

He couldn't figure out how to get out of the prone while he had the covers on, and it seemed the extra pillows under his feet were going to be a problem too. So I took the covers off him and also removed a pillow from under one ankle. Before I had a chance to get at the pillow under the other ankle, he got onto his side in a pretty good position, so it could possibly work with those extra pillows. He now definitely knows this is something he needs to work on, and he needs to add in the additional complication of covers. We also decided this would be a reason to have a mirror over his bed, so he could see what position his legs were in and if he was okay (at one point, one of his legs would have gone off the bed if I hadn't been there to catch it).

He then did an IC, and I laid in my bed. After a while, I checked on him – his last two ICs had been unusually low, and I was afraid this one would be way too large, maybe even too large for the bag. But it was going fine. He finished and put the bag on the table to be disposed of in the morning. Next task for him (and me) – go back to sleep. Only, his covers were off and he wanted them on. I almost put them back on him, but then stopped. Feeling a bit guilty – and sorely tempted to just put the covers on him so I could go back to sleep – I asked if he could put them back on if he used his grabber – which I handed to him. If he'd told me he didn't want to practice now, I would have put the covers on for him, but he didn't say anything, merely attempted it. He did pretty good, but we decided this was another reason to have a mirror put over the bed, so he could see where the covers were and how to move them.

So now he settled back onto the bed for some sleep. But he had a stiff look on his face. "Are you okay?" I asked him, standing at the head of his bed. "Yeah," came the quiet reply. The way he said it didn't convince me. "Are you a little frustrated?" I asked. "It's hard," he said, his voice breaking. I leaned down, gave him a kiss, and caressed his head, saying, "I know." His voice changed. "But I'll get it," he said resolutely. "Yes, you will," I told him, adding, "it's just not fun practicing at 4am." "No, it isn't," he agreed. I told him I loved him, even if I made him use his grabber on his covers at 4 in the morning. He said, "(It was) Good for me. Tough love." ('Tough love' is the term the therapists use for how the caretakers should treat their family members – not doing for them what they should be doing (or learning to do) for themselves.)

Now it was 4:50. I got into bed. Sleep didn't come, so I meditated, then finally fell back asleep around sixish. At seven, I tore awake from a nightmare. In the dream, I had left Gary in the TLA, gone down the hall, found a bed, and gone to sleep. An hour later (in the dream), I woke up and went back to the TLA. The room was now longer and there were two beds in it. The man in the first bed wasn't Gary, and neither was the man in the second bed. Panicked, I asked where Gary was. The nurses told me he'd called out in delirium and they'd discovered he had a horrible infection and was going to die, and no, I couldn't see him ever again.

Do you think this could possibly have been a guilt dream related to my almost leaving him for a couple of hours to cook my zukes?

At eight, I heard Gary call my name. "Yes?" I answered, no doubt more sweetly than I would have had I not had that dream ;-). "I need to turn," he told me. "So, turn," I said. I don't know if he appreciated my humor. Anyway, I got up and went over to his bed, and forty-five minutes later, he was turned onto his other side – again, I helped only when he gave up on some maneuver.

Over the intercom (which fortunately hadn't gone off during the night) they announced breakfast trays were on the floor. I got Gary's, then thought about trying to catch a little more sleep, but felt that was hopeless after about fifteen minutes.

So I set up his breakfast tray and started cooking myself some poha. Gary's nurse for the day shift (from the third floor of Shepherd) came about nine-thirty with his morning pills and asked how things had gone. He said he'd discovered there were more things he needed to practice. He mentioned about the 4am IC problems in turning from prone position to side position, and so forth. She suggested that this week they try to put him on a different IC schedule, one where he extends the IC time overnight to about eight hours (his levels would have to stay low enough for this to be "allowed"), and that he stay in that prone position for those eight hours. So the idea would be he would do an IC about 11 pm, then prone until 6 or 7 am before doing the next one. If he can't get into the proper position immediately before or after that IC, or he can't get the covers off or on, or some other problem arises, at least it would be easier on me to help him at 6 or 7 am than 4am. Gary isn't absolutely sure he can always take being in a prone position that long (so far, after about six hours, he has an urge to turn), so he still wants to work with the OT on that even if he is able to extend his IC time to eight hours.

And if he can't extend his time to eight hours, I guess for a while I may have to get up with those cows that probably still live out on Gold Hill.

After he finished his breakfast, it was time to start his morning routine. First came the bowel program. He finds it easier to lie on one side than the other for that (because of his flap restrictions, he can't sit on a cut-out toilet seat to do the program), and he was the "wrong" side. So he turned from that side, onto his stomach, over to the other side (the advantage of a hospital bed is that it has rails for him to grab; the disadvantage is there is not much room to maneuver). "There, that was easy," he joked as he finally got into the correct position himself. He looked at the clock. "Good thing Debra isn't coming until 12:30. I should be ready by then." (He thought he was joking, but it turned out he wasn't.) He then pretended he was having a conversation with her. "How did I spend my morning? Doing bowel program, then bathing, then dressing. . . . And putting on these damn gloves," he added as he struggled to put on a second pair of latex gloves over the first pair. We laughed, and he remarked, "Good thing we can laugh about it." I then reminded him that we also had his skin check and his stretching routine to add to that list of things we had to do this morning.

He then started in on the bowel program. Happily for both of us ;-), for just the second time ever he was able to do it all by himself, with a final "all's clear" check by me (you really wanted to know that, didn't you?). The only thing we took note of that we hadn't realized before is that he may need more than one bed table to put all his stuff on.

It was already time for another IC, so I got all the washcloths ready (three soapy, three moist) and handed him all his equipment. (He had thought he'd be up by the time for the next IC, so hadn't had his stuff prepared for it.)

Next it was time for a bed bath, so I brought a ton of washcloths and towels to bedside, and filled up his plastic pan with warm water and brought over the liquid soap. He did all but his back and legs, which I did for him. He had checked the parts of his skin that he could see during his bath, and I checked the rest.

Next came getting dressed (we were supposed to put lotion on him after the bath, but we forgot). He got his shirt on, I got the t.e.d. hose and the pants on him. He had planned on wearing the Dockers for when we went out to eat with Debra, but I asked him to please wear the stretchy pants, which he agreed to. This reminded me that I needed to see if I'd heard from Debra by email – I wanted to make sure she knew where we were. I realized I hadn't turned my cell phone back on, and thinking she may have called, I did so. She had called and left a message to say that she was sick and wouldn't be able to make it. I was very sorry to hear that, of course, but delaying her coming to another weekend worked out better for us too.

We next went through his stretching routine. Then, at last, it was time for him to get up. And it was almost 12:30. He joked, "Only seventeen hours in bed!" and that his work day would have to be from 2 to 4. He turned serious and said that only now did he realize that he'd been relying on the nurses a lot more than he had thought he had been – he'd thought they were only doing things for him that he would find easy to do himself, but this experience showed him this was not the case. I fear I was rather shell-shocked from experiencing how much help he had needed from me (being tired from the disrupted sleep didn't help matters) – we'd done the parts, but never before put them into the whole. I tried to keep in mind that it would get better in time, for both of us. But in considering the immediate future, we wondered how were we going to do this on our own when he has to be at Day Program at 9am?

He joked I'd have a lot to write up about this experience for the blog, saying I should put, "We discovered we weren't quite as ready as we thought." Actually, that should be as he thought, since I'd approached this experience with much more trepidation about our preparation than he had.

We now had a few hours "free" but neither of us felt like going out anywhere or doing anything. I stayed in the TLA and worked on the blog, Gary watched some golf (I'm sure the golfers are groaning – it was some big tournament, a very emotional one for Tiger Woods), then he went on the one computer on the floor that was available for patients. He discovered we were front page news on the online version of the city newspaper (here's the link, for however long it works – it's long, so you may have to do a little copying and pasting:
http://www.oanow.com/servlet/Satellite?pagename=OAN/MGArticle/OAN_BasicArticle&c=MGArticle&cid=1149189327559

In the actual article, there is a picture of him in the wheelchair in front of the volleyball net; I am the unidentified woman in the background ;-). Jack Brown sent me a pdf file of the article – I'll try to send it through to those who get this by email, but make no promises that Yahoo! will allow a mass mailing of such a file). Gary came to get me to come read the article. I first skimmed it and noted I wouldn't have had to spend all the time I did in talking with her <ironic grin>. I then read it more carefully. I thought it was nice, and pretty accurate. One thing she said that wasn't true (but is minor) was that Gary had felt panicked after touching his leg in the emergency vehicle and realizing he was paralyzed. I know he never said that, and he never felt that way. He's always just said that it was a weird experience, though he noted it would be a natural response to feel panicked, and the reporter must have assumed it had been for him. I told him that at the time it probably hadn't really sunk in what being paralyzed meant, and he agreed it was a gradual realization – his first thought about it was that they'd patch him up in Birmingham and after a few weeks they'd send him home in a wheelchair. We laughed at that, and Gary remarked, "Yeah, we can laugh about that now."

Anyway, this article came out just when I needed a little bucking up. Gary pointed out a couple of quotes of mine that he'd really liked. He asked me how I liked the last one of his: "I was never depressed about this situation," he said, attributing much of that to his wife. "It's much, much harder to go through this alone."

I told him I liked it very much – but that I wasn't sure it was true, as I'd thought he wasn't the type to get depressed. He said the quote was true, and that he would be depressed. He got emotional, and I gave him a hug. He said it was a good thing the interview hadn't taken place at 4am this morning, as he would have said, "Yes, I'm depressed – I can't move my legs around in this bed." I said I would have said, "The hell with this – I'm outta here." We gave little laughs and exchanged another hug.

We were eager to move back to his room – he needed to do another IC, I had to get back to the hotel for my massage, so we packed up and called the nurse to come get the bed. Gary said we could tell her our stay went as follows: We came, we got unpacked, we went to bed, we got up, we packed, we left.

Well, it was definitely a good experience to see what needed work on. Also, to realize how much time this might take us in the beginning, tho with experience we'll get faster at it – when we can just do it and not think about it. Gary says we ought to be able to cut at least half an hour off ;-).

I zoomed back to the hotel and threw myself on the massage table that had been set up by the person I'd arranged to have a massage from (okay, it didn't happen exactly like that, but it felt like that). This person was very good, and it was an added bonus that he came to me instead of me having to go to his office. The only hitch in that regard was, I wanted to go back to the hospital right after the massage and he was in Mellow Massage Therapist mode. (When I told this to my chiropractor, he summed up my exact feelings: "Okay, I'm relaxed, now get out.")

Just when I stepped into Gary's room, about a half hour later than usual, my cell phone rang. I knew it was Joe, because he had called when I was on the massage table (I hadn't picked up but had later gotten the message that he was going to call). Gary talked to Joe while I got the bed ready for Gary to get into it. Gary told Joe we were running late and still had all our evening routine to do, so the call was a short one (Gary apologizes to Joe if he seemed abrupt – we were very tired). Gary relayed the news to me that Joe and Dolores made it back to their home safely, and the dogs survived their absence. I could also hear that they talked about the house and the crew of math volunteers.

After Gary ended the call, we got him transferred into bed. Next was supposed to come the stretching, but Gary said we should skip it. “Duty” warred with fatigue, and I asked if he was sure we shouldn’t go ahead and do it. He said it would be all right to skip one night. Fatigue won, and I didn’t put up any more of an argument. I changed his dressing, got him proned, hoodled a short time, then we said our goodnights and I told him I’d see him tomorrow. “But thankfully not at 4am,” he said with an ironic smile.

Now to finish with some odds and ends. I got emails from Janet Rogers and Jo Heath about the furniture moving. They said they’d almost made a party of it, and Janet sent us a picture of the “movers.” I’ll insert it here in the blog. Don’t get too comfortable, guys. (I hear you freaked poor Blackjack out, when he came into the room and suddenly realized he’d walked into a roomful of strangers. In Jo’s words, he bolted out faster than she would have thought a cat his size could move. (You should have seen him the time he took off so fast he couldn’t gain purchase on the kitchen floor, and though his legs were moving like mad, he stayed in place – just like what happens in the cartoons.))

Speaking of pictures, only two pictures were saved by the people who took the publicity shots of Gary for the news article. The one they put in the paper is one of those pictures, but the one they didn’t use I think is the better photo of him. I’ll put that in the blog too. (Notice me in the background trying to skulk out of the picture ;-)).

All for now.

July 24, 2006

Today’s therapy started off with the PT, and she started by having Gary practice tub transfers (onto a shower bench in a regular bathtub, as many places he’ll travel to are not going to have a roll-in shower). At this stage, she has to help him quite a bit – 50 to 75% , mainly with getting his legs in and out, but also with the transfers – so unsurprisingly she doesn’t expect him to be “cleared” to do this by the end of this week. She claimed, however, that she should be able to clear him for bed transfers on his own by the end of the week. “Naturally” I felt uneasy about this, but Gary did too – his near slipping off the edge of the bed is too fresh in our minds. We told her about that, and she reminded him that if he found himself with less than half each thigh on the bed, he should throw his head forward and down while depressing, in order to scoot his butt back on the bed. But of course, this is assuming he has the balance to do this – as well as the immediate recognition that he should.

Our bringing this up decided her on having bed transfers using the hospital bed in the gym be the next thing he worked on – the bed is like the one he’ll be getting for home use. After he did a couple transfers back and forth (why is it he always does exceptional ones when they're watching?), she had him try something new – "hovering." Here he was supposed to depress upward in his chair as if he was going to do his transfer to some other surface, but then he was to hold it there for a second, and then " reverse" the direction, literally using his head to do so, in order to end up back in the chair. A harder version of this exercise would be to actually begin to carry through the transfer to the other surface, but then reverse it in mid-air so that he ends up back in his chair and not on the other surface. ("O. . . kay," Gary had said dubiously when the PT brought this exercise up first – she then had him do the easier version.) The application of this harder exercise would be the following: if it should happen that some time when he is doing a transfer he realizes there is something not quite right about it, he would be able to reverse his direction (thus going against the direction of his momentum) and go back to his chair without making the transfer.

He didn't advance to that harder version of that exercise today, but even practicing the easier version would build his strength, the PT said, and Gary could see that. The PT also pointed out that it would help him develop more control with his transfers, that he needed to learn to transfer out of strength and control, not just out of momentum as he has been doing up to now (and was what they'd wanted at the time – the first goal is to always have the patient end up in the chair! Finesse comes later).

It was the end of his session with her, and he asked her what the therapy tech would do with him later (the therapy tech does what the PT tells her to do). When Gary found out it would be strength training, he brought up his shoulder problem. It now seems to be centered in the front of his shoulder, and the PT said it was biceps tendinitis. She told him not to do any exercises that gave him pain and to ice the area after his session with the tech (I brought him ice wrapped in a latex glove after both that session and this one with the PT).

We had a little break before his "Bladder Two" class, and he used it to call the people who would bring out a van for him check out. The person emailed him with the information, and later in the day Gary picked out a minivan he'd like to see (a Toyota Sienna with a ramp, removable seats, wheelchair tie-down) and arranged for it to be brought to Shepherd tomorrow afternoon.

The "Bladder Two" class was on dysreflexia, which I've already told you about. After that came a break for lunch and so forth, and then the first thing scheduled for the afternoon was a session with the OT.

With the OT, Gary brought up the problems we'd run into during our TLA experience, so she had us simulate the experience. First Gary and I got him transferred into bed. I went to lift his legs up, but she asked him what of that he could do on his own. He surprised himself (and me) by getting his upper legs onto the bed (by leaning on his elbow on his side and tugging at them). After that came another surprise of him being able to sit himself up from this side position by hooking his arm around his thighs and pulling (he'd done this a couple times before, but this was so much smoother than he's ever done). He needed to do this to get himself properly oriented in the bed, i.e., head toward the top. Because of flap restrictions this was about the best he could do, which left his lower legs for me. But since that was so much less weight for me to handle, that was much, much easier than getting his entire legs on the bed. Easier on me, that is. I guess it’s going to be a matter of whose needs are greater at the particular moment he needs to get his legs up on some surface, since as you can probably see, he had to do quite a bit of work to get this far. But, he wants to be independent, and this is what he has to do to help get him to that state.

He and I then got him in the prone position, as I’ll have to help him with that for the time being. I got him padded off and put the sheet and blankets on him as I always do. Then we pretended it was that four in the morning time, and he needed to come off the prone position and go onto his side all by himself. It actually worked okay after the OT gave him a couple of tips. The blankets didn’t seem a problem – he got them off far enough that he could maneuver, and later, got them back on – whereas the previous day he’d found them an insurmountable problem (insurmountable without help, that is). We’re not sure about his foot padding, because a pillow ended up directly under one foot, whereas ideally the foot would float, so we’ll just have to try that out and keep a watch on his skin for any negative changes there.

Once on his side, he was able to get a pillow between his legs, by following the OT’s advice of getting up on an elbow and “walking” it so he ended up in a position curled enough to enable him to push the pillow with one hand and pulling it with the other (and the same technique would allow him to remove such a pillow). (Speaking of pillows, the OT remarked that in moving about the bed, he looked like he was swimming in a sea of them. Gary laughed. “And I need them all,” he noted.)

I asked him why he’d had such problems the previous day with the covers, etc., so that we could recreate the difficulties, but he said that he didn’t know, that maybe he’d just run into a mental block at 4am and given up too easily.

The OT said she had to soon leave to see another patient, and told Gary to now work at getting over to the edge of the bed and his lower legs over it from the side-lying position he was in. As he worked at it, she remarked, similarly to what she had before, that he was not at all like a member of the senior team (again, “senior team” meaning those over 55), that he was more like the twenty-year-olds she worked with (we still can’t quite believe that). She also mentioned that he was far more advanced than people she usually worked with, that people usually left here earlier than at his present level of skill. Again that surprised us. Gary told me later he would have thought it downright dangerous to leave much sooner than where he was at now, and that he would have found it scary to leave much sooner than we plan to.

Back to his task of getting over the edge of the bed in preparation for a transfer to his wheelchair: it took a lot of time and a lot of effort – and the OT left before he finished, but he did it. He said it was great to know it was possible.

Next up was a session with the therapy tech. Gary did his terrible threes, then some balance exercises. One thing he has definitely improved on is that he now catches himself well when he loses his balance ;-) (Actually, that is very important.) He even made up an exercise of his own, trying to reach out for a two-handed touch. It took him a few tries before he could do one of those with a degree of control instead of a quick bat. After the successful one, he looked up at the tech and asked, “Isn’t time up yet?” We all laughed (including Gary), though we knew he wasn’t saying this purely in jest. Time really was up, though, so we did his transfer and went back to his room. I went to the chiropractor a little earlier than usual (he expressed approval of the work done by my latest massage therapist) and then I did my usual evening routine.

Through most of the day I had still felt a little subdued by our TLA experience, but I felt back to my normal by the time I returned to Gary’s. I got there as early as I could, so we could have a bit of a phone conversation with Joe. In order for things not to go too late, I threw Gary into the bed (well, okay, we did a transfer – and in fact, Gary got his own upper legs on the bed just as he’d practiced with the OT earlier! Saved me some effort, cost him some, and at this point he won’t always have the energy to expend on that, but it’s another sign of his growing independence), and he talked to Joe while I did the stretches on him (I caught snatches of conversation about the house, the new garage, our pets and Joe and Dolores’s pets). After their conversation ended, Gary and I went through the rest of our routine.

While lying in bed with him, I had the thought that I should probably follow him around at the university his first few days – so I can give y’all a report on how things go ;-). Gary joked that if I stuck to the accomplishments at home, the entries would look like: “Today, Gary successfully fed the kitties.” He then decided that would actually be nontrivial – that he was now so slow at everything that by the time he’d opened the bag and put in the measuring cup, the cats would have dived into the bag and inhaled all the food – not a mark of success (unless you’re taking the feline point of view).

As typical, our conversation was stopped by the speaker phone conversation of Gary’s roommate. We heard him talking about the hoyer, and whoever was on the other end of the phone misheard and thought he’d said that in order to lift him, he was attached to the hoyer by his neck (he’d really said “net”). I told Gary we should tell his roommate that that was indeed the new method for using the hoyer, and demonstrate it on him. We started laughing so hard that had the rails on Gary’s bed not been up we would have fallen out. (Lest you think otherwise, this roommate is a very nice guy and we really like him – except when he talks on the phone.)

To finish, another picture taken by Janet Rogers (see the blog http://drpeg2003.blogspot.com/). Evidently last Saturday the math volunteers decided our family room needed more illumination. The caption below the picture is Janet's.

July 25, 2006

The therapy morning started out at 8a.m. with another “wet run,” the OT and PT saying they wouldn’t open their mouths unless they saw something dangerous (which turned out not to be true

– one of them asked if we really wanted to keep Gary's shoes on while he was showering (hey, give me a break – you know I don't sleep well when I have to be somewhere early, and he needs to wear the shoes until he has actually transferred onto the shower bench (one never transfers without wearing shoes – the feet act as pivots and will have some body weight on them, so they need to be protected. Is this enough parenthetical thoughts for you?))). We speeded through the wet run, finishing it up in an hour (yes, I am being ironic). The OT next wanted Gary to practice dressing while in his wheelchair (this was his first attempt at doing so). While it is the case that if he is lying in bed, he can get his pants on the rest of the way once I have put them on over his knees, if he can learn to dress while he is in his chair, he won't need to go back to bed after his shower in order to get dressed.

I put his t.e.d. hose on him and got the pants up to his knees (he should eventually be able to do all of the pants himself), and he attempted to get them up the rest of the way. He alternated trying to lean way over to the side of his chair to get the pants up his thighs with trying to do a depression with his thumbs hooked inside his pants to try to slide into them. After half an hour of this, he still couldn't get them up over his butt. The OT decided to call it quits for now. (But I guess he could still get dressed in his chair even now, with me pulling his pants up for him as he does a depression lift.)

After this he needed to get back into bed so I could dress his flap wound. We were running a little late, and while I was doing this his rec therapist came to the room. Gary said she could come in, that he was used to everyone seeing his butt. I finished what I was doing, and as he and I went through the routine of getting him back in his wheelchair, she informed him that two people had cancelled out on seeing the Braves game, and as he was second on the waiting list, he gets to go to it on Wednesday night (we didn't ask about me – when I'd found out that the soonest they would get back is 11pm, I'd said I didn't want to go; sorry to disappoint you, Jack Brown ;-)). Then she asked him about his rec therapy goals for Day Program. They decided on the Easystand, on getting onto the recumbent hand cycle, on billiards, and possibly on going out to a driving range for golf if Gary's shoulders are up to it.

Next she began testing his knowledge of what had been covered in the rec classes; this time the test concerned the ADA. She asked him what areas it covered. He first said public buildings, and she quizzed him about various aspects of that, including businesses. She summarized by saying that the law says that businesses, etc., need to make their services available to him in a reasonable way, which of course can get a little gray, as one person's interpretation of "reasonable" may not seem reasonable to another. She asked if any buildings weren't covered, and he said privately owned buildings and those that were "mom and pop shops" (less than a certain number of employees). She told him he'd forgotten one, but he couldn't remember. I was in the background about to burst ;-), so she let me answer: historical buildings (would sort of ruin the idea of being historical if Abe Lincoln's cabin had ramps and so forth added to it).

The next area he mentioned as being covered by the ADA is government buildings open to the public, and she told him that was true only of state and local government buildings, not federal!

(Odd!) That hadn't been stated in our classes, and she said she'd only recently found that out.

Next he mentioned job discrimination, and they covered various aspects of that – if an employer can ask you about your disability (only the aspects of it directly pertaining to the job you will be doing), what if the workplace isn't accessible, and so forth.

Gary was stumped on the last two, so I got to answer: transportation and telecommunications. (Gary asked me how I remembered all this, and I told him it was because I'd heard the lectures twice and I'd written about the stuff in the blog.)

The telecommunications aspect won't apply to Gary, but for those unable to open a phone book, for example, they are entitled to free 411 (information) service. Transportation was the other area. Buses we pretty well knew about – the public system and paratransit services (first brought to our attention by Phil Zenor), but she went into rail systems as well – similar principle, though they will probably only offer a cutout area and not a tie-down system for the wheelchair. She said the main thing there was to make sure the desired stop was accessible (I didn't think to ask – wouldn't that be required by law?).

She then asked him how assertive he thought he was, on a scale of 0 to 10. He said "two." She asked him what he'd do if he went to a restaurant and they said he couldn't come in because they didn't have the facilities for him. He said he'd tell them about the ADA, but that he wouldn't feel comfortable insisting they accommodate him – he'd leave. She told him that opening a dialogue with them by telling them about the ADA was an assertive act, then asked him what other kinds of responses disabled people might have in that situation. He said to leave or to get angry, which is basically what she was looking for – an assertive response, a passive one, and an aggressive one. She said she understood he might not always want to make a fuss about a situation – that one had to choose one's battles – but that if there was a place he really wanted to go to, he had the right to pursue the matter. And even if he wasn't comfortable with being assertive, there were times he should be, or else he might miss out on something he'd enjoy. She gave the example of going to the Braves game tomorrow. If a lot of people were there and he waited for them all to get through before he made his move, he might miss the game!

She then asked him why he thought recreation, in any of its forms, was important to him now. He said he needed to stay healthy and fit with the more active forms of recreation, and that he needed to fill his life with more than just work and ICs ;-), though he considers much of his work to be recreation because he enjoys it so (except for grading tests). She made the point that those with SCIs are more susceptible to secondary health complications (urinary tract infections, pneumonia, skin problems), and that by maintaining an active lifestyle he was less likely to have these complications. She finished up by reminding him about the Bridge Program, that they'll be asking him about his working out and his traveling plans. This reminded me to ask about how exactly the Bridge Program worked – if there was something we needed to do to start the process or if it would just happen; they'd talked to us so early in the process here, Gary and I have both forgotten the details. She said she'd find out for us. She also told us she'd be giving him a list of Home Care

Instructions before he is discharged on Friday, and that he'd be getting such a list from everyone on his team.

One thing I think is a little odd – the rec therapist spent two sessions quizzing him on the material they cover but there is no such "intensive" quizzing of the medical-related stuff, though he did get a little multiple choice test to fill out.

After lunch, he had a session with the therapy tech. She laughed to herself as she read her list of things to do. He was to start with – you guessed it – pushups. One hundred. He looked at her, dazed by the news. "You can do them in sets of twenty-five," she comforted him. "How generous," I said as Gary just laughed in disbelief. But, as you've guessed again, he did them, giving mighty groans at the end of each set. After the fourth set, he remained unmoving for a rather long time, and I had to check for a pulse ;-).

Next was the "terrible threes," and Gary told me he needed a second hit of Juven (he'd already drunk his allotted one pack for the day), so I went off to get him some Purple Power (the choice of flavors is grape or orange). On my way to get it, the case manager stopped me and told me Gary should pick up his "going home nursing supplies" and any prescriptions at the apothecary on Friday. She also said he needed to see the Day Program manager to sign paperwork agreeing to have a new case manager take over once he goes to Day Program.

I came back to find Gary doing the threes. After them he took a long swig of Juven and was glad to find he had no time to do dips. So we did balance exercises for the last five minutes, him reaching for my hand. I'm not sure the PT wanted him to do them this way, but he found he had much more control if he put a hand behind him and reached with the other.

Next he did the paperwork for Day Program, then wearily wheeled his way back to his room. He had an hour's break before the next session, and he said he needed a nap after all the work of taking a shower and the tech's session. So I got him settled into bed. Dietary came around; he hates missing her because when he does he gets the "non-select" menus for the next day, which have always been things he hasn't liked. But he didn't want to stay awake until she got to him, so he told me to choose for him. I told him I was worried I wouldn't choose what he wanted. He mumbled, "At least I'll know it's healthy," and went out like a light. I chose his food (he later approved of my choices), then worked on the blog a little. While I was doing this his nurse for the shift came to introduce herself to him but fortunately didn't wake him when she saw me there. She asked who I was. I told her Gary was my husband. She was surprised – she said for weeks now she's been seeing me all the time around the hospital, seemingly always there, rolling my suitcase along. She said she had no idea I was a family member – she'd thought I was in the biomed department and was wheeling my equipment around. She said she should get an honorary name tag for me. I said I'd take it ;-).

The mail also came during this nap time: Thanks to Justin Towe (my little sister's son), Mom G (what, no picture? JUST KIDDING), Ella Schmidt and her daughters Mariana and Lucia, Marilyn

Foreman, and the approximately sixteen people (not sure I counted the signatures correctly) who signed a card from Sofia University, Bulgaria, attending a conference dedicated to Pioneers of Bulgarian mathematics.

Speaking of mail, for the next little while, it should be addressed as:

Gary Gruenhage
c/o Marilyn Taylor
Shepherd Day Program
Shepherd Hospital
2020 Peachtree St. NW
Atlanta, Ga 30309

Again, the mail here isn't delivered in the most timely manner, so you may not want to risk sending anything up much after this week.

It was soon time to wake Gary up, which I did reluctantly, to get him back in his chair for his PT session. Gary says I have to admit on the blog that I put his shoes on the wrong feet (hey, I get confused when they're not my own feet).

The PT had the two of us practice car transfers in and out of my car. It did not go as smoothly as Gary's Saturday session with the other PT, but at least the objective was accomplished. It's hard to recreate being in exactly the same position, and so forth.

Also at this time, the PT suggested that when we go to buy a new car, Gary go along and try transferring in and out of various models to see what ones are easiest for him. She suggested we get a car with a low profile, which I guess means it's slung low to the ground and so has more head room. The wisdom of this became apparent when I got his cushion beneath him (he always has to sit on that, or an equivalent, no matter what he transfers to) and his head was nearly touching the roof.

The PT told us who Gary's PT and OT will be for day program. She has talked to them and told them what she thought the goals for Gary should be – this is so they don't waste time doing their own evaluation. She told them she thought he should continue to work on transfers between uneven surfaces. Also, right now he is at "minimal assistance" on his various transfers, meaning others are giving between 25 and 75% assistance during them. She would like him to be at the "supervision" level (meaning I or someone else would just be standing by in case of problems – maybe still with hands on for balance, I'm not sure) for his transfers to and from the exercise mat and the bed. They both are confident he'll accomplish this for the exercise mat, but she admitted she wasn't sure he'd be able to reach this level for the bed by then.

We ran out of time for him to practice curbs and wheelies, but those are of secondary importance anyway, she said, since there are always ways to avoid them. But, being able to do them would increase his independence.

On our way back to his room, someone stopped us – maybe our Bridge Coordinator? (I have a hard time keeping everyone straight) – and gave Gary a packet on the Alabama Vocational Rehab department. Turns out there is an office right in our town.

We had a short time before the van from a local dealer was supposed to arrive for Gary to check out, so Gary decided it was time for a shave (FINALLY ;-)). While he did that in the other room, the assistant chaplain came in. She asked me how the TLA went, and I told her it'd taken a long time for us to get through his routine. She asked me if I was worried I wouldn't be able to handle it, and I said "a little," adding that I knew it would get easier as time went on and we got the routine down and he was able to take on more and more. She told me it said a lot that I was here with him, that in general (not at Shepherd) many people didn't make it this far – they couldn't handle dealing with their family member who'd suffered this kind of accident (reminded me of how many people with CFS are abandoned by their families). Gary wheeled in and she asked him how he felt about it almost being time for us to take on his care on our own. He said he felt ready to handle it but was a little worried it might be too much for me, though he intended to be as independent as he could be as soon as possible. She told him not to worry about me, that I was tough, that whenever she saw us in the hallways we were always smiling or laughing, so we'd obviously kept our senses of humor.

After she left, we went down to the gift shop to see if they sold fanny packs – Gary wanted something to carry his money in at the Braves game. They were out, and when I asked where around here they might sell them, they suggested the CVS drugstore. There were a few minutes to go before the van was supposed to arrive, so I dashed up the street to CVS. No fanny packs, but they did have something called a "Munchsak," like a thermally insulated lunch sack. I would have preferred something a bit smaller, but since its handle could be threaded through Gary's seat belt and it only cost $5, I decided to get it. (Gary thought it would work just fine.)

By the time I got back the van was there. The man showed us how the ramp was automatic: he pressed a button on a remote control and the side door opened and the ramp came out. Gary couldn't get up it unaided, but that turned out to be due to the extra slope of where the van was parked – later, after I'd left, they moved the van to another spot, and Gary got up the ramp fine. The Transfer Seat for the driver turns ninety degrees to facilitate the transfer from wheelchair to driver's seat (because of its cost – $2000 – it is usually not put in the passenger's side, as the person in the wheelchair can just transfer into the rear seat). The man cautioned Gary that should he buy a van now, not to have a Transfer Seat installed in the driver's side, because when Gary has his driver evaluation they need to clear him not only to drive, but to drive in such a seat (as opposed to his wheelchair, which confused me a little since Gary was cautioned against doing as being less safe).

I had to leave at that point – time for my first session with the personal trainer. Now you may want to skip down in the journal, because I am going to talk to myself ;-) (so you all talk amongst yourselves). I am going to record what she made me do, so that when I go home I can (hopefully) carry on with the workouts.

First I did about a ten minute warmup on the exercise bike (set to "off"). Then she had me do wall squats: I put my back to the wall, stood some distance from it, and squatted down while sticking my butt out to touch the wall; this exercise can be made harder by moving farther away from the wall. She told me to do about twenty reps, but I'm sure I did more since she was talking to me at the same time and we both lost count. Next I was to do the same movement, only this time with a large (twenty-two inch diameter) "stability ball" in my hands, which I was to swing all the way diagonally upward as I came up from the squat and diagonally downward as I went into the squat. It was hard to swing the ball and remember to "lead" the squat with my butt (let alone remember to push up through my heels, then my quads, then squeezed my glutes). She told me in general I was supposed to do ten to fifteen of those, but I counted twenty-three before she made me stop; then of course I had to swing the ball in the opposite diagonal direction, and we didn't stop at fifteen there, either.

Next she had me stand with my legs at shoulder width, one about five inches in front of the other. I was to bend my knees so that I was doing a modified lunge. My butt was supposed to go back first, as in the squats, and my rear foot was supposed to rise up on its toes and my arms were supposed to rise forward together to act as a counterbalance – she must have mistaken me for a coordinated person. To top it off, my vertigo got in the act, adding to my difficulties of staying balanced. She had me do twenty reps. Then she had me do another twenty, this time reaching across my body with the hand that was on the same side as my leading leg in order to touch her hand. Then another twenty, reaching the opposite hand forward and pulling it back as if I were starting a lawnmower (the old-fashioned kind, of course). Then I had to switch legs and do all this again! (I had told her I had CFS and needed to get into this gradually – I shudder to think what the workout would have been like if I hadn't told her this.) When I would do the ones where the arms were sawing back and forth, my rear knee kept turning out, and she would correct me. So there was a constant litany of : "Watch your knees! Lead with your butt!" I thought Gary would have loved being there and getting his revenge by hearing this person constantly correcting my form.

She told me that, for future reference, to make the exercise harder, I could widen my legs, and to make it even harder, add weights. I decided not to test that out now. By this time, I felt that "dead leg" lactic acid buildup and could hardly follow her into the other room for the next exercises. Fortunately, they weren't for the legs. They were wall pushups. She had me put my hands lower than I would naturally have put them, and wider, so that my elbows were bent at a ninety degree angle when I was in the down position. She had me do twenty of them, nose to the wall if I could (which I could). Actually, those weren't nearly as bad as those leg exercises. She told me they could be made harder by moving back farther from the wall or by lowering my arms or by pushing off from the wall at the top of each pushup, then fall back toward the wall. I was afraid of getting too sore, so I didn't make them any harder. As it was, when I reached down to pick up my notebook from the floor after this exercise, my legs cramped. I hope I can walk tomorrow!

After that I did twenty reps of side raises using an exercise tube, standing with one foot on the tube. That can be made harder by using a thicker tube.Or by stopping the downward motion of the tube when the resistance slackens. As she pointed out, any exercise can be made harder by stopping just when resistance slackens, and starting the exertion phase again, thus not giving the muscles a chance to rest.

She also pointed out during this exercise that one should never hold one's breath during weight-training exercise, that one breathes out on the exertion phase and in on the rest phase. I had mentioned this to Gary just weeks ago. Actually, nothing she had told me was new to me, but it's been a long time since I've put it in practice.

Then it was time for stretching (thank God!). She told me that at home I should do each stretch two or three times, holding the stretch for twenty to thirty seconds, but that now we only had time for one repetition of each stretch. We did a sitting hamstring stretch, one leg on the bench; I got the feeling she would have liked me to stretch farther, but this is the kind of stretch that sets my leg symptoms off. Next we did some shoulder and back stretches that I was familiar with from my swimming days – arm across the body at shoulder height; reaching down the back with one hand; interlacing fingers behind the back and bending forward and down; arms straight out in front grasping some stationary object while sticking the butt out and flattening the back. I finished up with a quad stretch (grasping your foot behind your back and pulling), and a calf stretch (the one you always see runners do – hands on the wall in front, one leg bent forward, the other straight back, and stretch the back leg).

At this point she also mentioned that a stability ball was good for stretches – you could relax forward onto it, or lie on it on your back.

As I left, I told her I'd had fun, and I had. When I got back to Gary's, I showed off my free T-shirt (not that I totally agree with their motto, "Choice, not chance, determines your destiny," as to me destiny is determined by an interplay of them both) and told Gary about my workout. He said we could now commiserate and thought it pretty cool I'd been able to get through the workout. He hopes, as do I, that I will be able to handle it so I can get stronger (he has a little vested interest there ;-)).

A little later, when I was getting him blanketed for the night, his speaker phone roommate called out and asked if I was in the room (as he knows I am there much of the time). I said I was, and he asked me to come over when I got a chance. So I finished putting the covers on Gary and went over. The man's nursing tech had forgotten to put his call button where he could reach it. I looked around for it but couldn't see it, and I said it must not look like Gary's. He told me it was "the red thing," and I realized I was a little slow. The man's injury is an incomplete one at the C-level – he has a little use of his hands and arms, but not much, so of course he wouldn't have a call button of the type Gary had. His was a long tube that he could blow into. I hope I hid my shock and sadness at the renewed realization of what he was going through. I am so thankful Gary doesn't have that level of injury. And I really wonder how I could borne having to take care of him to that extent.

No doubt we would have had home care. But I think of all those people who probably can't afford that.

July 26, 2006

I am sore, but no other noticeably ill effects from the exercise. I'm usually worse the second day after it, so we'll see how I feel tomorrow.

Today was a rather light day, which Gary didn't seem to mind (he is a little worried about his shoulders, and we have been icing them several times a day). First up was the therapy tech, and today's work was done on the queen-sized bed in the gym. He transferred onto the bed and then, sitting along its edge, did hops up and down the side. I asked if he wouldn't get more lift if he bent more, and he said he probably would but he was afraid of falling off the bed. The tech was right in front of him and promised him she wouldn't let that happen, so he tried it and did noticeably better scoots.

Next he got his legs up on the bed with a little help from the tech, and by himself got to the middle of it and sat up (a seemingly impossible goal when he first came here). With his legs straight out in front of him on the bed, he practiced the hops again, first to one side, then the other. I pointed out that while he was getting his head down the opposite way of travel, he wasn't much allowing his body to follow it – only his head was dipping. So he tried to use his body more, and again the difference was noticeable. He called it "using the trampoline effect."

Next he was to practice going from a prone to a side-lying position and then getting the pillow from under his legs to between them – the goal being not to wake Peg every single morning at 4am to do this for him ;-). The tech said she had to go get a pillow and told Gary not to move. "Don't worry," he told her. "I won't run away."

He remembered the OTs tips about getting on his side and "walking" on his elbow into a curled position, and he got the pillow put in the proper place with no problem.

His final task was to sit himself up and get himself back onto the edge of the bed for the transfer to the chair. The tech gave him only a little help with his legs.

We went back to his room, and since Gary was to go to the Braves game this evening, his flap dressing had to be changed sometime during the day while I was there, so since he had an hour's break before seeing the OT, we did it then. The PT came around during this time to tell us that in their team meeting this morning, it had been decided he didn't need a special mattress – or even a hospital bed – when he goes home. The PT confided to us that she and the OT wished they had known that before now, that there would have been more practice on a regular bed. But Gary and I thought it would be best if he starts out with the hospital bed anyway. It is what he is used to, and throwing in a new factor at this stage of the game makes us uncomfortable. The PT said she'd also thought it best for him to start with the hospital bed. She said he could practice using the rails on it less and less, and whenever he was comfortable with the notion, he could sleep on a “regular” bed.

The good news about this is that it means the medical staff agrees his flap is healing well, that it no longer requires he sleep in a special bed. I know from dressing the wound that it is looking so much better lately – there are just two tiny holes that haven’t quite healed up, both at the junction of two seams.

Though the PT had previously demonstrated to us how to “break down” Gary’s wheelchair for its transportation, we’d actually never done that, so when the OT asked Gary what he wanted to do during her session, he suggested that. The task is slightly more than he can handle independently, but for now the important thing is we have hands-on experience doing it so we can get his chair in the car!

She next wanted him to transfer entirely without help from the mat to his chair. He gave me a nervous grin. I told him he could do it. He said to the two of us, “And you’ll catch me if I fall, right?” and we assured him we would, the OT adding that she was sure he wouldn’t need any assistance, that he could do this himself.

It took him a while to psyche himself up, and then he tried the transfer – but he landed on the tire (very bad for the flap) and the OT had to help him over. He then made the transfer back (the downhill direction, and therefore easier), the OT saying it had been on his own (though I noticed she’d kept hold of his pants this time). She commented that it hadn’t been a very high depression transfer, however, and she said that she was learning how much help I’d been giving him, that I was stronger than I looked. She asked me how much lift I thought I’d been supplying him with, and I said it varied, that sometimes he seemed to get tremendous lift on his own, but sometimes little, that he wasn’t consistent (depending on how tired he was, etc.). I didn’t admit, but maybe I should have, that I never acted purely as a guide – I’m too scared to not give him a little lift, as I want to make sure he lands where he’s supposed to. But maybe that’s made the OT think he is better at it than he is.

She had him do another transfer both ways, the OT saying that it was “all him” both times (though she’d been hanging onto his pants), but that he wasn’t getting very high. The PT walked by, and the OT said to her the same thing, that she was learning how much help I’d been giving Gary, that I’d been giving him lift. But the PT said that she’d done the transfers often enough with him that she thought that even though he doesn’t always get tremendous lift, he still gets enough to clear the wheel.

So, I’m not absolutely sure he’ll get cleared to do even the mat transfers on his own this week – there’s really only tomorrow to go. He did confide to me after his attempts that he’d been afraid to bend as much as he normally does in the transfers because of his “balance issues”; without the security of having one of us have our hands on his hips he was afraid he might fall. And of course, if he doesn’t bend his upper body as much, his butt doesn’t lift as much – that equal and opposite reaction thing.

After the OT session he had a "group" session (an outing up the block to Chick Filet), but before they took off on their outing, there was a graduation ceremony! He and another patient are being discharged this week, so their teams members had a ceremony for them, while everyone else in the therapy gym clapped and cheered. In the background "Chariots of Fire" played, and the therapists put traditionally styled caps on the two graduates. They both got Shepherd T-shirts, which say, "Outroll, Outmaneuver, Outlast," and fanny packs (good thing the gift shop hadn't had any more yesterday). Each of them got a certificate of graduation from Shepherd Inpatient Therapy, and since they'd both completed their course work, they got Super Student Award certificates. The other man also got certificates for Best Tolerance of Stretching (I think that was a joke) and Best Homegrown Tomatoes. Gary got a certificate for Most Likely to Need a Helmet for Doing Wheelies and a "Shiny Hiny" certificate from the skin team, the certificate in the shape of a butt and covered with foil. Gary thanked his team, saying they were the best, and then pictures were taken – Gary's had the members of his Shepherd team in it and me. The pictures came out pretty good, but I don't have a scanner here, so I guess I can't put them up on the blog until we get home.

I know it's silly, but I cried a little during the ceremony.

After the ceremony, Gary told the skin PT, who'd handed him his certificate, that he'd now like to see pictures of his flap. She wasn't sure they still had any, though. When he and I got on the elevator to go on the group outing, I looked on my cell phone camera and showed him a couple of pictures of the area in question – I'd taken them to make sure I'd know if things "down there" got any worse. One picture was taken at the end of June, before his flap surgery, and the other taken after the surgery. He said he was glad he hadn't looked at them at the time.

Next came the "group push" to Chick Filet. Gary's task was to check out the men's room for accessibility. The PT assigned to him (not one who has worked with him) commented as she watched him maneuver to get through the door, "He never gives up, does he?" I agreed he doesn't.

The members of the group ate their ice cream or drank their shakes, which someone else had had the task of ordering (Gary only had a little of his shake because he was worried about the effects on his IC levels), and then the Shepherd leader of the outing gave Gary the task of handing back change to four members of the group (everyone had given a few bucks to cover what they thought they'd be buying). Gary's PT joked that since he was a mathematician, he ought to be qualified for the task. The leader gave Gary the receipt, and she started explaining to him how to make change! (So-and-so has given five dollars, and his shake cost $2.79, so you need to subtract –) I couldn't help it – I said, "I think he knows how to do that." And yes, he lived up to my expectations.

On the way back, he still couldn't make it up his nemesis curb cut, but other than that, things went smoothly. The PT assigned to him gave him help up the Blue Carpet instead of making him do it himself because she said he would be doing a lot of pushing at the Braves game tonight and she didn't want him to tire himself out beforehand.

After he got back to his room, he and I got him transferred into bed so he could have a little rest before his Braves outing – and to get his feet up for the benefits to the IC.

So, that's where I left him today. I went off to the chiropractor then went to the hotel and used the time I'd normally be spending with him tonight to catch up on the blog. I'll let you know tomorrow how things went at the game!

All for now. (Except, yikes, I've just noticed how much sorer I am now than I was earlier today!)

July 27, 2006

I have put the pictures of Gary's Shepherd graduation up on the blog. For those of you who receive these journal entries by email, go to http://drpeg2003.blogspot.com/ and scroll down to view the pictures.

I asked Gary how the Braves game went, and he said it was a good game, lots of home runs, and the Braves had won 6-5. I told him that was not blog material ;-). So he told me that there was an area of the stadium set up where seats could be removed to accomodate wheelchairs, and that's where they'd sat. He'd found out that one member of their group, a man who works at Shepherd and is paraplegic, travels all around the world to fish at different locations, so Gary is going to get together with him next week to ask him questions about accessibility in different locations around the world, in this way hoping to get some useful information for future travel to math conferences.

Gary also said he was supposed to get his own hotdog, but a therapist volunteered to get him one, so he didn't refuse. She brought it loaded with onions and catsup, and he got that all over his shirt.

Sorry, that's all I could get out of him about his outing :-)

Gary's last day in inpatient therapy was pretty light: an OT session, a seating clinic, and a PT session. The OT started her session with him by going through the ASIA test with him again, the one where they test him for sensation and proprioception. Her results showed that his ability to feel sensations stopped (or in certain areas, lessened) higher on his chest than they'd found when he first entered Shepherd, and that as a result he would be classified as a T2 not a T4 as they'd told him at the beginning. But as she pointed out, functionally speaking there's not all that much difference between those designations.

At the start of this session with the OT, Gary had asked to try to transfer by himself to the mat. So the OT and I stood at ready – me in front of him, her behind – while he attempted it. Unfortunately, he landed on the edge of the mat and lost his balance backwards, which under other circumstances might have caused his butt (and therefore him) to slip off the mat. Both the OT and I grabbed him, so there was no mishap, but he can't be "cleared" to do such transfers on his own yet. He tried again on the transfer on the way back, the OT hanging onto his pants just in case. She said she'd had to give him a little guidance during the transfer to make sure he landed in the right place. He was disappointed – he was certain he could do the mat on his own now; he hopes it was only due to nervousness that he still couldn't do it today. I reminded him that he still has the two weeks of day program coming up to practice this, so hopefully by the time he goes home he'll be able to do at least this type of transfer independently.

After the OT session, he went to "seating clinic" and got fitted for his loaner wheelchair (we don't know how long it will be before the one he ordered will be delivered). This chair is the same model as the one he is getting, though slightly too wide for him. Gary found it more comfortable than the Shepherd chair he's been in – mostly because the back is lower so it gives him more mobility, and also because the chair had less "dump" than the other one, enabling him to lift both hands up and even bring them both forward a little while still maintaining his balance, which he can't do in the other chair. So he will most likely use this chair during day program unless some other difficulties with it arise.

The seating clinic guy went through with us how to inflate the cushion of the chair and how to test it to see that there is the right amount of air in it when Gary sits on it. The procedure was a little different than what we'd been told by the PT – easier, fortunately.

Gary wheeled back to his room in his loaner chair, and I brought the Shepherd chair along in case he runs into some problem with the loaner. Back in his room, he said he needed a nap – he hadn't gotten back from the Braves game until about 11, and by the time he'd done his IC and the nurses had proned him it was midnight, and at four-thirty a.m. various routines for his roommates had begun, so as a result of all this he hadn't gotten much sleep. Fortunately his session with the PT wasn't for another three hours, so he and I did a transfer to his bed and got him settled in. His PT dropped by while he was asleep and told me he and I were officially cleared to do car transfers together. We're thinking that for Day Program (starting Monday!) I may drive him over instead of us taking the Shepherd bus. That way not only will we get more practice at car transfers but we'll have about another half hour of time in the morning to get him ready – and as we found, every second we can squeeze out will help!

Noonish, he did another IC and ate his lunch in bed, then relaxed a while longer before it was time to get up (he hasn't had the luxury of relaxing like that in quite a while!). As we prepared for his transfer out of bed, I noticed he hadn't re-tightened his binder yet, so I joked, "All passengers, fasten your gut belts!"

When I pulled his loaner chair over to the bed and angled it as we had the other one, we noticed he was going to have to transfer a farther distance than with the other chair – this chair has a wheel-to-wheel width about an inch and a half wider than the other one, and, additionally, there seemed to be something about the chair's construction that prevented it from getting as close to the bed as we expected it to. Another thing we discovered to our dismay was that the tires of the loaner chair seemed to slip on the floor (the wheel locks were on, of course, but this still happened), and since Gary has one hand on the chair when he transfers, it often happens that he pushes against the chair slightly, which in this case would push the chair away as he was trying to transfer onto it. Because of these various factors, I helped with the transfer from in front of him instead of to his rear like I normally do (because if I'm in front it would be easier to catch him if he fell forward), and I put my hands under his sitting bones instead of on his hips. Plus, because of the slipping tires, I hooked a leg around a tire while kneeling on the other leg. (My chiropractor would not have approved of the position I found myself in ;-)) Between Gary giving a super effort to make the distance and me giving him extra help to counteract the various factors, we almost went too far the other way and I had to pull him back slightly while he was in midair to make sure he didn't overshoot his mark!

So when we went to the exercise mat in the gym for the PT session, we mentioned to the PT these difficulties with transferring to this chair. She showed me how I could do the transfer standing to his rear, as I prefer, while still preventing the tires from slipping by keeping one foot on the handrail of the wheel (the handrail being where Gary puts his hands to push the wheels). She said that the different kind of brakes he has on this chair ("scissor brakes") didn't grip the wheels as firmly as the other kind, and if he was going to have this kind on his own chair (which he plans to, as they have the advantage of folding back out of the way), that someone could chisel notches onto the surface of the brakes so that they would grip the wheel better.

So then he and I did the transfer to the exercise mat. For some strange reason, when we set up for it, we didn't notice any extra distance from chair to mat. Don't ask us to explain this ;-). Anyway, the transfer went fine. I commented to Gary, "Of course it did. One of your therapists was watching." I'd meant it as a joke, but he said there was truth in it – that when the therapists were there he had more confidence.

Once he was on the mat, she redid the ASIA test in the area near his right armpit. She too found that he had little or no sensation there (making him a "T2"), whereas when he first came they had recorded that area as having normal sensitivity. But Gary claimed he'd known essentially ever since the accident that that area had been affected. So the PT thought that maybe whoever had first done his testing had been extra lenient with him at the time.

After the ASIA, he practiced wheelies, the PT keeping the gait belt around his wheel axle and her hands lightly on his chair. Gary said that getting up into the wheelie from a stopped position was easier in the loaner chair, but I noticed he had a harder time when it came to actually popping the wheelie while moving. They next practiced taking curbs, and it seemed about the same as before, the PT giving him significant help. It's fine with me that he is nowhere near being able to do these on his own ;-)

The PT interrupted her practice with Gary when some old hands at this paraplegia stuff set about demonstrating to some of the other patients floor transfers and wheelchair uprighting. Gary won't even begin to practice these skills until his flap restrictions are lifted – and he would have to get a heck of a lot more flexible! – but the PT wanted him to see what is involved. The men demonstrating these maneuvers practically bent themselves in half in getting from a "seated on the floor" position back into their chair. Their moves looked smooth and easy; one had had lots of practice, having been a paraplegic since the late eighties, the other had arms and shoulders about the size of tree trunks. Gary's got a little ways to go in that regard ;-)

The wheelchair uprighting, Gary's PT explained, came in useful when someone's chair had tipped over backwards and one needed to get back into the chair oneself. The demonstrator went through the maneuver, and it was obvious it would require a lot of flexibility and strength. I commented to the PT that I wondered how practicable this skill was – given how Gary had felt right after tipping over backwards, I don't think he would have attempted getting himself back into his chair no matter how flexible and strong he had become. The PT gave me no argument.

And on this note, Gary ended his therapy sessions as an inpatient (tomorrow he is discharged and we move into the apartments provided by Shepherd for the Day Program). We went back to his room, and then I took an early leave until evening because I had my second session with the personal trainer to go to.

So now I am going to talk to myself again, and you can go wander off for a while if you like.

I got on the stationary bike (turned off) for ten minutes. The trainer came in while I did this, and we talked about how I felt after the first session. I told her I'd gotten sore and had been at my sorest last night, but that now, while still sore, it wasn't too bad. She said we wouldn't work legs today, and I immediately said, "Good," as I certainly wasn't up to a repeat of that workout!

But then what did we do? She had me do squats similar to the ones we did Tuesday. Only this time, I was to touch my butt back onto the exercise bench while swinging my arms forward. Though I had to go lower to touch the bench than to touch the wall, I found these easier. After twenty reps, she told me to do the same thing, only I was to swing a medicine ball diagonally while doing it, much as I had the stability ball last time.

She handed me an eight-pound ball. I handed it back. "This is too heavy," I told her (gone are my macho days). She then handed me a four-pounder and that seemed about right. I did twenty of the squats swinging the ball in one diagonal direction, then another twenty swinging the ball in the other direction. Again, I found this easier than those we did on Tuesday – they didn't require as much coordination. But I knew already my abs were going to be sore tomorrow, particularly because she wanted me to emphasize the twisting motion at the top of the swing. I told her I could see where this would be a functional move for me – when I help Gary with his transfers, I end up twisting from one side to the other while supporting some of his weight (of course, soon now, he won't need me for that ;-)). She said that was why she had thought of this exercise as one I should do (I'd told her before about the kinds of moves I make in transferring him).

Next I sat on a 55cm stability ball, an exercise tube of least resistance secured underneath it, and used the tubing to do shoulder presses, 12 reps. She told me I could make the exercise harder by putting my legs closer together. She also explained that the reason for doing exercises while sitting on the ball was that in order to keep my balance I would be recruiting more of my lower back and abdominal muscles than I would if sitting on a solid surface.

Next I did rows with an exercise tube (one that gave more resistance), fifteen reps, this time me sitting on an exercise bench (she said that at home I could sit on the floor or wherever was comfortable).

Next we went back to one of the first exercises, the ones with the medicine ball. “You lied,” I said to her. “What do you mean?” she asked. “You said we weren’t going to do legs.” “Well, we’re only doing them a little,” she rationalized, then added, “You’ll find I often lie, making you do more reps than I say you will, and so forth.”

And I thought I’d been miscounting because of my CFS. I gave her the evil eye, but apparently it had no effect.

Next we did the shoulder presses again, and then another twisting exercise, that also mimicked the transfer motion: I sat on a 55cm stability ball, wrapped an exercise tube around a post at shoulder height, faced diagonal to the post, gripped the handles of the tube, and pulled from directly in front of me away from the post as far as I could go. I did twenty reps on each side. She told me the way to make the exercise harder was to bring my feet in closer, and that that applied to all other exercises done while sitting on the ball. She also told me not to let my arms go any closer to the post than the center point of my body, because that would allow the tension on the band to lessen too much and give my muscles a rest. We wouldn’t want that now, would we?

Next we did a ball placement exercise, which I told her was just another sneaky way to work in more squats. A six-pound medicine ball was on a bench in front of me. I was to squat down, getting the ball in the process of doing so, then put the ball on the floor, then stand up. Then I was to squat down and pick the ball up and put it on the bench. Twelve of those.

Then I sat on the stability ball and again did those twisting motions with the exercise tube.

And that was the end of my strength workout. It had taken a half hour, because we did some chatting here and there – intentionally on her part, so as not to overwork me (and hopefully she didn’t succeed in doing that anyway). One thing I found out during our chats was not only do we use the same massage therapist, but also the same chiropractor. She’d found the massage therapist through the chiropractor, and I’d found the chiropractor and her through the massage therapist.

I thought she would have me do stretches on my own, since our half hour was up, but she spent about fifteen more minutes doing them with me. I told her after the session that I was glad I’d found her, that I’d had fun. She said it was fun for her too, and she’d call me to let me know what time she could meet with me on Sunday.

I went back to the hotel feeling very happy with myself for completing another workout – I hope I can continue this with no ill effects. I told Gary, when I got back to the hospital, that I bet I wouldn’t have been able to do this a few months ago, that having to help him with his transfers and all the pulling and pushing and lifting I’ve been having to do have made me physically stronger than I was back then.

I did my routine with him, and then climbed into his hospital bed with him. I wondered aloud how the Plainsman (the university's student-run newspaper) article had turned out. Janet Rogers had typed out in an email to us the editorial about Gary that had also appeared in the newspaper, and that editorial was wonderful (made me cry, and Gary said he read it about a half-dozen times), but we haven't heard much about the main article on him yet (though I'm sure one or more of the math grapevine will send us the article before too long). Janet emailed us that the main article made the front page, that they used the publicity picture of him that I'd liked better than the one in the city newspaper, and that they'd put in the address for the blog. I told Gary I wasn't sure the last was a good thing. I told him that when I finally "allow" him to read it (I told him long ago that I didn't want him to read it because I thought it would inhibit my writing, and he agreed not to), he may feel terribly embarrassed and want to divorce me. "That won't happen," he assured me, continuing with, "Who would finish up my bowel program for me?"

Hmm.

;-)

July 28, 2006

You may recall (if you have a long memory ;-)) that when we took the "Been There Done That" class, the Shepherd alum had said that after leaving the hospital one had to find the new normal. Gary dryly remarked this evening, "I hope this isn't it." I thoroughly agree.

It was a tough day. We had planned to start the discharge process about 9am, but when I got to the hospital, Gary was still in bed. I thought maybe the nurses had left his bed bath for last since the others in his room would have to be gotten ready for their therapy sessions. But that wasn't it. When they'd turned him from his prone position at 6:30, he'd had a large, very red spot on his thigh, and at first they thought it signified a first stage pressure sore, that he'd somehow put pressure on that area during the prone. But then they noticed a large bump there, about three inches in diameter, and the nurse thought it might be a bug bite . By the time I got there, the area was only slightly pink, and in feeling the area, I wondered if it could be a torn muscle (not that I know what one feels like – that just popped into my head). Gary's doctor came in and examined it but didn't offer an opinion, just told us to put ice on it. He was going to have an ultrasound done on it, but the person who does the ultrasounds for Shepherd isn't qualified to do it for muscles. Then we heard they were thinking of doing an MRI on it, but those people (from Piedmont hospital, I think) were booked for the morning. Finally the resident who works with Gary's doctor told Gary they thought it was a torn muscle and to basically ignore it unless it got worse. I asked for clarification, and the doctor said that at this point Gary wouldn't need to modify any of his activities or therapies. I asked if Gary's occasional leg spasms might have caused it, but they didn't think his spasms were strong enough to have done it. So basically it is a mystery why this has happened.

That set us back about an hour and a half – not that we had big plans for the day, but I wanted to get settled into our apartment as soon as possible. The next glitch was the right brake on Gary's loaner chair. Somehow overnight it had tightened so much that Gary couldn't get it locked or unlocked without practically giving himself a hernia. Plus, in the locked position, the wheels still easily slipped along the floor. I went to the room where Gary had had his seating clinic, hoping to find our supplier there. He wasn't, but I got his phone number, and Gary left him a message about the brake, and also about the call we'd received on our home phone about equipment being delivered, including a hoyer, which we didn't need. Soon after, we transferred Gary to his chair, and during his weight shift a half hour later, his wheel nearly fell off! His nursing tech for the day happened by at this time, and she tilted the chair (Gary still in it) while I pushed the wheel in. These incidents did not give us supreme confidence in this chair. The next thing that happened was a bladder accident, which had never happened before (it happened a couple more times over the next eighteen hours, so now we have to have him checked for a bladder infection). We were like, why are all of these things happening today? I told Gary we should transfer him back into bed and then transfer him out again on the other side, because the side he'd gotten up on was obviously the wrong one.

Our supplier arrived at about this time, and he and the nurse did a two-person transfer on Gary to get him into his old chair. The supplier worked on the loaner chair, the nurse cleaned the seat cushion and cover, and Gary and I took care of him.

All throughout this I had been packing up Gary's room; I know he would have liked to help, but there really wasn't much he could do except pack his multitude of pillows into plastic bags (and talk to his roommate, who is obviously going to miss us and wanted to talk a lot! Other staff people came by to say goodbye to Gary as well – he is well-regarded around here). Gary went off to lunch in the cafeteria and I continued with the room. By the time he returned, I had almost finished – I ended up filling two hospital carts, one with the must-haves, one with stuff we could come back and get tomorrow, if need be (I had planned on returning for the second load right away, but other things intervened). Gary went down to the apothecary to pick up his supplies (unfortunately we found out later he forgot to get the ones that hadn't been on the list given to him by Shepherd – they were necessities, but insurance wouldn't pay for them, so they hadn't been put on the list; we were able to improvise for the time being), while I went and got the car and Gary's head nurse rolled down our cart of essentials. Then it was time to help Gary transfer into the car – we didn't want to fill the car with other stuff until we could make sure his chair fit in. Naturally, because other people were watching, the transfer took a little longer than our trial runs, but it went fairly smoothly. Then came the trick of packing the stuff in the car while still allowing me to see out the rear window. With a lot of pushing and shoving (of the stuff in the car, not each other ;-)), the nurse and I accomplished this goal. The nurse, who has been great throughout Gary's stay, gave us big hugs :-) – even though we'd probably at the latest see her when we came back for Day Program on Monday, since Gary will still go to the third-floor gym for it, only now he'll be on the side opposite where he has been up to now.

It was now about two-thirty. Gary took his first car ride since the accident – we went across the street! The apartment we have is that close to Shepherd, which is nice. I put the wheels, arm rests, and tip bars back on his wheelchair and angled it next to him in preparation for the transfer, but we noticed the tires were slipping badly. Somehow, the brake (wheel lock, actually), had angled itself to the side and so was no longer in position to grip the tire. I wasn't strong enough to realign it. Fortunately, we got help from the housing guy, who was right there, having just finished checking out our apartment to make sure the last people had cleaned it up properly. (Shepherd only leases four apartments in this complex; they own another building a few blocks away in which most of the Day Program people live.) The housing guy realigned the brake, showing us how to do it should it come out of place again – I hope we remember. This took a half hour, and Gary was getting hot in the car, even with the AC going, so I got him in the apartment ASAP. We were disappointed with how the place was stocked. At the hospital there are tons of towels and washcloths, etc., but here there weren't enough to hold us through one day. We asked for more of those, as well as blankets. The housing guy wasn't all that gracious about our requests, IMHO. Perhaps he felt he had done his duty by us (and more, with helping us out with the wheelchair), or perhaps he had a lot more to get done that day and we were delaying him. Anyway, he brought back a few more washcloths and a couple of thin blankets. Fortunately I would have my bed warmer and comforter, once I got them from the hotel, but as for washcloths and towels, it looks like we are going to be running the washing machine a lot – good thing there is one right in the apartment.

After I got Gary's stuff unloaded, it was nearly time for the massage I had previously arranged for – my reward! It was the same guy I had used the previous Sunday, and he came to the apartment. After the massage, I decided to go get my stuff from the hotel, rather than go back to Shepherd for the second load of Gary's stuff. While in the hotel room packing up what I would need for sleeping and cooking, Gary called with another personal emergency, so I threw my stuff in the car as quickly as I could and came back and took care of that.

He had ordered take-out pizza for dinner, and I had had my rice going in my slow-cooker in the hotel, so at least we didn't have to worry about that meal (I forewent making zukes). By now it was almost 7:30, time to get him into the bed and do our evening routine. I was tired and seemed to be moving in slow motion, plus there was the added complication of us figuring out how for him to maneuver in the bed, as it is much smaller that the hospital bed he has been in. At one point Gary started crying, saying he was mostly okay with "this" (meaning what life after his accident entails), but that he hated seeing me run myself ragged because of him. So then we both cried some and held each other in a hug. He promised that things would get better, and I told him I knew they would. Then we got on with the routine. We finished after nine, and I still had to go to the grocery store to get him breakfast supplies. I also picked up paper towels and soap – things not supplied in the apartment. I decided we both cheering up, so I brought back a bouquet of pretty flowers as well. But I had to save my surprise, as he was fast asleep by the time I got back at 10. I knew he had to do an IC at 11, after which I would need to help him get proned, so I didn't bother to lie down. Close to 11 I got a worried call from him – he hadn't been aware I had returned. He did his IC, we got him positioned, and then it was time for bed (after we said some mushy stuff ;-) and joked that maybe we should try to get him checked back into the hospital). It was close to midnight. I needed a relaxing bath, so I didn't get into bed until about 12:30. I woke several times during the night, thinking he had called my name – his hospital bed was out in the living room area, and I was in the small bedroom next to it. I woke again at about 5:15 and couldn't go back to sleep – I knew his alarm would go off at 6 for an IC, and the possibility he would need me then didn't allow me to settle back down – so I meditated. He did need me at six; we finished with that at about seven, I put a load of laundry in, and then I wrote some of this. Now I am going to get back into bed and see if I can sleep a little!

Oh, and his leg is looking better, so perhaps we at least won't have to worry about that.

Thanks to Janet Rogers for sending us the Plainsman article and the editorial. I forwarded it to those who get this report by email.

July 29, 2006

Our morning routine was about the same as last week's, except we put off doing the bath until evening since that is what we'll be doing for day program in order to save some time in the morning. We finished just in time for me give Gary a kiss and run off to my chiropractor appointment at 11:45. After that I went to the hospital to a) ask them what to do about the bladder situation, and b) collect Gary's second load of stuff. Concerning a), they told me that because Gary had been discharged as an inpatient, our options were to go to the Piedmont emergency room or to try the outpatient services number, which they gave me. (Later, when Gary called the number, the only item on the recorded menu that seemed to pertain to the situation at hand was to call the urology emergency number; since he doesn't feel bad and isn't running a fever and has no other symptoms of a urinary tract infection, he decided to wait and see what develops.)

So I collected Gary's stuff, went back to the apartment, unloaded a few of the items we'd decided we needed, gave him the report concerning a), then gave him another kiss (I decided we both needed lots of those today) and went off to Fresh Market. I swooped down the aisles, sacrificing my principles for convenience ;-) by buying pre-cooked items for him at the deli in addition to the fruits and vegetables (including a case of zukes for me). Gary was delighted with my choices and said that though he'd learned which items to choose from the hospital menus and which to avoid, he was really looking forward to having some real food again.

After I dashed in with the groceries and gave Gary another kiss, it was time to head out for my next session with my personal trainer. So what comes next is another accounting of my workout, be forewarned.

I started out with ten minutes on the bike as before, then we moved into the main workout. For the first exercise, she stretched an exercise tube between the posts of a squat bench at mid-shin level, and I did "step-overs," first stepping over the tube with one leg, then stepping back with it; the tendency, she said, was to let the knee turn out during this, but the correct form was to keep it pointed straight ahead. She said my form was good. My hip flexors burned after about six reps. She had me do twenty (mean person ;-)), first with the right leg, then the left. Then another fifteen with the right leg and then the left.

Next I was to have my back against the wall and be in a seated position (the deeper you squat, the more difficult the exercise). She handed me a weight (oh, shoot – I forgot to write down how heavy it was), and the exercise was to lift the weight from a downward of about forty-five degrees to over my head until it touched the wall – so, a type of front raise, being careful not to arch my back. I did fifteen of those. (At this point she mentioned that wall squats – by which she meant simply holding the position I was in (without using the weight) for an increasingly longer amount of time– was a very good strength builder.)

Next I did a type of lunge: I started with my feet together, then took a small step forward and bent both knees in a lunge, similar to what I had done the first day, only without the arm movements and with the lunge being dynamic instead of "in place." She said my form was good – I found it much easier to maintain my form than during the exercise on that first day when I'd had to coordinate arms with legs. I did 15 reps stepping forward with the right leg, then fifteen with the left.

Next I repeated the "wall squat with weight" exercise, twenty reps. Then I repeated the lunges. She said that that exercise could be made harder by "sitting back" farther during it, and/or bending the legs more, as long as the knees don't go past the toes. She again commented my form was good, and I believe I can thank all my years of standing in front of a mirror watching my form while I did weights for that.

Next she had me sit on a stability ball and simply lift my leg at the knee, the goal being to keep my balance on the ball, having to recruit some core muscles for that. It was easier on my left leg than on my right, for some reason, so to make the exercise harder, I lifted my leg out straight. She said to make the exercise even harder, one could do bicep curls at the same time.

We finished up the strength-training aspect of the workout with angled pushups – she put a bar on the squat rack and I did twenty pushups leaning on that. I almost told her about Gary's one hundred pushups, but thought better of it – wouldn't want to put ideas in her head! I told her I found those relatively easy, and maybe we could have put the bar down lower. She said she hadn't been worried about the strength issue with me but with how the exercise would affect my back, so she had been having me do a progression – first wall pushups, now these, next time maybe knee pushups on the floor. I should have kept my mouth shut ;-)

We next did stretching, she leading me through them. First a "plié" stretch, where one was supposed to lean to each side while in the plié. I'm glad I couldn't see myself in a mirror and I'm glad my former-ballet-dancer little sister couldn't see me. Next I did a chest stretch, one arm angled on the wall at a ninety degree angle. Then a couple towel stretches: stand on a towel with one foot and pull on it while using the other arm to reach across the head and stretch the neck; lie down on the floor and loop the towel around the foot to do hamstring and calf stretches. Then I hugged my knees to my chest, then from that position I put arms out on the floor at shoulder level and twisted to one side then the other. Then I rolled over and arched my back up like a cat, then went into yoga's child's pose. Then I stood and did a couple arm stretches, first pulling one arm across the body, then reaching down the back with the hand.

I thanked her for the workout. She told me she'd been easy on me today because on Monday I'm supposed to meet with another trainer, the one with a background in physical therapy, and he would really work me. Uh-oh.

I had seen a pharmacy across the street from the workout place, so went there to see if they had the supplies Gary had forgotten to get at the Shepherd apothecary. They didn't, but they sent me to a nearby pharmacy that carried some medical supplies, and I was able to get everything there, so that worked out great.

I called Gary once I got to the hotel – which I hadn't checked out from yet – and he said he was doing fine, that he'd had a nice conversation with Norma. I then made up for the fact that my workout was supposed to have been an easy one: since I had to make at least a half-dozen trips of going up and down the stairs carrying things, I'm sure that counts as a leg workout in itself.

After checking out, I had one more grocery item to get – some laundry detergent I can tolerate – so I got that at the Publix close to my hotel. I realized after I got to the apartment that I should have gotten more, given all the times we are running the washer to do the towels and washcloths. Unfortunately, the Publix close to the apartment doesn't carry any "natural" washing stuff. I can do with just baking soda in the wash, but Gary has the psychological need for something that suds ;-).

I made it back to the apartment by six, brought in some stuff from he car, then made my dinner and turned on the oven so Gary could warm up his Italian sandwich from Fresh Market in it. While he finished dinner I tried to organize some of our stuff (I'm sure Debra is going to think the place is in chaos when she comes tomorrow ;-)). I remembered some more things I needed from the car, and went to get them. There was a fantastic lightning display going on. Two men were sitting out watching it. One was in a wheelchair. He looks to be in his early twenties and is in the Day Program (Gary had talked to him earlier and found out he'd started it last Wednesday). The other man I assume is his father. As I passed by, I greeted them, and they asked me if I could take them grocery shopping tomorrow. My stomach dropped. I made some excuse about having company tomorrow and not having the time. When I got back inside the apartment, I told Gary about it, and told him I felt really bad because while I know they are in a tough situation themselves, I just can't help them out – I can't take on any more (I meant psychologically, if not physically). I was upset; Gary said they'd find someone else and that he understood, that he was amazed at all I'd been able to do for him.

I don't know what to say when I next run into these people if they ask again. I suppose I should try to be somewhat forthright, but my inclination is to park around the side of the building, go out the back of our apartment, and avoid running into them.

After Gary was done eating, about 7:15, we got him in to bed so we could give could do the bath and the rest of our regular routine. We finished about nine. He had decided to do an IC about 10:30, and I would need to help him prone after that. He dozed, but I stayed awake and worked on the blog – I figured it would be harder to go back to sleep if I dozed, then helped him prone, then went back to bed.

By the time we got him proned, it was close to 11:30. I took a five minute hot bath and went to bed. I fell asleep quickly, fortunately. Gary was going to try to delay some of his program in the morning, instead of doing a practice run for Day Program, as we'd originally planned. By delaying, his intention was I would get more sleep. I was awakened by his light at 6:15am. I peeked out and watched him a short time, but he had gotten himself turned and seemed to be doing his IC fine on his own, so I went back to bed and dozed/meditated/slept until about eight. He was sleeping lightly, and when I woke him he said he wanted to rest some more, so he did that and I worked on the blog. When he was ready, we started in with the morning routine. We are going to time it, so we know how long we need to allow in the morning to get him to day program at 9. We are going to skip his morning stretching routine during the weekdays these next two weeks, figuring they'll do that sometime at day program.

. . . We have figured out it will take us about forty-minutes to get him dressed and into the wheelchair. About thirty-five minutes of that was spent in getting his t.e.d. hose on. And that's not all that much of an exaggeration! I told him they should have given me classes in that.

He also figured out we'll need to get started at six in order for him to catch the bus at 8:20. We decided to have him take the bus because with us having to transfer him into the car, we'd have to start that about 8:30 anyway, and this will be simpler on the both of us. I could ride in the bus too, but I'm going to take the car so I won't feel stuck over there.

Debra Talley, fellow SteeleWatcher and RSFic'er came at noon. She and I went to Fresh Market to pick up something for her and Gary to eat. (She got a small uncooked pepperoni pizza .I picked up one of those for Gary for some other meal but had the Fresh Market person make up some salmon and tuna and California roll sushi for Gary. This was much less work than having Gary either push his way up the street to the restaurants, for which he would need help from me, or go through the process of breaking down his wheelchair, loading it into the car, transferring him into the car, driving about two minutes, putting together his wheelchair, transferring him out of the car, then going through the whole process again after we ate. That process will go quicker once he gets the car transfers down really well, but as with the other stuff, it's going to take more practice.)

We returned to the apartment and had a nice conversation and a nice meal, Gary even getting a slice of the key lime pie that Debra had also bought. Then we watched Debra's "The Matador" DVD, which we really enjoyed seeing again and she enjoyed seeing for the third time ;-). After that, Debra showed us pictures that had been taken during her L.A. interview – she is going to be in one of the extra segments (the one about the fans) on the soon-go-be released fourth-and-fifth season Remington Steele DVD. She also showed us the wonderful watercolors she's painted – she only discovered fairly recently that she could paint! Then we said our goodbyes. I was very happy that we were able to get together with her while we were in Atlanta – this was the last chance we would have to do so before our return home.

Both Gary and I were then ready for the nap, so we got him transferred into his bed, and now I'm headed off to my own.

All for now. ;-)

July 30, 2006 into July 31, 2006

We had a few phone calls in the late afternoon, early evening – these people had probably just read the blog and had wanted to make sure we were still surviving ;-), Gary returned a call from his brother Donne, only, as usual, Donne was out on the golf course ;-), so Gary held the conversation entirely with his sister-in-law Phyllis. My older sister, Janet, called. And Gary's Uncle Rollie called as well.

Also this afternoon, Gary checked into walkie-talkies and the like, and ordered us two-way radios with an 8mi. radius – quicker communication than by cell phone, should that be needed.

We had thought the bladder situation had improved on its own, but the problem arose again and Gary found blood in his urine, so we're thinking it's a UTI. He'll have it taken care of tomorrow (we hope) – I don't know if they'll deal with it in day program or if we'll have to go to Piedmont's emergency room.

Based on our stay at the apartment so far, Gary has come up with a few more goals for Day Program. First, he'd really like to be able to do some transferring on his own, even if that means using the transfer board. The only times he's practiced with a transfer board is in getting in and out of the car. He feels confident that if he could practice transferring with a board to and from wheelchair and exercise mat, and then to and from wheelchair and bed, he should be able to do those without assistance by the end of Day Program (and maybe even those same transfers without a board by then). But right now, he is at other people's "mercy" – he's stuck in bed or in his wheelchair until I or someone else assist him with the transfer, and he doesn't like that feeling.

The other thing he'd like to work on is maneuvering in the hospital bed (turning, sitting up). The therapists had been having him practice such maneuvering in a double bed, but there, he has lots of room for rolling – if he tried that in the hospital bed, he'd either roll right off the bed or into the bed rail, the bed being much narrower than the one he'd been in at Shepherd.

July 31, 2006

Good thing we didn't go straight home. In addition to the bladder problem that has arisen, last night while changing Gary's bandage the skin along one seam of the flap looked very red. We brought these concerns up to the nurse assigned to Gary for Day Program during his nursing evaluation with her (which occurred right after his Day Program orientation). After finishing asking him some standardized questions (major surgeries, etc), she had us transfer him to a low and wide table then took a urine sample and looked at his flap. His Day Program doctor, who turns out to be the same doctor he has been having, was supposed to meet with him the following hour, so until that time the nurse had us go out to the gym and have Gary prone on an exercise mat (which would get his weight off the area) until the doctor could see him, which was about ten minutes later – and we had to go back to the same room we'd just been in and have Gary get back on the table again. So in the space of less than an hour, we did six transfers, and we had already done three before this time, so that was a bit of work!

The doctor thought the problem might be with the loaner chair (yet another problem with it!), so later Gary's Day Program PT put some foam on the back of the chair where it might have been pressing into him. So now I just keep an eye on the red area. We hope that fixes the problem as otherwise we are clueless as to what has caused it – which is scary.

His urine sample came back negative for bacteria, so the next possibility is the his bladder has become overactive, which is not uncommon in those who have a spinal cord injury. The first solution to try is to make sure not to drink more than 6-8 cups of fluid per day (yet on the other hand, you don't want to drink less, in order to keep skin and bowel happy) and go back to an IC every six hours (which means I'll have to help him prone about 12:30 am – ychh; anyone know how to survive without sleep?). If that doesn't bring the problem under control (and I have my doubts, since I don't think he's been drinking more than that), is to go back to doing ICs every four hours (with the negative effect that has on one's sleeping schedule!). If it still doesn't come under control, then they start looking at things like medications to stop the reflexing or continually wearing a "condom catheter" (a condom-like thingymabob is worn, and it attaches to a tube, which attaches to a leg bag) to catch the leaking, while still doing the ICs as always (in other words, we're not talking a permanent indwelling catheter, which carries its own problems that I believe I mentioned to you long ago).

The orientation, the nurse evaluation, and the doctor consult used up the entire morning. Gary ate in the cafeteria and I brought my rice and joined him (Gary noted that the cafeteria food – at least today's – was better than the food brought in trays to the patients' bedsides).

After lunch came an hour-long evaluation by Gary's new OT. One thing she brought up is that Alabama's Vocational Rehab Department should help pay for Gary's driver evaluation and for any modifications made to a car we already own that would enable Gary to drive it.

She and Gary also went over his goals, and in addition to the transfer and bed mobility ones I mentioned above, he added dressing on his own and bathing (though given his restrictions it is highly unlikely he will meet these goals for a while) – and doing the dishes. Yes, you read that right ;-). He wants to take on his previous chores as much as he can, except for mowing the lawn ;-). (At this point, the OT said many people decided they didn't want to learn how to do such chores again, and I thought, just who does she think is going to do them? I mentioned this to Gary later, and he said he'd had the same thought, and that it would be very selfish of him to make such a decision. Now you see why I married the guy? ;-))

The OT asked if he was returning to work, so he told her about the plans for that. She then asked if he had any work-related issues, but he said that the people in the math department had taken care of that!

An hour-long PT evaluation followed this, and the one thing they added to the list of goals was working on his balance.

After this I was supposed to get him on the mat and stretch him for a half-hour, but the nurse had told us to use that time to get him prone and off his "area of concern." Then came a half-hour session of goal setting, where everyone on Gary's new team got together and Gary was asked to state his goals, even if he'd already gone over them in some of the other sessions. He started by saying his goal was to be as independent as possible, and then it was mostly a repeat of what he'd said to them earlier. The case manager gave him a written list of what they'd come up with from their side (I think they were getting this together during that previous half hour). She told me she was going to give us a copy, so I didn't need to take notes. That intimidated me into not taking the notes (which means I don't remember much of what was said), but then we didn't get a copy – maybe it's coming later. I think that the only things that hadn't been specifically mentioned before came from the nurse. She said her goal was to help him get his bladder under control, teach him medicine management (should that become a necessity), and make sure he understood the medical complications that could arise as the result of having an SCI. They also want to know that he can verbalize all the aspects of his care to someone else, in case there is ever the need for someone else besides me to help him with something.

After this I drove back to the apartment to start my dinner. Gary arrived soon after, having taken the bus. I then went off to my next session with a personal trainer, this time with the guy with the rehab and physical therapy background. I'm afraid I wimped out. I'm more tired from this new routine (specifically from the interrupted sleep), and I was afraid to do too much for fear of pushing myself over the edge.

Well, I have much less time now for blog-writing, so I'll skip writing my workout here. This guy actually had his stuff written out, so I have a record of it for myself.

Well, now I'm going to try to doze before getting up at midnight . . .

August 1, 2006

. . . Ychh, felt sick at midnight from waking up at the wrong part of the sleep cycle. And we rush like mad in the morning to get everything done. As Gary said about 8:15 am as he wheeled out the door for the bus, "This (Day Program) schedule is a bitch. School is going to seem easy compared to this."

All for now.

August 1, 2006

Gary decided we had another Day Program goal to tell his team about: for us to get enough sleep while on the program! Evidently others feel the same way – Gary told me the discussion on the bus this morning (I took the car so I wouldn't feel trapped at Shepherd by having to be on the bus schedule) was about runaway caregivers, the discussion brought on by one of the caregiver's remarks that she needed a break; they all agreed the program was hard on the caregivers. Gary told them we'd only been on the program one day, and already his wife was frazzled (actually, I count from Friday on as being on the program), and I'm afraid I am, not being used to the extra physical work and the sleep interruptions. I guess Gary got somewhat used to "power-napping" in between the nightly interruptions in the hospital, but I am not (and my mood today was not improved by the fact that I got my period complete with cramps, the temple piece on my glasses broke at 12:30 a.m., and I slightly pulled a muscle helping Gary transfer out of bed in the morning). And this bladder thing is a downer, causing extra work (for which Gary apologized that I bore the brunt, as he is not independent enough yet for it to be otherwise) and cutting into both of our sleep times – we were both hoping the problem would go away, but as yet it hasn't, and I fear it won't. The latest strategy is for him to do ICs at four hours during the night (10pm, 2am, 6am) and six during the day (12pm, 6pm), which would mean I'd have to get him proned about ten-thirty p.m. and get up sometime between six and seven am, which sounds better to me than my having to get up at twelve-thirty a.m. and seven a.m. as I have been doing these past few days, but we suspect he is going to have to do it every four hours round the clock, so in order to fit in with the Day Program schedule, he'd be doing it and at eight, twelve, and four around the clock, putting me back to the twelve-thirty a.m. prone. The bladder problem interfered with his Day Program schedule today as well, causing him to miss out on his session with the rec therapist (and causing me more physical labor).

The chair problems I mentioned previously caused him to miss out on part of his "scap class" in the afternoon (a class for strength training targeting the scapula). But fixing the chair problem was definitely the more important thing. The theory is that the canvas backing on his chair was tightened too much, which put pressure on his sacrum, which caused the beginning of a pressure sore (which looked better today, by the way). So our supplier loosened the backing, and Gary immediately noticed a difference – now he falls forward when he lifts his hands, just like in his "old" chair. Not that he wanted that (indeed, he would prefer to feel more balanced, as he did in this loaner chair before this adjustment), but it indicates that the new chair before adjustment distributed his weight differently – and in his case, deleteriously.

The supplier also replaced the scissor brakes with the other type that Gary prefers.

Okay, now to the accomplishments of the day, starting with the PT session this morning. As you may recall, Gary wants to be able to transfer independently on his own, using a board, if need be, until he is strong enough to do the transfers without one. Well, he essentially did it on his own with the board (but he is not cleared to do this without my supervision, which means I keep my hands close and at ready in case he runs into problems, but I no longer have to keep in physical contact with him and give him lift or balance). He did nice hops along the board from his wheelchair to the exercise mat and back (and later, during the OT session, to the gym's hospital bed and back). Then the PT had him go through his stretching routine, and then she had him do pushups using pushup blocks. To get into position for the pushups, he had to first sit up from his supine position, and this was the first time he managed to do that while having the extra encumbrances of pillows underneath him and his shoes on his feet (the shoes give extra friction, which inhibits his ability to push his legs around). She then had him do the pushups while having his legs crossed "Indian style," pointing out that this would be another good exercise for him to stretch out his tight hips.

After the PT, Gary had a nursing session scheduled, during which the nurse was supposed to go over medicine management with him. She asked if he'd brought his meds. He said yes, and pulled out his one bottle of colace. She asked him if that was it. He said yes. She asked him why were we having this session. We said we'd wondered the same thing ;-). The session did serve one useful purpose, however – she checked his flap and agreed the area looked better than yesterday.

Next came a half-hour session with the rec therapist, who asked Gary what he did in his leisure time. Joking (or probably, at this time, not joking), Gary said, "ICs and bowel program." The therapist then went over again what Gary would be doing in terms of rec therapy these two weeks – hand cycle, billiards, standing frame (a precursor to the Easystand). Gary also mentioned he wanted to meet with the guy who could tell him about his firsthand experience with accessibility issues around the world.

In the afternoon OT session, Gary worked on dressing while in the wheelchair. This new OT seems very knowledgeable, and Gary got some tips that enabled him to get much farther along in this process than he had before. She then had him get on the hospital bed in the gym and practice some movements in it, using the electric controls, and so forth, to help him sit up and to change position. It was by no means easy for him, but again, he made definite progress. Whether he actually applies this knowledge remains to be seen, however ;-), as in the evening he preferred to do our usual method of him pulling and pushing on the rails of the hospital bed and me tugging on the draw sheet. I can't say I blame him, seeing all the effort it takes him to do the position changes on his own.

After the OT session he then went to scap class I mentioned, where they started out with some stretching and limbering of the back muscles, then went into strength training. The first exercises Gary wasn't allowed to do because they involved bending far over in the chair, and once again, his flap restrictions came into play. But he did the one-armed biceps curls, tricep extension, and punches, and also the seated pushups using the armrests of the chair.

Just before the scap class started, we had a flower delivery – beautiful anniversary flowers from my mom. Thanks mom!

Gary and I have decided to postpone our own celebration of the event until some time after we come home “for good.” There is no time to properly mark the occasion now.

August 2, 2006

Michel Smith, chair of the math department, has the answer to Janet Rogers' question of how many mathematicians does it take to change a lightbulb. I quote him: It takes one theoretician to prove that there is a solution to the problem, an applied mathematician to develop an algorithm to approximate the solution, and the chair of the department to figure out how to get the old (damn stubborn broken) bulb out – thereby reducing the unknown problem to the known case.

Thank you, Michel ;-)

Now to the day. I felt more rested, having gotten to bed around 10:40 after proning Gary and not having to help again until around six a.m. (except I woke up at two because his light went on and he has to move around in his bed to get to his IC stuff, but I fell back to sleep fairly quickly).

The bus that takes the people from the apartments to Shepherd has been about a half-hour late each morning so far. I suggested to Gary that we could go by car if he wants to take the trouble to do the car transfers. I’m not sure he’ll take me up on the offer – it means he’d have no excuse for missing out on part of his first class ;-)

His first class was a group fitness class, and I’m sorry, I just don’t think these group classes are very good – the exercises are done too fast, sacrificing form. I occasionally whisper in Gary’s ear a reminder for him to slow down (for one thing, so he doesn’t wreck up his shoulders, which he still has to be careful of). I also suggest things about his form, etc. The person in the wheelchair next to us commented to Gary, “She really keeps on you, doesn’t she?” Gary agreed I did ;-)

In the class he did punches, side raises, trap squeezes, front raises, tricep extensions, shrugs, lawnmowers, and wrist curls, 3 sets of 20 for each exercise. Gary uses a light weight, the limiting factor being his balance not his strength.

During the session, we got another flower delivery! Thanks go to my sister Janet and her husband John.

After that he/we had a session with the nurse on padding and positioning and on skin checks, working toward the goal of him being able to do this all independently down the road. For the padding and positioning, the nurse suggested ways he could position the pillows and get himself into the prone position. She had to help with the padding, and at this stage, both Gary and I are dubious of him being able to do it on his own for quite a while – but we can always hope to be pleasantly surprised. Right now, when it comes time for him to get into the prone position, he is too tired to go through the rigamarole of working at it on his own as much as he can before I step in to finish the job – when we get home and the schedule isn't so hectic, I'm sure he'll practice it.

After that session, as we waited for the PT to come for the next session, our inpatient case manager walked by. She asked if things were going better now, saying that we'd looked like dead meat on Monday. Gary told her we were getting more used to the routine (some of us more than others ;-)).

Gary had a different PT today – in fact, he hasn't had the same one yet, as the one assigned to him is on vacation or something, but she communicated with the others what he is to work on. So, he worked on transfers, but without the board. I had commented to him this morning that it seemed clear he could do transfers with the board pretty well and therefore would probably be easily cleared to do those on his own, so maybe he should go back to the depression transfers without the board, which are harder because they require more strength and balance to make the transfer in one hop; the reason why those are preferable is because the goal is to perform as many tasks, including transferring, with as little equipment as possible, so you don't have to lug around a bunch of things with you everywhere you go. Gary had been thinking the same thing, so this is what we told the PT and it is why she had him practicing the transfers without the board, her keeping her hands on him. He did well with her – she said she didn't give him any help, even when he transferred onto the mat raised higher than his chair. She told him that she thought he had the strength aspect of it, that he needed to practice more on his balance, and that, like any skill, all he needed now was lots of practice. He told her it was also a confidence thing – that when someone had their hands on him "just in case," he usually did good transfers, but he'd gotten too nervous the couple times the inpatient OT had had him try such transfers completely on his own.

After the transfer work, the PT had him work on getting his legs up on the exercise mat, then maneuvering on it (he gets a lot of practice at commando crawling!). She then had him work on getting from a side position to a properly padded prone position, her technique slightly different than the nurses, but not any easier – and it looked like he needed a lot more room than what is available in the hospital bed. The OT came by during this and told us she was going to write Gary a script for outpatient OT, and he will also have one for outpatient PT, so he can continue his therapy at home (we don't know where, yet).

After lunch, Gary had a "proning session with his caregiver(that's me ;-))." Since he didn't want to lay prone the entire hour, we turned it into a practice session for him maneuvering into the correct position on the mat. Once in the prone position, I suggested he do the terrible threes, taskmaster that I am ;-). He did them.

Next came an OT session, and Gary worked on dressing in the chair again. The OT had some good tips, showing him how he could scoot forward in his chair, grab one of his legs, and lean backwards in his chair to bring his leg and foot up so he could get his pants over them and also get a shoe on, then to lean way over in his chair katycorner to work on getting his pants up his thighs and hips and butt . Not that he did it all himself, but there was definite progress. She told him that the first time the “Been there done that” guy had put on his pants by himself, it had taken him 30 minutes, but now he could do it in 22 seconds.

Next a PT helped him transfer to the standing frame, which as you might guess, stands him up. He started in a seated position, his knees padded by the frame in front of him. Then I pulled on the lever arm and cranked him upright, though stopping slightly more than halfway (unlike the tilt table, it isn’t good to stay at the intermediary positions because of the awkward position it puts the body in, putting pressure on the joints). After a few minutes of being upright, he felt a little yukky, so I cranked him back down. After a few minutes break, I took him up again, and he was fine. A PT brought us a deck of cards and we played some version of rummy (no points kept; I conveniently forget who won ;-)).

He said he could stay upright longer, but I persuaded him to “come down” after thirty minutes. It just seemed to me he shouldn’t push it, as in the last four months he’s only been standing upright five minutes. I asked a PT, and she said he could stay up in it for an hour, but it was okay if he came down now, just to make sure the pressure of the frame hadn’t affected his flap negatively.

So, we finished a half hour before the end of the scheduled day. I suggested we go back by car, rather than having him wait another hour for the bus (although it comes at four, it is about four-twenty before it leaves Shepherd). Gary was agreeable, so we had some more practice in breaking down and assembling the chair and in getting him in and out of the car. His transfers into the car go smoothly, but the transfers out are still a bit rough and take awhile.

In the apartment, I put his vegetable kabob in the oven for him since he can’t reach the controls, then we got him onto the bed so I could check his skin and help him change his pants, then we got him transferred out again. During all this, the phone rang. I wasn’t going to answer it because I still had to get my own dinner started before leaving for a session with the personal trainer, but Gary told me to answer it. The person on the other end of the line asked if I was going to be there in the next twenty minutes, and I said I was going to leave in exactly twenty minutes. They said they had a delivery to make and would be there before then . They were, and I opened the door to a huge vase of twenty-five long-stemmed red roses. I said, “Wow,” and turned to Gary saying, “look what someone sent us for our anniversary.” I then asked the delivery guy who they were from, and he read the card and told me, “Gary Gruenhage.” I told him, no, that they were TO Gary and me, so – then I realized Gary had sent them to me! And what did I get him? Hagen Daz vanilla Swiss almond ice cream. (Hmm. Well, I had told him I’d make him a special pizza when we get home and that we’d celebrate later.) After that I had to run off to the personal trainer, and just before leaving I told Gary I was sorry I hadn’t gotten him anything special, and he said I had (and he didn’t mean the ice cream).

I told the personal trainer that my legs were a little wrecked up, so I didn’t want to work them too hard today. I also told her I was on the worn-out side, and she kept the workout relatively light. I did dumbbell side raises, while having one knee on a bench and the other leg on the floor (15reps, 5#). Then I put my hands on a stability ball and raised one arm and the opposite leg while leaning on the ball (the trainer had to steady the ball a bit), she cautioning me to use my glute muscles to raise the leg rather than momentum (20 reps each leg). Then I repeated those two exercises. Then I got to lie down over the ball to stretch out – but not for long. I then did knee pushups – 15. Then I flipped over and lay on my back to do an ab exercise where I kept one leg straight, then curled up from the top and brought my other knee toward my face (15 reps each leg). The I repeated the pushups and the ab exercises. I sure don't know how Gary managed 100 pushups! My trainer had to hold me at the hips to help me crank out the last one so that I wouldn't lose form and arch my back (it is so good she stays so conscious of it). In my defense, however, I get my nose down to that mat, and Gary was doing his pushups only partway – he said he did them that way because he knew he wouldn't be able to do 100 otherwise.

After that, we finished up with stretching.

After I got back to the apartment, it was time to start the evening routine. While I stretched Gary, he talked to his mom, who had called to wish us a happy anniversary. He also talked to Joe, who had called for the same reason but also to warn us that we might not be able to get up the driveway of our home this weekend, which would mean we wouldn't go home for our "test run" as planned (I did tell you we planned on doing that this weekend, didn't I?), since there is no way I could push him up the steep slope of our grass. Even if people volunteered to help get him into the house, and out again on Sunday, he'd be essentially stuck in the house the remainder of the time, and we don't think that's a good idea as a safety issue. (Note: I got the message later from Janet Rogers that she and Michel Smith and Jo Heath were at our house and they thought getting into and out of the house very doable. Gary and I are still debating whether or not to come home this weekend; we're extremely tempted to just stay here and veg out for once.)

The routine went as usual. The one glitch during the night was Gary dropped my cell phone, which he's been using as an alarm, so I had to come out and pick it up for him at 2am. But I was awake anyway, because with my door open I am always awakened by the light he needs to turn on and by his moving around in the bed, plus I am subliminally listening for him to call, afraid I might not hear him (which is a silly fear, given how light I sleep). I will be glad when we get the walkie-talkies we ordered from Amazon so I can keep my door closed and not always be on alert listening for his call.

August 3, 2006

Today Gary started out on the standing frame. He didn't feel so great after the first few minutes, so I took him back down, but then he was fine and after I brought him up again he went for about forty-five minutes total. We played cards again – Concentration (we each won a game, evenly matched, me with my CFS brain fog and him with his SCI-induced dizziness ;-)), and War – an extremely mindless game of pure luck (we didn't finish that one).

Next he had a session with a PT – again, a different one – and she taught him a different way to scoot in a hospital bed (shifting his body katy-corner), which worked quite well. He also worked on turning himself from lying on one side to another in a hospital bed while at the same time keeping the proper padding (which is more strict for him than for others because – let's say it all together now – because of his flap). The problem is how to get a pillow tucked behind his back so that if he should try to roll over on his back during his sleep, his hips would still basically stay where they were, namely perpendicular to the bed so he is off his sacrum (the pillow can't be placed ahead of time because of all the maneuvering he needs to do to get into various positions on the bed). He could get a single pillow behind him, but it wasn't thick enough to do any good. The therapist had the idea of doubling the pillow over and taping it, but I took the pillow, doubled it over inside the pillow case, and wrapped it in the remainder of the case. The therapist applauded my creativity. Gary noted with a smile that I was highly motivated to solve this problem (since it would arise about 4am), thus implying my creativity was born of desperation. I am so insulted ;-).

Gary practiced this turning from one side to the other after the therapist left (he had a half hour before the next scheduled activity), but he couldn't get the pillow quite right to do any good. Maybe it'll just take more practice or maybe something like a wider pillow would work.

After this, he went off to do an IC, and then he went on a group outing to T.G.I.F's, a restaurant just before Fresh Market. The rec therapist wanted him to go without me, saying he'd probably be surprised at how much he had depended on me when we had gone on our previous (supervised and unsupervised) outings. I had argued against that, saying I never helped him unless he asked, and he never asked unless absolutely necessary.

It was clear she didn't want to take my word for it (or maybe it was to see how Gary would do without me – Gary said later maybe she had noted he had a protective wife and she thought he might fall apart without me ;-)), so he went off on his own. He told me later I would have been proud of him, because of the following. On the way back (and you may recall what a hard time he had on the way back from Fresh Market, his very first outing), a therapist started pushing his chair to aid him, and he said to her, "If my wife were here, she wouldn't push my chair unless I asked her to." She asked him if that meant he didn't want her to push him, and he told her that he thought he could do it himself. He did need just a little pushing, but he did it mostly on his own, with rests – a vast improvement over his first outing!

When he got to steep ramp that led up to Shepherd, one of the construction workers there (they are expanding the hospital), came to help him up it. Gary told the man, thanks, but he could do it on his own, and he did (he certainly couldn't that other time!). Later, the rec therapist who hadn't wanted me to come complimented him, saying she wished she had videotaped that encounter because his assertive response was perfect. She asked him how he thought he'd done on an outing without his wife, and he told her his wife gave him less help than the therapists did (which we have both noticed on past outings), so I got my revenge ;-).

I returned to Shepherd at 2pm for a session with the psychologist. She asked Gary how things were going, and he said fine, that things took a long time, but we'd get faster when we got the routine down and didn't have to think through every single step. He also brought up that he was afraid I was getting stressed out. I agreed that I had found the transition stressful, having to do essentially all the moving of his stuff, then of my stuff, then having two medical complications arise over the weekend, plus having to take over the aspects of his care he is not yet capable of doing on his own (much of which the nurses had been doing for him), plus, because the apartment isn't accessible, having to do the majority of the domestic drudge work (which is more a psychological hang-up of mine than the actual labor involved), plus having the interrupted sleep (which I think is the major factor in making me feel stressed) – made worse by being afraid I won't hear him if he called – plus not having the 24-hour backup of the nurses for medical situations, particularly those he is relying on me for (like, I wonder if his flap – which he cannot see in the skin check mirror – had actually shown signs of being worse Saturday night, but I had missed it until it was so obvious Sunday night).

The psychologist emphasized that things would only get better from here on, which of course, I know, and that in time I would get more comfortable with feeling he was safe on his own (which I'm not sure is a major source of stress for me, but she and Gary seemed to think it is – I mean, true, I had kept in touch with him on Saturday when I'd spent several hours of the day away from him, but that was not because I thought some dire emergency would come up – I hadn't want him to be sitting around needing a change of clothes due to the leaking problem which had just arisen, which since he as yet can't get out of his chair on his own and he can't change his pants on his own means he would be uncomfortable until I got back; I didn't think to bring this up to them). She also suggested the obvious thing that I could rest some of the time in the 9-4 schedule that I'm not required to be there. I said I knew that, but that I wanted to be there, I liked being there. I didn't say it so explicitly to her, but watching Gary's progress, helping with it, and sharing it and our other experiences with y'all by writing about them is what gets me through this. I told her I knew I was responsible in part for the overload, that, for instance, I was doing this thing with a personal trainer that used up time I could be resting, but that I wanted to do that too, since I had the chance, and that I had already decided I could "take whatever" until the end of Day Program, and that after that I would be able to build more rest into my schedule. As we left her office, I said to Gary, "So, you think I'm stressed out, huh?" "If you had seen your face at 2 a.m. . . ." he replied. I hardly think that is the time of day to be judging someone's state of being, do you? I told him to not look at my face at 2 a.m., that I was trying to stay asleep then, so that at that time he should just tell me what to do and not expect a lot of conversation on my part – and certainly no perkiness!

Next he had a PT session, where he learned several things. One was that if he couldn't find something in the backpack on the back of his chair (he was looking for his action pad, a.k.a. "chicken fat," to put on the tire of his chair to protect him from hitting it when he does a transfer) he could do a little depression in his chair while twisting his body to the side, and from that position lean around the chair and look in his pack. I remembered he had been told that a long time ago, probably before his flap surgery, but at the time he hadn't had the skills to do this, and since that time both he and I had forgotten about this rather obvious solution. He then did a transfer to the double bed in the gym, the therapist saying she hadn't done anything but have her hands under his legs. Then he got his legs up on the bed on his own, and then she had him practice scooting in various directions on the bed with his legs straight out in front of him. She showed him another technique for doing this – bouncing a bit on the bed to make use of that momentum. Gary called it the trampoline effect and really got into it, which had the three of us laughing – he told us that when he was a kid, a neighbor had a trampoline, and he used to jump on it all the time. “Bet you’d be surprised if I did a flip,” he said. I agreed I most certainly would, and that they’d probably call over everyone in the gym to watch. He got really good scoots with the bouncing technique and later he used it to advantage in the hospital bed in the apartment, so it is a very useful technique.

She then had him circle sit in the middle of the bed, “circle sit” evidently being the PC term for “Indian sit” (that, or “ring sit”). She suggested that this position would be a good one for him to get into and practice balance exercises on his own, it being a “safe” position, and balancing being something major he needed to work on (she noted as he lost his balance and landed on his back on the bed). She asked him if he found the circle sit position comfortable, and he said he did. “Finally, right?” she joked (meaning that with all the things they’d made him do in his therapy, finally they had him do something he found comfortable).

To finish the session, she had him get over to the edge of the bed on his own and transfer into his chair – again, she said she hadn’t helped him with that except to provide a bit of balance – but no lift.

Next on the schedule was something called “Nursing Game,” which he wondered what it was and I said knowing them, it wasn’t going to be fun and games but something where they asked questions, and that was, in fact, what it turned out to be. Only Gary and one other person had this on their schedule, which I think made the session go quicker.

Some of the questions were as follows:

What size shoes should you buy and why (a size to a size and half larger, as your feet tend to swell (because not moving your legs tends to cause fluid to build up there), and you don’t want the shoes to put pressure on your feet).

When you go home and are looking for a primary physician, what two questions should you ask (1.If they are familiar with treating someone with an SCI and if not are they willing to learn about the condition, and 2. Is their office accessible to your particular needs).

When is the best time for bowel program (depends on the individual).

How often do you do skin checks, and what are you looking for (twice a day; changes in the skin. And, if you see redness, you stay off the area until it is no longer red; if the skin on a pressure sore has broken open, see a doctor).

Name two ways to prevent burns that those with SCIs may be especially prone to (don’t put hot food, etc., on your lap; keep the water temperature of your hot water heater at 120 degrees and make sure no hot water is dripping onto your feet from a leaky shower head).

How often should you replace your wheelchair cushion (every 2-3 years; check it once a week to make sure it is properly inflated so you don't get skin sores)

Name foods high in fiber (whole grains, beans and peas, the "p" fruits – prunes, peaches, plums – blueberries, raspberries, blackberries, many vegetables)

You wake up with an area of redness on your sitting bone, and you need to be at work/school by 9a.m. What do you do? (You have to stay off the area, i.e., you can't sit, so unless you can participate by staying in your bed lying down, you're going to have to miss out).

What are the symptoms of a blood clot? (One limb swollen and/or red/and/or unusually warm compared to the other limb.)

You start leaking during the night, but your IC volumes are low during the day. What do you do? (Drink most of your liquids (and have your liquidy foods) early in the day, and restrict the amount taken in after 6pm.)

What can you do to prevent pneumonia? (Stay healthy by eating right and exercising, etc.; dress for the weather; stay away from sick people and smokers and don't smoke yourself; cough out any secretions (aided by someone else if necessary); get pneumonia and flu shots)

What are natural aids for constipation? (Fiber, fluids)

So, class, how did you do? :-)

That was the end of the therapy day. I already forget if Gary came back by bus and I took the car, or if I drove him back, but I do know I got things ready for our meals and then left for another session with my personal trainer. After I had warmed up on the bike, she put ankle straps on me and attached them to "the lightest weight," which didn't feel very light to me (!) and I found out later was twenty pounds. I did exercises to strengthen the muscles in the upper front of the leg. First I just lifted up at one knee; then I lifted up slightly at the knee, kept the knee in place, and flexed and extended the lower leg; then I lifted the entire leg up and down from that extended position, working the quad muscles. The legs were alternated, 15 reps of each exercise on each side.

Next I lay on my back on a bench and did a bench press motion, only my trainer took the place of the barbell. She pushed against my hands on the way up, and on the way down I was also supposed to press up against her hands, resisting her as she pushed my hands down (I can tell you, I was sore from this the next day!).

Next she looped an exercise tube around my waist (protecting my waist with a barbell cover), and

I had to walk around the room as she pulled back against me. I'm not absolutely sure why we were doing this <grin>, but I felt it in my shins and glutes, and so forth. I felt like a horse in harness ;-).

We finished up with a balance exercise. I stood on a pad, closed my eyes, first lifted a leg at the knee, then after awhile, extended the leg forward, toe pointed, then after awhile, extended it back, toe pointed, then did the same with the other leg. (I forgot to ask how long we did this.) She kept a hand on my arm to aid my balance.

We then finished with stretching. After that, I went back to the apartment and Gary and I went through our routine. Gary told me he had let the math people know that we weren't going to come home for the trial run this weekend. I had told him before I left for the trainer that in the short run, I would rather just stay here and rest up for next week but if he thought it would be better in the long run that we go home and see if anything came up that we needed to work on back here next week, that that was okay with me. He decided he'd rather just stay here and rest too – we're both rather pooped!

August 4, 2006

Today started with a "group push" to Chick-Fil-A (I just realized at that time that I've been misspelling the restaurant's name all this time – shows you how aware of this restaurant chain I was before this) – the therapists must have a thing for this place, as this is the third time Gary has been on an outing to it. I think his time could have been spent more profitably doing something else, but they didn't ask my opinion ;-).

On the way back, Gary and another Day Program person, a person we've seen around here for as long as we can remember, were split off from the others to practice curbs and wheelies. The other guy, a young man I would guess in his twenties, was fairly proficient – he could hold his wheelies effortlessly, and he made getting up the curb using the wheelie technique look easy, having the timing down perfectly on the way up – though a couple of times he came out of the wheelie too soon in going down the curb. As others had, he told Gary he needed to be more zen when he tried to hold the wheelie position, to give it a light touch, using only the palms of his hands on the handrail; Gary tends to grip the handrail tightly, which they say actually makes it harder to make the small corrections needed to keep in balance. On the curbs, Gary still needs lots of practice – he tends to pop the wheelie too soon – which means he has to take two strokes to get up the curb – and too high, which tilts him too far back – and since he can't have the tip bars on to take the curbs, this is not a good position to be in! Again, he needs to be more relaxed when he practices curbs, they said (easy to say, hard to do), saying that it looks like he goes into "freak-out syndrome" whenever he gets close to the curb. Gary told me afterward that the four or five times he got to practice the curbs at this session really didn't help much, adding that he needed to practice them about forty or fifty times.

They did show me how I could help him practice if we want to do it on our own – put the gait belt around his axle and hold onto it from behind him, pulling up on the belt if he overbalances, plus keep one hand in front of his chest so he doesn't fall forward in the chair should he come down too fast. I'm not absolutely sure we'll practice this on our own – my fear being I don't want to be responsible for him falling on the back of his head. If he wants to practice it with me, I'm going to try to persuade him to wear a helmet until he gets it down (he may not need much persuading). We're thinking he probably won't need this skill for awhile, as we don't think our town has many curbs to contend with, and there are usually ways to avoid them; if worse came to worse, he could always back down them, which he can do without help – it's just that that takes time, and if one is trying to cross in a pedestrian walkway at a light, the light may change too quickly.

The session finished up with the other guy going down a steep ramp while in the wheelie position (with the help of the therapist). I believe I mentioned this before, but the purpose of staying in the wheelie position down a steep ramp is that if one goes down it otherwise, one's weight is forward, and if there is some unevenness at the bottom of the ramp, one's chair could tip over forward since the small front wheels would hit it first.

One change that was made as a result of this wheelie session was that Gary's tip bars were raised to a less conservative height. The other guy noticed that when Gary had tried to take his nemesis curb cut across from the CVS store, his tip bars had dragged, and that may be what has always caused Gary to veer to the left there, as the curb cut is uneven and the left tip bar probably is hitting first, causing him to pivot on it.

After this session, there was another group weight-training session; as before, I held Gary's shoulders for some of the two-handed exercises, though he always tries to do them by himself first (which at one point, resulted in him saying, "I can do this – oops!" and I caught him as he went forward). They did three sets of twenty of shoulder shrugs, lawn mowers, bicep curls, triceps extensions, side raises, and wrist curls; Gary did dips in his chair when they did bent rows.

Then we were done with therapy for the week! Yes! (Well, not quite, as nearly everything is still therapy.) As we were about to leave, Gary's head nurse from his inpatient team (the one in the previously posted picture) came up and gave us goodbye hugs, saying she was going on vacation and wouldn't see us next week. We told her how much we appreciated her help – she was really great. Earlier in the day, one of his inpatient nursing techs had come up from behind me and given me a hug, and then hugged Gary, so that was really sweet.

We then left in my car. We decided after his transfer out of the car at the apartment that maybe he should ask them to help us with those some more; while we can do them, the transfer out is still time-consuming and awkward (I had to grab him as he nearly slid off the transfer board, him having gone too far forward in his hop); maybe these new-to-us therapists would have more pointers for Gary.

Inside the apartment, as Gary savored not having any formal therapy until Monday, he declared as I brought him his lunch, "Now you can spend a relaxing afternoon waiting on me." I gave him a look. After lunch, he decided it was time for a nap. After helping him transfer into his bed, I decided this would be a good time for me to take a nap too. Gary said later that he was out as soon as his head hit the pillow; it didn't take me much longer. I slept for an hour and woke up feeling insane ;-) (lots of times I feel terrible for a short time after taking a nap); Gary slept for another half hour. When he decided to get up, instead of helping him as I have been doing in the mornings in the interest of time, I said, "So, Gruenhage, how much of this are you going to do yourself?" (After all, this was some of what he'd been practicing with the therapists all week.) He looked at me and said, "Well, I'm not going to bed to sleep, so I can't use that as an excuse." He thought some more, then said, "They didn't work me hard, so I can't use that as an excuse." He thought even harder, then said with a silly smile, "Because I don't want to?" I was about to say that if he really didn't, I would help, but he started maneuvering himself on the bed so I kept my mouth shut. He reached behind him a moment, and then said with an even sillier grin, "Because I can't find the clicker?" I reached behind him, found the bed controls, and handed them to him. His last excuse shot down, he worked at getting himself to the edge of the bed, and then we did the transfer to his chair.

We piddled around awhile, me working on the blog, he finding us some outing to do over the weekend (we decided on seeing the Prairie Home Companion movie on Sunday). At six, I had a massage from the guy who has come over previously. After that, it was time for our usual nightly routine, and then glorious bed.

August 5, 2006

I managed not to wake up for Gary's 2am IC (yea!), but I did wake up at 5:30 for some odd reason, and didn't really go back to sleep after that (boo!). But at least this is a sign (I hope, I hope) that I am getting used to this schedule. I'm sure knowing that Gary didn't have to be in therapy at 9 am helped my sleep. At 6:30 he called me to supervise his turn, since instead of getting up he wanted to sleep in a little, and thus needed to change his position to lie on his other side. His final position wasn't textbook perfect, but it may be all right for him to stay in for an hour or so – we'll just have to keep an eye on his skin, as that is the test.

I got up at eight and started catching up on the blog. About 8:45, Gary wanted to get up; I got his t.e.d. hose on him (I had a therapist give me a tip on that, but it doesn't seem to always work), he got his shirt on, and we went through his stretching. But then since we didn't have to be anywhere, I quelled the urge to save myself some time (in the short run) and after I took the bed rails off I suggested (demanded? ;-)) that, firstly, he maneuver himself over to the edge of the bed by himself, if possible, and secondly, that he try to get his pants on after he was in his chair.

It took some thinking on our parts, but the only problem we ran into with him getting himself situated upright on the edge of the bed was that the hospital bed has these tubes where the rails go in and they seem to be placed just where his feet always go down, so I have to guide his feet past them so he doesn't cut himself on them.

Once in the chair, he applied some of the tips he learned this week in dressing. He got the first part great – he got his shoes off (which I'd put on him for the transfer), then got the legs of his pants up over his knees (after he made a small correction, deciding he would not make a new fashion statement by putting both of his legs in one pant leg), and he also got his shoes back on (while a leg is still crossed over the other one after putting the pants leg on, a shoe goes on the foot that is up, rather than waiting to put the shoes on at the end, which would mean getting each leg up again). Getting his pants up his thighs was done with some depression scoots and some leaning over in his wheelchair onto another chair and tugging his pants up his hips – this part was where I had to supervise, because on the scooting he goes far forward in the chair and then leans back and we want to make sure he doesn't slide off the chair; he is probably safe with the leaning, but better safe than sorry. The problem was the last little part – he couldn't quite get the pants up over his booty. We called it quits after half an hour at the dressing task, and he depressed up in the chair while I pulled his pants up the rest of the way.

I then ran off to the chiropractor and from there to a place down the block where the chiropractor had said I could get my glasses adjusted (I had used a temple from an old pair of glasses (same style as my present ones) to replace the temple I broke, but the adjustment was not quite right, and I'd been seeing cockeyed all week (no remarks from the peanut gallery, please)). I came back to the apartment, got Gary's pizza ready, wrote in the blog, and then went off for another session with the personal trainer.

Which I am now back from, but I think I will post what I have now before continuing!

August 5, 2006, continued.

With the personal trainer, I did seated rows (using a pulley machine, at twenty pounds), 15 reps. Then I did back extensions while kneeling with my upper body supported by a stability ball, 15 reps, the trainer reminding me to use the glutes to squeeze up (and to keep those abs sucked in!). I repeated those two exercises. Then I did rows while standing up and leaning over, supporting myself with one hand and using the other to pull on a low-pulley (set at 40 pounds, though she had to help me make the last reps of those – I did twelve reps). Then I did "supergirls," lying face-down on the floor, arms extended, and lifting one arm and the opposite leg – 15 reps. I repeated the one-armed rows and the supergirls again. Then she had me sit on the stability ball, and she threw a six-pound medicine ball at me and I was supposed to throw it back immediately upon catching it. Only, I didn't realize how heavy the ball would be, and the first thing that happened was that I didn't stop its momentum in time and it hit me in the nose! No harm done, though. I think she threw the ball more gently after that :-). After fifteen reps of those, I did fifteen "side throws" on each side – she threw the ball at me from the side, and after catching it I swung it to my far side and then heaved (or as much as a heave I could manage ;-)) it back to her underhand. For the last exercise, we faced each other, knees slightly bent, and put our hands out to push at each other's hands, the object being to try to make the each other lose their balance, either from pushing them hard or pushing them easier than they were prepared for. I think I "won," but I think she let me. Then we stretched.

When I got back to the apartment, Gary said he was ready to be put to bed for a nap (he'd had a hard afternoon of watching golf ;-)). I decided I was ready for that too (only, I had to put myself into my bed).

In the evening, during our routine, Gary asked if I was excited about going home. I said I would be glad to be in our own house, in my own bed, and with my cats (assuming they forgive our absence), but that I would miss having the "cheerleading squad" at Shepherd giving encouragement at every accomplishment (and I'll miss not being able to fill the blog with the day's happenings). I then asked him if he was excited about going home, and he said, yeah, that he was ready, that now it was just a matter of practicing what he'd learned. He said he'd also be glad to get back into our old routine of watching "24" or some such program; we then realized we'll have to be doing that from 7-8, or maybe even a bit earlier, in order to get our "new routine" done in time for him to keep to his 10 pm IC schedule.

Nothing will quite be as it ever was. But we've still got the most important things. Foremost, each other.

August 6, 2006

After we finished the morning routine over, I spent some time trying to make space in my car by reorganizing, and I also did as much packing up as possible at this point. I can't believe they expect us to check out by 9am on Friday – somehow by then I am supposed to do all the cleaning up (and packing of the car, though the Kuperbergs are helping with that) on top of doing the morning routine with Gary. I have decided I'll just do the best I can. I'll do like I did at the Shepherd apartments, trying to clean up in the days beforehand, and if they don't like it they can charge us a cleanup fee, because we are not getting up a whole lot earlier so I can get the cleaning done. Thank goodness the Kuperbergs are coming to help us with our move back (bringing both their cars!); no way could we do this ourselves.

Okay, bitching over for now ;-). Let me tell you we went on our first "real" outing by ourselves today! ("Real" meaning something that didn't involve just pushing down the block.) We went to the "Prairie Home Companion" movie, which we both enjoyed, both being fans of the radio show (we each said our favorite part of the movie was the "bad jokes" segment). When transferring in and out of the car for the outing, Gary tried angling and positioning his chair slightly differently, and he discovered a new way to place his hands for "the push," and all this worked great: with me aiding, he made his best ever transfers both into and out of the car (a total of six transfers for the afternoon – I got lots of practice at disassembling and reassembling his chair). However, we discovered that even though we take off the shoulder belt on his side of the car for the transfers, he definitely needs to wear it during any trips, because otherwise he loses his balance and has to catch himself on the dashboard at any change in speed (yes, we know, one is suppose to wear those all the time – he forgot to put it on). And we also discovered it is very advisable to drive smoothly while he is doing any weight shifts during travel, again so he can keep his balance (if that weren't possible, I would have pulled over while he was doing them).

In the theater, the last row (which fortunately wasn't all that far back) had three groups of two seats, and wheelchairs could pull up in between the groups; we sat in the middle group.

After the movie, we went to Fresh Market to stock up for the next few days. Gary commented that while on his last "group push" to the T.G.I.F.'s right next door, he couldn't believe how close the market was to Shepherd – on his first push it had seemed so very far away. The checkout person at the market greeted Gary warmly, saying that she was glad to finally meet him, that she knew what he ate, but she'd never seen him. She then asked where his ice cream was. I gave her a look – I'm trying to wean him off that! (For my sake.)

So, we had a successful outing. It did feel a little weird to me to be doing something "normal" with Gary again; it was just like real life ;-). I mentioned this to Gary after he said he'd had fun going out with me, and he said it wasn't a wonder I found it strange – we haven't experienced "real life" in a long time.

August 7, 2006

Well, after successfully making it through the weekend without waking for Gary's 2am IC, I shot awake at 1:59am, and then drowsed and shot awake repeatedly after that. Just something about knowing we had to be on schedule for his 9am session at Day Program. Can we say overly conscientious?

First up was the (futzy) group weight-training session, the usual exercises: biceps curls, triceps extensions, shrugs, trap squeezes, lateral raises, lawnmowers, front raises. The group was much smaller than usual (just three patients and two caretakers, me included), because a number of people had "graduated" from the program on Friday; that gave the group a much more intimate feel, which I liked. They still went through the repetitions too fast though ;-). At the beginning of the exercises, one of the patients who has been here longer than we have, I believe (he started out in the Brain Injury unit), asked me if I was going to do the exercises with them; he and his wife (the other caretaker there) said they had found it very important for her to do the exercises too, since all the tasks involved in caretaking took a lot of physical strength – even just to catch the guy when he lost his balance. Don't I know it! Fortunately, Gary isn't nearly as big a guy as this man was – and fortunately for the man, his wife is a lot bigger than I am. Anyway, I couldn't wimp out (though I didn't want to overdo things because I have my own training sessions now), so I did all the exercises except the ones I had to hold Gary's shoulders for. I also didn't keep up with the official count ;-)

Next up was a session with the OT. Gary first practiced tub transfers with her, doing quite well. Then she had him do "bed work" (maneuvering in the bed) using the double bed in the gym. He has gotten much better at this than when he was an inpatient (just due to practice, he thinks), and she told him she saw no reason for him to use a hospital bed (as medically it is no longer necessary), and she urged him to work toward using a bigger bed, maybe having both in his bedroom and alternating between the two until he felt comfortable using the bigger bed all the time. The bigger bed would definitely give him more space to work in, but he'd have to give up his dependence on the rails and the electronic raising and lowering of the various parts of the bed.

She then taught him her way of what starting position he should get in (from on his side) and where and how he could place pillows and quad pads in preparation of getting himself properly padded off in the prone position. This went better than the other methods he's tried, and it seems promising. It's interesting, but disquieting, how each therapist has her own techniques she passes on – it makes it seem like it's the luck of the draw whether or not you will get a therapist who will have the right technique for you.

After the OT session, Gary had an "IC check" with the nurse, so once again three of us crowded into a stall in the men's room. The nurse commented that Gary was meticulous, and told him that his technique was excellent and that if he continued doing it the way he did, he should have not get any urinary tract infections resulting from faulty technique.

That finished the morning, and we got to lunch early, meaning we had nearly an hour "free" before his next session. I suggested he could go to the weight room and work out, since they really haven't been giving him good strength sessions (no zillions of pushups and dips and rickshaw and terrible threes). He didn't look thrilled, so then I suggested we could do balance exercises. He decided that sitting on the edge of the exercise mat and reading the newspaper would be a good one. Hmm, not exactly an exercise the therapists had had him do, but it did challenge his balance.

I noted that coming up a little later on his schedule was a "stretching and proning session with caregiver," so I told him to get in the middle of the mat and circle sit while reading the paper (so if he lost his balance he wouldn't fall off the mat), then I went off to the car to get his chain loops. On the way, I met his supplier, with whom Gary had left a message about the delivery of our bed table and about adjusting the back of his chair. I directed the supplier to Gary, and when I came back to the gym, the guy was working on the chair – Gary wanted it angled more so he doesn't fall forward when he lifts his hands.

While this was happening, Gary's PT for the day came, and she expressed concern about the back of Gary's chair because his flap hasn't looked as good as it did just before he got the loaner chair and it seems to have stopped improving since from what it looked like last Sunday night when I first noticed it seemed to have worsened (this is a terribly constructed sentence, but I'm afraid I don't have time to work on it ;-)). After some discussion a little later in the day with the OT, the therapists and the supplier decided the best thing to do might be to have Gary go back to a solid back on his chair, but one that isn't as high as the one he had as an inpatient. These backs leave a gap between the bottom of the back and the seat of the chair, so that should mean nothing would be putting pressure on Gary's sacrum, unlike the cloth back he is in now.

The PT also wondered, given the delicacy of Gary's flap, whether he should be practicing the dressing skills he has been learning on Day Program. She got the skin PT (the one Gary had been seeing throughout his time as an inpatient) to come and check the flap out (so now there were three of us under a sheet in the gym looking at Gary's butt). The skin PT had Gary get in different seated positions, mimicking what he would do to dress and so forth, and she decided that the positions themselves were okay, but that he needed to be careful about shearing the area with his clothing. So this puts off part of the dressing skills for now, since to get his pants up over his booty he ends up scraping the sacral area quite a bit with his pants as he shifts from side to side in the bed or in the chair trying to pull them up. So all he's supposed to do now is if he is sitting in his chair he can get the pants on up over his knees. Then he'd have to depress and I'd pull them up the rest of the way. It'd be easier for me to get them on him in the bed, but I suppose this depends upon whether or not he has taken a shower or something and we want to do the transfer back to the bed.

The skin PT also told me how to dress his wound over the next few days to see if we can get any further improvement. I sure hate going home with this still being a problem.

After this, the PT wanted him to practice – gulp – wheelies, with me being the one to hold on to the gait belt. I didn't think we had an auspicious beginning – suddenly, when he was sitting on the edge of the mat talking to her, he lost his balance forward. I lunged toward him with an arm out to catch him at his chest, but it proved unnecessary as he caught himself. The PT remarked that that was "a good reaction from both of you guys." I'd rather not have those reactions tested!

She took his tip bars off, and then she showed me how to put the gait belt around his axle and how to loop the other end around one of my hands and how I could keep my other hand lightly on a handle on the back of his chair. When he first popped a wheelie, I was scared to let him go back too far and held his chair up with the belt, but she said I needed to let him get to the balance point or he would never find it for himself. He and I were both very unzenlike, I'm afraid. He still couldn't get very relaxed with his handholds on his wheel and he couldn't stay in one place, and I was in constant tension, bent over peering at his wheels evaluating whether or not he was overbalancing – which he never did, by the way; I was always able to keep some slack on the belt. She told us we could practice this on our own at the apartment. Oh, yea.

We finished up that session by Gary asking to go back on his tip bars to make sure they would hold him, so we did that gradually, again me holding onto that belt for dear life. The tip bars held, we are both pleased to report.

After that, Gary and I went through his stretching routine, and then he practiced placing the pillows and proning himself. Again, it was promising, but as when he'd tried it in the morning, a pillow ended up right under his knees (which would put pressure on them) instead of below his knee (that, and the pillow above his knees would allow his knees to float); so, for the time being, when he practices this I will have to check to make sure his final position is satisfactory – neither of us would be comfortable with him doing this on his own until he positions himself perfectly say fifty nights in a row!

While he was proning, the nurse came by to go through some discharge procedures with him, mainly stuff like seeing his primary physician within a few weeks of going home and setting up follow-ups with his doctors here. He will come back to see his rehab doctor in about eight weeks, and he will see the “flap doc” during Thanksgiving break – at this appointment we will hopefully find out for how much longer his flap restrictions will need to be in place.

After this, Gary got in the standing frame for a short time. As before, he gets a little dizzy after a few minutes and has to be taken down, but then after a few minutes more he can go up again. The PT said that if he did some arm exercises while in the frame that would help keep his blood pressure up, and he will probably try this when he is in the frame again tomorrow morning. The PT also told us a standing frame is something we could buy for home use (so is the Nu-Step) if we want to spend the money on it or try to find some funding for it, but Gary wondered where we’d possibly put it (inside the new garage?).

We then went home by car, and the PT joined us to practice tub transfers (for places that don’t have roll-in showers). They went well enough, and Gary and I are now cleared to do them on our own.

After that (well, after getting Gary’s baked potato out of the oven and his soup off the stove) I ran off for another session with a personal trainer, this one again with the guy who gave me such an intense leg workout last week. But this time I found it really enjoyable – not being tired makes a big difference in my attitude toward everything, I find.

And on that note, time to quit writing this and go to bed!

Hah! Made it to 6:15am without waking. Yea!

August 8, 2006

Okay, the driveway of the apartments where we are living leads to a red light. Across the street is Shepherd. There are two lanes at this light. I assumed that since I was going straight, I should be in the right lane (I was taking my cue from what one does at stop lights on the street). As I sat in that lane, a guy pulls up behind me and starts honking his horn. And honking and honking and honking. I kept looking straight ahead, but pointed that I was going straight, not turning right, which was obviously what he wanted to do. He kept honking (the light stays red for a very long time in that direction). He even pulled forward and hit my bumper, scaring me, though he didn't do it hard. I did nothing but stayed in the car my heart going a mile a minute and my blood pressure going all over the map. After eons had passed, the light finally changed and I drove straight into Shepherd. So tell me, was I in the wrong lane? I mean, if someone had been turning left from that other lane, I sure wouldn't have wanted to be stuck behind him. (Gary thought I was in the correct lane and the guy was just an asshole; he said it would have served the guy right if after he bumped me if I had called the cops and insisted on filing an accident report to delay the guy further; but of course, I was afraid to get out of the car and confront the guy).

That little bit of anxiety over, Gary decided to give me a new source for it ;-) He wanted to practice wheelies for a short time before he got up on the standing frame, which was what was first on his schedule. So we did that, and since he was not going to practice curbs while doing them, we kept his tip bars on. Maybe because they were still on, he seemed a bit more relaxed than yesterday when he did them, and he stayed in place better.

Next I cranked him up in the standing frame. He got a little dizzy a short time in, so I brought him back down, then took him up again when he felt recovered. We played rummy to pass the time, plus he called the LETA bus service to find out about "Paratransit." They said he would need his doctor to fill out a form saying he needed the service, and after his approval, the service would be free for him -- apparently that is true for anyone connected with the university (I assume the university contributes to the service).

Next was an OT session, during which he practiced transfers. The exercise mat was first kept at the level of his chair, then after he'd done that transfer there and back, the mat was electronically raised about two inches. He did a great transfer there and back; the OT praised him and said it was time to raise the mat. He asked if he couldn't rest on his laurels instead. The answer was clear when she raised the mat again. Afer each successful transfer back and forth, she raised the mat farther until it was about six inches higher than his chair. All his transfers were really nice, the OT helping with his balance but not his lift. This reminded me of a question I had, and I asked her how we would know when Gary was ready to start transferring on his own. She said that we could now go to the stage where when the transfers were between two level surfaces I just stood at ready but didn’t actually have my hands on him (her words causing me a little case of the jitters :-)). She then lowered the mat so that it was even with his chair and had him do a transfer on his own where she just sat close in front of him. He looked a little wary, but she reminded him that she was right there. So he did the transfer – not as impressive as the ones he’d just did, and she told him she thought that was psychological. She then had him switch his chair around so he’d be transferring from his other side (since he needs to practice transferring from both sides), and she had him do it again, with a similar result: he made the transfer but didn’t get much height and landed closer to the edge than one would like. She then went through the process of raising the mat again, telling him to emphasize lowering his head (I think I mentioned before that he tends to just dip his head without getting his whole body into it), to aim his nose down past the knee opposite to his travel, reminding him of the physics involved: head low and to the left means butt will go high and to the right. For some reason this finally clicked with him, and he swung his head and upper body down low and as a result got even greater height on these transfers, the last one, the hardest one, his best. Inspired by the paralympics T-shirt the OT was wearing, I joked that they ought to make this a paralympic event: the butt jump – they could keep raising the mat until the contestants couldn’t make the transfer anymore.

Next we went out to the “family area,” which has a couch and some chairs. There he practiced transferring to the incredibly low couch – the OT pointed out that if he could master this one, he could do any couch there was! Going down onto the couch, was, of course, not much of a problem, but getting up from it to his chair was another matter – the difference in heights was much greater than the transfers he'd just done, and the OT told us she was supplying about 50% of his lift. Since she's not planning on living with us ;-), she had me practice it with him. Since it was something new, in my nervousness I supplied probably much more lift than he really needed – at any rate, he rocketed through the air and made the transfer no problem.

Next up was a session in the ProMotion Gym, where he got on the Easyglide for the first time – you might recall I told you this is a machine like the standing frame, except not only does it lift him to a vertical position, but also he can pull and push on some handlebars to move his legs back and forth like he is on a cross-country machine (this machine being good for stretching the leg muscles, for circulation, and for weight-bearing, according to the rec therapist with us). As always seems to happen, he had to go back down after a few minutes because of dizziness, but after a few minutes more he got back upright and stayed there nearly thirty minutes. He didn't work the machine the whole time though – all that transferring had tired him out some.

Across from us, we watched a man on a "Robot Assisted Walking Trainer," called a "Lokomat" (if you search for that on the web you can find a picture of it). It kind of reminded me of "6 Million Dollar Man," for some reason, the guy on the treadmill seemingly covered from neck to toe in all kinds of wires and slings and such (his injury must have been in the lumbar region). We also watched someone lying down on his back and pedaling with his hands to make his feet, which were strapped into pedals, go round and round like on a bike (the machine was called a Giger) – the rec therapist told us that machine was mostly good for cardiovascular training, and the Nu Step, which is like a seated version of the Giger is good for strengthening the muscles as it gives greater resistance.

Next came Gary's IC time, followed by lunch. While waiting for Gary I checked my email and got the report that all the concrete had been poured for the garage so we will be able to get Gary into the house this Friday without having to wheel him over our lawn. I also got two separate reports that it was probably due to Janet Rogers', um . . . gentle persuasion techniques? . . . that the job was done as speedily as it was (remind me never to get on your bad side, Janet ;-)).

After lunch, we had a little more time to spare, so we went to the library where I drafted the opening paragraphs of this blog entry and Gary looked through a book called "From Here to There," which was narratives about various people with spinal cord injuries at various levels. Gary commented that "From Here to Eternity" would also have been a good title for such a book, if only that title hadn't been taken yet.

After lunch Gary had a proning session with me. I suggested he could do his terrible threes or instead of proning for the whole hour we could do stretching or balance exercises. He decided it was a good time to take a nap. Hmm.

But maybe it was good he rested up – next was a session on floor transfers. This is not something he can really practice now (because of his flap), but they wanted to show the two of us how we could do such a transfer if need be – the need being if he accidently ends up on the floor, which they claim is inevitable (this of course is not the only reason one learns such transfers – it is used for any activity where one wants to be at ground level; for instance, gardening).

There are three ways to make a transfer from wheelchair to floor and back, but two of them involve more bending than Gary is allowed, which is unfortunate because that left us with the one requiring brute strength as opposed to taking advantage of body mechanics. The two requiring a great deal of bending were the backwards transfer and the side transfer. In the backwards transfer one slides forward in the chair, and then with hands on the end of the chair lowers oneself butt first to the floor – it requires shoulder flexibility, which Gary is unlikely to ever get on account of his arthritis. To get back up, from the position you now finds yourself in, you do a version of a depression transfer, practically bending yourself in half to get your butt up on the chair by bending your head down low while pushing with those hands you have behind you on the edge of your chair. In the side transfer, you lower yourself down sideways very similarly to the backwards transfer, but one hand is on the ground or on a couch or some other object instead of having both on your chair.

The front transfer is a bear. You get to the edge of the chair, bend over and walk your hands down the frame, and reach for the ground as soon as you can, then walk your hands along the ground in front of you until you are in a prone position (it might help you to think of that "wheelbarrow" game you played as a kid, where someone held your legs and you walked along the ground on your hands). Instead of ending up prone, you can also twist and get on your side.

Now for the hard part: getting back up. Basically you have to curl up next to the chair on your side with your legs folded, put one hand on the seat of the chair to the side near the back, put the other on the seat near the front, then use brute strength to push up onto your knees (and remember, since you have an SCI you don't have use of your legs or your abs), probably resting your head on the chair to catch a breath, then push up again to get your body straight, your head resting on the back of the chair, then push up again and twist to get your butt on the chair. She had me practice this while she went to talk to someone else a moment – she wanted me to see what it was like. It was a killer. I finally got the hang of how to get all but the last part – though what I was able to do was quite exhausting – but I couldn't twist my body around while pretending I had no use of legs or abs.

When she came back, she showed me how she would help me with this transfer (so, I was playing the part of Gary and she was playing the part of me), and it was much easier with her first helping me lift at the hips to get me on my knees and then lifting me under my knees to help me with the pushup and twist parts– but then, she, who is bigger than I am, was lifting me, while I, who am smaller than Gary, would be lifting him.

She next helped Gary get on the floor from his wheelchair using the front technique (he had looked at her like he hoped she was joking, but she wasn't), and then she helped him back into the chair – this was not easy for either of them, Gary's lack of shoulder flexibility coming into play here, hindering his ability to push himself up. The OT this morning had said she wanted us to learn this in case Gary ever ended up on the floor before the time he really learns these transfers, so that this way we could get him back in his chair without calling on someone else to help. After this afternoon's OT (a different one) went through this with us, she thought our wisest course of action would be to call on someone else and me and that person do a two-man transfer of Gary back into the chair. So, hopefully Gary will never accidently spill out of his chair when there is no one anywhere around and we can't get through to 911!

But she pointed out that the floor transfers are useful to learn – they are a big independence thing. It is good for paras to know that they can get themselves back into their chairs by themselves should they take a spill. So when Gary comes back for Day Program after his flap has healed, this will be something they will work on (this should motivate him to keep his strength program up!).

After this, Gary had "scap class," for working the shoulder girdle muscles, the upper back, and upper arms. The leader should be the one who teaches those group weight training sessions. She was really good, keeping all the participants working throughout the entire time. I did the exercises too, as they use a theraband (exercise band), and the exercises could be modified so Gary could do some version of them without needing any help from me. We did two circuits of an external rotation exercise, an abduction exercise, and triceps extension, and then two circuits of an exercise she called "diagonal pain," biceps curls, and one where you mimicked pulling an arrow back on a bow. Each set of an exercise was 30 reps. They burned!

After that I ran off to the chiropractor for my last visit with him. I thanked him and told him I thought he was excellent. Then I came back to the apartment and ruined my adjustment ;-) by organizing our stuff, packing it up, and loading the car for a couple hours, trying to get everything that we won't need in our last days here packed. After that came dinner, and then we had our own "wet run" – Gary wanted to take a shower instead of having the usual bed bath. We discovered it is a lot harder to have him take a shower with the shower bench in the tub rather than in a roll-in shower, so we are so very grateful Joe has seen we have one of those! The main problem was having so little room to maneuver, making my helping with his transfers awkward. And it gets hard to lift those heavy legs over the side of the tub in that cramped space (there really wasn't enough room for him to do it himself, at least, not unless we wanted to spend all night there – as it was, it took us forty-five minutes, in the interest of time me helping with the soaping and rinsing a bit more than we'd done on our official inpatient wet runs).

We finished this portion of the night with our usual routine of stretching, wound care, positioning, then went off in search of dreamland.

After the time the therapist said we could do the transfers where I am "on standby," (ready to aid, but not touching him unless necessary) Gary and I did three of those during the rest of the day Tuesday. Each time he didn't get a lot of height and he landed too close to the edge, but he accomplished the objective, getting to the other surface, not losing his balance, and doing "hops" to get safely away from the edge. But Wednesday morning I had to grab him and help get him back onto the bed, momentarily fearing that we were going to have to make use of a floor transfer after all – he had made it less than half way to the chair from the bed. He did the transfer over again, this time finding his target.

Well, that was one way to get the blood pumping in the morning!

August 9, 2006

Today's sessions started out with the group weight training again. Shortly after it began, our supplier came to put the hard shell back on Gary's chair and to tighten his brakes, so Gary transferred out of his chair onto a mat and did the exercises from there while the supplier worked on the chair. The exercises were two-handed ones, however, so I acted as his back support and wrapped my arms around him from behind to help him keep his balance. That was rather nice, actually, but a PT saw me doing that and brought Gary over a wooden adjustable wedge to use as a back support; I told her she just wanted me to do the exercises too. I did end up doing part of them (I am so happy I seem to be tolerating a little exercise these days), although we had another interruption when Gary needed to transfer back into the chair and see how he liked the new back. He thought it comfortable, but later decided maybe he was angled back too far – he was popping wheelies when he didn't mean to.

After that was an OT session, during which he had to go through the ASIA test again even though he just did it two weeks ago; evidently it is a requirement at admittance to and discharge from Day Program, though since he came straight from being an inpatient, at least they let him skip the admittance one (since it would have been just four days since his last one). This time the OT's results were that he was a T3 on the left and a T4 on the right, so obviously there is some subjectivity involved in these tests. What is clear is that he has no feeling or function from T4 down, and that he begins to lose feeling a ittle higher than that on his left side.

His flap was checked out again, and the consensus is it is slowly improving. Not fast enough for me!

Next Gary had a session in the gym without a therapist. He used the Bowflex for about ten minutes, but then the Easystand Glider (I think that's it's official name)became free, so we transferred him onto that. He said it tired him out fast but that every time he stopped pulling on the handles he got dizzy. I got the idea of pulling on the handles for him during the times he needed a break, and this worked quite well – it kept his legs moving, which evidently circumvented any dizziness (and I got a bit of a workout too this way).

After lunch, an OT took Gary down to the seating clinic and showed him a couple other backs for wheelchairs; Gary liked best the one she recommended, and so now that is the one on order for his own chair. It is hardback, with a gap at the bottom, more padded than the one he has been using, and more contoured, molding more around his sides – we hope this will keep him straighter in the chair, as he tends to slump to one side.

In order for him to try out the other backs, he had to make a transfer to a mat to get out of his chair and into another one; he and I did this transfer when the OT stepped out of the room to get the other backs. I crouched in front of him at ready but not touching him, which is what we've been doing the last two days. He made his best transfer yet this way, getting good lift. I told him he must be getting more confidence in doing them on his own. He told me that actually he'd been thinking, "Oh, no! She's not holding onto me!"

Well, better that than overconfidence. (I don't think there's any worry of that happening soon though – on his next transfer he lost his balance, I closed the gap between us, and he used my shoulder to catch himself. But I'll bet it's only a matter of at most weeks before he is doing level transfers completely on his own.)

On the way out of the seating clinic, Gary had trouble getting the door open. Naturally, I didn't rush to open it ;-). After several attempts at trying to get the door open, he complained that a pair of crutches that were standing to one side of the door were in his way. I asked if that meant he wanted me to move the crutches or open the door for him. "Just open the damn door!" he told me, then we laughed. There are limits to this independence thing ;-).

The OT rejoined us, and on the way back to the gym she told Gary she thought he should get a van with a lift rather than a mini-van with a ramp, because she was concerned about the long-term affects on his shoulders of frequently wheeeling up a ramp; in the gym, we happened to run into a person who holds the driving classes and she too recommended the van with lift on account of his shoulders. I asked Gary after they left if he had now changed his mind; if so we needed to let the garage people know. Joe had just called us a couple days ago saying the garage people needed a decision on the height of the garage; we had told him to tell them we wanted the garage to be of standard height, but a van would require the garage to be higher.

But Gary said he was still thinking of the mini-van with the ramp. He'd be mostly using the ramp when at our house in the garage (which would be level ground) or at the university (where he was sure he could find a level enough area), so he was not concerned with having to use the ramp while the van was parked on a steep slope, which would obviously make getting up the ramp that much harder. He said if he later changed his mind, we'd just pay to have the garage modified.

The session ended with the OT having Gary practice some wheelies while traveling. Still needs work ;-)

Next on the schedule was "proning with caretaker." During this time we returned Krystyna Kuperberg's call about when to come to our apartment to help us pack up (thank you, thank you, thank you).

Last on the schedule for the day was a meeting with a paraplegic who has traveled all over the world (Gary had told me the guy does this out of his love of fishing around the world, but apparently the guy also travels with some of Shepherd's sports teams). The guy wrote an article on accessible traveling for Shepherd's magazine, "The Spinal Column," and he gave Gary a copy of that. Then he talked about his travels. I think the main value of it for Gary was making him feel it was possible, and as well we picked up some tips.

The guy's main point was to prepare oneself as much as possible, then persevere and have a sense of humor, because things will likely not all go as planned. If Gary wanted to "test the waters" of foreign travel, the guy said, Gary could start by going with a tour group for those with disabilities. Gary said that he was mostly interested in the foreign travel to go to math conferences, and he was sure that the mathematicians who lived near where the conferences would be held would be willing to help him out on accessibility issues.

In terms of finding an accessible hotel, the guy recommended the foreign versions of American chains, like Marriott Residence Inns, when those could be found, but cautioned that Gary would still need to call and ask about his specific needs, since just because a place advertises itself as accessible doesn't mean that it is. Bathroom doors may need to be taken off their hinges, for example, so that Gary can get into the bathroom. And most places won't have shower benches, so it is advisable to bring one's own – he then told us there are plastic shower benches that fold up very small for travel (we did not know this). Such things count as medical necessities and airlines shouldn't charge for them if bringing them causes one to go over the baggage limit, but the guy cautioned that he himself had had to argue that point with such airlines like Air France, British Airways, and Lufthansa. (And speaking of baggage, he said to be sure to bring double of everything like the parts for your wheelchair and your medical supplies; and he recommended using a "vacuum packer" that would compress your clothes down to a small size to help you save space.)

For transportation in foreign cities, the guy recommended cabs. He suggested calling the city's disabilities office (he claims every city has one) and finding out if the city had any "London cabs," meaning cabs that a wheelchair can be wheeled right into from either the rear or the side. If they don't – and maybe even if they do – it is best to have an able-bodied person hail a cab for you, he said, because a handicapped person is not likely to flag one down – a cabbie is not likely to stop for a person in a wheelchair because such a person slows them up, cutting into the fares they can make; also, when the cabbie sees you wheel from out of the shadows, he is likely to say he can't fit your chair in his cab, so you or your able-bodied companion will have to insist that it can be done (and of course, the cabbie won't do it for you). Another way to get a cab if you have the option is to have your hotel call for one for you.

The guy said to, in general, forget subways in foreign travel, because most stops are not accessible and you have to get off at the stops very quickly. He also thought most train systems were pretty cruddy for the same reason. He said that if you were going to use a train, to call ahead at least 24 hours to let them know you are coming. He said to go first class, because second class was generally the equivalent of a human cattle car, with no air conditioning and likely no accessible bathrooms.

And speaking of bathrooms, his advice was to “know your bathrooms,” so you can get to an accessible one when you need to. He said museums and hotels would likely have accessible ones.

He thought the hardest places to get around in in Europe were in the former Soviet bloc countries. Cities where recent Olympics had been held also held Paralympics and so tended to be more accessible. He claimed Seoul was good, Sydney was fantastic, but Barcelona was still a bit tough to get around in. He hadn’t been to many places in Canada, but he thought they’d be pretty good on accessibility, except for Montreal because it was such an old city and very hilly. One gripe he had about Toronto was that at the airport there was only one working wheelchair lift for all the smaller planes where one had to enter them from on the tarmac rather than from inside the airport.

He didn’t know about Japan, but he said Hong Kong was remarkably accessible, including their rail transit and subway trains. He hadn’t been to London much, but he thought it was good except for the tube (comments, David Fremlin? :-)).

He’s been to Warsaw and Budapest, but of all the former “Eastern bloc” cities (that’s what he called them – not sure if that’s politically correct these days), he thought Prague was the most accessible (here, Gary noted regretfully that he was supposed to have gone to Prague next week), despite the challenges of its cobblestones (which brought up the point that Gary could get larger pneumatic front castor wheels to make his travel over cobblestones and other rough surfaces far easier, because they could get over more obstructions and they were more shock-absorbing – the guy noted that traveling over cobblestones caused him spasms). About Prague, he said that, for example, the main castle and cathedral had accessible bathrooms and the castle was about 85% accessible.

In terms of the U.S., he mentioned that San Francisco was probably the least accessible city because of all of the hills, but it did have its accessible areas. He thought the National Parks were very accessible.

Gary had brought up that he goes to conferences in Mexico, and the guy thought that Mexico would probably be a tough way to start one’s experience with getting around in a foreign place as a paraplegic and thought Gary might not want to start with that; Gary tended to agree.

The guy emphasized again that one should be as prepared as possible. Ways to do this would be to contact the disabilities office of the cities one is going to, and ask for the information in English as to what is accessible in their city. Another recommended way was to search on the web for “wheelchair travel + __” where you fill in the blank with your city of interest. He also said blogs were a good way to find out about accessibility – that people would write of their experiences (in terms of accessibility) in traveling to various places. He made the point that no matter how prepared you thought you were, you should always have a plan B. And a plan C, D, and E.

He said he’d been scared the first time he went off on a foreign travel experience – it was to Budapest – wondering how he was ever going to do it. But he did, and that gave him more confidence. He said his attitude was that where there's a will, there's a way; it may be rough, but once you do it, you'll have a real sense of accomplishement.

This was the end of the therapy day. I got Gary's dinner, then ran off to my last session with the personal trainer. I am sorry for that part to end, and I will also miss the chiropractor and massage therapists (though I am eager to get back to my own massage therapist – you've got your work cut out for you, Connie ;-)). And I will miss no longer following the progress of the person who got bucked off a horse, the one who while riding his bike got hit by a drunk driver, the one who got hit by someone running a stop sign, the one who got very angry and to let off steam jumped into his truck and drove it at over 100 miles per hour until it flipped over, the one who dove into a lake and broke his neck when he hit the bottom – and all the others.

But I think I'm ready to return home now – I wasn't sure of that at all a week ago; I didn't feel prepared enough. The only thing that still makes me wary of returning home now is Gary's flap still having problems with healing up.

All for now.

August 9, 2006

Last exercise session.

Suggestion for three times per week: one day like Drew's leg stuff; another day of upper body; third day of balance and arms and foundation stuff and stuff didn't get to the previous days.

First thing we did, lunges. 15 reps each leg on each exercise.

To make lunges harder, put feet farther apart, or do walking lunges.

Walking lunges: bring the feet together after each lunge, i.e., don't go straight into the next lunge (easier on the back). Be sure to straighten straight up, not forward.

Walking lunges with a twist. Once in the lunge, raise the hands (as in "you're under arrest") and twist to one side.

Step lunges – do the lunge so forward leg lands on a step, then step back. Can alternate legs or do the same leg.

Rows with a tube or tubes. Have the tubes high on a post. Lean back and keep knees bent – but don't have tubes supporting weight completely as they might break. Keep shoulders low on the pull. 15 reps.

Flies with tubes, same positioning as above, knees bent. Keep arms straight and up. 15 reps.

Repeat lunge walk.

Do a variation of lunges: lunge and then reach forward and up to the sky; then lunge and reach out to the side, shoulder level; then lunge and reach forward at shoulder level and twist around.

Repeat rows and flies.

Lifting exercise, done with speed. Place 6 4-lb medicine balls in a row along the floor. Squat down to the first one and throw it to partner, then back up to the next ball and repeat. On the way back, partner throws the balls, and I would catch it and place it on the floor (by going into a squat).

Back against wall. Lift a 10-lb weight plate all the way up until touches the wall. (A type of front raise.) 12 reps.

August 10, 2006 (a quickly written entry)

Today started out with a Life Training session: the OT came over to the apartment at 9 am (Gary liked that part, since he got to stay in bed longer and be served breakfast in bed), and she observed various parts of our routine. First she watched and offered suggestions as Gary practiced padding himself off and getting in prone and side-lying positions – he is getting better at that. Next came a shower, and she had him do more than what he had done when the two of us went through a shower practice on Tuesday. For one thing, she had him try to get his own legs in and out of the tub, with the unfortunate result that in the small space he had to work in he really banged a leg on the cabinet in both getting it in and taking it out, causing all three of us to groan in sympathy with it.

One new tip he picked up concerning taking a shower was how he could wash and dry his lower legs and feet himself by doing something similar to what she had taught him to get his own shoes on and off – namely, get closer to the edge of the shower bench (but not too close, especially since the bench is wet and slippery), grab a leg and bring it up as he leaned back on the bench, then put the ankle over the opposite knee. Because of the extra danger of sliding on the wet bench, she told him to do this only if I'd wrapped the gait belt around his chest and the shower bench. She also said that as long as he had the gait belt around him, I didn't have to stand right there while he took a shower but could be off somewhere within calling distance.

Once he'd dried off, he did another practice run at dressing in the chair. After he worked at that a while, she concluded it is still the case that he'll have to hold off on getting his pants up all the way (by himself, I mean – he won't be wheeling around with his pants around his thighs :-)) until after his flap restrictions are lifted.

After this, she left, telling us we were to finish getting ready and then go to Shepherd. Naturally after she left was when the real life training session began: after we'd gotten him back on the bed and I'd put xenaderm on his flap, we discovered his condom catheter had become disconnected, the result being I had to change his pants, his t.e.d. hose, and the sheets. Then when we got to Shepherd, he tried placing his feet slightly differently for his transfer out of the car and his feet got kind of stuck between the wheelchair and the car door and it took us much longer than usual to get him out of the car.

Once back in the building, we went through the discharge procedure with our case manager. She made sure we knew how to contact our Bridge Coordinator, when Gary's follow-up visits were scheduled for, who our external case manager is and how to contact her, reminders about his personal care, things like that. She also told Gary she had scheduled an outpatient occupational therapy appointment for him with Rehab Works on August 14th (Gary was a little dismayed by the appointment being that soon, saying he was eager to get to the university on Monday, so I don't know if he'll try to change the appointment).

After this, the OT who had talked to him yesterday about vans versus mini-vans brought Gary a ton of brochures about the various models. While Gary looked through those, she ran off a copy of his home exercise routine, the exercises to be done in his chair with either an exercise band or dumbbells. He is supposed to do the exercises once a day, two to three sets of fifteen. I didn't see the ones like pushups and dips on the list, so I'll have to give him another exercise routine of my own ;-) (actually, he knows those are good for developing his strength, so I would think he'd stay motivated to do those).

She'd also found an article on the web about wheelchair maintenance, listing what should be checked daily, weekly, and monthly. He and I were both glad to see this, because this hadn't been laid out so clearly in the wheelchair maintenance class.

After this Gary proned for a while, and I went to find the guy we'd been told knew about travel shower chairs. I asked in the seating clinic room if the guy was in, and one of the other persons there went and checked the various rooms then told me he wasn't. "He's in a wheelchair," she added helpfully. I gave her a look.

I went down to the gym to look for the other person who I'd been told knew about these shower chairs. I found him and he took me to a Bridge person who had a catalogue with such equipment in it. They ran off copies for me of information about two different such chairs.

Next Gary had a group weight training session, but it was on a different floor than usual and with a different person. Plus there was only one other patient in the group, which usually lends to efficiency ;-). The leader was pretty good, I thought, going through the exercises without taking excessive rests, though she did go through the exercises too fast, of course. (Early on, Gary got bold and asked if they could slow down, which worked temporarily until the exercise leader noted that slowing down made the exercises harder <peg rolls her eyes ;-)>; Gary wondered where these people got their training, as any weight training book will tell you not to be flinging the weights about.) One nice thing was she also had copies of all the exercises she went through, so now Gary has a good selection of home exercises (plus I can always look back on the blog and see if there are any that he has done in the past that didn't make it onto the lists we got today; I'm sure he'll be thrilled to have even more exercises to do ;-)).

That was the end of the therapy day, and Gary and I went by car first to CVS for some supplies then back to the apartment. Unfortunately, when he transferred out of the car, he again slid forward too much on his transfer board, as he tends to do with this new technique he's come up with, and I was a tad too slow or too weak in stopping his movement and he ended up laying across the passenger seat with his legs stuck between the wheelchair and under the car door. We tried various things, but he wasn't budging, and when he heard a car start up he told me to ask the person for help. Fortunately the person was a young man, and he was able to pull Gary upright in the seat, and from there Gary and I were able to complete the transfer. I apologized to him for not pulling him back onto the transfer board strongly enough, and he said he should have been aware where his butt was heading. I said maybe we should ask the OT to go over car transfers again with us tomorrow, but he said that we had the principles down, but that no doubt we'd occasionally make mistakes like this one and we'd learn from them.

Back in the apartment, I spent time trying to get through the list of things I'm supposed to do for checkout (cleaning the fridge and stove and bathroom, mopping floors, etc. – the main cleaning things left for tomorrow morning will be laundering and folding all the sheets, pillowcases, towels, and washcloths, and vacuuming the entire apartment – but the vacuum is a heavy one and the apartment is carpeted, so I am hoping to pawn off this job on someone else ;-)).

Gary found blood in his catheter during his 6pm IC, so now we have to ask the nurse about that – I sure wish these extra complications would just go away . . . . Did I say I was ready to go home? <Ironic grin>

Before Gary's transfer back to bed in the evening, because I could tell he was tired, I asked him if he wanted me to have my hands on him to help, but he said no, just to put a pillow over the tire as extra cushioning as the OT this morning had suggested we do when Gary wasn't feeling 100% confident. He should have taken my help ;-) – in his transfer he didn't get enough lift, and he ended up briefly landing on the frame of his chair (which wasn't covered by the pillow) before I could give him the extra push off it. His first transfer this morning was also one where he hadn't quite made his target, landing slightly on the wheel before I could help him over it, so we have decided that, for now, on his first and last transfers of the day I will give him more help, either holding him under his thighs or if need be going back to where I held his hips or even to where I had my hands under his sitting bones. Transfers still take him quite a bit of concentration, him trying to get his timing and technique down, and he finds it hard to keep his concentration on those first and last transfers of the day.

Well, tomorrow is our big day of coming home. My understanding is there is some chance that our cable may be out (evidently having accidently been cut by some construction crew), in which case I may not be on the internet until it's fixed – I'm letting you know so family members and so forth don’t get worried if they don’t get an email or see a new blog entry.

August 11, 2006

Well, I didn’t sleep as badly as I’d feared I might; I would have slept better but a certain person who shall remain unnamed ;-) accidently set the cell phone alarm for 12am instead of 2am and then had to wake me up to get him back into a prone position after he’d gotten himself out of it, thinking it was time to do an IC. Given the way my body felt at the time, I briefly wondered if you could die from being woken up at the wrong part of the sleep cycle (which amused this certain person when I told him this later, though of course he was sympathetic as well as sorry he couldn’t avoid waking me). But fortunately I soon settled back down and it didn’t take too long for me to fall back to sleep, and I made it until a little after six before waking again. I got up at 6:30 because we were doing our morning routine a half hour earlier than usual in order to be checked out of the apartment by 9. The Kuperbergs arrived about 7:30, bearing gifts (Gary got some high-quality weight-training gloves; I got a book of poems by Maya Angelou); then they helped me pack up and finish the cleaning up – Wlodek did the vacuuming and carried out boxes to the cars; Krystina carried out boxes and also took the boxes I had previously put in my car amd put them into the two of theirs so I could just have Gary’s immediate medical supplies in my car plus plenty of room to load his wheelchair; then they and I folded towels and sheets freshly washed and dried (well, nearly dried). We actually finished with ten minutes to spare (I felt like I was running on warp drive), only, I forgot to notify the housing guy that the first thing I did in the morning was turn on what in my not-quite-awake state I thought was the kitchen light and which turned out to be the garbage disposal, managing to get a spoon stuck down it, but I’m sure he found that out quick enough (oops!).

Then, since Gary still had a morning of therapy, the Kuperbergs and I took our cars to Shepherd – Gary had left just before us in the Shepherd bus. First on Gary’s schedule was “group standing.” He and another woman were cranked up in standing frames, another guy was brought toward vertical on the tilt table, and another woman who after her C-level injury has regained some ability to use her legs stood with the aid of a walker. Then the four of them played poker for about forty-five minutes (and I’ve forgotten the name of the game already – Texas something; I guess it’s supposed to be very popular now, shown on TV). Unfortunately I missed Gary’s big win at the end because I ran off to the apothecary for some supplies. He thought that if the chips had been counted up at the end, he would have won the most money overall; a vast change in fortune, as up to this point he had lost nearly all of his poker money.

After this came a group push. Gary and two other patients went out to the parking garage and pushed up the ramps – Gary was the only one who made it to the top, going up all six ramps of the three levels. After that the group returned to the Shepherd building then went through the tunnel to Piedmont Hospital and pushed around there (carpeted and tiled surfaces). The challenge for this part of the push was to go up a long rather steeply inclined hallway; it became more of a challenge than it was supposed to be when the new back of Gary’s chair popped out of its brackets, due to a design flaw which became apparent when Gary leaned way forward in his chair against his chest belt in order to get up the ramp, which put pressure on the back of the chair. Wlodek helped me pop the back into place, but it kept popping out again every time Gary leaned forward to make it up the slope. Time was running out, so the patients got out of having to push up the incline backwards, but they were still supposed to push up (forwards) the even steeper dreaded Blue Carpet. Again, the back of Gary's chair kept popping out, and so the therapist had me just push Gary back to the third floor gym so no mishap would happen (I had been staying behind his chair the whole time, and when he would stop for a rest and thus stop leaning forward, Wlodek and/or I would pop the back of the chair in again).

The last thing on Gary's schedule was a group weight training session, and Gary transferred out of his chair onto the mat to do the exercises (me acting as his back support again) so Wlodek could work on the chair – I had called our supplier and left a message to tell him of the problem, but we didn't know if he was going to be able to get back to us before it was time to leave, and Wlodek had an idea of how the chair could be fixed. Wlodek had the correct idea – the clips on the chair frame that secured the back in place were upside down, but fixing it made the back of the chair too low, endangering Gary's flap. An OT took the chair off to seating clinic, hoping to get it fixed there.

The morning finished with a graduation ceremony – not quite the to-do that the inpatient one had been, but it was nice. Gary got another certificate of graduation and Super Student certificate for attending the classes he was supposed to (which turned out to be none since he'd had them all as an inpatient). He also got a certificate for "Most compliant with skin precautions." He didn't get to roll out the door with the other two graduates because he didn't have his chair. Moments later his chair was returned to him, but it hadn't been fixed: evidently the seating clinic had been very busy and the OT hadn't been able to get any help. So we were left to make do until the supplier got back to us (Gary didn't think he would run into any steep ramps in the meantime, and if he did, he wouldn't go up them without someone's help – plus Wlodek planned to tie the clips on firmer with string).

After this, Gary went off to do his IC. I went to get my lunch from the car, and then I joined the Kuperbergs, who were sitting in the Shepherd garden – my graffiti sign is still up!

Gary rejoined us, and next the Kuperbergs got to experience hospital cafeteria lunch (the cooks must have known they were coming, the food seeming better than usual ;-)). Towards the end of the meal, our supplier called, and he came down to the cafeteria to work on Gary's chair. He did essentially the same thing Wlodek had done, except I think the difference was he moved the chest belt to a different place (I forget the details now). So now the clips are facing the correct way (and Wlodek assures us there is no way that back is going to pop out because of the clips), and though the back is lower, it is not by much – I'll just have to keep my eye on Gary's flap to make sure it doesn't cause any problems with that. (This is the loaner chair we are talking about, so hopefully we won't run into such problems when Gary gets his own chair). Our supplier gave us the card of the guy in or area who would actually be the one to come out and work on Gary's equipment should it need servicing.

Then it was time to leave.

I helped Gary transfer into my car, Wlodek helped me break the wheelchair down, and then we formed our caravan back to home. The first part of the drive through all the Atlanta traffic I found nerve-wracking (and it wasn't even rush-hour), but the entire drive went pretty quickly, even though I stopped about every half-hour to try to give my back some relief (my leg symptoms were still set off by the drive, though). As we got to the highway turnoff for home, it felt somewhat unreal – hard to believe it'd been four months since we'd traveled these streets. When I turned into our subdivision, I went very slow – it was time for Gary to do another weight shift (he's had to go back to doing them every twenty minutes because of the latest concerns about his flap), and we thought it might be nice for him to have that over rather than delay his getting out of the car (since we'd heard there was going to be a little welcoming committee for our arrival).

The first thing we noticed coming up the drive was the new structure of the garage going up. It looks very big! As we pulled to a stop, we were met by Janet Rogers, Donna Bennett, and Piotr Minc, complete with umbrellas as it was raining a bit (the Kuperbergs were there too, of course). After Gary and I got him transferred out of the car, we entered our house – or so we assume ;-), the changes making it seem not quite ours. The first thing that caught our eye – well, the first thing after the beautiful bouquet of flowers on the table which no one admitted to bringing – was the futon frame built by John Henrichsen, the idea being to lift our futon couch up so that Gary can make a relatively easy transfer onto it. Next I noticed the wood floors in the back rooms and then the "new" hallway bathroom, which looks great, the only familiar thing about it the tub!

Then we viewed the pièce de resistance, the master bathroom. What an incredible job, and it seems just perfect! Later in the evening I discovered another new feature that I really like – the new blinds. These should actually keep the sunlight out, unlike the ones we had ;-).

I'm afraid the other people got stuck with bringing the boxes in, because I was too busy oohing and ahhing over the house ;-). The others also did a bit of rearranging of the furniture in the master bedroom so Gary's medical supplies would be more accessible to him throughout the night. Janet and Donna gave us the basic idea of where our stuff might be found, but they warned we'd probably have to do some hunting for a while – since everything had had to be taken out of the three bedrooms for the flooring to be laid and painting to be done and so forth, things did not necessarily end up where they'd first been; we were also warned that all our books had been put back in shelves in various rooms but with no idea of how they'd originally been arranged.

Janet pointed out that Tigger was walking by the window of the master bedroom, so I went out the family room door to see if he would remember me. He did, coming right away at my call, and so did Blackjack. I got to pet them both awhile, but they were a bit skittish because they could hear the other people. Gary tried to get them to come to him, but as expected they were afraid of the chair.

A short time later, the Kuperbergs said it was time for them to go, and Gary got overwhelmed when he made to thank them; Krystyna gave him the hug he needed. Soon after the others left, but not before Janet took a picture of Gary and me, which is up on the blog. (Speaking of pictures, the Kuperbergs took some at Shepherd, and you can see them at http://topo.math.auburn.edu/pub/Gary/)

Not very long after the others had left, Michel Smith turned up (having been delayed by a dean's meeting), complete with cheesecake (!) made by his daughter Sarah – since our refrigerator had been stocked with other items for our arrival, we didn't have to worry about Gary's meal for the night. While Michel was there, Gary made the discovery that he couldn't get into one of his closets, so Michel took off its doors.

After Michel left, I set about trying do a little unpacking (as little as possible), getting Gary's supplies for the night ready and so forth. Fatigue really set in for both of us, and after dinner Gary said he was ready to be put to bed. I told him I wished someone would put me to bed, too. We went through most of our routine but skipped Gary's bath, even though Tigger decided to try to help with that by giving Gary some licks. After everyone had left, Tigger had stayed glued to me, constantly talking at me, demanding to be petted. I had picked him up and took him to Gary for some petting, and since after that I was around Gary a lot, Tigger finally got a little more used to the chair, coming up to Gary for petting at one point. But he mostly steers clear of the chair, and Blackjack doesn't come around it at all, though I bet it will be only a short while before they are used to it. Anyway, where I was going with this is that once Gary got into bed and I was helping him stretch, Tigger hopped up on the bed and demanded some petting from Gary as well as me. In fact, Tigger got quite comfortable on the bed and wanted to stay there, but I finally took him out when I was going to bed and put him behind the cat barrier, which I had to reinforce with a cinder block (I'm not absolutely sure about Tigger, but Blackjack is a strong cat, and I'm sure he would have just reached a paw under the door and pulled it toward himself with enough force that the sliding latch would have come undone and the door opened; he has done that kind of thing before). Tigger raised a ruckus from behind the barrier so I went out and petted him for a while to reassure him we weren't going anywhere.

Jack Rogers had gotten our walkie-talkies ready for use, and we had tested them out before going to bed, so I slept in the small bedroom with the door closed and my air purifier on so I wouldn't be woken by the light going on in Gary's room at 2 and 6am nor hear him moving about in the hospital bed. I wasn't awakened by either of those things, but I still woke up several times during the night – hopefully I'll break that habit.

At 7am, I helped Gary get into a side-lying position, then left his room. A few minutes later we had our first test of the walkie-talkies when he called me. We held the following conversation:

“Sorry, pookie, I need another pillow.”

“Tough.”

“Hey, it’s not supposed to work that way.”

Oh.

After I got him his pillow, Gary went back to sleep and I worked on the blog. The cats hung around me all morning, talking and wanting petting (when Gary heard Blackjack carrying on, he said, “I remember that sound. Unfortunately.”). When Gary called me again on the walkie-talkie, wanting to start the morning routine and get up, Tigger hopped on the bed, and we discovered a new goal for Day Program when Gary returns: how to get padded and positioned in the bed and do stretching and getting dressed while lying on the bed, with the added complication of a cat on the bed – maybe we can bring our cats to illustrate the problem.

We had made a list of things to do in the very near future but we are not accomplishing much (or, so far, anything ;-)) today. Between the routine stuff (including the stuff that had to be done due to “medical supply failure”) and being still so tired, neither of us seem inclined to make any headway on that list (and obviously, I’d rather blog ;-)).

Okay, maybe I’ll now go and see if Gary wants to do any of those things on the list. But first, thanks to Judy Roitman and Steve Lombardo for the beautiful flowers!

I’m back. We went grocery shopping, taking about an hour and a half to do so. I think that’s enough for today. ;-)

August 12, 2006 (continued)

STAN Lombardo, not Steve Lombardo, is who along with Judy Roitman I have to thank for the flowers. I really did know that was his first name. It could have been worse – my spell checker tried to change his last name to “Lombard,” but I caught that. But I did not catch it when it changed John’s last name from Hinrichsen to Henrichsen. Sorry about that, Stan and John. I will make the corrections on the blog entry, but of course it's too late to do that for the emails that were sent out.

In the evening, Gary tried to make a dent in the mail we’ve received lately. Thanks to Kitty and T.Y. Tam for their card, and to Marilyn Foreman for hers. And thank you, little Laura, for the anniversary “Amelie” DVD.

Gary also got a most amazing card – it was from the person who was first at his side at the scene of the accident (she found out who he was when she read the article about him in the local paper a couple weeks ago). She said she was pumping gas at a nearby station and heard the accident, ran to Gary’s car and screamed at him to talk to her, then yelled at the gas station attendant to call 911. She said Gary just sat there and looked at her until the ambulance arrived. Gary remembers none of this, and reading her card made us both cry.

We were both still wiped out today, but our intentions to get the evening routine done a bit earlier so we could get a bit more rest were thwarted by more “maintenance issues.” We are still wondering when we get that 50% leisure time.

All for now, except to mention something I meant to say on the entry for Friday, namely that we both think Piotr Minc has very good taste in bedding and towels!

August 13, 2006

Today we did a little of this and that. Janet Rogers and John Hinrichsen came by to fix the futon frame, shortening it a bit so the top of the futon is even with the top of Gary’s wheelchair seat. I found the theraband that Gary had been given at Shepherd and Gary took the hint and did his exercises (I did them with him). Joe called and we talked about the house, the state of the garage, and how good the cats looked (the only other time Gary and I both left them (for about a week) they were fat as hogs when we got back, having done a lot of stress eating, apparently. Tigger, by the way, is getting more and more used to the wheelchair; Blackjack still won’t come near it; Tigger loves the hospital bed when Gary is in it – or rather, he loves lying next to Gary in it; we have to keep an eye on where those claws are kneading, making sure it isn’t happening on Gary where he can’t feel. We are also re-experiencing how Tigger likes to be in Gary’s face when Gary is eating – a habit we’d hoped Tigger had gotten out of (he doesn’t get in my face, evidently not being into rice and zucchini); the cats and I have, however, quickly re-established the habit of going for a little cat walk around the outside of the house before the cats’ meals are served. Okay, you’re probably sick of hearing about our cats ;-)).

Our big adventure for the day was a trip to Lowe’s, which took us a couple of hours. We bought stuff like waste baskets (deciding our remodeled house deserved something more high-class than cardboard boxes for that purpose), airtight food containers for pet food and ours (we’d had the cats’ food in an airtight plastic clothes bag, but that has disappeared out of the pantry), a couple of different latches to experiment with for the cat barrier, a small halogen desk lamp for Gary’s use during the night, a stool for me to sit on at Gary’s bedside when I am helping him with his stretching and so forth, and castor cups for the hospital bed which currently slides even with the wheel locks on (only, we’re now not sure if we’re going to use the cups, because the kind we got would make it very difficult to move the bed at all should we decide we need to). At checkout at Lowe’s, we discovered the credit card swiper (what is the official name for that?) isn’t quite accessible. First of all, it was bolted to the counter, though the part Gary needed to swipe his card through and sign could be lifted out of the holder and brought to him. The pen was still attached to the holder, however, and it didn’t reach very far, so Gary had to do some maneuvering of his chair to face the counter sideways in order to sign. I noticed that the checkout person announced over the speaker that another checkout aisle was open to take the people waiting in line behind us (grin).

We are still working out the best (or even a good ;-)) way for Gary to transfer out of the car – the transfer in is going fine. We had noticed that the technique he had first been using to transfer out (with both feet first placed outside the car) had been efficient, but he was getting bruises from it on his lower left leg, evidently from banging his leg on the car. So then we went to a one-foot-in-one-foot-out technique, which takes us a lot more time; he thought it good enough, but I pointed out that he needs a lot of my help with it, so if his goal was independence in this kind of transfer, we might want to try to come up with another way. Neither of us had any ideas at the time I brought this up, but then when he transferred out of the car to go into Lowe's I noticed that at the last part of the transfer he would have had a better body position had he had both feet in the car – I told him this, but I also told him I couldn't guarantee that that position wouldn't inhibit the start of the transfer. When we got home and we prepared to do the transfer out of the car, he said we might as well try my suggestion – we'd tried all the other possible foot placements. So we did, and it worked great! ("By George, I think you're onto something," Gary said halfway through the transfer.) The position not only allowed him to make the transfer in just a couple hops, but his angle was such he kept on the board without needing major help from me – maybe he would have needed none at all, but we won't test that theory until he's consistently done it successfully with minimal help from me. Anyway, time will tell if this is the technique that will work, or if that was a fluke, but we are hopeful.

After our shopping spree, Gary needed a nap and I meditated. As dinnertime rolled around, Gary suggested we divide up the chores differently. For instance, since he can't maneuver his chair to get the dishes in the dishwasher, rather than me do most of the cooking and him do most of the cleaning up, as we'd done before, he said he'd help out with the dinner preparation then rinse the dishes in the sink afterwards. Tonight we had planned on tostadas for him, so he got ingredients like taco sauce and lettuce and tomatoes and cheese from the fridge then sat at the table and sliced tomatoes and grated cheese while I warmed up the beans (canned, I confess) and the tortillas.

As we went through the stretching routine later in the evening, Gary pointed out that one nice thing about the situation we found ourselves in was that we did a lot more things together, that the shopping trip had been fun, whereas before if he'd had to go to Lowe's, it would have been a chore. I was reminded of how things are when you're dating – you do everything together, and even the most mundane stuff is more fun that way, whereas when you divide up the chores, things may become more efficient, but you may lose that fun element.

So, you can take a lesson from that if you want to ;-).

August 14, 2006

Today Gary met with the local OT Shepherd had hooked him up with. When we got to the rehab place, first he had to fill out a form asking about his medical condition and what he could or could not do. "Think I should check this box?" Gary joked when he got to the line "Difficulty walking." After a bit of a wait, we met the OT – I had been worried I wouldn't be able to come in with Gary into the rehab area because there was a sign on the door that said "Patients only," but I wasn't stopped. I hope they continue to let me accompany him during his rehab here – I find watching (and helping, preferably) with his therapy fulfilling, and that helps me cope with the aspects of his recovery I don't enjoy – namely, extra domestic chores and getting up during the night. Gary said he hopes I can come, too, that he liked having me there during his therapy sessions at Shepherd and is glad I want to continue to do it here.

The OT had gone over Gary's records from Day Program, so it was more a "get-acquainted" session than a "start from scratch." She asked him details about how much of the tasks of daily living he could do now, what his flap restrictions were, what his goals were. She tested the muscular strength of his arms, then had him transfer onto a mat. She wanted to see how we did the transfer on our own, so we did one where I would just supervise unless my help was needed; my help wasn't needed that time – these days it usually isn't in cases like this where the mat is lower than his chair. On the mat, she watched him get his feet up on his own and get into a prone position; she showed him a back exercise she wanted him to do, and he showed her "the terrible threes." She might have had him do more, but he needed to do an IC, so she had us do a transfer back to his chair. Gary didn't get much lift during it, not completely clearing his seat cushion upon "entry" into the chair so I had to help him over the cushion. I thought that was all right, though, because it gave the OT an idea of what his level of proficiency is.

Though it is hard to judge just by meeting her, we are hopeful that he can continue making progress with her – as Gary says, she wasn't thrown at all by him having an SCI. She also mentioned that with some of the goals he can't yet meet because of his flap restrictions, he could make use of adaptive aids, for example, a leg reacher that would enable him to bring his leg toward him when he is lying in bed, which might enable him to do more of his own dressing and which could be used to help him get his legs untangled when they cross over each other when he turns over, which impedes his ability to move about the bed. I know Shepherd wanted him to avoid getting dependent on external aids, and I mentioned that to her, and she said he could try to do the tasks without the aids but if he got stuck and couldn't make any progress he could use the aids. That sounded reasonable to us.

He is going to go to rehab again this comingThursday, and next week he is scheduled for three times, MWF.

It had started to rain when we left the rehab place, and by the time we got home it was raining a goodly amount. I had picked Gary up a sandwich at Paneera's, and since it takes him awhile to make the transfer out of the car, rather than get soaked he decided to just eat in the car and wait out the rain (we never had rain in Atlanta during any therapy sessions, so it never really came up how people confined to wheelchairs handle the rain – assuming there were any tips to be had). When the rain died down a bit, we got him inside (after I threw a rain poncho (which unfortunately had no hood) over him and tried to prop up an umbrella on the car door so his wheelchair seat wouldn't get wet); the first thing he did was go on the internet and find a rain poncho made for use in a wheelchair.

So, that's about all we accomplished today. We did a few things in the afternoon – Gary started sorting our accumulated mail, I screwed on a new cat barrier "hook-and-eye" latch that hopefully

Blackjack isn't strong enough to pull out. I also spent time staring at bookcases and bags of clothing wondering how to reorganize – I know this is a good time to get rid of a lot of stuff, but I have not yet become inspired to do so.

In fact, what I am inspired to do is take a nap. Since that is what Gary is up to right now, Tigger with him, this would be a good opportunity for me to catnap too. :-)

Zzzzzz. Okay, naptime over. Before our evening routine, I moved a few books around, and while I stretched Gary in the evening, he got in a call to his brother Bob and his mom.

All for today, except to say that Gary says some day soon we hope to actually have time to turn on the TV and have "leisure" be something other than shopping or going to appointments ;-).

August 15, 2006

Still digging through the mail ;-). Thanks to the forty-two or so (depends on how well I counted the signatures ;-)) attendees of the Conference in Topology and Theoretical Computer Science in honor (or honour ;-)) of Peter Collins and Mike Reed, Mathematical Institute, University of Oxford, England. Jack Brown tells us that many of the conference speakers expressed well-wishes to Gary and me during their talks :-)

While sorting through some mail and papers, I also came across an interesting read: a sheet of paper detailing all the job assignments the volunteers had taken on for the various parts of the house – bedrooms and study, the baths, hall, living room, kitchen (and of course the important tasks of keeping the cats in food was included). The paper served as a concrete reminder of the tremendous organizational effort that went into re-making our home, and we thank you once again from the bottom of our hearts.

This morning we talked to the garage people about water seeping into our house through the side entrance; they thought the drain they are putting in that area would solve the problem but said they would also caulk around the side door. We also mentioned to them that Gary wasn't going to be able to easily get in the side door to the garage because there is a one-and-three-quarter inch gap between the sidewalk and the bottom of the threshhold. They had put a piece of wood there, but that would be of no help, we told them, so they said they'd make a ramp of concrete for that entrance. Joe happened to call shortly after that, saying he'd talked to the builder (who'd informed him that they put on the wrong color of roofing tiles so the tiles would have to be replaced), and I told Joe what we'd said to the workers. Joe said he'd tell the builder of the problems, just to make sure the "main guy" knew, and gently suggested that in the future, for the sake of accountability, we find out who it is we are talking to. Joe called back a little later, saying that the builder hadn't been aware of these problems we'd brought up, but now he was and he would see they were taken care of.

Gary made several calls today. He tried to make an appointment with his physician here, but her computers were still down, like they were yesterday. He called the DMV about getting a handicap placard, and they said he couldn't use the form he'd brought from Shepherd but had to fill out their own form, which they are mailing to him. Gary also called the local paratransit service to see if their fax had gone through to our case manager at Shepherd (the fax was a form which Gary's doctor at Shepherd would fill out saying Gary needed the transit service), but they said the fax hadn't gone through, that the number was always busy. So Gary called the case manager to tell her of this, but she wasn't in her office and so he just left a message; he didn't hear back from her today. He called a couple local pharmacies to see if they carried some of the supplies he needs by this weekend, and they don't. He called the pharmacy at Shepherd to have them send them, but he couldn't reach the person who sends out supplies. Luckily, the Bridge Coordinator called at about that time, and when she asked Gary how things were going, he mentioned not being able to get the supplies locally and that he needed them soon. She said she would contact the right person at Shepherd pharmacy for him and have them sent out immediately, which she did.

So we now know that Bridge Program can be useful!

In between all these calls Gary made, some calls came in, but the caller(s) hung up without leaving a message. Gary and I thought of a new greeting he could leave on the phone: "I'm sorry, but it takes me a hell of a long time to get to the phone. I may pick up before you hang up, or I may make you listen to this recording and then leave your message – whatever I'm in the mood for."

After lunch we did our outing for the day: to get a university parking hang-tag for us and a cell phone for Gary. I couldn't find the already-filled-out parking tag application that had been forwarded to Gary at Shepherd, so we just went to the university parking services building to get a blank one. Once there, we couldn't figure out where to park (so much for their services ;-)). There was construction going on in the area where we would have parked, and behind the building itself were dire warnings not to park there, saying we would either get ticketed or towed. There was a handicapped parking space, but as I mentioned we don't have the placard for that yet. I parked behind the building anyway rather than search for a place and chance having to leave Gary in the car some distance away (we weren't going to bother with me putting his chair together and us doing the transfer out of the car and then reversing the process for what we hoped would be a quickly accomplished task; but I figured I'd probably need to ask him questions so I wanted him close). I got the form from inside the building and took it out to Gary to fill out, then I took the form back in. The woman wasn't going to let me get the hang-tag for him, even though I had his ID and his driver's license (the latter of course no longer valid), saying she would mail it to him; I explained that he was right outside in the car, and that in order for him to come in I would have to put together his wheelchair, but if she really really wanted me too . . . She asked me if he was in the handicapped space, and I said no, that we didn't have the placard for that yet. She then chastised me for parking in the back, saying we would get ticketed, and I basically said that that would have to be the way it was then. As Gary had told me to, I then asked what the "D" zone hang-tag is, as apparently that is something new and before this Gary always got the "A" zone tag. Gary had thought that by her reply I would know which to get him, but I didn't – the D zone was for the new parking garage, would work in C zones, but wouldn't work in A or B zones or in the library parking deck. The A zone worked for B and C zones and the library deck but not the new deck (which I guess is close to the math building). So I ran back out to the car and asked Gary, he decided on "A," then I ran back into the building – fortunately the woman had said I could come to the front of the line rather than wait in it again (there were about a dozen people in it all the while). She then asked me if he wanted to wait on the tag for a few days until we got the handicapped placard, at which time he'd only have to pay half the amount; she said his last year's tag would do until the end of August. But I didn't know where the old tag was – I had taken it out of his wrecked car when I came back home for that one day April 17th to take care of some business, but I figured I couldn't put my finger on it by tomorrow (though that turned out to be wrong – it had somehow ended up on the kitchen table). Before we had gotten on campus, Gary had mentioned that if we couldn't get the tag today, I could help him out of the car when he goes to school for a while tomorrow, then find someplace off campus to park before rejoining him (not that I have to accompany him tomorrow; I just thought I'd like to). So now I wasn't sure if he'd rather I parked off-campus until he got the handicapped placard. I ran back to the car again to ask him. He said to go ahead and pay full price (the woman had warned he wouldn't get a refund), so that's what I told the woman, after cutting through the line again. That settled, I apologized to the line of people – though I don't think I held them up all that much, because the woman wasn't simply waiting for me to return but helping the next customer. Gary and I then left campus, fortunately without acquiring a ticket for parking where we shouldn't.

We made a brief stop at the health food store for free-range eggs for Gary and nutritional yeast for the cats (or was it vice versa ;-)), then we headed to T-Mobile, which is where I had gotten my cell phone – or rather, Connie had basically gotten it for me on April 17th, she doing all the talking and me looking on in bewilderment. Gary decided to make things simple by saying he wanted the same model cell phone I had. Of course, they had been upgraded since then, which was all right because now his looks slightly different than mine and we can tell them apart.

It turned out not to be a simple matter of popping in the place for a phone, because we have a fraud alert on our credit cards (while we were at Shepherd, we got notices from Ohio University saying their data bases had been broken into and there was a chance our information was compromised; to protect from identity theft, they suggested we place the fraud alert). So instead of being able to set up an account by computer, the salesman had to talk to a live person, which slowed things up. In fact, it took about an hour to get the phone.

All this had taken us until about four o'clock, and that was enough for the day, so we returned home. I did a little organizing (actually, because there are now little piles lying around, the place looks worse), and Gary did his theraband exercises (I better get back to my own exercise routine soon). This morning I had reminded him that he hadn't been doing his terrible threes, so he'd done them while I was dressing his flap and putting his t.e.d. hose on him (because of the way his legs have rotated outward since the accident, I find it easier to get the hose on him while he is on his stomach than on his back).

For dinner he decided on an omelet, so this was another thing we could share the preparation of.

(He also had soup and bread and salad and an apple, if you really want to know – I'm reminded of how we used to tease my mom because in her letters she would always talk about what they'd had to eat recently.) After dinner he rinsed the dishes and I loaded the dishwasher (after unloading what was already in there.) So, we are feeling our way into developing a new domestic routine.

At bedtime, it could no longer be avoided: it was time to cut his toenails. I don't know about you, but it makes me nervous to cut someone else's nails. Fortunately, I didn't hack off any little piggies.

To finish this entry, a news item from the other border, courtesy of my brother and sister-in-law:

The flood of American liberals sneaking across the border into Canada has intensified in the past week, sparking calls for increased patrols to stop the illegal immigration.

The unflinching arrogance of the Bush Administration is prompting the exodus among liberal citizens who fear they'll soon be required to hunt, pray, and agree with Bill O'Reilly.

Canadian border farmers say it's not uncommon to see dozens of sociology professors, animal-rights activists, and Unitarians crossing their fields at night. "I went out to milk the cows the other day, and there was a Hollywood producer huddled in the barn," said Manitoba farmer Red Greenfield, whose acreage borders North Dakota. The producer was cold, exhausted and hungry. "He asked me if I could spare a latte and some free-range chicken. When I said I didn't have any, he left. Didn't even get a chance to show him my screenplay."

In an effort to stop the illegal aliens, Greenfield erected higher fences, but the liberals scaled them. So he tried installing speakers that blare Rush Limbaugh across the fields. "Not real effective," he said. "The liberals still got through, and Rush annoyed the cows so much they wouldn't give milk"

Officials are particularly concerned about smugglers who meet liberals near the Canadian border, pack them into Volvo station wagons, drive them across the border and leave them to fend for themselves. "A lot of these people are not prepared for rugged conditions," an Ontario border patrolman said. "I found one carload without a drop of drinking water. They did have a pleasant little Napa Valley cabernet, though."

When liberals are caught, they're sent back across the border, often wailing loudly that they fear retribution from conservatives. Rumors have been circulating about the Bush administration establishing re-education camps in which liberals will be forced to drink domestic beer and watch NASCAR.

Liberals have turned to sometimes ingenious ways of crossing the border. Some have taken to posing as senior citizens on bus trips to buy cheap Canadian prescription drugs. After catching a half-dozen young vegans disguised in powdered wigs, Canadian immigration authorities began stopping buses and quizzing the supposed senior-citizen passengers. "If they can't identify the accordion player on The Lawrence Welk Show, we get suspicious about their age," an official said.

Canadian citizens have complained that the illegal immigrants are creating an organic-broccoli shortage and renting all the good Susan Sarandon movies. "I feel sorry for American liberals, but the Canadian economy just can't support them," an Ottawa resident said. "How many art-history majors does one country need?"

In an effort to ease tensions between the United States and Canada, Vice President Dick Cheney met with the Canadian ambassador and pledged that the administration would take steps to reassure liberals, a source close to Cheney said. "We're going to have some Peter, Paul & Mary concerts. And we might put some endangered species on postage stamps. The president is determined to reach out."

August 16, 2006

This morning I suggested to Gary that he try out the tip of the OT here for getting his pants on up to his thighs by using the bed controls to raise the upper part of the bed and then getting his foot over the opposite leg to work the pants up. Her advice worked pretty good! And he was even doing it with the dockers, not the sleep pants (since he wanted to look “nice” for school).

Later in the morning, Gary noted we've definitely gotten better at our morning routine, having cut off a couple hours from it from that time we were in the TLA apartment. :-)

Shortly after noon, we headed for the university – Gary would keep his word that he'd be on campus for the first day of classes. We thought that it might be fairly simple to get around campus at that time (our theory being that people would be off-campus, out to lunch) – we were wrong. It didn't help that Gary wanted to stop at a fast-food place near campus first, and we ended up having to make nearly all left turns after that. I haven't driven through campus in years, and I have the following observtion: left-turn signals are needed!

We got lucky with the parking, though – at least, I thought so, having been afraid I'd have to help Gary out of the car and then park blocks away. We ended up in a spot not all that far from the ramp Gary needed to enter the math building by, and in fact the parking place was an end spot so there was extra room for Gary to transfer out of the car. Once we get that handicapped placard, we'll be able to park even closer, but for today I told Gary to think of it as "push practice." Since it was only about a block, through parking lots, it was an easier push than he'd had to do in the groups at Shepherd.

On the way into the building, we ran into Kevin Phelps, who greeted Gary. Chris Rodger was going up the stairs at the time, and he waved to me through the glass, then shortly after that, as we came off the elevator, we met him in the hall and exchanged a few words before he had to dash off to class. We also ran into Pete Johnson and spoke to him as we made our way to the math office, and Gary also spoke to Ming Liao.

Also on the way to the office, we had to pass through some glass doors that Michel had been worried might be too difficult for Gary to get through. Gary managed to do so, however, saying that though they weren't trivial, being a little heavy, it was nothing he hadn't encountered before.

Gary had lost his keys to his office in the accident, so he needed someone from the main office to let him in. He planned to ask one of the secretaries, but Michel Smith was there, and he accompanied us to Gary's office to open it up for Gary (on our way, Michel said to me, "So, what would you like to teach?" When I laughed he said he was only half-kidding, that if I wanted to teach, it could be arranged; I didn't take him up on it – I'll spend my spare time writing :-)). When we got to the office, Gary noted with approval the straightening up that Brad Bailey had done for him. The next order of business was checking out the desk. It turned out Gary couldn't get his knees under it. Michel told him there was a wooden table on the second floor that might work, so we went to check it out. Gary also couldn't get under that, but Michel figured it could be modified. Upon returning to Gary's office, Michel had the thought that if the middle desk drawer were removed, Gary could fit under the desk. That turned out to be the case. But Gary said that he wasn't sure the desk would be better, that he needed to think about how to best rearrange the office so he would have the most accessible space, and then he'll decide whether he wants to keep the desk or use that table. As Michel left, Gary again thanked him for all he had done.

Gary's graduate student Asli Gulderdek dropped by, and she and he talked about her courses and schedule. Later, Gary's new student from Italy, Santino Spadaro, stopped in, and they talked about the courses and the mathematics Santino has been doing. While they were talking, Pat Goeters poked his head in and said Gary had just missed a Graduate Council meeting. Pat wasn't seriously suggesting Gary should have been there, but Gary asked if the plan was for he himself to again be on the committee (Pat had taken Gary's place after the accident). Pat said he thought it was, and Gary said he'd go to the next meeting, assuming it was in approximately a month.

Someone I've never met, Nedret Billor, also poked her head in during this time to welcome Gary back. (I hope I haven't forgotten anyone by the time this entry is over.)

After Santino left, Gary decided to check out the accessibility of the second-floor bathroom. I automatically started to go with him to check it out too, and we laughed about that. At Shepherd, it is common to see women in the men's bathroom, but we figured the students in the math building probably weren't ready for that.

So off he went, and I got on his computer to start drafting this blog entry – and ended up telling a dozen students where the heck room 319 was (you'd think in a math department the numbering of the rooms would be a little more logical ;-)). A little while later, Phil Zenor popped in to say hi to me, saying Gary had told him I was up here (Gary was down in Phil's office – I forgot to ask him who else was there with him). Phil commented that Gary looked great, that if he weren't in the wheelchair one would never be able to tell he was in such a bad accident (Phil had seen Gary on May 2nd, back when Gary was in the Birmingham ICU). Phil said he was surprised that Gary had come back to school so soon after our return, and I said Gary had been eager to get back to the math department. Just then the man himself wheeled in, and after a bit more conversation, Phil took his leave. Gary then said he was ready to go home (it was about three-thirty). I asked him how he felt, if he was tired. He said no, he felt good, that he was excited to be back in the math department – but added he might feel tired by the time we got home (though he didn't).

On our way out of the building we had to go through those glass doors again. I let Gary try this direction himself too; it took a little maneuvering, but he did it. After we got through, I realized we'd had an audience of students sitting along the wall behind us. I asked Gary if it was okay that I hadn't helped him with the door. He said sure. I mentioned the students. He said they'd probably been thinking, "She's right behind him and she's not helping – what a bitch." We laughed, and he added, "That's okay – they don't know the situation."

On the way home we made a stop at the health food store, needing more laundry detergent and food – we're not used to Gary having his lunches at home, which means we're not used to planning on what he should eat at that time and what supplies to lay in. In the store, I talked to the manager while loading up my basket and discovered she had found out about the accident a few days after it'd happened. She told me that someone had come in (she didn't remember who), talking about the accident and saying how I would fall apart. She had told the person, no, I wouldn't. The person protested that I wasn't well myself. But the manager insisted that I would get through it. Fortunately she was right. I haven't thought about that in a while, how I was so worried that first month that I might crash. I believe it's fair to say I've ended up stronger than I started, though I still don't want to tempt fate (or CFS flare-ups) by taking on more than I am. Coincidentally, Gary said to me at bedtime, hours after I wrote the above, that I really had risen to the occasion, just as the store manager had said to him when I wasn't there, explaining that he meant that at the time of the accident I could hardly do anything because of my back, but now I was tossing him around like a sack of potatoes (grin); I do wish, however, my back symptoms had cleared up – I still can't sit for any length of time without tingling down my butt and leg).

I had suggested to the manager that she go out and talk to Gary while I checked out, which she did. When I came to the car they were talking about the intersection where the accident had happened – she knew a family that had been in a bad wreck there, everyone in the family hurt, the woman in a cast for months; she'd also heard of other accidents at the same place. Gary said he planned to do something about trying to get a light put in at that intersection.

The manager then looked over at me and said to Gary, "She's a strong woman." Gary said, "She is. She pushes me. Makes me do my exercises." The manager said to him, "You need that. It really is tough love. Tough for the person giving it, and tough for the person receiving it."

Well, I don't know how tough it is to give it – I can be pretty bossy ;-). No, actually, the hard part is not wanting him to get mad at me when I suggest he do certain things. But he never has, probably because I do know he has limits – if he says he's too tired to do something himself, I believe him and help him or do it myself.

Anyway, the manager's words made me feel good, lifted my spirits. I like my strokes ;-). As you know, I am not strong enough to do this on my own without broadcasting what has been going on. This makes me worry a bit about ending the blog, since I imagine it won't be all that long until I haven't got all that much to say (at least, not until Day Program and driving school, etc.). I'm sure it won't keep your interest if all I have to report is stuff like, "Tonight, Gary (and, unavoidably, Tigger) had chicken." (Speaking of which, tonight we prepared Bombay curry with potatoes, carrots, and garbanzo beans ;-).)

The manager's parting words to us were that if there was ever anything from the store we needed and we just couldn't get out to get it, she would bring it to us! I then drove us home, where we discovered that our new garage doors were up – both the side and the front. They also painted the garage this morning, and it is looking really nice! When we entered the house, Blackjack ran off – he still is scared by the moving wheelchair. Gary voiced the thought that maybe he should take Norma's suggestion and smear himself with tunafish – though I'm thinking that may attract every cat in the neighborhood EXCEPT Blackjack.

During dinner Gary brought up the day's events again, saying it'd been fun going to the math department, that it was so nice to be there after four months of being away.

So, a satisfying day all around!

August 17, 2006

Today's outing was first to Wal-Mart, where we ran into Janet Rogers (how's that for a neat coincidence!), then to the rehab place, where we sat around waiting for the therapist for a half hour. We were worried this might be typical, since we'd waited a half hour last time too (certainly not the way Shepherd was run), but it turned out another therapist at the place hadn't been able to make it that day, so Gary's therapist was double-booked. I wish someone had explained that to us ahead of time, so we could either have come later or at least known what the delay was (I did ask at the front desk if Gary was down in the appointment book and if they were aware he was there) but I guess I should be complaining to them, not you. But then, I am a big talker unless it is to the person the complaint is aimed at ;-)

The therapist had Gary start out with grip and wrist strengthening exercises. For the first exercise, he squeezed a Digi-flex, which as you might guess, flexed each finger. This he did for two sets of thirty. Then he did a series of wrist curls, starting with reverse curls. These he did one hand at a time, in order to keep his balance. He noted that his right hand was stronger than his left. I asked him if that meant he'd "like" a heavier weight for it. He smiled and said he knew I was going to say that, but agreed to a heavier weight (three pounds instead of two). After he did one set of thirty, the therapist had him do the second set emphasizing the eccentric contraction – in other words, he lifted the weight to a count of two but lowered it to a count of four; if you've never tried that before, you will discover that definitely makes the exercise harder! He did a set of fifteen that way (neither he nor the therapist seemed capable of keeping track of the number of reps the entire session, so I did it for them – see, I knew I was good for something ;-)). The next type of curl imitated a hammering motion: keeping the forearm stationary, raise and lower the wrist with the palm facing in (officially, "ulnar and radial deviation") – two sets of fifteen. The last type of wrist curls were what I think of as "regular" curls, palms facing up. Two sets of fifteen, emphasizing the negative.

Next she had him do some exercises for his upper arm and shoulder muscles. She reminded him that now that he was so dependent on his arms for his locomotion, he was at risk for repetitive motion injuries in his shoulders, so he needed to keep those muscles, as well as his chest and upper back muscles strong. On a cable machine, she had him do tricep extensions, where, facing the machine, he pulled down and back. She stabilized his shoulder for him by gripping it in the front and the back (she was being extra careful because of the shoulder problems he already has). He did thirty of those on each arm. He finished the strengthening part of the workout by turning his back to the machine, taking the handle on the cable, and punching forward – these she said would strengthen his pecs (and I think she said his anterior deltoid, too). He did two sets of twenty on those.

She mentioned that any bench press type of exercise would have a similar effect, saying he could do them while lying on his bed holding some weights. I asked how often she thought he should do these exercises (he's only being doing the theraband and terrible three exercises since being home, and I want to make sure he doesn't lose the strength he built at Shepherd, though on the other hand I know he doesn't want to start back in with heavy exercises like pushups and dips until his shoulders feel better). She told him he could aim for two-to-three times a week, depending on how he was feeling.

She had him finish up by doing some isometric exercises which she said were for his stability. She had him hold a stick (like a shortened broom handle) out in front of him, then she gripped it too and told him not to let her move it (but telling him ahead of time what direction she was going to attempt to move it in). First she tried to pull it to his right for a few seconds, then his left, then up and down, then backward and forward, then she tried to twist it out of his grasp (so, like wrist curls), then she tried to move one-half of the stick upward and the other side downward. She then did the exercises with me (which pleased me and gave me more hope she won't eventually throw me out of the rehab gym ;-)) in order for me to see what Gary was feeling during it, though I know it wasn't entirely the same because I was recruiting ab muscles to stop her movements. She thought he might have some ab muscles helping him too, but he said he didn't. She didn't seem quite convinced and had him bend forward and then sit upright in his chair a couple of times. Gary did so and assured her those movements were governed by his head movements, not the use of his abdominal muscles; she felt his abdominal wall as he did them and then was convinced. She said he made it look easy, and I told her it certainly hadn't looked that way at the beginning.

She said the two of us could do these stability exercises with Gary sitting on the edge of the bed and holding a broom handle, but she had immediate second thoughts and said we'd try it first in the gym (one of those "don't try this at home" admonitions ;-)), just to make sure Gary would be stable enough (so that I'm not calling math volunteers to help me get Gary off the floor after I pull him onto it ;-)).

After the session, Gary remarked that so far he really likes this therapist, and it seems to me too she's going to be a good one, which is so gratifying to us both – we weren't sure what we'd find here after being with the therapists at Shepherd who work only with those with SCIs.

All for today.

August 18, 2006

Gary received a big box from Norma and a package of DVDs from Donne and Phyllis, both pertaining to the Alaska cruise. Norma very cleverly divided the contents she sent into thirteen smaller numbered packages (she says number fourteen will be sent soon) – I'm assuming the numbers correspond to which day of the trip they were from. Gary has opened the first four packages so far, which contained postcards, a flashing magnetic pin depicting the flag of Canada (Donne's idea for an item of memorabilia – I could have guessed that ;-)), a sampler of "Alaska wild teas," a DVD "postcard" of Mendenhall glacier, and a T-shirt from Skagway, Alaska, where the family took a scenic train ride.

Mom G's anniversary card also arrived – it had been forwarded from Shepherd. Thanks for the nice card, Mom G!

This morning the guy who put up our garage doors came back and added a glass sunburst design to the top row of the main door. Looks nice! He also showed us how the door could be electronically raised and lowered, except that for the moment we'd have to run an extension cord from the house because there is no power in the garage yet. Later in the day, when Gary and I returned from today's outing, we found that the garage people had made a short ramp of concrete up to the side entrance of the garage. Entry that way will still be nontrivial, Gary says, but doable.

Our big adventure for the day was a visit to Gary's primary physician. Or should I say, the big adventure was in doing a transfer from his wheelchair onto that oh-so-narrow examination table. The table was a couple inches higher than the chair, and of course Gary has practiced transfers onto higher surfaces, but they've always been onto things with back supports or onto wide exercise mats, and so this made me a bit nervous – though rare, he has fallen backwards after a transfer. There was also the possibility that he'd fall forward, although that too doesn't happen all that often (but it would only take one miss at my catching him to make a, shall we say, unimpressive transfer). The doctor asked if we wanted her to help and took Gary's arm, but Gary told her that holding his arm would impede him and that she could just stand in front of us, that we were trained to do such transfers. Meanwhile, I'm thinking, "Oh, God, don't let him go splat on the floor." Since it was an upward transfer, and most especially because it was onto an unfamiliar surface, he asked for and I gave him the maximum form of support, putting my hands under his sitting bones from a position behind him (with one knee on the exam table and the other leg on the floor). He did lose his balance, going too far forward during the transfer (or at landing – I didn't stop to analyze it that closely ;-)), but I had already reacted by bringing an arm up to encircle his chest and hold him on the table. The doctor noted as she and I then helped Gary lie on his side on the table that he would have done better to marry a bigger and more muscular woman – I have a feeling that comment was related to the transfer. ("But then it wouldn't have been me," I protested.)

The doctor checked Gary's flap. She thought it was looking great – I agree it is so much improved from a couple weeks ago. She also checked out the incision from his spine stabilization surgery, and then she and I turned him onto his back while keeping him on the table (obviously there wasn't room for him to roll into the position) so she could do the usual poking and prodding of the abdomen.

Then it was time for the transfer back to the chair. She said something like, "Not that I don't think you did great on your own, but I think I'll call in a nurse to help." Gary told her there was no need, that this was the easy direction, downhill. She looked at him then at the chair, which I had positioned, then said, "I don't see how you're going to do this." I said, "Wait (and see)."

Gary scooted a bit on the table so he was positioned properly (sideways to the wheelchair), I put his foot on the footplate rather than him take the time to do it, then we did the transfer, this time me giving the next step down of support, just holding his hips from behind. The transfer went beautifully, and the doctor smiled and said, "Amazing. Shepherd really has something going, don't they?" She noted that Gary was going to get even stronger and better at everything he did, and told us she had a patient who had been paraplegic for about fifty years and he could do "everything." She finished the exam by saying she thought we were really on top of things, which was nice to hear. (Oh, and I forgot to mention she started off the appointment by talking about the intersection where Gary's accident occurred, saying that she'd always thought it was so dangerous and just hated crossing there. She said there really ought to be a light there, and Gary said he hoped to work with others to get one there. She said she hated that he had to be the one to be "the poster boy" for it, but maybe this would be just the thing to finally get a light put in.)

After returning Gary home, I took off for something I've been looking forward to for a long time: writers group meeting! There was lots of banter and nonsense, and, oh, yes, a little talk of writing (depending on current output of the members, the meetings could be a *lot* of talk of the writing and a little of the – no, there is always lots of banter and nonsense ;-)). The biggest news was one of our members just sent off her fabulous fantasy novel to a big publisher; she is trying to "come down" from that and get back to work on the second book of her trilogy-to-be. (Come to think of it, I was always a bag of nerves after I sent off a paper to a journal; I wonder how common that is.) Over the summer, another member finished his final version of a novel he's written, so I get to look at that starting next week. And our other member has several novels in various stages of completion.

As for me, they thought I shouldn't think about turning the blog into a book for at least several months, that I should get some distance from it. Which means, of course, they think I should go back to working on the mystery novel I had been writing before the accident. So now I have some inertia to overcome – when I last left the story I had declared the first rough draft done and had been within a couple of weeks of letting Gary see it (this being just days before the accident), but I still considered it quite a mess; the worst problem being the characters not quite "jelled," a relatively minor problem being scenes needing to be majorly filled in.

Now, if I could just find a pen in this house . . . ;-)

Here on the blog I inserted a picture of why I am having difficulty with this task.

(Okay, I cheated. This was the family room before the math volunteers made their best guess at where this stuff belonged and neatly arranged it in the various rooms. Doesn't mean I know where they put the pens, though ;-) Maybe this would be a good time to start in on my newly arrived Remington Steele Season 4 and 5 DVDs. Just for the inspiration, of course.)

August 19, 2006

Last night Gary proposed that we try out the roll-in shower this morning. All week he's been saying we should try it out, to which I would reply a neutral "uh-huh" – after all, doing that takes a lot longer than doing the bed bath, at this point adding about an hour to our routine. Besides, I suspect he just wants to have the shower so he can get breakfast in bed first ;-) (he says he needs the energy for the extra effort). This morning as he rolled into the bathroom, he said he was excited to be trying out Joe's beautifully designed shower (we think it deserves to be photographed for a magazine).

Since the set-up of the shower is different than Shepherd's and Gary couldn't get his chair angled quite the same way, we ended up using the transfer board to get him onto the shower bench, so as to make sure he didn't land on the brake lock of the wheelchair. Everything went fine, though he passed on trying to wash his own lower legs and feet (because he would have to sit near the edge of the slippery shower bench, then grab a leg as he leaned backward on the bench; even with me right there he didn't feel like trying it). Afterwards, he said the shower felt great.

After breakfast, he called our former housecleaner, who had said she would work for us when we got back. But it turned out that she just recently took on a different job. So now we have to hunt for another cleaning person, and we are not looking forward to that, given our past experiences at it.

Our outing for the day was to Kroger. When we got back, Gary found an email from his primary physician. She told him that after seeing him yesterday, she had been inspired to write a letter to our local state senator, whom she apparently knows, asking him to use his influence to get a stoplight put at the intersection where Gary's injury took place. I hope the senator pursues it.

My leg has been acting up since coming home, so yesterday I decided I couldn't wait any longer: I called one of the massage therapists I see, and he agreed to come out to the house today, so I indulged in a massage this afternoon. The drive back from Atlanta aggravated my leg, I know, and I think the fact that I have been doing more sitting since being home may have worsened it too – I barely sat at all while in Birmingham and at Shepherd. My brother previously mentioned to me that the mattress in the small bedroom where I'm sleeping is deteriorated, so I've put some memory foam on it to see if that makes a difference to my leg; if I don't notice a difference in the next couple days, I'll have to look into buying a new mattress.

Gary talked to Donne and Phyllis in the evening. Donne teased Gary about having it easy, what with his six hours of leisure per day. Gary remarked that he only had that if things like grocery shopping and paying bills counted as leisure (we still haven't turned on the TV yet!).

All for today.

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"Any fact facing us is not as important as our attitude toward it, for that determines our success or failure."

...Norman Vincent Peale

August 20, 2006

Today's exciting adventure was to try to get out of the house the damn little ground squirrel that one of the cats dragged in before or on the day of our arrival home. This morning I saw it run from the cat food bowls back into the storage room erstwhile dining room, but I have no hope in finding it there. This afternoon I saw it in the poinsettia plant on the stand in the kitchenette. I closed the doors to the dining room and to the family room, stuffed towels under those doors, and then wondered what the heck to do. I called to Gary, and he came out and suggested I put a big box in the kitchen doorway to hopefully block the critter from going in there (I thought surely it would just leap over the box, but Gary thought it would be dissuaded). The only exit now seemed to be the side entrance to the house. Gary stayed by the kitchen door, and told me to go get the little beastie. Ri-i-i-ght. I poked at the poinsettia with a broom handle, and the thing came flying. I just about went flying too. It ran back toward the family room and storage room, right past Gary, me batting at it with the broom while trying to stay as far away from it as possible, hoping to get it to take the clear exit out the side door. But it kept circling back to the closed doors. Stupid thing. It dove under the towel blocking the storage room, and Gary told me he could just pick it up in the towel. Ri-i-i-ght. Here is a man who can't keep his balance, and he is going to lean over, pick up the animal, and, keeping it in the towel, wheel over to the door with it? Needless to say, the thing didn't stay still enough for him to put his hands on it (thank God). He told me *I* could pick it up in the towel. Ri-i-i-ght. I did a lot of hesitating (and as you know, she who hesitates is lost), wondering why I was taking the trapping advice of a man who some years back saw something fly into the chimney, reached out and grabbed it, and got bit by a bat.

At one point I thought I had enough toweling between my precious flesh and the varmint, so on my hands and knees I shuffled the towel along the floor to the side exit then shoved the towel out the door. Nothing. I went outside and picked up the edge of the towel and threw it away from me while at the same time executing a graceful leap backwards. No wild thing put in an appearance (well, other than me). So I guess it had managed to crawl under the towel under the door to the storage room before I ever got a start on moving the towel.

Sigh.

I managed to move the stand with the poinsettia to just outside the side exit doorway. I can always hope the little monstrosity will decide it needs a poinsettia treat bad enough to go out there, and then discover the freedom of the outdoors. . . . With our luck, it's probably decided it would prefer to be our pet. . . .

Yup. Hours later, I saw the thing back at the cat food bowls. So I put the bowls outside next to the poinsettia. Hopefully we won't be feeding everything in the neighborhood!

On a different topic, Gary watched the first DVD sent by Donne and Phyllis of the Alaska trip. He says the pics are really nice! I looked through the CD that Janet Rogers brought over of all the photos taken of the house and the volunteers by her and Jo. Very interesting, seeing the house go through its various stages, but my favorite part was looking at all the "action shots" of the volunteers. :-)

This evening Gary opened package number five from Norma: mementos of Sitka, Alaska – postcards and a package of Alaskan Smoked Salmon. Norma and Bob went on a Sea Otter and Wildlife Quest there, and saw sea otters, humpback whales, bald eagles, and a brown bear. The others of the family went kayaking (Gary saw Donne's and Phyllis's pictures of that on the DVD!).

August 21, 2006

Today Gary had another rehab session. The therapist had him do the same exercises as before, with the addition of lat pulldowns. She also told him to start incorporating those scapula extensions that the PT at Shepherd had told him to do (and which he had been doing haphazardly), telling him to do at least ten repetitions every time he did a depression weight shift (she then had him do three sets of ten – that's the exercise where after you lift your seated body up by your hands, you do the extra "push-down" of the shoulders). The therapist told him that it would be by developing the muscles used in this exercise that he would get the extra inch or so of lift he needs in order to do his transfers independently. She emphasized that that was what was going to make the difference between he himself doing the transfers without a board and me having to be there with him, so I think he'll now be more diligent at that exercise.

Oh, and there was one more exercise. As we were driving away from the rehab place, I said to Gary that I didn't know if he'd noticed, but I have been trying to drive less jerky, as he claims I do (and I reject that notion ;-)). He said it was all right, that my driving gave him balance practice. Hmm. Maybe they should incorporate that at Shepherd ;-).

We went to the courthouse and waited in line to get a handicapped placard; it looked like it was going to take forever, but the office had mercy on all of us waiting in the line and let the people simply renewing their tags go to a different line. So now we've got our placard, which will really help with the parking – up to now, at Kroger's, for example, we've been parking rather far away from the entrance in order to get a space with an empty space next to it that we hope will remain empty until after our return to the car, so Gary has room for his transfers. The placard should also make parking at the university easy, because there are several handicap parking spots very near where Gary would enter the building to go to the math department. That was certainly the case today – we went to the math department from the courthouse, and found such a parking spot.

Like last Wednesday, Gary found his time in the math department today very energizing. He says he so appreciates just having the ability to go there, and to see the people in the department. Speaking of whom, Michel, Jack Brown, and Ed Slaminka dropped by. Gary's computer monitor wasn't working correctly, and Michel told him he was getting him a flat monitor, so as to make more room on his desk. Jack and Ed went off to find a replacement for now, and Ed carried it in. Ed then spent time encouraging Gary to go with him to the golf course soon. :-)

Michel asked Gary if he'd be interested in doing a directed reading in the history of math with a student, and after asking me whether I thought that would be okay (the concern being his level of energy), Gary said sure – he likes teaching history of math.

After a couple hours we headed back home. On our answering machine we got the message from our supplier that insurance won't pay for the power-assist wheels. We will pay for them out-of-pocket.

In the mail we got another anniversary card from Mom G. This one with a check. Woo-hoo! My mom also sent us a check, so now we're rolling in the dough ;-)

Gary opened package number six from Norma. This one pertained to Hoonah, Alaska. There was a pocket calender entitled "The animals of Alaska," a postcard of Icy Strait Point, and a ceremonial cedar chip – the chips are evidently traditionally added to the fire at Campfire Point by all visitors to the Strait. Norma said the highlight of the day was seeing a pod of orca whales swimming through the strait.

In preparation for our evening routine, Gary did a transfer using the board while I just supervised. We had talked to the OT this morning about the fact that Gary wants to do this kind of transfer (with the board) unsupervised; he thought that if he practiced it a day or two with me watching, and he did the transfers well, that he could do that kind of transfer with me not around. I wasn't comfortable with a day or two – I thought a week (at the minimum, but I didn't say that, because I figured he'd never agree to more than that!). The OT said it was whatever we were comfortable with, but thought it should be more than a day or two. She thought he should try it often enough with me just supervising so that various situations arose and were handled. Like, what if the board slipped slightly (which it sometimes does, maybe because he doesn't get enough height and sort of takes it with him), would he be able to handle that?

So, our plan is for him to use the board at least a couple times a day with me just supervising, until we're both comfortable with him trying it unsupervised (or at least as comfortable as I'm going to get – anyone have a periscope I can borrow?). That way, if there's some time like in the afternoon that he wants to take a nap and I'm off to writing group or something, he can just get himself in and out of the bed.

But the rest of the times he does the transfers, we'll stick to the way we've been doing it, without the board, since he won't learn to take those big hops without the board without lots of practice at them (not only do the therapists not want him becoming dependent on the extra piece of equipment of the board, but some transfers, like those between surfaces of different height, especially where the difference is great, are not possible to do independently with a board).

All for today.

August 22, 2006

Today I tried a chiropractor different from the one I had been seeing just before the accident. He was recommended to me by two massage therapists I've seen, though one of them commented that I could just ignore the spiel I would be given, that the results were good. The chiropractor did give me his spiel, and he asked me if I followed the theory. I smiled and told him "the proof is in the pudding." (Bold of me, yes? :-) I've heard too many theories in my time.)

We'll see how it goes. Despite the theorizing, the actual adjustment was the same as what the other chiropractors did.

When I got back to the house, the garage people were doing more painting. I had been thinking of asking one of them to open a window in the kitchennete to see if the ground squirrel could be persuaded to leave by it – when I had chased the thing out of the poinsettia, it had kept on trying to crash through that closed window instead of going through the open door; I had tried to open the window then, but it was painted shut. While I was at the chiropractor, Joe had called and left a message on my cell phone. He suggested opening a window in the storage room/dining room where the critter had taken up residence (there was a "duh" moment – I hadn't thought of that).

Anyway, I wasn't actually sure the beastie was still in the house – I was hoping my poinsettia/cat food trick had lured it outdoors. I went into the storage room to see if I could open that window myself before asking the manly men to do it. As I went to the window, something shot past me, and I nearly shot through the roof – yes, it was still in there. So I got one of the garage guys to open the windows in both those rooms. I hope this works.

After lunch, Gary and I went to a couple furniture stores so I could test out some mattresses. I. am. so. confused :-(. I laid on some awhile, and though I could tell differences, I wasn't sure what I would actually like to sleep on (and I didn't think the salesman would let me sleep there overnight to test out the mattresses). The stores we went to had Serta mattresses, and when we got home Gary looked up reviews of these mattresses and found they said that after a few months Sertas form "troughs." Sigh. So I've gotten nowhere on that.

After the furniture stores, (well, after the ice cream stop Gary insisted on after the furniture stores ;-)) we went to a pharmacy where Gary hoped to get his prescription supplies. The store's handicapped parking spot was designed for the handicapped person to get out on the driver's side – there was a ramp to the building on the left side of the spot, which forced me to park on the right side of the spot, which meant there was no room for me to put Gary's wheelchair between our car and a neighboring car, should there be one there, which fortunately there wasn't. I just thought that spot oddly designed. Later, on our way out of the store, I was letting Gary get the door himself when a woman came from behind us and, noting I had my hands full of packages, asked if she could help get the door. We told her, no, that Gary was practicing. She said I was lucky, that her husband was in a wheelchair and he wouldn't do anything for himself. She sounded very beleaguered. Gary and I told her she should show her husband some tough love.

It turned out the pharmacy didn't carry the prescription supplies Gary needed, and rather than order them for him (as Gary's physician had thought they would), they sent us to a medical supply place (too bad we hadn't known that beforehand, as the place was on the other side of town back where the furniture stores were). It took about an hour to set up an account and for them to find in the order book the supplies Gary needed, but now that that's done his order will automatically be put through every month (though if he needs to make any changes, he can call in a week before the order is sent out).

We were both pooped after this. For me, it was both due to the actual shopping – I hate shopping, and most especially when it's unproductive – and due to the fact that I had had to take Gary's forty pound wheelchair apart and pick it up and put it in the car, and take it out of the car and put it together ten times in three hours on this very hot day (almost made me wish we had a van already). For Gary, it was the heat, the extended outing, and the ten transfers.

Not entirely unrelated, Gary decided to not get the power-assist wheels at this point in time. Transfers are non-trivial right now, and if he were to want the wheels on his chair, say to go to a graduate council meeting across campus, he'd have to get someone to help him transfer to an office chair or something, then change the wheels for him, most likely, because they are twenty-some pounds apiece, then help him transfer back into the wheelchair; then he'd toodle across campus. It'll be less of a rigamarole when his transfers are better. He said for now he'd just get someone to drive him, but I told him I had seen a bus on campus with a handicapped symbol that seemed to indicate the bus had a lift, and I thought maybe he could use that to get to such meetings. He is going to look into that.

In the evening, Gary opened package number six from Norma. It contained a postcard of beautiful Hubbard Glacier and a little box containing a genuine Tip of the Iceberg (well, that's what it says). And don't worry, Norma, though Gary is sorry he couldn't make the trip, he is enjoying getting these gifts – they don't make him feel sad. He thinks you all did a wonderful job of putting together these little surprises for him, and he is very touched by it.

August 23, 2006

Oops, correction to yesterday: Hubbard Glacier was the topic of package number seven.

Today Gary had another therapy session, and again we all started off with the various kinds of wrist curls. For some reason Gary's left wrist has started bothering him, so he had to skip the regular curls on that hand. Naturally nobody but me could keep track of the repetitions, and the therapist asked Gary if she could borrow me to count repetitions for all her clients. I think not!

After the curls, she had him do what she called wheelchair pushups and which the Shepherd person had called scapula extensions. She said she could tell he was stronger at them already! He did thirty of them, then held that position while doing a weight shift.

Next he went to the cable machine, and she had him do some cross-cable work: while sitting sideways to the machine, he pulled the cable down and across his body with the arm nearest the machine for thirty reps (targeting the shoulder flexors), then pulled the cable down and out with his far arm, twisting his neck and head with each rep (targeting shoulder extensors). Ten reps with the weaker, left shoulder; fifteen with the right.

Next came punches using the cable machine – he added another plate on that exercise to what he could do with his right arm on Monday, and in fact even a second plate, though he had to cut the reps from thirty down to twelve for that set.

Lastly came seated rows, thirty reps.

After the session, I stopped at Paneera's to get Gary a sandwich, and then I took him to the university. After we did the transfer out of the car, he toodled off by himself. Yes, I really let him out of my sight unaccompanied (well, okay, I surreptitiously backed up the car in order to see that he made it safely inside the building). I was dismayed, however, to learn as he got out of the car that he'd forgotten to bring his cell phone (so I smacked him with the chicken fat ;-)). True, he didn't plan to go anywhere but the math building, but still . . . .

We had a little discussion about the cell phone before bedtime, too, similar to one we had a previous night. Gary doesn't see the need for him to have the phone by his bed at night since he has the walkie-talkie link to me, and tonight he pointed out that the reason he'd forgotten to bring the cell phone to the math dept. was because it was on the bedtable, not in his fanny pack. I, however, want him to have the phone at bedside in case there was an emergency and something happened to the walkie-talkie so he couldn't reach me, or in case something happened to me – then he'd be stuck in bed, unable to help. He said he could get out of the bed in an emergency by using the transfer board, and I said that he'd also have to take down the bed rails, which he's never done, and by the time he did all this and made it to the phone it could be too late for me. He said what were the odds of that, and I replied with what had been the odds that he'd be in a bad car accident. He still wasn't convinced, but he accepted my solution of keeping the cell phone in his fanny pack but putting the fanny pack on his wheelchair, which we keep next to the bed.

When I picked Gary up at the math dept., he told me that the day had gone well. He gave the seminar in Topology, and he'd really enjoyed it – said he hadn't been nervous at all. He'd thought he was going to have to use transparencies on an overhead projector, but it turned out he could reach high enough to use the board. The only "mishap" occurred when he dropped the chalk. Someone got up to retrieve it for him, but Gary said that he could get it himself, that he's had plenty of practice in picking up things he's dropped ;-). Actually, at first picking up things from the floor wasn't easy for him to do, but he says now it is – unless what he's dropped is heavy, of course, or if he drops it on the footplate of the wheelchair; since he's not allowed to bend forward, he can't retrieve such an item. But anything of reasonable weight that he can wheel up to sideways, he can get off the floor.

Meanwhile, while he was at the office, I went home and held an intelligent conversation with the electrician who was working in the garage. "Are you having sheet rock put in the garage?" he asked. "I don't know," I replied. "Where is the electrical pipe buried?" he asked. "I don't know," I replied. I called Joe, twice, for the answers, finally turning the phone over to the electrician so the two of them could converse.

I also called the hotel in Birmingham where I'd stayed and asked them what kind of mattress they use. Turns out it is custom-made for them, and available to the public. I haven't checked on the price yet, but that may be a possibility – I had thought the mattress very comfortable.

I also did things like my exercise program, and a little organizing, and a little revising of my mystery story. Very little. I may have to have my critique group kick me in the butt so I can quit procrastinating on that. Part of me feels I've earned a little goof-off time ("Things have been a little intense these past four months," she understates), the other part thinks I'd do better to get back into it.

Gary opened Alaska package number eight tonight: Anchorage. There the family went on what nephew David called the easiest hike in Alaska – and which Norma said she thought was the toughest hike she'd ever been on. She said she wished she had eaten an energy bar beforehand. I guess that is why today's package contained an Alaskan chocolate bar ;-). She also sent along a Alaska Bald Eagle bookmark, which Gary gave to me – hope you guys don't mind ;-)

Well, that's it for today, except to answer someone's question as to what a ground squirrel is: a small striped semiterrestrial eastern American squirrel with cheek pouches, according to a dictionary. I haven't heard the little critter today, so I'm hoping it went out the window.

August 24, 2006

This morning Janet Rogers came over to help sort through some boxes in the dining/storage room – the math volunteers had had to get everything out of the back rooms on short notice when the people came to lay the floors, and things had been put into boxes placed in the storage room and upstairs. No ground squirrel ran out of that room, so we're hoping that means it found its way out the window.

After I paid another visit to the chiropractor, I stopped into the health food store – and ran into my long-time massage therapist! She has been traveling these past few weeks (I'm assuming that's with the swim team) but will be back in town to give me a massage next Tuesday – I am so looking forward to that. I also talked for a short time with one of the workers in the store; both he and my massage therapist sent their best wishes to Gary and said we've been on their minds.

Our "big" news of the day is Blackjack didn't shoot off the couch and out the cat door when Gary rolled up in the wheelchair to pet him. We'd been wondering just how long it was going take before this cat would allow Gary to get near him in the chair. Gary has hardly gotten to pet Blackjack at all, because the cat also won't stay for long on the hospital bed when I bring him over to Gary for petting. Tigger usually doesn't stick around when Gary wheels by in the chair, either, but he still likes to get up in the bed when Gary and I are going through the evening routine, though he's not there as often as he was when we first got home – I guess we're being taken for granted, again ;-).

Gary opened package number nine tonight: a postcard of Matanuska Glacier and a carved moose. Near the glacier, his family rafted through thirty-five degree water, which Norma said you could feel through your layers of clothes and wet suit when the spray hit you (Brrr!). She said that while rafting they saw a mother moose and its calf.

Tomorrow our ad appears in the paper for housecleaning. No doubt we'll again get about a hundred calls. We're not looking forward to the process of choosing someone to clean the house.

August 25, 2006

Last night Gary discovered a few of his pepper plants, which had been moved to behind the garage (we were probably told they were there, but it slipped our minds). They were rather parched, so I watered them – the tabasco plant now once again looks impressive, with its tiny red and green peppers. I also discovered three rosemary plants back there, so have put those on the patio – otherwise, out of my sight, out of my mind (no comments, please ;-)).

This morning I shot awake about five, dreaming that I'd heard our smoke alarm go off and our house was on fire. I got up to check, but everything was fine. At six-fifteen, I woke again, again thinking I heard the beeping. I got up. Nothing. A little after eight, I heard a beep again. But it wasn't coming from the hallway where the smoke alarm is, so I was totally confused. Gary, with his hearing loss, heard none of these beeps. I checked the house again. Again nothing.

Just before we left to go to Gary's therapy session this morning, the garage people pulled into the driveway, blocking my car. I told them I needed to leave, and a man said he'd move the car – then he introduced himself as the owner of the company putting up the garage. He told us they were putting in a drain on the opposite side of the garage from the one they'd already put in, and that after that they'd backfill and top with pea gravel all the ground that had gotten torn up (it turned out they ran out of gravel and will finish that next week).

The therapy session consisted of the same exercises as last time – Gary was able to add another plate to some of the cable exercises! The therapist also made some leg bands for Gary (circles of a cloth-covered foam, held together with velcro) to take home. These he can fasten around his lower thighs and grab onto them to help him maneuver his legs while he's on his back – he wouldn't need to use them in a double bed because he would have room to roll onto his side and then he can grab a leg and pull, but in the hospital bed there is no room for him to roll. (You remember I told you what he has to do to roll, right? Swing his arms from one side to the other, his head and trunk following the motion, until he gains enough momentum to roll? If he tried that in the hospital bed, he'd roll right off it.)

After therapy, we went to the university and got Gary's keys to his office from the Access Control office. I tried to get the keys just by showing Gary's ID, but of course that didn't work. When I explained that Gary used a wheelchair and that I would have to put it together to get Gary into the building (not to mention that I'd have to help Gary transfer both ways and take the chair apart again, all for the few minutes required to get the key), the man immediately agreed to come out to the car to get Gary's signature and hand him the key. After getting the key, we went to the math department, and I left Gary there for the day – and I didn't even stick around to watch him go up the ramp ;-).

I went back to the house to discover the garage people still there, including the business owner. The shingles were being put on the garage, the cement around the garage was being hosed down (to get rid of all that southern red clay that had gotten smeared over it these past weeks from the ground being dug up), and dead branches from a tree in the driveway that someone had obviously parked too close to earlier in the summer were being trimmed away. The owner asked if I'd like the branches of trees lining the driveway and those overhanging the garage to be trimmed as well, and I said sure :-). A little later, my doorbell rang, and the owner presented me with a large basket of candy, saying he appreciated our business. He then said how much he thought of my brother, saying there weren't enough people in the world like him, that he was a man of few words but had a big heart.

Indeed.

I went into the diningroom/storage room to get something, and "guess who" scooted past me. Damn, the thing is still in there. I suppose one of those "Hav-A-Heart" traps is next. Stupid cats aren't interested in the critters once they've brought them into the house.

Before leaving for my writers group meeting, I noticed that the messages on our phone read "full." I didn't bother listening to any – finding a housekeeper is Gary's job ;-). After my meeting I picked Gary up. He told me he'd had lunch about a block down the pedestrian walkway in front of the math building – at Einstein's Bagels. He's not sure how he'll maneuver in there if it gets crowded – I can't think of the name for it, but like there are at airports, they have a roped-off corridor that one has to follow to get to the counter, and it's too narrow for his wheelchair; since the place wasn't crowded at the time he went, though, he could go straight up to the counter.

He said he'd had a good day, but it was a little tiring. He showed me a couple of postcards he'd gotten from Toposym – the Topology conference in Prague – from people sending their good wishes for his continued recovery. I counted eighty-one signatures. :-)

When we got home, we discovered more cards to the two of us – from his mom, my mom, and Gary's brother Bob. I got birthday checks from both my mom and his, so now I'm really raking it in ;-). Thanks for the very nice cards, moms, and no, Mom G, Gary will not be making me a spaghetti dinner for my birthday ;-).

Gary opened package number ten this evening: from the Flightseeing trip over Mt. McKinley. There were a couple postcards, a brochure of the flight, and a little pin commemorating it. Norma said she thought the flight was the most awesome thing she'd ever done, and thanked Gary for suggesting it be part of the trip.

About eight p.m., just as we were going to start our evening routine, I heard three beeps and told Gary about them. He wheeled out into the family room, and at about eight-fifteen, a single beep sounded again – this time he heard it. But he agreed it wasn't coming from where the smoke alarm was. On the off-chance the Rogers might know something about it (I recalled that Jack had put in a new smoke alarm for us), I called them. They returned the call shortly, and Janet suggested it might be the old alarm beeping, indicating the battery was low. Fortunately she knew where the old alarm was (otherwise I would have gone nuts ;-)), and Gary was able to open the back of it and take out the old battery. Hopefully that solves the problem. (Gary said he was glad the Rogers thought of this and knew where the old smoke alarm was, as otherwise, he was sure, knowing me, I wouldn't have slept at all but lay there listening for the next beep; he is undoubtedly right ;-).)

All for tonight.

August 26, 2006

Either it wasn't the old smoke alarm, or at 5am I was dreaming I heard beeping. I tend to think it was the latter, and hope it was, as I haven't heard the beeping throughout the rest of the day. (And if you don't know what I am talking about, read yesterday's entry.)

Displaying more energy than a person has a right to ;-), Janet Rogers came over this morning and helped me (or more accurately, I helped her), go through more boxes in the dining room. Progress is visible in the room. We filled up the large garbage can, plus Janet hauled at least a couple wagon-fulls of garbage down to the curb, plus she filled a recycling bin with glass jars. At one point as we worked in the room, the little beastie scurried by, so now I have an eyewitness that it still dwells among us. We didn't see which way it went, but Janet opened the window in that room again (that task wasn't easy!) and I opened the doors in the family room, in faint hope that the thing would take the hint. Our low expectations were met: late in the afternoon, Gary wheeled back to the bedroom, and moments later I saw the critter scamper in the other direction past the family room – I'm sure it went back to the dining room.

Janet pointed out a few possible water problems. Water is standing in the drain the garage people recently put in. I don't think it has rained recently, so I don't know what that would be from; I'm a little worried about mosquitoes finding it to their liking. Also, the threshold to the side entrance of our house seemed wet, and we can't figure out why – the garage people put some kind of sealant there. Finally, there seemed to be water standing under the sink. I don't know if these occurrences are related.

While Janet and I worked on sorting, there was a flower delivery: a vase of sunflowers from Gary for my birthday – unique and pretty (the flowers, I mean. Well, Gary too ;-)). Interestingly, the delivery man from the flower shop grew these sunflowers on his nearby farm! See the blog for a picture of them. I got a message on the answering machine from another flower shop that they had a delivery for me, but I didn't hear the message until too late, so I guess it will remain a mystery until Monday to find out what else I was sent and from whom.

After Janet left, I was ready for a nap ;-), but it was not to be. After lunch Gary and I needed to go to the grocery store and the health food store. I did take out time for relaxation after that (okay, I admit it – I watched part of a Remington Steele episode).

In checking my email, I found out the Prague postcards were instigated by Peter Nyikos. Thanks, Peter. Peter also left comments on the blog about travel to Prague and accessibility. You can see his comments by going to the August 7th or 9th entries.

Gary cut his hair this afternoon, and he asked me to finish up the back of it. I thought he surely was joking, but he wasn't. He promised not to move ;-). I suppose it doesn't look as bad as the last time I cut it ;-) but if this keeps up I'm going to have to find a book or something that tells how to shape the back of a man's hair – or maybe I should just go around and stare at some napes.

Before starting our evening routine, Gary transferred to the bed using the board, me just supervising. He's been doing this since last Monday, and it has gone well. He said he thought he was ready to do this without me being in the room, like if he wants to take a nap. I reminded him that he that isn't all there is to it – he hasn't been practicing what comes after the transfer. To begin with, lately he hasn't been practicing getting his own legs up on the bed. And what about his shoes, I asked him. Is he going to take his own shoes off? If so, how (he hasn't done that in bed before, and he'll need to leave them on until after the transfer). If he thinks he wants to leave his shoes on during the nap, we need to test that it's all right now for him to do so – at Shepherd they had him take his shoes off when he was lying on some surface because he was getting red spots (pressure sores) on his feet when he left them on.

He also would have to position and pad himself off properly once in the bed, and he hasn't practiced that in this sort of situation; it would probably mean he'd need to keep the far bed rail on so he can use that to prop a pillow against his back to keep his hip up and the pressure off his sacrum.

He admitted he hadn't thought about all the rest of this stuff, and that by the time he accomplished all of that, he might not be in the mood to take a nap!

So, anyway, tonight after he transferred and I mentioned all this, I put the leg bands on him (if alone, he'd have to do that himself in his chair) to see if they'd be of some help to him to get his legs up. They were – the goal is to get his legs up without their help, of course, but for now they make the job easier.

He was too tired to practice the rest of it tonight, though, so then we just went into our regular routine.

August 27, 2006

No beeping, so I think we've got that problem solved, thanks to the Rogers!

I haven't had to help Gary with his bowel program for several weeks now, but I did this morning. Remember how I told you theoretically it takes about twenty minutes? Well, evidently that's when you don't have flap restrictions and can do it sitting up and use gravity to your advantage – Gary typically takes a half hour, though one time it took fifty minutes. It took an hour and a half this morning, though I only had to help the last twenty minutes or so (ready for some bathroom humor? How did the mathematician treat his constipation? He worked it out with a pencil.) "By the way, Happy Birthday," Gary said during the procedure. "Gee, thanks, what a present," I replied. We both started laughing. Then he asked me to bring him breakfast in bed because he wanted to do a wet run. I told him something was wrong with this picture ;-).

Breakfast finished, we did the wet run. For the first time, Gary transferred to and from the shower bench using the transfer board and me just supervising. That went fine, but we haven't figured out what he would do with the wheelchair if he were to try to shower on his own (which won't be for some time, though); he would need to push it out of the way so it wouldn't get wet, but not so far that he couldn't get it back to him; maybe the OT when she comes to our house, as she's said she would, will have some suggestions.

It still takes a lot of effort for him to shower, so I helped him with it, doing a little bit more than usual, actually – we were expecting someone to come for a housekeeping interview at 11, and it looked like we were going to be cutting it close (that person never showed up).

Instead of him transferring back to the bed after the shower, he stayed in the chair and I dressed his flap and got his t.e.d. hose and pants on him that way, him helping. I don't think it took any more time, and it saved us a couple transfers, so that was good to learn. After this, I half-joked I needed a nap now. He said, "Poor pookie – you can write on your blog how much fun you had on the morning of your birthday." ;-)

I heard the answering machine go off, and I recognized my sister Janet's and brother-in-law John's voices singing Happy Birthday, so I picked up. We talked for a time, and I found out it was they who had sent the flowers I had missed delivery of yesterday – I'll look forward to getting them tomorrow, and also to something from my mom, which Janet said was also coming.

Janet said she was amazed Gary was back at work already. She then pointed out that the fact that he was was due to me as well as him; I hadn't thought about it quite that way, so that made me feel good. Janet and John then talked to Gary for a bit.

After the call, Gary handed me a letter he had written for me a couple weeks back and had saved until now, the gist of it being what it means to him how I have devoted myself to seeing that he gets back to as much of a normal life as possible, and that he knew before the accident that I loved him but he hadn't realized how much and he hoped to repay me in some way (adding, without me having an accident or something too of course!). The letter made me cry.

(He also told me he bought me some pairs of drawstring cargo pants, which are what I wanted, and that he would buy me a new mattress when I decide what one I want.)

Janet Rogers came over with a Hav-A-Heart trap that John Hinrichsen had found in his attic (and may belong to Donna Bennett). She also brought some sunflower seeds and showed me how to set the trap -- let's hope the beastie goes for it.

Two people came for housekeeping interviews in the afternoon; they both seemed promising, but we've made no decision yet.

Later in the afternoon, Gary smiled prettily and asked me if I wanted to take him out for ice cream for my birthday. I gave him a look. "Remember, this is a day for you," he said. "YOU got to help me with my bowel program, YOU got to help me take a shower, YOU got to bring me breakfast in bed, YOU get to take me out for ice cream, and YOU get to make me dinner." Funny guy.

(He did note that he would have taken me out somewhere had that made sense, and he did choose something simple – pasta – for dinner, and made his own salad.)

Joe and Dolores called just at that time, so we talked for a while about mattresses and chipmunks and drains and this and that, and then I took Gary out for ice cream.

In the evening, my little sister Di called – so again I got Happy Birthday sung to me. After we talked for awhile and as we made to end the call, she told me to go do something I enjoyed. I told her it was time to go and help Gary stretch. "Do it joyfully," she said. We laughed.

So, anyway, that's what I now plan to do. And later, after I help Gary prone, because I get up later than he does, I will joyfully watch a little Remington Steele before going to bed.

Thanks to those of you who sent me birthday greetings!

August 28, 2006

Well, sister Janet and brother-in-law John, that has to be the most unusual flower arrangement I've ever seen, let alone gotten – a flower cake! Wow, that is really something, thank you so much! (Gary, however, was hoping there really was a cake under the flowers.) Everyone else, see the blog for a picture of it. And mom, thank you for the stuffed animal (blue-footed booby bird) from the World Wildlife Association and for all the mementos and pictures of my childhood – it was fun looking at the snaps of me from babyhood through high school. And Laura, thank you for your postcard from Sweden.

This morning Gary had a therapy session. The therapist asked him what was new, and he told her that for the first time he'd made it through the rehab place's door without my help :-), which was true – it's probably the hardest door he's ever encountered. (It was kind of funny in an ironic way last week when we told her about shopping for mattresses and going to drug stores and so forth, she had asked if he'd had any accessibility problems anywhere, and he'd said, "Yeah, getting into here." The ramp that they have in front of the building doesn't level off at the top, so Gary has to get up it and take an immediate left while it is still sloping, and then at the entrance to the rehab place they have this really heavy door that slams shut the moment you let go of it; plus the sidewalk slopes slightly backward in front of the door, so he can't let go of his wheels to grab the door or otherwise he'd roll backwards.)

I told the therapist that it was also new that yesterday he'd done his first-ever transfer to the shower bench with me only supervising, but that we had a question about what he would do with his wheelchair when he gets to the point where he can take a shower alone. After talking about this for a while, and after he and I transferred him to the exercise mat not from our usual position but from the angle we would take if the mat were a shower bench and then he and the therapist maneuvering the chair about as if he were in the shower, we came up with a plan A and a plan B. Plan A is that if there is room for him to maneuver the chair just slightly to the side, we could hang another shower curtain perpendicular to the one that is in there and Gary would pull that between the shower bench and his wheelchair (the hope being that that would keep his chair dry). If that doesn't work, plan B is to push the chair forward out of the shower area and to have some kind of rope on it so Gary can reel it back in after the shower. If it can be accomplished, Plan A would be easier (plan B would also involve having to maneuver the chair so he can unlock both brakes after his transfer to the bench in addition to pushing the chair forward and pulling it back). We will have to test that.

Gary's shoulders were feeling good this morning, and he was again able to add weight to some of his cable exercises! He did great, and the therapist said he looked noticeably stronger. I hope his shoulders continue to improve (I'm speaking specifically with regard to the arthritis, tendinitis).

After therapy, we stopped at a place where I picked up a stability ball for my exercise routine (I started back on that last week and I intend to continue doing it three times per week). Then we stopped at the grocery store where I got sushi for Gary's lunch, and then I dropped him off at the university, where he stayed until five, meeting with a student and going to the Continuum Theory seminar.

When I got home after dropping Gary off, I found the beastie trap had been tripped, but no beastie. Darn. I wasn't absolutely sure if any sunflower seeds had been eaten, so I put cat food in there along with the sunflower seeds, to see if that would lure the thing. Hopefully I won't find Blackjack's head stuck in there tomorrow morning.

After I picked Gary up, we decided to ask one of yesterday's interviewees if she'd like the housecleaning job. She had impressed us with her interview, acting very professional. She said she'd take the job, so we're hoping this works out.

In the evening Gary opened package number twelve – a postcard of Alaska and a booklet, "Alaska, a Scenic Wonderland," with nice pictures. On the postcard Norma noted that she and Phyllis agreed that they could deal with being on a cruise for a long time, that there was something about being waited on hand and foot that really appealed to them.

I think it runs in the family.

JUST kidding, and I assume that you know that I am. Not that this is related ;-), but after I helped Gary transfer into bed tonight and he said he was tired and was just going to lay down (rather than work at getting his own legs up on the bed), I asked him when he was going to practice doing for himself the part after the transfer, since he was always too tired to do it at bedtime. I said I knew he wasn't being lazy but –

He broke in and finished the thought, saying, "but how will I ever learn if I don't practice, right?"

Then he said he knew he needed to practice, but at night when he was tired and because it was no simple matter to get his legs on the bed himself and when he had a nice wife who would do it for him the temptation was to just have me do it. I guess I could have displayed “tough love” right then, but I suggested we practice that part on non-therapy days early in the day when he was fresh, so that is what we’ll do for now until he is more proficient at it. Or until I get tougher ;-)

August 29, 2006

This morning when we looked at the wheelchair, both Gary and I noticed the cushion looked low in air. I never had to fill the cushion we had at Shepherd, and I have filled this one at least once a week, so we think there is something wrong with it and will contact our supplier. After Gary got in the chair, it slipped sideways on him, and looking at it we were frightened to see that either the wheel was coming loose or the wheel lock (brake) had slipped. We got Gary transferred back to the bed as soon as we could and figured out it was the wheel lock. Gary took a hammer to it, and that fixed it, at least temporarily.

Mechanical things continued to be our bane today. Whenever I apply the brakes on the car or turned a corner in it, I hear a squealing sound. Plus, water is flooding the floor of the car on the passenger side, coming from in front of where Gary’s feet would be. It is cool water, so Gary thinks it has to do with the AC. So I will have to take the car in to get it checked out. At least this car stuff has happened after getting back from Atlanta.

I talked with both the foreman of the “garage people” and the owner today, the latter person coming to the house. They again both said that Joe was wonderful to work with, the owner adding that we were blessed to have such a generous relative who postponed his own work to come out and help us out – and that we were also blessed to have such generous friends in the math department who gave of their time to aid us as well. Don’t we know it. We are also blessed to have connected – or re-connected – with so many people who sent us their good wishes and shows of support through their emails, cards, letters, and visits. I know I’ve said this before, but you really can’t say thanks too many times, can you?

In terms of work on the garage, the final inspection by the city was made today, and work will begin on building the breeze way between the garage and the house tomorrow (so Gary won’t ever get rained on). That is expected to be finished by Thursday. The owner also said he plans to clean off the cement of all the red clay that accumulated on it during the construction, and he will partially fill the drains with cement so the water level is raised to the level of the pipe and water doesn’t stand (and thus provide a breeding ground for mosquitoes).

In the afternoon, Gary asked me to come into the shower and see what I thought about “the curtain problem,” that is, how he would keep his chair dry if he were taking a shower alone. He parked his chair next to the shower bench, and then wheeled it in a way that would imitate what he would be able to do from the bench. We decided it would work to put in a curtain perpendicular to the existing one, but then I suggested he go ahead and make the transfer to the bench and manipulate the chair from there to see what he would really be able to do. He said it was a good thing I had suggested that, because it turned out the problem wasn't a problem. He was able to push the chair far enough out of the shower area that he could close the existing curtain on it, but the chair was close enough that he could reach it without any danger of overbalancing and bring it back to him.

Gary opened package number thirteen tonight, the last one except for a still-to-come video of the Flightseeing trip. I confess we're not sure what the little gift is – a replica of a moose antler perhaps? It does have carved moose on it, but for all we know it could be a replica of a whale's tooth.

The postcard included by Norma said she wanted Gary to know she thought of him the whole time during the trip, which made Gary cry. The thoughtful little packages you all put together for him touched him very much. Thank you.

August 30, 2006

Whoo boy, did I get a dirty look this morning from someone in the waiting room at the rehab place when I let Gary struggle to get the door open. She didn't seem at all mollified when I explained that Gary was practicing and that if he had wanted my help, he would have asked for it. Oh, well.

Gary did the same exercises as before plus a couple new ones, namely, reversing one of the cable exercises by pulling up and out, and walking his fingers up the side of a doorway to develop his range of motion. On one of the old exercises, rows, he was able to increase the weight by two plates! (Not because he is that much stronger, he says, but because his shoulders aren't bothering him.) Plus, no one had to hang on to his shoulders as he did the rowing exercise, indicating that he had better stability.

He talked to the therapist about some information he is supposed to get from his doctor for the university, information about what his limitations are for his job and what accommodations need to be made. He has no limitations regarding his duties, as far as any of us see, but in talking about his office situation, the therapist recommended he move down to the second floor of the math building, if possible (that is the lowest floor on which there are offices, at least for math people, I believe; the second floor is accessible by a ramp). The concern is that if the elevator would go out – as it occasionally has – he would be unable to get to his office, or from it if already in it, without someone bumping him up or down the stairs (and I'm afraid that someone isn't going to be me! It would have to be someone much stronger.). And in case of fire, he shouldn't use the elevator, so again, this would not be a good situation to be in. Fortunately, later in the day, Phil Zenor, whose office is on the second floor, reiterated his offer to change offices with Gary, and Gary took him up on it.

The garage people, who'd come about 8am, were still hard at work on the breezeway when I returned home after dropping Gary off at the office. Minutes after I arrived, Janet Rogers came, and soon after that Donna Bennett also came, and these gracious people helped me start in on the project of sorting the clothes that had been put into plastic bags (the vast majority of these clothes came, I believe, from a portable wardrobe that had been in the study before the new floor was put in there). I managed to throw away a bunch of old shoes and a couple bags of old clothes, and to collect a smaller bag of clothes that hopefully are in good enough condition for Goodwill. There is probably some more of the clothes I could throw/give away, but I haven't made myself do it yet; I'll have Gary look at what's left and see if he can persuade me to do so.

Janet figures the beastie has departed because none of the sunflower seeds outside the trap were disturbed. She got the window to the dining room closed (I was unable to do so!) so that the thing doesn't invite itself back in.

I left for a massage, leaving Janet and Donna to tidy up (oh, the guilt ;-)). It was great to once again get my massage from my long-time massage therapist. Thanks, Connie, you are good for my body and my soul, though as you probably would guess, I am wiped from the massage! (I told Gary you said to tell him that I was the best wife in the world ;-). Actually, that brought tears to his eyes and he said I was, and thanked me. At bedtime, as I got his pants off him, he patted me and said, "You're the best wife in the world, but you're nobody's missus." (I hate being called "Mrs." because it makes me feel like an appendage, so whenever anybody uses that title with me, I correct them and sometimes add, "I'm nobody's missus.") I asked him what had brought that to his mind, and he shrugged and said it was an interesting juxtaposition.)

After the massage I picked Gary up from a math meeting (since he was sitting right up front, I couldn't be too surreptitious about this!). When we got home I found Janet and Donna had finished clearing off shelves in one of the closets in the small bedroom and had even put some stacking racks in there so as to make it more usable for clothes storage. Blackjack seems to have survived the sorting ordeal – earlier in the afternoon I had seen him run on his belly into that bedroom to hide under the bed (he didn't go outside because the garage people were out there, and at the time he scrambled into the bedroom Janet and Donna were in the front part of the house so he probably thought he'd be "safe").

Oh, and Janet, remember how you said the back on the ergonomic "Balance Ball Chair" didn't look quite right? When I looked at the one owned by one of the massage therapists I realized I had put the back on backwards (hey, I was a set-theoretic topologist, not a geometric topologist ;-)).

After Norma told me in an email what yesterday's gift was, I felt like smacking my head, having had a vague feeling as I was writing yesterday's blog that I should know what the gift was. Norma explains: "The last gift that you opened is a scrimshaw (which is usually done on ivory or a whale's tooth) on a musk-ox horn. (A musk ox looks a little like a cross between a buffalo and a cow and apparently it is native to Alaska.)"

Tonight Gary viewed some of the Flightseeing images that Phyllis and Donne sent; he said it was quite impressive!

All for today.

August 31, 2006

Sending you to the blog?

I am not sure what to do about these emails now that Gary is out of rehab and the pace of change has slowed. I'm thinking I might continue keeping track of things that happen during the day at least for myself and putting that on the blog. But I'm not sure what I've been writing lately is worth cluttering up your inbox with on a daily basis ;-). If there is a "first" that happens, I'll send out an email notice of that, if you like. But otherwise, maybe you'd just prefer to check the blog if and when you feel like it?

If you would like to continue getting the daily updates by email rather than by going to the blog, please let me know, and I will continue sending them to you as I have been. Otherwise, see you in the blogosphere.

Thank you for your support.

The downside to Gary practicing only board transfers last week is he got out of practice at the depression transfers without the board, and it's been showing this week – he hasn't been getting the height and distance he had been; in fact, he tried one this afternoon with me just supervising, and he did one of those ones where he only got one butt cheek on the bed. I grabbed onto him and intentionally pulled him over sideways to make sure he didn't slip off the bed. As he lay there, me trying to figure out the best way to haul his legs onto the narrow bed and straighten his upper body without him falling off the edge, he suggested we go back to the transfers where I give him more help (either with my hands under his sitting bones or at his hips) until he does those consistently well before trying the ones where I only supervise. I'll bet you can guess I agreed to that!

When I left for the chiropractor, the garage people had already been hard at work for a couple hours. They were gone by the time I got back. I believe they have finished the breezeway except for painting it. They also cleaned off the red clay from the cement, and it looks really nice (now we and the kitties won't be tracking that stuff in!). The owner had told me he was going to fill the drain partway up with cement, but I see they put pea gravel in there. I don't know if they will cement it later or not – the owner had said cement would be better because it would give less chance for mosquitoes to breed in there, but maybe that decision didn't get to his crew.

After seeing the chiropractor, I took my car in. I got an oil change, new brake pads and rotors – whatever they are. At least there's no squealing. They told me they had fixed the water problem by cleaning the AC system – evidently all the leaves and stuff that I hadn't been cleaning off the front of the car around where the windshield wipers are had decayed and gotten into the system and clogged it. Oops. Well, I had other things on my mind.

Gary talked to someone in the engineering department of the city where Gary's accident took place, a guy who is supposed to have something to do with traffic lights being put up. The guy said a study had been done a year ago of the intersection where Gary's accident was, and it had been concluded that there wasn't enough traffic there to warrant a light being put up. Gary told me that didn't mean the quest is over, however, as he had heard that the mayor of the city wants a light there. Also, a developer of the property around the golf course out there is pushing for a light; Gary hasn't talked to him yet.

I spent several hours today critiquing a story by one of the members of my writing group. It felt good to do that again. On my own story, I haven't made it past the first ten pages in revising it. Something (or a certain someone ;-)) always seems to come up to distract me. Self-doubts creeping in don't help, either.

On the kittie-front, Blackjack has decided it's okay for Gary to wheel up to him to pet him when he is laying on the couch or futon. But he doesn't actively seek Gary out. Tigger still regularly comes up on the hospital bed when Gary and I go through our routine in the morning or night. He isn't pleased when I move him out of the way when Gary needs to turn over, however.

I had mentioned to Gary last night that I really didn't see much improvement in his flap the last couple weeks and that maybe he should prone some during the day, at least on the days when he doesn't have therapy, in order to take the pressure of that area and help it heal faster, because the goal is to have the flap doctor lift his restrictions when he sees him next November. Gary agreed to that. This evening he said, "The photos you took of my butt with your cell phone camera can be posted on the web, right?" "Yes," I replied slowly, wondering if he was worried I had put them on the blog (I do have SOME limits as to what I put on there ;-)). "So you can take one each week and we can compare and see the changes (in the flap)." "Oh," I teased, "I guess you mean you want me to email them to you. I was wondering if you wanted me to put them on the blog so everyone can keep track of the progress." "That might be interesting," Gary said, "but let's not do that." So I guess it will have to be left to your imaginations ;-)

September 1, 2006

Today I suggested to Gary that he take the LETA bus to and from therapy starting next week, and he said okay and that he would also start taking it home from the office. I'd figured he would react along those lines, but I'd been a little afraid he'd be disappointed I wasn't going with him to therapy, which would give a pinch to my heart. I had brought the topic up because I am feeling the need to get back to doing some of "my own thing" now. Of course I still help him from about 8am to 9:30 am (or later if a shower is involved) for the morning routine (he starts it at 7 am), and from about 8pm to 10pm for the evening routine, and with other things besides his routine that he needs my help on that come up during the day (and night, though fortunately that has become rare, she says with fingers crossed)). But basically all I am at these therapy sessions is his cheerleader – it's not like Shepherd, where he was doing a variety of things and I was helping out, enabling him to become more independent; here he has basically just been doing weights. Of course I will go to the sessions when he is doing something “fun” like practicing wheelies, which the therapist said they may do next Wednesday, or if he is learning some other skills, but otherwise, on plain ol’ weight-training days each of those sessions use up three hours of time (counting the transportation, transferring, etc.) that I would now like to use in other ways (most particularly, in writing-related activities, though some of the time will, for the present, have to be spent in organizing the house).

My other decision of the day: to have as a goal to throw/give away half of the stuff Janet and Donna and I sorted the other day. I did manage to throw away half of my T-shirts (the ones with the stains). I guess sixteen T-shirts is enough to hold me (I used to collect them at swim meets and math conferences and so forth). I went through the other piles but didn’t reduce them nearly as much. The effort, however, exhausted my enthusiasm for organizing today ;-)

This evening at dinner Gary mentioned that he’d noticed the calender on his wall at school was still on April. He said he’d noticed that the day of his accident was Good Friday. “You didn’t remember that?” I asked. He said no. He said he wondered if that was why my sister Janet had made a reference to the resurrection in one of her emails. I told him I thought she had gotten the reference from something I said, and I reminded him about what I’d read to him on Easter Sunday. He said he had absolutely no recollection of that. “Read the blog,” I told him with a smile. He asked if he could now, and I said yes, provided he started chronologically.

As we did the stretching routine later tonight, he said he had done a search (I’m not sure if he did it of the blog or of the webpage where everything is in chronological order) and found the Easter reference. He said it made him cry but he still had absolutely no recollection of that day. He then said he noticed I apologized for writing about myself on the blog and said he thought that the best part of the blog was when I wrote about what I was feeling about what was going on, which touched me but made me feel shy.

I asked him what he did remember about those days in ICU. He said he remembered he lived for my visits, that the staff would only let me stay for such a short time and he always looked forward to the next visit and he would keep track of how long it would be before I’d be there again, but that he would get confused about when the next visit after that was and so would always ask me when I was about to leave when the next time was that I could come (I remember that!).

He remembers all the visits made by family and friends during that time. He also remembered laughing when the male nurse threatened him with a visit from Bobby Lowder. :-)

September 2, 2006

This morning Gary told me he forgot to ask LETA if they would drive their bus up our driveway, a concern, Gary said, because he can’t get up it or down it himself (it is very steep). Then he amended that, saying that he could get down it one way or another, but that might cause other problems. “Yeah,” I agreed, “they’d have to scrape you – ” “Off the side of the bus,” Gary finished.

So, we will have to check after Labor Day into whether the bus will come up the drive.

Another hitch in the plans. Gary looked at the brochure on LETA that arrived in the mail today. Apparently, even though you make your request for them to pick you up at a certain time, they may come up to fifteen minutes before that or after that due to the popularity of the service. This is making Gary reluctant to use them to go to therapy.

Well, you'll have to stay tuned to see how this plays out.

We had another wet run this morning, Gary again doing the transfer to and from the shower bench by himself with the board (me supervising). I even left during part of the shower (staying in hearing range), knowing it wouldn't be for long so it wasn't really so I could do other things but just so Gary could feel like he was on his own in there (I was in the small bedroom and I admit to jumping when I heard a clunk, though I immediately realized it couldn't have been caused by a body hitting the floor – he'd dropped the bottle of soap). He called me back to get the soap, and also (as a safety precaution) when it was time for him to lean way over to his side on the shower bench, and then again to wash and dry his lower legs and feet (though it is theoretically possible for him to his legs and feet himself, since he can't bend forward because of the flap restrictions, it is "too much work" (Gary's words) to do so – I believe I explained before what this would involve, so I'll spare you ;-)). I stayed after that and supervised his transfer back to the wheelchair (the shower curtain trick worked, by the way – he was able to push his chair out of the way, cover it with the curtain, and then retrieve it after the shower, and it didn't get wet).

We guess that it is because of the angle he has to have the wheelchair in in order to do the shower transfers as opposed to the bed transfers, these are still quite a lot of work for him, especially the one back to the chair (maybe because in addition to the other factors it is slightly uphill); he said that at this point he would definitely not be comfortable doing this transfer with me not in the room. Being naked also adds to the difficulty of the shower transfers – his skin, unlike his trousers, tends to stick to the board. Maybe we'll have to powder the board (or him).

When he was in the chair I got his ted hose and pants and shoes on him, then left him to finish his dressing and grooming. He told me afterwards that he can now get his shirt on in one minute. He said if he could do that with his pants, then he'd really be cooking.Then he added, he'd like to be able to get his pants on, period.

Related to that, we got our final bill from UAB hospital today. $100. We think they should pay us (and a lot more than that, given these ongoing flap restrictions!). (If I remember right, I think the total cost of Gary's stay at UAB was close to a half a million dollars – fortunately insurance paid for all but a couple thousand.)

Our outing for the day was to the grocery store. I have made a point of staying in the background when we are at a counter (like at the fish counter or the deli or at the checkout line) and "forcing" people to address and deal with Gary (and to let him get the practice of paying for stuff ;-) – I don’t know if it’s true, but I thought I noticed a tendency when I was right there next to him for people to address me. Now, since he’s a man and we still live in a man-centered world, this would never happen if he were able-bodied (this I know from our outings together when he WAS able-bodied), so I have to conclude they are behaving this way because he is in a wheelchair. So I figure the benefit is two-fold – Gary gets to exhibit independence, the other people learn to deal with someone handicapped.

September 3, 2006

Figures. We hire the most professional-sounding housecleaner we’ve ever interviewed and she doesn’t show up for her first day of work (today) and doesn’t call. I’ll never understand why people do that kind of thing.

So, anyway, it’s back to interviewing housekeepers :-(

I called my mom this morning. Among other things, she told us how Gary inspires her – whenever she gets frustrated at how long it takes her to do things that she used to be much quicker at, she thinks of how much longer it takes Gary to do things and how well he is handling that reality (when Gary heard this, he commented that it’s not like he doesn’t get frustrated sometimes, but I said I am sure that happens a lot less often and to much less a degree than it would to most other people).

Today my main organizational accomplishment was sock sorting. I went through a huge bag of all my socks that the volunteers had collected together. I found thirty pairs. Very few of those are wearable, actually, as most are full of holes or stained or stretched out of fit because they’re so old. Others are thick woolen things only wearable on a seasonal basis. But for right now I was mainly interested in just finding matches. Besides the pairs, I came up with fifty-two unmatched socks. I decided to no longer wait for their mates to appear from the fourth dimension (since they haven’t in the past twenty years) and threw them out.

Our excursion today was to the mall to buy Dockers for Gary – he needs to get them with the waist a size bigger than before the accident (even though he weighs less, his abdominal muscles don’t function to keep guts tight). He had brought with him a pair of Dockers he had gotten over the internet to exchange them in the store of the same name, and after we went to the counter the woman informed us we were in the wrong store. Naturally, neither of us had looked at the name of the store we had entered, each of us following the other assuming the other knew where he or she was going. A foolish assumption on our part, and you would think we would know better after twenty-five years ;-).

We went to the correct store, and it turned out they didn’t have the size Gary wanted, so he will have to get them over the internet after all. The excursion wasn’t a total loss, however, as I did get five new pairs of socks. Plus we ran into the Mincs and had a nice chat with them. Oh, and Gary got an ice cream cone on our way back home, which is probably the only reason he wanted to go out anyway ;-)

During the transfer out of the car, I heard some clunking and told Gary I thought he was hitting his knee on the dashboard and that he needed to be conscious of that, as its happened before. He said maybe it was his head that was hitting the doorframe. So I asked, “Well, you could feel it if it was your head, couldn’t you? You can feel this, right?” I gave him a playful knock on the head. “Ow,” he faked. “Don’t do that. Now I have a C minus two injury.”

I assume it was because he was thinking of the LETA bus that he then wanted to see how far down our driveway he could get in his wheelchair (with me with him, of course – he had the sense not to be comfortable doing this alone). The last part, we confirmed, is definitely too dangerous for us to attempt even with me hanging onto the back of his chair.

We had a Blackjack breakthrough in the afternoon – the cat came up to Gary while he was in his wheelchair, asking for petting. :-)

During our evening routine, Gary asked if I wanted to stay overnight in Atlanta when we go back for Gary’s follow-up appointment with his Shepherd doc at the end of this month, or if I just wanted to drive up for the day. He noted that if we just drove up for the day, we’d have to get up a bit earlier than usual but would be home by late afternoon. He then noted that if we stayed overnight that we’d have to contend with finding a suitable place to stay, that he would have to sleep in a regular bed, which he isn’t used to and would require some adjustments to his/our routine, and that I would have to pack up all the supplies he needs and also all the supplies I would need, which I’d then have to unpack in Atlanta, and then I’d have to do pack and unpack them all again the next day.

I’ll bet you can guess what my choice was.

September 4, 2006

We interviewed another person for the housecleaning position today. She seemed like she’d be good, and she certainly is tender-hearted. She told us she rescues abandoned cats, and as she left she looked down at our threshold and said, “Come here, sweetie.” She then proceeded to move the caterpillar that was there so we wouldn’t step on it.

I spent the day doing a little organizing and working on revising my story. Gary worked on Topology Proceedings stuff, among other things. For dinner he wanted to try the Alaskan smoked salmon his family had sent but wasn’t sure what to have with it. I suggested he have it with fresh bread and goat cheese, which he did and said was very good. Just in case you ever want to try it ;-)

September 5, 2006

This morning before we started the part of the routine I help Gary with, he practiced turning onto his right side and padding off the position properly after being on his left side for several hours. He did it quite adequately. He is more comfortable sleeping on his left side (because of his shoulders) but would like to try to do his bowel program while lying on his right. It is supposed to be anatomically better to do it while lying on the right because of the way the bowel is coiled in the body, but he hasn't been doing it that way because of his bionic finger – it was too stiff to do the rectal stimulation. Now his finger is much more flexible than in previous months, and he is much more hopeful it will return to full function.

We had another interviewee for the housecleaning job this morning, and we liked her too. But we made the rational decision – for the position we chose the person who saved the caterpillar.

The painters came and finished the garage and breezeway, so I believe the job is finished! Yesterday I noticed that there is a metal eagle up on the garage below the decorative circular window. Don't know when they put that up, could have been a week ago ;-).

Gary talked with a state engineer about putting up a light at the intersection where his accident took place. The guy said the study that would determine whether or not there is enough traffic to warrant a light being put up there is taking place this week. So everyone who reads this blog should go travel those roads constantly for the next few days ;-) (and if you do, be very careful!).

Last night after we finished bathing the front half of Gary, in order for me to get the back half he needed to prone. As usual, because this takes place after we stretch him, he was too far to the middle to be able to turn into a prone, so he said, "Now I need to get my upper body over farther to my left," and looked at me expectantly. "You're going to do that, are you?" I replied as I wrapped my arms around him and tugged. "Yes, your body is an extension of mine now," he joked. (Gives new meaning to "the two become one.") So tonight, when we were about to do the same thing, Gary recalled the moment by saying, "Now we're going to move our body to our left." :-)

September 6, 2006

Last evening I asked Gary if he's ever yet had a dream where he's in a wheelchair. I know that it wasn't until years after I got CFS that I in my dream had it. Somehow, I was glad of that, as if that meant it wasn't part of me, and I was disappointed when my dream self also got the disease. I know it's a different thing, though, having an SCI. Rather hard to deny something so visible ;-). Perhaps I shouldn't have brought the question up – he hadn't had such a dream before this, but last night he did. He dreamt he was in the university gardens (where he used to take his walks), and he was worried he'd get stuck.

I took Gary to rehab, and we told the therapist we didn't know what was going on with Gary's tip bars. Yesterday at home he had wanted to practice wheelies with the tip bars on (not that I was thrilled by that), but first we were going to make sure that the tip bars would hold, so I got the gait belt and wrapped it around the axle of the wheelchair and around my hand, and he went up in the wheelie. Or rather, he tried to go up in the wheelie – he was on the tip bars before he was at the balance point. Since we hadn't changed the setting on the tip bars, this confused us; the only thing we could figure out was that all my assembling and disassembling of his chair somehow affected the tip bars (the chair he was using at Shepherd was never taken apart, so we had nothing to base this on other than we couldn't think of anything else that would affect the bars).

The therapist figured out that it was his foot placement! When she moved his feet further back on the footplate, he got up in the wheelie before hitting the tip bars. I don't think we would have thought of that. We – or rather, Gary – will have to be more conscious of his foot placement – he is supposed to have the balls of his feet on the plate, and I think he has been having them too far forward lately.

I had intended to work on my story while he was doing weights, but you know what they say about good intentions ;-). First I decided I'd just do the wrist curls with him as always, because that's the only weights I do there and I figure it's good for me. Since we started in on the weights after we figured out about the tip bars, by the time we were done with the curls there was only forty minutes left to the session. I rationalized that I wouldn't be able to concentrate on my story in that time because I am doing some nontrivial cutting out of unneeded plot threads and some rearranging of material and a lot of changing of dialogue (I conjecture that it is going to be harder to revise the first half of the story than the last, because when I wrote the first draft the characters and the plot weren't clear in my mind at the start and I threw in everything but the kitchen sink. Well, I probably have the kitchen sink in there, too). But even if I hadn't had that excuse, I am such a busybody about what he is up to I don't know if I could be at rehab with him and not get involved with whatever he is up to. He playfully mocked me after the session. "I thought you were going to work on your story. Instead, you're over with me telling me, 'That looks too easy – sure you don't need more weight?' 'Control your movements, don't use momentum.' And when the therapist said I was done, you go and say, 'He hasn't done lat pulldowns in a while. Was that intentional?'"

Which it wasn't, and when she asked if he wanted to do them, he said sure. Fortunately he wasn't dismayed I had brought that up. I'm always willing to make him work ;-)

He again showed definite signs of progress during the session. He hadn't done triceps presses in a long time, and he added three plates to the exercise and said he could go even heavier next time. He added a plate to the rows, and after doing thirty reps, he said he could try heavier. So I added another plate – it turned out he couldn't do those completely on his own, but with me holding his shoulders so he wouldn't fall forward, he cranked out thirty reps of those, too. On the "diagonal pain" exercise, on his "bad" side (left shoulder), after doing thirty reps with a one-pound weight like last time, he was able to do fifteen reps with a two-pound weight. Finally, he added a plate to what he could do before on the lat pulldowns.

I don't know if I've added any strength to what I came home with, but my massage therapist, who I saw today, says I definitely have more muscle in my arms and back and calves than I did last

April.

I had arranged to have my massage to finish about the time Gary finished with his seminar. I called him on his cell to let him know I was coming, and he met me at the place I've been parking. First I noticed his pants were covered with chalk. I told him that at least that covered the stains and that I hoped not many people had noticed his pants needed washing – after we'd gotten them on him this morning, we'd both noticed they were filthy, but neither of us were in the mood to go through the rigamarole of taking them off and putting another pair of pants on him.

He got a call from someone who is also very interested in having a traffic light put where his accident occurred – this woman had told him she'd nearly been in a similar kind of accident. Today she told him she noticed there is an electronic traffic counter near the intersection – for the study they are doing.

While we were going through Gary's stretching routine, he mentioned he was having phantom sensations. I thought he meant this was new, but he says he's had them since the accident, though he's never mentioned them before. He says they aren't painful, but they're like electric charges, and he knows they aren't real because they don't occur where his legs really are. He said that for instance, he now felt like he could feel that his leg was lying on the bed, only it wasn't because at the time I had it straight up in the air doing a hamstring stretch on it.

For some reason he started thinking about the first day he'd gotten to eat, after the trache tube had been removed. All the food had been colored green because the therapist was watching it with a little camera to make sure it didn't go down his trachea. He said despite its color, it had tasted great. He said he remembered really wanting a milkshake, and that I'd gone and got him one.

He said he also remembered how his voice was so weak at the beginning (I told him he'd sounded like Donald Duck). He remembered how nice it had been that his first talks to someone besides me or the hospital staff had been to our moms for Mothers Day.

September 7, 2006

We found out a few days ago that insurance won't pay for a hospital table; since it is so much handier to have a table that rolls, we are going to pay for one ourselves (Gary looked into other tables that roll that aren't billed as hospital tables, but the weren't any cheaper). Today we found out that insurance also won't pay for the hospital bed or mattress, which if we get them ourselves would come to $3000. Gary hasn't decided what to do about that yet – he is worried that at this point his shoulders aren't doing well enough that he'd be able to do all that swinging of them that would be required for him to turn himself on a regular bed. I suspect he is going to want to keep the hospital bed and mattress for a while – I guess we'll sell it some time in the future.

For the first time, he took the LETA bus to school – fortunately they did come up our drive. I was a little dismayed to see they don't secure him in the bus as well as he was secured in the Shepherd bus. In the Shepherd bus his chair was anchored firmly by straps and locks to the floor, plus he had a shoulder and seat belt around him – it took several minutes to get him all secured. In the LETA bus, his wheelchair was quickly secured by two straps put around the frame of his chair and attached to the floor (at first the driver put the straps around his wheels, but Gary told her to put them around the frame because the wheels could come off), and there was no shoulder and seat belt that was attached to the bus – all he had was his own chest and seat belts. Evidently Gary thought that was good enough.

The garage builder came today to take pictures for advertising purposes to potential clients and to collect his final payment. He seems a very nice guy, and he said to let us know of any problems or questions we might have in the future about the garage.

Thanks go to Gary's Aunt Joyce and Uncle Roland – they sent us a letter and a lap blanket. The blanket looks like it could be handmade, but we're not sure.

September 8, 2006

Well, today we found out insurance won't pay for the commode seat. This seems preposterous – the hospital bed was never meant to be a permanent fixture, but the commode seat is something he'll need for the rest of his life. I suggested Gary contact our Bridge Program person, and Gary's therapist thought it might do some good to talk to the university insurance person. Gary is skeptical either of these moves will help.

At therapy one of the other therapists came through the door from the gym to the waiting room and nearly hit Gary's wheelchair. Not that it was the therapist's fault, it was ours, or really, mine. The little waiting room is crowded with chairs along each wall except for right behind the door, and that is where I usually stand, because my leg starts bothering me if I sit (I wonder if there is a Guiness Book of World Records entry for longest time not sitting), and there is also room there for Gary to put his chair against the wall. The therapist apologized, and Gary said that it was okay. When the guy had left the room, Gary added out of the side of his mouth to me as if he were still talking to the guy, "I didn't even feel it." This set us both to laughing, but I'm sure the guy wouldn't have thought it funny, which is of course why Gary didn't say it to him.

I managed to pay only half-attention to Gary this time, using my other half of attention on editing my story. I can tell you that he again increased weight on one of the cross-cable exercises and on the lat pull-downs, and that he was able to do thirty reps instead of fifteen when he did the "diagonal pain" exercise with his left arm using a two-pound weight – it was just last week when he couldn't use any weight at all on that exercise.

The therapist thought the curb around the corner of the little group of buildings where the rehab place is might be low enough for Gary to practice wheelies on, so we checked it out. We were in front of a pizza place, and apparently we managed to freak the owner out. First he came running out apologizing that one of his employees was parked in the handicapped spot, and she moved her car, which wasn't affecting us at all (though, granted, she shouldn't have been parked there). Then when Gary prepared to try to take the curb (the therapist holding onto the gait belt around his wheelchair's axle), the guy ran out again and asked if we wanted help getting Gary up the curb. We told him we were practicing. Maybe he thought we were going to report him to somebody, or maybe he was trying to make a good impression so we would order a pizza from him :-)

Anyway, the curb was too high for Gary to practice on, much higher than anything he'd ever done, so after one failed attempt, he passed on trying some more. The therapist told us if we located a suitable curb we could take a little outing one day and Gary could practice there.

Next Monday, the plan is that I will take Gary to therapy, but then he will take the LETA bus to school afterwards and then also home. He is reluctant to take the bus to therapy because they may come fifteen minutes early or late, which means to be sure to make the therapy session he might end up getting there half an hour early, and he doesn't want to waste that time. So far I have not pointed out that by having me take him, that eats about an hour of my time (that is about what it takes to just help him into the car, disassemble his chair, pick up some food for him, take him to therapy, assemble his chair, and then leave him at therapy and return home). By having him take the bus as he will do on Monday, that will give me about two hours of time back on a therapy day. I haven't decided whether or not to press for more by having him take the bus to therapy as well (if you've been following the blog, you know that I put in other time on his care).

Of course we may have days like today where other things arise that increase "maintenance" time. After I brought him to school and assembled his chair, I was about to help him transfer out of the car when I said, "Something smells." We looked at each other. "Better check," he said. I did, and said, "Oh, crap."

So I had to disassemble his chair and take him home and help him get cleaned up and changed (and he had to do another bowel program session). By the time he was ready to get back in his wheelchair (an hour and a half later), my writing group meeting was about to start, and one member was supposed to be going to talk over some ideas she had after hearing from a publisher and a new member was supposed to be there as well (or so I thought – it turned out she didn't come). But all week Gary had been planning to go to the math colloquium today. I thought maybe I could just throw him in the car (figuratively speaking, of course) and drop him off, but he wasn't ready to leave, not having had lunch and still having some cleaning up to do. Though I felt a little torn about it, he told me to go to my meeting, that that was the way it goes. I know he was frustrated with his body and disappointed about not going to the colloquium and he was also sorry that I had to spend the extra time helping him, but I don't begrudge him the time when it is out of his control. It's the time that is in our control that we are still working out. ;-)

By the way, the therapist agreed with me that the LETA bus strapping in was inadequate, and she questioned whether the driver had known what he or she was doing (funny aside – I thought the driver was a she, Gary thought the driver was a he; if the same person comes again, I'm not absolutely sure how we're going to resolve this). She thought Gary should insist on a four-point strap-down, and she also thought the bus should have a seatbelt/shoulder strap for him. So, we'll see. Gary didn't seem to be as concerned about it as we were.

September 9, 2006

Today, after Gary was fortified with locally made chocolate almond coconut ice cream in a cone, we went on another trek to the wilds of Lowe's, for things like another waste basket and rubber padding to put his hot food on when he is carrying it on his lap, and to Krogers, for food, to Walgreens, for some supplies for Gary, and to the health food store for more food. Gary had to do quite a bit of wheeling around at Lowe's in order for us to locate our items, and he was pleased that his shoulders had no problem with it whatsoever. I had been encouraging him to go out on "pushes" to get the exercise, but he had been leery of the effect of doing such on his shoulders (he thinks doing so many at Shepherd was actually detrimental to his shoulders, though at the same time they built his endurance), so maybe this is a sign that soon he will be able to make such pushes a part of his exercise routine.

It took us about an hour to get the things at Lowe's. Our bill came to about $11. We spent an hour at Kroger. Our bill came to about $150. Yikes! That's a lot of zucchini! ;-) Total time shopping, three and half hours. Oh, what fun ;-)

September 10, 2006

What we have here is a failure to communicate ;-)

Note to the person not doing the cooking: it is not wise to tell the cook in the late afternoon that you want that whole chicken that was bought yesterday cooked for the evening meal and on top of that, you'd like bread stuffing in it.

Apparently Gary was under the impression that I was going to cook the whole thing today and then he'd have leftovers. I, on the other hand, had figured that someone (hopefully him) was going to cut the chicken into pieces and we'd freeze most of it, uncooked. When he told me he didn't want to cut it up and couldn't I do it whole, I said okay, and when he said he wanted it stuffed since I'd bought some herbs yesterday, I said okay, but I wasn't really thinking of just how long that would take. I still had my exercise routine I wanted to do, and when I finished that I ran off on the computer printer the one recipe (I don't stuff chickens that often, maybe at most once a year) for bread stuffing that I always follow. Well, sort of follow. It's pretty rare I follow a recipe exactly and I usually do a some substituting. Sometimes a LOT of substituting, so that the original recipe is pretty much unrecognizable. Anyway, he got the chicken out and prepared it and put it on a baking pan, and then as I was going nuts in the kitchen and telling him that he had to help out by cutting some slices of bread, he said he was sorry, that he didn't realize how long this would take and that he thought I could just throw a few things together and make good bread stuffing. I said I only knew the one recipe and it was not one I knew how to fool around with. He then realized if I did the whole chicken that we probably wouldn't be eating for a couple of hours. So he decided to cut the chicken up after all (which he said had been hard enough before his accident and was now even harder), and I made the stuffing separate.

I cooked scallions, a diced apple, sage, fresh parsley and thyme, and a pinch of mace (because I couldn’t find the nutmeg and by the way mace is probably not what you’re thinking) together, then added toasted bread cubes and a cup of freshly pureed apples. This was put into a baking dish in the oven.

While everything was cooking (except the asparagus, which was steamed later), I gave him the extra apple puree. He said it was the best applesauce he’d ever had, and I said it was the apples. He said, no, it was the cook, and I said, no, it really was the apples – all I’d done was puree apples. He was really surprised at this (I used one Gala apple and the other one I think was called a Jazz).

Everything was served about an hour and a half after I had started my part of it. The stuffing turned out really great, he said. Almost worth the effort, right? he joked. Almost, I joked back. It was just at the beginning when I was faced with this unexpected task that I wasn’t all that happy about it, but I got satisfaction in it turning out well.

September 11, 2006

For the first time I didn’t accompany Gary in therapy, not that I didn’t feel ambivalent about that – but I survived ;-). I drove him there (after making a stop at Paneera’s to get his lunch and by the way they don’t start serving soup until 11), helped him transfer into his chair, then he puckered up his lips for a kiss goodbye. “You want me to go any farther with you?” I asked. “No. But watch from here and make sure I get in the door,” he said with a smile. I told him that even though I knew he didn’t always make it inside the door himself, I was certain someone would help him – whether he wanted the help or not. I then got two surprises – he made it in the door the easiest ever, and no one leapt to his aid (those two facts are probably related).

In the evening he told me that the session had started out with the usual weight-training exercises, and he had again gone up in weight on one of the exercises. The therapist also retested his functional strength, repeating the tests she'd done the first day we went there (she would tell him to resist her as she pushed down on various arm parts), and she pronounced he’d made a great improvement (this doesn’t seem to be a very objective test, however!). They also went outside because she thought another of the curbs was low enough and he could try to practice curbs, but it turned out not to be low enough; he thought he spotted a lower one, so he wheeled over to it, but it wasn’t any lower. So they went inside and he practiced wheelies for a while. He held one for one and three-quarters minutes. The therapists were all impressed, but Gary told me he was sure his Shepherd therapist wouldn’t have been <G>.

The therapist asked him what was new, and he told her he was working on his goal to get more independent at taking a shower. He told her the real sticking point – literally – is his transfers back from shower chair to wheelchair using the transfer board. His skin sticks to the board and he takes it with him. I have suggested he powder himself, though then I'd have to make sure to get the powder washed from his flap afterwards, and this past Sunday I suggested that next time he use the longer transfer board – my idea being that that way he could keep his hands on the board when he transfers, and since he'd be pressing down on it, it would be less likely to stick to his bootie.

On a different task, the therapist also suggested he see if his shoulders are more flexible now so that maybe when he is trying to get his pants on he can reach his hand way around to the back of his pants while he is lying in bed to try to get the pants over his butt while protecting his flap with his hand. (He hasn't tried to get them all the way up for a long time because he didn't have that flexibility and the pants were shearing his flap when he tried to tug them up over his butt.)

Evidently this was review day (maybe because he's been going four weeks now), because she also asked him how he was doing on cooking and laundry. He told her he makes his own breakfast and lunch (though neither of those are cooked), that he can make a taco dinner except for turning on the stove for the frying pan (though now that he's got a new reacher, maybe he can do that, he told me), and that he helps with the preparation of close to half of the dinner meals (we need to get those seminars moved to an earlier time ;-)). He also is able to bring the dinnerware from the table to the sink and wash them off (though he can't maneuver his chair to get at the dishwasher). As far as laundry goes, he can do everything except put the clothes from the washer to the dryer – well, with his reacher he could probably do that too but it would take him a million years (well, close to it ;-)).

I called him in the afternoon to make sure he'd gotten to the university all right, and then I called again about 5:30 – I'd thought he'd said he was going to be home at five, and I got worried. He told me he'd said 5:30 because he was attending a seminar until five, but that he would in fact be late – the bus had just come. He said the Kuperbergs, however, had been keeping him company. In fact, Krystyna had chased after and flagged down the bus because the driver was new and didn't know where to go to pick Gary up!

Meanwhile, I spent much of the day revising my story, and I also spent a little time getting some books together for a Friends of the Library book sale that Janet Rogers told me Donna Bennett had told her about. Janet is trying to light a fire under me ;-) to get the upstairs organized (and continue doing so with the downstairs). I confess I didn't spend nearly as much time on it this past week as I did the previous week. I'd much rather work on my story :-). But I don't think Janet is going to let up until I get my rear in gear . . . :-) She came over and hauled away a couple bags of clothes for Goodwill, and a couple boxes of books. Thanks, Janet!

September 12, 2006

Janet Rogers returned this morning to boot me up the stairs (JUST kidding, Janet. Sorta ;-)). The idea is to consolidate and organize the stuff up there, to hopefully reclaim part of the room as an exercise room as I used to use it as (in the future Gary could conceivably use it this way too, after he is advanced enough to bump himself up the stairs), and to move things from the dining room/storeroom to either up there or to the garage, leaving just the frequently used things and things Gary needs to get at downstairs. We found a few things to send to the Thrift store and made a list with Gary's help of other things we found that perhaps some graduate students might like: racquet ball and tennis racquets, a mattress, bed-sized foam pads, a blender, an upright vacuum, a couch. (Janet says she's heard there is some kind of website or something for the university's graduate students which lists free things they can come and get.)

But most of the stuff upstairs is things I'll have to decide whether or not to keep – books and, especially, gardening stuff. We did manage to fill about fifteen garbage bags with things to throw out. After about two hours of this, I started coughing – I had been getting rid of old row covers (lightweight spun fiber material that is spread over crops when gardening organically to keep out insect pests) and several bags of dried luffas which I'd never yet turned into sponges (because of the work! Maybe it was because the seeds I bought were mainly for the "eating" variety of luffa, but the mature ones were hard to "skin" after they'd dried on the vine and had been soaked, and it took forever to shake the seeds out), and whatever I'd gotten into set off my allergies. When I gardened, I always wore a mask, and often one of those "paint" respirators, though I don't know if that was overkill, but anyway, these things minimized my allergic reactions. I had thought about wearing a mask when I worked upstairs today, but I couldn't remember where last I'd seen them. When I started coughing, Janet said maybe I should go downstairs and get out of "whatever," and she would do some last finishing up. I didn't argue. I had suddenly gotten a headache and felt really tired, but I would have felt guilty lying down while Janet was still up there working, so I went through a couple of boxes of papers that had been in the dining room/storage room while she continued working up there. I'm not sure exactly all she was doing, but I think I heard the sounds of sweeping and things being moved, so I think I'll wait until the dust has settled (literally) to check it out.

She worked nearly another hour (!), and when she came down Gary and I told her she was a great help to us, Gary adding that we weren't quite sure why she'd taken us on as her project (other than the goodness of her heart, of course! Basically it is just that, we know. She also claimed it was kind of fun – some people have an odd notion of fun ;-)).

After she carted away in her car the stuff for the Thrift store, I went to my room for a nap. I fell asleep immediately, and woke up an hour later. I still felt really tired (I tend to think it was from the allergic reaction more than from the labor), and I kind of dragged around until it was time to leave for my dentist appointment. I had been scheduled to go last April, so I hadn't seen the dentist since last December. Yikes. There I got the happy news that I have two cavities, so I get to go back in October to have them filled without anesthesia. I am so looking forward to that.

I asked them about Gary coming, and I was told the dentist has several paraplegic patients, so Gary should have no problem with accessibility. The paraplegic patients the dentist has are advanced enough that they don't need help getting into the dentist chairs, but the chairs lower far enough that I think Gary and I can even do the transfer without the board.

I was still tired when I returned home from the dentist (hopefully I have learned my lesson and will wear a mask when working upstairs from now on; or maybe Janet will realize the reason I put that stuff upstairs is so I wouldn't have to look at it or think about it for the rest of my life and she will agree this is a good idea. Nah . . . I have the feeling she has my work cut out for me ;-)), but fortunately for me Gary had decided to make bean tacos for dinner, and he made them all by himself, even turning on the stove with his new reacher.

He called our external case manager about the hospital bed being turned down by insurance. She told him a mistake had been made, that it had been put that we were buying it, not renting it. She said a new form will be submitted. Hopefully that will enable us to have insurance pay for it. I asked him if he'd asked about the commode seat, but he said he hadn't, wanting to concentrate on the hospital bed because it is about twenty times the cost of the commode seat.

Well, just as I was going to end this entry, I checked my email and found one from Janet. She gives the link to a NYT article on interactive web sites for those with serious health conditions. Thanks, Janet -- very interesting. We all sort of discovered on our own the benefits, didn't we?

Here's the link:
http://www.nytimes.com/2006/09/12/health/12cons.html?ref=health&pagewanted=print

September 13, 2006

Gary told me that at rehab he was again able to go up in weight on the wrist curls exercise. He also practiced wheelies again, and said he held one for over three minutes. He said he never achieved the state of zen, however.

In the late afternoon, the cleaning person, who came for the first time last Thursday, called and told us she couldn't work for us anymore. Grrr.

At bedtime, as I was about to help Gary prone, I told him about my idea for a new kind of hospital bed, Peg's Proning Pallet. A spatula-type of thing would come out from underneath the bed and flip you over like a hamburger. Good idea, yes?

September 14, 2006

Gary came the closest he's ever gotten to getting his pants on himself – just not quite flexible enough in the shoulders to be able to pull them up all the way in the back.

This morning he sat outside waiting for the LETA bus, which he was going to take to school. Having returned from the chiropractor, I stood in the study at my laptop, working on my story. After a short time I looked down at my watch – the bus should have been there by then; I checked to see if somehow I'd gotten so absorbed in what I was doing that I hadn't heard the bus come up the drive. Nope, Gary was still there. I went back to the computer, and a few minutes later I heard a beeping sound, like the sound garbage trucks make when they're backing up. I looked out the window, expecting to see the bus coming up the drive. I saw it, but a short ways down the street. Then I saw it go around our cul-de-sac (we live on the end of it) and stop a house away, pointed in the direction away from us. I got worried and went out to the driveway. By that time, it was another two houses away, but stopped. I walked rapidly down the drive, and as I did, it started to drive away. "Hey," I yelled, running into the street and waving my arms, "back here!"

Fortunately the guy saw me. Turned out he was late because he couldn't find our street. Then he couldn't find our house number (evidently not thinking to look on the curb, which is where the numbers are painted – guess I'm not the only non-sensate person ;-)). I'm not sure if he'd simply given up!

For lunch, Gary embarked on his planned adventure: to go from the math department down to the main street that runs by the university and eat at a barbecue place. He said it took him twenty-three minutes to get there, most of that uphill, and ten minutes to get back going in the downhill direction (I asked if he'd mowed anyone down, but he claimed he hadn't ;-)). He was proud of himself for making it (and I was too), and he said it was good exercise. He couldn't, however, stay on the sidewalk the whole time: the entrance to a motel on that street only had six-inch curbs on both sides, which he can't yet get up, so he had to go into and along the street for about ten feet in order to find a place he could get back to the sidewalk at. He assured me he had waited for traffic to clear and it hadn't been dangerous.

For his reward, we made a pizza for dinner. Yes, from scratch. I made my secret dough (Gary says if I ever want to go into another profession, I could sell my pizzas and make lots of money, based on the dough itself – even though it's simplicity itself), and I had Gary prepare the cheese, the peppers (jalapeno plus a mild one from one of his pepper plants that volunteers had evidently kept alive during our absence), scallions, and olives. I also added cilantro and some homemade roasted red pepper puree from a previous meal to the toppings. Gary said the pizza was, as usual, great, and noted that he hadn't had one of mine for at least six months.

Janet Rogers had come in the afternoon and worked upstairs for about four hours (!). She told me she'd come at a time when I was otherwise occupied, and I had told her I liked to spend Thursday afternoons critiquing the other members of my writing group's stories, so she had said she would come then. I am simply amazed at her energy, thankful for her help, and guilt-ridden for not working away right next to her (well, okay, the first two of those three ;-)).

In checking my email, I see Janet has sent me a link to a site warning against the infamous Al-gebra Movement. If you haven't taken precautions against it, you may want to read this: http://www.murderousmaths.co.uk/alg.htm

September 15, 2006

I drove Gary to therapy this morning only to find it had been cancelled, the receptionist somehow having forgotten to notify us until too late. Gary's therapist had a family emergency yesterday and might not be in for the next two weeks. The receptionist said she would call Monday if they got someone to take over for her. As we drove away, I got to thinking it wasn't a good idea for Gary not to have therapy for two weeks if they couldn't find a replacement. Gary agreed, and said that since all he was doing there was weights, and he knew the routines, maybe they'd let him come and do them himself and just have somebody else in the gym change the plates on the cable machine for the different exercises. I said that if they were too busy for that, I would do it for him for the next two weeks. He called them on his cell phone while I went into the medical supply store to pick up some "skin prep" he needed. They told him that his therapist was the only licensed occupational therapist they had who comes on MWF, and that even thought doing weights was also physical therapy, since he didn't have a doctor's script for physical therapy, none of the physical therapists could oversee him; this of course meant I couldn't oversee him, though Gary joked they should call Shepherd – after all, it'd been the occupational therapist there who had joked that I shouldn't do their jobs so well because it would make them lose theirs <G>. Evidently the place here has a licensed OT on Tuesday and Thursday, however, because they said he could come in then, so that's what he plans to do.

So, anyway, I took him to the university and dropped him off. When I got home near lunchtime, Janet Rogers, who'd come about 9, was still up working in the attic. She had a list of things to ask about, but I don't think I was all that helpful ("Do you want to keep this?" "I don't know." "What about this?" "I don't know."). Of her written list of about twenty things, Gary and I (mostly Gary ;-)) decided this evening on all but a few things. But of the things NOT on that list, I'm afraid my answer is still "I don't know."

So, anyway, looks like we have a few more things to give away to grad students or to the Thrift Store or Goodwill.

Jack Rogers came after his morning class and helped removed a leaf from the dining table (it hadn't been removed in about twenty years and there was no way Janet and I could do it!). Gary was thrilled when he came home to find he could maneuver in the dining room again – between the large table and all the shelving in there, he hadn't been able to much farther than the doorway before. He'd like to reclaim the room as an office/study.

When I got there, Jack had left to bring him and Janet some lunch, and after that Jack left and Janet returned to the upstairs, her goal to clear a path so that volunteers can drag down some of the large things from the upstairs. Originally I think she planned to be in our home a short time this morning, but she stayed until mid-afternoon until I left for writers group! She continues to astound.

When Gary returned home, he told me that since he hadn't had therapy, he'd gotten some exercise by wheeling from the math department to Haley Center. Since there is construction for a new student center going on in the vicinity, he said it hadn't been easy. He'd gone around the women's dorms, been directed up a ramp, and so forth. It was mostly uphill, and he said it took him over twenty minutes. Only about ten on the way back, however.

Gary got a nice card and letter from his old friend Marilyn Foreman. In it, she called Gary a fighter and me a saint. Thanks, Marilyn, but I am sure I am not a candidate for canonization ;-). But thankfully Gary is a fighter.

To anyone who sent me emails last weekend, they seem to have disappeared into cyberspace, so please resend them. I've had three people tell me they sent me emails, and I didn't get them (I did get the ones Janet and Jamie re-sent).

To finish, Janet came across a couple of our wedding pictures, one containing my brother, Joe. I uploaded the pictures to the blog, http://drpeg2003.blogspot.com/

And if a certain someone calls me a hippie wannabee again . . .

September 16, 2006

Showering continues to be a major effort for Gary (and still shoots practically the whole morning), the hardest part being the transfers using the transfer board when he is unclothed. I had to do more than just supervise today – he lost his balance and fell forward in going from his wheelchair to the shower bench. Fortunately I (and the toilet) caught him and helped him back onto the transfer board. Needless to say, we both agree he isn't ready to do those transfers unsupervised. I had again suggested he use the long transfer board, but for some reason he didn't want to. After today's efforts, he says next time he'll take my advice (we'll see ;-)). I think it will help – he can keep his hands on it while pushing down and in this way the board won't stick to him when he moves; the short transfer board does.

Gary commented that even though taking a shower is work, it is worth it because it feels so good.

I guess Saturday has become our grocery shopping day. We made sure to go during the game so to avoid any crowds ;-).

A big wave to Mom G, who has now joined us in cyberspace – she got a computer from a friend, who also showed her how to set up email, so now she doesn't have to go to her friend's to read the blog.

September 17, 2006

Judy Roitman sent us an email about the architect and designer Michael Graves, who became paralyzed after a spinal cord infection. One of his current projects is designing home health care products, see http://www.aarp.org/bulletin/yourlife/living_by_design.html

Judy commented to us, I am sure due to yesterday's blog/email, that maybe he could design a better transfer board. Gary replied to Judy's email by saying, "Yeah, I need one that doesn't stick to a damp ass!"

We'll see what Mr. Graves can do – Judy sent him an email about transfer boards being perhaps something he could re-design. I don't think she mentioned to him Gary's problematic anatomical area, though ;-)

This afternoon a group (set?) of math volunteers converged on our house. Integral to the operation was Janet Rogers, who tested our limits. Much topological discussion ensued, mainly about how to get the !@#$% (yes, that's a mathematical term) mattresses down the narrow stairway and out the back door, as well as a bookcase from the small bedroom to the study. I am afraid that no one was able to solve the latter problem in three-space. Trying to shrink the bookcase to a point or bend it in such a way as to preserve volume proved unsuccessful. But thanks to Jack Rogers, Wlodek Kuperberg, Andras Bezdek, T.Y. Tam, Phil Zenor, and Michel Smith for trying. (Others sent their regrets that they were unable to attend the function.)

The group divided the tasks into more manageable units. A truckload of garbage and recyclables was taken down to the curb. Mattresses and sofas and various other things were put in the garage for future distribution to graduate students – or to the Thrift Store or Goodwill, if the students don't want them. A portable wardrobe and some shelving were moved into the garage as well. A nice desk I had upstairs was moved downstairs to replace the table I've been using to set the desktop and my laptop on. (Yes, I've run out of math plays on words – feel free to send in any, and I'll rewrite this blog entry ;-))

When a few of us were in the living room, Michel asked me if I'd ever found my swimming medals (I had had them in the portable wardrobe). I said no. Michel pointed to a lidded, ceramic, decorative pot on a shelf on the cabinetry we have in the family room and said they were in there. This cracked me up – I told him I would have NEVER found them. (Not that I would have been distraught over that, only that occasionally in the past Gary would say something, and I would say, "Ya wanna medal or something?" He'd say "Yeah," and I'd go get him a medal – a standing joke we had.)

Gary once again got his own meal tonight, using the oven for the first time (on a frozen organic tortellini meal – yes, I've relaxed my standards to letting him regularly have canned or frozen natural foods). I was a little dismayed to find him adjusting the temperature of the oven by pushing the button with a long knife – him holding the blade end in his hand and using the handle end to push the button! He said it was a dull knife and he was wearing gloves, but I told him to use his reacher next time.

Tonight he was more tired than he has been lately. He said when we first came home, he was really tired every night, but now he has nights when he feels pretty good. So in general, he has more endurance.

September 18, 2006

This morning Gary said he had proof that I was indeed a saint, because I offered to help him finish up his bowel program. I told him that I had offered because he was whining ;-) about this one taking so long, and I'd felt sorry for him. He said he'd have to remember the whining trick. I told him he better not whine like Blackjack – that kind of whine doesn't make you feel sorry for him, it makes you want to kill him! Gary said he'd keep that in mind. (He also said it's a good thing we can laugh about it.)

A few graduate students came by in the afternoon and took the racquets, blender, vacuum cleaner, one of the two badminton sets, the old set of golf clubs, and Jarts.

Late afternoon I got a little worried about how Gary was faring – it began to downpour about the time he was supposed to be leaving for home from the university. The bus pulled up the drive, and I got an umbrella to meet him – he had said this morning he was taking his new poncho to school, but I figured it wouldn't hurt to have the extra protection of an umbrella. He was glad I came out – turned out he had accidently taken his old poncho, which doesn't have a hood. I wondered aloud why he his hair was dry, and he said it hadn't started raining until right after he got on the bus – so he was lucky!

For dinner Gary elaborated on the recipe I had in mind. We started with spicy black beans (adding cumin, cinnammon, chives, scallions, jalapeno, fresh oregano, and homemade chili powder to the beans), and I had intended him to have them in a pita bread with cilantro mayonnaise. Gary decided to add feta cheese, tomatoes, and olives to the sandwich, because, he said, pitas are Greek. He said his creation turned out great.

As an addendum to yesterday's entry:

David Fremlin suggested that finite dissection followed by affine operations could have been tried on the bookcase. Actually, finite dissection was suggested, but fortunately no one had a saw on hand.

September 19, 2006

Took the car in again today – Sunday I had noticed oil leaking onto the garage floor (didn't take the car in yesterday because the mechanics couldn't give me a ride back that day). Fortunately it doesn't seem to be a huge problem – there are a couple leaks (not being mechanically minded, I forget where the guy said they are). Unfortunately they didn't have the parts to fix it today, but they said they'll fix it tomorrow. I left my car with them.

Gary took the bus to rehab, as well as from it to the university and from the university to home, as he has been doing. His substitute therapist at rehab didn't seem all that interested in what the other therapist had been doing with him. She did her own evaluation, but other than the wrist exercises, she didn’t have him do weights. She is interested in improving his shoulder flexibility and gave him some new exercises for that. Though it’s true his shoulder flexibility is important – today he got his pants on all the way by himself except he couldn’t quite reach around to the back to pull them up the last little bit because of his lack of shoulder flexibility – I worry that she is not going to have him keep up with the weights. Plus, it could be that Thursday he’ll have someone new again, because they’re just getting people to fill in for his own therapist, so if each different person has to do her own evaluation and her own stuff, then he might not be doing anything consistently for the next two weeks. I told him he should do weight-training stuff on his own (he does do theraband exercises on his own on the days he doesn’t have therapy, but that’s not quite the same).

September 19, 2006

Warning, full of random thoughts:

More than once, I’ve driven Gary home from somewhere and gotten out of the car and started into the house before remembering, “Oops, I’ve forgotten something.” Namely him – I’d been expecting him to just get out of the car and walk into the house. Every once in a while, the reality of the situation slips by me.

Having nothing to do with that, the other day I went to the pharmacy to get him some supplies and took the items up to the counter. “Need to pay for that?” the checkout person asked me. “Unless you’re giving them to me for free,” I told her. Sometimes I amuse myself. (The other checkout person also got a laugh out of it.)

A couple graduate students came today and took some of the big stuff – we got rid of the loveseat and one of the mattress sets. No one is grabbing up any of the foam pads, however.

If you want to read about a controversial new bill that was introduced into Congress Tuesday that would defend marriage from sharks, go to http://www.theonion.com/content/node/52984 Thanks, Jamie, I had no idea sharks were perceived as such a threat to this sacred institution.

I think that I should make Janet Rogers my official photographer. I rarely like photos of myself, but she and/or Jack have certainly taken some good ones. Here’s another old one from their collection, which I am putting up for no good reason other than I like it (e-mailers will have to go to the blog, http://drpeg2003.blogspot.com/):

September 21, 2006

“So, how’d I do?” Gary asked from his bed when I came back into the master bedroom this morning to check on his progress in getting his pants on. I helped him roll to one side then the other, making sure the back pockets weren’t bunched up (we’ve decided he should just cut them off – they are of no use to him, only can cause problems if they’re bunched up and therefore press against him causing pressure sores, and he isn’t flexible enough to reach back into them to straighten them out).

“Well, I believe we can say you got these on all by yourself!” This was the first time I hadn’t had to hike the pants up in the back. We gave each other a high-five and a kiss. It took him about ten, fifteen minutes, we’d say (since we weren’t expecting it, we didn’t have a timer running ;-)). (A later step will be for him to get them on without use of the electric hospital bed controls and the handrails. He uses the controls to help him sit up so he can get the pants on up to his thighs, and then when he is lying flat again, he uses the handrails to help roll himself from side to side to gradually work the pants on up the rest of the way.)

Coincidently, at rehab, his therapist, the same one he’d had Tuesday, said she’d talked to his regular therapist and they’d decided he should practice getting his pants on. He informed her that he had done that this morning, and since he would be in the hospital bed awhile, it didn’t seem all that useful to practice getting them on while lying on the exercise mat (which would be more like what he’ll have to do when he is in a regular bed). So instead she had him do shoulder flexibility exercises and balance exercises (moving cones on and off a board) and some weights on the cable machine. (When he told me this I said I was still a little worried about him losing strength since they weren’t doing all the exercises he’d been doing before, and he said he would continue to do pushups every morning in bed, like he had started this morning.)

To do the balance exercises, he first transferred onto the mat. The brake on the wheelchair had messed up like it did before (the time we fixed it by taking a hammer to it), so the therapist hung onto the chair and had another therapist help Gary with the transfer. This therapist obviously hadn’t any experience doing transfers (and I assume neither did the one working with Gary as clearly the two of them could have exchanged places), and gave Gary way too much help. I felt a little guilty at this and asked Gary if I should come and help with the transfers, but he said no, that to be independent he needed to learn how to tell people how to help him – he said he should have told the guy that he could do this kind of transfer pretty much by himself, but that he sometimes had problems with his balance and all he needed was for the guy to catch him if he went forward or backward, but that he didn’t need the guy to hang onto him and boost him over.

By the way, just to lay it out, it is not good to help someone in a wheelchair unless they ask for help, and not just as an independence issue. If you take hold of the wheelchair and push or something and they’re not expecting it, it could be dangerous, since they have gauged how much force to use in pushing their wheels based on doing it themselves.

The bus that picked him up this morning didn’t come up the drive, the driver saying she thought it too steep for the large bus, so he had a new adventure of going all the way down the driveway – the last part being the problematic part. He wanted to save my back, so he had the bus driver hold onto his chair as he went down the last bit (naturally he was also using his hands on the wheels for his own braking, but the driver was aiding that). Since I’m not an entirely trusting soul ;-), I had a hand on the side of the chair as well.

Around dinnertime Gary thought he needed a little more exercise so asked me to go around the outside of our house with him. Good thing he told me he was going to do this and I therefore accompanied him, because otherwise he likely would have tipped over in going down front patio to the grassy area on the side of our house – the drop-off was a bit more than he expected, the slope of the land tilts down there, he didn't have his chest strap on, and he fell forward. I had had my hands on the handles on the back of his chair as he started to go off the patio, however, and I gripped them as he went off of it since this was new terrain and I was in better-safe-than-sorry mode, and then I grabbed him around the chest as he fell forward. Since he had his seat belt on, at this point there wasn't any danger he could've have fallen completely out of the chair, but the whole thing scared him because he didn't hear me say I had my hands on the handles and he thought he was going to tip the whole chair over forward.

He put his chest strap on and tightened his seat belt after that (brings to mind shutting the barn door after the horses have escaped ;-)). The rest of the way around the house was just rough terrain – high grass, a narrow path, the land sloping to the right so he had to keep fighting to go somewhat straight.

We only went around the house once. ;-)

His bedtime transfers from wheelchair to bed haven't yet become impressive ;-), and after another one tonight where he landed on the edge and had to be yanked back from it, he decided maybe we'd better practice transfers on his non-therapy days. Just doing them twice in a day isn't giving him enough practice on the technique, and at this point we believe it's more a matter of getting the technique down than of strength.

Janet Rogers informed me that it is her husband, Jack, who is the real photographer in the family, she having taken it up only recently. He was the one who took the old photos of me, and of Gary and me. She says her main contribution has been in scanning and cataloguing the thousands of slides in their collection, and sometimes cropping and tweaking them in Photoshop. Well, you did an excellent of photoshopping out the toilet bowl plunger from that picture of Tigger, Janet! ;-)

September 22, 2006

Gary said he got a good test of his new rain poncho today. It started pouring while he was outside at the university waiting for the bus to take him home (he said he realized later he should have called the bus people and found out exactly when they'd be there to get him). The poncho worked well except his shoes and t.e.d. hose got wet. (Note to ourselves: Gary needs a spare pair of shoes!) So I got him changed out of those, put his tennies in the dryer, and found an old pair of slippers that fit him loosely. I told him to watch his feet while he had them on, as part of the function of his shoes these days is to protect his feet should he bang them into something while wheeling around in his chair.

Oh, someone asked about the ground squirrel. Apparently it slipped out a window one of those nights we had one open. At least I assume so – haven't noticed a smelly carcass around anywhere ;-) (of course, knowing me, it's possible I've overlooked it).

September 23, 2006

Well, Gary tried using the long transfer board in and out of the shower and then to the bed afterwards (so I could dress his flap and get his hose on him, etc.). Guess what? He said, "That was easier." By being able to keep his hands on the longer board and push, the board didn't stick to his "damp ass," as he put it. The man should have listened to me weeks ago ;-). But this is not to say the transfers were easy. There is still no way I would not be standing right in front of him during these transfers – I had to hang onto his hips at one point because he still nearly slid out of his chair on the way back to it from the shower bench, due to the angle of transfer being different than the bed transfers.

When we got him transferred back into the bed afterwards, he said he was so tired out from taking the shower that he would like me to put his pants on for him. As I did so, he noted that one of the Shepherd therapists had said he could practice getting his pants on while sitting in chair while watching TV. He gave me a look. "So far, we haven't had any time to watch TV." He then commented, "I suppose we'll get there. Eventually."

He then told me he likes his "new" office – Phil Zenor's old office on the second floor (the elevator not a necessity to get to it, in case it ever is "out"). He said Wlodek Kuperberg watched him closing his office door and had a suggestion (Gary has been closing his door in increments, reaching for and pulling on the door, backing his chair up a little, reaching and pulling on the door, etc.). Wlodek suggested Gary tie a rope around the handle and pull on that – one of those, "Now why didn't we think of that?" suggestions :-). Gary thought that idea might come in handy other ways. He said, for example, he could learn how to lasso and when he wanted me he could lasso me. I told him he was going to have to get damn good at lassoing. ;-).

Janet and Jack Rogers came to load up and take to the Thrift store the stuff no graduates came to get – the foam pads, a mattress set, an old couch. Thanks so much! T.Y. Tam came and put on a stove hood that Gary had meant to do around the time of the accident. Looks good! And matches the stove, unlike the old one ;-).

I managed (barely) to accomplish my goal to finish revising a chapter of my story by the end of this week. 50 pages down, 750 to go :-p (that is the symbol for having your tongue hang out, in case you don't know).

September 24, 2006

Cleaning person came today. Seemed to do a good job. Keep your fingers crossed.

Gary timed how long it took him to get his pants on (by himself). Seven minutes forty seconds. :-)

There is an article about Christopher and Dana Reeve in the new Readers Digest. Good article, made us cry. Also again made us thankful Gary's injuries weren't worse. And it had us wondering how Chris could have gotten a pressure sore with all the care he must have had – an infection from one was what killed him.

September 25, 2006

Today's big adventure was a trip partway down our steep driveway, farther than before. I held lightly onto the handles of Gary's wheelchair, prepared to grip them if needed. It wasn't, for the distance he went. He said it was hard, though – he needed to lean way back in the chair to keep his balance, and he had to grip the wheels constantly so as not to go too fast. (Supposedly when he gets good at wheelies, it would be best for him to go down that steep incline in a wheelie – he's pretty far away from being ready to try that!) Going up the drive was also a challenge – the hardest part, he said, was at the beginning, getting started from a dead stop. We went up and down twice.

Some guard cats we have. I heard a strange noise this evening while doing the routine with Gary. I went out to the family room, and there in the hallway was a strange cat eating out of our cats' food bowls (the noise I'd heard was the bell around its neck tinkling). Our cats just sat on the futon watching it. It ran off at my approach, however.

September 26, 2006

Today the substitute therapist asked Gary how he was coming along in accomplishing his goals. One thing on the list was the preparation of simple and complex meals. She asked him what he was able to do, and he described the meals he's made. She said, "Oh, you can do simple ones, then."

What does she want, Le Cordon Bleu? :-)

September 27, 2006 (10:20pm)

Stupid cat! Tigger brought in a ground squirrel. I much preferred it when Gary could go chasing after the things – my tactic was to go into the bedroom and cower behind the closed door until we were once again varmint-free. Since that wasn't going to happen anytime soon, I got a towel at Gary's direction and scurried around the room chasing after the thing. I think Tigger had broken its leg – otherwise I'm sure I wouldn't have gotten it before Christmas. I threw the towel over it, but then had a hard – very hard – time making myself pick the critter up in the towel (which is what Gary kept telling me to do). I finally picked up the towel, but it didn't have the beastie in it – it ran between my legs and I hopped up and down and let out a little (but just a little) shriek. I cornered it again, threw the towel over it, and this time managed to make myself grab the towel right away. I had the beastie between my hands, and I went hurrying out the door all the while letting out an "ohhhhhhh." I put it down in the woods behind our house and tried to catch Tigger as he came down the path after me. I didn't get him, but he soon came back into the house sans animal. I told Gary I didn't know if I'd done that chipmunk any favor, as I feared it now would die a slow death from being crippled, but Gary said I'd done us a favor by getting it out of the house. He said he was proud of me (gee, thanks, I said), and that he could tell I didn't like picking the thing up even though it was wrapped in a towel – at which point he imitated me trying to keep at arm's length while grabbing the chipmunk. I was tempted to swat him, but I refrained ;-). Later on in the day I coincidently came across an online article about aggressive squirrels in a park in California that in the last three months have bitten three people. Gary did not take this as evidence that I shouldn't try to rid the house of chipmunks.

September 28, 2006

Today's adventure was trying to go a little bit farther down the driveway. Gary's goal is to be able to get to the mailbox, and, a harder task ;-), back up the drive with the mail. He has a ways to go – he lost control of his chair on the way down – but, of course, I had had my hands lightly on the handles, so I simply grabbed them harder to stop his chair.

September 29, 2006

Today was Gary's 6 week follow-up appointment with his rehab doctor at Shepherd (whose pic you saw on the blog). We had to get our routine started an hour earlier than usual, and it was going to be a long day, with me driving us there and back, so naturally I slept lousy, getting about four hours of sleep. I made it a thousand times worse by doing something stupid. Last night I started to feel tense about the prospect of the trip , so I "lost it" and ate a big bowl of Gary's cereal, and, adding insult to injury, had it with milk. I woke up at 3 a.m. with a monstrous headache, feeling sick to my guts. I kept the headache and the sick feeling the entire day, and it will probably take several days to get back to "normal."

On the way to Shepherd, Gary commented that he'd been there so long, this felt like going home. I teased him about wanting to check back in, and he said it would have its definite advantages – the nurses could take care of his bowel program and do his ICs for him, while he could just lounge. I told him that with his luck, he'd probably have to share the room with three other patients with speaker-phones turned up loud. That and the fact that he wouldn't get much sleep during the night seemed enough to dissuade him from taking up occupancy there again. ;-)

On our way into the building, Gary told me that at least I wouldn't have to be embarrassed about someone seeing me not helping him with the doors. "No one helps you here," he noted. I'm not sure he was being entirely complimentary. ;-)

We had gotten there a little early, and he went off to do an IC (which was a whole lot easier than doing it in the car while I was driving, which is what he would have done had we gotten there later). Meanwhile, I went out to the garden. Yup! My graffiti sign is still there! I then went to the library and took out my laptop to while away a few minutes. I discovered that since Gary had been in residence, they'd put in wireless. (Not sure if it's in all the patients' rooms – it wasn't available in the exam room we went to after this.) So, I looked at my email then worked on my story until Gary came to collect me.

The exam room surprised me – the exam table was very narrow, and it didn't lower to the height of a wheelchair. No coddling of quads and paras here! Gary and I did the transfer, me giving the maximum help of "under the sitting bones" and having to help him regain his balance and get him farther back on the table. I'd been telling him he needs to practice his transfers more (with me), because he hasn't made a whole lot of progress in becoming independent with them. It seemed evident to me that this "uneven height" transfer showed the lack of practice.

Once he got on the table, I weighed his chair – the nurse had weighed his chair with him in it a few moments earlier. He is about the same in weight, maybe slightly lighter. He took this as evidence that I should take him out to the local ice cream parlor more often.

The doctor first checked out his flap. He said it was looking good. I said, "So, then it's okay that every night when I check it after he transfers into bed it looks purple and swollen?" Okay, maybe that sounds like a dumb question to you, but I couldn't understand why the doctor thought it was healing fine when to me it doesn't look like it's improved in weeks. Anyway, Gary said it was a good thing I'd said that, because the doctor replied, "No, that's not okay," and thought maybe it still had something to do with Gary's chair, since Gary has been diligent about doing his weight shifts, and said he'd go look at the chair while Gary was getting dressed.

He then asked if Gary had any other concerns. Gary said that he was concerned about the bowel program pattern his body has gotten into – nothing for two days (while still having to spend the 20-25 minutes doing digital stimulation) then having to spend 1 1/4 to 1 3/4 hours for "everything to come out" on the third day. The doctor suggested he try doing the digital stimulation every other day, since the transit time was so long, and using a stool softener. On the days Gary isn't scheduled to do the digital stimulation, he would still do a rectal check (stick the finger in and feel around), and if "all's clear," he can skip doing the digital stimulation; otherwise he'd have to do it, of course, to avoid having "an involuntary" later on in the day. So, Gary is going to try that. If that doesn't give good results, the doctor said it might indicate Gary's colon is weak, the muscles not propelling hard enough, and that the next step is to try senna. I dunno, he's the doctor, but Gary and I thought trying a regular addition of prune juice or magnesium oxide or citrate tablet (not every day) might be better than the harsher, habit-forming senna (the doctor did say if Gary went the senna route, he'd have to be weaned off of it as the body becomes dependent on it). In this second case, Gary would have to go back to doing the bowel program every day because if it's the case that the colon is weak and not simply that the transit time is slow and things are "too high up," then "things could get backed up."

The doctor corrected Gary when Gary called the digital stimulation program "the dil program," which is what all the Shepherd nurses call it (even though we were warned that no one outside of Shepherd calls it this). He told Gary that "we scientific types have to stick together," that "'dil' is short for ‘dilatation’ and is therefore not correct because we are not dilating the rectum. This has nothing to do with pickles.” Gary and I later came up with the possibility of shortening “digital stimulation” to “dig” – yes, pronounced “dig,” not “dij.” Seems apt ;-).

Gary’s final question concerned the t.e.d. hose. He asked if it’d be all right to change to the knee-highs instead of the thigh-highs – so I don’t have to struggle so hard every morning to put them on him! Since Gary’s swelling is in his feet and ankles, the doctor said this would be all right.

The doctor told Gary to get dressed, and he and I went out to look at Gary’s chair. The doctor immediately noticed that the foam at the bottom of the chair’s back, where Gary’s “bony butt” (that’s doctor talk ;-)) presses, is not as thick as at the top. He told me we should go to someplace like Home Depot and buy some foam to put into the bottom of the back pad of the chair (it zips open).

We went back into the exam room, and the doctor chided Gary for still being laid out on his side with his pants down, saying, “What, you still have your wife put your pants on for you?” I thought this was vastly unfair and said Gary could put them on himself, that, in fact, his being able to do so was a recent accomplishment but that he couldn’t do it on such a narrow exam table because he needed to roll from side to side. I am usually (unfortunately) diffident around doctors (otherwise I would have told this one that I had a name, it was “Peg,” and to quit referring to me as if I wasn’t standing right there, always saying, “your wife,” to Gary whenever I was being referred to), but this I couldn’t let him get away with.

So, that was pretty much it. The doctor handed me some forms to take up front, and left. I then got Gary’s pants on him – it was hard for ME to do it with that narrow table – and then we got him transferred into his chair. Gary made a follow-up appointment for six months from now, and then we went to the apothecary to get the new t.e.d. hose, a couple “reachers,” and a new long-handled bath sponge, his original one having never rematerialized after our return home.

We next made a stop at Fresh Market, where I picked up Gary an Italian panini sandwich for lunch. Then we headed home. I was just thinking I was handling this journey back home much better than the last time (the last time, the traffic had me on the edge of my seat), when Gary called out, “You’re supposed to take that exit!” Fortunately there was a break in traffic and I zoomed across four lanes, just making the exit. Turned out I had missed where 75-85 split into the separate expressways and had stayed on 75 instead of getting onto 85, so I then had to take 285 for a while. Other than that, the journey home was uneventful. I did decide Gary deserved an ice cream, so we stopped for that when we were close to home.

At dinnertime, Gary brought up that he hadn’t asked about something I had thought he should – namely why he now always coughs while he’s eating – things get stuck in his throat. I said, “Yeah, I almost asked him myself, ‘How long am I going to have to put up with this annoying new habit he has?’” Gary told me to remember that I was a saint, and saints don’t whine. I told him I was turning in my halo ;-).

But Gary thinks the coughing is due to something that they did in Birmingham – he thinks some little “pouch” was (accidently) created when they put in the trache. He’s never done this coughing thing before.

Gary then asked me how I was doing, and I gave a little shrug. “Okay, considering,” he interpreted, then continued, “Well, that’s better than this morning when I radioed you on the walkie-talkie and you answered by saying, ‘Somebody just shoot me.’”

I’d forgotten about that. ;-)

September 30, 2006

Speaking of annoying new habits (see yesterday’s entry) but from a different quarter, Blackjack has taken to hooking his paw under the “cat barrier” (door) and practically shaking the thing off its hinges if I don’t get there early enough (in his mind) in the morning to feed him. The first time that happened, I ran out there with my heart in my mouth, not knowing what was making all that racket – I thought someone was trying to break in. I told Gary that if this starts happening while I’m fast asleep, I’m going to have to tie all Blackjack’s paws together, like a roped calf, before I toss him on the other side of the cat barrier for the night. Gary said I should be sure to stuff a gag down Blackjack’s throat as well. Good point.

This afternoon we did a little transfer practicing. Gary went back and forth three times between wheelchair and bed, me with my hands on his hips, giving as little help as possible. Turned out I didn’t help him at all. He tried changing his technique a little, and his latest hypothesis is that it is better for him to aim his nose toward the inside of his knee when he is swinging his upper body for momentum, and then to do the twisting motion (provided by the way he is pushing with his arms, no ab twisting possible) after he’s got his butt in the air. Before, he was aiming his nose toward the outside of his knee (which is what they told him to do at Shepherd), but he thinks this other way gets his butt up higher.

We also went a bit further down the driveway, and this time I didn’t need to provide any braking power at all. Gary says even when it becomes “safe” for him to go up and down the driveway himself, he doesn’t think he’ll be getting the mail on a regular basis – too hard of a process.

Gary came up with a new balance exercise: petting a kitty while sitting on the bed. Tigger likes that one.

October 1, 2006

Our Sunday routine now seems to be: do the shower in the morning, go to the grocery store after lunch while the housecleaner is there. Gary has been having to pay more attention to getting fiber into him. Last week at Kroger I came across a Masada Bakery bread, “rich in natural fiber” – five grams per slice. Gary made a face when I showed it to him, saying anything that good for you couldn't taste any good. But, he decided to try it, and was surprised to find it tasted all right ("not as good as Paneera bread, though" – the stuff without any nutrition to it ;-)). So we got more this week.

He still, however, refuses to try the natural cereal I found that proclaims on its cover that it contains twigs. He says if he wants twigs for fiber, he'll go into the woods in our backyard.

October 2, 2006

Gary set a new wheelie record: in the position for 5 ½ minutes. He says he still only has flashes of a Zen-like state, however. ;-)

Ronnie Levy informs us that the cereal with twigs is great. Gary says he'll have to try it, then. You better not be joking, Ronnie!
October 3, 2006

Gary attempted – and conquered – the route he would have to take in order to get into the math building should the elevator not be working (he would have to go in the front, instead of the back). He said he must have looked like he was really struggling up a long incline, because there were two separate incidents of people asking him if he wanted help, including a man who jumped out of his truck and trotted over. Gary told them both thanks anyway, he was just getting exercise.

We continue to find our amusement anyway we can, including figuring out just what it is that Gary has caught between his feet or dropped into his lap. Tonight after helping him transfer into bed, I picked up a mystery item from his lap and said it must have been part of his (Mexican) dinner. He said that at least it wasn't the whole enchilada.

Two little notes:

*Caller I.D. can be so much fun. I knew it was Gary calling me, so I answered the phone by saying, "I suppose you want something of me," which made him laugh.

*I don't think goosing a person is an intended use for a reacher.

October 4, 2006

Gary set a new record: 8 minutes in a wheelie. About half of that time he was zen-like, he claims.

October 5, 2006

Uh-oh. I feel like crap today. Hot and achy all over, headachy, tired. It seemed to start last night. It was a chore to give Gary his bath and go through the routine. All I wanted to do is go to bed. I did lay around most of the day today (well, except for a nap I was spending the time critiquing my fellow writers' stories in preparation for tomorrow's meeting). I hope I'm not going to get sick. I started worrying about who was going to give Gary his bath, get his clothes over to him when he's in bed, and get him out of and back into bed. When Gary realized I wasn't feeling well, he started worrying that if I went into the hospital he'd be up shit creek. I told him hopefully I wasn't going to be THAT sick.

He was happy today that he had an idea for some math research problem and got involved in it. He said it didn't pan out, but it felt good to be doing research anyway.

He did a little reading about the Christopher Reeve Foundation. He said that there is a charity dinner in New York coming up for research in spinal cord injuries. $1000 per plate. He said what would really hold him back from going, however, is that it is black-tie. He said he thought he should complain about them having this requirement, thereby not making it easy for quads and paras to attend. I told him he could wear black sleep pants and a white T-shirt with a tie printed on it.

October 6, 2006

Still feel like crap.

Gary's family has still been trying to get reimbursed for the cancellation that Gary and his mom had to do regarding their room on the Alaska cruise ship (actually, I believe it is Bob still trying to get reimbursed since he ended up paying for the room he was sharing with Gary and his mom). The insurance company evidently wouldn't take the documents of the cruise ship that showed the room was paid for and thanking Gary for the payment as evidence that he actually paid for the room. (Norma wondered in an email to Gary what planet the insurance company was from. Gary told her that like most insurance companies they are from the planet Justtrytogetmoneyoutofushaha.) The insurance company wanted the credit card statement from last April that showed Gary had paid for the room. Fortunately (in a rare display of organization ;-)) while I was paying all the bills when Gary was hospitalized I had printed off and stuffed things like this in a manilla envelope, and Gary found it.

He told me he is still increasing the weights in rehab. Today he went up to more weight in the wrist curls. He said he tried for half of the wheelie time to do it while watching the little TV there instead of his feet. He said doing it with his head up is much harder.

He went to the barbecue place for lunch again, but he said this time they had the door to their outer room closed, instead of open as it has been before. He said he was having difficulty getting in – if he went up on the sidewalk to the entrance, he was too close to the door to get it open, but if he didn't go up on the sidewalk then he had to reach across and hold the door open with one hand while at the same time trying to get up the two-inch curb to the sidewalk. He couldn't do it. The bus driver got out and helped him. I suggested he program the restaurant's phone number into his cell phone and if their door was shut to phone them to tell them to open the door for him!

October 7, 2006

Ow. Ow. Ow. Ow. Ow.

I guess this is turning into a cold. Still hurt all over.

Ow.

Told Gary I was worried about giving “whatever” to him. He said it was inevitable he was going to get a cold or something sometime. I’d rather not be the cause.

October 9, 2006

A “connection” problem with the condom catheter caused Gary to have to have the LETA bus take him home instead of to the university after rehab. I suppose after we got his clothes changed I could’ve taken him to the university, but he didn’t ask, saying there wasn’t anything vital he had planned to do there, and I’m still not feeling good, so I didn’t volunteer to take him – actually, perhaps a measure of how not-with-it I was, it didn’t even occur to me to offer until too late in the afternoon.

He had another bit of a disappointment at rehab. He was doing a wheelie, and it suddenly became very easy. He thought he’d achieved the state of zen. He told the therapist it was so easy he felt like he could take a nap in that position. Evidently that made her suspicious. She looked down and realized she hadn’t locked his tip bar in the upward position, and it had slipped down and he was balancing on it. We had to give rueful laughs at that.

We discovered something is eating into the wood at the bottom of the columns on the back patio and leaving little piles of “sawdust.” The termite inspection guy is supposed to come soon, so we’ll ask him if he knows what it is.

Gary’s new pants-getting-on record is 6 ½ minutes.

October 11, 2006

I am finally feeling somewhat better today. At least, I was until my massage therapist got ahold of me this afternoon ;-). I’ll give it another day or two before I resume any exercising, though – not quite up to par.

And speaking of exercising, Gary has increased his weights on a number of exercises: the wrist curls, cable cross-overs, punches. He can also do two sets of thirty on lat pulldowns and row, instead of just one set as before. He did his entire wheelie session with the therapist while watching the news on TV. She then asked him to tell her what he’d heard on the news. He said he couldn’t remember much :-). His excuse was that it was a long story, not just headlines. She told him next time she was going to give him a quiz.

He also proudly noted tonight that he got his entire dinner himself (mixed salad, and spaghetti with sauce and grated cheese). He said the whole wheat capellini, which he tried for the first time tonight, is pretty good. I never thought I'd see the day when he ate whole wheat spaghetti. He also says the cereal with twigs is pretty good – though not as good as the more name-brand high fiber cereals. I suspect he finds this to be the case because the twigs cereal contains only about two-thirds the sugars as those other kinds ;-).

October 12, 2006

Record-length dig this morning :-(. I had to zip back from the chiropractor rather than stop in the store first cuz when I left for the chiropractor, Gary was still in bed, and he was frustrated at having to be in there so long this morning. In fact, everything took so long he had to cancel the bus to take him to the university, but again he said he didn't feel the need to go in.

October 13, 2006

A few emails are prompting most of tonight's entry.

Jane Brown passed on an interesting article about a fledgling study on functional electrical stimulation (FES) training in those with SCIs. Two days a week the participants train on the bikes with the electrodes and functional electrical stimulation and then one day a week they have them try to achieve some voluntary muscle contractions without any artificial assistance or stimulation. See http://www.utexas.edu/features/2006/spinal/index.html

Someone thought Gary's wheelie practice seemed rather risky – I guess I should have made it clear that when he is doing the wheelies, a therapist is behind him holding onto the gait belt that is wrapped around the axle of his wheelchair, and she would pull him upright with it should he overbalance. Don't worry, I wouldn't let him be doing wheelies without this supervision, and he says he learned his lesson at Shepherd not to do them on his own at this point ;-)

Someone else said it is hard to tell how things are going over here now that I've tapered off on the blog. Not sure exactly what to say. "Maintenance" still takes us a ("ridiculously") long time (especially Gary, of course), but progress is being made slowly but surely. Most of "my time" I've been spending on revising my story (or at least, staring at the pages while ripping my hair out). Sometimes I like my writing, sometimes I don't. I am "worried" about the characters, that people aren't going to like reading about them. I think I may have to write under a pseudonym. Or at least put a disclaimer to my family: "I am not any of these characters and neither are you so don't worry about it." Sometimes I think I should go back to fanfic ;-) I wish I could write the story faster.

These past few weeks I haven't been spending time organizing the house, because, frankly, that isn't fun and I was in need of some serious fun (which, despite my moaning, writing is). I had planned to get back to some organizing last week, but then I got ill and I didn't feel like doing much of anything, I was so tired. I am still not quite recovered. Our major goal in the organizing respect is to clear the gardening stuff from the "dining" room and put it in the garage. That would give more room in there for Gary to have things he would like to get to handy. My other "major" goal is to get my books organized, and I still haven't gotten around to that.

The housekeeper seems to be working out fairly well.

Neither of us have gotten on the futon and watched TV. Gary watches the news or sports when he does his elastic band exercises on non-therapy days. I haven't turned the TV on at all. As I said, "my time" is mainly spent on my writing, "our time" on maintenance stuff, "his (non-maintenance) time" on therapy or work-related stuff or whatever else he is doing that he isn't telling me about ;-). When the time needed for his maintenance activities goes down, then I presume we can get a little "joint leisure" in there (which right now only seems to consist of grocery shopping, if you call that a leisure activity ;-)), but I don't expect that to be for awhile – not until his flap restrictions are lifted or modified, and the soonest that would happen is the last week of November when he sees the "flap doc."

So, let me know if there is anything you are curious about :-)

October 14, 2006

Gary spent the day organizing.

October 15, 2006

Today's lesson: pull away slowly from the ice cream place's drive-up window after handing your paraplegic husband an ice cream cone that the people in the store may not have packed the ice cream down into. "Fortunately" the ice cream landed in his lap and not on the car floor.

October 16, 2006

The termite inspector guy came today. He said it is carpenter ants that are burrowing into our wood columns on the back patio. I guess the wood has been softened by water damage, and that attracted them.

Gary found out the results of the study of the traffic intersection where his accident took place. It claimed that the traffic count is not high enough to warrant a traffic light there. I guess we'll have to wait until the population of the area increases or someone with influence is in a bad accident there.

October 17, 2006

Gary said he read one of my recent blog entries and noticed I said our joint “leisure time” consists of grocery shopping. He said I should add in our periods where I help him stretch and give him a bath, since we also listen to music and talk during those times. That certainly *is* more relaxing than going up and down grocery aisles ;-). He said there is another half hour after dinner and before our evening routine that we could use to watch TV. We thought about watching last year’s “24" (we’ll have to start over), but since that would take us 48 days of watching it straight through, maybe we’ll start with movies. :-)

I had to go to the dentist for two fillings. It was a much easier experience than last time, for some reason – the area numbed up better (I have to use carbocaine, a less effective numbing agent but one that doesn’t affect me as badly as some of the newer ones). I didn’t even feel like biting his hand off this time. Unfortunately, however, they took a full set of x-rays and discovered two more cavities! Grrrr. I guess I am going to blame all the stress of the past few months for causing my teeth to rot.

As of today, I have just been supervising Gary with his transfers (crouching at ready in front of him) instead of having my hands on his hips. He is still getting too close to the edge of the bed for us to feel comfortable with my leaving the room while he does it, but this is progress. I think it’s partly psychological that he doesn’t get as far back on the bed when I don’t have my hands on him, because I haven’t been giving him any lift at all.

October 18, 2006

Blackjack brought in a critter today (chipmunk), which surprised the heck out of Gary and me. He’s never brought in anything before, and we didn’t think he was fast enough to catch anything. Luckily, it went out the kitchen door, which Gary had opened, while I was off after a towel (I was going to ask Gary if I should use a bowel – oops, I mean, ‘bowl,’ Jamie – but by the time I got back, the beastie was out of the house). Blackjack then ran after it , but he stopped when I yelled at him in a voice of reprimand and let me pick him up and take him back into the house – Tigger would have had no truck with that. It probably helps that Blackjack is not much of a meat eater – he’s never interested when Gary has chicken or fish, whereas Tigger is right in Gary’s face. I’m wondering if Joe had a similar experience.

Next, Tigger had a dead beastie on the patio, but we shut the doors and I got it in a grocery bag (and into the trash) before Tigger could bring it into the house. But then he did later bring one into the house (dead, fortunately). And I found another dead one right outside the side door. Hmm.

Today I was sick from yesterday’s anesthesia – felt like poison was circulating in my body, making my body hurt and making me feel sick to my stomach. I don’t know if it was such a good idea to make my appt. to have the other two teeth filled tomorrow. But if I didn’t do it then, it would be over a month before I could get in. *Sigh*

Gary went to his first graduate council meeting. The LETA bus let him out right in front of the building, so that was good! And he said his push back to the math building was no problem – said it was downhill all the way, and he made it in twenty minutes. He said a fast walk would take someone fifteen minutes. He then said he could have made it in fifteen, but he'd been being careful because it was new territory. He then imitated going back in fifteen, saying, "'Whee! Look, no hands.' Crash."

Which reminds me. I was a little perturbed with him Monday when he called from school saying he needed me to help him in the door when he got home later in the day. He hadn't doublechecked his tip bars after the therapist put them back on after therapy, and first they had fallen off when he went to get in the LETA bus, and then when the therapist put them on, she put them in too far. You might remember that that is exactly what the therapist at Shepherd had done, and when Gary went into a wheelie with them like that, he overbalanced and landed on the back of his head. Gary insisted that I didn't need to come to the university to put them in right, that there were no places between school and home where he was going to need to do a wheelie (whereas at home, he needs to do a little one to get into the house). I worried some about that until he got home. I had told him to get someone to accompany him to the bus when he left school, but since he said "I'll think about it," I'm sure he didn't.

October 19, 2006

Back to the dentist for the other two fillings. I always wonder why at the end they ask you if your bite feels all right, when by then you can't feel much of anything (maybe I should have said, "Let me bite you and I'll see").

Next it was off for a massage. Not that I purposely timed it that way, but it was a good way to start getting those anesthesia toxins dumped into the lymph system. On the other hand, that can sometimes make me feel pretty sick, but as of Friday morning, I don't notice any increase in the ill effects of the anesthesia. Fingers crossed.

Later in the afternoon on Thursday I took Gary to his appointment at an office of the Department of Vocational Rehab in the next town over. The woman Gary saw is going to hook him up with a person from the Lakeshore Rehabilitation Facility in Birmingham. Evidently this person specializes in the "adaptive drivers evaluation" for those with SCIs and head injuries. Based on the evaluation, the guy will recommend a vehicle for Gary, along with what modifications should be made to the vehicle for his particular case. Based on our income, we will most likely have to pay for the modifications to the vehicle ourselves, but it is possible it could be presented as a "RAVE" case ("Retaining A Valued Employee") through the university, and if so the Dept. of Vocational Rehab would pay for the modifications. It wasn't clear what the likelihood of that is – I guess we'll wait and see until after the evaluation.

By the way, if you are telling someone an anecdote, after fifteen minutes, it is too late to say, "To make a long story short." We could have been done with that appointment a lot sooner ;-). The woman was very helpful, however.

Gary found a nice article about a paraplegic golfer. He doesn't seem to have been inspired to follow suit, however. You can find the article at: http://www.palmbeachpost.com/sports/content/sports/epaper/2006/10/18/a1c_trick_shot_1018.html

October 20, 2006

Well, shoot. We discovered Gary has an ingrown toenail. At least, I guess that's what it is. It's further down the side of the nail than I thought those things were. We (and I say 'we' because I am the one who has to get the wash basin ready) are soaking it in antibacterial soap several times a day (Gary got on the internet to see what we should do about it). If it doesn't clear up in a couple days, he is going to the doctor or emergency room – I ain't going to fool with this.

October 21, 2006

I decided a new mattress wasn't going to magically appear on my bed, so this past week I once again called around to mattress places. Found two in the area where they let you have a trial period. Today Gary and I were going to go to these places. One was close to a Wal-Mart, and Gary said he also wanted to stop in there to look at shoes. On our way, we discussed mattresses. I don't really know what type I want, not even what level of firmness, and I feared it was going to have the same result of the last time we did this – me laying around on different mattresses, but not really knowing which felt right. Consumer reports claimed their research showed if you laid on a mattress for five minutes on each side and on your back, your feeling for how much you liked the mattress was strongly indicative of how you would feel about it months later. I am skeptical, however. Anyway, Gary suggested I just get one of the Marriott Residence Inn mattresses (they sell these commercially), since I had thought them pretty comfortable during my stays at such inns both in Birmingham and Atlanta while Gary was in the hospital. Not that I slept well during those times (ironic grin).

So, I decided to do that. Gary said it was okay if after I got it, if I found I didn't like it then I could sell it and go back to these mattress places.

Gary said my shopping trip was thus a success, since I decided what I wanted. :-)

At Wal-Mart we looked for shoes for him. Turned out he just wanted something he could cut the toe out of, in order to let his toe heal. We got him a cheapo pair of velcro tennies. He complained after he got home that he looked like a dork with his black sock sticking out of the toes of the shoe. I told him that with the toes of the shoe cut out, he couldn't avoid looking like a dork. He said, "Good point." I told him that if he wore white socks, it wouldn't look so noticeable, and he decided that was a good idea.

Someone emailed Gary and asked him if his attitude about what is important in life had changed any since his accident. He told me it has, slightly. I asked him how. He said his relationship with me was more important now. And not just because I had to help him with his bowel program. ;-) He also said relationships in general were much more important.

October 22, 2006

Gary read the blog and corrected me, saying that last Monday it had been the bus driver who noticed his tip bar had fallen off and who then proceeded to put it back in, incorrectly as it turned out. Now I feel SO much better that Gary let a bus driver put his tip bars in for him ;-) (Needless to say, in the future he will do that himself!)

Today at the fish counter at Kroger, Gary asked for some Mahi-mahi. The fish man picked up a fillet, laid it in one of those little plastic trays, and asked if that amount of fish would be enough, tilting the tray toward us as he spoke. The fish slid out of the tray and off the counter, the fish man winced, Gary groaned – and I caught the slippery flying fish. :-) Gary and the fish man looked at me in astonishment, and the fish man asked me if I practiced martial arts, given my reflexes. I laughed and said no, and then as we left the counter I joked to Gary that my reflexes were probably so highly honed from having to be prepared to catch him in case he lost his balance during transfers and such. He said he wouldn't be surprised if there was some truth in that.

As we drove to the ice cream shop, Gary laughed and asked me if I remembered the very first "trip" I had taken him on, to the movies. I said I sure did, that at the time he had reminded me of one of those bobble-head dolls, what with all the "wobbling about" he was doing in the car. Since he doesn't do that kind of thing much any more, I asked him if it had really been my driving, as he seemed to indicate at the time. He admitted it had mostly been his problems with balance, which he is much improved with now. But he also thought I drive smoother now. Mostly ;-)

Speaking of improvements, this morning Gary did his best transfer ever from bed to wheelchair. He was very, very pleased with it. Now, he's hoping that it is repeatable. He also said he felt really, really good today, and since the accident he has only made that comment a couple times before. He says most days he still feels "not quite right" in the afternoon (muzzy, I think) and tired out in the evening. But he said he felt good all day today, and he felt that way last Wednesday. Hopefully these times will become ever more frequent.

Dolores suggested we get a cat door that locks, so our cats can't get in without us letting them in – this way they couldn't bring critters without our approval (which we would not give:-)). But we think our cats are too old to learn to be outside cats (they're fourteen). I have visions of them always hollering to be let out when they're in, and then coming around to my study window and hollering at me to let them back in. Not to mention that if a big dog comes in the yard (and there are those who let their dogs run around unleashed), they'd come tearing to the cat door and brain themselves on the locked door. And since, in general, they can't tell when the door is locked or not, this seems a little cruel to have a peephole to the nice warm house with food on the other side, but they can't get in ;-)

We got the bill for Gary's helicopter transport to UAB Hospital. $18,000. According to the bill, insurance is only paying half of that!

October 23, 2006

Gary continues to go up in poundage on the weights.

I found the head, tail, and some entrails of another chipmunk, plus another dead whole one. Fortunately both of those were outside.

October 24, 2006

Gary's new chair was delivered. It has side guards and a more contoured back, both of which should keep him straighter in the chair – unfortunately he thinks the side guards are too high, as they dig into him when he bends to the side to pick up something from the floor. He left a message with the supplier to see if anything can be done about that. The front of the chair is more compact, so he can pull up closer to things. The back has more padding, which I'm hoping will be a boon for his flap, and it doesn't go up as high on his back, which should give him more freedom of movement. He discovered he can do a three hundred and sixty degree turn (that's all the way around, mom (wink)) in the kitchen while in it, rather than having to back in to get to the fridge and back out and turn around to get to the sink.

The supplier who brought the chair said they still talk about him at Shepherd, though not by name – specifically, they talk about the guy who smacked the back of his head on the floor because the therapist didn't put his tip bars in right.

October 25, 2006

Today's big adventure was to the podiatrist, whose manner we really liked – very personable. He started by asking Gary some general questions, and one was, "How old are you, if you don't mind my asking." That struck me funny, so I said, "What if he does mind you asking?" The doctor smiled and said he'd ask anyway. He gave Gary some antibiotics to take for the toe infection and recommended that he have a procedure done where the doctor removes a vertical strip of nail on the edge of the toe to prevent future infections. The doctor said he did three or four of those a week, and maybe three or four came back in a year with infections in the same area. He said he commonly did it with people who have paralysis. I asked a couple things: whether Gary had gotten this infection because I hadn't cut his nails properly, and what made the doctor think the infection would recur, given that Gary didn't have a history of them. The doctor said that if he knew the answer as to why Gary had gotten the infection, he would say it had nothing to do with how I'd cut the toenails – they looked fine to him, and the infection was in the middle of the nail, not at the top edge. He thought the reason Gary got the infection was a result of the fact that his feet swell as a consequence of the SCI. The toes also swell, and this makes the nails press into the sides of the toes, a condition ripe for an infection. Because Gary's feet will continue to swell, he is at greater risk for infection. The doctor seemed to indicate that there was a greater risk of the infection occurring at a place where Gary had already had one, which is why the doctor recommended removal of part of the nail of that toe. But he was not going to take a pre-emptive strike by removing the edges of nails of the other toes.

So, Gary got a prescription for an antibiotic and some betadine for soaking his feet (twice a day for twenty minutes using two capfuls of betadine). He is to take the antibiotic twice a day, and supposedly should see marked improvement in three days. We also set up an appointment for him to have part of the nail removed on Monday.

But we got to talking about it at home. I'm still a little leery of the "cut it off" approach, thinking maybe Gary should wait and see if this actually is a recurring problem. I suggested he call Shepherd and ask their opinion, and he said he is going to do that. He also said if his toe looks much better by Monday, he'll ask the doctor again about it again.

One weird thing – Gary has had a problem with fungus on three of his toenails for the past fifteen years, and now, suddenly, it looks like the fungus problem is clearing up – the new nails growing at the bottom of the toes look fine right now. We're not sure how that could be a result of his SCI, but we can't think of another explanation (though we doubt that, in any case, getting an SCI would ever be a recommended treatment for the problem ;-)).

Let's see, what else. Gary had to go back down in weights on a couple of exercises he'd recently gone up in weights on – the lower back on his new chair led to some problems in being able to balance while using those greater weights. He'll no doubt go back up in weight when he gets use to the chair. He also finds balancing in a wheelie to be different in this chair – so far it takes more concentration and effort.

One strange thing about the new chair is the tip bars don't adjust very high – Gary even drags the bars when he is doing a little wheelie to get into the house, and he certainly didn't do that in his old chair. The supplier said that the only way to get this tip bars up higher would be to saw about an inch off them, and then drill a new hole in them so they will click in place. I hope this doesn't become a problem, as right now we are not inclined to do any sawing – but if he is out somewhere where there is a small curb, he might have to have someone bump him up or down it, as neither of us is comfortable at this point with him flipping his tip bars out of the way and taking the curb without them.

Oh, and speaking of curbs, the podiatrist's office had accessibility issues. Gary couldn't have gotten in the door himself – there was a curb at the threshold of the door (which seems an odd construction), and Gary would have had to do a wheelie while holding the door open.

Another ADA-related note. Gary said he read that some blind people are suing Target because their website is not accessible to blind people (I don't understand the facts behind this – Gary knew a little about it, saying there is some software that makes webpages accessible to blind people, something like it translates the links into words). Target is claiming the ADA only applies to physical space, not cyberspace.

Tomorrow Gary goes to the dentist, our next adventure.

October 26, 2006

The dentist's office was accessible, but a tight squeeze for the wheelchair. I had to climb onto the rear of the dentist's chair to help Gary with his transfers. They were pretty easy transfers, however, since the dentist's chair adjusted in height. The hard part was getting his wheelchair cushion under him in the dentist's chair – Gary depressed on the arms of the dentist's chair while me and the dental technician pushed and pulled the cushion under him.

Gary had no cavities.

Later in the day, I noticed that the footplate on Gary's new chair was too low – his feet barely touched it. To adjust the plate I had to get on the floor and use an Allen wrench (who is Allen?) on screws on the back of these little holders that were on the bars holding the footplate – naturally they would put the screws in back where I couldn't see them. I kept trying to loosen the screws a little at a time, but I couldn't budge the plate, so I finally unscrewed them all the way and some unknown pieces went flying across the floor as the holders slid down the bar. I had no idea where those pieces were supposed to go. I still had to put a lot of effort into tugging the footplate into position, and then I had the problem of figuring out where to put the mystery pieces. Finally, after a lot of swearing, I figured out a likely place for them. I then hoped that was where they went as I tightened the screws back in, and it seems to have been so. At least, Gary's footplate hasn't dropped off, indicating I was wrong. At least, it hasn't dropped off *yet*.

Gary and I watched our first bit of t.v.(while Gary was soaking his foot) – twenty minutes of The Brooke Ellison Story, directed by Christopher Reeve, about a girl who becomes a quadriplegic after an accident – Gary chose the movie. I understand the story is supposed to be inspirational, but I tell you, I could hardly stand to watch the first twenty minutes which covers her accident and the first six weeks she was in the hospital (she was in a coma for a while). Brought back sharp memories of Gary in ICU.

It has been brought to my attention that Joe, not Dolores, was the one who suggested the locking cat door. Blackjack said he is too old to be climbing trees to get away from stray dogs.

If you *really* and *truly* like to be scared, below is a Halloween link, sent to Gary by his brother Bob. I don't want my mom or Gary's mom or anyone that doesn't have a strong heart to follow the link, however. I mean it, so don't get mad at me if you go to that website and don't like the consequences. Here is the email being sent around that pertains to the link:

Subject: Two Almost Identical Photos
Date: Mon, 23 Oct 2006 21:06:41 -0600

Check this out. See if you can get it. If you can, you're a genius like me. There are two pictures almost identical to each other; you have to find three differences.
If you can find three differences, then you are part of an elite group of individuals.

This has been tested on 1000 people, and only 10% could find the three differences.
All three differences exist. Try it!! (Hint: Look at the town) Two almost identical pictures
http://members.home.nl/saen/Special/Zoeken.swf

October 27, 2006

Gary went back up in weights on those couple he had to drop down on because of his new chair, so he accommodated to the balance differences fast! His therapist adjusted the angle of the footplate on his chair, which I had thought should be done but was willing to let her do it ;-), and she also raised the plate a little. But unfortunately now Gary can't roll up under the kitchen sink because the raising of the plate made his knees too high to get under it, so I'm going to have to fool with the plate again. Rats.

We had rain throughout the day, and I feared Gary was going to get his feet soaked because he hadn't yet gotten galoshes like I suggested, but the bus driver pushed him from rehab into the bus and again from the bus into the math building, so Gary's feet didn't get wet (the rest of him and much of the chair was covered by a poncho).

We watched another twenty minutes of Brooke Ellison. If I hadn't known it was based on a true story and that Christopher Reeve had directed it, I would have thought they had their facts wrong. The girl was definitely not at Shepherd! I can't imagine the staff at Shepherd talking to the girl and her parents the way these staff were doing, or trying to regularly serve up a sedative to the girl because "it made things easier." (Not to mention that I doubted they'd leave the medication with the mother.) The part where the neighborhood showed up to help Mr. Ellison remodel his home had me bawling, thinking of the volunteers who worked so hard to make our own house accessible to Gary.

On a completely different note, Gary's increase in the amount of fiber he eats has really been helping regulate his bowels – it took awhile for his body to get used to it.

October 28, 2006

We tried a few things differently with the shower routine. First, since Gary has been practicing transfers where I'm supervising, only sticking an arm out when it looks like he might have lost his balance a little or is a little close to the edge, we decided that trying to do that kind of transfer to his chair from the bed while naked would be a lot easier than for him to do the transfer using the transfer board. So, we tried that, me holding his hips because this was his first such "naked transfer." But I didn't give him any help on it – no lift or twist – so if he's comfortable with it next week, I will just supervise him on that kind of transfer.

Also, we decided to turn the shower bench ninety degrees so that Gary's back is to the controls instead of him sitting sideways to them. This allowed him to get his wheelchair in a similar position to the bench as he has the wheelchair to the bed when he makes those transfers. It then looked like a depression transfer – without using the transfer board – to the shower bench would be pretty easy, although since this was his first time doing it and particularly since he was naked, I aided him by hanging onto his hips. On the way back, I aided him by putting my hands on his sitting bones, because the transfer was an uphill one. He hasn't been practicing any uphill transfers since Shepherd, so he'll/we'll either have to add that to "things to do" or he'll just get used to them slower by practicing them once a week in the shower. He couldn't do these depression transfers with the bench facing the way it had been, so I am glad we had the idea to change the position of the bench – these depression transfers are a heck of a lot easier than the transfer board transfers.

We watched more of Brooke Ellison. I find it less traumatic now. I am still extremely glad Gary isn't quadriplegic. I certainly know I couldn't have handled his care alone. When we started the movie tonight, Gary said he wondered if they'd show I.C.s and the bowel program. I said I bet they wouldn't. I was right, and Gary said later he bet they weren't going to, either. And he said that he wished they would. They give some idea of the time it takes for the girl's "maintenance," like her mom having to get up at 4:15 am to get the girl to school on time, and they did show things like the mom bathing her and brushing her teeth, but Gary thought they should show ICs and bowel programs – he wanted it "more realistic." I told him he'd have to wait until I wrote "his" movie. We're trying to figure out a good ending. Traveling to his first math conference as a paraplegic?

Oct 29, 2006

Today after we finished shopping at Kroger and we'd gotten Gary into the car, we saw Phil Zenor heading into the store. I hailed him, and he came over. I was breaking down Gary's chair, and Phil asked if I wanted help or if I "had it down." I told him I had it down, and Gary piped in that I do it all the time. I then proceeded to lose my balance backwards (not sure how), went stumbling several feet, and landed on my butt. Unfortunately, a woman with a grocery cart was passing by just at this moment, and I bashed the back of my head on the side of her cart. Ouch.

Gary was quite amused (after making sure I wasn't seriously hurt, although I did get a headache and now have a sore head), and he laughed about my claiming to "have it down" and his saying "I do it all the time," and then my falling on my butt – that was not what we meant!

We watched more Brooke Ellison in the evening. I believe the movie is based on a book, and I may have to get the book. We are wondering how realistic the movie is. This girl is always up. And at this point in the movie she's at Harvard (it is true she graduated from Harvard – her mom right along side her all the way as her care giver) and this handsome, witty, lovable guy has apparently fallen in love with her. We are wondering if he knows about bowel programs.

Oct 30, 2006

Today I took Gary back to the podiatrist. We asked what would happen if Gary was only treated with antibiotics and didn't have the procedure done, and the doctor thought it was likely the infection would come back, because the nail would still be pressing in there. So Gary decided to have the procedure done. The doctor had said he planned to "numb" the toe, and we made sure that he knew he should use the same amount as if Gary had feeling there (to avoid setting off dysreflexia – we're hoping Gary never experiences that). Because it was Gary's toe and not mine ;-), I watched the procedure. I think looking at that great big needle containing the anesthetic going into my own toe might have made me faint! Interestingly, Gary's foot knew something was going on, because it did some twitching. Gary didn't feel a thing though. Then I watched the doctor cut a vertical strip of toenail off down the side of the toe – he said he was taking out a bigger strip than he normally would, because of the swelling of the feet that Gary has. I winced in watching him cut the nail down all the way – Gary said he watched part of the procedure, but not all of it. After this was done, the doctor applied phenol at the base of where the nail had been, the idea being that this would prevent the nail from regrowing there.

The procedure took about ten minutes. The paperwork took about double that. And the wait to get into the treatment room took double that. My pet peeve about doctors is their scheduling.

To finish, the doctor wrapped Gary's toe up good, then put him in a "goofy shoe." Since Gary has been wearing his own version of a goofy shoe, he didn't mind too much. He is still taking the antibiotic, and tomorrow I will take the bandage off. After that we go back to soaking his foot twice a day, and Gary will continue to wear the goofy shoe the doctor gave him, along with his regular t.e.d. hose and sock. We go back for a follow-up on Thursday.

We discovered the doctor has a little wooden portable ramp that enabled me to get Gary in the door much easier (i.e., without giving myself a hernia!). Gary would still not be able to do it alone. He'd need someone to hold the door on the way in. On the way out, there is hardly any distance from the end of the ramp to the curb of the sidewalk, so if he did it himself, there would be a danger of him going off the ramp and continuing on flying off the sidewalk. Needless to say, I held onto the handles of his chair.

Speaking of the foot twitches, one thing that started happening after we got home from Shepherd that never happened there are all these leg spasms Gary now has. Fortunately they don't interfere with his activity (if there ever comes a time they do, the standard procedure is to put him on medication to stop them). They mostly come after he transfers into bed at night, and after I stretch one leg and am about to start the other. We joke that his legs are trying to run away. None of the movement is voluntary.

We finished the Brooke Ellison story tonight. Both of us cried through the ending – of course, we are saps ;-) Gary is even worse than me when it comes to crying during movies – and TV shows, for that matter. I have always found that endearing.

Oct 31, 2006

Two Sundays ago, our housecleaner called us just before she was due to arrive, saying she had some church thing she'd forgotten about. Last Sunday morning, there was a message on our machine from her saying she would not be coming, and that if we wanted more information, to give her a call. We didn't think that was a good sign. Gary called her today. She told him she couldn't work for us anymore, because the situation was not what she was used to. She meant – get this – that she couldn't work around the fact that we still have boxes on the floor – she couldn't take the "clutter." (There are two rooms that she is supposed to clean that still have boxes – the master bedroom, which Gary is still trying to organize, and my study – I'm still organizing my books on the shelves; yes, I'm slow. We had told her not to bother picking up the boxes or anything, just clean around them; evidently this went against her sensibilities.) I would find this hysterically funny if not for the fact that we have to find yet another person to houseclean. We called the next person on our list . . .

Nov 1, 2006

Well, this made my day (and more ;-)): I found out (thanks, Debra!) that the person who has been writing a book on the Remington Steele series gave a copy of my fanfic novel to the creator of the show! I emailed Gary about it, and he asked if this meant that a movie based on my story was not impossible. I told him we could upgrade the likelihood of such a thing happening from impossible to highly improbable.

Oh, I suppose I should put something about Gary ;-). He has begun writing up a paper of some results he got shortly before his accident. He says it is coming along slowly but surely.

We found out a little more about that huge bill for the helicopter flight. Turns out we owe around fifteen hundred – but now we have to argue that we were mistakenly billed. Still seems like $18, 000 is a ridiculous amount to charge for that distance. I would hate to be someone without insurance who needed that ride!

Nov 2, 2006

Now we're trying where I watch Gary do his transfers while standing about two feet away. I still tend to move forward as he makes the transfer ("just in case"), but he says that's okay – that when I'm to the point where I'm half a room away, I won't be able to cross over to him that quickly anyway. At this time, he's not comfortable with me leaving the room during the transfer (and neither am I), so we are proceeding with me moving back maybe a foot or so each day.

I took him to the podiatrist. His toe is healing nicely. I'll take him back for a follow-up in ten days. Right now we're back to soaking the foot twice a day, and he is finishing up the oral antibiotic.

Nov 3, 2006

Tonight I moved back to three feet away during the transfer. Gary noted how surprising it is that after months of not seeming to be able to improve on transfers, something has finally kicked in – though he's not sure if it's strength, technique, or what – and now he is doing them so much better. Yea!

Nov 4, 2006

Well, so much for me braggin' on Gary's transfers ;-) I had to go charging forward and help him back onto the bed this morning because he didn't make it all the way onto the wheelchair during his transfer – maybe because it was a "naked" transfer (since he was going to take a shower). We were a little worried because he probably landed on the brake handle with his flap – all we need is for that to poke through him – but we could find no damage, thank God. But the incident didn't stop Gary – he still had me stand back three feet while he tried it again. He made it fine, and in fact after his shower did one of his best transfers back onto the bed (which is where he dresses).

Nov 5, 2006

Gary asked if I was nervous about watching him do the transfer from four feet away. I said, yes! I know he's been doing the transfers so much better now, but I can't help worrying that one time he won't, and I won't get there in time to prevent him from going on the floor. And then we'll have the problem of getting him back up on the bed, and he might hurt himself, and it'll be all my fault – Gary stopped me right there and said that that won't be the case, that it's his choice. I told him his mother will be mad at me, though.

We started to watch the movie "Crumb" a few days ago, but saw all we wanted to see after the first twenty minutes – sorry, Donne. So now we are watching DVDs of Dorothy Sayers mysteries sent to Gary by J.P. and Pam Holmes while Gary was in the hospital.

Nov 6, 2006

Had to take Blackjack to the vet today. Noticed yesterday that his voice had changed, and today he could barely croak out a sound. Of course, that tempted me to NOT take him to the vet, but since he wasn't eating very well and just laid curled up looking pathetic, I decided I'd better ;-). The vet couldn't find anything obviously wrong with him – he didn't even have a fever. But she gave him a shot of penicillin and gave me a bunch of antibiotics for him to take. Rats. Giving antibiotics to cats was another one of "Gary's jobs," or at least a two-person job. I could never hang onto one of our cats and get the pill down its throat. Somebody finally invented chicken- and fish- flavored "pill pockets" that you can stick the pill in and supposedly the cat will eat the pocket right down without tasting the pill. That has worked on Tigger, but I have my doubts Blackjack will go for it – we'll see.

Gary told me Michel Smith visited him in his office and asked him about accessibility issues. Michel had gotten the university to put in a sidewalk behind the math building so that when Gary wheels down to the handicap parking area he doesn't have to wheel behind parked cars but can stay on the sidewalk. Gary was hoping that sidewalk would be extended farther to another parking lot where the bus picks him up. Michel is going to look into that.

Gary said Michel also asked him if he was going to go to the Spring Topology Conference, and the way Gary said this to me I could tell he was feeling me out on it (since I don't think either of us thinks he'll be independent enough to go by himself by then), saying he wasn't sure I'd go for it (I'm not sure if this is what he said to Michel). My first inclination was to say, "No way!" because it would be such a huge undertaking – getting all my stuff there and his stuff there (it's in Missouri, so I'm pretty sure we'd fly), having to do his routine in a hotel room in a regular bed instead of his electric hospital bed, which would involve a completely different set-up that he (and I) would have to figure out how to deal with before then, not to mention whatever challenges the conference itself would pose. Etc., etc., etc. But I said if he really, really wanted to go, I'd help him attempt it. I told him that we would have to first practice by going to a local hotel sometime. He said he's not sure he'll be up to going by then, anyway – he said that he certainly couldn't undertake such a thing now. So, we'll see.

Nov 7, 2006

Today Gary made his first transfer to the futon – the idea is for him to do his stretching there. Because it was a new surface for him to transfer to and from, I "helped" him by holding his hips, but I really didn't have to give him any help at all. I had to pad him off and put the chain loops around one foot, and then the other foot after he had gone through his exercises with the first leg. Before this, I was basically stretching his legs for him as there wasn't enough room on the hospital bed for him to maneuver his legs around. So, another step in his independence.

Nov 8, 2006

After Gary transferred into bed this evening, he told me that his therapist had a trainee at rehab and that they had discussed his case while he was doing his exercises – he said he found it weird to have them discussing him while he was right there. I asked him what the therapist had told the other person, and Gary mentioned things like how his balance has improved a great deal and he is stronger, things like that. I guess this must have set him to thinking back on things, because he then commented that when he was in the hospital in Birmingham during those beginning days, the thought of being on an exercise mat was scary. I didn't understand and asked him to explain. He said that a PT had come and seen him there a couple of times but didn't really do anything with him, saying she couldn't do so until they got him on a mat – so he knew that would be part of rehab. But he had found it scary to think of having to use such a small proportion of his body (from nipple level up) to move the all the deadweight (below nipple level). He said that when he was just lying in the bed in the ICU or in the nursing unit, he didn't have to think about it – one doesn't move about much in bed anyway. Though he is now used to it, he found it hard to think of the "stuff" below his nipples as part of his own body – it felt like someone else's.

Nov 9, 2006

The new housekeeper, who said she absolutely was still interested in working for us and would be at our home today at 1 pm, was a no-show (Peg crosses her eyes).

Nov 10, 2006

Well, turns out the cleaning person was in the hospital with pneumonia! We decided this was a reasonable excuse for not showing up and are having her come next week ;-).

Nov 11, 2006

Michel Smith came over to see if Gary could transfer into his SUV, with help. First Gary thought it might be easier to get into the back seat because there was more room to maneuver, so he and I tried that uphill transfer with a transfer board. But we couldn't figure out a way to do it successfully (without having someone actually pick Gary up) – we only got him about halfway up the board. So next we tried to do a transfer into the front seat, and it worked! Going into the front seat he had the front door to hang onto and help him, whereas the back seat had a sliding door that gave him nothing to hold onto. I gave Gary a bit more aid than usual during the transfer, mainly in preventing him from sliding back down the board as he did little hops up the incline, but I didn't really try to pull him up the board. Transferring back out of the car – downhill – was a piece of cake. We showed Michel how to break down the wheelchair, and it fit easily onto the back seat of his car when placed upside down. Michel put the chair back together again, and then it was his turn to help Gary do the transfer. I am going to claim that Michel gave Gary much more lift than was my intention to do – surely it can't be because Michel is stronger than me ;-) – and the transfer went beautifully. Gary was delighted. Michel has offered to drive Gary home on Mondays after the seminar Michel runs and Gary is attending. This way Gary will have some nice company for the trip and he won't have to wait around for the bus.

However, we discovered in the evening that his uphill transfers from the wheelchair to the futon still need practice before I start standing away from him (he came up short and I had to pull him back onto the futon – he ended up in an awkward position on his side, and it took us a little thinking of how to get him in a seated position again). For his transfers between the wheelchair and bed, I am probably about ten feet away. If he's ready to try it, tomorrow I will be out of his sight around the corner.

At bedtime, after I congratulated Gary again for his successful SUV transfer, he thanked me for my encouragement throughout his attempts at it; he said I really supported him, and he appreciated it :-)

Nov 12, 2006

Gary made his first transfer with me out of his sight – his easiest transfer, the one where he goes from his wheelchair to the bed. I stood around the corner of the bedroom and made him count out “one, two, three,” so at least I would know when he was making the transfer. Then I stood there and silently said “Please, please, please,” to myself (as in, “Please let him make it”). As soon as he said “three,” I came around the corner. He had done a great transfer, getting well onto the bed. He asked me if I’d been nervous. I said, “Yeah.” He said that he had been nervous too at not being able to see me, but that maybe that was the reason why his transfer had been an extra good one.

Nov 13, 2006

This morning Gary did another exceptionally good transfer while I was around the corner of the bedroom not able to see him. He said maybe the two he’s done that way have been so good because he knows he damn well better make it. ;-)

Blackjack is no longer fooled by the pills being hid in the chicken-flavored pill pockets. So now I set him on Gary’s lap and hang onto all four of his flailing feet while Gary struggles to open the cat’s mouth and get the pill down it. The poor thing then shoots off of the wheelchair (the cat, I mean, not Gary ;-)). I then give him a reward of some Fancy Feast Cat Food (again, I mean Blackjack ;-)) Blackjack then doesn’t whine for food as much as he usually does, because he’s afraid it might mean I try to shove another pill down him. Gary and I joked that maybe every time Blackjack whines for food, we should shove a placebo pill down him. That would probably cure him of this habit – a little negative reinforcement!

Gary then later yelled that Tigger had brought into the house a big long worm. Turned out to be a little snake – probably the tiniest one Tigger had ever brought in (and unfortunately, he does seem to like to bring in snakes). The only way I can get them out is by sweeping them with a broom into a box, but Gary said this one was so small I could pick it up. No way. Gary decided he himself could get it, and he leaned over and picked it off the floor and took it out of the house. Now, if he could only get the “foot-long plus” ones that Tigger brings in.

Gary had a couple appointments today. On the way to the foot doc, we somehow got talking about car-make recognition. Gary recalled how when he was a kid he wanted very badly to be able to be able to tell the make of a car just by the car’s appearance – all the other boys seemed to be able to do it. So he used to consciously look at cars and try to memorize their distinguishing characteristics – but it never “stuck.” He then finished up this reminiscence by saying that at least he was better than me at it – I sometimes forget what kind of car it is that I am driving or what color it is :-).

The foot doc says Gary's toe is healing nicely and he doesn't think Gary needs another appointment to see him unless there is some problem. We were both glad to hear Gary doesn't have to soak it twice a day :-)

After that, Gary had an appointment for his driver evaluation. Unfortunately, it turned out we went to the wrong place for it, so we ended up being about twenty minutes late. The evaluator asked Gary questions like, "How is your endurance now – pretty good, or are you totally wiped out by the end of the day?" Gary told him it was pretty good. Gary got to skip being asked a whole lot of questions pertaining to his cognitive abilities because he wasn't documented as having had a head injury. The evaluator had Gary go through some balance tests: Gary had to raise both arms straight up (his arthritis definitely limited him on that – not sure how much his balance problems affected that), then straight out to the side, etc. The evaluator said he did fine. He next wanted to see how far Gary could bend forward and bring himself back upright, and then to each side and then back upright, all without the aid of his hands. Not having trunk muscles Gary couldn't bend very far, but he could do it some as the result of learning at Shepherd how to use his head as a counterbalance.

Next Gary had his grip tested. It turned out his grip is about thirty-five to forty pounds below normal. We are not sure why this is so – maybe just from the disuse of his muscles during the hospital stay. I guess this is why Gary can't open the bottles of spring water we get – I have to do it for him. We had been laughing about that, thinking it was somehow psychological or some technique he didn't have down, but I guess it really is physiological.

Next Gary had his vision tested, and it turns out he is color-blind to green! We never knew that before. The tester said that was no problem, however, since he would be able to figure out if a light was red, yellow, or that third color.

Next Gary had his reaction time tested, each hand separately, right then left. He put his hand on something that looked like an accelerator pedal, and then when a little light on a machine changed from green to red he was supposed quickly move his hand to what looked like a brake pedal next to the accelerator pedal. The tester said this machine used to be used in high school driver training classes but it isn't made any more. He also said it wasn't what Gary's hand controls would look like or how it would function. Anyway, Gary scored average on that (both hands), which was fine, and the tester thought that with practice on the hand controls his reaction time would improve.

The tester finished up with a simple strength test where Gary pushed then pulled against the tester's arm.

The tester said all in all Gary did fine and he foresaw no problem in training Gary to drive.

Next he talked to us about the different kinds of mini-vans, mentioning the Dodge Caravan, Chrysler Town and Country, Honda Odyssey, Toyota Sienna, Chevy Uplander, and Buick Terraza. (The Sienna is the one we looked at while at Shepherd.) He told us basically all mini-vans are the same, as far as conversion goes, except the Kia, Hyundai, and Nissan, although there've been some problems doing it with Fords. In the conversion, the floor will be lowered and the middle seats will all be taken out. The driver and front passenger seats start out as “quick-removable,” for access by a wheelchair in their stead, but since Gary won’t be driving in his wheelchair, the driver seat will be replaced by a “transfer base,” which will no longer be quick-removable. The transfer base will, at touches of a button, go back toward the middle of the van (where Gary will have entered in his wheelchair), face Gary, and then after Gary has transferred into it, face around to the front and go back to the driving position.

For floor ramps Gary has the choice of an in-floor ramp or a fold-up ramp. The evaluator said they take up about the same amount of space and he recommended the fold-up ramp because if there was ever any problem with the electronics, it would be much easier for Gary to work the fold-up ramp manually than the in-floor one. Also, the fold-up ramp is slightly less steep, an 8% grade instead of a 9% grade – every little bit helps when it comes to arthritic shoulders.

After Gary transfers out of his wheelchair to the driver’s seat, he would need to lock down his wheelchair in the van so it doesn’t become a projectile in case of sudden stops, etc. The evaluator said the usual place he gets a lockdown system from doesn’t make one for Gary’s type of chair. He called around to some places all during Gary’s evaluation, but I don’t think he came up with a source as yet.

Other modifications that would be made: a spinner knob on the wheel for one-handed driving, and a manual gas-brake hand control. Gary would drive with his right hand and keep his left on the hand control to accelerate and brake. We saw a little video of the “sure-grip hand control” – it kind of looks like a long stick with a grip and is situated to the immediate left of the wheel. You push it in to brake and tilt it back to accelerate. (See http://www.suregrip-hvl.com/) I wouldn’t need to learn this, fortunately – I would just drive the van as I normally would.

I think the last thing he mentioned was a column shifter that would be between the front seats, but I’m not sure if that is any different than the kind of shifter we are used to.

We would have to buy the chassis on our own (i.e., the unmodified van), the typical price around $25,000. The modifications would be in the range of about another $25,000. As I mentioned before, based on our income, we will most likely have to pay for the modifications to the vehicle ourselves, but it is possible it could be presented as a “RAVE” case (“Retaining A Valued Employee”) through the university, and if so the Dept. of Vocational Rehab (VR) would pay for the modifications. It wasn’t clear at our previous meeting with the VR person what the likelihood of that is.

We are to go around and decide what van we want, but we are not to buy one until all the quotes are in. That is, we decide which van we want, and then we tell the evaluator which one that is. He will then collect quotes for the various modifications to be made (he thought that would take about ten days), and he will give these quotes to the VR person. The VR person will then meet with us and tell us what her department will pay for, if anything. Based on that we tell the evaluator whether or not to go ahead. Then the evaluator will work with us and a "mobility dealer," not a regular dealer, to get the van.

Since everything in the middle of the unconverted van will be taken out and the third row seats will not have the option of being stowable because the gas tank will be moved back to make room for the floor to be lowered, the only things we are supposed to be concerned about with the vehicle are the cockpit setup, the warranty, the outside appearance, the accessbility of the van, and things of that nature.

Once we have the converted van, the evaluator will train Gary to drive it. He didn't think it would take long. He said he'd start Gary off in an empty parking lot, then on residential streets, then moderate city roads, etc. He'll be training Gary a couple of hours a day, but I don't recall if he said exactly for how long he expected the training to go on. Since Gary has been driving for 40+ years, what the training is really about is getting used to automatically using the hand controls in an emergency situation. The trainer said that it is automatic that one goes to use the feet to brake in an emergency (dog runs in front of you, etc.) – but of course Gary's feet aren't going to get that message. So the idea is to practice, practice, practice, so that the emergency response is to go to the hand for the brake, not the feet.

We thought it was great that this one person, whom I have referred to the evaluator, not only did Gary's driver evaluation but will get all the quotes, help us get the vehicle, and then teach Gary to drive! Needless to say, Gary gave him the highest marks on the satisfaction survey that finished our meeting.

I was a little sore the next day, Tuesday, as I had to break down and put together Gary's chair ten times on Monday to get him to and from his various appointments – now that Gary takes the bus, I'm not doing that as often as I used to. This will be another advantage of the van, since when he drives it I won't have to be breaking down his chair in order to transport him ;-)

Nov 15, 2006

Bad storm came through today – a funnel cloud was seen on the highway going by our town and the tornado warning sirens went off. We had winds of 50-60 mph, but I didn't see any damage done locally.

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One type of email I have gotten occasionally that I find particularly gratifying is how the blog has affected different people's own lives. I've had a couple people tell me about elderly relatives of theirs who have fallen ill and had to go to the hospital, and how by reading the blog they know they have to keep on top of things and not depend on the hospital staff to do things right. Another person wrote to say how she viewed people in wheelchairs differently, that though they may be handicapped physically, they can be brave and strong mentally (and, she adds, so can their caretakers ;-)), and how every day these wheelchair-bound people may be working to increase their capacities, that the training is on-going, which is not something you would realize unless you know of someone in this situation. I want to thank those people who wrote such things for sharing those thoughts with me.

Nov 16, 2006

Yesterday (Wednesday) the cleaning person said she'd be here today, Thursday, at 1 p.m. She never came and she isn't answering her phone. Our imaginations are going wild wondering what happened to her.

I am now at the doorway to Gary's bedroom when he does the bed transfers. I asked him if I should just keep backing away, and he said he guessed so. He joked that soon I would have to get in the car and drive to Montgomery in order to get farther and farther away. Later would come Texas.

But, actually, I told him that the next step should be for him to do the transfers without me sticking a board under the castor wheel of his chair farthest from the surface he is transferring onto, and he agreed. His chair tends to slip slightly on the wood floor when he does his transfer, so to avoid that I have been putting a board under this wheel (using the transfer board for that, actually). But of course when he is doing this on his own, he won't have me to put the board there. He is hoping the board will not be needed, that is, that he can compensate for the slipping wheelchair. He will have to practice this however, so we will start this process over with me close to his chair and with no board under his wheel.

Nov 18, 2006

Another wet run this morning. After Gary's transfer back from shower bench to wheelchair, the transfer board sticking to him as if it were glued to his butt, we decided to have him try it again without the board. It was an uphill transfer, and he needed my help, but I think if we make it a point to practice this, he should get it down, and it'll be simpler than with the board. Now that we've turned the shower bench perpendicular to how it was, the transfers are easier than they were.

In the afternoon we went to check out mini-vans. We went to the Toyota place first. I helped Gary transfer into the passenger seat of a Sienna, and then I went for a test-drive, the salesman in the back seat. The ride was very smooth, but I felt like I was driving a motor boat (not used to big cars). Then I had to take Gary home and help him change because at some point his condom catheter had disconnected and he didn't notice it. Wonder if the Toyota guy will send us a bill.

Then we went to the Honda place and tried out an Odyssey. We should have asked for the cheapest model, because instead we got a plush one, and it didn't seem a fair comparison to the Sienna no-frills model we tried. I thought I'd like the Odyssey driver seat better than the Sienna one – it was one of those power seats that adjusted eight ways and even had a bun warmer – but it set off my leg symptoms, for some reason. This did not make me happy – I already had a lousy night's sleep last night because I sat too long at critique group during the day and set off the symptoms (I feel too self-conscious to stand up all through our meeting at Paneeras!). I despair of ever being able to sit again for any length of time.

Anyway, I couldn't really make a decision about which car I like better – hopefully I won't have to do much driving of whatever we get. We realized we didn't really understand if the modified vehicle will use the seats that come with whatever chassis we choose or if the seats are special, so I don't know if my complaints about the Honda seat factor in – plus, maybe a non-power seat would be fine. Gary said he is leaning toward the Sienna because he likes where the controls on the cockpit were and he likes the fact that Toyota has a "mobility program" – the salesman showed us a number of brochures of converted vehicles, including one with a modification we hadn't considered – the passenger seat swings out of the car for a transfer. We don't know how much easier a transfer that would be, though – nothing for Gary to hang on to when he makes the transfer, whereas with a regular seat transfer into the passenger seat, he can hang onto the door, though since the transfer is an uphill one I'm not sure he could ever do it by himself. Maybe with the swing-out seat he could. Anyway, something to consider.

We realized the two of us had understood differently about the cost of the modifications. I thought the basic car would be about $25,000 and the modifications another $25,000. Gary thought the modifications would be $50,000. He is hoping I am right.

Nov 20, 2006

Today was another jaunt up to Atlanta, this time for Gary's six-month follow-up on his flap surgery. The doc said Gary's butt looked great and pronounced him healed! (I had been noticing a marked improvement in the way the flap looks since Gary has been using the new chair, but the right side of the scar is still puffy and discolored and wide, so I wasn't sure if that could be said to be healed; the doc said the difference between how the right, vertical side looks and how the other two, more horizontal sides look – like thin smooth seams – is a matter of pressure.)

The doctor lifted all restrictions (except, of course, weight shifts every 20 min., though possibly Gary can increase that to 30 minutes if his skin tolerates that). So now Gary can do any bending he wants, can have his butt submerged in water (like in a bathtub or a pool), can sit on a cut-out toilet seat, can lie on his back if he wants to (gradually working up to 4 hours at a time, though he's not sure if he'll do much lying on his back as his legs spasm and kick around whenever he does), and so forth.

This means that Gary should be able to do more dressing of himself, for one thing. And it also means he is ready for another round of Day Program. We spoke to the Day Program Manager after seeing the doc, and she is going to talk to the insurance company to see what they'll pay for. The plan is for Gary to go to Day Program from Dec. 11-22. (I admit to be dreading the morning schedule, having to get up early and rush around to get him ready to go; we'll be at the apartments again.)

At Day Program he'll work on things he was restricted from, or limited on, or just hasn't had enough practice on. I'll bet a big thing will be floor transfers – how to get himself onto the floor from his wheelchair and vice versa. Also, one of the biggest things will be practicing how to maneuver in a double bed, so we can start weaning him off his dependency on the hospital bed (he loves those rails!) and so I hopefully won't have to help him prone at night (so he can be more independent, eventually travel by himself, and so forth). I'll bet he'll also practice putting on trousers and socks and shoes while in his chair (he has already been able to put on trousers and socks while in the bed). They'll no doubt have him practice transfers to a cut-out commode seat, which he thinks is supposed to be a difficult transfer (hopefully, this will soon mean he won't have to do any more bowel programs ("digs") lying in bed – I think that'll be the change that'll make him happiest, assuming it decreases the time the program takes, which it should, since gravity will aid him). I imagine there will be more curb work – he hasn't practiced any curbs since he's been home. Maybe they'll get him in the pool, though he says that would be a lot more enticing in the summer time.

Before leaving the flap doc, I asked him about Christopher Reeve. I told him I'd heard he died from an infected skin sore – that the infection had gone into his heart. The doc gave the proper terminology, saying Reeve had died from sepsis, as a result of his skin sore. I asked how that could happen to someone like that, someone who surely was taken care of round the clock and could afford the best of care – I wanted to know because it worried me that no matter how diligent we were at skin checks and pressure relief, that something like that could happen to Gary. The doc said he had no worry about something like that happening to Gary, that it had happened to Reeve because he hadn't complied with the procedures for avoiding and treating skin sores (not a "good patient"). No chance of Gary that happening to Gary! (He and I both agreed Reeve should have been subjected to Tough Love.)

For Gary's reward for getting all restrictions cleared ;-), I bought him an Italian panini sandwich at Fresh Market before we headed home. This time I managed to be in the correct lanes at the right time. (We tried out the HOV lane for the first time -- the one for buses and car pools of at least two people. It was significantly faster. We couldn't figure out what "HOV" stands for, though, except we figure the V is for vehicle.)

After he transferred into bed this evening, I told him he should now be able to get his own shoes and trousers off, instead of me doing it for him as I have been doing. He said that he probably should – but that he was too tired and didn't wanna ;-). So I told him, okay, no tough love tonight – he could be a big baby ;-). He was happy to take me up on that.

Nov 20, 2006

Thanks to those who told me "HOV" stands for "High Occupancy Vehicle."

One other thing from yesterday. Gary's weight was about the same, though he's been eating more than he did before (the creep! Wish my metabolism would let me eat more and not put anything on!). He was hoping the doc would say he needed to gain weight to get more padding on his butt so he'd have an excuse to have more ice cream ;-), but the doc said there was no need for him to gain weight, and "it never goes where you want it to go anyway."

Today Gary called and got it straightened out with the helicopter people that we owe about $2000, not $9000.

Gary told his therapist at rehab that his flap restrictions have been lifted, so she had him practice getting his socks and shoes on and off while in the chair – he lifts his leg and crosses his ankle over the opposite knee to do this. He didn't even have to scootch way forward in the chair and grab his leg while falling back to get his legs in position, which shows he is more flexible than when he left Shepherd. He'd better be, with all the stretching we've been doing of his legs!

This evening, when I was giving him his bed bath, I said, "You should be able to do this now, right?"

"Yeah, except my back," he replied.

"So, maybe you should start doing it."

"Thought you were going to suggest that soon."

"Notice you didn't bring it up yourself," I said with a smile.

"Well, it'd be too overwhelming if all at once I started to do everything for myself I now should be able to," he replied, and I am sympathetic to his viewpoint. He then went on to say how at first getting his own trousers on had seemed so daunting, how he wasn't very good at it and how it'd taken him forever. But now, with all his practice, he's pretty good at it – though he doesn't think he'll ever get them on in the few seconds that "Been there done that guy" can.

In Kroger on Sunday I found a greeting card that had me laughing out loud in the store. Gary and I were looking for birthday cards for our mothers – amazingly, they were born the exact same day the exact same year. I got two for my mom, one specifically a birthday card, and the one I will share here (so, mom, don't look at this before your birthday). On the card the font gets continually smaller – hopefully I can reproduce that on the email/blog. Here is what the writing on the card says:

When in doubt, repeat this:

Let me change what I can.

Let me accept that which I cannot change.
Let me ignore that which I cannot change or accept.
Let me run away from that which I cannot change, accept, or ignore.
Let me lock myself in the bathroom, hold my hands over my ears, and hum about that which I cannot change, accept, ignore, or run away from. Let me …

Nov 22, 2006

My new bed came today. The delivery men set it up on the wood frame I have. I'd forgotten how tall the bedsprings are. I practically have to do a high jump to get onto the bed. Hopefully I won't fall on the floor when I get out of bed in the middle of the night ;-)

Nov 23, 2006

We made the Thanksgiving meal together. I got out the recipe for the bread stuffing and brought over a lot of the ingredients to the kitchen table, and Gary sat at the table and chopped scallions and peeled and diced apples and cubed bread I toasted. I pureed some of the apple, then I cooked the scallions in a little olive oil, then added diced apple and fresh sage, parsley, and thyme. Finally I added the bread cubes and the pureed apple. I stuffed a Cornish game hen with this and put it in the oven. There was stuffing left over, so I put that in a separate baking dish. I also peeled a sweet potato and carrot, cut the potato into wedges and the carrot into chunks, and put those into another baking dish with some leftover diced apple and some maple syrup. That went into the oven about 25 minutes after the bird.

I was going to skip making the cranberries because we discovered Gary had no sugar (or if he did, we had no idea where it was). But Gary discovered some Country Time Lemonade Mix, so, he said, since I typically do a lot of substituting anyway, try that! I did, and he said (with puckered cheeks) it turned out good!

The last item on Gary's menu was broccoli with pecans. Gary both steamed the broccoli and toasted the pecans. He said it was fun making the meal together.

As we sat down to our meal, Gary said, "So, what are you thankful for?" "You," I said, tears coming to my eyes. "That's what I was going to say," he said.

Tears were in his eyes too.

Nov 24, 2006

Gary finished writing the math paper he's been working on – the one with results he'd gotten before his accident. He says it's ready to be sent off for publication.

He called another person on our list of potential house cleaners. The last one just never showed up, never returned our call, never gave us any kind of explanation for why she didn't come. "She must be dead," I said to Gary. "She'd better be," Gary replied.

Gary took over more of the personal task of giving himself a bed-bath. I brought over the soapy and plain washclothes, and he did the front of himself and his legs. I did the rest. However, I forgot and at the start of this process began to undress him. “Hey, you’re supposed to be doing this!” I told him after a short time. He said he was waiting to see how far I’d get before I remembered that. I gave him the evil eye.

Nov 25, 2006

Tonight we watched about twenty minutes of Christopher Reeve’s remake of Hitchcock’s “Rear Window,” sent to us by Debra Talley. So far, we are really enjoying it. One thing we both noticed and said we liked was how they don’t shirk in showing the disability. (In comparing it to The Brooke Ellison Story, Gary said, “All they did was show her happy and smiling all the time – I’d like to see her doing the bowel program!” (Actually, they haven’t been *quite* that detailed in Rear Window ;-)))

Nov 28, 2006

We finished “Rear Window.” An unsatisfying ending, I’m afraid, but we liked it up until the last second. We also liked how they pulled no punches about the disability, though Gary still complains that they didn’t show a bowel program, LOL.

We are taking bets as to whether the housekeeper we called will show on Thursday.

Nov 30, 2006

For those of you who bet our housecleaner wouldn’t show up today, you win. We are incredulous. This is the same person who didn’t show the last two times – each time she had a dramatic reason why she didn’t show, so we gave her another chance. However, three times, she’s out.

On to the next person.

One unfortunate consequence of this is that I had to mop the kitchen and dining room floors today because my sister Janet and brother-in-law John are coming tomorrow for the weekend. I would have let the floors go as they were, but Gary was too embarrassed by them. He tried to help out by sweeping them first, but I had to sweep them again. Maybe I should suggest he review that task during day program ;-)

Anyway, Janet and John, when you come tomorrow you need to ooh and ahh over the floors. Lie, if you have to ;-)

Dec 2, 2006

Now I will rant about medical discrimination against the elderly. My mom, eighty-seven-years young, had an infection in her nose a few weeks back. The doctor gave her an antibiotic to take. After she finished the antibiotic, the infection came back, stronger than before. She called the doctor's office; the nurse got back to her later and said the doctor said he couldn't prescribe any more antibiotics for her. The infection got worse. She called the doctor again to get an appointment. They said they'd get back to her. Meanwhile, my older sister just happened to call my mom, and my mom complained that she was in such pain she could hardly stand it and was having to spend her time in bed she was so tired. She also said her nose looked like a circus clown's, it was so swollen and red. My sister told her to go down to the doctor's office and stick her nose in so that they would see she wasn't just some old complaining woman. My mom said she would do that if she didn't hear from the doctor's office by the next day. They did call the next day – a Friday, five minutes before the office closed. They gave her an appointment the following Monday. My mother waited. When she got to her appointment, they wouldn't even let her go home – they whisked her off to the hospital. She hadn't had much to eat, so they whisked her off into surgery immediately. She had a staff infection in her nose. She ended up on three weeks of antibiotics, the first of those weeks a drip, so she had to go to the doctor's office every day to get the antibiotic by I.V.

My sister says that in Florida the doctors are great with the elderly when they come for their annual visits, but if they show up any other time than that, they are treated like hypochondriacs. This is a travesty of medical care.

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We spent a nice day with Janet and John. We went out to a Mexican restaurant for lunch, then to an early afternoon movie – our first one in Auburn. The wheelchair accessible area was in the second row of seats – the seats didn't go all the way to the end, but left enough space for Gary's wheelchair and for me to stand next to him (since I can't sit comfortably). For some reason, we were all quite pooped when we got back to our place. In fact, later in the evening, I had to swoop in when Gary did his transfer from futon back to wheelchair. He probably would have been all right, but it wasn't clear he wasn't going to fall off the chair – he didn't get on it like he usually does – and I didn't want to chance it (and he said it was good I hadn't). I put that down to tiredness.

Little by little he has been doing more and more for himself. Today, he did the entire shower himself, except for me helping him with the transfers (his shower-bench-to-wheelchair transfer is still his hardest one, me providing the maximum help of lifting him with my hands under his sitting bones; he hit his head on the wall while doing the transfer, so we practiced it again and he hit his head again – there just didn't seem to be enough room for him to maneuver, though we are going to try moving his chair in slightly a different place next time and raising the bench, provided the latter doesn't cause his legs to dangle).

Dec 3, 2006

We took Janet and John to brunch at the Conference Center on Sunday – a very nice affair (for those who can eat ;-)). There were omelets made-to-order, all kinds of breakfast and lunch items, and many different kinds of desserts. After that we went to the university's art museum. Some of it, like the Audubon collection, Gary and I had seen with István Juhasz when he visited last spring, but other items in the collection were new to us. We had an enjoyable time, staying for about an hour-and-a-half. I fear I miss about 99.9+% of what art is supposed to be about, though. We ran into Virginia Transue near the end of our stay, and she told me some stories about some of the paintings – I wished she had been with us the whole time :-)

After that, Janet and John went back to their hotel for a bit, and Gary and I went to Kroger. For some reason, I was horrendously tired in the evening, and I just kind of muddled through while Janet and John came back for a couple hours for the last of their visit.

Later, when I went to help Gary with his routine, he said we have a very computer-literate cat – Tigger had managed to walk over the keyboard while Gary was on the computer and pulled up something called "windows narrator," which we did not know was on there. A few years ago, Tigger walked across the keyboard and up popped a calculator, which we also didn't know was on the computer. The calculator, at least, has been very useful.

Dec 4, 2006

Well, Tigger may be computer-literate, but he is not a welcome sight in the middle of the night. Somehow I missed seeing him before going to bed, and he ended up on "our" side of the cat barrier. Gary said Tigger was very affectionate at 2 a.m., jumping up on the hospital bed and purring away and licking Gary's face. Fortunately for me Gary wasn't disturbed enough to skyrocket me out of bed by calling me on the walkie-talkie to tell me of the intruder. Gary fell back asleep, and he thought that cat must have left because when he did his 3 a.m. IC there was no sign of him. But the cat turned up again in his bed about 3:30. And then he came to visit me, but not in nearly as endearing a manner – he scratched furiously on my door and yelled out meows. So I was ripped out of sleep and had to find the little bugger and put him outside.

In the evening, for the first time, the bus didn't come when scheduled to pick Gary up. They didn't answer when Gary called to remind them he was waiting for them, so I ended up having to get Gary. The bus people claimed the reason they didn't come had something to do with the fact that the power in their office went out, but we're not sure what they mean by that! Fortunately, this has been the only time they've forgotten to get Gary.

Dec 5, 2006

We got confirmation from Shepherd that we are on for Day Program from the 11th to the 22nd. Also, Gary's therapy here officially ends this week (meaning insurance won't pay for it any longer). Gary looked into working out at the university's weight room, and it looks like that will be good – the person he spoke with said there would be someone to help him with his routine (he may need someone to hand the cable to him, for instance). Now Gary just has to figure out how to get to and from the weight room, either by using the university bus or the LETA bus.

For all but the transfer from futon to wheelchair and the shower transfers, I am now out of the room where Gary is doing the transfer. He still lets me know when he is going to do the transfer and counts to three out loud, though, so I can be prepared to run into the room he is in if he has any problem.

Dec 9, 2006

Odds and ends, a tabulation of the progress made in the last few months,

When Janet was at our place she told an anecdote she had read in Readers Digest that she said reminded her of me. It was about a woman who had bought a new car, and she went to a shopping mall. Later when she came out of the mall, she forgot where she'd parked. And she forgot what the car looked like. She called the police, and they came to help. They asked her to describe the car. She couldn't remember the make or model or color. All she remembered was that, because it was new, it had four white-wall tires on it. The police eventually found the car. It had a sailboat tied to the top of it.

An amusing thing happened (well, amusing in retrospect) when Janet and John and Gary and I were going out to the Mexican restaurant. I was supposed to be leading our little caravan of two. Unfortunately, a car got in between us, of the same color as the one they were in (although later I realized their car was much smaller), and when I made a turn, I thought they turned too, since this other car did. Only, this other car turned off behind me soon after that and I realized it wasn't Janet and John. We were taking a roadway that goes around a shopping mall, so I pulled into one of the entrances into the mall parking lot, did a U-ey, and pulled into a parking place to see if I could see J and J. I did, and they turned into the same entrance. I was the only car in the vicinity, and I assumed they saw me. They didn't. Well, John saw me, but Janet didn't, and she was driving. John didn't bring up to Janet that she had just gone right past me. I couldn't believe she kept on going, and I swung around trying to follow her. Only, there were now about four cars behind her, so I had this bright idea to cut across the parking lot and get parallel to her. When she was about halfway across the mall, she turned around – evidently that was when John told her she had gone past me a long time ago. So now I had to swing around and go zooming across the parking lot, still parallel to her – I felt like I was in a car chase in one of those thriller movies. At one point, she for some reason turned down one of the parking aisles and then went parallel to how she had been going. I actually got right behind her and started honking my horn like crazy. She never heard it. Finally she noticed me, and we made it safely to the restaurant.

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Gary got a nice card from his therapist yesterday (Friday the 8th) – it was the last day he goes to her (because insurance will no longer pay). In the card she told him she is proud of how far he's come since his start of seeing her and hopes he'll let her continue to know how he is doing. She also wrote that he should call her if he ever needed anything. Gary told me she asked him if he thought he could get along on his own if I had to go into the hospital for a week. Gary said he gave a hesitant "maybe," as a reply, saying he'd be scared. I told him he should tell her I don't want to go into the hospital for a week, so we don't have to worry about that ;-)

Today, Saturday the 9th, I suggested we raised the shower bench a few notches higher, so we tried that, and it turned out the transfer was easier that way :-) (and he didn't hit his head on the wall, either ;-)). I still have to give him the "maximum help" on that one by giving a little lift under his the sitting bones.

I also suggested to him that with his other "most difficult transfer," the one from futon to wheelchair, that he start in a position farther back than he's been. That also turned out to make that transfer easier. So although Gary is so much more independent of me these days, I still make a contribution now and then ;-). Speaking of which, I had a dream the other night that related to that. In the dream he was the honored guest at an awards ceremony. He started to roll his wheelchair to where he was supposed to go, and I noticed his tip bars were off and I yelled out to him. (For some reason, this ceremony was taking place next to a pool. I was in a racing suit, sitting with kids teen-aged and younger, with whom I was going to start training again (before I got CFS, I worked out with the local kids team for about ten years). The kids were talking about saints, for some reason, only they called them some name in some language I never heard of before – I think that may have been a stray thought from the novel I'm working on. Also in the dream, there was a choir of kids, who I think were going to sing for the awards ceremony. Anyway, back to Gary ;-)) I was on the other side of the pool so couldn't get to him, but he didn't need my help. He got right out of his wheelchair, like he's going to learn to do in day program, and started doing these amazing things that in reality he will not be learning to do – like being on his hands and knees – in order to fix his chair himself. Some people were going to try to help him, but someone yelled out, "Don't help him, don't help him." Now, I bet you're thinking I was the one yelling that ;-), but it wasn't – but it was the wife of one of the local university's math professors, with first name Yvonne, for those who can guess who I'm talking about. At this point in the dream I found a screw that went to the tip bars, and that was the only contribution I could make, to return this tiny part to him (I guess he had a screw loose, heh, heh).

When Gary first started doing more and more for himself, needing me for less and less – going off to therapy and to the university on his own, etc. – I admit I felt a bit of a pang: he didn't need me anymore. I don't mean this to sound degrading to him, but I felt like a mother whose child was going off to school and she wasn't needed anymore in quite the same way. I got over these pangs pretty quickly, however ;-). I am happy to have him do more and more for himself so I can go back and do more and more of my own thing.

These days my main "jobs" concerning him consist of the following.

I take pillows off his bed after he's finished with his IC and bowel program in the morning; this is so he can maneuver easier in the bed (I suppose he could just throw them off the bed and take care of them later, but I have to be in there anyway for other things so they'd get in my way). I grease his flap in the morning and evening (I used to put prescription xenaderm on it, but the flap doc said I could just use vaseline now; the reason for putting the thick lubricant on the flap is that it would be dangerous for the skin on and around the scar to dry out – it might cause the flap to open if that tender skin got too irritated) – while I am doing his flap he is doing "the terrible threes" with three-pound dumbbells I bring over to the bed. Then I put on the bed his trousers, his t.e.d. hose, regular socks, his short tube for the condom catheter, the straps for the catheter leg bag, his binder, his mirror so he can do his own skin checks now (except for his back and butt, which I check), and some skin cream – again, in general, he needs to guard against dry skin because his skin doesn't get the circulation it once did and so it can break down easier; keeping it lubricated helps prevent problems.

After he gets himself dressed and so forth, I come back into the room and take the bed rail down so he can get his legs over the side of the bed for the transfer. I put his shoes on for him, though since his flap restrictions have been removed he can bend forward and do that for himself now – I just always forget to put the shoes on the bed so he can! Then I leave the room and keep an ear out while he transfers (he still calls out "One, two, three!" so I know when he is doing the transfer).

In the evening I stand pretty close while he does the futon to wheelchair transfer after he's done stretching on the futon – that one he is still iffy on and I've had to render assistance. Or maybe I didn't HAVE to, but I felt it too chancy to see if he would fall out of the chair, and he agreed with me. Except for the one time when Janet and John were there – I was probably a little too overprotective that one time, but for some reason I would have felt worse if I was standing right there with witnesses to see I'd let Gary fall on his face.

At bedtime if he is really tired I will help him get his legs onto the bed. After he gets himself undressed, I bring in hot wash cloths so he can give himself a bed bath (except I wash his back for him, and later I wash his butt right before greasing the flap). He could prepare the wash cloths himself and bring them to the bed in a basin, but they'd be cold by the time he got himself undressed! While he is washing I bring over to the bed his long tube for the condom catheter and his ankle pillows. After he's done washing I do his back. He then puts on his bed socks and ankle pillows while I bring over the various pillows he needs for padding himself for lying on his side. Then I leave until after he does his IC. When he is finished with that, I empty and wash out his urine bag and catheter. Then I bring over pillows and help him prone – he can't pad himself below and above the knees or put the pillows under his chest and one under his head because he doesn't have enough room to maneuver in the small bed.

So that's all I have to help him with in his daily maintenance routine these days. He does the stretching himself on the futon, and he washes most of himself and dresses himself. And since he's upped his fiber, I haven't had to help out with his bowel program. So whereas at the beginning I was probably spending most of the time from 8-10 am and 8-10 pm helping him, now in those same hours I only spend about thirty minutes helping him – the most drastic reduction in time occurred recently after he got his flap restrictions lifted and was allowed to do more than he could before.

I know he finds it a bit frustrating that he has so little "productive time," and, in particular, has to spend two-and-a-half to three hours going to the bathroom. Each of his five ICs takes about twenty-five minutes, most of that time used in preparation and clean-up. It's possible he may be able to go down to just four ICs per day, but that is the minimum. Then his bowel program takes thirty to fifty minutes. When he learns how to use the commode chair for this, it's possible that may take less time, but we're not sure how much less.

I still help out with his laundry a bit – it would take him forever to empty the washer stuff into the dryer. A big thing I help him with are transfers into the car – he can't do those on his own, but these days since he takes the bus to school (also did so to rehab) I haven't had to do that nearly as much as at first.

He is very bad at packing the car ;-), which was again noticeable in packing to go to Shepherd, but of course there are just some things he is never going to be able to do, at least not without a totally unreasonable amount of effort on his part.

So, on the ninth we spent much of the day figuring out what we should bring to Shepherd, and I packed into the car as much as could go in ahead of time. Gary pointed out that while we're on the day program at Shepherd we'll have to start the morning routine an hour earlier to make it to Shepherd by 9. Only, since on account of the time difference we lose an hour going to Atlanta, that means we'll have to be getting up two hours earlier. Ychh! I told him we should tell them we want to do the Half-Day Program, starting in the afternoon, and he agreed. We were kidding around, however, because unfortunately, there is no Half-Day Program.

On Sunday morning I finished packing up the car, and we left for Atlanta at about 11:30. I did a little unpacking once we got there – we are in exactly the same apartment we were in last time – and then we went to Fresh Market to do some grocery shopping. Coincidentally, as we were leaving we ran into the chiropractor I'd been going to here!

Gary decided to test his progress by trying to see if he could wheel up the driveway of the market. You might remember, he couldn't do it the last time he tried. Well, he made it, and with no rests! Of course, we knew he was stronger, but it was nice to see this proof.

On the drive up, we had gone over his day, noting the places where I was still helping him, among other things. From this he drew up a list of goals for day program, since we knew they'd be asking him for such a list.

So, here are his goals that he wants to work on while he's here:

Commode chair – how to transfer onto it and how to use it for the bowel program

Work on Transfers from wheelchair to the following and from the following back to the wheelchair:

commode chair
floor
our car (by himself and possibly without use of transfer board)
an SUV like Michel's, which has a seat so much higher than our chair
shower bench
low to high transfers in general

Dressing while in the wheelchair, trousers especially (so he doesn't have to get back into bed to dress himself)

Decreasing the number of ICs to four (though that may be a problem because at this point it would mean he would have to get himself out of the prone position at midnight and lay on his side to do the IC, and he would then have to wake up an extra time during the night because he's not allowed to stay on his side for more than six hours and he isn't comfortable staying on his side for even that long – and he doesn't want to wake up an extra time!)

Curbs and wheelies

"Regular bed techniques" – in other words, now he does everything in a hospital bed, which has those nice electronic controls and rails to aid him. Since he eventually wants to travel, he wants to be able to do his maintenance tasks in a regular bed, so he needs to "re-learn" how to pad and position himself, and turn from side to side, and do his bowel and bladder stuff, etc., in a regular bed. Also, he wants to learn how to prone himself, because he is definitely dependent on me for that.

Find out if there's anything else he should be doing for the "leaking problem," see what the possible solutions to it are and what their long-range effects would be

Grease his flap himself

Do his own skin checks of his butt and back

Get another wheelchair evaluation – it's possible the wheels on this could be brought in to make the chair narrower; also, we want to see if his tip bars could be raised and if the footplate is in the proper position (I had to fool around with it from what it was when his new chair came, because he couldn't roll under the kitchen sink – the position of the footplate made his knees to high – only now, in the position the plate is in his heels don't rest on the plate). A minor goal is to learn to breakdown and assemble the chair himself, but he doesn't really see himself doing that, like to get it in a car – it's too heavy for him. He won't need to do that when he gets his van, cuz he'll be able to roll the chair right in; and if he's a passenger in someone else's car he'll depend on them to get the chair in and out for him.

He also hoped to persuade the recreational therapist that a good goal to have would be for he and I to go to the Atlanta symphony Christmas concert next week. The catch is that we'd want permission to not have anything scheduled until 10 am the next day, as it would be a later night for us than usual – otherwise we wouldn't need to mention this to them as a goal!

Other rec therapy goals: they may get him in the pool; they are putting him in the standing frame; they may go over a weight training program with him that he would be able to use at our university gym.

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So, on Monday 9am we were back at Shepherd. They had him scheduled for an hour orientation with his case manager, but that took less than half that time. So we went down to the library where I hooked up to the internet to find out how to get a replacement adaptor for my computer – mine died Sunday night, and I'm really not supposed to be running my computer on Gary's adaptor (different wattage), though Dell said it shouldn't hurt if I didn't do it too long. They didn't define "too long." We were also supposed to have internet access at our apartment, but when Gary tried to connect us he got a message saying the Shepherd account had been cancelled, so we don't know what is up with that. I left a message for the housing guy who was supposed to take care of that. Right now I am suffering from internet withdrawal.

Anyway, at 10 am Gary had a PT evaluation. He told the woman what he's been up to these last four months, and she said she was impressed with how much he can already do at this point, that many people even without having the extra complication of the flap wouldn't be as far along as he is. In the evening I asked him if that had made him feel good, and he said yeah, but that progress seemed slow to him. I said I realized that, and gave him a kiss. Then I told him to cut himself some slack – that he'd had an accident that had broken his spine, for Pete's sake! He laughed and said I was right.

He went over some of his goals with the PT, and she did part of the ASIA test with him again – the one they always do where they test his ability to feel touch at different points in the body and to distinguish sharp and dull pricks of a safety pin. She didn't finish, but neither I nor Gary noticed anything different this time in his responses – he has no more function or feeling than he had before.

Next came a "group planning." We weren't sure what that was about, but it turns out there is a Holiday party this Friday. "Our" group of four patients (plus me) was assigned "Christmas around the world." The PT asked us what we knew of Christmas traditions around the world. I thought this was strange to be asking us – I certainly couldn't remember anything off-hand! One guy remembered hearing that in Germany the children put out their shoes for gifts from St. Nicholas (I then thought that might be the case for Holland). Fortunately the PT had gone on the ’net and looked up some facts. Then we were asked what supplies were needed to decorate the sugar cookies our group is assigned to overseeing. Gary suggested “something chocolate,” of course. Sprinkles and icing were decided on. Finally, our group was assigned the task to lead everyone in singing “Felice Navidad,” so we sang that a couple of times. I am a grinch – I think Gary should be spending his time Friday on therapy goals, not partying ;-)

Next we had a meeting with the rec therapist. She asked the usual stuff everyone is starting out with – how has he been doing and what are his goals, in particular related to their area. For rec therapy, Gary put forth the idea of going to the symphony. She said she’d see if she could accommodate us by giving us that first hour off the next morning, possibly by assigning that hour to herself. We are not supposed to tell anyone she is doing this, so keep it a secret ;-). Gary will go online and see if there is accessible seating assignments, or if not, call and see what they have. The few times we have gone, we haven’t noticed accessible seating, but then, we weren’t looking for it. The therapist said that if they didn’t, Gary could transfer to a regular seat and then we’d have to do something with the wheelchair. I said that in that case he’d better make sure he got an aisle seat, as it might be problematic if he had to go hopping down from the aisle seat to a center seat. We all laughed at the thought of that.

Next we met with the OT. He told her how slowly he is doing more and more for himself and how at the beginning I was helping him with maintenance tasks for three to four hours a day and now it was probably more like thirty minutes. She assigned him some exercises to do “in his free time” – five sets of twenty wheelchair pushups spread out through the day, and three sets of twenty on the rickshaw, to be done consecutively with one to two minutes rest in between. She didn’t think he’d been getting enough tricep work in his therapy at home. She had him do a set on the rickshaw to see how much weight he needed. She put on seventy pounds and was going to add another twenty, and I said that when he was here last he only had twenty pounds on the machine. So she stopped at seventy. Gary then tried the exercise, and that seemed to be about the right amount of weight. Pretty good from when he left here!

Next came the hour “lunch break.” Gary did an IC and I ran off to the library to check email. Then Gary came to the library and we went up to the third-floor gym and ate our packed lunches – he would not get his fiber in if he ate at the cafeteria here, not to mention the food wouldn’t be as healthy.

Next was a nursing evaluation. The only thing new Gary had to report was that he has been having increased discomfort in that “demarcation line” in his back, the area between feel and no-feel. He has always been aware of that area, but now by late afternoon it sometimes aches and he has to take a couple Tylenol for it. It is possible this is related to his new chair – the back is lower on it. He also brought this up to the OT, saying maybe he’ll get used to it when he gets more used to the chair. But they may also try raising the back of his chair.

After the nursing evaluation we had about twenty minutes before his goal-setting meeting with his team. That was not enough time for him to get on the mat and stretch, but he thought he could do some in his chair. Just then the housing person came up to us and we asked him a couple things. About a second after he left, I told Gary he could get back to his stretching. “I see you’re back in pushing mode,” he teased. He then said he was surprised I suggested the therapist was putting too much weight on the rickshaw, that I don’t usually go in that direction. I said I had just been worried about him blowing out his shoulders the first day – that if he needed more weight, it could have been put on.

At the goal-setting meeting, Gary again re-iterated all his goals, reading from his list. They noted there was a month’s worth of work there, but he couldn’t be persuaded to stay longer. The OT then said that what he and I’d have to do is practice the new techniques and tips we learn in the apartment after each day’s sessions are over – I guess we’re supposed to do this in all that free time we have ;-). So, this could be pretty intense for us both. I have to say though, that after all this talk of how they were going to really be working him, I look at his schedule and see lots of time that could be put to better use. Just one example – on Thursday they have an hour slotted for him to “prone on his own,” and then another hour where he is supposed to “stretch on his own.” Well, he doesn’t need to prone – he prones six hours each night. And his stretching takes him a half hour. So we are going to discuss with his therapists – or on our own – figure out ways to put such times to better use – either practicing techniques, or getting him down to the gym, or whatever. As you can see, I am back to being a taskmaster. I want him to make maximum use of this time. I suppose that the reason they don’t pack his schedule is because the therapists have other people to work with, but hopefully they won’t object if we come up with things to do on our own.

One thing they brought up based on our meetings was that they’d really like to get him better at taking showers so that they don’t add an extra hour to his morning routine. They want to wean him away from his bed baths.

The case manager then summarized everything, which pretty much just reiterated the goals Gary had come up with. They had him sign a paper to the effect that he was committed to these goals (and that he wouldn’t be holding any wild parties, the case manager said, as a joke), and that was the end of the meeting.

Gary then did his rickshaw exercises, and then we went home. I went for a walk and pondered something that had come up during my critique group last Friday – maybe the last time I’ll be able to think of such stuff for the next two weeks. Then I got my dinner and went to meditate. After that, I helped Gary make his omelet. We ate and pretty much started in on our evening routine. Went to bed earlier than at home, which because of the time change was even earlier than my watch indicated ;-). Naturally my bad karma concerning apartment/motel neighbors continued. It seemed that for hours some elephant was walking the floor above my head. I’d doze off for a second, and then the clumping upstairs would wake me up. I guess I have to resign myself to another two weeks of lousy sleep. On top of it, I had a dream where Blackjack yelled at me to get up and feed him, so I lost an hour's sleep in the morning because of him, even though he wasn't even there!

Now it is Tuesday morning, and first on the schedule is an outing to Wal-Mart, again a waste in my opinion, but Gary didn't want to see if they would let him do something different. Our assignment is to get some things for Friday's party, including two $5 gifts for a "white elephant gift exchange." We also have some things we want to pick up for ourselves. I have been writing this while in the bus, and now we are Walmart! Bye for now.

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Gary has been reading the book I got about the quadriplegic Brooke Ellison. He says little mention is made of "maintenance activities." So far it's gotten one mention, when the mother says there was one day filled with activities on the Harvard campus that she worried about getting Brooke back to the dorm to do the I.C. Oh, and there is the mention that it takes her four hours to get ready to go anywhere in the morning. A mishap that occurred that wasn't seen in the movie was that one day something went wrong with her five-hundred pound electric chair, and she couldn't stop it. It was stopped when it ran into a fountain on the Harvard campus. Brooke had to stay in her room a week until the chair was fixed.

Gary noted that even though he is impressed with Brooke, he is more impressed with her mother. Me too. I sure couldn't have done what she has done all these years. For one thing, I can't imagine having to get up every two hours during the night year after year to turn someone in their bed. We definitely would have had to hire someone to do that!

Dec 12, 2006

At Walmart we were assigned to get the ingredients for sugar cookies. So we got three bags of cookie mix and four cans of different frostings. Ycchh ;-). For our two $5 gifts, we got a set of two stoneware bowls as one gift and an oven mit and pot holder ensemble as the second gift. We also then got a few supplies of our own – floss and stuff like that.

We got back around lunch time, and I ran off to the library to check email while Gary did his IC. Then we went down to the cafeteria and I had my rice while Gary rounded out his pb and j sandwich and apple with cafeteria-style overcooked vegetables ;-). According to his printed schedule, after lunch he was supposed to meet with the team nurse for "medicine management." Of course, he doesn't have any medicines, so this message must have gotten through to someone and his meeting with her had been erased from his schedule on the big board in the third floor gym which lists what everyone is supposed to be doing that day. This gave us an hour of unscheduled time. Horrors! Naturally I asked him what he intended to do to fill that hour. He decided to stretch, and then he did his rickshaw exercises. He went up to eighty pounds on the machine – four times as much as when he left here!

Next was a session with the OT, and today was spent on “bed mobility.” To be “checked off” on this meant being able to do the following things: transfer onto the bed from his wheelchair, get his own legs up on the bed, be able to hop sideways from one side of the bed to the other and back, be able to hop forward from the top to the bottom, be able to hop backward from bottom to top, be able to roll from his back to right side and similarly to his left side, and be able to roll to each side and get up into a sitting position from that side. He was able to do all this except the transfer with relative ease. When I commented this evening to him that I was reminded of the first times he tried to get into a sitting position and how today it had seemed rather easy, he remarked that the particular bed he was practicing on today was extremely bouncy and he was able to exploit that. He noted that when I had left for a short time while he did his stretching today, he had tried getting into a sitting position while on the mat – which is not springy – and it had been more difficult. But still, he had been able to do it by going all the way over into a prone instead of only to the side like they were having him do on the bed. Back in the summer, the first times they were trying to teach him the technique to sit up from being on his back, his thought had been, “God, I’m never going to be able to do that!”

His transfer to the bed, an uphill transfer, wasn’t the greatest; in fact I had to stick my arm out to make sure he didn’t go off the bed and the OT also came forward and put her hands on him to make sure he wouldn’t. So, she made him do two more transfers to the bed and back – he got better each time. She had suggested he put his hand that goes on the bed (one goes there and one stays on the chair when he transfers) a bit further away from his body. He was skeptical, thinking he wouldn’t get as much lift, but to his surprise his transfers were immediately better.

After he had gone through the basic mobility skills, as listed above, she showed him a few more for sitting up in bed from a supine position (i.e., lying on his back). The skills she showed him would be particularly useful if he was in a narrow bed and couldn’t roll all the way over to help himself sit up. The first technique was to grab his pants to each side near his butt and pull (this would take the place of having abdominal muscles to curl himself partways up – try it), and then rock from side to side while walking up on his elbows to lift himself up. That’s the best I can explain it, but I don’t think I understand it correctly, because I get nowhere doing it without using my abdominals. He didn’t make progress on it either without a lot of help from the therapist. Another technique involved starting while on his side, say his right, and pressing down on the mat to his right side with his left hand and while simultaneously digging his right elbow into the mattress while his right hand is pressing into his forehead – and you also rock to the right while doing this. The idea is that this gives you leverage to sit up. He was slightly better at that one (and so am I, I discovered when I tried it later). In the third technique he would again be on his side, say his right, and press both hands together in front of his chest while digging his right elbow while rocking up onto it, again a leverage thing. He was most successful at that one (and so am I).

Then she did the rest of the ASIA test on him. She told him the results said he was a T4. So, he’s been declared anything from a T2 to a T4 when they’ve done these tests on him, though it hasn’t made any functional difference.

She finished by having him do five transfers back and forth from the bed to wheelchair. She gave him another tip of not moving in the backward direction on his preparatory swings, but rather just going from the midpoint forward – she thought he was losing momentum when he went all the way back. He isn't sure that is the case, but what was clear was that his transfers were better when he did that (combined with her previous tip). He thought he had better control of the forward part of the swing by not going all the way back. He said it was a subtle thing, but hopes to ingrain it with practice.

He finished up his therapy day by being in the standing frame for about forty-five minutes. He wondered if he would have any problems with it since he hasn't stood upright in four months, but he didn't have any real problems – it took him a few minutes to adjust to it, but then he was fine. We played cards.

After that, I drove him back to the apartment. While I went for a walk, Gary tried to get us hooked up to the internet. He spent about two hours trying to do that, but was finally successful. Most of the evening was a repeat of last evening.

All for now.

Dec 13, 2006

First on the schedule was the group fitness session. Gary asked me if I was going to make sarcastic comments throughout it again this time. I said, "Probably." It was run the same way as it was last time, so I have the same complaints – too fast through the exercises. But I kept my comments to myself because Gary didn't rush through the exercises. He has noticeably better range of motion, and of course he can use heavier weights than when we left here in August – and I didn't have to help him at all by hanging onto him so he could keep his balance, like I did last time. I did the exercises too.

Just before that session started, Gary's team nurse from when he was an inpatient here came into the gym, gave us hugs, and talked to us a short time. One of his other nurses had seen him here at Shepherd yesterday and is evidently spreading the word he is back. We have seen quite a few familiar faces, and they all say how good Gary looks and are impressed that he is back on the job. His "old" PT commented yesterday how much better his balance is.

Next he had a session with the PT. I think they got my not-so-subtle message that there were times in his schedule that could be put to better use – she told him that next Monday he was going to have a double session with her and a double session with the OT, and that at any other time we thought that what was on the schedule wasn't useful, we could practice things like what he would be learning with her in this very session – which was the beginning of floor transfers.

So, he got on their mat (which is about at wheelchair height), and they had a second higher mat right next to it – it would be like transferring from the floor to a low bed (not as high as his wheelchair). She had him start by sitting so his legs were parallel to the side of that higher mat. Then he pulled his legs up so his knees were bent and facing the mat. Next she spotted him by holding at his hips, and he got himself up to kneeling position. This he did by having one hand on the lower mat and pushing with that one while having the other hand on the upper mat and pulling with that one – it would probably be more instinctive to have both hands on the upper mat and pull, but what she had him do is more like the technique used in the floor to wheelchair transfer.

The first goal in this pushing and pulling was to get his chest onto the upper mat. She put a pillow on the upper mat where his face would end up because a lot of people end up smashing their face into the upper mat. After he got his chest on it, the next step was to put his hands back behind him near the edge of the mat and push himself further onto the mat. Once he was reasonably well onto it, he could roll to the side and sit. To get himself off the upper mat, he scooted to the edge, mader sure his legs were extended a little (so his knees wouldn't end up too bent when he ended up in his final position), turned to the side, and (gently!) pushed himself off so he would again end up sideways to the mat with his knees bent.

She had him practice this a few times, and then it was time for the next step – transfers between the floor and the low mat (which is wheelchair height, and this made for a significantly higher transfer than the mat to mat transfer). She did it with him a time and then it was my turn to spot him on it. So, for the first part, where he is trying to get onto his knees (or rather trying to balance on his knees with his chest on the mat), I held him at his hips. I was supposed to give him actual help as little as possible, but I did find I had to put significant effort into pulling him up – I am sure the therapist didn't give him that much help on the lower transfer from mat to mat. Then, on the second part, where he is trying to pull himself onto the mat, I held him under the knees and gave him lift if it was necessary. It *was* necessary – I gave him a couple little pushes as he, in stages, tried to pull himself onto the mat, because he didn't seem to be going anywhere – but I didn't have to put as much effort into it as in the first part.

Anyway, now we know that if he ends up on the floor he'll be able to get up on his hospital bed – definitely with my help and probably with a lot of huffing and puffing if he tried to do it on his own. So, one possibility if he fell off his chair at home – or intentionally got off it onto the floor, is he could get back on his bed and then transfer from his bed to his chair. Of course, if I wasn't around, he'd first have to commando crawl to his bed, and he'd also have to drag his chair with him.

Then he did the next step in the progression of learning to go from floor to wheelchair – the wheelchair doesn't have the room for pulling himself onto it, of course, so a different technique is used. In fact, you may recall I listed three techniques to go from floor to chair (and back). But I think they are only going to go over with the one they think it most likely he would use.

So, anyway, the next step was to practice "bump-ups." He got back up on the lower mat, and this time sat with his back to the upper mat, about an inch away from it. They strapped a J-pad to him – a cushioned seat that is held on by straps around his legs and waist. He put his legs in frog position, and then “on three” he was to throw his head down and forward and at the same time do a depression to get his butt up high and going backwards to land on the upper mat. Then he was to more depressions while “wiggling” backwards first to one side then the other so that he got further back on the mat (since he initially lands pretty close to the edge). She had him do this a number of times. She was helping with his lift, but I don’t know how much. Not enough to stop her from raising the electronically controlled mat – on his last bump–up there was a 7 ½ inch gap between lower and upper mat!

She told him that he now essentially had a way to get off the floor directly onto his chair provided he had a portable “step” he could use. That is, say for home use, he could build, or have built, a little platform that he could put in front of his wheelchair and bump up to, and from that bump up to the wheelchair. Actually, since his wheelchair cushion adds three inches of height, he’d probably have to remove it, bump up to the wheelchair, then go to the bed and transfer to it, then put his cushion back on his chair, then transfer back to the chair.

So, anyway, this gives him some options for when he is at home alone (or home with me), at least. She told us we could practice these skills anytime he has time in his schedule (or we decide to take the time from some other activity we deem of lesser importance).

His “old” inpatient PT walked by about this time, and his “new” day program PT filled her in on Gary’s progress today. The “old” one greeted this news with enthusiasm, and I remarked that this is what we missed, having our own personal cheerleaders. The new PT laughed and said it did help with motivation. Gary remarked that I was good about saying “good job,” however, so I’ll take that to mean he hasn’t felt a lack of encouraging remarks :-)

The PT gave him one more exercise to do in his “spare time” – when he depresses, to hold that position momentarily. She feels he goes to fast in the middle of his transfers and that this practice will enable him to become more controlled about it.

Next they had rescheduled him to go over his meds with his nurse – I guess the message hadn’t gotten through yesterday but the meeting had been taken off his schedule for other reasons. I had seen his nurse earlier so had told her Gary had no meds, so she then said she didn’t have to meet with him. So now we had a “free hour.” Gary stretched for around twenty minutes of that time, and then he went off to his IC early. The reason for this was because he was to get into the pool in the afternoon, and rather than take the time to get him into his suit then and cut into the pool time, we were going to get his suit on him during the lunch hour. So, after his IC, we went to a corner mat on the third floor gym, and I rolled over some screens for privacy. In the interest of saving time, I helped him get his trousers off, and then I put his swimsuit and his trousers on him. Then we had lunch.

First after lunch was an OT session. She started with “dressing in the chair.” She had a stretchy pair of pants for him to put on over his own pants. So, first he moved himself toward the front of his wheelchair, then grabbed his leg under the knee while falling backward to get his leg up. Then he crossed that ankle over the opposite knee and threaded his trousers onto the lower part of his leg. Very important – when you have crossed your legs, the leg that is on the left is your right leg and still needs to go into the right pant leg ;-). At this stage, before proceeding farther, one puts one's shoe on that leg – easier than waiting until the end, since at that stage you would have to get each leg up again. After putting the shoe on, one scoots forward as far as possible in the chair so as to have as much thigh as possible off the chair. Then one pulls up the pants so that they're like short "capri" pants, making sure to tuck the middle (crotch) under oneself as far as possible.

Next one does a high depression and moves back, hopefully not dragging the pants off. Pull up the waistline of the pants as much as possible.

Then there are a few different things to try in order to do the most difficult part of getting the pants up over your butt.

The first thing she had him try was to roll his chair next to and parallel to the mat, which was playing the roll of his bed. Then he was to lean to the side, digging his elbow into the mat to get his hip up – she said some people even cross one leg over the other to help with this. Then he was to grab the pants as far to the middle of his back as possible with the hand facing outward, and pull up until tight. Then he was to either spin his wheelchair around so the other side was next to the mat, or to keep the chair as it was and lean on his far tire or over to the floor and proceed similarly with pulling up his pants on the other side. One continues to go from side to side as long as necessary to get the pants up. To finish, the idea was to grab his pants behind him and pull up as he slides forward, and hopefully the pants will finish going up.

He was able to do this with her, and he said it was challenging but easier than he thought it'd be. BUT, I don't know if it the bits of help she gave him, or her talking it through with him as he was doing it, or the fact that the pants were stretchy, that accounted for his success there, because he couldn't repeat this with success after he dressed after being in the pool. More on that later.

Anyway, another technique she showed him for "the hard part" was to move way forward and to the side of the chair so his butt was already half off the chair. Then he was to use the mat or the back of his chair or his tire to help him bend over and get his hip off the chair. This was even easier for him than the first technique, but he couldn't replicate the success while dressing after the pool.

The final technique was to "depression lift" into the pants: put two fingers of each hand into the sides of the pants with palms up, then use the wheel of the chair to do a depression lift with the rest of the hand, and go forward into the pants. He didn't try this one – this was what they showed him when he was an inpatient and he had gotten nowhere with it.

Getting the pants off was easier – either reverse the above last technique, i.e., do a depression and push them off, or go side to side and pull them off. Then repeat as necessary until they are far enough down. To get them off the lower leg, again reverse the procedure of getting them on that part: scoot forward, get a leg up, cross it over the other one, take your shoe off, then your pants.

So, another assignment she gave him was to practice dressing in the wheelchair whenever he is putting on or taking his clothes off while here (unless he is rushed for time).

Next she went over how to prone himself in the double bed. He sat in the bed and positioned a quad pillow (which is shaped as a long, thin rectangle) under the ankle closest to the middle of the be, then under and below the corresponding knee, then under and above that same knee. Then he crossed his opposite ankle over the pillowed ankle. Then he put his pillows that would go under his chest in approximately the position they should end up being in. Lastly, he turned over, reaching over with one arm and pushing with the other so that he was sort of in pushup position, making sure to aim his head to the top of the bed, so his body follows and ends up straight in the prone position. He did this very well. I might have to adjust the pillows at his knees a bit, just to make sure he isn't putting any pressure on that area. He tried proning himself in the hospital bed tonight at bedtime. The problem with the narrow hospital bed was he ended up farther on one side of it than he liked, so I had to move him over. The padding seemed acceptable, but we decided to have me adjust it "to be safe." At some other time we'll let him pad himself completely on his own and have him stay in it for an hour just to make sure that the slightly more pressure some areas looked like they might get when he does it himself won't be the cause of any problems, and then he can try to go for his entire regular nighttime proning like that.

Back to day program. He finished up his OT session by doing his "terrible threes" in the prone position, and then he transferred back to his chair and we headed to the pool!

We both headed into the men's bathroom. There were two areas with mats that were curtained off. I changed into shorts and T-shirt and Gary, while in his chair, stripped down to his swim trunks (he finds getting his pants off far easier than getting them on!). Then we went out to the pool area. A rec therapist and a lifeguard helped him transfer into the "pool chair." It wasn't a difficult transfer, so I think Gary and I could handle it (and probably a lifeguard is required to be there too). The lifeguard is required to operate the pool chair. After we got Gary strapped into it and a floatation belt was put around his chest, it swung around over the water and lowered him into the water. The therapist and I went down the pool steps and met him in the water. He was unbuckled from the chair, and then he was floating! The first thing the therapist went through with him was how to keep his balance in the water – again, a head and shoulder thing, aiming them in the direction opposite the one you are overbalancing in. His arm movements were a little frantic, and the therapist told him it would be easier if he were more gently with them. I was reminded of the wheelie person telling him he needed to be more zen. After a few minutes of talking and just getting used to the water, the therapist asked him how he felt. "Excited!" he exclaimed. And then he started to cry. Naturally, that made me cry too. After we'd calmed down ;-), she had him swim a lap of elementary backstroke. She just stayed at his head as he went down the pool, not touching him. I was surprised – I'd thought that he might need more help in the water, but with that belt on he was free to move on his own. We did a lap – she had him circle at the deep end by leaving one arm still and just using the other so he'd pivot around. If he and I were in a crowded pool I'd help, because his circle was rather a wide one. We got back to the shallow end, and she asked him how that was. He said, "Great!" We did two more laps like that, after each one her asking him how he was doing. His reply was always, “Great!” with a big smile on his face. Next she taught him some exercises that she thought might be particularly useful with his arthritic shoulders. Standing behind him, I was to balance one of my knees under his butt and to hold him lightly at the shoulders to help him keep his balance while he did the exercises. The exercises were simple ones: bringing his arms from shoulder height at the side to down to his thighs, and bringing his arms from shoulder height in front of him down to his knees. She said we could stay in longer on our own (we had been in the water for about a half-hour and it was about 3 pm), but we were both popsicles by this time. So she showed me how to get him back into the pool lift chair, and that took him out of the pool. They have shower chairs there, so he and I transferred him into one of those with the lifeguard standing nearby. The shower chair isn’t easy to wheel oneself, so I wheeled him into the shower. We were afraid they were going to keep the water at a nice safe lukewarm temperature, but the showers were nice and hot! After taking them and drying off, Gary attempted to dress in the shower chair. It was now 4pm. The dressing in the chair didn’t go as well as it seemed to at therapy, and after trying to do it for a half hour, Gary called it quits – he couldn’t quite get it up over the last part of his bootie. So I helped him with that.

So mom, you mentioned how frustrated you used to get after going to the pool and seeing how long it took you to get dressed after, and how you were inspired by how Gary copes with things taking him longer. Now you have his pool experience to compare with. It took him an hour and a half to shower and dress after his swim, and he didn’t finish the dressing on his own.

But, we are confident in time he’ll get this chair dressing down. It’ll just take practice, just as his learning to dress himself in bed did.

We next went back to the apartment. After letting Gary into it, I did some grocery shopping, and then our evening routine was pretty much as before. Gary commented that he didn't know why the swimming had been such an emotional experience for him. He said he’s always liked the water, but he didn’t know he liked it THAT much! :-)

We had planned to sleep in about a half hour because Gary was doing life skills training at the apartment Thursday morning, and he was to be in bed when the OT and PT came. Too bad the elephant upstairs decided to start stomping around at 5am. Just as he/she did yesterday. Given that he/she is stomping late at night too, this is truly an elephant that doesn’t sleep.

Dec 14, 2006

Well, we had expected the OT and PT to show up at nine like they did at the summer day program. They were there at 8:15, and I was still in my pajamas, about to bring Gary over his breakfast (because he wasn’t getting out of be). I wished they had told us they would be there that early so time wasn’t wasted watching Gary eat his breakfast.

After that, he transferred to his chair from the bed (and the therapists noted that when he shops for beds he should get one high enough that in his transfer he clears the brake bar on his wheelchair –

the hospital bed was set too low for that, and there was a danger he could land on it). Then he went into the bathroom to learn to transfer to the commode chair. We had all decided that it would be better for him to have already done his bowel program before they arrived – Gary joked that otherwise the three of us twiddling our thumbs while he was twiddling his finger (sorry, back to bathroom jokes). Gary had read somewhere that that transfer was supposed to be a difficult one, but it didn't seem to be especially hard, he said. In fact, it was much easier than the transfers he does at home from the shower bench to his wheelchair. This gave the therapists the idea that in getting into and out of the shower, he will transfer first to the commode chair over the toilet seat, and from that to the shower bench, because we are almost positive we can set them up right next to each other. We'll have to see if he actually does this, but it is an alternative.

It looks like we will have to have an in-floor grab bar installed next to our toilet so he can lean to one side to do the bowel program. He will have to keep his supplies for the program on a rolling cart or maybe on the back of the toilet if he can reach them there (I have a little doubt about that). We will just have to see. I was thinking maybe he could set his transfer board over the sink and put his supplies on that. Another suggestion was to keep them in a bucket on the floor, but I don't know if he could safely lean over that far.

He is supposed to try doing a bowel program this way over the weekend. If he has any problem, the OT will come back to the apartment on Tuesday and go over it with him again.

Another fact about using the commode chair is that sitting in the cut-out hole puts extra pressure on his bottom, so he'll need to do weight shifts ever fifteen minutes while on it. And since he sticks a little to it, he is supposed to make sure he carries the family jewels along with him when he hops along it to get into the correct position. (Evidently men have "torn" things down there.)

Another thing the therapists suggested is he buy shower shoes or "crocs," so he can just keep his shoes on in the shower and not bother with having to take shoes off for the shower and then put them back on for his transfers.

Next he did a transfer to his wheelchair, and they set up the commode chair next to the tub bench for him. So he transferred to each of those and ended up in the bathtub (one tip they gave was to leave his feet out of the tub during the transfer – gives a better angle for the transfer).

Gary asked what he should do if he was ever in a place – like the home of a family member – which doesn't have a handheld shower attachment. They said there are portable ones that one can buy, like moms use for their babies. They also said he should buy a pad for those times he is using a hotel shower bench, as they are not as well-padded as he needs.

They had a couple safety issues they noticed when he was taking his shower. They did not like the fact that he was picking his legs up in order to wash and dry his feet. He had been taught to do it this way when he was last at day program, but at that time they had had a gait belt strapped around his chest to make sure he didn't slip off the bench (because in order to pick up his feet, he needs to move forward on the bench, grab under his leg, and fall back while picking up his leg; then to wash a foot he crosses it over the opposite knee). He has felt safe enough to do this at home without me there, but they didn't like this because he has abdominal and leg spasms, which he didn't have when he was last here. They can be fairly strong and they cause his legs to kick forward (and sometimes his trunk jerks forward too). It is best for stability that his feet stay straight under his knees, not kicked out in front.

So instead of him picking up his legs, they want him to use the grab bar – while hanging onto that he can bend forward and wash his legs and feet with a long shower brush.

Also for safety, they would rather he clean his bottom on the commode chair rather than leaning from side to side on the slippery bench without being tethered to it. So I guess we have been lucky he hasn't slid off the bench. But I'm guessing he'll still wash his bottom as he has been doing, knowing him ;-) I told him he'd better just make sure he never falls off the bench, and he said, "All right."

Next was dressing in the chair. One thing he learned was that if he leans over the side of his chair and put a hand over the floor, he can get his hip up much higher than during the other techniques. They also incorporated a lot of "depressing into the pants," leaning side to side and pulling – lots of pulling. I think it'll just be a matter of him practicing now. There wasn't really anything else new they could tell him to do. They did say that regular pants tend to fall down in the back, and that if he went to the website wheelchairjeans.com he could find pants made to order specifically for those who are in wheelchair. For one thing, the backs are elastic, making them a little easier to get on. They said they come in jeans and khaki styles.

As he was dressing, the therapists noted how much more muscle Gary has now. Gary said, yeah, he had muscles he'd never had before in his life. They told him he was buff ;-).

Yesterday while we were gone someone came in and replaced my single bed with a double bed. So now Gary can practice double bed techniques in the apartment. Maybe even try doing his routine in that, though I'm not sure he'll want to try to get used to the changes while he's on day program.

So we went into the bedroom for some more practice. The PT had him transfer onto the bed and take his shoes off, while his feet are off the bed – usually he takes them off after he's gotten his legs onto the bed, so this was different (and more sanitary ;-)). So he leaned way over to the side and down and did this. He wouldn't be able to do this in his hospital bed – it's too high. They suggested he could use a grabber to undo his velcro tops and then push the shoes off with it, but I'm sure he will just continue putting his feet on the bed ;-).

Then she had him scoot to the middle of the bed and lay down and practice rolling to each side and sitting up – without grabbing the edge of the bed, as he wanted to do "cheat." ;-) Next she had him practice proning himself, and he did it pretty well. Next came a floor-to-bed transfer. This bed is lower than one he'd get for himself, and he did this transfer quite well – I spotted him, but this time

I didn't have to give him any pushes, I'm pretty sure because the bed was lower.

We had forgotten to grease his flap after his shower, and it was at this point I remembered that. So, he lowered his trousers a bit and while on the bed leaned to each side to see if he could cover the area with vaseline. He did quite well, though we all agreed I should be supervising him on this at least for a while to make sure he gets the entire area covered.

The last thing we worked on this morning was car transfers to and from our car. First, she told us no more could I put the transfer board under him – she wanted him to do that himself. So she taught him to do that by putting the board under his leg while he was sitting back in the chair, angling it from the corner of the chair to the corner of the car seat, and then hopping up onto the board before starting to transfer across it. She wanted the wheelchair in a position further back than we were taught, so he did that as well. She said the reason for that is it gives more room ahead of him. I'm not absolutely sure why that is important. It didn't seem to make much of a difference for the transfer in, but it did for the transfer out, mainly because she wanted him to do that a different way than he was doing. The way he had been doing it up to now was how I suggested he try it after we were having such problems with it when we first came home. She told him she'd never seen any transfer that way before (which is to put both hands in front of him and back out along the board). So, at least I was innovative ;-). He'll try her way for a while to see if it ends up better for him. His balance is so much better now that techniques that didn't work for him before may work now.

So, anyway, her way is to transfer by going sideways down the board, not backwards – she said he should be able to get his butt farther along the board before his legs and feet get "hung up," which has definitely been a problem, his feet getting twisted around each other or stuck in various positions. In her technique, he places the board in a different position than we had it, which should facilitate her method. She also wants him to have both feet out of the car, whereas we had had his feet in because he didn't like his legs dangling. But she said he could scoot up far enough so that he could get one foot on the footplate and the other on the ground. We tried her method when getting out of the car after day program. Naturally, problems cropped up (they always do when a therapist isn't around ;-)) – he was scraping along the ridge of the car door frame, plus he hit some little metal dohickey in the door frame, plus the board seemed to be sitting on top of his brake bar, which didn't seem too good for the brakes. The transfer wasn't much better than what we'd come up with ourselves, BUT I realized afterwards that he had forgotten to scoot up far enough to place his feet on the footplate and the ground. So we will try that. In any case, he will discuss it more with the therapists and try it some more, but so far he prefers "our" method.

I then drove Gary to Shepherd, where he was scheduled to meet with his doctor sometime between eleven-thirty and twelve. There were five other patients scheduled for the time between eleven and twelve. The doctor was running about a half hour late. First we were told Gary was second in line, then a little later he got bumped back. So he ate his lunch while sitting in the gym, but then the doctor left for "a brief five minute procedure on someone," which we had serious doubts would only take five minutes, so we went down to the cafeteria and Gary got some tomato soup served in a hunk of sourdough bread. He brought that back to the gym and ate it, then we sat in the gym some more (I spent the time writing some of this up). A little later, we found Gary had been bumped back again. So Gary went off to the other side of the gym and did his rickshaw exercises. Then, after two and half hours of sitting there waiting for the doctor, Gary's team nurse (a person who has never impressed me – I'd wished we had the one we had last time) told us she had made a mistake and that the doctor wouldn't meet with Gary today because he was an "old" (as opposed to "new") patient. HUH? I was pretty mad about Gary having wasted that time just sitting around. If he hadn't had another therapy session scheduled, I would have complained that we'd been sitting around waiting AND that his meeting with the doctor was up on the schedule board for everyone to see AND that we had missed a scheduled therapy session on account of the waiting, so why couldn't we get worked in? But I didn't want him to miss another therapy session, so I kept my mouth shut. Afterwards Gary sounded like he was sorry he himself hadn't been more assertive about trying to get in to see the doctor today. The nurse had taken a urine sample earlier, because we wanted to see if there was anything more that could be done about his "leaking problem." The urine analysis came back positive, so they are sending the sample for further culturing. We should get the result Monday. If they are negative, next week Gary may be scheduled for a urodynamics study, where they investigate what is going on in the bladder.

Anyway, we started the next therapy session. It was with the OT again, and the skill was to try to figure out how to get his own self covered with the sheet and blankets after getting himself proned (and without doing so much wiggling around that he messes up the position of the three pillows that are padding off his legs). Turned out the therapist hadn't ever dealt with this problem before, so it was basically a brainstorming session. One idea was for him to use safety pins to pin the covers to him like a superman cape, and then after he flops over into the prone position to undo the pins. He tried other things, like trying to pass the covers over the back of his neck by tugging at one end. Or maybe he'll have to figure out a way to "adapt" a blanket by attaching a short rope to it that he can use to pull it across him. (I had the idea he could sleep in some sort of pup tent made of blanket material that after he got in he could pull the rip cord and the blanket would fall on him – hey, I never said the idea was practical.) Anyway, it'll be something he'll just have to play with in the future. When I asked him about it later this evening, he said that if he was alone without help, he might have to resort to sleeping on his sides (and turning so as to not remain on one side alone), a position in which he can fool around with the covers without difficulty – unless it was very warm out!

After this, Gary mentioned that he was thinking of getting a knapsack for the back of his wheelchair instead of using the open bag he got at Shepherd last summer. The knapsack would be able to carry more, and the items in it would be protected from the elements. So the OT got a knapsack and he practiced with it. He didn't have any real difficulty getting it on and off the back of the chair. The technique is to turn his body sideways in the chair and then get it on (or off) one of the handles on the back of the chair, then turn to the other side to work with the other handle. He did get a little wobbly when working with the backpack after the OT had put books in it, and since I had just before this mentioned that he has trouble sometimes with losing his balance repeatedly when he tries to get his foot of the chair before transferring, and the OT had a suggestion related to that. She said that although he is good at doing balance exercises and good at activities that don't require so much of a balance technique, when the two combine he can get wobbly. She suggested that when he finds he is losing his balance a lot in an activity, to first try to get his balance point and then proceed with the activity, rather than just forging ahead with the activity. We'll get him to a state of zen yet ;-).

So, for instance, with the activity of getting his foot off the footplate, she said he should stop and analyze why it was he was losing his balance so much. She thought it was because he was doing it when he was so far forward in the chair. So rather than try to do it when he was at the end of his chair, she suggested he go partway forward and get it off as much as possible, then move to the end of the chair and get it off the rest of the way. And with the backpack wobbles, she had him lean against the back of the wheelchair while working with the backpack rather than trying to do so while sitting in the middle of the chair with his back unsupported.

After this, he was scheduled to do "the nursing game," but the nurse said he didn't have to do it because it was the same thing he had done last time he was here. I had wondered how valuable it was going to be, because I figured that would be the case. Anyway, there was another hour now unscheduled – too bad he couldn't have met with the therapist he'd missed out on earlier.

So, Gary decided to do his stretching and then call it a day. I told him we could practice some of the other stuff, like floor transfers or bump-ups or something, and we laughed and joked that I could always find something for him to do – but he couldn't be persuaded to be productive ;-) so we went back to the apartment.

Then our evening proceeding much as the previous ones have.

We saw a couple more "old faces" during the day. Gary's flap doc came by and asked us both how Gary was doing – and said for Gary to take care of his handiwork! We also saw the tech who always seemed to be "fighting" with me over who was going to get to help Gary with something. I saw her at the nursing station and asked her if she wanted to see Gary, because I knew she was someone he wanted to see while he was here. The first thing she says to him is, "I see your wife has been taking good care of you," and he said, "Yes, she is." Later, I wondered if she had used those words because she was skeptical I could take as good care of him as she could. Gary laughed and said he didn't mind having women fight over him – that it didn't happen often ;-).

All for now.

Dec 15, 2006

The morning was spent at the Holiday Party. First we went to a table where a Kwanzaa display was set up, and we learned a little about that celebration from one of the therapists. Then they had a jeopardy-style game on the facts that had been presented --pretty tough, since the various facts had just been rattled off to us! Also at this table, some rice krispy treats and small bags of M&Ms

were handed out, along with a party favor that listed the principles of Kwanzaa. At the next table the patients decorated sugar cookies. And at the final table we learned a little about Hanukkah and played a gambling game with a dreidel with letters of the Jewish alphabet on it. Then came the gift exchange "game." Each patient picked a number out of a hat, and in order they could either select a gift from one of the wrapped ones on a table or they could "steal" a gift that had already been unwrapped and "belonged" to another person. A gift could be stolen only twice, however. Evidently no one was overly thrilled with the five-dollar gifts that had been bought, because only one gift -- a lady bug massager -- was "stolen." Gary ended up with a three-pound dumbbell.

Then they served cafeteria-style tacos for lunch. Gary had one of those but will also have his bag lunch and I will have my rice. The only other thing we have scheduled for today is a seating clinic at 2, so right now we are sort of hanging around for that. I have already suggested to Gary that while we wait we should practice something he's learned. He said he'll think about it (he is off currently doing his IC). In terms of his therapy goals, this morning was a waste, but I'm sure you could have predicted I'd say that ;-)

We learned that next Thursday he doesn't have anything scheduled until 10 am, so Gary is looking into buying us tickets for the Atlanta symphony on Weds. night.

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Okay, now for a continuation. After lunch, we went to the gym, and I helped Gary transfer onto the Easystand -- that is the machine that is like a cross-country machine. He stayed on it forty minutes! (Not continuously moving his arms and legs, of course.) He had no blood pressure problems with it, so I didn't have to lower him at all during the entire session. He then worked out on a machine that was supposed to be good for his shoulders, and then finished with the bowflex.

The seating clinic, which we went to next, was very useful. They moved his wheels in, so that the chair is narrower. He immediately noticed he could make sharper turns. He has greater mobility in it, can get into tighter spaces, and probably gets more force for each push on his wheel since he doesn't have to reach as far out for the wheel -- at least, he says it feels like he gets more for his efforts. They also sawed his tip bars some, so they won't get caught on low curbs and inclines as has been happening. They made his footplate more level -- I couldn't get that adjusted right when I had tried to do so before. Finally, they adjusted the back of his chair so that it hits him higher up on his back, which will hopefully help with the aching he has been getting in his back in the late afternoon, and they also adjusted the angle so that he sits straighter in the chair, which should of course help his posture but also enable him to push more efficiently.

After that we went home. I took a walk and then finally got in one of my own weight-training programs. Then our evening proceeded similar to the previous ones.

Dec 16, 2006

Gary said he thought about why the swimming was such an emotional experience. Suddenly, all the deadweight from nipple level down, which is so difficult to move around, was floating, weightless, moved easily.

This morning he tried doing his bowel program on the commode chair for the first time. It took him about twenty-five minutes, his minimum time for doing it the other way. He found it easier to do it “the old way,” lying down, what with all the leaning he has to do in the sitting position, but we expect he’ll get used to doing it this way and will eventually prefer it. He got a little redness in his booty area from using the chair so ended up going back onto the bed and proning to give the area a little relief. Turned out that he had forgotten he was supposed to do weight shifts every fifteen minutes while on the commode seat, and he didn’t do one. Not sure if that would have made a difference.

He next greased his own flap, me watching to make sure he got vaseline on the entire area. It will take a little practice, but he does it pretty good, using the feel of the seam and “memory” on the places where the seam isn’t obvious to the touch.

Next came the new task of dressing in the chair. Partway during his getting his pants on, I heard this big “whoa!” come from the living room where he was. I raced around the corner from the bedroom, and helped him sit back up in his chair. He had lost his balance while leaning over the side of the chair and had been afraid he might slip out of it. So, I stayed with him while he continued to try to get his pants on. He gave up after about twenty, twenty-five minutes, and I tugged them on the last little bit over his booty – he’d already spent forty-five minutes dressing. He wonders if dressing in the chair will ever be easier than dressing in the bed. He could sure use a third arm! Two for depressing, the third one for pulling the pants up while he is in that depressed position.

So, we had gotten up about eight, though Gary had done his IC at seven (we had supposedly slept in, though I had still, for some obnoxious reason, again woken up at five and hadn’t gone back to sleep for quite a while; the elephant, at least, hasn’t been here the last day – we’re hoping he/she is off visiting relatives for the holiday and won’t be back until after we leave ;-)). Gary’s morning then was: eat breakfast in the nude while in the chair, go to the bathroom using the commode chair, get dressed in the chair. It was just about noon when he finished with these three tasks. This is reminding us of our first day in the Transitional Living Apartment.

Debra Talley, my friend from RS Fanfic, is coming about 12:30, and we will go out to eat to Mellow Mushroom Pizza (I’ll bring my rice), and then we are going to go to a movie at the same place Gary and I went to last time when we were here. We are going to see “Stranger than Fiction.”

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Debra saved me a lot of effort and time by stopping at an Indian grocery store on her way to our apartment and picking up 60 lbs. of Basmati rice for me. That should hold me awhile ;-). We went to the pizza place and Gary and Debra ordered small pizzas. They said the pizzas were very good. We ate and talked for a while, which is always enjoyable with Debra, then headed for the movie. We all liked the movie – I found it very creative and different and funny, sometimes in a dark or tender way. Debra characterized it as "quirky."

After the movie we headed back to the apartment and said goodbye to Debra. (She said it had been very enlightening to watch Gary do his transfers and watch me break down the wheelchair, to actually see what I had been talking about on the blog). I took a very short walk while Gary did his IC, and then he wanted to "practice" in the double bed in preparation for this evening. So he transferred into it and padded himself off for proning. I checked him, and he did it pretty good, just not leaving quite enough of a gap between the quad pillows that go below and above his knees. The he said he wanted to pretend it was 3 am and time for his IC when he would have to get out of the prone position and into the side position for that. I went into the other room, and I hear him say, "Oh, damn, it's 3am and I have to do my IC." Funny guy. He said he thought the repositioning he had to do was easier to do on the double bed than on the hospital bed, so it is a "go" for him to sleep in the double bed tonight. The only drawback for this from my point of view is that I had unmake and remake both beds, because I had my bedwarmer on the double bed and now it would have to be put on the hospital bed. This makes five times I have had to make a bed since last Sunday. I am getting pretty sick of that task ;-)

December 17, 2006

I slept great on the hospital bed, much to my surprise. And Gary did just fine in the double bed. So, maybe we will switch beds when we get back home. Only, we'll have to get someone to take my mattress and box springs off the bed frame – that would be a very high transfer for Gary to have to do twice a day!

He practiced with the commode chair again, only he had trouble keeping his balance while doing a weight shift on it because there is no back of the chair to hold him. So he wanted me to help hold him up while he was depressed upward! That was tough – we'll have to ask the therapists what he should do, as I'm certain we're not supposed to do that for the rest of his life;-). The next time he needed to do the weight shift, he said to try just holding him in place for his balance and not actually lifting him up. That was easier on me! I guess like other things he will just learn to keep his balance better. He said that he thought doing the bowel program on the chair was faster than in the bed. It took him fifty minutes from start to finish. He took a shower after that, but skipped dressing in the chair – he hadn't dressed in the double bed, so he wanted to make sure he could do that. At any rate, it took him four hours to do the four things of eating, bowel program, shower, dressing – it would have taken even longer if he'd dressed in the chair. But he says that he thinks he is going to like using the commode seat once he gets the transfers down to where I don't have to help him with that (and as well figures out how to do his weight shifts on it without my help).

We spent a "lazy day" around the apartment, except for going grocery shopping in the afternoon. I spent time working on my story and also went online to buy Gary some Christmas gifts.

December 18, 2006

Were you worried something had happened? :-) No, just decided not to push things by trying to get the day's happenings down on the blog in a timely manner while on Day Program. So, will be catching up in the next few days.

Today was a very full day, and it went very well, with the exception of interaction with the nurse. The first thing she told us what that Gary's urine sample from last week had been thrown out instead of cultured. She said she would cut into his therapy time before lunch to take another sample. We won't get the results of it back for forty-eight hours, and it will be too late to schedule him for a urodynamics study here, if that is what the results indicate should be his next step. So he will have to do that at home. He is scheduled to talk with the doctor tomorrow anyway, about possible future steps, but it would have been nice to have the results in hand on which to base our questions.

First on the schedule was the group fitness training. We made it better by proceeding at our own pace, and for some of the exercises I got Gary a theraband I saw lying around for him to do them with. It didn't make sense to do exercises for traps with dumbbells like they were doing (holding the dumbbells, bringing the elbows back, and squeezing the traps) because that mostly worked the muscles holding up the dumbbells, not the traps. But by holding an exercise band with both hands and doing the same motion the lower traps were targeted.

The next hour was a PT session of practice bumping up into the wheelchair. First she put the "bump-up" chair-like device in front of his wheelchair. It had a sling seat about twelve inches off the floor that he was supposed to bump up onto. He sat with his back to it and put his hands on the handles at his sides (which were about at the seat level), and then on three he threw his head forward and depressed so his butt went up and back. He made it to the sling chair. Next a belt was wrapped around his knees to keep his legs stable underneath him rather than having his knees splay out. This, they said, was key – his weight was partially supported by his legs during the next bump-up, and they could act sort of like a fulcrum. From this position, he put his hands on the next (upper) set of handles on the device, and repeated his movements so that he bumped up to his wheelchair (the seat cushion had been taken off, as that would give him three less inches that he would have to overcome). He did it, and the therapist said, "That was completely too easy." :-) To get back down, the thing he had to keep in mind was to start with his hands below him to gently lower himself, rather than keep his hands at his current height and end up plunking down to the lower level. After he did that a few times, I took the place of the therapist in spotting Gary. I was really amazed – all I was doing was providing him guidance (making sure he ended up far enough back on the chair), not lift. I wouldn't have believed he was lifting his booty up that far and getting on the chair basically all by himself if I hadn't experienced how little help I was giving him – I thought surely the therapist had to be helping him more than that!

I will have to remember to take a picture of this bump-up device. They no longer manufacture it, but maybe we could find someone to make Gary something like it, although maybe he will decide just to use a portable step, which is what he practiced on next. To do that, first he strapped himself into the J-pad, which is what he would do if he was going to spend some time on floor-level. The step they had was a little low, but we figured out that one about nine inches high, twenty-two inches wide, and fourteen inches deep would work quite well – we would also put a nonskid surface on the bottom of it and several layers of carpeting on the top of it to protect his butt. He practiced bumping up to the stair and then from the stair to the chair (without its cushion) a few times, the last time with me as his spotter, and again I thought him astoundingly successful. To get back down from the chair, he would lower his hands to the step, and then ease down. After the last time of going to and from the chair, he stuck out his tongue, indicating he was beat :-) Fortunately ;-) the session was over. So he transferred over to the mat and put his cushion back on his wheelchair, like he would have to do if he ever “really” bumped up to his chair at home, then transferred back into his chair.

So, if he ever wants to go upstairs in our house, he now has a way to do it, as the technique is similar. He’d strap on the J-pad to protect his booty and then bump up each stair. (Added a few days later when he and I actually practiced bumping up the stairway at Shepherd under a therapists guidance: it is not quite as easy as his bump-up practice to the chair. It is scarier for him because he is throwing his head downward in the direction of a flight of stairs when he is bumping up them! But he would do this with a companion, if at all possible (unless he is alone in an emergency situation), who would spot him (holding him at his waist, etc., as I'll describe on a later day's entry)to make sure he didn't lose his balance.)

Next was an PT session. Since Gary was having some trouble leaning while on the commode chair, she suggested he use his chain loops to wrap around the grab bar that will be to his right and behind him (it is in the shower, actually) when he is at home, and then loop his arm through it and lean. She also said that if the commode chair placement over the toilet seems awkward when we are home, that he could always set the chair over a bucket lined with a trash bag. In fact, she pointed out, this is what he may have to resort to when he is traveling, if the bathroom setup isn’t perfect. It might be easier to do the bowel program in bed, he thinks, rather than lug a commode chair around with him.

Gary’s next task was learning how to do skin checks of his own butt and back. The PT taught him a double mirror technique, lying on his side on the bed and looking into his small flexible-handled mirror to see the reflection from a large mirror. This worked quite well, and she suggested we get a large wardrobe mirror and have it mounted horizontally to the side of his bed.

Next he again practiced coming to sit from a supine position in the bed. As long as he has room enough to roll over practically into a prone and then sit, he is fine, but that coming straight up by grabbing onto his pants or under the back of his legs and then wiggling from side to side trying to get his elbows underneath him is something he can’t do by himself. We can’t see him running into the absolute necessity to do it this way, though.

She taught his some towel roll stretches, because his shoulders and chest are very tight, and also, his posture in the chair isn't the greatest – he always curves to one side, and the PT thinks it might be because his left chest wall needs stretching out. Both the PT and seating clinic commented on his posture, so I think that is something he needs to make a more conscious effort of being aware of ;-). It would just not be good for him to get permanently deformed in that curved position.

The first stretch she showed him was simply to roll up a towel or two and put the roll lengthwise along his spine as he lies on his back. He then puts his arms out at shoulder level in "crucifix" position, palms up. She said he could do some weight training exercises in that position, like a bench press (or "bear hug," as she called it), which would, on account of the weights, give him even more stretch. The second exercise was lay on his right side and put the roll of towels under his side. (She said we could use a bolster, but in the catalogue she had, they cost around eighty plus dollars – maybe there'd be just a firm foam roll we could buy cheaper.) For more of a stretch, I could put one hand on his hip and the other under his armpit and stretch him out by pushing on both hands. She said he should do these stretches for fifteen minutes in each position, so while watching TV on the futon would be a good time for this. Fortunately she said it wasn't necessary for me to be constantly stretching him when he is in the side position, because that would be quite tiring!

Next was an OT session. Since Gary had been having trouble keeping his balance doing his weight shifts while on the commode chair, she had him get on it (fully clothed) and practice the weight shifts. She helped him learn where he needed to put his hands on the chair to maintain his balance to do the depression weight shift. He may not be able to hold it as long as he is supposed to, so she also went over another kind of weight shift which he is now allowed to do but couldn't before on account of his flap – the weight shift where he bends straight forward over his knees, the goal being to bend far enough forward so that he lifts his butt from whatever chair he is in. She thought that if he did a series of depression shifts for short intervals and then this lean-over shift for awhile, for a total time of about a minute, then he should be fine. In general they don't encourage the lean-over shift because it doesn't develop/maintain arm and shoulder strength at the same time as relieving pressure on one's bottom – a sort of "kill two birds with one stone" method.

She then had him wrap chain loops (the ends of a piece of cloth are sewn together to make a circle and then these "loops" are "chained together" to a length good for the individual to use for stretching, etc.) around a support in a position behind and to the side of him – the position they would be in if he wrapped them around the grab bar in the shower while he was on the commode seat over the toilet – and she had him use them to lean over while simulating doing the bowel program. Gary thought that technique will work out well.

He will need to put a support under his feet while on the commode chair so that they don't dangle, for one thing. More importantly, that would keep his knees slightly above thigh level, and that would put a little pressure on his abdominal cavity, she said, aiding with the bowel movement. We figured out he needs a step about four inches high.

She then went over some arm exercises with dumbbells and back exercises with an exercise band (theraband) that she would like him to incorporate into his routine, three sets of twenty of each exercise. She said if he did them every day, that would be great, but he should do them at least three times a week (I'm betting he goes for the latter ;-) – I could see him resisting the idea of adding in more exercises to the routine he has been doing; but he really hasn't been doing the triceps work they would like, for one thing; hopefully he will talk to a trainer at the university and figure which exercises he has been doing target the muscles this PT wants him to, and hopefully he will then add in any additional exercises he really should). The first two are done while seated in the chair. The first exercise is a front extension to ninety degrees – in other words, lift arm straight out in front of you to shoulder height – and do so nice and slow. Next, biceps curls, two sets with palms up, last set "hammer curls" where the thumb is up – those are only done to ninety degrees, though. The next exercises are done on the mat. Lay with the towel roll under the spine for them. The first is the triceps extension, elbow pointing up to the ceiling and the other arm supporting the working arm. The arm is lifted straight up. Next were serratus punches – both arms are extended simultaneously straight up, and one "punches" them toward the ceiling simultaneously. Next was the bend press, circling the arms around as in a bear hug and squeezing the pecs. Finally for the arms was external rotation. You lie on your side, keep your top elbow tucked to your side, and lift the weight from bed (or mat or whatever your lying on) in a semicircular motion as high as possible (still with elbow pressed to the side).

Then came two back exercises, done in the chair with the theraband. The first you loop the band around a post and pull straight back and squeeze your traps for five seconds. The second you hold both ends of the band in your hands, keep your elbows up and out to the sides, and squeeze straight back.

Next with the PT came car transfers to an SUV. She taught him a slightly different way to do it, so we will have to go over that with Michel Smith (don't worry, Michel, it'll be easy ;-)). Gary is to angle the chair more straight in at the car seat, giving less slope to the transfer board, and he also is to put his feet into the car first so their weight doesn't dangle. He pulls his legs forward as far as possible, scoots to the left corner of the transfer board, and then transfers up. The key to getting out of the SUV is to go slow down the board. The helper (me or Michel, for instance) only needs to stay behind him and keep a knee aimed under his butt in case he needs the support or help with his balance.

Next with the PT he practiced transfers to and from a low sofa seat. He needed a little help, but was so much better than when he did these last summer.

The next hour was with the nurse, during which she was supposed to be going over skin checks with him. She was of no help, in fact, didn't seem to have a clue. Most people here are helpful, many extraordinarily so, but occasionally there is the person that is not very good. One thing that Gary didn't like was when we brought up the problem of how he would do skin checks of his back if he was traveling alone, and she told him he wouldn't be traveling alone. He told her that NOW he couldn't travel alone, but that he would in the future. He commented to me afterward that he didn't appreciate her saying to him that he wouldn't be traveling alone.

That was the last of the day, so we went home and carried on our usual routine. I had checked my email, and on the RSFic list someone was “complaining,” at least partly in jest, that she was blocked in writing a “fic” (fiction story based on the characters of a TV show, etc., in this case “Remington Steele”) because she wanted L.A. to be cold, wet, and rainy. I wrote her back and said she should get over it, because L.A. was unlikely to experience a dramatic climactic change soon. She wrote back something on the order of, “Bugger! How am I supposed to recreate a Yorkshire moor if the weather won’t wuther?” Her “weather won’t wuther” made me laugh, and while I was on my walk (and more later, while I was meditating) a poem for her came to mind. In case it you can get some enjoyment from it, here it is (I suppose I should say that this person is Australian, and her name is Robyn. I hope she won’t mind me identifying her that much):

Why, weather, won't you wuther?
Robyn rants and raves.
Frost and sleet and frozen feet,
Is what the Aussie craves.
But no, L.A., you do not provide
That which Robyn seeks.
You give her sun, you give her tide –
If she is lucky, rain for weeks.
This, she cries, just will not do –
What story can be made from these?
And so, dear weather, we beg of you:
For Fic's sake, her appease.

December 19, 2006

This morning (Tuesday) I was frantic, for a reason that had nothing to do with Day Program. I realized when I woke up that the changes I had made to my novel on Sunday I had saved to my USB drive but had forgotten to save them to the computer. (I like to save documents to at least two separate places, in case “something happens” to one of them.) So while Gary was getting ready for Day Program and in between doing things I needed to do for him (I do a little more for him on Day Program than I now normally would at home, just so we don’t have to get up so early while on the program) I tried to open the WordPerfect file that my story was written on, and it wouldn’t open! The file had somehow become corrupted. This has happened before, but I had always been able to use a “trick” I picked up on the Corel WordPerfect newsgroup to get the file to open and then with some work (usually a few hours!) “fix” the corrupted part of the document. Well, the trick wouldn’t work. I was trying to get to about page 275, and the document wouldn’t let me get there – I couldn’t scroll to it, couldn’t use the “Go to” dialogue box, nothing. The program kept shutting me down. So then I thought I better try to remember the changes I made. I went to the most recent document I had before that – I have learned from the past that I need to save a separate copy of each day’s changes, so if I lose a document, I “only” lose a day’s work – and tried to write what I remembered. But it was time to go to Day Program.

First up for him was practicing curbs, and he and a therapist started with the four-inch-high wooden platform in the gym that they use for that, the tip bars on his chair taken off. I was so upset about my file that I fired up my laptop right there in the gym and started typing the changes I could remember, stopping each time Gary approached the "curb" so I could cheer him on – talk about your divided attention. I thought I was able to pretty much reconstruct Sunday's work (it is amazing how much time I can spend thinking about how to write something and have so little to show for it), though I knew I had said some things in a way I liked better on Sunday. Meanwhile, Gary was doing great at the curb practice. I was astonished, seeing that we haven't practiced curbs at home at all. But as he told me, he's much stronger now, plus, the technique is greatly a matter of timing (push on the wheels, push on the wheels, push on the wheels, pop the wheelie to get the small front castor wheels up the curb, immediately lean forward and push hard on the big wheels to get them over the curb as well), and he has had some practice at that even in getting up the small rise at the entrance to our house. So he got to the point in the gym where he was making the four-inch curbs about fifty percent of the time. Obviously that means he's not at the point where he would do them by himself – that other fifty percent of the time he could land on his head – so the next step was for me to learn how to spot/help him with these. So I took the place of the therapist. I had my hands lightly on the push handles (the handles on the back of his chair), the idea being not to help him if he didn't need it. We did a couple that way, and I wasn't providing any lift at all!

Next came six-inch curb practice, and that was harder for him, using his momentum to get those back wheels up that height. He only made a couple of those, with help from the therapist. She didn't have me try any of those with him. She also reminded him that when he went down something of that height, at the time his large wheels went off the curb and were on street level he should stop his chair and make sure that he and the chair were balanced – if he just continued to push, that momentum he had going backwards might cause the chair to flip if he didn't have his weight forward enough.

Next he was to go outside and practice on a "real curb." So I shut down the computer and followed him (I was confident that I had at least recovered most of what I had written). Unfortunately, a van was parked where they usually practice curbs of about four-inch height, but we found a curb nearby of approximately six inches, and Gary did a couple attempts at those with the therapist. Again, he would not be doing those on his own, and in fact at this point he wouldn't even attempt to take them in a wheelie *with* me helping. Fortunately he never has to do curbs around the university or when he eats at the places around there, but so that he is prepared in case he does meet up with some, we reviewed the technique of what I or another person would have to do to assist him. It would essentially doing the above technique, but in "slow motion." The tip bars would be off, and his chair would be right at the curb (no moving approach for this). I would hold his push handles (firmly!). I would tell him I was ready, and he would push on his wheels to pop up into the wheelie and get his castor wheels up on the curb. The he would wait until I said I was ready, and then he would push on his wheels to get them up on the curb while from the back I would be pushing on the handles to help get him up the curb. To get down the curb, he would be backward to it and would back down it gently while I would hold onto the push handles and have one hip on the back of his chair for it to rest on, both my hands and hip there to make sure the chair was going slow and easy and wasn't going to go over backwards.

Next we had a session with the OT, and we asked her about how Gary should do his skin checks of his butt and back while traveling. She thought a moment, saying, "I appreciate the thoroughness you two have, but you make me have to think more." Evidently no one else had ever asked her such a question. She suggested he look into buying some kind of small travel mirror if a hotel mirror couldn't be used to his advantage and I wasn't there to check the parts of himself he can't see.

Next he did more practice at dressing in the chair. One new tip she had for him was to really push the material of the crotch as far under him as possible, "overcompensating," because the hard part is getting that middle material up in the back.

Getting pants on while in the chair is difficult for most paraplegics. (She told us that one of the patients said he was going to look into joining a wheelchair-accessible nudist colony so he could avoid the problem.) The advantage of being able to do so in a reasonable amount of time is that it saves you a couple transfers, i.e., transferring onto the bed to get your pants on, then transferring back into the chair.

While Gary was getting his pants on, the OT asked him how he liked the adjustments that had been made to his chair, and he said they were working out great. His back feels much better now that they have raised the back of his chair.

Next she went over "balance issues." She said while at home he could work on his balance by sitting on the edge of the bed (me there) and reaching for things on the floor or out to the sides. She suggested that a couple times a week he should sit on the edge of the bed, me behind him to make sure he didn't fall over backwards, and practice "Tai Chi"– like movements: slowly moving one arm at a time to the front and up and out to the side and back. In fact, she thought it would be good if he took an actual Tai Chi class, that the arm movements would be good for his balance and range of motion – and they'd be relaxing (she said as she told him to relax his shoulders!). If he takes such a class, she told him to sit forward in his chair (me standing behind him to make sure he doesn't lose his balance) so that he isn't resting on the chair back.

She left for a moment and I suggested he try some of the balance exercises the therapists were having him do last summer – in particular, pressing his palms together in front of him at chest level with elbow raised to the same height (kind of like the "prayer" position) and then raising his arms keeping his palms together. He was able to do this much better than last summer. In fact, he thought I was holding him, but I just had my hands lightly touching him.

Next on the agenda was a meeting with his doctor, during which Gary had wanted to discuss urinary issues, but the meeting didn't turn out to be much. The doctor said that the tests had shown Gary does have a urinary tract infection and wrote him a "pre-emptive" prescription for an antibiotic – that is, they hadn't cultured his sample yet to see what organism they should be fighting, but they wanted him to start on this antibiotic anyway. Gary tried to ask about having a urodynamics study done and about the drugs that people used to stop "leaking" if the leaking was due to bladder spasms, but the doctor didn't want to talk about that and was curt, saying he wanted to go one step at a side. (This doctor I'm sure is excellent as a rehab doc, but neither Gary nor I have ever been impressed with his bedside manner.) Gary later decided he'd just talk this issue over with a local urologist.

Another thing I had wanted Gary to ask the doctor, which he did, saying "Peg wants to know . . . " :-), was about all the coughing he does while he is eating or taking pills. He says he feels like there is a "pocket" in his throat where food and pills get stuck. Gary wonders if such a pocket could have been created as a result of the intubation that was done to him in Birmingham soon after the accident. The doctor told the nurse to have one of Shepherd's speech therapist come and do some tests to see what the problem was. I guess the nurse emailed the therapist, but he or she never came and saw Gary. Supposedly the nurse will now refer him to a speech therapist near home, so I hope she follows up with that; otherwise we'll have to get on Shepherd about that! I can't help it – I find the frequent coughing noises he makes during meals a bit irritating. I told him I would never know if he is really choking on something and needs a Heimlich maneuver. He told me that if he was really choking, he'd hold up one finger, then two, then three – like he was taught as a child to do if he was drowning in water. That set us to some black humor laughing.

He was then supposed to practice "bed mobility with care giver," i.e., with me. About the only thing he really needed practice on in that regard was getting to a sitting position from the supine position without rolling to the side first. He decided he wasn't going to use that technique much and didn't really want to spend a whole lot of time on it, so we practiced it a little and then he did his stretches on the mat. Then he went off to do his IC, after which we had lunch.

Oh, perhaps I should mention what is different about using the hospital bed as opposed to a regular bed. In the hospital bed, he can use the hand rails to help him roll from side to side while trying to get his pants on over his butt or for turning himself during the night. He can use the electronic controls to help sit him up for getting his pants on over his lower legs or for bathing himself in the bed (as much as he is able to reach). But he says using the double bed wasn't nearly as difficult as he'd thought it would be. He can do the turning and sitting up without the use of rails or controls when he has the room of the double bed – it's just that doing these things is a little easier in the hospital bed. In traveling he wouldn't have a hospital bed, so he needed to get weaned off it.

After lunch he was supposed to meet with the case manager for a half hour and then the rickshaw was scheduled in for a half hour. The case manager stuff didn't take very long. Must not have been too exciting cuz I didn't take any notes and I can't remember anything in particular ;-). I then set up the weights on the rickshaw for him. After he finished that exercise (takes at most ten minutes) I suggested various things we could work on – floor transfers, low-to-high transfers. Instead, he made a phone call to the Atlanta Symphony Orchestra to find out about the handicapped parking situation (they said the parking garage was very convenient to the Arts Center where the concert was to be held), and then he went down to the apothecary to get his prescription filled. I let him get away with this sloughing off of his therapy ;-). While he was being lazy, I was back on my laptop still trying to see if I could recover the corrupted file. Gary suggested I try opening the doc in WordPad. That worked, kinda sorta. All the words appeared, but so did a lot of strange symbols, taking the place of punctuation and God knows what else. It seemed a daunting task to figure out where the revisions had been made, but it could be done if I really wanted to spend the time on it – which I would have because I am compulsive that way. But then I recalled another strange trick I had heard about, which was to open the doc in the spreadsheet program Quattro Pro. So I did that, and there were all the words, minus the strange symbols that had appeared in WordPad but without any punctuation. Okay, this was a bit better. I could at least read what had been written without too great a difficulty, and so I could just read it sentence by sentence and compare it to my most recent version of the file before the corrupted one. What I really would have liked to have done, however, was just copy the revised section from Quattro Pro and paste it into the most recent uncorrupted WordPerfect document of my story, but when I copied the "cells" of Quattro Pro and pasted them into WordPerfect (or WordPad), I got one big *vertical* column of words. I then had the thought, what if I pasted it into NotePad, a text editor which strips all formatting and "hidden data"? And this worked! This made it easy to compare the revisions that I had re-composed from memory with the revisions that I had made Sunday (sans punctuation), and I was able to recover everything I had done Sunday. Whew!

Oh, and by the way, it didn't work to try to open the corrupted document in Notepad without going through Quattro Pro first – I got tons of strange symbols when I did that. I have no idea why it worked to go through Quattro Pro first.

Okay, back to rehab. Next was the major task of getting back into the wheelchair from the floor, whether one has ended up on the floor intentionally or not. First Gary positioned himself sideways in front of the chair with his legs bent so that his knees were slightly to the inside of one of the wheelchair "legs," (i.e., so that his knees were to the inside the castor wheels, so that when he pushed up to his knees he would be directly in front of the chair). Next he was to push himself up with his right hand on the chair leg closest to him and his left hand on the floor, the goal being for him to end up on his knees with his chest on the seat of the chair to keep him balanced on his knees. While he was doing this pushing up, the spotter (first the therapist, then after he did it a couple times, I was the spotter) keeps her hands on Gary's waist, either to help lift him or to keep him in place once he was on his knees (since, obviously, he doesn't have any leg muscles to help keep him on his knees). We did it a few times and I found that it varied how much help I had to give – sometimes very minimal, one time I had to use a bit of effort – but it was never a major effort. Mostly I helped keep him in position so he didn't slide back to the floor (if he's not perfectly balanced on his knees, they collapse to one side and his body follows them down). Now, after a rest, from this position (on knees, chest on seat of wheelchair – seat cushion removed to make this transfer easier), Gary was to put his hands on the wheels of his chair and do a (mighty) push up on them, walking his hands up the wheels, keeping his neck extended, the goal being to get his chest on the back of the chair (and not his neck or his face!). The spotter puts her hands under Gary's knees before he does this push and supplies whatever force he seems to need to accomplish this next stage and also holds him so he doesn't slide back down while trying to walk up the tires. The PT wanted me to use as little force as necessary – sure, I could have helped heave him up – but she wanted him to do the work (after all, it could happen he could fall out without anyone around to aid him). The amount of force I had to apply again varied, but it was never a huge amount – Gary did the vast majority of the work of the push up, while I mainly held him in place while he walked his hands up the tires.

The last step, after a rest, was for him to take his right hand from the tire and put it on the seat in front of him but to the left side. Then he twisted his head and shoulders to the left, trying to “flip over” to get his right hip on the seat and eventually his butt on the seat. As the spotter I was mainly maintaining the progress he was making, holding him so he wouldn’t slide back down off the seat.

So, as Gary states, it is a difficult maneuver. BUT, he wasn’t at all sure he’d be able to do it at all, even with my help. But we met that goal and are confident that if the need ever arises, the two of us can get him back in the chair this way. The PT told him that if he ever falls out of his chair in public, this is the way she wants him to get back in the chair – not by “cheating” and having two people do a “two-man lift” to get him back in (that is, one person holding him around his chest, the other person holding his legs, and the two of them lifting Gary into his chair). Gary said, “Not even if it’s two big football players?” She said no, but I’m not sure Gary wouldn’t take the easy way out ;-). If there were two people available, she would want one to play the role I was playing, and the other person to stand behind the chair to make sure it didn’t tip over backwards with all the heaving he was doing (if there is only one person, the chair is preferably situated so that that wouldn’t happen, like putting the back of it against a bed or couch, though a wall wouldn’t work because his head ends up behind the chair for a brief time). The second person would also ideally make sure Gary didn't "face plant" (end up with his face on the back of the chair) or end up with his neck on the back of the chair -- this they would do by keeping there hands near his chest. This might happen if, for example, he didn't push up high enough or didn't have his hands in the right position or didn't keep his neck extended.

Anyway, we are delighted we were able to do this. You might remember a therapist tried to teach us to do this last summer, and after our attempt she said, “You’d better just call 911.”

Last on today’s agenda was a scap class – working on the scapula muscle. We all took therabands and did punches, “diagonal pain,” chest flies, external rotation, diagonal punches keeping the elbow at shoulder height, “thumbs-up diagonal pain,” and lat pulls.

December 20, 2006

Oops, I forgot to put in another the thing Gary learned yesterday. After we did the floor-to-wheelchair transfer, the PT took us outside to the garden area where there is a flight of steps, and Gary learned how to go down them backwards while in his chair. The stairs had rails on both sides, and the technique was for Gary to hang onto both rails, lean way forward, “nose to his knees” (not quite physically possible for him), and slowly back down. I was to stay behind him, hanging onto his push handles, one leg on the stair below the one where his wheel would next go (so he wouldn't run into me), the other leg on the step below that, my hip to his chair to help support it as it came down. I don't know how much help I was supposed to give, but I was in "better safe than sorry mode" and I hung onto that chair for dear life, supported the weight of the chair on my hip, and guided the chair down slowly.

Wednesday morning began with the group fitness class, which went much as it always does ;-). The next hour was more swimming! The Shepherd pool was ideal for the pool exercises the rec therapist went through with Gary – in fact, I've never seen another pool that has an underwater ledge along the side that you can sit on and be about waist-deep in water. In a more typical pool, Gary would either have to sit on a step to do these exercises, or, the therapist suggested, stack some pool aerobic steps (assuming the pool has water aerobics classes). He would need to stick a towel under his bottom so he doesn't scrape it on the pool floor, and, in case I forgot to mention it before, he should always wear pool shoes so his feet don't scrape on the pool floor.

She gave him a pair of "resistance paddles" – they are about fifteen inches long, have a bar in the middle that you hold onto, and have paddles on each end with little holes in them, the paddles providing resistance as you push them through the water. For something similar to what he was using, see http://www.waterworkout.com/products.amp?product=pp.

She took him through a series of exercises, doing twenty reps of each. I sat behind him on the ledge and held him under the armpits to help him keep his balance. Indeed, he said that the exercises mainly worked his balance, not finding them difficult in the strength sense. I wasn't sure how much support he would need, so tried to give as little as possible, but I did find I had to put forth effort – he definitely needed my support and it was a little bit awkward and tiring for me to stay in that position behind him holding him upright the entire time.

He started with his arms out to the sides at shoulder height and pushed the paddles down to his thighs. Next he held his arms out front and pushed them down to his knees. Next were one-armed biceps curls. Next he held his arms out in front at shoulder level and gave big sideways sweeps to the back and then to the front, one arm at a time. Next he did stirring motions with the paddles, one arm at a time, clockwise, then counterclockwise. Finally he did punches, one arm at a time.

I asked her if they ever taught a type of "drown proofing." I had meant like what is taught in swimming lessons, a method for surviving in water disaster scenarios: you float vertically (assuming you are not one of those relatively few people with negative buoyancy), making minimal movement, face-down in the water; when you need a breath, you gently push down on the water, exerting just enough effort to clear your mouth from the water to take a breath, and then relax.

But she misunderstood me and told him that if he is ever near water in his chair (on a boat or a dock) that he doesn't want to have his seat belt on – if he falls in the water, he doesn't want his chair attached to him. I wish I had pursued my question, but I didn't. I want him to try the drown proofing method next time he is in the water, though.

After he finished with these six water exercises, we swam a couple laps, him on his back, the therapist and I swimming along. I asked the therapist if he'd be able to do the crawl stroke, and she said first she would want to teach him how to breathe by rolling over onto his back in case he wasn't able to catch a breath the normal way one does while swimming the crawl. This was more like what I had been trying to get at with my question of drown proofing. So, anyway, she taught him how to do that. If he couldn't clear his mouth for a breath while doing the crawl, he was supposed to put his arms in "Indian chief position," to use a politically incorrect description (one arm folded on top of the other), then since he breathes to his right side, he was to punch up with his right elbow while pushing down with his left hand against the water and, at the same time, attempt to roll over to his left side and onto his back. So he practiced this a couple of times, and then he tried to crawl stroke. He said it felt very different, not using his legs. The therapist was holding onto his waist as he did this, walking along the pool bottom with him as he swam along. I do not know how much support she was giving him – since his legs don't float, but rather would drop down, and he couldn't use them for any stability in the water, I suspect her help was not insignificant. She didn't have me try it with him, and I regret not asking to do so. So, we will have to try it on our own the next time he is in the water. Or, maybe the next time he'll be in the water is with the therapists, because he wants to go to the Adventure Skills Outing on Lake Martin that Shepherd holds annually, and he can try it again at that time.

The therapists called the pool at the university for Gary, and they found out that there is no pool lift chair, like Shepherd has, but they do have a wheelchair ramp down into the pool. I assume this means they would have a pool wheelchair for him to use to get into the water. If not, he could bump out of his chair as he's just recently been learning, though he would have to be very careful of his bottom on the rough surface of the pool deck and the pool – maybe we'd have to get some pad to put under him. Anyway, we'll just have to see.

After this session we lingered in the hot showers and then we were supposed to do "Dressing with Caretaker." I don't know if they had wanted Gary to practice dressing in the chair, but by the time we were out of the shower it was 11:30, and there wasn't enough time for him to practice dressing in the chair, do his IC, and have lunch, if we were to make the 1pm session. So, he dressed on the mat in the men's restroom instead, and of course I was with him, helping him with the transfer out of the shower chair that he had transferred into at poolside and getting our clothes out of the locker and helping him with his pants in the interests of time.

The first session of the afternoon was with the PT, and she told us to do the floor-to-wheelchair transfer; she wasn't going to help at all, and I was supposed to give minimal help. Gary got a battle wound this time – he cut his lip during the process. The PT said he could say I gave him the fat lip, but he said he was going to tell people he got it because he didn't do what his PT told him to do – which is true, but perhaps not in the way people might take that. What happened is he didn't put his hands on the wheels during the second push up when he was trying to get his chest on the back of his chair. He had his hands too far back, on the legs of the chair, and he ended up scraping his face along the back of the chair.

The next task was to go backwards down the stairs in the wheelchair while using just one rail, since most stairways don't have two. He said this was actually easier on his shoulders. The only "problem" was that he forgot to communicate with me and nearly ran me over, taking the next step before I had backed down another step. He said he didn't realize I was back there doing anything. I didn't let him try it by himself so he could tell what help I was giving. ;-) We had an audience of Nurse Mark, one of our favorite people here. Mark gave Gary the thumbs up and applause, and was suitably impressed that we had mastered the floor-to-wheelchair transfer.

Next we went back into Shepherd to practice a "low sofa to wheelchair" transfer. We passed through the rec room where a Christmas party was going on. A quadriplegic was singing a blues song – he was very good. It was all the more impressive because he had only recently gotten off a trache tube, and I'm sure his lung capacity had been diminished.

At the sofa, the PT told us that if Gary had to make such a low transfer, he could, if he wanted, stack the sofa cushions on top of each other to make the surfaces more equal in height – though that might make the surface of the couch squishier, which would affect his transfer. He could also stack blankets, or if it was to a surface in our home that he would regularly use, he could put a piece of thick plywood under the cushions. She did the transfer with him, and then it was my turn to do it with him. I had to give him a bit of lift, but not a huge amount.

Next we had a session with an OT, a different one than we have been having (that one left for the holidays). First on the agenda was, again, dressing in the chair. This person also had a useful tip for Gary – to lean on one hand and push up on it to get the opposite hip to raise up for getting the pants over his hips and butt. It now just seems a matter of practice. He has had various people give him various tips, and he will just have to practice to see what works for him. We should hold a celebration the first time he gets his pants on entirely on his own while in the chair ;-). Since at this stage it takes so much more time than dressing in the bed, he doesn't seem eager to practice it at home.

Next we headed for the "practice kitchen" on the second floor of the building. On our way we passed a sight that gave my heart a wrench – a newly injured young girl, maybe around eight (I didn't get a look at her face-on), in a wheelchair.

In the kitchen the OT showed Gary a short-handled broom that many patients seemed to like. Gary had told her the story that he had tried to sweep the floors before my sister Janet and brother-in-law came to visit and that I hadn't been impressed with the results :-). He liked this broom – it was easy to handle and had a broad sweeping surface. The therapist said another one of the therapists had been selling them and she'd look into seeing if there was one Gary could buy. She then showed him a short-handled dust pan that "closed up" when the handle was lifted. Gary liked that too, saying he found it impossible to sweep into a regular dustpan. (He hadn't told me this and had evidently been sweeping the stuff into a pile and then putting it into the trash by hand – ewww!) She said they had picked theirs up at a Dollar Store, but maybe we could find one in a place like "Bed, Bath, and Beyond." (Not that our town has one of those.) She also pointed out the mirror they have on the stove so that one can see how the cooking is going in the back pots. Gary told her he got such a mirror (which either I didn't know or simply don't remember) but hasn't figured out how to attach it to the back of our stove.

For another "kitchen problem" Gary has, she showed him the velcro strap they have on their oven, and Gary thought that was something he'd find useful. Our stove door tends to slam shut if you don't pull it down all the way, but if he pulls it down all the way he can't get anything in or out of it because he can't get the wheelchair close enough. So he says it's been a hassle trying to hold the door partway open with one hand and reach in with the other – a challenge to his balance and on the dangerous side, but he never told me about this problem before.

Next on the agenda was "Gym with caregiver," so we headed there and got Gary strapped into the Easystand. A Latino woman came up to us and started talking to us about it. The young man with her, who didn't speak much English, was very excited to see Gary in this piece of exercise equipment and wanted to know how he got to do it. So we told them that Gary had done the standing frame a few times first, and because he didn't have a great deal of problems with dizziness, they then let him use the Easystand, with me supervising. (Neither of us knew how it would be for him, using this equipment after not having stood for several months, but he has had little problem with it, just once complaining of not feeling good, a feeling which soon passed.)

We skipped out of the gym about fifteen minutes early because we had things to do before going to the concert tonight – we wanted to have everything ready so that when we got home from it Gary could pretty much just "hop" into bed and do the things he needed to do before sleep (undress, skin check, greasing flap, IC, getting into prone position – skipping the bed bath because he had showered at the pool).

At the Woodruff Art Center, we parked in the parking garage and took an elevator that disgorged us on a patio-like area from where we could enter the Art Center. We had to go to the box office to pick up our tickets. The signs to the box office were strangely marked – it turned out we made a complete circle of the building (or actually, a square) and ended up almost at the point where we had entered the building. We joked that if the arrow on the sign had pointed in almost any other direction than what it did, we would have found the box office quicker. After getting the tickets we had to cross to the other side of the building – it was like an obstacle course for Gary, trying to pick out a path to go, what with the crush of people.

In the auditorium the wheelchair seating was in the second-to-last "row," which consisted of spaces for wheelchairs to pull up into and plush folding chairs for the people accompanying those in wheelchairs. We had a good view of the stage, better than if Gary had taken an aisle seat, which would have been our only other option.

The guest conductor was Michael Krajewski, who had also been the conductor the last time we were here, last Christmas time. He likes to liven up the performance with the occasional (bad) joke. After the introductory piece of "Winter Wonderland," he turned to give his opening remarks.

At that moment a family with several children was causing a bit of a disturbance, moving down one of the first few rows all the way from the aisle to the middle seats (there is no middle aisle at this facility). So Michael made some cracks about that, saying something along the lines like, “Children, when mommy says to hurry up or you’re going to be late, she means it.” Somewhere in his introductory remarks he talked about how in getting here he had been going through the airport and had noticed that they had hung mistletoe over the baggage check-ins. He had thought that strange, so he asked the airport personnel the reason for that. The reply was, “So you can kiss your bags goodbye.” You saw that coming, didn’t you?

After the “March of the Toys” was played, Krajewski introduced the featured artists, the Von Trapp Children – these are four children from ages twelve to eighteen who are the great-great grandchildren of Captain von Trapp and Maria, of “Sound of Music” fame. After the von Trapps came to America, they earned their living as a singing act. These descendants revived that tradition. They were very good, not just living off their name. They sang a few songs from “Sound of Music” – “Do Re Mi,” “My Favorite Things,” and, as you might guess, “Sound of Music” (which reminded me that when I was a kid we had to sing this in glee club, and as a joke one day, we all screamed in mock fright after singing the first few words, “The hills are alive.” I decided not to recreate this experience for those in the audience this night.) My favorite songs they sung were: “Carol of the Bells” (one of my favorite Christmas songs), “Do You Hear What I Hear,” and what might seem an odd thing to include, “Anything You Can Do” from “Annie Get Your Gun.” It was sung by one of the girls and the twelve-year old boy. My favorite part was their duel, “Anything you can sing, I can sing higher.” The twelve-year-old boy “won.” I guess they’re going to have to delete that selection when the kid’s voice changes in a few years.

We left after intermission because we didn’t want to make too late a night of it, but I was very glad Gary had suggested we do this – it was a lot of fun. We had a slight problem coming out of the building – we couldn’t remember in which direction to go to get the elevator. We made the wrong choice and ended up wandering around for a while.

We got home and got to bed about a half-hour later than usual. But, we would get to sleep in about an hour because the rec therapist had conspired to make her the first thing on the schedule for Thursday, with the understanding that we would not show up for it because we had done a “rec therapy outing” on our own by going to the concert.

And that ended Wednesday!

December 21, 2006

Shoot, there’s another thing I forgot to tell you about the floor-to-wheelchair transfer – namely, how to do the reverse, that is, how to intentionally and directly go from the wheelchair to the floor. For that, Gary locks the brakes, puts his feet forward off the footplate, puts one hand on the chair leg, the other on the floor, and then walks his hands forward QUICKLY so that his body follows and ends up straight out on the floor (do you remember “wheelbarrow” races from when you were a kid?). As spotter, I kneel next to him and hang onto a belt loop (or belt, if he wears one) with one hand, while the other hand I put under his chest to keep him from falling on his face. After the first couple arm movements he makes, however, he goes too fast for me to keep up with him (scrambling along on upright knees), so the rest is up to him. In our practice, that went fine.

As we moseyed toward the third-floor gym on Thursday morning, we ran into Gary's doctor. He asked Gary if he would talk to a recently admitted patient, someone in the senior group, as Gary had been. The guy's level of injury is a bit lower than Gary's (T9, complete), but fairly comparable. The doctor said the guy is bummed out, and the doctor thought Gary would be a good person to talk to him, so that the guy can talk to someone who's been through therapy, been home, and has seen improvements in his capabilities over the months with therapy. Gary said sure, he'd do that, though looking over his schedule, he and I thought he'd probably wait until tomorrow after he was all through with therapy (and Day Program!).

We then passed by the PT, who commented on the scabs Gary now had on his lips. She said she was sorry that had happened, but he said it would serve as a reminder to get his hands up on the wheels when doing the floor-to-wheelchair transfer.

First on the agenda was a meeting with the case manager, who filled out Gary's discharge papers (though she jokingly reminded us we couldn't skip out until tomorrow). She commented that both Gary and I had a calm, confident look about us, that even if we are not quite there on some things, we know we *will* be there. I was wondering if she was contrasting our look to when she first saw us enter Day Program last July. We (and probably especially I) were frazzled and distraught on account of the whole new crop of problems that had arisen over the weekend (that's when his leaking problem started and also his flap suddenly looked worse) on top of the getting used to doing the whole shebang of his care on our own.

At any rate, she is exactly right. Gary (with some help from yours truly) has accomplished more in this session of Day Program than he thought himself capable of. And the things he is not quite there on, for example getting those damn pants on while in the chair, we know is just a matter of practice – he has the techniques.

The next hour was spent (wasted ;-) on doing that ASIA test again – the "touch tests." It seems rather silly to have it done ten days after the last time he had it done, especially seeing that nothing had changed from last August to Dec.11 when they tested him. But evidently it is somebody's requirement that he be so tested.

The next hour we met with yesterday's OT. She had a broom for us to buy and also had made Gary a velcro strap for the oven, so he tried those out in the practice kitchen. Then we went back to the third-floor gym and Gary practiced dressing again. He picked up another tip – to try leaning straight forward in the chair as far as possible in order to get the pants up in back. Since his balance is so much better, he is more confident of making such a lean. (And now he knows that if he should overbalance and can't catch himself, he can walk forward on his hands as in the chair-to-floor technique.) The OT also suggested we could sew loops inside Gary's pants so he has something to hang onto when he is pulling them up. I'm not sure we'll do that, but it's something else to have as a possibility.

Next came IC and lunch. After that we met with the therapist who had gone over curbs with us, only this time it was for more bump-up practice from the low mat to the high mat – this is where he has the J-pad strapped under his bottom, has his back to the upper mat, and "on three" throws his head down and pushes with his arms to get his butt up and back over the higher mat. I assume this practice was in preparation for the next hour when Gary would be bumping up the stairs. I think the PT had been giving him a not insignificant amount (which is somehow different than a significant amount ;-)) of help last time when he did these, because he was not able to do them without the therapist and/or I guiding him back over the top mat – he got his butt up, but not back. He did a bit better at them when I suggested he sit cross-legged instead of frog-legged, since he could get his head down lower that way. He made a couple of those with minimal help. BUT, he didn't want to overpractice because these are tiring, and he knew going up the stairs was coming next. Before that happened, however, a little performance took place. A teen-aged girl who had been recently admitted had apparently been taking dance classes. A couple friends of hers put on a little dance performance. I guess that girl is braver than me – had I been a dancer and could no longer dance, the last thing I would want to see so soon after my injury would be a performance put on by my dance friends.

So, in the stairwell, the PT first had Gary do a transfer from his chair to a stair – this was a different kind of transfer than he'd done before, and he did a good one. Then a belt was tied above his knees to keep his legs together and in good position. The actual bumping up (and down) the stairs Gary said was scarier than the other bump-ups – because "on three" he was throwing his head downward toward a flight of stairs. First I spotted him from in front and the PT from behind, then the PT and I switched places, and finally, I spotted him all by myself. When spotting him by myself while he was going up the stairs, I had to switch positions from being in front of him to behind him, depending on what stage of the process he was in. When he is doing the actual bumping up a stair, I am seated two stairs above where he starts, and I hang onto his J-pad and make sure he lands on the next stair (he did these better than the mat transfers we had just done because his legs are in a better position to help him). Then I continue to hang onto him as he does little depressions wiggling first one hip back then the other until he is fully on the stair (the PT said that that is the most dangerous part of the maneuver and for me to hold on good). Now his legs are two stairs ahead of him and he needs to get them to the stair just below him. At this stage I go in front of him and put my hands on him to make sure that while he is moving his legs up to the next stair he doesn't lose his balance and go tumbling down.

Getting back down the stairs I hang onto the J-pad from behind as he lowers himself down to make sure he goes down gently, then come to the front to spot him while he repositions his legs on the stair two away from his butt.

The PT said we had now basically met all the goals Gary had when he came here, that now it was a matter of practicing what he/we had learned, and that because of that, and because there was still some time left in our hour with her, she was going to go through with us an advanced technique she hadn't expected to get to with him: how to get his chair upright, him in it, if he should go over backwards in it. The first thing he should do if his chair is going over backwards is to put his right hand behind his head (to protect it) while tucking his chin and put his left hand on his right knee, to prevent his legs from coming up and smacking him in the face. Now, instinctively Gary wants to instead bend and reach forward with both hands to try to counteract the fall – but that ain't going to work if the chair's momentum is backwards.

Once he is on the ground, he puts the brakes on and pulls on the tires so his hips are firmly in the chair, then he snugs his seat belt. At this point the PT looked down at Gary and said, "Now you have to get up from there." There was a pause, and then she said, "Why are you looking at me like I'm crazy?" He said, "Because you are."

His next step was to push up on his right elbow and get his right hand on the ground, then to reach with his left arm over and up to the right top side of the wheelchair's seat frame. Then he pushes with his right hand and the idea is the chair rotates around the fixed tire and into an upright position. Now, supposedly when he is advanced enough he'll be able to do this entirely by himself, but how we did it at this time is that I am holding his push handles while he is on the ground and at the time he starts to push with his right hand, I push upward on the handles to help raise the chair. But, I wasn't using much force at all to do this – it was mostly Gary. In fact, for both of us it was less effort to get him upright in the chair this way than it was to get him in the chair doing the floor-to-chair transfer. I half-joked that if he ever fell out of the chair we should get him back in it this way, but of course if we tried that there is the problem of getting him in that initial position of being seated in the chair.

The PT now asked Gary if he still thought she was crazy. "That I can do this myself? Yes," he replied.

The PT then left, that being the end of the session. Gary was obviously thrilled we could do this advanced technique with no problem. He started to say to me that this particular PT was really good – and he became so overwhelmed he started crying. He finished his statement, saying that the PT really had a way of instilling confidence in him, that he can do things with her that he never thought he'd be able to do.

The day finished with a group exercise session, led by a different therapist than usual. She had a good tip about balance in the chair – that in reaching forward it is good to have the large part of the castor wheel pointing forward because that gives greater stability to the chair. She was really into breathing ("Now hold the position and breathe and breathe an breathe"), and as the session went on she revealed she taught yoga classes to those in wheelchairs. I'm afraid I had all I could do to keep from laughing at her manner, though. She spoke in a dramatic tone as if she were addressing a large group of people rather than five of us, and she reminded me of one of the instructors at "Freidlich Sensitivity Spa" in the episode, "Sensitive Steele," a reference that only a very few of you will appreciate, to your loss ;-).

On our way out of the building I made a mistake and held the door open for Gary. I joked that we had to go back inside so he could open it himself.

The rest of the afternoon and evening I spent much of the time packing up as much as possible, loading the car, and cleaning the apartment. I should have skipped the stupid vacuuming though – my back and leg hurt when I was done.

Gary wanted fish for dinner, and for some reason the oven started smoking while the fish was cooking. That set off the fire alarm. I couldn't figure out how to shut it off, so I opened the door to the apartment to let any smoke out and stood on a chair fanning the fire alarm. That shut it off, fortunately!

December 22, 2006

As figures, I woke up at 3:30 and couldn't go back to sleep. I got up when I heard Gary stirring – he had set his alarm for a half hour earlier than usual (5:30) to give me more time to throw stuff in the car before Day Program. So, while he was doing his thing and in between doing what I needed to do for him I packed up the stuff as it became "available" to be packed, and loaded the car, and did more cleaning, and laundered the sheets and towels like they said I was supposed to do before vacating the apartment. There was just enough time to get it all in before we needed to leave for Day Program, and I was glad I didn't have to miss any of his last day. While we were still in the apartment and Gary was helping me fold the towels, he said, "I am impressed with the job you're doing this morning." I said, "Oh, you mean the way I pulled the sheet out from under you while you were in the middle of your bowel program so I could wash it?" (which did happen). He laughed and said, "Yeah, and the way you demanded the peel from the banana I was eating for breakfast so you could throw all the trash in the dumpster." (which also happened).

His first hour at Day Program he was in the standing frame, and as balance exercises the PT played catch with him, first with a tennis ball, then with what I guess was a soccer ball – at least, it was about that size though it was on the heavy side and didn't bounce very well. She threw the tennis ball to both his left and right sides and he was supposed to use each of his hands to catch it. While they were throwing, she asked him if he was sore from all he'd done yesterday. He said he had been sore yesterday afternoon and evening, but wasn't now. They changed to the larger ball, and he was supposed to use two hands to catch it (he first asked her if there was any danger of him falling out of the standing frame if he leaned too far to one side to get the ball, and she assured him there wasn't). All of a sudden while they were throwing the ball back and forth, Gary whips it in my direction (I was off to the side of them). He hadn't looked at me beforehand, and not only wasn't I prepared for the throw, but I was just finishing putting my notebook back in my pocket, having just written that they were now using the larger ball. Fortunately I got my hands up in time to catch the ball. Gary laughed and said it was an amazing catch. I am not sure why he thought I should think him funny, seeing that if I hadn't gotten my hands up I would have gotten hit in the face. Must be some obscure Gruenhage humor ;-).

So then the three of us played catch for a while, at good speed and in no particular order – kept us all on our toes. Then the PT got some ping-pong paddles and we tried to play ping-pong with the tennis ball. The PT soon left me and Gary to do this ourselves. This is not my game anyway, but it was definitely not my game under these circumstances – there was only a limited amount of area that I could hit it to for Gary to be able to hit it back, and my aim wasn't that great. I got more exercise than he did, what with me running around the gym to retrieve the ball. We did a lot of laughing, though.

The next hour we went on a push, but it wasn't a very lively one. There was only one other person on it, and she was fairly newly injured and didn't have anywhere near the skills, strength, or endurance Gary had. We went out to the door to the parking garage, near the elevators, and the therapist had Gary open the door. Of course, he's had practice opening doors for the past four months, so he did it easily. Then it was the young woman's turn. Not only was this the first time she had tried to open a door, but on account of her injury – C6-7, incomplete – she didn't have full functionality of her hands. Gary, myself, and the therapist stood watching her attempts, and at this time another woman entered the area to use the elevators. She punched the button for the elevator and it came almost immediately, but it was then that she became aware of the woman in the wheelchair trying to get back in through the door from the parking area. "Does she need help?" she cried. "Is she stuck?" She moved toward the wheelchair person, but I assured her that this was a practice session. The woman then said, "Oh," and left, taking the elevator. I then said to the closed elevator door, "Yes, she was stuck. The three of us are just cruel people, standing around watching her struggle to get in the door." We all started laughing, and then we shared what had happened with the young woman who had finally made it in through the door. Next came more door practice, and the woman was amazed how easily Gary could do it. I assured her that Gary had been practicing it for four months and that she would be able to do it in time. We then headed toward the tunnel that led to Piedmont Hospital so that Gary and the other person could attempt the dreaded Blue Carpet – you might remember that is a carpeted long and steep incline. But on the way, the therapist disappeared (Gary and I were way ahead of the others). The other person in the wheelchair pulled up, and she said she had no idea what happened to the therapist, that she didn't realize the woman wasn't with her. I thought maybe she'd gone to the bathroom. After several minutes, Gary said he was going to check his email in the library, which was close by. I waited with the young woman, who I guess to be in her late teens, early twenties. She asked how Gary got injured, and I told her about his accident. She said she had been in a car accident too, that she'd been a passenger in a car driven by a drunk driver, and that he'd slammed into a parked car at 105 mph. Nothing happened to him – she said he was still out playing baseball and driving drunk. I couldn't help having the thought that while it is inexcusable to drive drunk, it also isn't wise to get in the car with a drunk driver.

The therapist showed up with some strange excuse about having to buy the pecans that were being sold in the passageway because they were going to run out, and that there had been a long line. They have been selling those pecans ever since we arrived, so I didn't "get" her excuse. Anyway, Gary came wheeling out of the library at this time, and we headed toward the Blue Carpet. He made it “the easy way,” which has a smaller and shorter incline at the end, with little difficulty, and then after a rest it was time to tackle the hard direction. His record last August was to get up this incline with three rests. He made it in one shot! It still wasn’t easy for him, but he did it. The young woman needed lots and lots of rest breaks to get up it, gasping away, the therapist hanging onto her chair so she wouldn’t go backwards. Reminded me of the first time Gary was in the chair and he needed rest breaks to even go for a relatively short distance on a level floor.

We then headed back toward the parking garage, and Gary and I thought the therapist was going to have them go up the parking ramps, like they did the one other time Gary was on a push like this. But we didn’t go there, instead turning into the Marcus building and taking the elevator back to the third floor. I thought maybe it was because the parking ramps would have been too much for the young woman, though the therapist said it was because it was wet out.

Last on Gary’s schedule was a group exercise session, the group being the same four of us (me, Gary, the young woman, and the therapist). After that was Gary’s graduation ceremony. His therapists and me and others in the gym cheered as Gary received his certificates. His special award this time was for being “Most Improved since last Day Program.” I had thought they might make it a funny award, one referring to his split lip. They then gave him a nice send-off – they sang the Shepherd Graduation Song, and he went wheeling out of the gym, giving them a regal wave as he left.

So, the Day Program this time around was a very satisfactory experience – Gary was very, very pleased, thought it was very worthwhile, said he’d learned to do some things he’d never thought he’d be able to do even with me giving some help. As for me, he astonished me in a number of ways. I knew he was stronger (though it never occurred to me he would be able to use four-and-a-half times as much weight on the rickshaw than he did last August) and had better balance, but this was concrete evidence of how he’s not only improved on so many tasks, but can do things like floor-to-wheelchair transfers that were simply impossible for us to do last summer. I think he astounded his Day Program team, too, seeing that the first day we were there they told him he’d need a month to accomplish his goals, and then he goes and essentially gets through those goals, and more, in two weeks.

But we were not quite through with Shepherd. We went to the room with the “bummed-out patient.” The man didn’t seem out-and-out depressed, but he did question his ability to learn to “move all this deadweight around.” He said he’d watched Gary in the gym and had been amazed at what Gary could do, and that he himself couldn’t even imagine being able to get himself into a car. Gary said that still wasn’t the easiest thing in the world for him to do, and that when he first came here, he certainly couldn’t do the things he can do now, but that the therapists here were very good and in time the man would learn how to do them too. The man still seemed a little skeptical, saying he weighed a lot more than Gary does, but Gary insisted that in time he would develop the strength and techniques.

Anyway, the guy said he appreciated Gary coming around to talk to him, that it was good to talk to someone in much the same boat (they also shared experiences of how much they had hated being intubated – the man was still being weaned off his trache tube). The man said that Gary seemed to have adjusted well, and Gary said he had. The man said he hoped that he would adjust that well, and then we said our goodbyes.

So now we were through with Shepherd. Traffic was thick all the way from Atlanta to home, I guess it being the weekend before Christmas. We stopped at the Target a few exits before our own, in order to look for a few things that Gary wanted to get based on the ideas that had come up at Shepherd. So, as Christmas presents I got him a knapsack and an exercise mat for when we practice floor transfers. I thought we'd find some crocs there, but we didn't, so I will get them elsewhere. I will also buy him some Jobst socks, which are supposed to be not only better but more stylish than the t.e.d. hose, according to the "Been there done that" guy. I'm also getting him wheelchair gloves, and will take him to the movie of his choice. Oh, and I also already bought him a cashmere V-neck sweater and a knit polo shirt.

We were both pretty exhausted by this time, and I still had the car unloading to do. Ycchh. I had to put the bed warmer back on my own bed, and while I was doing that, Gary rolled by. "There's Peg, making a bed, as usual," he joked. I swear I've made more beds in the past two weeks than I have in my life. Gary was too tired to make anything for himself for dinner, so he decided to have the peanut butter and jelly sandwich he had made for his lunch (I had stopped at Fresh Market and gotten him an Italian panini sandwich for his lunch) and also have some Amy's organic soup. I made my zukes and rice. There were still two hours to go before bedtime, and I spent the time pretty much just wishing the time would pass more quickly, too tired to do anything. I couldn't go to bed early, because Gary had to keep to his routine and there were things I had to help him with.

I was very happy to hit the pillow that night.

Dec 23-24-25, 2006

Tigger was happy to have us home. He followed me around for the rest of the day on the twenty-second, demanding lots of petting. Blackjack was just happy to have someone to yell at when he wanted food.

We looked through the mail that had been sent to us over the past couple weeks. Found some nice fat checks from my mom and Gary's mom ;-) and some lovely Christmas cards. Debra Talley had done a watercolor of a bundled-up little girl with up-turned face greeting the swirling snow, and the print of it was marvelous.

We called my little sister, and I listened in when Gary talked to her about Day Program and such. He told her they had him doing things he'd never thought he'd be able to do but that he could on account of not only the techniques they showed him but their encouragement. In particular he mentioned getting the wheelchair back upright if he falls over backwards in it (and let's hope that never actually happens). He told Di that he was stronger in his upper body than he's ever been before – and I note that he's certainly got muscles like he never had before!

She must have asked him something like if he ever got depressed, because he said somehow he never did, that he always focused on what they said, that he would, in time, be fully independent. He said that his "support group," headed by me and including his family and friends, helped in that regard. He noted that lots of people with SCIs do experience depression, that one of the workers at Shepherd had told a group of us that she'd been depressed for two years after her accident.(On Christmas, we talked to my mom, and the topic must have come up again, for he said much the same thing, in particular how grateful he was to my brother Joe for taking time out of his life and coming to work on our home and to the math department people who devoted time to the project, helping Joe out.)

Di asked about his job, and he talked a little about that, saying that it would have been very difficult to return to a nine-to-five job, but that he was fortunate not to have time commitments in that way.

When I was on the phone with her, Di told me a funny-but-not-funny story of how she is supposed to be cat-sitting for a friend and the cat, an "outdoor cat," has run away. Fortunately, through the humane society the cat has been located – it is staying about two blocks away from Di, being fed by a woman who noticed it hanging around her house. Now all Di had to do is catch it by this coming Wednesday.

We went to Kroger in the afternoon, getting back into our routine – including the stop at the ice cream parlor afterwards. Joe and Dolores had said that for Christmas one thing that we should do as our gift from them was to buy or do something special for ourselves. They suggested Gary get a gallon of ice cream "with his name on it." I told him we were getting that gallon scoop by scoop. (As their gift to me, I intend to buy myself a copy of the soon-to-appear book on the Remington Steele series.)

One thing that was not routine in the day was that we were going to a Christmas party in the evening – this was Gary's first outing to someone else's home. Gary called the Stuckwisch's to make sure he could get into the house. They told him he could come in through the garage door so as to avoid the sunken living room – because Frances didn't want him doing wheelies in her house in order to get out of the living room and into the rooms where the food was ;-). The garage door led into the kitchen – where the rice and beans and chili would be kept – so Gary didn't mind that at all, since he tends to gravitate to the kitchen at parties, he says. Through the kitchen he could also get into the dining room, and on the dining table there was a big spread of food as well. This was just fine with Gary. We stayed a couple of hours – probably a lifetime record for me ;-) (parties make me anxious) – and then we left so Gary could start his evening routine. The only "problems" we ran into was that in getting to the Stuckwisch's we couldn't see the names on the posts they use as street signs down here, and I had to keep on getting out of the car to see if the cross street was the one I wanted to turn on; also, at their house the outside was very dark which made it harder for me to put Gary's wheelchair together – but since I've done it often enough, I could essentially do it by feel.

Sunday I spent much of the time catching up the blog. I also composed a Christmas letter for Gary. On Christmas morning we started off the holiday by reading each other's cards and crying over them. We are sentimental saps ;-). Then it was present time! Joe and Dolores had made a donation to the Christopher Reeve Foundation in our names, and they bought us "Superman" and "Superwoman" tags to wear and said they bought some for themselves too. We had made a donation to Toys for Tots in their names. Janet and John sent us a four-foot LED Fiber Optic hanging Christmas tree so we would have some Christmasy decoration. Since it was morning, we couldn't get the effect, but in the evening we turned the lights out and plugged in the tree and were treated to quite a show! We gave them gift certificates to amazon.com. And that is what I also gave my little sister Di and her two boys. From Di I got some mystery books and Gary got the book "The Last Three Minutes," conjectures about the ultimate fate of the universe, and I also got some loungewear. For some strange reason ;-) Gary's side of the family decided Christmas was about kids, and so it was our nephews an nieces that made out with the goods, though Bob did send Gary a St. Louis Cardinals World Series Champions T-shirt. Oddly, I forgot to give Gary the presents that had already come in the mail, only remembering to do so in the evening. I joked that I was getting him a rickshaw weight machine too, but he didn't seem to think that was very funny.

We made calls to or received calls from the various family members, though we didn't get in contact with Joe and Dolores until Tuesday morning. My mom, as usual ;-), has been keeping busy going to party after party. Joe and Dolores are coping with 23" of snow in a town in Colorado that, as may surprise you, is not prepared to deal with that amount of snow – the main streets are plowed, but not the others. Usually the snow there doesn't stay very long, sublimated from solid to gas by the dry air and the intense sun they get there in the winter time. Joe and Dolores sent us pictures of the results of the blizzard. Their dogs seem shorter than the drifts, though Joe says they get along all right by leaping from footprint to footprint.

Gary and I had fun making our typical holiday meal – yes, nearly identical to the Thanksgiving meal I described. I think the only differences were the type of bread used in the stuffing, the fact that asparagus was had instead of broccoli, and that I added cranberry juice to the maple syrup that was poured over the sweet potatoes. The juice we had on hand because we are going to incorporate that in Gary's diet as a preventative for UTIs.

Gary had intended on Christmas morning to try out the raised toilet seat, which evidently is the correct name for what I had been terming "the commode chair" (evidently a commode chair is a different piece of equipment, similar to a shower wheelchair, and in fact can double as a shower chair). I told Gary "raised toilet seat" just sounds like some man forgot to put the toilet seat down, and he said he was sorry but that was the official name for it. At any rate, the chair turned out to be much higher and much smaller than the one Gary had used at Shepherd, and neither of us were comfortable with him making such a high transfer onto something he would essentially have nothing to hang onto, not to mention leaning over sideways on it and being half a foot higher from the floor than what he'd practiced on. So, we skipped that. Gary called the company on Tuesday and it turns out he got an old model, so he is trying to get our vendor to replace it with the new model. Dealing with vendors tends to be a little like pulling teeth, we've found.

So, now I've pretty much caught up on our doings, except in the next entry I want to make a bit of a summary of Gary's achievements at Day Program and what we are incorporating of what we learned.

Dec 26, 2006

A reiteration of the goals Gary had going into Day Program and how he/we fared:

Goal: Raised toilet seat – how to transfer onto it and how to use it for the bowel program

Result: Gary has the basic technique down. He will need to practice the transfers with me for a while until we are comfortable with him doing them by himself – and first, we need to get a proper-height piece of equipment, because we discovered on coming home that the raised toilet seat they gave us is much too high! So, we haven't yet had the chance for him to actually get on it at home; in particular, we haven't been able to see if looping his chain loops (which are normally used to assist him in stretching) over the grab bar in the shower and then hanging onto a loop while he leans over to do his bowel program is going to work for him – it seemed a little scary for him to do so to me, the grab bar being so far away. If that doesn't work we'll have to figure something else out, maybe installing a floor-mounted grab bar.

Goal: Work on Transfers from wheelchair to the following and from the following back to the wheelchair:

raised toilet seat (Result: see above)

floor (Result: We got the techniques down, both the technique of bumping up into the chair backwards using an aid like a step and that of going directly into the chair frontwards, both ways requiring assistance from me at this point in time)

our car (by himself and possibly without use of transfer board) (Result: he still needs assistance and we still need the transfer board and we decided the way we had made up was better than the "official ways" being taught to us, because by going from the car into the wheelchair backwards Gary doesn't have to worry about banging his butt on the frame of the car.)

an SUV like Michel's, which has a seat so much higher than our chair (Result: Gary learned the technique and got it down, with assistance of course.)

shower bench (Result: an alternate way was suggested, that of transferring from the raised toilet seat to the shower bench, which would eliminate the problem of not being able to get the wheelchair at an advantageous angle to the shower bench. We haven't tried this at home yet.)

low to high transfers in general (Result: Gary can do these much better than at previous Day Program; requires assistance at this point in time)

Goal: Dressing while in the wheelchair, trousers especially (so he doesn't have to get back into bed to dress himself)

Result: he has the techniques; it will just require practice to be successful – he hasn't been able to get the very last part of getting his pants on over his butt without assistance. So far, he hasn't been eager to practice this at home, sticking to dressing in the bed.

Goal: Decreasing the number of ICs to four (though that may be a problem because at this point it would mean he would have to get himself out of the prone position at midnight and lay on his side to do the IC, and he would then have to wake up an extra time during the night because he's not allowed to stay on his side for more than six hours and he isn't comfortable staying on his side for even that long – and he doesn't want to wake up an extra time!)

Result: because of the aforementioned problem, no change was made.

Goal: Curbs and wheelies

Results: able to do four-inch curbs about fifty percent of the time, less able to do six-inch curbs; therefore, he will in neither case be doing these on his own yet as we don't want him tipping over backwards, even if he now knows how to get the chair upright, him in it, should that happen (assuming he isn't too dazed to even try); he can do these curbs with assistance, however.

Goal: "Regular bed techniques" – in other words, now he does everything in a hospital bed, which has those nice electronic controls and rails to aid him. Since he eventually wants to travel, he wants to be able to do his maintenance tasks in a regular bed, so he needs to "re-learn" how to pad and position himself, and turn from side to side, and do his bowel and bladder stuff, etc., in a regular bed. Also, he wants to learn how to prone himself, because he is definitely dependent on me for that.

Result: This didn't turn out to be as big a problem as he thought it might be. He can do his bowel and bladder care, and turn from side to side, and pad himself while on his side with no problem. As for proning, he can get padded off and in the prone position, but at this point I still need to check that his pillows have ended up correctly above and below his knees to make sure there is no pressure on his knees. We also had a tradition of a "thank you very much pillow," which is the pillow he puts under the side of his face while he is lying in the prone (face-down) position, and is the last pillow that is put into place for the night. Our tradition was that I would throw this pillow with some force on top of the back of his head every night, at which he would say, "Thank you very much" and then put the pillow under his cheek. Hey, we have to have our fun. We missed our tradition when he was putting that pillow in place himself, so we went back to me smacking him with it.

He hasn't practiced in a double bed at home. First we have to figure out what to do about a bed for him. I am going to try sleeping in the hospital bed at least one night – and Gary will have to make the high transfer into my double bed. If we like the results, we have to figure out if we are going to move my bed into his room and the hospital bed into mine, or move both beds into mine and shop for a double bed for him. The hospital bed is rented, and we have it for a total of six months, we think.

Goal: Find out if there's anything else he should be doing for the "leaking problem," see what the possible solutions to it are and what their long-range effects would be

Result: He was discovered to have a UTI. We wonder if he may have a near-constant low-level one, which may be causing the leaking. He is going to incorporate cranberry juice in his diet. He is also going to speak with a local urologist about the problem.

Goal: Grease his flap himself

Result: success

Goal: Do his own skin checks of his butt and back

Result: We think he will be successful with this when we get a long horizontal mirror hung on the wall next to his bed.

Goal: Get another wheelchair evaluation – it's possible the wheels on this could be brought in to make the chair narrower; also, we want to see if his tip bars could be raised and if the footplate is in the proper position (I had to fool around with it from what it was when his new chair came, because he couldn't roll under the kitchen sink – the position of the footplate made his knees to high – only now, in the position the plate is in his heels don't rest on the plate). A minor goal is to learn to breakdown and assemble the chair himself, but he doesn't really see himself doing that, like to get it in a car – it's too heavy for him. He won't need to do that when he gets his van, cuz he'll be able to roll the chair right in; and if he's a passenger in someone else's car he'll depend on them to get the chair in and out for him.

Result: he didn't bother with the breaking down and assembling of his own chair. All the changes to the chair mentioned above were made, and in addition the back of the chair was raised. He is quite pleased with the changes, and especially the fact that his back no longer aches as it had been doing in the new chair – there is still discomfort there, but it is like it had been before getting the new chair.

Goal: He also hoped to persuade the recreational therapist that a good goal to have would be for he and I to go to the Atlanta symphony Christmas concert next week. The catch is that we'd want permission to not have anything scheduled until 10 am the next day, as it would be a later night for us than usual – otherwise we wouldn't need to mention this to them as a goal!

Result: We went and had a good time ;-)

Goal: Other rec therapy goals: they may get him in the pool; they are putting him in the standing frame; they may go over a weight training program with him that he would be able to use at our university gym.

Result: He got in the standing frame a couple of times and in the Easystand in the gym with me a few times; the OT gave him a home exercise program; he went swimming twice, the first time being a very emotional experience as he felt the freedom of being able to move his body about in the water easily. It takes so long to shower and dress afterwards, however, that he is not at this point inclined to make swimming a regular thing. Come to think of it, I'm not sure how the university would handle me needing to be in the changing room with him, but we don't have to worry about that at this point.

Other things that happened on Day Program not on this list:

He learned the technique for getting his wheelchair upright should it fall over backwards – this the two of us were able to do with no problem.

He learned how to bump up and down stairways. We can do this together, though he isn't eager to be doing a lot of this ;-).

He learned how to go down the stairs backwards in his wheelchair using one or two handrails, with my help – he said he wished he had known how much effort I had been putting into it, because he found it easy and he would have liked to have known if it was all right with the therapist if I didn't help so much with it.

He learned how to manipulate a knapsack on the back of his wheelchair.

He learned how what tools to use so that he could sweep better (so that when I follow up with the mop, I'm not just smearing the dirt he hasn't picked up;-)).

He learned about using a velcro strap so that he can hold the oven door open in a way that allows him to balance better.

Finally, we are supposed to be getting a referral to a speech therapist to see if there is something that can be done about his coughing problem (or rather, my problem with his coughing ;-)).

Okay, enough of him for a while. Now I need to get back to my novel and wrestle with my characters ;-)

Dec 27, 2006 – Jan 1, 2007

Happy New Year!

A smattering of thoughts since the last entry.

Turns out the quotes for modifying a Toyota Sienna were turned into the Voc Rehab Dept. on Dec. 11. The person who needs to review them is out of office until Jan. 3 – don't know when she left the office, but since there was no message from her left while we were in Day Program, we assume she hasn't done any work on our case. She is the one who will tell us what, if anything, the state will pay for the modifications.

On the 27th Gary went to another party. I took him to the Kuperbergs. We got to practice curbs, because in order to get the wheelchair into the house we went in the back way, and there was a step up to a porch and then another step up from the porch into the house. Wlodek offered to help, but I wanted to do it, since Wlodek isn't going to necessarily be around when Gary needs to get up such a curb ;-). It went fine – perhaps the height was a little higher than we'd practiced at Shepherd, since I found that I had to tilt Gary back a little when he did his stationary wheelie in order to get the castor wheels up on the next level, whereas at Shepherd Gary got the wheels up on his own, me just holding his push handles.

I went home and ate and laid down for a while – I was feeling tired. Besides, I'd met my quota of one party every fifteen years ;-). When I went back to get Gary, Pam Holmes came up and greeted me. Soon after, she was snapping photos of Gary and me. A inordinate number of them, I thought :-). Later I asked Gary if she'd been taking photos of everyone. Gary said he didn't know, that he hadn't been aware of her taking photos. He then mentioned that there is a woodpecker (the ivory-billed, I later found out) that was thought to be extinct but recently people have claimed to have evidence of; in fact, researchers from our university claim to have evidence that suggests the bird is living along a river in the Florida Panhandle. Evidently no one has a clear photo of it, however – just blurry video. Gary then went on to say that perhaps Pam felt this was a rare sighting of the "Peg Daniels bird" and she now has photographic proof that it is not extinct. Ho-ho ;-)

Gary found an email group on the web of people with SCIs. He says there are some stupid ones out there. One paraplegic said he'd fallen out of his wheelchair, and although it hadn't hurt (he has an incomplete injury, so there was the possiblility it might have), his leg had swollen to twice the size of the other one, and when his knee was in bent position, "something funny sticks out." He wondered if he should go see a doctor. Another paraplegic had a sore on his butt. He wasn't sure if it was a bedsore, but it bleeds when he touches it. He too wonders if he should see a doctor. Duh!

Gary has another common problem of paraplegics: his hair sticks straight out in the morning. Pre-injury, he would dunk his head under the faucet in the bathroom sink. Unfortunately, he can't roll his chair up close enough to any sink in the house in order to dunk his head. So far he has not come up with a solution that would enable him to dunk his head without getting himself or his chair all wet.

He *has* discovered that with the changes they made on his chair at Shepherd – namely, the fact that they made it narrower – he can do a three-sixty in kitchen. So that is nice – he doesn't have to roll out of the kitchen, turn around, then roll back in every time he wants to switch directions.

Speaking of discoveries, I discovered my massager that had been “relocated” during the time modifications were being made to our house. Just in time too, since I had given up and had intended to order another one the very day I came across it. Turned out that a box in the dining room/storage room that on top had things like financial statements, on the bottom had various unrelated items. Not only did I discover the massager, but I also found some story research material and a little notebook in which I had put thoughts related to the story I’ve been working on. Glad I found them! The only reason I did was I was wondering how long it would take someone to search through someone’s household box of papers . . . .

Yesterday we had another housecleaner interviewee. Before she came, Gary said, “I wonder what will be wrong with this one?” I said, “Should we ask her?” He said, “Yeah.” And then he pretended to be talking to her: “Why aren’t you going to work out?”

She was supposed to come at 1pm, and at 1:20 we figured we had another no-show. But she arrived at 1:25. She seemed nice (don’t they all), and arrived with her boyfriend who does odd-jobs around the yard – that would be handy. She is in her middle years and has lived in the area for quite some time. We’ll probably just go for her rather than interviewing several people – our careful interviews in the past haven’t done us much good!

Yesterday, Gary started doing some unsupervised transfers, not telling me when he is going to transfer from the wheelchair to the bed or vice versa, or from the wheelchair to the futon. He still wants me there when he goes from futon to chair, however.

I haven’t yet thrown him on the floor so we can practice getting him back in his chair. ;-)

One last random thought for this enty. I never posted a picture of "Nurse Mark" when I posted the other pics of the staff at Shepherd. I managed to snap a shot of him while we were on Day Program, so here it is (if you are getting this entry by email, you can see the pic on the blog at http://drpeg2003.blogspot.com/):

Jan 1, 2007

Gary said he happened to look at the blog entry for May 31st. At that time, the therapists had thought we might have to hire help when we got home. They thought Gary might need one of those portable hoyers – at that time he couldn’t lift himself up in a depression lift for more than two seconds (I remembered that he couldn’t lift his head off the pillow), and we weren’t sure that with my back I could even operate the hoyer. We are both very happy not to have had to contend with that!

The new housecleaner is coming Thursday at 1. “Or so she says,” to quote Gary. ;-)

Jan 2, 2007

Quote for the day: “There is a fine line between tough love and cruelty.”

– Gary Gruenhage

The above was prompted when Gary called me into the bedroom after he’d transferred into bed and told me he’d knocked one of his urine bags onto the floor and would I pick it up. I told him he could transfer back into this chair and wheel around to the other side of the bed and pick it up himself. Maybe he was also thinking of how, earlier in the day, he called me into the laundry area and, with a big pile of clothes on his lap, told me he’d dropped a sock and would I pick it up. I told him it would be a good balance exercise if he picked it up himself. He said that then I would have to pick up a lot more clothes. I said no I wouldn’t, he would.

(And yes, we were joking around both times, and I picked up the bag and the sock for him ;-))

Jan 5, 2007

We found out that insurance will pay for that second round of Day Program. Evidently it is not usual that they do so, but the insurance representative got together with the Shepherd people, who told her how valuable the program had been for Gary and what his accomplishments had been, and insurance then agreed to pay for it.

We are, however, having problems getting the new-model raised toilet seat. Our supplier won’t take back the old one they gave us and exchange it for a new one, they say because they never charged us for it. Fat lot of good it does us, since it is something he’ll never use.

It would be nice if little frustrations would go away. Gary has evidently developed an allergy to latex – or maybe to the powder on the latex gloves. He got rid of the rash on his hands by putting on vinyl gloves first and then latex ones over that (he needs to wear two pairs of gloves for the bowel program, and the vinyl ones are hard to get on). But for some reason neither of us thought about where those latex ones still touch him. So now we have booty-rash to contend with.

Jan 6, 2007

A little unwelcome excitement tonight – Gary lost his balance while sitting lengthwise on his bed, and the top half of him went off the bed. Fortunately, I was in the room, since he had recently called me in to put his pillows on his bed for him, and I ran over as he was falling (me, yelling “Gary!”, him, saying "Oop!Oop!Oop!"). I dove and caught him and heaved him back onto the bed. He said it was a good thing I'd been there and noted we almost had had an opportunity to try a floor-to-chair transfer. I was shaking.

Jan 7-23, 2007

Oh, dear, I have been derelict in my duty. I got engrossed in a guilty pleasure, and I wasn't able to set it aside long enough to keep you guys updated. Yes, I admit it, I succumbed to writing a short piece of RS fanfic. It was a very weird experience. I felt guilty about setting aside my work on my novel in order to work on a "frivolous" piece. I call it frivolous because I knew from the start I wasn't going to put my heart and soul into it for a long time and try to turn it into something truly memorable – I was writing it for fun, and hopefully to amuse fellow like-minded Steele fanatics. But I got sucked in by it and spent more time on it than I had intended (though I am glad I didn't finish it with the first draft). I think it's almost ready to be posted to the fanfic group, but this depends on final comments by certain reviewers of the story. Actually, I think I have pretty well lost my objectivity on how it reads – after reading it a zillion times, I no longer know if what I originally thought was funny is still funny.

Okay, so to update you on the goings on. After the scare on the 6th of Gary nearly falling out of bed, I persuaded an initially reluctant Gary that it would be best if I put his bed rails up after he transfers into bed at night. Better safe than sorry. Occasionally he still delays a bit longer than I'd like in calling me in to lift the rails, saying that he's more careful now that he knows there's a possibility he could fall out of the bed (famous last words). I keep the rails up longer in the morning, too. When he's all dressed and ready to get up, he always calls out and asks me to let him out of jail. I ask him if he's served his time, or if he's made bail, etc. Have to think of some more responses . . . .

We talked to Norma on the 7th. A topic that came up was about him visiting his family in summer. I overheard him tell her he'd like to do that if possible, but would probably need me to do so. He brought it up again at lunch. I confess, I started worrying about the effect of such travel on my back, but when I looked up from my thoughts I found Gary crying – he repeated that has been worried from the start he won't be able to visit with his family. So I gave him a hug and told him of course he would. So we have tentative plans to go to Nebraska this summer. Not sure if we'd fly or take the van which we hopefully will have in the near future. (Concerning the van, our application for funding help from the state has been turned in. Who knows how long it will take to get through the beauracracy.)

On the 8th, Gary tried out the gym at the university. They have a cable machine, so he did essentially the same exercises as he did at rehab. His "personal trainer," whose title Gary says is "Director of Health, Wellness, and Fitness and stuff like that," noticed Gary struggling to make thirty repetitions on some of the exercises, and said that they would reduce the amount of weight on the machine so Gary can keep his form. The director said he may also have Gary go to 3 sets of ten instead of one set of thirty, this to work on strength rather than endurance (and in fact, on the 22nd this is what he did).

In order to get back to the math department, Gary had to go up a big hill. He wasn't sure he could make it by himself, so when someone asked him if he wanted a push up it, he accepted. I told him he was a wimp ;-), but he protested that I should give him a break, that he'd just had an hour's worth of weight training. Poor baby ;-)

Once up the hill, he couldn't figure out how to get to the front entrance of math building – there didn't seem to be a direct route. All three sidewalks leading to it are being repaired in places, with 6-foot sections covered by straw and mud. He didn't want to try wheeling across those. So he ended up having to go around to the back of building. At least he got good exercise ;-)

On the ninth, he taught his first large class since the accident – linear algebra. I went to the first thirty minutes of the class – just because. I don't know what I expected – a marching band heralding his triumphant return, I guess – but the students didn't act as if anything out of the ordinary was happening. I guess that's good.

On the tenth, I went to a different chiropractor than the one I've been using since returning home – he was into "Zone therapy," and I decided my zones had zoned out. The new chiropractor has a decompression table – think of it was being stretched on the rack (at the hips). I had had this modality (such an impressive word) tried on me before and had thought it might be helpful. But I had only had it done a couple of times before Gary had his accident, and the chiropractors in Birmingham and Atlanta didn't have such a table. I didn't go back to the same chiropractor as back then, though, because I thought there was something fishy about his billing – four months after I last saw him, I was still getting bills from him. At the time I was too preoccupied with Gary to figure out what was going on, so just paid them. I finally sent a note with my last payment saying the next time I was sent a bill I wanted a clear explanation of what it was for. I never heard from them again. I figure I wouldn't be able to make head or tail of their books if I demanded they show them to me, so I'm just writing that off. At least this way I won't have to listen to the Christian music that he has constantly blaring at eardrum-shattering levels (maybe he has it that loud so you can't think and wonder just what those bills are about).

Anyway, no only does this new chiropractor put me on the decompression table, but they also do ultrasound micro-massage on me and EMS – electrical muscle stimulation. (Now it is the 23rd and I have noticed some improvements in my pain level that I attribute to these modalities.)

On this day, the 10th, when Gary wheeled all the way around to the back of math building on account of the broken sidewalks, he discovered the elevator was out! He gave up and and called one of the math secretaries to wheel him around to front.

Gary told me that his trainer, whose specialty is exercise science, said he may also occasionally, to work on power, decrease the number of reps and weights and increase the speed of performance.

On the 11th, our housekeeper showed up for the second time in a row. We are on a roll!

We got a nice email card from Joe and Dolores, a recounting of their year for family and friends. It came with pictures showing the forty-four inches of snow that inundated the area where they lived! In the email she told about how Joe had devoted himself to the remodeling of our home, with help from the math dept volunteers. She noted everyone needs a brother like Joe. Ain't that the truth!

The two of them are coming to visit in early Feb., and they will be bringing their dogs. I'm sure our cats are thrilled. I am looking forward to meeting them, however – I've been hearing for years how cute they are (and not just in looks).

We continue to find amusement in little things. One favorite activity is to discover just what Gary has on or under his feet. One day after his weight training, as he was wheeling back to the math building, he noticed he had a sock lying across his feet. Evidently he'd dropped it there when he was putting his dirty socks in the laundry. I didn't notice it before he left the house. If his trainer noticed it, he didn't say anything. Gary also found a key on his footplate after he transferred into bed one evening. Evidently he'd dropped his office key without noticing, and that was where it ended up.

On the 15th, Gary finished the DVD of Alaska that Norma had recently sent – it was a documentary of their entire journey. Gary said it was fantastic but noted that the "Hi, Gary"s were much more enthusiastic at the beginning of the DVD than at the end – I mean, really, just how much can kids be told to say "Hi Gary!" before the thrill wears off ;-)

On the 19th, Gary made it up the hill entirely himself. The previous time he was going to try it himself, a student asked him if he needed help and he declined. But the student turned off his car and ran over to help Gary up the hill anyway. Gary decided not to put up a fuss.

Our maid is continuing to show up. Not only that, but she can clean. So we are happy. Fingers crossed.

Let's see, anything else . . . . Oh, yes. Gary transfers between the futon and his chair by himself now, without even telling me he is doing so. The only in-house transfer I have been still helping him on is the shower transfer – but, we just today (the 23rd) got the raised toilet seat, so I will be helping him with that. He also transfers into the car by himself now. I still guide him on the way out – he is going backwards then, and we don't want him going right off the board, since he can't feel it.

He still has the booty rash, so we are calling the bridge nurse at Shepherd to see what our next step on that should be. Not related to that, I am taking him to the urologist on Friday. One thing we'll ask him about is the leaking problem. It stops when Gary is on antibiotics and starts in again after he's through with the antibiotics, so, we don't know, maybe he has a near-constant low-level urinary tract infection.

He is participating in a study by the University of Washington on fatigue and pain in people with spinal cord injuries. He doesn't think he's really the kind of subject they are looking for, however, because he's not troubled by these. Thank God.

That's all I can think of, so, all for now!

Jan 26, 2007

I took Gary to the urologist today, and the focus was Gary's "leaking problem." The doctor seemed very knowledgeable about spinal cord injuries and their effect on the urinary system, which was a relief. In fact, he explained the effects much more thoroughly than Gary's doc at Shepherd did, though we are sure that is because that doc's manner with patients is brusque. (Gary parodied it as, "You don't need to know that, go away and don't bother me.") This local doc mentioned how the kidneys can cause a lot of problems (in fact, kidney problems used to be the #1 killer of those with SCIs). He said that the signal to the bladder is relaxed – hyporeflexive – so the bladder doesn't know when to contract and relax. This evidently causes high pressure on the bladder, which puts pressure on the kidneys. The problem with that is made worse if there is some infection in the bladder, because that infection can then travel to the kidneys. So the goal is to keep the pressure in the bladder as low as possible and to keep the bladder as clean as possible (i.e., free of bacteria) – by using "clean technique" in doing the Ics.

To deal with the leaking problem, the doctor suggested three things. First was to have x-rays done of the urinary tract (kidneys, the bladder, the ureters, and the urethra) – the test is called an IVP. Gary is having that done at the hospital (tomorrow, the 31st). Normally one is supposed to drink a prep that "cleans one out," but fortunately the doctor said Gary only has to prepare by sticking to a clear liquid diet from 4pm on. Thank God – I would hate to have my saintliness be tested by having to clean Gary up all night long due to the effects of a laxative. Gary considers having to be on a clear liquid diet that long sacrifice enough. We are going to take quad pillows to pad him off so he isn't lying on that hard exam table for hours (the test is supposed to take an hour, but we are supposed to allow 2- 2 ½ hours from arrival to departure). Also we are hoping they let me back in there with him because it would seem like he would need help in doing weight shifts while on the table.

The second thing Gary will have done is a urodynamics test to see what his bladder is doing. The bladder will be filled and a catheter put in that has a pressure sensor, to measure the pressure at various times. The test will also measure how well the bladder muscle stretches during filling, how well it holds the urine, and how completely it voids. Gary will have this test done the last week in Feb.

The last thing the doctor suggested is that Gary go on a medication called Vesicare. The doctor suspects Gary's bladder is contracted and spastic, so in between his IC's it is spasming (LOL – I first wrote "spamming"). The med will relax the bladder and allow it to hold urine longer. The doctor said the side-effects are typically dry-mouth and constipation. He says children with spina bifida are on such meds from birth and no long-term side-effects have been noted other than the above. So far Gary hasn't noticed any side-effects but neither has it stopped him from leaking. He read somewhere that it may take a few days before effects are noticed.

I took Gary to the university afterwards. As I pulled into a parking lot, someone swung around the corner of the parking lot that attaches to it (making a T with it). The driver had her head turned and was talking and laughing with her friends. I hit the horn, which fortunately stopped her from plowing head on into us. She smiled at us and drove on. Meanwhile I'm having a heart attack.

Feb 1, 2007

Catching up on this journal out of order, let me first say that Gary's hospital test went fine – at least as far as he's telling me ;-). They did not let me go back with him, even though both of us asked several times for me to be allowed to do so (I confess it touched my heart when Gary gave it one last try: "So, she can't come with me?"). Gary told me they did a two-man transfer on him to get him onto the x-ray table. Maybe at that point he was glad I wasn't there, cuz I would have said, "No way, you wimp, we're doing a depression transfer!" (Actually, I probably would have let him be a wimp – he said the table was very high, higher than any transfer we've ever attempted.) For weight shifts, they turned him from side to side. He had to do an IC for them, and then they shot dye into his arm and took their pictures of his urinary tract. We got to the hospital at about 10:30, and he came back out into the waiting room a little after noon. Then he wanted to go to the burger place nearly directly across from the hospital, saying he needed some solid food in him!

After taking him to school, I had just enough time to go home and have some lunch before racing off to the chiropractor. I have definitely had some pain reduction, especially during the day, though the pain still interferes with getting decent sleep. The chiropractor has given me some stretches and abdominal strengthening exercises and some exercises to help increase mobility of the pelvic region (I call them my "bump and grind" exercises).

Oh, by the way, speaking of wimps, Gary says he hopes people who read the blog don't think he is one, given all the times I mention him crying about something ;-).

On Jan 27, I had a rather bizarro experience after finishing my walk. I've been parking at the end of a street a few blocks away, where there is a flat stretch of road. I walk down that road to where it dead ends (it wasn't until I came to the south that I knew "dead end" was a verb) and then turn around and go back to my car. It takes me about an hour to take this at a stroll. That evening, there was a truck parked in the place I usually put my car, so I parked behind it. When I got back from my walk, a man was in the yard near my car, and he asked me if it was my car. I said it was. He identified himself as the owner of the house in front of which I had parked, and anticipating him, I asked if it was the case he didn't like me parking in front of his house. He indicated this was the case. I said, no problem, I wouldn't park there anymore. (I happen to know that legally I can park on the street there, but my purpose was not to antagonize anyone.) He mentioned there had been some problems at his home, which he didn't want me to get involved in (whatever that meant), and I said again that it was no problem, that I had parked there just in order to take my walk, but that I wouldn't park there again. On the drive home I decided I would park at a school about a block up from there.

So, I drive home, and about ten-fifteen minutes later, this cop is at my door asking me if the car in the garage is mine. I said it sure was. He then goes on to talk about how this guy is upset about my car being in front of his house, that he'd had a break-in at his home, and so on. The cop "assures" me that they're not thinking I was involved in the break-in (meanwhile it's going through my mind that I would have to be pretty stupid to break into this guy's home and then regularly leave my getaway car parked in front of it while I take a walk) but that they didn't know what I was doing in the area. I told the cop I was taking walks and that I had already told the owner – twice, and in what I thought was a friendly way – that I wouldn't park in front of his house anymore. The cop then asks me if I couldn't leave my car in the garage and walk around the blocks near my house. I'm thinking, "Huh? Since when are people restricted to walking around their homes?" But I say, no, that I have back problems and I can't take the hills around my house, that I go to a flat area. He informs me I can go over to the university or to the high school track and walk there. I don't say anything but I'm thinking, no way am I going to go traipsing clear across town when I can drive a few blocks away. The cop finishes by saying I haven't done anything wrong, and leaves. I'm still wondering why he was saying all that stuff in the first place, unless it was to somehow intimidate me on the house owner's behalf.

Upset, I went back into the bedroom and told Gary of the cop visit. Gary told me I should have come and got him when the cop came, and I wish I would have. I was very upset that night, and it still bothered me for days, first of all that that guy had called the cops on me after I'd talked to him and secondly that that cop was saying those things to me. My massage therapist gave me some perspective, however. She said that the guy had probably called my license plate into the cops long before the guy had talked to me, and the cop probably hadn't known I had already talked to the guy. When he found that out, he probably felt obligated to find something to say, since he'd bothered to run my tag down and had come all the way out to my house. Vindictively, I hope the cop felt a real idiot, because he certainly ruined my night and had me upset for a few days. I literally shook each time I went by this guy's house in order to take my walk. My massage therapist told me I should make a story out of this. She also told me I should take a bunch of photos of my car, and every time I walk by this guy's house, I should slap a picture of my car on the guy's curb. I nearly fell off the massage table laughing.

On the 28th, Gary ran through the logistics of using the raised toilet seat. It looks like it will be a fairly easy transfer onto it, as he has the height approximately equal to his wheelchair. The difficult part will be in leaning to the side on it for the twenty or so minutes required while performing the desired task. I looped the chain loops around a grab bar in the shower, and then he looped his arm through them, to give him stability while he leans, but he says he wants to use something else for that – he is afraid the loops might tear (I don't really think they would), and that would be a disaster. He is going to try it out "for real" this coming weekend.

On the 28th, I also finally felt like I had my short fanfic story where I wanted it to be. I finally yielded to its pull, and as a result I felt like it finally came together. I was still anxious about posting it, however. The "test readers" I had asked from the RS Fic group for advice really seemed to enjoy the story, but it didn't get as big a reception from my local critique group. In fact, after the first week's work on it (I spent a little over three weeks on it), one of those members told me the story fell flat, which almost led me to throw it out. Gary, however, told me that just because that one person didn't think it was funny didn't mean it was funny – *he* thought it was funny. The other person in the group thought it was ready to be posted on the 26th, but there were still things I wasn't satisfied with. But after working a few more days on it and running the final prospective version past the RSFic test readers, getting their comments, and making some changes based on those comments, I felt an internal voice tell me, "Now, it's ready." So I posted it and anxiously awaited the reaction.

Boy, am I ever glad I didn't throw it out! It got the biggest positive reaction of anything I've ever posted to the list (though it doesn't, in my opinion, match the quality of the RS novel or another short piece I wrote). To enjoy it I think one would have to have a pretty solid knowledge of the characters of the series and as well some familiarity with fic writing. In fact the people who would get most out of it would be those who are immersed in the TV series and in the RSFic list, and if they had already seen the movie that I had gotten the inspiration for the story from, that would probably further increase the enjoyment. A pretty small percentage of the population! But I felt really good about the response, I can tell you!

Feb 4, 2007

Gary tried out the raised toilet seat today for bowel program. So far it's hard to imagine he's going to find it preferable. It took fifty minutes to get through the bowel program while sitting on the seat, whereas lately doing it in bed takes about thirty. He found it hard to be in that position so long – having to lean over to one side all the time in order that fingers reach the proper aperture. I stayed with him to make sure he didn't lose his balance, especially on the weight shifts, though he thinks he'll soon be at the point where I wouldn't need to. He does need to work on technique. He has to regularly change to a new pair of rubber gloves, and a couple overenthusiastic snaps of the gloves he was taking off led to instances of flying poop (in my direction, unfortunately; I told him if he hit me with it, I was outta there). After he was finished, Gary noted it'd taken him until 11am to have breakfast and go the bathroom. He noted that at least it wasn't like our experience at the Transitional Living Apartment, where it'd taken us what seemed like the entire day to get through his morning routine. We'd worried it was always going to be like that! Hopefully the time it takes him to get through this will get shorter too. But, who knows. He still sticks to bed baths except for the once a week shower, due to how long the shower takes.

Feb 8, 2007

On the 8th we found out that the state will entirely pay for the modifications to the type of van we selected (Toyota Sienna)! Gary called the Driver Rehab specialist to tell him this, and he said he was waiting for the authorization from the Department of Vocational Rehab. Unfortunately, Gary forgot to ask him what the next step is, but we think he goes out with us to pick out the van.

Gary has been continuing to do well with his rehab weight training at the university. He says he gets a lot more sore doing three sets of ten with more weight than he did with the one set of thirty routine, even though while he is doing the exercises the new routine feels easier than the old did.

He recently made it up the hill from the Student Rec Center (where the gym is) to the math department with just one rest (at first, he needed three). He said he turned down two offers of help from people asking him if he wanted to be pushed (I'm so proud ;-)). He says his record there is being asked three times if he wants to be pushed up the hill.

He says that when he is going across the parking lot to get to the hill he actually is asked more often than that if he wants a push (and he has never accepted). It's not a steep push, but it is a fairly long one. He notes that he is getting good exercise doing it and that he notices improved lung capacity as a result of those pushes. He says he can cough much better, for example – though his sneezes are still weak (I'm sorry, but I can't help laughing sometimes when he sneezes – the sneezes sound funny to me).

We switched beds last night (the 10th) so Gary could try out a double bed at home. It went fine – for him. I got cold in the other room and slept badly. I guess in part that shows he's in much better condition, healthwise, than he was while at Shepherd. He used to get cold so easily – we were constantly at war with one of his roomies over the temperature controls. And he used to get so cold after his bed baths that his teeth would chatter and I'd have to bring him hot chocolate or tea to warm him up.

I had a bunch of weird dreams all night last night, though I don't remember them. But I do remember a recent one. I was in an airport to catch a plane, and the security procedure had been changed. I had to be interviewed by this woman. The result of this interview was that you could "get" to be one of the people assigned to stop any terrorists on your plane – I guess we were supposed to throw ourselves at the terrorists. The alternative was to do an hour of community service. I didn't say so aloud, but I planned to opt for the community service (didn't want this woman to know I was a coward, I guess ;-)). She noted that I had read Kurt Vonnegut. Boy, I didn't know the government knew such details. I admitted I had, but that it had been required in high school (I didn't admit I liked the book ;-)). She was quite disapproving and told me she had voted for Nixon. Then she asked me if I was paraplegic. I thought the answer should have been quite obvious ;-), but I said "no." I assumed the question had to do with my ability to throw myself at a terrorist, but when I told Gary the dream, he said that probably the questioner thought that all paraplegics were subversive.

We finished the Dorothy Sayers mystery videos sent to us last summer by J.P. and Pam Holmes. Recently we watched the original version of King Kong, and now we are watching the recent remake to compare. I was surprised by how well I was liking the movie – until last night. They went too overboard and made it unbelievable (yes, I could suspend disbelief up to then – I would even have accepted shooting one giant grasshopper off the back of a man with a machine gun, but not a whole horde of them – at least, not without killing the man).

I will finish this entry by passing along a little story someone sent me by email. Thanks, Vicki – most of the techniques for dealing with the burdens of life had me chortling.

Stress Management

A lecturer, when explaining stress management to an audience, raised a glass of water and asked, "How heavy is this glass of water?" Answers called out ranged from 20 grams to 500 grams. The lecturer replied, "The absolute weight doesn't matter. It depends on how long you try to hold it. If I hold it for a minute, that's not a problem. If I hold it for an hour, I'll have an ache in my right arm. If I hold it for a day, you'll have to call an ambulance. In each case, it's the same weight, but the longer I hold it, the heavier it becomes."

He continued, "And that's the way it is with stress management. If we carry our burdens all the time, sooner or later, as the burden becomes increasingly heavy, we won't be able to carry on. As with the glass of water, you have to put it down for a while and rest before holding it again. When we're refreshed, we can carry on with the burden. So, before you return home tonight, put the burden of work down. Don't carry it home. You can pick it up tomorrow. Whatever burdens you're carrying now, let them down for a moment if you can. Relax; pick them up later after you've rested. Life is short. Enjoy it!"

And then he shared some ways of dealing with the burdens of life:

* Accept that some days you're the pigeon, and some days you're the statue.

* Always keep your words soft and sweet, just in case you have to eat them.

* Always read stuff that will make you look good if you die in the middle of it.

* Drive carefully. It's not only cars that can be recalled by their maker.

* If you can't be kind, at least have the decency to be vague.

* If you lend someone money and never see that person again, it was probably worth it.

* It may be that your sole purpose in life is simply to serve as a warning to others.

* Never buy a car you can't push.

* Never put both feet in your mouth at the same time, because then you won't have a leg to stand on.

* Nobody cares if you can't dance well. Just get up and dance.

* Since it's the early worm that gets eaten by the bird, sleep late.

* The second mouse gets the cheese.

* When everything's coming your way, you're in the wrong lane.

* Birthdays are good for you. The more you have, the longer you live.

* You may be only one person in the world, but you may also be the world to one person.

* Some mistakes are too much fun to only make once.

* A truly happy person is one who can enjoy the scenery on a detour.

Feb 14, 2007

Happy Valentine's Day! Gary gave me a nice e-card and Poirot and Garrison Keillor CDs to listen to while I walk. I got him a couple e-cards (one funny, one serious) and flowers and chocolates – and I made him a pizza from scratch for dinner. The next celebration will be Gary's birthday on the 24th.

Gary found out the next step for the van. We are supposed to go to this place in Montgomery that is authorized to modify vans. There, we buy the van, and they modify it and send the bill for the modifications to the State Rehab Office. We are thinking of picking out the van this Saturday. Oh, boy!

By the way, I forgot to mention that the reason the state is going to pay for the modifications we are sure is in large part due to the letter that Michel Smith, head of the math dept., wrote in support of Gary, stating that he is a valuable employee and needs the van for his transportation to work.

Feb 15, 2007

The Dept of Rehabilitation person dropped by today with Gary's "plan" for him to sign so he can get the money for the modifications to the van (should come to approx. $20,000, so I was right about that :-p). The form he had to sign is a standard one and had been filled in for him, just requiring his signature. I looked it over. For employment goal, "Professor (math)" had been filled in. In the section entitled reasons for selecting employment goal, it said, "I explored options and feel this is a good choice. I have received training in this area. It matches my interests, abilities and strengths. The job outlook for this type of work is good." Thank God Gary felt this was a good choice and decided not to pursue, say, carpentry ;-). I hadn't realized he had been considering giving up his secure, tenured position for some other form of employment. As for the outlook for this type of work being good, this is of course especially so since he already holds the position ;-).

There was also a list of responsibilities he needed to agree to. For example, he is supposed to attend all scheduled meetings and appointments, he agrees that he understands the importance of attendance and punctuality (fortunately the woman didn't take off points there today – his bus was late getting home and he was late for his appointment with her), he is supposed to cooperate with all job placements efforts, and he is supposed to take all his prescribed medications.

Anyhoo, things are moving along there. Not absolutely sure I'll have the energy to take him to Montgomery to pick out a van this Saturday. Originally, Shepherd had scheduled him a follow-up appointment with his Shepherd doctor tomorrow (Friday), but they had told us they would cancel that for him because they scheduled another one for him in March. We got a call yesterday reminding him of this appointment, so apparently they forgot to cancel it. We decided to go ahead and go to it because we are making no progress in clearing up the rash on his booty. This does mean I don't get to go to the dentist and have another two cavities filled tomorrow. But fortunately the dentist had a cancellation for next Friday, so I will have it done then.

We are now watching Star Wars, Episode 3. I missed episode 2, but if it was anything like episode 1, no great loss. This one isn't too bad – at least there's a story in there amidst all the light-saber rattling. But I don't buy how Anakin becomes the ruthless Darth Vader seemingly in one swoop. Of course, Gary says he'd destroy a republic without remorse in order to save my life. Just call him Darth Gruenhage. Except I think he is conflicted. He spent the rest of the evening trying to talk like Yoda, putting his verbs at the end (or maybe he was just being German ;-)).

Feb 16, 2007

I don't think I mentioned that Gary has two different kinds of booty rashes. The one developed in the triangle of his flap surgery scar during Day Program, and we thought it might be latex allergy. The other one developed a few weeks after that. I don't know by how long we missed the beginning of it, because Gary had taken over "greasing his butt" and doing the skin checks, and the new rash was in the hard-to-see area of his crack. But when we went back to me doing the greasing to make sure the stuff he was putting on wasn't aggravating the old rash, I became aware of the new rash. He called the bridge nurse about it, and she told us to put antifungal cream on it. It didn't seem to help, so after a few weeks she recommended an antifungal in a moisture barrier cream. After a few weeks of this, I still hadn't noticed any improvement, so that is why we went up to Shepherd on Friday the 16th. When the doctor saw it, he commented, "This is not good." It is definitely a fungal infection and the area affected is too near the ischial ("sitting") bones to be sanguine about it. He gave Gary a prescription for a stronger cream (one with steroids in it) that I will put on him twice a day (like I've been doing with the other creams). Gary hates the fact that the doctor also told him he has to go back to doing weight shifts every twenty minutes instead of every thirty. I told him it could be worse – the doctor could have told him he needs to stay in a prone position until the area is healed.

The doctor asked Gary how his "peeing and pooping" were going. Don't you love doctor talk? It certainly wouldn't have occurred to me before Gary's accident that this is of primary concern with those with SCIs. Anyway, Gary told him about his visits to the urologist. The doctor didn't seem all that impressed that they had done the IVP on him without having him empty his colon by taking those preparations – in fact, he said it was useless without that. Oh, well, the urologist hadn't seemed to think so – and I think we would have had to hire someone else besides me to deal with the aftereffects of the preparations all through that night!

The doctor also said that for the urodynamics to make sure they are doing it with video, again saying it was worthless if they didn't. He said Gary should have that done every 3-5 years. He also said that Gary should have a kidney ultrasound done and "KUB" pictures taken – kidney, ureter, bladder – both of those things done once a year.

I was exhausted by the time I got us home about five p.m. and felt terrible, counting the minutes until bedtime. Gary suggested I go to bed after dinner, but I reminded him that that would mean he'd have to go to bed then, too. He might have been willing to skip the bed bath – at least the parts I help him with – and I suppose he could have organized things to he'd have his pillows where he could get at them and so forth, but he couldn't be sure he was putting the cream where it needed to go. Fortunately I revived a bit later in the evening, but I was ever so glad to hit the pillow that night.

The next day, the 17th, Gary wanted to go to Montgomery to buy the van. As we were leaving, Gary tried to call the guy who was to sell us the van. Gary couldn't get hold of him, either at the work phone or his cell phone. I didn't want to go because I didn't want to make a two-hour trip there and back for nothing. Not to mention that I was still tired from yesterday and didn't want to subject my back problems to more driving, especially if it was unnecessary. Gary was confident the guy would be there because we'd just told him on Wednesday that we'd be there on Saturday (the dealership isn't usually open on Saturday, but the guy said he'd come in special), and Gary had called the dealership yesterday to say we were coming. I was pessimistic and warned Gary I was going to be mad if we made the trip for nothing.

Well, we made the trip for nothing. Gary tried to call the guy several times during the trip, and he never answered. No one was at the dealership. We hung out there a few minutes and then headed home. I told Gary that for future reference I was never going to do anything like that again. Grrr.

I definitely needed a nap when I got home!

Feb 18, 2007

I think I'm still a bit tired from all that driving the past two days. When we got home from Kroger, I went to get Gary's wheelchair from out of the back of the Ford Escort. "Oh, my God," I said. No wheelchair. I had left it in the parking lot at Kroger.

In my defense, Gary had transferred himself into the car while I had loaded the groceries in the back. I'm used to helping him transfer and then immediately breaking down the chair and loading it into the car. This time, he got in and closed the door because it was so cold out. Not having my usual cues, I simply got in the driver seat and drove away. Obviously Gary also didn't take note that I had forgotten to load the chair.

I was very anxious driving back to Kroger, fearing that someone had taken the chair, but fortunately it was still there.

We have finished Star Wars 3 and are on to March of the Penguins.

Feb 19, 2007

Gary got in contact with the car dealership guy. He apologized for not being there on Saturday. Gary asked him if he could bring the van to our home instead of us traveling there again. First he said he would bring it tomorrow (Tuesday). Then he called back and said he would have all the modifications done to it first, and then bring it to our home later this week for us to buy! So, Gary may get his modified car by his birthday! Of course, he'll only be able to look at it for a while (or have me drive him around in it).

In watching our current movie, Gary and I both agree we are glad we aren't penguins.

Feb 22, 2007

Gary had called the urologist a couple days ago and found out that they don't do the urodynamics (my spell checker keeps automatically changing that word to "aerodynamics," so if that ever slips through, be assured we aren't having Gary tested for how well he is built for flying) test with video, as the Shepherd doctor said should be done, but Gary decided to go through the test anyway. Turned out, though, that we wasted about an hour of our time (can you tell by now I hate to waste time?) – the technician had no idea how to perform the test on Gary, because according to his procedure, he would be filling Gary's bladder with water and as he was doing so asking Gary to tell him when he first had the urge "to go" and when the urge was, well, urgent, etc. Gary never feels those urges any more. The doctor wasn't there to ask about what should be done, so we decided to just leave without having anything done here – we'll have Gary do it up at Shepherd sometime.

Since we now had time we didn't expect to have, I asked Gary if he wanted to shop for shirts for his birthday (I am also getting him some "wheelchair" khakis and jeans, and some "goodies"). So we went to Penny's and he picked out a handful of short-sleeved pullover knit shirts for when the weather gets warmer (though today was a beautiful day – 70 degrees). He said shopping was much more fun than a urodynamics test. We then stopped in at Brewsters to get him an ice cream cone before going home.

We finished the March of the Penguins movie and have been watching the Special Features. We have been enjoying that even more than the main feature, because it is more informative and personal.

Feb 23, 2007

My brother Joe and sister-in-law Dolores showed up a little before seven – with cupcakes and Ben and Jerry's for Gary's birthday! I knew they were bringing the goodies, but Gary didn't, so he was happily surprised. They stayed for about an hour before going to a local campground where they had left their trailer and dogs, and during that hour we talked of this and that – they have spent most of the past month getting my mom moved from her house into an apartment. And they thought they were going to be having some vacation time – hah!

Feb 24, 2007

Happy Birthday to Gary!

Joe and Dolores came over around 10:30 (timing it so Gary would be done with his shower). We gave them a tour of the house. Dolores had only seen pictures, and Joe hadn't seen the finished garage or things like the shades he picked out being in place. Of course we couldn't let Joe get by without doing some work for us ;-). He noticed the stopper in my bathroom sink didn't work and so fixed that, and when he asked why the garage door was up, I said because it doesn't work. It kept slipping our minds to call somebody about it, and we just got used to having the garage open all the time. Joe figured out that the electric eyes weren't lined up correctly, which was why the door usually wouldn't close, and that the setting on some dial wasn't quite right, which was why on the rare occasions the door did close, it would immediately bounce right back up.

Tigger was fairly friendly fairly immediately with Joe and Dolores – no doubt hoping someone would finally break out the Fancy Feast again, since he hasn't gotten any since Joe left. Blackjack, however, would not come around. Joe thought him rather ungrateful, since Joe had gotten up around 5 every morning to feed the whining beast. (This is why we have the cat barrier, which keeps the cats in the kitchen, on the opposite side of the house from our bedrooms.)

For lunch we went out to Paneera's, which Joe evidently had eaten at nearly every day while he was here this summer but hadn't eaten at one since. Mostly the lunch was spent Bush-bashing ;-). After lunch, Joe and Dolores went back to their trailer so they could walk their dogs and "rest up." I took the opportunity to rest up, too. Gary talked to his family and read email and snail mail birthday cards (thank you to those who sent them!). Dimitrina called him from Bulgaria (!) to wish him a happy birthday. Ronnie Levy sent him Belgian chocolates. Since I had given him a bag full of goodies (chocolates, peanut brittle, dates), his sweet tooth was well satisfied.

In the evening, we went in Joe and Dolores's minivan to a Mexican restaurant for a 6pm meal. Earlier in the week we had called and emailed the people who had helped Joe out this summer, so that they could have a reunion with him and also meet Dolores. It was just good timing that they happened to be able to come when it was Gary's birthday. At the dinner was Phil Zenor, Donna Bennett, Janet and Jack Rogers, Krystyna and Wlodek Kuperberg, Krystyna and Piotr Minc, Narendra Govil and his wife, Jo and Bob Heath, Andras Bezdek, and Michel Smith.

We had Joe and Dolores sit in the middle of the table so the maximum number of people could talk to them (at least, that was our intention), and Gary and I sat at one end, so we wouldn't hog them. In a rare instance of foresight ;-), I had bought a little guest booklet for people to sign, which was supposed to be in appreciation of Joe and Dolores. They were quite surprised by it, and also to find that they were the guests of honor. Musical chairs were played a couple times that night, so I think everyone got to mix fairly well. Everyone seemed to be really enjoying themselves. People mentioned we should do this again – they probably said that because I paid the bill. JUST joking.

The party broke up a little after 8. Out in the parking lot, Narendra's wife gave Gary a Bundt cake! Joe and Dolores came inside our house for a short time, where Belgian chocolates and cake were served. Then we said our goodbyes, because Joe and Dolores were leaving for Colorado early in the morning (and God knows, I wasn't going to get up early to see them off ;-)).

Gary said he most definitely had a happy birthday!

Feb 26, 2007

Oh, I forgot to mention, Joe and Dolores brought a small box of keepsakes for me from mom. Among other things, it contained: A stopwatch (from my early swimming days); A caricature of my dad in a toga and wreath, drawn by a street artist in Athens in '82; My eighth grade diploma from St. Raphael's and my high school diploma from Benet Academy; My baby book; My first formal baby picture (what a hoot); Tons and tons of pictures from babyhood on; Academic achievement awards; Report cards.

I like the report cards best. On my kindergarten (!) one, the teacher remarks that I got a little too cocky in the past six weeks and thought I knew so much I didn't try like I should. My mom replied that they would meet the teacher to discuss what further methods should be used on me. Evidently whatever she tried didn't work since throughout grade school the teachers remarked I didn't produce a quality of work measuring up to my ability. (I also evidently needed improvement in the area of good conduct while in first grade, my handwriting remained atrocious throughout grade school, I didn't keep my desk and materials neat, and I only did average in math. I guess I made quite a turnaround in all these areas in high school – except for the part about keeping my environment neat.)

This afternoon another gift for Gary was delivered by a local flower shop – from Janet and John. It was a basket containing turtles, chocolate-covered pretzels, Guinevere chocolates. Hope he's going to be able to push himself in his chair after he polishes all this stuff off!

Speaking of pushing, Gary told me yesterday he was setting himself a push goal of getting from the student activity building to the math building without stopping to rest. He said he's been taking four to five rests. He thought by the end of the semester he should be able to do it without any. Today he told me he thinks he's going to make that goal a lot sooner than he thought – he took only one rest, in the middle of the steep hill he has to wheel up. He says slow and steady is the key, and noted that last summer he wouldn't have been anywhere near able to do what he can do in this regard. I said that after he accomplishes that goal, he can work on speed, and I joked that I now had a stopwatch that we could time him with. He said that, actually, his physical trainer said the same thing (that he should next work on speed, not that I should time him!).

Gary called the car people this morning to ask if the part they'd been waiting for had come in yet. The person who answered the phone took Gary's message and phone number so that the guy Gary needed to talk to could call back. The guy never called. I am not impressed with their customer service!

Feb 27, 2007

Gary has been invited to give a keynote address at the Conference "Advances in Set-Theoretic Topology" in Honour of Tsugunori Nogura on his 60th Birthday, to be held on June 9-19, 2008 in Erice, Sicily (Italy). They are asking Gary to reply at his earliest convenience, and we suppose that means Gary will have to decline. He thinks it sounds like a pretty tough trip, and he hasn't even attempted an overnight U.S. trip, yet.

Speaking of trips, Gary got ahold of the minivan guy. The part we've been waiting on has supposedly been shipped, and we could have the van this Friday. Keep your fingers crossed!

Feb 28, 2007

The drug the urologist put Gary on for the leaking problem has had no effect. Gary is almost out of the prescription. He is going to call the doctor and as if he should be tested for a UTI, again. He talked to a bridge program nurse at Shepherd, and she told him in a few rare cases some people with spinal cord injuries constantly have a low-level UTI and constantly stay on a low-dose of antibiotics. I am not happy at the thought of Gary staying on an antibiotic all the time, but neither am I happy with the prospect of him constantly having an infection.

Mar 5, 2007

Gary already achieved his push goal. He went the entire way from the student activities center to the math building with no rest. He timed himself: fourteen minutes and forty seconds from door to door. He remarked that for the first time no one even offered to push him. I told him it was obviously because he didn't look like he needed help. Quite a change from his first push, when he couldn't even make it down the hall at Shepherd without resting.

He continues to gain in strength at his workouts on campus.

We have recently watched a couple movies we very much enjoyed: "Something New," about an interracial relationship; "Shattered Glass," a true story about the fraudulent journalist Steven Glass who fabricated parts or all of more than half of his articles published in "The New Republic." We are currently watching "Babel," and are about halfway through it. I came across this same director's first movie, "Amores Perros," at least a year ago. That one I found compelling from the start, even though it is a dark tale about some rather unsavory characters. So far all I can say about this one is it is interesting.

Mar 7, 2007

Today was a day of very contrasting emotions. Gary's mom fell and broke her hip this morning. She had surgery in the late afternoon. So far all we know is the doctor expects her to be able to bear weight on it soon.

On the other side of the emotional spectrum, I took Gary to Montgomery so some things on the mini-van could be customized to him. First came paperwork, and then we waited around until the guy had finished installing something or another (I had figured we were going down too early when the guy had told us to delay an hour in coming, but Gary was so eager to get down there I knew he wouldn't listen to me if I told him we should go down there even later than the guy said). The guy said it would take him five minutes to finish the installation. His secretary warned us that meant fifteen minutes. I think it was more like a half hour, maybe more (I had brought my story to work on, so didn't pay attention to how much time had passed). Finally, though, it was time for us to get into the van and check it out. The guy showed us how the controls worked on the transfer base for the driver's seat. One for moving the seat forward and backward, one for moving it up and down, and one for rotating it from facing to the front to facing to the side (I think it goes 360 degrees, but we only needed it about 90 degrees). It's going to take me awhile to get that straight, if today's attempts are any indication ;-).

Gary rolled up the ramp, and I helped him transfer into the driver's seat from his wheelchair. Actually he didn't need my help – he says it is an easy transfer. But we both experienced something strange when we sat behind the wheel as if we were driving. The wheel seemed too low. When Gary would turn it, it would rub against his knees (not that he could feel it, but he shouldn't have something rubbing against his legs all the time). For me, when I would use the gas and brake pedals (I took it out for a short drive), my right knee kept hitting Gary's hand controls – I am sure I am going to have bruises there tomorrow. (Gary was sitting on his special cushion, which he will have to sit on for drives of an hour or more, while I was just sitting on the bare seat, which accounts for why the wheel placement affected us differently.) We thought this was very strange, because we are both small people. If some tall person tried to drive this van, his knees would be up around his ears. We never figured out why this should be, but I guess we're going to have to live with it to some extent – Gary already paid for the car, and we were never given an option of who to deal with in getting the car (the disadvantage of getting help from the state I guess, but $23,000 is nothing to sneeze at). The guy said he thought he should be able to lower the seat a little and move the hand controls so we don't have this problem when we take possession of the car. We'll see.

Another thing that didn't quite work out as expected was the lockdown of the wheelchair after Gary transfer out of it and into the driver's seat – it needs to be locked down so it doesn't go flying around the van in case of abrupt braking. But, the guy thinks he's figured out a way, involving bolting down a seat belt into the floor of the van. Gary would then put the belt through the spokes of his chair.

The last thing that needed fixing, at least as far as we discovered, was that the outside mirrors didn't adjust.

The guy showed us all the controls for various things (lights, wipers, ramp), not that I'm going to remember :-). He also showed us how to take out the front passenger seat and how to manually lock Gary's wheelchair in position there in case Gary wants to ride like that. To do that uses four separate locking mechanisms – for the front right and left and back right and left of the wheelchair. Given the effort it took this guy to take out the passenger seat, we are not planning on having Gary travel this way, particularly since I would be the one trying to remove the seat! He can just transfer into that seat from outside the van, similar to what he has been doing. That's a safer way for him to travel anyway.

We had left for Montgomery at one, gotten there around two, and weren't out of there until five – so we got home around six. I was pooped!

The guy claims we will have the van tomorrow (they will deliver it to us), but since we have learned that five minutes means thirty, that "you will have it this week" means we will be close to having it after two weeks, we figure that we should be getting it sometime next week ;-). Actually, the guy had claimed if we brought someone with us today they would do any last-minute work on it today and we could drive it right home. I'm glad we didn't get someone else to go with us – either they would have come for nothing, or we'd probably still be there now at 10 pm.

Gary is very excited. If we do get the van this week, he wants to find a parking lot this weekend where he can practice. He asked me if I was comfortable driving it, and I said not terribly and that he could do most of the driving. He then asked me if I'd do some of the driving to Rolla for the math conference, so looks like I'm going to get sucked into that ;-). He's really got his hopes up to go to the conference, so I hope they come through and get the van to us so Gary can practice and have his new license in time to drive there.

Mar 8, 2007

Gary talked to his mom this morning. The doctor already had her on her feet (with help). She will stay where she is for a few days, then go into what she called "the swing shift," which Gary gathered was a ward where she will undergo rehab. This will be for about ten days, after which she will go home. I understand the others in the family are trying to make arrangements so she won't be alone when she goes home.

The car guy called this morning and said he still planned to bring the car about 3. There was some discussion of the placement of the wheel, and Gary pointed out that the state vocational guy who is going to teach him to drive will certainly know if the wheel is positioned correctly. Subtle threat there :-) from Gary, Gary's meaning being that although we've already paid for this, if it's not done right, perhaps the state will no longer do business with this guy.

Gary called me in the afternoon and said the car guy called and claimed the car was ready but they wouldn't be able to deliver it today. I said, surprise, surprise.

But then the guy did surprise me – he called back in the late afternoon and said they would bring it today after all. He also said he managed to get the seat lowered about five inches – much better than the half inch he was saying yesterday! Wonder if that was on account of Gary's threat ;-)?

So, we've got the van! They delivered it about 6pm, and Gary and I got in and checked it out. The seating works perfectly for Gary. Me, I'm going to still be hitting those hand controls with my knee some, because, being small, I have to get up so close to the wheel in order to reach the floor pedals comfortably. They didn't manage to fix the outside mirrors to work electronically, so we'll have to take it into the local Toyota dealer for that. The seat belt contraption to lock the wheelchair in place seems to work fine.

Gary can hardly wait until tomorrow so he can call the state guy and see "when he can get his butt here and teach me to drive," in Gary's words. And Gary is all set to find some parking lot this weekend to practice with me. The guy who brought the van (who was the one we have been dealing with all along for the modifications) didn't seem all that encouraging that Gary should try to drive even in a parking lot without instruction from the state guy, since Gary needs to learn to have a light touch on the hand controls. Gary was not dissuaded, however. Wish us luck this weekend!

Mar 9, 2007

This morning they already had Gary's mom walking some! After ten days of rehab in the hospital, she will go into a rehab nursing home for thirty days. They say she should be ready to go home after that. Bob is traveling to be with her for the next week.

Gary has gotten several emails from people cautioning him about driving in a parking lot this weekend. He wants to assure you, it will be an empty lot. He knows he doesn't have any insurance on the car yet, and no valid license. He will not drive out on street.

And he has learned that there is a prison that houses paraplegic criminals, so don't worry, if they throw him in jail there are facilities for him.

I am going to try to try to put up pictures of the van on the blog. If you are getting this message by email, go to http://drpeg2003.blogspot.com/ to see the pictures. I can't get the text to center, I am afraid!

Mar 11, 2007

“I’m driving!” Gary said as he released the tension on the hand control and the van went forward under its own power.

We spent an reassuringly uneventful half hour or so with Gary going up and down the empty part of a parking lot at the university. He practiced parking as well (the hard part is the van is so big it’s hard to see if you’re between the lines). Then Gary said he was ready for the freeway. I gave him a look. “You’re joking, right?” I asked. He was.

After he was finished, I too tried driving using the hand controls. Everything works easily enough. It’s just a matter to remember to push for braking and pull for accelerating (I tended to want to pull for braking – whoa, horsey! I guess ;-)). I think I’ll stick to the usual foot pedals, though.

The hardest part may be to learn to back out of our steep driveway (Gary didn’t try that). I went very slowly but did the last part somewhat blindly since I couldn’t see the driveway out the back window.

Mar 18, 2007

Gary has his push from the Student Activities building to the math department building down to thirteen minutes and twenty secs. Look out Peachtree Road Race ;-).

I had had the thought that there was an area behind a local shopping mall where there were businesses that would be closed on the weekends and that therefore Gary could get the feel of driving along the roads there without fear of a lot of traffic but it being a step up from a parking lot. Gary thought that was a good idea so I took him out there on Saturday. When Gary got behind the wheel, I tried not to be too much of a “passenger seat driver,” but I did let out an anxiety-filled, “Don’t cut across the parking lot!” when he decided to go into the mall parking lot and do just that. He thought it was a way to avoid cars, but it made me nervous. I also kept my thoughts to myself that his driving was rather jerky. Okay, *one* time I told him. He commented that that must mean his driving was like someone else’s he knew. I gave him a dirty look.

We discovered a little “design problem.” In order for Gary to use the blinkers, he has to take his hand off either from the wheel or from the accelerator/brake! It seems to me they should have designed an adaption so that all he would have to do is stretch out some fingers from the knob that he has his right hand on to steer (located on the wheel). Maybe his driving instructor, who is coming next Wednesday, will have some tips about that. Of course, Gary pointed out there would be a similar problem if he ever wanted to scratch his nose while driving!

Another “problem” with the design set-up Gary noticed is that he has to keep his right arm elevated in order to keep his hand on the driving knob, which is tiring to do. I wondered about the arm rest on his seat, and he found he could adjust it to angle that helped some, but not entirely.

On Sunday, Gary started directly in the driver's seat while at our house. He successfully backed down our steep driveway, then drove some of the neighborhood streets. When we turned onto Owen Drive, I saw a guy up ahead who was a little into the street. "Watch out for that guy," I told Gary. "That guy better watch out," Gary replied. It was then that I saw the guy's white cane. "Well, he's going to have a hard time doing that," I told Gary. "He's blind!" Gary commented that this was not a good combination, a blind guy in the street and a paraplegic driver trainee. Fortunately ;-), we missed the guy.

I commented to Gary a couple times about forgetting his turn signals and that "that turn you just made was awfully wide." Then on another street I told him to watch out for the cat that was in the road. Gary laughed and said he didn't think he could hit a cat if he tried. I tried to keep my mouth closed as much as possible, but I was not very relaxed, even though Gary was doing fine. I would not make a good student driver instructor! (Gary assured me I wasn't making him crazy with my comments :-))

We went on Shug Jordan parkway for some highway driving, then Gary turned off it and drove to the math department and practiced parking. Then we went back home. Gary had spent about forty-five minutes driving, and said he felt much more comfortable today. He confessed that after yesterday's experience he had felt discouraged about making the trip to the math conference, that he didn't think he'd be comfortable driving there. But he said today his old driving instincts had kicked in and he felt much more confident out on the road.

Mar 19, 2007

Gary's mom continues to progress. She has been walking with the aid of a walker and a therapist close by for quite some time now. She is in a rehab/nursing home facility, where she can stay for thirty days. She gets rehab M-F.

Mar 20, 2007

Something weird is going on with the car title. The dealership that modified the car claim they haven't gotten the title from the dealership they bought the car from, and the latter claimed they sent it to them. And we can't get license tags for the car until the title is tracked down. Sheesh!

Gary got a brochure from Shepherd about this year's Adventure Skills Workshop in mid-May, a Friday late morning to Sunday early afternoon. Gary wants to go. Cost is $150 for participants, which they make sure to spell out are the disabled applicants, and $140 for other family members. This is to cover meals, lodging, a T-shirt, and for the participants, instruction. I guess this means I pretty much only get a lousy T-shirt out of it ;-), since it doesn't sound like I get to do the activities, unless I go swimming on my own (it's at Lake Martin, a good-sized lake). I'm not even sure if I'd lodge there, because there are only a limited number of private rooms for couples, and I told Gary my love stops at being housed in a group cabin (which made him laugh).

The activities are: water skiing, zip line, jet skiing, riflery/skeet, scuba diving, climbing wall, all-terrain vehicles, swimming, canoeing/kayaking, water polo, rugby (!), tubing, fishing, golf, archery.

Mar 21, 2007

Gary had his driving lesson today. For the first half hour, the state guy readjusted the hand controls of our car. Now the acceleration/brake bar has been rotated upward so it is closer to the turn signal, and Gary can easily reach the turn signal without removing his hand from bar. The guy also moved the entire apparatus upward, more in line with the steering wheel, so now there is more knee clearance, and he also tightened it so it wasn't as wobbly (why the people who adapted the van, who supposedly have been doing this for ten years, didn't know to do this, we don't know).

But for the actual driver's lesson, Gary got in the state guy's van, which has dual controls in case the guy needed to override Gary on something. Because of insurance requirements, I wasn't allowed to ride along. Rats! (Or maybe they wouldn't let me come along because they were afraid I'd do too much screaming ;-).) Gary was going to go home in that van, so I left to go home myself. Gary came home about an hour later. He said they'd driven along 280 (in fact, they passed the place where he had his accident), then to the interstate, then to College Street, then the math department, then they took the back way home. Gary "passed," and the guy is filling out the papers necessary for Gary's new license – all they have to do is add the restriction that he must drive with hand controls. The guy does want Gary to drive with a torso-chest restraint, however, and is having one ordered for him (the guy kept calling it something that sounded like "grandma," which I thought was a little weird, but then he pronounced it "gran-mar," named after the manufacturer or something) . It will fit over the driver's seat and will be essentially be two velcro straps that wrap around Gary's chest. This is so that when he makes his turns, especially sharp ones, he won't lose his balance sideways (since he doesn't have those abdominal muscles). The guy noted that Gary was occasionally in need of that extra support.

The guy's assistant is going to drive around with Gary tomorrow morning, just so Gary can get more practice in. Gary still hopes for us to leave next Weds. to begin the journey to Rolla, Mo. for the math conference. Gary will probably be fine for the trip – me, we'll probably have to tie to the roof of the van. I am so bummed out! About two weeks ago, I started feeling a little pain in my right knee. I have been doing a lot of kneeling, because that is the most comfortable position for my back/leg problem (and yes I have one of those chairs that has the kneeling pads on them, but it still puts too much pressure on my butt (sciatic nerve), so I just kneel on the floor on a rolled up exercise mat). But I have also been doing lunges in my exercise program since last August, since they were recommended by my trainers (and my current chiropractor read through my program and thought it was a very good one for my back/leg problem and general strength conditioning) and I recently had been trying to walk a little faster during part of my daily walk (though Michel and Mimi occasionally meet up with me and blaze by me), and actually it seemed to be the latter that affected the knee. Anyway, one night about two weeks ago I was scheduled to do my exercise program. I was feeling tired and wanted to put it off until the next day, but then I went ahead and did it. Big mistake. Big knee pain the next day. So I cut out the leg exercises and the fast walking, then cut out arm exercises too because they still put added weight on the leg. And then last Sunday when I was doing an easy walk, the pain got really bad. And I was still ten minutes away from my car. So since then I have been doing no exercising except for an exercise Gary did for his knee when he had problems. But since that walk the knee hurts really bad to bend it, say 90 degrees. So I can't kneel anymore. And I can't sit on my stability ball for long, because that bends the knee to much (and that was my second favorite position to be in). And I can't sit on a regular chair – haven't been able to do that for quite some time. And I can't lie supine because that affects my back/leg, as, again, has also been going on for quite some time. So I stand up for a while working on my novel, and then I have to lie face down to recover (standing also makes my knees and back of my legs sore after a while). I even went on the web to see if I could find something that I could lay prone on and still work on my laptop, but I really didn't know how to search for such (I tried "proning table" and "proning bed"). And now, for some reason, my entire right side feels wrenched. GRRRRR!!!!!!!!

Mar 27, 2007

We survived the first leg of our journey ;-). First time I've ever been the one waiting for Gary to be ready to leave. We left the house at about 10:30 am, and we arrived in Clarksville, TN about 5:30 pm. Gary did most of the driving, but for some reason wanted me to be the one to drive through the heavier traffic of Birmingham and Nashville. I'm not sure that was safer ;-).

While I drove we listened to "Never Have Your Dog Stuffed," Alan Alda's autobiography on CD, which Norma had given us while Gary was in the hospital. While Gary drove I worked on my novel.

We took separate rooms at the Holiday Inn, where Gary had made us reservations – we didn't end up all that close together. The desk person probably wondered just what the heck I was doing, since I spent at least half an hour unpacking stuff from the van to bring in for the two of us. Then I get to pack it all up again tomorrow morning, then unpack everything the tomorrow night. Hope my body holds up!

Gary arranged all his accouterments for the morning bowel and bladder programs on a low table in the room, and I put it next to his bed after tucking him in for the night. In checking his skin, it seemed to me that the right side of his flap showed signs of increased redness after the drive, so he is going to have to do more frequent weight shifts during this trip.

So far, so good!

Mar 28, 2007

Made it! We arrived in Rolla about 5:30. Only thing eventful to happen during the trip was a stupid trailer truck with a load of cars nearly ran me off the road while we were going through St. Louis.

I laid on the horn, but he kept coming into my lane (the far right lane), so I ended up on the shoulder of the road.

I did more driving today so we could save a little time – Gary needed to increase his weight shifts to every 20 min. instead of every 30 because of the increased redness on his flap, and of course he can't lift himself up off the seat when he is driving, so whenever he drove we'd have to pull off the road every 20 min. Not that I'm complaining – it was better for my back to make those frequent stops, so I could get out and stretch.

At the hotel we got adjoining rooms, and they even have a connecting door, so that is nice. After I unpacked the car, I got my zucchini cooking and then meditated. Gary ordered a pizza to be delivered – seemed the easiest thing to do. About 8pm we went across the street to the motel where registration and a welcoming party for the conference was being held. We asked at the desk where the party was, and were told it was upstairs – and that there was no elevator. I joked to Gary that this was an opportunity to practice bumping up the stairs.

The guy at the desk called upstairs and some math people came down to register Gary. Meanwhile, Alan Dow showed up, and so did Darji, so we talked with them for a short time. The organizers and Darji and Alan offered to carry Gary up so he could join the party, but we had only intended to stay a short time – just long enough to register – as we were both pooped; if we had gone upstairs, I think Gary would have felt obligated to spend some time there. So he declined the offer.

Back at the hotel we ran into Judy Kennedy, and a little later while getting something for Gary I ran into Frank Tall. So, I am running into all sorts of people I haven't seen in years.

Well, have to help Gary arrange his things (tonight we are using the motel's ironing board as a bedside table!), and then we are going to hit the hay!

Mar 29, 2007

Well, my knee started hurting badly after I got into bed, so I had a rough night. Always seems to be something, doesn't it? ;-)

Gary was ready to go to the conference talks about ten-ish, so I drove him over. I wanted to make sure he was going to be able to get around without my help, so I went in with him to see what the layout of the rooms were (plus to figure out where his talk is, as I will go to that). We didn't get too far into the building before people came up to greet Gary. Since I didn't write down the names immediately, I have forgotten most of who came up – sorry! I remember Dennis Burke, Frank Tall, Peter Nyikos, Alan Dow, and Mirko. The first talk Gary was going to was at the opposite end of the hall, and he'd only wheel a few feet before someone else would come up and say how glad they were he made it and that they'd heard rumors he might come but no one was sure. He'd tell them it had been a goal of his to come, and that he himself hadn't been sure he'd make it – that he'd only learned to drive the van in the past couple weeks and he hadn't been sure he'd be comfortable driving all this way. I know that he is thrilled to be here.

We figured out that he would have to enter the room he is giving his talk in by going down a ramp to another hallway and entering at the front of the room, since if he enters in the back he would have to go down a series of steps. He also decided to listen to the first talk from the front of the room it was in.

Everything seemed under control, so I left him there to come back to the motel and work on my story (and rest). His talk was at 3:50, so I went back for that. After Gary had finished, Justin Moore, who was chairing the session, said he felt like he should say something special, but he didn't know what to say. He said he had thought of saying, "Welcome back," but then, Gary had never really been gone. Gary cracked, "Yeah, I was at last year's conference." Then Gary added it was great to be here, and everyone gave him a nice round of applause. I went up to him afterwards to see what his plans for the rest of the afternoon were, and I asked him if he had been having fun. He said, yeah, and with a smile added that about a zillion people had come up to him during the day and said they were glad to see him. And he said it was important to him to be here and to have everyone know that he was still involved in the thick of math.

Mar 30, 2007

Today Gary wanted to go to an earlier talk (9:30), so in order to make that he had to get up a half hour earlier (6:30) and I had to help him a tiny bit with his morning routine. I drove him over rather than him driving himself, for a couple of reasons. Firstly, to save time. With practice he'll be able to make the transfer to the driver's seat faster, but now he's still at the stage where thought is required – in what position to put the driver's seat (and keep straight which of those controls does what – move the seat forward and backward, up and down, spin it), is he in the position he wants to be for the transfer, are his legs properly arranged under the steering wheel after he makes the transfer, etc. If I drive, all he has to do is transfer into the passenger seat using the transfer board, which we've now done hundreds of times (though not that often in a van!), and then I wheel his chair up the ramp and lock it down. The second reason I drove him is the confidence factor in the transfer back and forth from the driver's seat. Gary is not quite confident of doing it on his own. For now, better that I be there rather than getting a call from him of the "I've fallen on the floor and I can't get up" variety, particularly when I don't have a car to get to him. But he is getting more and more confident of that transfer, and soon, maybe even by the end of this trip, he will be confident enough to drive himself back and forth from the math dept. at home. Though the LETA bus service is greatly appreciated by the both of us, it will be nice when he isn't dependent on them for his transportation.

So, anyway, I took him there and sent him off with a goodbye kiss. I spent most of the day on my story, with a nice nap there in the middle ;-). I spent a short time trying to find a massage therapist who would do outcalls, but couldn't locate one.

It started raining in the afternoon, and it was coming down hard when I left the hotel to get Gary about 5:30. The first thing I did in coming out of the hotel was my impression of an uncoordinated ice skater – the pavement was so slick I almost fell, only saving myself by grabbing onto a post (causing my audience, three elderly people waiting under the arch of the building, to gasp). I'm sure that body wrenching did wonders for my back/knee problems. Maybe it snapped things back into place ;-)

I brought Gary's rain parka for him, and we decided he'd get less wet if he wheeled into the van and then transferred to the driver's seat. Peter Nyikos wanted to take pictures of the hand controls, saying the pics of them on my blog were too small to make out any detail – which I had figured might be the case, but I only have my camera phone and that's as good as I could knew how to get them. Peter had his camera at his motel, across from ours, and since this seemed a good time to take the pictures, Peter became Gary's first passenger other than me. We told him to fasten his seat belt ;-). After Peter took his pictures, we bid him goodbye, and Gary drove to a drive-in chicken place for his dinner. (Last night it was Steak and Shake, so we are really hitting the culinary highlights of Rolla.) There was the traditional conference banquet this evening, but Gary decided to skip it. He has to start his evening routine so early that he wouldn't be able to be at the banquet very long.

Speaking of meals, that reminds me that yesterday I asked him how he had handled lunch. He said he'd wheeled with a group of people to a Paneera's fairly close by. He assured me that though they had pushed him up a steep ramp and during part of the journey when the sidewalks were so bad he had to go into the street, other than that he wheeled himself.

I asked him how today had gone, and he said very well. There was a lunch meeting of the Steering Committee, and as he was on it, he'd gone to that. This was supposed to be the end of the three-year term he was currently on, and he wasn't the only one for whom that was the case. All such people were asked to stay on. Gary's position was "Summer Conference Link," which he didn't think he should stay on as, because the summer conferences for the next couple years are in foreign places that do not seem like they would be very accessible, so he was doubtful he'd go to them. Wayne Lewis, who is the head of the Steering Committee, still wanted Gary to stay on in some capacity, but Gary pointed out that he'd been on the committee in one capacity or another since its inception. This didn't deter Wayne, who then suggested Gary be given emeritus status on the committee (one other person has that status, Mary Ellen Rudin). The others agreed this would be a good thing, so that's what happened. Gary said that at least this way he gets a free lunch (and they all laughed).

Murat Tuncali gave Gary a little box this morning and told him it was a present (!) for him and me. Gary waited until we were together at the motel in the evening, and then we opened it. It is a beautiful "Shaman Small Pot." I believe it was created by an artist local to where Murat lives (Nipissing, Ontario).

Though the conference isn't over – the talks in General Topology go on until about noon and then there are problem sessions that go into the late afternoon tomorrow – we are leaving tomorrow as soon as Gary is ready (ten-ish) so that we can get back home Sunday evening.

My massage therapist better have me scheduled for this coming week (are you reading this, Connie?) ;-).

Apr 1, 2007

We're in bad shape at the moment, as Gary says – and I wish that were an April fools joke but it isn't. It is Sunday morning, and we still have half the trip to go. After my bit of driving yesterday, I was in significant pain with my knee. When Gary got into bed last night and I got a look at his flap, I was appalled – it was a bright angry red and looked very dry along the right side of the flap. You may recall I had thought it looked quite inflamed after the first night of our drive to the conference and no better the second night. It seemed to improve during the conference, but not go back to pre-conference condition. Last night it looked so bad I really don't think he should be sitting. And this morning, while slightly improved, it is still pretty bad – which would seem to mean the driving is making it worse. I guess something about the seat, the way it puts pressure on this area, is giving him the first stages of a pressure sore.

So what this means is we are going to have to lay the passenger seat down so he can lie on his side or put him on the floor for today's journey. In other words, little to no driving for him. Which means I have to do it which means my knee is going to be cursing me. The way the van has been modified is just not good for me – my legs can't get comfortable while driving. (And another thing, I didn't realize that the non-ramp door would be so difficult to open and close. Joe and Dolores's van simply requires that you start the door to close and it automatically shuts on it own. Our van's door I have to heave closed, and often it doesn't close hard enough and I have to do it again. This has not been good for me!)

Apr 2, 2007

Thanks Judy, Ronnie, and Dimitrina for sending words of en-courage-ment on Sunday.

Yesterday (Sunday) in the car I alternated between sitting on one of Gary's cushions, for the sake of my left leg and butt cheek, and not sitting on it, for the sake of my right knee. Gary still drove some, but when he was not driving he tried to spend as much time as he could on his side and off his flap. We made it home about 4:30 and after unloading the car and getting my dinner I waited for the hours to go by in all their minutes so I could go to sleep. Gary spent most of the time after we arrived in bed and off his flap. He commented that provided he hadn't permanently damaged his butt nor I my knee, the trip was worth it. I told him I'd have to get back to him on that. JUST JOKING. Or at least, half-joking. I know it was extremely important for him to go to this math conference. And as he says, he doesn't know the next one he'll be able to get to. Conferences coming up are in inaccessible foreign places. And the next spring conference is in Milwaukee, and he says (thank God) that that is too far to drive to (in fact he says that if it's not a special conference, as this one was for him, driving two days to a conference isn't worth it – we'll see if he changes his tune should the opportunity arise again). He's not too keen on flying to the one in Milwaukee, because of all the stuff we have to cart around, and it would be "we," because at the least I'd have to rent a car to get him around – unless he wants to rely on public transportation or the conference shuttle, which he does not. Maybe with his greater experience the next time he won't need me for the other stuff I helped him with this time (the night before last I even had to catch him and heave him back on the bed when he landed too close to the edge of the bed during his transfer – that was the first time in a long time he would've ended up on the floor if I hadn't been there; I commented to him, "Well, that was exciting.").

But his family needn't worry about the summer visit to Nebraska. The new plan is for us to fly, and we will ship our supplies there ahead of time or possibly prevail upon Norma et al to bring stuff for us.

During Sunday's drive, having finished Alan Alda's book-on-CD (which we really enjoyed though it was not comical as we at first expected it to be), we started "Marley and Me, Life and Love with the World's Worst Dog." And from the tales John Grogan tells, this dog really does seem to be the worst, the antithesis of Joe and Dolores's dogs. So now when I start moaning about something, Gary says, "Cheer up. It could be worse. We could have Marley as a pet."

Speaking of obnoxious pet behavior, Tigger twice peed in places he shouldn't today (Monday) – once on Gary's bed, once in my bathtub. I don't know if he was excited to see us, or expressing his anger at us leaving him, or if he was mad because at the time I wasn't giving him attention, thinking it more important to help give Gary his bath (silly me), but I hope his behavior doesn't continue. I know such behavior can be a sign of a medical problem as well, so I hope it's not that.

He is such a jealous cat. He always pounces on Blackjack whenever he thinks Blackjack is getting some attention, and always kicks Blackjack out of wherever he has decided to take a nap so HE can take a nap there. You'd think that Blackjack, who at 17 lbs outweighs Tigger by 3 lbs, would throw his weight around, but Tigger has him cowed. And ever since we returned from Shepherd last summer, Tigger is jealous whenever I go into Gary's bedroom to do something for him (wash his back, get his clothes out, get him settled into a prone for the night). Tigger always comes in and meows and wraps himself around my legs until I give him attention. I guess he's trying to prove to Gary that there can be only one alpha male, and he, Tigger, is it.

And again on pets, while we were driving Sunday, Gary called out, "There's a cat!" I had no idea where to look, but then I noticed cat eyes calmly staring at us from the SUV passing by. I thought that was unusual, a calm cat in a car. Our cats go nuts just going the few blocks to the vet in our car.

We also passed by a van with a cat/dog carrier strapped on the back bumper. Seeing that it was poring rain at the moment, I told Gary that I hoped there wasn't an animal in there.

We discovered Gary's reflexes are good. A car started pulling into our lane while he was driving and his immediate reaction was to push in on the hand brake – no inclination to try to slam on the brake with his foot. He said in a way that aroused pathos in me that he thought this was because he is totally used to his feet not working.

His flap was still an angry red Monday morning. I wanted him to stay in bed and off his butt the day and possibly longer until it looked improved. He said he had to go in to prepare for class the following day (Tuesday), and he'd also been thinking of doing his weight training. I told him I didn't think he should be messing with this. He said it should be all right to sit on it because the redness was on the flap, not the sitting bones. I told him I still thought it'd be better for him to have nothing covering/touching the area or putting pressure on the area, that if he had flap surgery again they were going to have to cut skin and muscle from his hamstring to pull over his butt (which is what they'd do). I guess that was enough to convince him to stay off his butt as much as possible. He did go in to prepare for classes for about an hour (I dropped him, unfortunately had to go grocery shopping, and then picked him up), but most of the rest of the day he stayed in bed and off the flap. It didn't look any improved at bedtime, so he promised me he'd call Shepherd on Tuesday.

Which he did, but the bridge nurse is out for the week. Fortunately the flap looked better this morning (Tuesday) – bright pink instead of dark red. And it is not as scaly so maybe the antifungal cream, which I again started to put on it Sunday, is helping.

Last comment for Monday: Gary's mom is now walking on her own with a walker and should be able to go home next week! Bob will stay with her for a while.

Apr 3, 2007

Gary received an Easter email today (from Marilyn) and asked me today if this Sunday was Easter. I said it was. He said hopefully this Good Friday will be better than the last one (last year's Good Friday was the day of his accident), that that day hadn't exactly been a good one. I told him it hadn't exactly been a good one for Jesus, either. Gary said it was unfortunate he himself hadn't risen three days later, that it took him more than a month, and at that he didn't rise very far. I told him from that we could conclude he wasn't Jesus.

His flap looked significantly better this morning and I felt in significantly better humor (and not just because of the flap, but on account of having caught up on some rest). But I still didn't think Gary should be up as much as he normally is, and he agreed and cut the afternoon short by a couple hours to get back in bed and off his flap. He got up for dinner but then got back into the bed.

When he called his mom, I heard him tell her I am making sure he is taking care of his flap, that I take good care of him. That was a better light on it than I had been thinking – I thought he might think I was being overcautious and tyrannical in making him stay in bed. ("Peg," he whined, "can I get out of jail?" "No!" I replied. "You've been a bad boy." Just kidding. Well, not kidding that that was a conversation we had, but I did put down the hospital bed rails so he could get out.)

I made an appointment to see an orthopedist next Monday about my knee. I had my massage appointment today, thank God, and Connie unscrewed my right leg from the 360 degree twist it had somehow got in, plus she pulled my knee out of my thigh, where it had somehow got lodged. The knee still hurts like the devil, but at least she doesn't think I've torn anything.

Apr 4, 2007

Gary's flap is looking much better, and we are so relieved (he said he'd known it was something to worry about when upon seeing it last Saturday night I'd yelled out, "Jeez O Pete!"

Apr 5, 2007

HAPPY EASTER, FAMILY
THIS IS JUST TO LET KNOW THAT WE ARE THINKING ABOUT AND PRAYING FOR YOU DURING THIS TIME.
THIS YEAR WE FEEL ESPECIALLY BLESSED THAT OUR BROTHER-IN-LAW, GARY, WHO WAS PARALYZED LAST YEAR, GOOD FRIDAY, IS MAKING REMARKABLE STRIDES. LIKE JIM, JOHN'S BROTHER, EVEN THOUGH HE HAS LOST LOWER BODY CONTROL, HE IS DRIVING, BACK AT WORK TEACHING AND TRAVELLING WITH HIS WIFE,PEG(JANET'S SISTER) WE ARE AWED AT THE COURAGE AND LOVE PEG AND GARY HAVE SHOWN. JANET'S BROTHER JOE WAS A BIG HELP BY REMODELING THEIR HOME,SO THAT IT WAS WHEEL CHAIR ASSESSIBLE. WHAT A GREAT BROTHER AND HIS WIFE DOLORES WHO LENT JOE FOR THIS PROJECT FOR OVER A MONTH. JOE AND DOLORES ALSO MOVED MY MOM, 87YEARS OLD INTO AN APARTMENT FROM HER BIG HOME. ANOTHER BIG JOB. MOM DANIELS IS DOING GREAT. JOHN'S TWIN, JOIE HAS ALSO GONE THRU A BIG MOVE THIS YEAR AND IS SHARING A HOME WITH HER DAUGHTER, ANN AND HER FAMILY. CONGRATULATIONS, JOIE.
JOHN AND I WILL BE TAKING A TRIP TO MINNESOTA IN OCTOBER TO CELEBRATE MARY(HIS SISTER) AND LES' 50TH. AND OF COURSE TO SEE ALL THE FRISCHMON CLAN, JOHN'S BROTHER BILL, HIS SISTERS ALICE, AUDREY, JANET AND BERNIE BESIDES THE ABOVE FAMILY ALREADY MENTIONED.
SO THERE IS ALOT TO CELEBRATE ABOUT OUR FAMILIES THIS YEAR, OF COURSE, NOT ALL RECORDED HERE.
JOHN AND I HAD A WONDERFUL TRIP, DOWN UNDER. WE HOPE YOU ALL RECEIVED VIA E-MAIL AN ALBUM OF OUR PICTURES WE SENT ABOUT 2 WEEKS AGO. IF YOU DID NOT PLEASE LET ME KNOW. TO US IT WAS THRILLING TO SNORKLE THE GREAT BARRIER REEF , PET KANGEROOS AND KOALAS AND VISIT THE FANTASTIC HARBORS OF SIDNEY.
NEW ZEALAND'S SCENERY WAS SPLENDID, AND WE FELL IN LOVE WITH THE NORTHERN BEACH TOWNS, SO LUSH AND WITH AZURE BLUE WATERS.

WE DINED ON THE SHIP WITH SOME WONDERFUL AUSTRALIANS AND GOT OTHER PERSPECTIVES ON WORLD POLITICS AND RELIGION. SO WE HAVE SO MUCH TO BE GRATEFUL FOR.
WELL, THIS WAS JUST A RUN DOWN ON BOTH SIDES OF OUR FAMILIES, TO CONNECT OUR FAMILIES TO EACH OTHER OVER EASTER.
WE PRAY THAT LIFE WILL HAVE DEEPER MEANING BECAUSE OF THE LOVE WE HAVE FOR EACH OTHER. OUR LOVE, JANET AND JOHN

Apr 8, 2007

Happy Easter!

And it was a much better one this year.
Gary's flap is pretty much back to normal – yea! I was scared about it last weekend (Gary said he'd known it was something to worry about when upon seeing it last Saturday night I'd yelled out, "Jeez O Pete!") I think the combination of him staying off it earlier in the week and not driving enabled it to gradually heal back up – though it is not quite as good as it was before the trip.

Gary spent time today practicing transfers between his wheelchair and the driver's seat of the van, without me being present (but both of us with our cell phones on). He has something to prove to the local bus drivers. He told them he wouldn't need their services after the conference, and they have been saying to him all week, "I thought you were driving on your own starting this week?" But, he didn't get in as much practice on the transfers as he would have liked, and thus still felt he needed me to be there "for the confidence factor," that is, he felt more confident in making the transfer if he knew I was standing right there in case he didn't quite make it over on his own. Yesterday when we went to Kroger I stayed in the front passenger seat rather than standing by him when he made his transfers. Today I stayed in the house, and he practiced the transfers in the van in the garage. He did three successful transfers, and he now feels confident about doing them on his own.

So, tomorrow will be another milestone! He is going drive to school on his own in the late morning, and then return on his own in the late afternoon – the important part being he will make the transfers unsupervised (of course, I will have my cell phone on!). This will also be the first time he has driven on his own, but he has been confident of the driving part for a couple weeks now.

We did have a little problem as a result of his practice today. He decided he should move the wheelchair closer to the passenger seat while making the transfer, so he can catch himself on it if he should fall forward. Well, in moving the chair to this different position, he tugged so hard at it he caused the back of it to go out of whack – it wouldn't lock into place in the upright position. I couldn't fix it with him in it, so he had to transfer out of it so I could fool with it. I broke it down (i.e., took off the arm rests and the tip bars and the wheels and the cushion) and then flipped it over and stared at the bottom of it. And stared at it. And stared at it some more. I had no idea why the frame wouldn't lock upright – I freely admit I am not mechanically minded. All I could see was the left side was locking in fine, but the right side wasn't down far enough to be in the proper position to lock in at the same time. I was ready to give up pretty much right away ("Let's call Wlodek!" I said, since I knew he was mechanically minded – he was the one who helped us out with Gary's wheelchair when he came to visit at Shepherd). Gary seemed reluctant, so we stared at the bottom of the chair some more. I finally noticed the two sides weren't sloped at the same angle, though the difference was slight. Gary then noticed that there was hole showing around a metal plate under the bolt on the right, but the hole was covered by the plate on the left. So I got out the trusty set of wheelchair Allen wrenches, and loosened the bolt on the right and then moved the frame so the hole was covered by the plate. I tightened the bolt up, put the chair back together again – and then noticed the back of the chair was now sloped too much forward. I had moved the wrong side of the frame. So I had to break the chair down again and adjust both sides in the other direction. I suppose I could have figured this out at the beginning if I were more mechanically minded.

Anyway, after close to an hour I got the chair properly adjusted. Gary crowed, "We did it ourselves!" I wondered what this "we" business was ;-). I *was* a little proud of fixing the chair, I admit, but I also lamented wasting so much time doing it!

Now, if I could only figure out how to do taxes.

Actually, Gary is taking me through that too this year. I would have been a mess (or rather, even more of a mess ;-)) if he had had his accident a bit earlier last year and I would have had to try to figure the tax stuff out on my own.

I talked to my sister Janet today. She told me some about their trip to Australia and New Zealand (she had emailed me lots of pictures!). I told her about how the cats are doing (ever since we returned home from Shepherd last August, Blackjack has had a phobia about going in Gary's room for some reason, though the cat is no longer afraid of the wheelchair – in fact, Gary wishes Blackjack were more afraid of it, since now the cat won't even bother to move out of the way when Gary is trying to get by him (I can always tell when this is going on, since I hear Gary saying, "Beep, beep!"); Tigger has, as far as I can tell, stopped peeing in undesirable places). Janet in return told me a story about her cat Morrie. Morrie was having terrible allergic reactions to something, which caused him to bite out his fur and scratch himself until he bled, and the vet put him on a rare foods diet! Now, I know about such diets for humans, but I had no idea they did that for cats – in fact, I had no idea cats could be allergic to their cat food. So, anyway, the vet gave Janet the choice of putting Morrie on a diet of rabbit or New Zealand venison or Australian kangaroo! Evidently the venison was the cheapest, and after a few weeks of this, Morrie is all better! Janet has to keep him on this diet, but it didn't sound like the food was all that more expensive than regular canned cat food.

When I later told Gary about this, I said, "Remember when I tried a rare foods diet?" He said, "How could I forget? It made you really, really sick." When I had all the gut problems concurrent with the CFS, I was trying to figure out what foods I could eat that wouldn't cause a reaction, and I came across the theory that it was the foods commonly eaten that caused the problem, so one should first clear oneself of the allergy symptoms by eating only foods one never or seldom ate. While this is a successful approach for many people – and evidently cats – it very much backfired for me. I ate some leafy green we'd gotten at the Atlanta Farmer's market (maybe cassava leaves? I forget). Pretty soon I felt like I was filled with acid from head to toe. I was so sick! I told Gary to remember what I ate in case he ended up taking me to the emergency room to have my stomach pumped.

Anyway, that little experiment totally backfired and I suffered the ill effects of it for a *long* time. Glad Morrie didn't have to go through that ;-).

Apr 09, 2007

Today (Monday) Gary successfully made his transfers and drove himself to and from school! Huge step in his independence, and I congratulated him. Now I'm waiting for him to do our grocery shopping himself ;-)

Monday morning at 10 I had an appointment with an orthopedic physician. I finally got in to see him about 11:15. One of my pet peeves is waiting around in doctors' offices. (Another one is standing in lines, so I guess the common denominator is "waiting.") These days I usually bring a hardcopy of my story to work on the revision if I think I'm going to have to spend time waiting, but I was at a sticking point in my story (and have been sort of stuck there since April 1st) and found it hard to concentrate on it in those surroundings.

Anyway, I finally got in to the doctor, and "Dr. Bob," as he calls himself (I should have introduced myself as "Dr. Peg"), looked at my x-rays and at least gave me the good news that there is no sign of arthritis in the knees – nice big gaps between the bones. The bad news is he thinks I have torn the meniscus (cartilage between the bones). He gave me a prescription for an anti-inflammatory. I couldn't read his writing, and after I filled the prescription I realized it was just naproxen which I probably could have bought OTC cheaper! He also set me up for physical therapy. They have the PT in the same office, and when I went over there to set up an appointment, they said I could have my first appt. right then, if I wanted it, which I did. They attached sensors to the muscles around the knee and took me through four exercises during which I was supposed to make this little monitor beep. I was surprised at how tough the exercises were – I thought they'd start me off easier, but the exercises were quite tiring and they made my shin ache. Actually, the PTs said they were starting me off easier because when they asked of my health history I told them I had CFS, though it was not as severe as it had been. All throughout one of the exercises, one of the PTs kept asking me about CFS. First of all, I'm not much of an exponent for anything, but even less so when I'm trying to concentrate on something else. I should have told him that some of my symptoms are cognitive, and in particular, I cannot keep my mind on two tasks at once – in this case, I couldn't keep track of the number of reps I was on while talking to him. "I have no idea if that is five or ten," I said at one point. "Guess you'll have to start over again," he said. He kept talking. I have no idea how many reps of that exercise I actually did.

They gave me a sheet with the four exercises on it and told me to do them daily. I will see them again on Friday. It was after1 p.m. when I was finished, so I went home, had lunch, and then it was off to the chiropractor at 2 for about an hour – so Monday morning was shot taking care of my right leg and Monday afternoon was shot taking care of my left leg!

I have been doing the exercises at home, and they seem easier – not because I am getting better at them but because I don't have some little machine I am supposed to make beep, and even though I try not to ease up on the exercises, I know I am – I give in to the aches when there is no taskmaster beeping at me.

Apr 11, 2007

Tonight I finally finished that scene in the story that had been giving me problems since April 1st. Even though I like it, I wonder what my critique group will say about it. It is the darkest scene in the story, I think. Originally it was only four paragraphs long, but now it is about eighteen double-spaced pages long. I wonder if they'll find it too dark. Another potential problem is that it is a flashback, and I think there is some unspoken (or maybe, spoken) rule about not having long flashbacks. On the other hand, it is a revealing moment about one of the characters.

It is strange how sometimes I can like what I've written and then later not like the same passage – and sometimes later read it again and like it again.

I have problems figuring out locations for the scenes. Like, I decided I needed to have something occur in a rural area not too far from Los Angeles. So then I had to go online and figure out some place near L.A. that was rural. Then I had to figure out what might be on such rural property, what the surroundings might look like. I had to go online and look at real estate properties. I couldn't find one for the original area I chose, so I had to keep looking around the internet until my requirements were met.

I can't even describe a scene in a house without getting out a book I have on housing floor plans and picking out a house to use. This seems weird to me that I need to do this, but I am frozen in writing the scene until I do.

I also have problems with technical stuff. I don't see how writers come up with scripts for movies like The Thomas Crown Affair, or the James Bond movies. I'd be stuck at, "But how does that really work?" In other words, I am not good at winging anything.

My desk is apparently not big enough. My cats have decided they are indispensable sources of inspiration to me, and that they can best perform this service by sitting on the desk next to me.

Now, Blackjack alone is not too bad – he'll usually leave a reasonable amount of space between the mouse and his head. Tigger, however, has to put his head right on the mouse, so that his head gets rubbed when I click the mouse. This he does whenever he is not trying to walk across the keyboard (I have lots of iuxp's and other nonsense words in my story on account of him). Since Tigger will not ever let Blackjack be anywhere close to me without him trying to horn in, the real fun begins when the two of them are up on the desk curled up as close to me as they can get. It is very distracting to be trying to write and having two furballs in such proximity. And it doesn't work to close the door on them – they will scratch at the door and/or howl until I let them back in.

Sigh I think I will have goldfish for my next pets. If they get obnoxious I can flush them down the toilet.

Apr 13, 2007

After going to a colloquium today, Gary had his first fully independent restaurant outing (actually, first independent outing of any type other than going to and from school). He drove himself to and from the restaurant and made the transfers on his own. He said he had an audience when he left the restaurant for home – a bunch of the math people wanted to see how he got himself into the van and driver's seat. "The pressure was on," I joked when he told me this. He said he'd said the same thing, and thought, "This better be a good one!" (meaning the transfer into the driver's seat; evidently it was good enough ;-))

Tomorrow is the first anniversary of his accident.

Apr 13, 2007

Apr 14, 2007

"So, how ya doing?" I asked Gary at lunchtime. "Fine," he replied. Moments later, he said, "I just remembered, today's the fourteenth (the anniversary of his accident)." "You did?" I said. I was well aware of that fact and it was why I'd asked him how he was doing. "So, how ya doing now?" I asked. "Still okay," he said, then went on, "Tears came to my eyes when I remembered, but I'm okay."

At bedtime I asked him if he'd gotten through the day all right. He said he hadn't thought any more about it, except to note that not only would it have been impossible for him to make the Alaska cruise last July, as the people in Birmingham said he should be able to do, but it doesn't seem likely that he'd be ready to do something like that by even *this* July. And that one thing we hadn't taken in to account was that I'd have to go along too.

Well, we certainly didn't know all what was involved at that stage of the game (last May).

I suppose I should have something profound to say to mark the day, but I don't. I'm just very happy to have him still with me.

Apr 16, 2007

This entry will be all over the map.

I got some test results back from the doctor today. Somehow since the last time the tests were done a couple years ago my body has managed to become very low in vitamin D and my thyroid is “mildly low.” I didn’t talk to the doctor, but the nurse told me the prescription for the thyroid is usually taken for life. CRUD!!!

(Well, at least “low thyroid” may now give a possible explanation for why since we got home from Shepherd last August I started putting on weight. I couldn’t figure it out, since it didn’t seem to me I was eating any more, and though I’ve been trying, I can’t lose it.)

Gary and I discovered over the weekend that though I had thought I had e-filed our federal tax return last year (when I raced home from Birmingham three days after his accident specifically to do so), apparently the IRS never got it. Oh, great. Gary told me not to worry, that he’s written a letter to them explaining the situation. He said he wrote, “It’s all Peg’s fault. She should be the one to go to jail, not me.” Funny guy.

Today I had my third therapy session for my knee. They added in another three exercises (I had gotten an additional three last Friday). I didn’t get to use the biofeedback machine – or “dinger,” as they call it – this time, the machine designed to tell you if you’re contracting the proper muscle strongly enough. I was disappointed I didn’t get to use it. I like the feedback. Although on Friday when the one PT yelled across the room, “Professor, I don’t hear any dinging,” I muttered, “You’re going to hear some dinging in a moment.” (Namely when I popped him in the head.)

I want to thank Gary’s Uncle Norman for his wonderful Easter card. It was absolutely beautiful and greatly appreciated.

I would also like to acknowledge my staunch friend, Vicki. Vicki, you sustained me with your frequent emails through those months Gary was hospitalized. I am so sorry for the loss of your mother.

Apr 18, 2007

What the man will do for ice cream.

Gary suffered through the ordeal of having to go get a new driver’s license. First he had to convince them that he did not, in fact, need to be examined by the state medical doctors and have another driver’s test (I guess the person he spoke with did not comprehend the piece of paper he had from the State Vocational Rehab Office, which said it was in lieu of all that). He then had to get a number and wait. He was number thirteen. He didn't think that was too bad. Until he found out they were on number seventy-seven and the numbers went up to a hundred. After waiting close to two hours, they finally reached number 100. Evidently the people there felt sorry for him and at that point waved him in ahead of the other dozen people.

After getting his license, he went to the Court House to get handicapped plates and a handicapped placard. Amazingly, he was the only one there! (I joked that they were all over at the other place). So in a few minutes he had our new plates. He pointed out to me that if we had had to do this last month, I would have had to go with him for all this. I'm grateful, I'm grateful!!!

(So, Norma, I hear you would have preferred that I had had to go with him, so you could read my complaints about it on the blog.)

But he thought it was wonderful (and so do I) that he could go all over the place and do this all on his own.

(But he notes, ironically, that he can wheel from the Student Activities Building where he does his weight training to the math building faster than he can drive there – because of the time it takes him to do the transfer into the driver's seat and get situated.)

After getting his license and the plates, he decided he deserved ice cream. At first he was going to go to the drive-in window, but then he realized that if he did that, having to hold the ice cream cone in one hand would mean that he would have only one hand to do everything else, namely, steer, brake, accelerate. Fortunately he decided not to chance that (I did point out there was a drink holder in the dashboard, but since he hadn't tested that out ahead of time, he didn't want to chance that the ice cream cone would stay in it when he drove from the window (and given his jerky driving, who knows if it would :-) – he said we'll test that when we go to Kroger this weekend ;-)).

So, to get the ice cream he would have to transfer out of the driver's seat and wheel to the service window. (Well, I told him he could have told the people at the drive-in window that he was just going to sit there blocking traffic until he'd finished his ice cream.) Unfortunately, after he transferred out of the driver's seat, he realized he'd left the keys in the ignition, and he couldn't reach them. So he had to transfer back into the driver's seat and get the keys (he noted he won't be making that mistake very often). Then he transferred back into his chair (he got lots of transfer practice today), and wheeled out of the van to the service window.

Finally he got his ice cream.

Now, I ask you, was that worth it? ;-)

Apr 21, 2007

Oops. Gary's gotten so independent lately I nearly forgot about him and left him in the van. After we went to Kroger, we switched positions and I did the driving to the ice cream shop, so that later Gary would be able eat his ice cream while I drove home. I've gotten use to him driving, and when he does, upon reaching home I just go inside and he makes his transfer from his specially built driver's seat (which, important for the transfer, rotates) to his wheelchair and rolls out of the van and into the house. But when I drive, I have to help him with the transfers: since the passenger seat doesn't rotate, we have to do the other kind of transfer where he slides (or hops) down (or up) the transfer board, the ends of which I place on the passenger seat and the seat of his wheelchair. Though he can make such a transfer on his own when in smaller car, he can't do so in the van, because the angle of descent (or ascent) is too steep.

And of course there is no possibility of him making this kind of transfer if I haven't taken the wheelchair out of the van!

Anyway, I obliviously left him and his wheelchair in the van for a while. I'm sure there was no danger of him having to stay in there long-term. I would have noticed later this evening that he wasn't there watching a movie with me. Maybe I would have noticed even earlier, at dinnertime, that he wasn't there.

;-)

(In case you are worried, Mom Gruenhage, it couldn't have been more than five minutes that I abandoned him – I had to bring in the groceries, after all, and I discovered him still in the van :-))

Apr 22, 2007

On Sunday, after his exercising, Gary did the transfer from the futon to his wheelchair without telling me – this was only about the third time he'd even done it without me hovering over him! Since that time, he's done that transfer without warning me, so now there is only one transfer that he normally does that I still have to aid him with – the transfer from the shower bench back to his wheelchair. I still have my hands on his hips when he does that one, but soon he thinks he'll be ready to try it with me "just there." (Although I'd first like to see him consistently not hit his head on the shower wall! (Not enough room in there!))

Apr 24, 2007

Yesterday Gary got information from the Shepherd Center concerning the Adventure Skills Outing in May. He is supposed to sign up for various activities, but they note that a person should allow at least a half-hour between the various activities, to make sure he has time to get from one place to another. In fact, they suggest that if a participant has a power chair it would be good to bring that along, because evidently the distances and/or terrain can be a challenge to cover..

So during the night he started worrying about not having time to make it from one activity to another and/or to change clothes (for example, in and out of his bathing suit – based on our experience at the Shepherd Center, that can take awhile!). When he told me that this morning, I said I would of course help him change clothes if he wants, but that unless my knee is better, there may be a problem with me helping him if he needs such help in being pushed from one place to another. Hopefully he won't – he's in pretty good shape for "pushes." I suggested that some weekend beforehand, we could drive out to where the camp is held just to check the place out. And I told him to make sure to keep up his pushes now that he isn't doing a push from the Student Activity Center to the math building after his weight training sessions (because he is driving). He said he's still getting pushes in, and in fact today he did a push up the hill to the Telfair Peet Theater on campus – which is a steep hill! He said that since this was his first time up that hill, he took it easy, by taking three or four rests to get up it, but he thought that he could most likely make it in two or three. Unfortunately, he forgot that what goes up must come down – and the downhill was on the scary side! He said it was so steep he was leaning way back in his chair and had his hands gripping the wheels so he'd go down very slowly, knowing it would be easy to lose control if he got up any speed. He said an expert in wheelies would go down in a wheelie, but he is definitely not in that category (in fact he told me he hasn't even practiced wheelies since we got back from Shepherd last December, that becoming good at them was so far out of his reach – like, not possible in his lifetime – that he thought it pointless to practice them).

Anyway, I asked him if his trip down had been so scary that he wouldn't do it again, and he said, "I don't know" – which I think is a measure of just how scary he found it! (Just not enough at first for him to call for help.)

Gary's Adventure Skills Outing must have been on my mind, too. I had kind of a funny dream. It started out like the James Bond movie, "Die Another Day," where Pierce Brosnan (a man I wish I could get in more of my dreams ;-)) is captured by enemy agents, finally released and returned to MI6, which accuses him of giving information to the enemy and so he must escape from them. In a parting from the movie, in my dream James Bond ends up at Gary's Adventure Skills Outing as the outing director.

Now, if I could only figure out what international intrigue a group of paras and quads would be up to, I could turn this into a story ;-).

Our recent movies include: "Inconvenient Truth," "United 93," and to give us some relief from those heavy films, "Mrs. Palfry at the Claremont."

Apr 25, 2007

Questions for the next Day Program:

How does a paraplegic catch a cat? (In order to take it to the vet.)

How many paraplegics does it take to change a lightbulb?

***

I had to take the cats to the vet today, and I joked that catching a cat should be on the list of Occupational Skills they teach at Shepherd, so Gary can take the cats for their checkups too. Fortunately, I caught Tigger unawares and stuffed him in one carrier. Blackjack would have been a greater problem had he put forth the effort to escape, but after taking a few steps he scrunched himself down into a ball and simply hoped he'd turned invisible. He hadn't, and I was able to stuff – and I do mean stuff – him into the other cat carrier. The two of them let out mournful cries all the way to the vet. At the vet's, I parked then lugged Blackjack in, set his carrier down on the waiting room bench, then went back for Tigger. By the time I got back inside the vet's (a converted large old house), Blackjack, in his carrier, was up on the exam table in the exam room, a few steps away from the waiting room. The vet was there, and I carried in Tigger. The vet said, "Peg, next time you come just toot your car horn in the drive and we'll come out and help you carry the cats in – I broke out in a sweat just carrying Blackjack from the waiting room to here." We laughed about that, but I sure wished I had known they'd help me with the cats – I think I made my knee worse carrying Blackjack all the way from the parking lot. But they have a sign in the driveway that says, "Do not block the drive," so I assumed that meant I wasn't supposed to stop there at all.

Anyway, the vet had already given Blackjack his shot (I took them in for their annual shots a few months ago, but there is a new vaccine that has only become recently available that they needed to get), and she reached into Tigger's carrier and gave him his too – I was surprised she didn't have to take them out of the carrier. Evidently the cats didn't believe that was all that was involved in this visit, because while I paid the bill, the two of them kept hollering away – they had quite a duet going. It was kind of funny, because usually they're silent once actually in the vet's office. The vet commented that while I was getting Tigger, Blackjack had been at full voice until she reached in for him, and then he started giving "wimpy little meows." I should have told her that I'd be happy for her to remove his vocal cords completely.

While she was giving them their shot, she told me she'd just gotten off the phone with a client who asked if she could bring her German Shepherd in. The vet said yes, and asked when they'd gotten the dog. Turned out they'd had the dog a long time, but had never brought it into her – though they'd always brought their cat in – because the vet has a sign that reads, "Small animals only." LOL! I told the vet that it's possible that I only knew that "small animals," in the vet sense, refers to cats and dogs and "large animals" to horses, cows, etc. because years ago when I first met Gary he took his cat to the vet school's clinic and they had separate clinics for large and small animals. I joked that had I not known this, I might have thought Blackjack too large to be seen by her.

My knee has been worse this week. Unfortunately it seems that adding in new exercises and doing the old exercises with ankle weights, as the PTs told me to do, aggravated it, and it's not much better than it was to begin with. Sigh.

Oh, and as far as the paraplegics and lightbulbs, I don't have a punchline for it. We were just wondering how a paraplegic would be independent and change bulbs like those in our dinette, which are in a fixture that hangs from the ceiling.. Guess you'd have to modify the fixture so it can be raised and lowered.

Apr 26, 2007

This morning I walked down the hall toward my bathroom to cut a piece of soap off from a large slab of glycerin soap I have. Gary met me in the hall and began, "Would you – "

I brandished the knife in my hand.

"Um, what are you doing with that?" Gary asked.

"Waiting for your next request," I replied.

"Oh. I was going to ask you to undo the fitted sheet on the far corner of my bed, but never mind." He hurriedly wheeled down the hallway past me.

I smiled.

(Of course, later I undid the sheet.)

Oh my, it's been awhile. Bet you thought I fell of the end of the earth. I was compulsively trying to finish a project and time got by me. I did take notes of certain happenings on different days, so here they are.

Apr 26, 2007

My knee continues to plague me. I joked to Gary I should drive around in one of those motorized carts when we're at Kroger – with him in his wheelchair and me in a cart we'll look real cute going up and down the aisles like a choo-choo train.

Apr 28, 2007

Gary went to a baseball game on Saturday the 28th, meeting up there with Jack Brown. Gary said it was a very exciting game and they had great seats – the area for wheelchairs was right behind the area for the most expensive seats. Jack brought a lawn chair and sat next to Gary.

I had a follow-up appointment with the knee doc today. It did not make me happy. My knee isn't as good as it was before the physical therapists had me add ankle weights to the first exercises they gave me – that turned out to be too great an increase in exercise, causing the knee to be painful again most of the time. The doctor is going to have me get an MRI. I'm going to continue with the physical therapy, and based on whatever the MRI shows and how therapy goes in the next couple weeks, I'll either simply continue with the therapy, or . . . consider . . . surgery. I don't want surgery, but the doctor seems to be suggesting that my knee won't get to a place where I'll be happy with it unless I have the surgery (this he said after I asked if with just the therapy the knee will ever get to the point where I can do exercises like lunges again). He told me that if I were a twenty-year-old football player, I would've already had the surgery done, and that if I were a sixty-year-old architect, I would probably be happy with where the therapy alone would take it. He said he suspected I was halfway in between the two (I didn't share my thought that I was sure I was more than halfway).

Just when I was enjoying being able to be more physically active . . . :-(

I was able to get a prescription for a TENS machine, and so now I have this small unit with electrodes that I put around the knee and shoot electric currents around it. The technician said it causes the nerves to "flatten" (his words), so you don't feel pain. I am suspecting it's just a distraction device – I don't notice the pain because my attention is on the pulsing of the electric current :-)

The chiropractor has been doing something similar to the TENS on my sacral region, and she said I could put the TENS electrodes the same places she has been putting her electrodes. Too bad you can't sit on the electrodes – I'd go around all day with my butt wired.

Gary jokes I should get a bunch of the TENS units and hook them up all over my body. Or maybe that wasn't a joke . . .

I do know you're not supposed to put the TENS electrodes around your heart or on your head, but I'm thinking it could only improve matters if I scrambled my brains. (Just kidding.)

May 3, 2007

We are watching "The Men," about paraplegic war vets. Not absolutely sure of the accuracy, though they said they were going for it. Some of it was definitely overly simplistic ("the patient's bowel and bladder functioning have now been regulated"). The patients were in their therapy a LONG time ("It's taken you three years to get to this point"), but evidently that was true that the patients were in the hospital for longer periods then – insurance didn't kick them out. Also, there was no differentiation between level of injury – everyone we saw had their abdominal muscles and were apparently capable of climbing up a rope.

Of course, I think it was meant to be partly a "message movie," that paraplegics could be contributing, productive members of society. The doctor portrayed in the movie was evidently based on the real-life pioneer who worked in getting the patients back into functional shape for society. And a group of paraplegic vets in Chicago were pioneers too, taking it upon themselves to push for rehabilitation rather than just being left to languish in hospitals.

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My sister Janet sent me these pages from a dog and a cat's diary. I have sent them on to a few people already. Amazingly, the dog people seem to think the entries favor the dog!

Excerpts from a Dog's Diary.....

8:00 am - Dog food! My favorite thing!
9:30 am - A car ride! My favorite thing!
9:40 am - A walk in the park! My favorite thing!
10:30 am - Got rubbed and petted! My favorite thing!
12:00 PM - Lunch! My favorite thing!
1:00 PM - Played in the yard! My favorite thing!
3:00 PM - Wagged my tail! My favorite thing!
5:00 PM - Milk bones! My favorite thing!
7:00 PM - Got to play ball! My favorite thing!
8:00 PM - Wow! Watched TV with the people! My favorite thing!
11:00 PM - Sleeping on the bed! My favorite thing!

Excerpts from a Cat's Diary....

Day 983 of my captivity.
My captors continue to taunt me with bizarre little dangling Objects. They dine lavishly on fresh meat, while the other inmates and I are Fed hash or some sort of dry nuggets. Although I make my contempt for The rations perfectly clear, I nevertheless must eat something in order to keep up my strength. The only thing that keeps me going is my dream of escape. In an attempt to disgust them, I once again vomit on the carpet.

Today I decapitated a mouse and dropped its headless body at their Feet. I had hoped this would strike fear into their hearts, since it Clearly demonstrates what I am capable of. However, they merely made Condescending comments about what a "good little hunter" I am. Bastards!

There was some sort of assembly of their accomplices tonight. I Was placed in solitary confinement for the duration of the event. However, I could hear the noises and smell the food. I overheard that My confinement was due to the power of "allergies." I must learn what This means, and how to use it to my advantage.

Today I was almost successful in an attempt to assassinate one of My

tormentors by weaving around his feet as he was walking. I must try This
again tomorrow -- but at the top of the stairs.

I am convinced that the other prisoners here are flunkies and Snitches.
The dog receives special privileges. He is regularly released - and
Seems to be more than willing to return. He is obviously retarded. The
bird has got to be an informant. I observe him communicate with The
guards regularly. I am certain that he reports my every move. My Captors
have arranged protective custody for him in an elevated cell,
So he is safe.
For now...

May 8, 2007

Gary went to the urologist. Despite the medication that was supposed to make him stop leaking, he never did. The doctor took a urine sample and said he had another UTI. The plan is to knock that out with a rather strong antibiotic, and if it appears again, knock it out again immediately. If the UTIs persist, the doctor is suggesting Gary take a low-level antibiotic daily – from now on. Before resorting to that, Gary plans to looking into which would be worse, to be on the antibiotic continually or to have the UTI continually. There doesn't seem to be anything he can do to prevent having these infections – he is doing the catheterization for the ICs as he is supposed to. The Bridge Program nurse told him some people are just prone to them.

May 12, 2007

I noticed something called "shea butter" (made from the fruit of an African tree) at the local health food store awhile back. Gary has been wanting to try something other than what he's been using to "grease" his flap. He's had various problems in using vaseline, xenaderm, Eucerin, and so forth – getting rashes or fungal infections, or the skin looking dry, etc. So we've been using the shea butter on it, as it claimed to be good for the skin) and so far it has been working better than the other stuff – the area has been staying moisturized having no skin problems.

May 14, 2007

Went to the doctor for the results of my MRI. After an hour and a half wait, I got the bad news – torn medial meniscus (knee cartilage). The doctor says it's not harmful and doesn't lead to arthritis, but neither does it heal. So the two options are 1) to keep the knee in good shape through rehabbing it, keeping the muscles strong and flexible, and live with whatever annoyances it might cause (he says the pain comes when the piece of torn cartilage gets in the groove of the knee, and it might not always be there – it may just move there when the knee is put in certain positions; unfortunately my pain is pretty constant, and more than annoying, the worst thing being it interferes with getting a decent night's sleep) or if one can no longer live with the pain or the restrictions of activity, 2) arthroscopic surgery, where they remove the torn cartilage.

The doctor says people usually take 3-5 weeks for recovery from the 30 minute operation and then can be as active as they want; the recovery is from the soreness and healing after the surgery, and it's impossible to say how long one is going to hurt or how quickly one is going to heal. Gary had this surgery a few years back, and it took him 6 months to recover, so he isn't advising me to rush into it, says the surgery is, as understatement, "no fun." Me, I wish I could hide my head in the sand and have the pain go simply go away.

(And FYI, sister Janet, since you wanted details, he says that for particularly bad spells I could get a cortisone shot for temporary relief. He also says the knee doesn't "miss" the removed cartilage, as only about 10-15% is removed, and so the knee will be no worse off.)

May 15, 2007

Gary is looking forward to this weekend's Adventure Skills Workshop. He still wakes up at 3 a.m. worrying about the time factor, making it from one activity to the next. He finally decided he'd just do as many activities as he can and not worry if he can't do all he'd like to do. Then he woke up at 3 a.m. worrying he wouldn't make it to lunch in time from some activity. I told him to pack a sandwich. :-)

He isn't sure he's going to be physically able to do all the different activities. He kept bringing up waterskiing as a case in point. I couldn't figure this out until I realized he'd forgotten that in the movie we saw of the Workshop while at Shepherd, they show that the waterskiing is done sitting down on a wide "ski." I started laughing, asking him, what did he think, they expected the paras (paraplegics) and quads (quadriplegics) to stand up and balance on regular skis? In which case they were probably scratching their heads each year why so few people signed up for this activity!

He also isn't sure about rugby. He thought the quads would have a definite advantage. This got us into some more dark humor laughing, where I commented that yeah, all they'd have to do was aim their three hundred pound chairs at the lightweight Quickie chairs the paras use – but I also noted that once a quad goes down, he's down! So all the paras would have to do is gang together and take aim at each quad one at a time . . . .

May 18, 2007

Gary's Big Adventure

We got to the camp about elevenish. It was not an easy push to get to the registration hall. I joked Gary should get a merit badge for making it, and after taking several rests, Gary joked, "I'm pooped, let's go home." In the hall, Gary picked up his registration folder and signed up for a few of the activities (it's not necessary to sign up for some of them, for example, canoeing, because they figure they have plenty enough canoes to accommodate any takers). For today's activities, Gary signed up for jet skiing and "Confidence Course," which involved climbing up a vertical wall and then zip lining from the tower to another tower. Tomorrow he's signed up to do waterskiing.

Gary asked one of the people doing the registering how far apart the various activities were. The guy said most were fairly close together but that others (maybe the rifle range? I forget) were "a fur piece." Love those Southernisms.

After signing up, Gary did an I.C., and then it was off to lunch – refried beans and hamburger tacos. In the dining hall his inpatient PT came up to greet us, as did his RT (rec therapist). After lunch, it was time for Gary to change into his swim suit. Unfortunately, there really wasn't a good place for him to change – since we weren't staying overnight, we didn't have our own place, and although he could've gone into the "male cabin," I couldn't go in to help him, and it would take him too long to change by himself. So, we ended up changing him in the car. Which would have been far easier if my knee wasn't preventing me from getting in certain positions. I changed too – wore some oversized IVY CREW swim trunks that I had bought him in Birmingham and which he never used, and also a tee shirt. I asked him I looked okay in them. He said I was no more handicapped than anyone else and then talked as if he was making an announcement: "Peg is sartorially challenged." Funny guy.

Next we made our way to the jet skiing. Unfortunately we listened to the wrong people in getting directions to it (note to camp organizers: make signs!). We traveled down a gravel path, which was quite a challenge to Gary, very tiring. He was not looking forward to coming back on it – that was going to be even worse since it would be uphill! He told me that if it weren't for my knee he'd be asking me to help push him. I told him I'd been watching him struggle and that if not for my knee I would've already offered to help. I did then give him a little bit of assistance.

At the jet ski landing, Gary was required to pass a swimming test. He and I greased him up with sunblock, and then they put a life jacket on him. They wheeled him in his chair backwards down toward the water, and even getting the chair into the water a little bit. Then a couple people did a two-man lift on him and put him in the water – by his intake of breath you could tell it wasn't bath water temperature! But he said it really wasn't that bad after the initial plunge. His test was to roll onto his stomach and hold his breath for 20 seconds with his face under water and then roll himself over onto his back. The staff person told him that if he had trouble holding his breath 20 seconds, he could breathe. I laughed at that; the staff person didn't seem to know why I thought that amusing. Anyway, he passed his test fine – but there was one problem. They didn't take him deep enough in the water and when he rolled over he scraped his knee. They stuck a bandage on it and told him not to worry, there weren't any sharks in the lake.

Next he was lifted onto a jet ski, and one of the staff climbed on behind him. She showed him the controls, and the two of them went off on idle until he reached a certain buoy far enough out, and then they zoomed away! I watched a little bit, but they went out of sight for a while and I couldn't keep track of which jet ski was his. I asked how long they'd be out and was told a half hour. I then wished the van wasn't so far away so I could get my laptop and start writing some of this and if finished with that, work on my story (I am not one for idle time). But it was too far so I tuned into a conversation being held near me. One of the conversationalists was the father of a young man who was being put on the next jet ski. The son had broken his neck in a motorcycle accident three years prior – an SUV plowed into him, and in fact landed on top of him and they had to call in special machinery to lift the car off him. He regained some use of arms and legs, as is not that atypical of incomplete cervical injuries, but I'm not sure how much use of his limbs he has as I didn't see him moving. He is going to China and having a stem cell operation – $30,000. (When I later told Gary this, he said he would want to wait until it's more proven a treatment and is afraid such people having it now may be being taken – but on the other hand, are serving as guinea pigs for "the rest of us.")

I saw Gary coming back in on the jet ski, and I was surprised because his time wasn't up. Then I heard someone yell and ask if I wanted to ride behind him this time. I yelled, "Sure!" I went down to the water and climbed on. We started going on idle, and Gary told me that he'd gotten up to 45 mph and it was scary-fun when going over the waves at that speed. Then we passed the buoy and took off, and I was . . . petrified when we hit those waves! There was nothing to hold onto except for him – believe me, I kept trying to reach out and grab the handlebars but they were too far away, and there was nothing to grab onto on the seat, and I couldn't squeeze the seat with my knees like I was on a horse – and I kept thinking, here I am hanging onto him for dear life, and he has no abs nor legs and I'm afraid I'm going to pull him off! But if I didn't hold onto him as I tight as I was, I was afraid I was going to go flying right off the jet ski! Scary fun indeed. He told me his hands hurt after from gripping the handlebars so tight, and I told him I was glad he WAS gripping them that tight.

When time was up, we went back to the landing. We were at a slight incline, sloping down toward me, and as I started to get off by sliding backwards Gary suddenly falls over backwards and lands on my head! After we got off I asked him what had happened, and he said he took both hands off the bars to remove his life jacket, and as soon as he did, he had the thought, "Oh-oh, I shouldn't have done that." I suppose it was a good thing my head was there for him to fall onto.

By the way, saw a funny T-shirt a guy was wearing: "Seen it all, heard it all, done it all. Just can't remember it all."

I asked Gary what he wanted to do next. We were right next to the canoeing and kayaking. But he said that after gunning an engine, that stuff was too tame. So we took a leisurely return to the van – fortunately we found out there was an alternate paved route to it! He didn't have another scheduled activity for over two hours and somehow about an hour and a half of that disappeared while we made our way back, had snacks, and changed Gary's clothes. (Actually, I wasn't a complete idler during this time and during his ICs. Yesterday I had jotted down ideas that had come to mind for a different final scene to my mystery story (a scene I had written long before most of the first draft was written and which didn't quite satisfy me) and I had enough time to sketch it out more fully; I think I like it better than the other versions I've had for this scene but won't be able to say for sure until I get it fleshed out.) At one point we were laughing because someone kind of peered into our van, I guess to see what the interior looked like, but the sun must have been such that they couldn't see we were in there. At the time, Gary was sitting in his wheelchair with his pants on only halfway up, eating a power bar (to give him the energy to get his pants up the rest of the way, I joked).

He said he was very unconfident of the upcoming "Confidence Course," since he couldn't see how he was supposed to climb a vertical wall. Well, they put him in a harness, knee pads, elbow pads, and helmet, then hooked him up to climbing equipment, and he went up a rope hand over hand. Staff members hung onto the other end of the pulley system so he wouldn't lose any ground. It was a four-pulley system, so at each of his pulls he was in effect only lifting a quarter of his weight – but also only going a quarter of the length he pulled (that is, if he pulled three feet of rope on the pulley, he traveled only 9 inches). There were protrusions with handholds on the wall, but they were of no help to Gary, he said. The guy ahead of him had some use of his legs and used the protrusions to help him climb the wall. There was also a climbing "ascender," but Gary said it was hard to use – far easier to just climb the rope. Then they attached him to a zip line and sat him on the edge of the climbing platform. He said this was the scariest part, because he couldn't feel them holding him – though he assumed they were because they'd probably get in trouble if they dropped him. Next he went flying through the air, gravity taking him down the inclined cable. After he had gotten to the top of the climbing tower I had made my way as quickly as I could to the other tower to watch his flight. He went fast! (Unfortunately, I didn't get to do this.) I had forgotten to bring my cell phone so I couldn't take a picture, but a staff member did, and hopefully he'll remember to send it to me so I can post it on the blog.

His old PT was there to cheer him on, and afterwards she asked me, "NOW what are you taking notes on?" She laughed and asked how many memo books I had filled at Shepherd (two or three, I forget).

Next Gary did an IC, and then it was time for dinner, which is probably best not gone into ;-). They told us at the dinner that there were 59 participants, 60 family members, and about 70 staff and volunteers there for the workshop.

There were more activities in the evening, but we went straight home. Sure am glad we're not in those group cabins – there will be people getting up for 5 am fishing! And we heard the cabins are cold.

The weather was perfect for the activities – it could've easily been too hot with the weather we've been having lately. And because it hasn't rained recently, the water was a pleasant temperature, though it might've been slightly too chilly in the morning. Which is why Gary didn't sign up for waterskiing tomorrow until the afternoon. He hopes to ride an ATV in the morning. Golf seems to be only an evening activity, so he won't do that at all. Rugby is only for the quadriplegics, so he won't have to worry about that (I guess that's to make sure the chairs are evenly matched).

We were hoping Gary's redneck roommate would show up at this, but he didn't.

The adventure continues tomorrow.

May 19, 2007

Gary woke up sore, but not too sore for day number two of the adventure!

We got there somewhat before ten-thirty. As Gary pushed his way up the incline in the direction of where the activities he was interested in were being held, he recounted a conversation he had yesterday with his former PT, concerning a man his doctor had wanted him to speak to at the end of Day Program in Dec. The man was down about his condition and dubious that he was going to be able to do transfers and so forth on his own. But apparently, by the end of being an inpatient, he had learned this skill (not sure to what extent, since Gary needed assistance months after he was discharged as an inpatient). The man had also thought he was going to stay in a power chair, but evidently insurance wouldn't pay for it and he ended up in a manual chair. "I don't understand," Gary said as he was puffing up a hill, "why anyone would want to want to be in a power chair unless he was too weak to operate a manual chair." Gary then stopped and sat with his tongue hanging out, breathing hard. I gave him a look, and we started laughing. There are certainly some situations where he might be tempted to use a power chair!

We headed for the ATVs. All the utility vehicles, which are enclosed and thus offer lateral support, were taken, and there was a line for them. Though those would be safer, Gary didn't want to sit around and wait, so one of the staff said they'd put him on a 4-wheeler, which is open, like a jet ski but on land, and see if that was a possibility. So they lifted Gary onto the 4-wheeler, and the guy sat behind Gary to provide support and kept his own hands on the handlebars with Gary's to keep the vehicle steady. I asked how this differed from jet ski operation, and was told this was much more difficult for someone with Gary's level of injury (and higher), that with the turns he would have a tendency to slide off. The ride is much more rough, less forgiving. Sudden ruts could throw him, since he has no muscles to keep himself upright.

So, they put a helmet on him and he took a slow ride. Which of course didn't make it as fun as the jet ski! I got a picture of him on the ATV, and I will put it on the blog.
http://drpeg2003.blogspot.com/

After his ATV ride, we made our way slowly back toward the bathrooms, where Gary did an IC (while I went to the car and worked on my story), and then we had lunch, Gary in the dining room, me in the van (too long a haul to carry my stuff there), where I also worked on my story some more.

Oh, and I had a question while we were walking around. Why is it that no matter which way we put our name tags on, which hung on a string around our neck (the tag having only one hole punched into it), our names never faced out? No one's name ever faced out! What made it so the tags always chose to fall face down!?

Anyway, next we were off to the waterskiing site. The special ski was like a wide slalom ski with a frame or "cage for the butt" in the middle of the ski that they plunked Gary down into. His butt was lower than his legs, and the sides of the cage held him firmly in place, though not so firmly that it would keep him in place if he "wiped out." To start off, they told him to bend forward and hang onto the frame down by his ankles. (His feet were put in a large rubber foot holder similar what is found on a regular ski.) Once he was "up and running" behind the boat and felt he had his balance, he could reach for the ski rope in front of his feet and pop it free of the slot it was being held in (by a knot in the rope), and then ski along like a seated water skier. A group of volunteers picked him up on the ski (like an emperor in his litter ;-)) and put him in the water. Meanwhile, I went over to the boat dock and got on the boat that was going to tow him. We got situated, and the boat slowly picked up speed and when the slack was out the volunteers let go of his ski, and he was cruising! After only a minute or so, he got brave and reached for the rope, and he was a skier! It was really exciting to watch. We cheered him from the boat, and it was really obvious he was having a great ol' time – a grin split his face from ear to ear the entire time he was out there! We kept trying to signal him to go over the wake, but he kept ignoring us ;-). The driver was a little "mean," and gave him some rough water occasionally, and slowed down and speeded up, and curved from side to side, but Gary never wiped out. Oh, importantly for the sake of his mother's heart, I should mention that the entire time a jet ski stayed close behind him in case he wiped out. Since he had passed the swim test, there should have been no problem if he did wipe out, but in any case, the jet ski would have been at his position in seconds and people would have jumped into the water off it to make sure he had righted himself, and to help him back into the ski. I asked the driver of the boat how often people wiped out, and he said if they were daredevils, they did it often.

Since we couldn't persuade to get Gary over the wake on his own, the driver did a sharp turn that forced Gary over the wake, and he zoomed over it just fine. Oh, and I should mention that the driver of the boat was a C7 complete – a quadriplegic driving the boat (that made me feel safe ;-)). The guy obviously had fairly good use of his hands, but not for fine motor coordination.

Anyway, Gary never used any hand signals he was given (thumbs up for "go faster," thumbs down for "go slower," a slashing motion at the neck for "I'm in trouble, stop," and patting the head for "I'm tired, take me in"). The people in the boat wondered if he'd been taught the signals, and I said he was, but using them assumed he was brave enough to take one hand off the rope – and it turned out that was exactly the reason why he didn't use any of the signals! I think he might've skied for fifteen minutes or so, and then they headed him toward shore. I saw them toss the rope off the boat, and I saw Gary go down and flip over and try to right himself. A bunch of people then converged on him, so I don't know if he made it over on his own before they came to help.

Anyway, he said it was a blast, the most fun thing he'd done. And he was so excited about it that he's thinking of going to a waterski clinic later this summer. Only, we don't know how far away it is (it's at Lake Lanier, in Georgia).

Next, we decided to head back to the jet ski and ATV areas to see if he could do one of those again. Turned out there was a cancellation RIGHT THEN for the jet ski, and since on Friday Gary got rated as independent on it, we got to go out by ourselves for 25 minutes! On Friday I only got to be on it a total of 6 minutes! I was a little more used to it, but it was still on the scary side – until I discovered a strap on the seat (either I hadn't noticed it yesterday or it wasn't on the jet ski we used yesterday). Well, once I discovered that strap, I was ready to cook! I hung onto Gary with one arm, gripped the strap with the other hand, hugged the seat with my thighs, and told Gary to let it rip – in particular, I told him to aim for the waves. When we would go over some big bumps I would still let out a yell and bounce right up from the seat, but I wasn't worried about flying off or taking Gary with me as long as I had that strap. Anyway, that was exciting and definitely the most fun *I* had, though a close second was watching the thrill Gary was getting while waterskiing.

After that, I asked if Gary wanted to do anything else. It was only 3 pm and dinner was three hours away (and the Daniels philosophy is, if you've paid for an outing, by God you're going to get all the fun out of it you can even if it kills you.) Gary pointed out we didn't have all that time to kill, however, since it would take him an hour and a half to wheel back to the van and change clothes. (And that wasn't all that much of an exaggeration.) So, we went back to the van and he changed, me helping when requested, and the rest of the time I worked on the story idea I had had yesterday. That took us to about 4:20, but Gary didn't feel like doing anything more. I gave my laptop to him and he read some stuff I had written, while I meditated. Rather, I fell asleep.

That took us to IC time, and then it was off to the steak and chicken banquet before going home. At our table at the banquet was a quadriplegic who had a very high level of injury; he was there with his mother. All I could think of was I was so glad Gary's injury hadn't been that bad. I felt terrible, but I could hardly look at the guy – his food falling out of his mouth, him taking agonizingly long to form a single barely understandable word. I kept looking elsewhere so he wouldn't try to hold a conversation with me. I did exchange a couple of words with him – I asked his mom what the previous night's social had been like, and he chimed in "Ice cream," and I repeated "ice cream," like I was talking to some backwards child. And I'm sitting there thinking, what must he feel, people ignoring him, him not able to communicate very well. I told Gary afterwards that I felt bad saying this, but I was so glad he hadn't been injured like that, and he said he too had felt guilty but hadn't been able to look at the guy. And we're in better position than most to know what his life must be like.

Well, that was the end of our adventure weekend. Gary didn't want to travel there and back for the Sunday morning activities. He wants to do it again next year, probably try some different activities. But I bet he'll want to waterski again!

I didn't get around to typing this up yesterday, and indeed spent much of today finishing fleshing out the story idea from Friday. Then I decided that while I had indeed made the final scene longer and brought together some earlier elements of the story, it was now a boring finish! So, I tossed it out, went back to the old version, cut out ten more lines from it, and now like it.

Oh, well.

May 22, 2007

Van or car in Nebraska.

If not for his accident, probably never would've gone waterskiing for the rest of his life.

Thrills and Spills.

Jun 2, 2007

"Look at me!" Gary cried. I looked up from where I was lying on my bed using my laptop to see Gary wheeling up to my bedroom door naked. No, he didn't want me to admire his guns (biceps), but I knew immediately what he was crowing about. He had been in the shower, and the fact that he was now out meant he had done the shower transfer not only without me sitting close by watching but without even telling me. Actually, I had thought him capable of doing so quite some time ago (the only "mistake" he makes on that transfer lately is that he occasionally hits his head on the shower wall because it is so close), but evidently this was the first time he was willing to do it on his own.

So now he can do on his own all the transfers that he normally has to do in the course of a week!

This is not to say that there won't be the occasional mishap. For instance, what happened this evening, June 5th. We finished our recreation time, during which we watched some of the movie "Murderball" while Gary did his stretching and I did my knee therapy, and then I went to take a bath. While I was running the water, I heard Gary yell out my name. I went running into the living room and found him on the floor instead of in his wheelchair. Well, I guess they warned us this would happen sooner or later. He said that while he was doing his transfer from the futon to his wheelchair something about it felt off, but he thought it would be okay. Obviously it wasn't. Fortunately he fell slowly, so he says, and he doesn't think he hurt anything. I was worried at first, thinking how was I ever going to help him get back in the chair, because a) we haven't practiced a floor-to-wheelchair transfer since Day Program, and worse, b) my knee is most likely too screwed up to be able to help him like I did then. Fortunately both he and I quickly realized that the way to go would be to get him back onto the futon. This actually went fairly easily, similar to the floor-to-platform transfers we practiced at Day Program. Due to my nervousness about the situation, I probably gave him more help than he needed. In fact, he probably could've done it entirely on his own. He says he is going to practice it some more this summer. He says that for him to be comfortable traveling alone, he would need to be able to make a floor-to-bed transfer on his own. I told him I wasn't so sure he wouldn't want to be able to do a floor to wheelchair transfer on his own since there won't always be a bed convenient.

Anyway, as he said when he was back on the futon, "Well, that was exciting." He said he was glad it had happened, actually, because it gave him the confidence that he can handle a situation like that.

Speaking of "Murderball," it is a very good documentary about quad rugby, which originally really was called "Murderball," and when you see these guys racing around on the court in their Mad Max wheelchairs, you know why – one of the strategies is to knock your opponent's chair over (I told Gary not to get any ideas about competing in a sport similar to it! I am absolutely sure they didn't play anywhere near that rough at the recent quad rugby sessions at the Adventure Skills Workshop; next year we'll have to stay in the evening to watch a little bit of it). The documentary mainly focuses on Team USA and the few seasons up to and including the Athens 2004 ParaOlympics. It wasn't purely about the sport action (fortunately); in fact it was more about the people – it interwove the lives of the players and one of the coaches (formerly a Team USA player who became embittered after being cut for the team and went on to become the Team Canada coach, handing the USA its first ever losses) – it goes into a little bit about what their lives were like before the accident, how they learned to cope and excel. Gary's one disappointment about the documentary was they show a quad getting his trousers on while sitting in the chair, but they stop showing it at the point where he gets them up to his butt – Gary wanted to see him get them all the way on to see if he could pick up any pointers! (This is another thing he hasn't practiced since Day Program; so little time, so much to do). We also thought it strange that they seemed to indicate that quads have no problems with their sex lives, that at most only an adjustment in position is all that's needed. True, these guys were all "incompletes," but the feeling both Gary and I got from

Shepherd was that even in that case sexual functioning was not a given (seeing that these were all fairly young guys – and I think it's safe to say "macho" guys – on the rugby team, it was a major concern for them).

On a completely different topic, our next adventure will be our trip to Nebraska in a few weeks to Gary's mom's. The entire clan is going to be there – all the brothers and sister and nieces and nephews. I am hoping my knee isn't going to be a problem. I confess to being worried about getting our luggage there and about transportation. Gary found out we could rent a wheelchair-accessible van that I would have to drive (the longest distance being the two hour drive between the airport and his mom's home), or a car that has been modified so he could drive it, but then I would have to put his wheelchair in it (and put it back together again). Unfortunately, dammit, I just can't bend my knee without significant pain, and I don't know how I could lift his chair in and out of a car.

Jun 6, 2007

Forgot to mention, went with Gary to the eye doctor yesterday. Everything went fine – he was able to transfer into and out of the examination chair by himself. The only thing he needed me for was I had to tell the doctor his rolling chair was on Gary's foot and would he please move it off!

Gary has been concerned about the pressure in his eyes – evidently there has been problems with that in his family – but his pressure was lower than it's been for several years. He guesses this is perhaps due to his spinal cord injury, since due to it his blood pressure is lower than it used to be.

We started a new movie tonight – "The Aviator," about Howard Hughes. The beginning part of the movie deals with Hughes making his movie, "Hell's Angels." Hughes wants every detail right, hires a meterologist to find him the clouds he wants, rebuilds the planes so they're perfect, shoots reel after reel. When they think they're done with the movie, "talkies" debut, and Hughes re-shoots his entire movie. Evidently the press mocked him throughout this, at one point saying Hughes should just show what he's got and debut the first 560-hour movie. At this point, Gary remarked, "This whole thing reminds me of your novel." Smart aleck.

Jun 8, 2007

Wheelchairs and semis don't mix:

http://news.yahoo.com/s/ap/20070608/ap_on_fe_st/odd_wheelchair_truck_ride

Jun 13, 2007

At the student activities building gym they have gotten new equipment – hand cycles. Gary used one for the first time today, and he says it was tough, perhaps partly because he did it after the weight training. He could only go for six minutes on it. He said it reminded him of when he'd had to do it at Shepherd, and it had been so difficult for him. I said I remembered that – his tongue was always hanging out after each interval on it. (The hand cycle is more tiring than a bicycle because of the less muscle mass of the arms.)

The other day when I was backing my car out the driveway to go to a flat area to do a short walk, I saw Gary start to wheel down the drive. He had commented to me a few days earlier that he hadn't attempted to go partway down the drive for a long time, at least since last Day Program in December. I wondered if I should stay at the bottom of the drive, but he didn't wave to me or anything, so I decided to go for a 15-minute walk and scrape him up off the street when I came back ;-). No need to worry – he didn't attempt to go down the steepest part of the drive by himself. He said he went as far as he'd gone with me before, but it was still too scary to attempt to go any farther. He said he would first attempt to go up it before he would go down it, since uphill would be the easier direction. I said, "What do you mean? Downhill is easier – you just let go!" We then joked about him going flying down the street, since it is downhill all the way; he said I would have to scrape him off the lawn at the end of the street (our street has a T-intersection with the next one), because he wouldn't be able to do a wheelie to get up the curb. I told my massage therapist this, and she pointed out that if he hung a left there, he could keep going because it was still downhill. I realized he could then make a right onto the next street, then a left, then another left, until he would finally hit an uphill part, at which point he could go back and forth, back and forth, like a pendulum winding down. He said that unfortunately he would then have a long upward trek back home – assuming he hadn't crashed well before then.

In about 10 days we are flying to his mom's. A wheelchair-accessible van proved to be too expensive and inconveniently located for us to rent (plus it wouldn't be modified for him to drive). So we are renting a modified car. I plan on corralling anyone I can to put his wheelchair into and out of the car for me, since I am worried about how I can get it in myself without hurting my back and/or knee. I already mailed to his mom's house a few boxes of things I would need, and Gary mailed some medical supplies.

We have finally gotten around to watching last year's TV program "24," which we had started but not finished before Gary's accident. Gary said he remembers that the first day of his accident, when he found out he was going to be paralyzed, he tried to tally up all he would still be able to do. He said one of the first things he thought of was that he'd still be able to watch "24"! I remember him being very concerned about that, and when I said something about it on the blog – or actually, I don't think I had started the blog then, it was all done in emails – anyway, Gary's brother Bob and Jim from my critique group both arranged to tape it for us. We are now enjoying it as much if not more than we did the first time around. Even though we've seen the part we are watching now, the tension is no less (perhaps helped by our bad memories ;-)). In fact, since we know some of how the plot plays out, we can appreciate the intricacies. As Gary says, the show is certainly well-written, something always happening!

After saying that, Gary then said something that made me feel great – he said he hoped they make my novel into a movie, that he thinks it would be a really good one. I'm afraid I think the odds of that very slim (heck, I will be ecstatic if it even gets published (heck, if it even makes it through my critique group ;-))), but it was wonderful to hear. But he has a long way to go before he is finished reading my novel, and since I am the insecure type when it comes to my fiction writing (among other things), I am still waiting for the axe to fall. I will momentarily indulge in the good feeling his words cause me now but won't get too happy this prematurely – just in case at some point he doesn't like the direction the novel takes.

Jun 15-16, 2007

After a seminar presentation by Michel on Friday, Gary and Michel went out for a beer. Gary didn't know how he was going to get into the place since from what he remembered it had a sunken floor. Turned out to be accessible. He wheeled into a box-like cage, which lowered him to the level of the restaurant. Almost. The front "flap" of the cage folded down and he had to wheel down that to get to the restaurant. He said the angle of that flap was pretty steep, though, and he needed a running start to get back up it when leaving the restaurant.

On Saturday he recounted how much progress he's made in being independent in taking a shower. Now all I do is turn on his bedroom light for him in the morning and put down the side rail of his bed and hand him his crocs (shower shoes) – I wouldn't have to do the last if he'd remember to put the shoes on his bedside table the night before ;-). He intends to "graduate" to a double bed this summer, so soon I probably won't have to be lowering the rails. I think I have heard of "clap on" lights, and if those are something useful, maybe he wouldn't need me for turning the light on for him in the morning, either, if we ever get those.

So, this is quite different from those beginning shower days, when I would turn on the light, bring him breakfast in bed because the shower process took so long he would perish from hunger if he had to wait to eat until he was done with the shower, lower the rail, put his shoes on him, help him with his naked transfer between the bed and the wheelchair using the transfer board, help him make his transfer to the shower bench ("Hips or butt?" used to be my question to him, asking whether he wanted me to put my hands on his hips or under his butt in helping him transfer from one surface to the other), wash and dry his legs and feet for him, help him with his transfer back to his wheelchair, struggle to put those damn thigh-high t.e.d. hose on him, moan and groan in getting his abdominal binder on him, toss him from side to side and help him get his pants on him.

Jun 17, 2007

Oops!

In the evening Gary decided to practice a floor-to-futon transfer before starting his stretching. "Let me know if you want help," I called from my bedroom (where I was of course working on my story). "I will," he replied. Next thing I hear is him making noises indicating something definitely did not go as planned. I ran out to the living room to find him on the floor on his side with a little blood on his forehead and nose. I made sure he was reasonably okay, and then he told me that in getting down from the wheelchair by leaning forward and walking on his hands along the floor his body dropped too fast for his hands to keep up with and he hit the floor with his head. Ouch. I got some skin wound cleanser and cleaned off the blood and stuck a band-aid on his forehead vertically because it was a long cut, then he was ready to try to get on the futon. My goal was to help him as little as reasonable, because the last time he made this transfer, after accidently falling, I had strained my back a little in trying to get him up. I am afraid I am less able to help him than before I tore my meniscus, so it's a good thing he doesn't need my help as much as he used to. This time I just kept his butt in place since his position caused gravity to want to topple him to the side, but I did no lifting. As a result, he had to exert more effort than that last time, but he got up on the futon successfully. I then reviewed in the blog I had written last December that when he/we had practiced getting from the wheelchair to the floor, I had knelt next to him and kept my hand under his chest and walked on my knees as fast as I could next to him exactly in order that he not hit his head on the floor. Oh, well. Since he had gone down smoothly when he accidently ended up on the floor, he hadn't expected it to be a problem this time.

So now he has "road burn" on his forehead and nose. Great, just in time for our trip to Nebraska. Hopefully it will heal enough so his mom doesn't think I've been derelict in my duty ;-). Gary assured me she would know it isn't possible to always protect a person who would ski off a barn when a kid.

Jun 19, 2007

Let's try that again . . . .

Gary wanted to try the floor-to-futon transfer again. This time I started off like we had done at Shepherd – I put my hand under his chest and kept it there, giving him support, until he had gotten from the wheelchair to the floor (I couldn't get down on my knees like at Shepherd, but stayed in a crouch). He "complained" I gave him too much support, but hey, I didn't want him to bonk himself on the head again. I did let him do all the rest by himself, the getting himself up on his knees by pulling on the futon and pulling himself up onto the futon. He did notice my lack of help then, saying it was much harder this time than last, but he did it! He was delighted by that.

Jun 21, 2007

Gary remarked that it was just about a year since he last saw family. He said hopefully they'll think he looks in better shape. Presumably they will. He was still being hoyered at the time, not having yet having learned or being strong enough to transfer out of bed by himself. And a short wheel down the hall would tire him out.

I reviewed my notes on last July's blog about Shepherd's airport outing. I also went on the TSA site to look at the prohibited items list – my last airplane flight was several years ago. I learned I'll have to leave my brass knuckles at home (I use them to keep Gary in line). And that I'd better not make any jokes about terrorism.

Jun 23-4, 2007

Today we traveled to Omaha. Gary had to get up at 5:45 in order to be ready to leave by 9. A few days earlier Gary had called David Martin, Sr. Specialist – Disabilities, Delta Airlines – that's the guy who had "shown us the ropes" when we went on Shepherd's airport outing – and he had suggested we park in the West lot, so that's where we went. Luckily, just as we were driving around trying to figure out how we were going to get to the terminal from there, a porter went by with a cart. He said he'd be right back to help us. So Gary parked and I unloaded our baggage and the porter returned quickly. He loaded the baggage and led the way to the terminal. Fortunately it wasn't too far of a push for Gary – not that it was all that close, either! The porter was very helpful, showing us how to get our boarding passes from the kiosks, and then he accompanied us to the baggage check-in. After that, Gary did an IC in the men's washroom (while I whipped out my laptop in the women's washroom and worked some more on my story). Next came security. Definitely not the relaxed affair it had been when we were on the outing. It was crowded, and I ended up not only being responsible for my stuff on the conveyor belt, but for Gary's, ,and I found it frazzling to keep track of everything. It didn't help that my carry-on had to go thru twice because I didn't take my laptop out of it. (I have only flown twice in the past dozen years, and I forgot the laptop was supposed to go into one of those bins separately.) And the security lady asked who the 4 oz. tube of KY belonged to. Well, Gary was nowhere in sight, so I said it was with me and she said it couldn't go thru security because it was over the 3 oz. limit. I mumbled something about thinking Gary had to declare it, then finally saw Gary and told her to talk to him. I found out later he told her it doesn't come in any size less than 4 oz., that he needs it to do Intermittent Catheritization, and that he'd already used at least half of it, so it was under 3 oz. :-). She said okay, but I guess there's no guarantee that that story will work in the future. I asked him later if security had made him lean forward and shift from side to side so they could check in back of and under him, as they'd told us on the airport outing they would do. They did make him lean forward so they could check behind his back. But they didn't check under him. Worse, in terms of security, they didn't check the pouch that is under the front of his chair and where he keeps the tools for the chair. They did, however, take out the hard copy pages of my novel that Gary brought along to read, and they ran those pages through the x-ray machine. I guess they wanted to make sure I hadn't written anything explosive.

We got into the train all right, and although I was nervous about Gary being able to get off all right with the crush of people surrounding us, people were very nice and he had no problem. As we approached the gate, a man yelled out, "Gary?" Turned out to be someone (by name of "Alex") sent by David Martin to see that Gary got on the plane all right. I mentioned that the hard part so far had been the getting from the car all the way through security, but of course got a "not my responsibility" smile (I'm not complaining about that). The plane was 45 minutes behind schedule. It turned out a tug had tipped in front of it (I assumed this meant a tug pulling the plane, but Gary thought it might mean that vehicle that carries baggage, so I don't know), and that delayed matters.

It was a very small jet ("sardine can" came to mind), and we had to get on it by going out to the tarmac. Before anyone else was let on, Alex and a strongly built woman came to escort Gary and me on. Gary accepted being pushed, no doubt so we wouldn't hold up the rest of the boarders. We took an elevator and went outside. At the plane they had a ramp set up – I don't know if this is the set-up they would've had had they not been having to get Gary onto the plane. Alex wheeled Gary up the ramp. Near the top of the ramp, Gary was transferred (two-man transfer by Alex and the woman) into an aisle wheelchair, then backed into the plane. That aisle was tiny! We were supposed to be in the sixth row, but when the flight attendant asked if it'd be better if Gary was in the front seat, I thought it might be so said "yes." We thus displaced a couple passengers, which caused a bit of confusion later – sorry about that, folks. Alex and the woman two-manned Gary into the aisle seat, which my knee greatly envied. The flight was uneventful.

We were the last ones off in Omaha, of course. This time Gary was two-manned by a rather petite woman and a young guy. Gary told the guy to hold onto his legs tighter. Gary's wheelchair was right at the gate, so they then transferred him from the aisle wheelchair to his own chair. The young man then left and the woman accompanied us. She offered to push Gary through the terminal, but he declined. She asked if she could pull my wheeled carry-on for me, saying she didn't feel like she was doing anything, and I said sure. I added that she could carry me if she wanted, but she evidently thought I was joking. She accompanied us first to baggage claim, and proved how strong she was by carrying all three pieces of our checked baggage (one of Gary's was rather large and heavy, though on wheels), while I resumed pulling my carry-on. We then went to Avis rent-a-car, where Gary had already arranged for a car with hand controls, and did the paperwork. Then she hauled our baggage out to the car for us, helped load it, and helped me get his chair into the car after he transferred into the driver's seat – which wasn't trivial, as he hadn't transferred into that side of a car before. The woman then said goodbye and headed off, but we called her back so we could tip her.

The acceleration on the hand controls seemed to be calibrated differently than on our van – in other words, every once in a while Gary took off like a bat out of hell, and I ended up with my bottle of spring water all over my clothes. Gary said at least that would cool me off. (I also had problems with that accelerator while driving.) He drove about halfway to his mom's and I drove the rest – it was about a two hour drive. We first checked into the hotel, so Gary could make sure he could set everything up conveniently for bowel and bladder programs. After I'd brought everything in and he'd gotten things somewhat settled, we went to his mom's for a while. I ended up breaking down and putting together his chair five times that evening, starting with after he transferred into the car at the Omaha airport, and I tell you, it was a hell of a lot easier and less painful before I messed my knee up.

To get into his mom's, there are four (I think – I don't quite remember) steps to go up. Gary's brother Donne and Donne's son Justin bumped Gary's chair backwards up the steps. I wasn't about to volunteer to help much, with this knee, but I stayed in front of him and hung onto his knees. He then turned around at the top and did a small wheelie to get over the last little step-up into the house – I chided him because he did the wheelie almost faster than I had time to get behind him and he had forgotten he didn't have his tip bars on. I put them on immediately when we got in the house. Gary's sister Norma and her family hadn't arrived yet, but Donne's family – wife Phyllis and children Carissa (a college student) and Justin (high school student) – were all there, as well as Gary's brother Bob and of course his mom.

We talked of this and that for a while: our trips here, what Gary's been up to lately, pet stories (Donne's cat has him even better trained than ours do us, waking him up every day between 2 and 4 am to be let out, this having gone on for eight years I believe he said; everyone else in his family hears the cat scratching at the door, but they all wait for Donne to see to kitty's needs). When we went to leave, Donne bumped Gary down the stairs – he said that was a lot easier than going up them! We got back to the hotel about 9:30. I had lost track of time and couldn't believe it was that late. Fortunately Gary skipped taking a bath, but as it was he wasn't ready for me to make a last check of him until close to 11 (we were pleased to note the trip didn't seem to have had any detrimental effects on his flap). I hadn't had time to fit in a hot bath before then, so I took it then. Then I put an ice pack on my knee, another one under my butt, and a heating pad under my back. Fog rolled through the room as a result. (Just kidding.) A short time before going to bed I had tried to pull the curtains closed, but they didn't budge. So I put on an eye mask and then I put a pillow over my eyes, but I still knew that light was out there. Between that and the elephants that had evidently moved from Shepherd to here, my sleep wasn't all that great so what else is new. I of course shot awake at 4 thinking Gary was calling (he wasn't) and the last person in my hotel room had set the alarm clock for 6, so just about when I'd finally gotten back to sleep that woke me up. I drowsed some more until Gary called me on the walkie talkie about 9.

He then informed me there were some inner curtains that could be pulled in order to shut the light out (peg crosses eyes).

I spent a while working on the blog and stuff, and around noon we met the others for lunch at a buffet in town. After that, Gary and I did a little shopping, the list being zukes, bottled water, and antibacterial wipes. We were a little worried when the grocery store didn't have the wipes, but the nearby WalGreens did.

We returned to Gary's mom's, and as Donne and Justin went to bump Gary up the stairs, Donne noticed the handle on the back of Gary's chair seemed loose. And then it pulled right out. A screw had evidently sheared right off at some point in time. At least that didn't happen AS Donne was pulling on it to get Gary up the stairs – that could've been a very serious problem (as in, control could've been lost of the chair and Gary could've gone tumbling down the steps). Without that handle, it was harder to get Gary up the stairs, though Donne thinks he's figured out a better technique to try next time. Gary will have to call his supplier on Monday and perhaps have a new screw Fed-Exed here so we can put it on, assuming we can get at the place where it needs to go. So tonight when Gary gets out of his chair we will have to look at it and see if the back removes easily. It looked to me like it did, but I'm not sure.

A little while later, the Norma and Wayne and their kids Megan (just graduated high school) and David (in the military) arrived. At some point the talk turned to needing to decide just what Mom

Gruenhage was going to take with her and what would be auctioned off and what would be thrown out (helping her with this move – she is moving to the new place on Tuesday – is the ostensible reason for the gathering of the family at this time). The others, I believe, convinced Mom Gruenhage that throwing the pistols in the trash was not the proper way to dispose of them. Who knew?

Jun 24, 2007

The sorting continued while I went to the motel to rest. When I returned, Gary was looking thru his dad's old money collection. He had pennies from the 1800's, and confederate money – including a paper bill for 10 cents with "Alabama" written on it. None of us knows if this stuff is worth anything, so someone will have to be consulted about it. Gary's dad also had a lot of rationing coupons from WWII.

After dinner at a local restaurant, Gary and I begged off and said we were returning to the motel because we were tired.

Jun 25-30, 2007

I'm afraid I got zonked, and thus was derelict in my duty of blogging, so will try to recall some of the rest of that week's happenings. Mom Gruenhage had to make a lot of decisions about what to keep for her much smaller place, what to throw out, what to give to Goodwill, and what would be auctioned off (the auctioneer later informed her a lot of stuff she had given to Goodwill could have been auctioned off, but I don't think she was too worried about that). Norma and Phyllis helped her with the sorting, while Donne, Wayne, Bob, and the kids did the carrying of boxes and so forth. Gary and I wrapped dishware in newspaper on Monday, and that was about the extent of my help. My various pains acted up more than usual and I slept lousy the whole week, aided by the thundering herd living above me at the motel (surprise, surprise). As a result, Tuesday afternoon I felt a sore throat coming on, and it turned into a bad cold. I stayed in the motel by myself on Wednesday and Thursday. I discovered the juice machine in the motel's dining area, so I drank a lot of orange juice on Wednesday and Thursday. Evidently they had accidently left the machine turned on, an error they discovered on Friday, and I got no more juice.

It was fortunate Gary is so much more independent now. He needed me for a few tasks in the morning and at bedtime, but other than that, when I was feeling too lousy to go to his mom's house with him, all I had to do for him in the morning was break down and load his wheelchair in the car after he transferred into the car, and unload the wheelchair and put it together so he could transfer into it when he returned in the evening. I told Donne I was going to miss him – he was the one who lifted the chair into the car for me all the time. (And as well he bumped Gary down the steps at his mom's all the time, and he and Justin bumped Gary up those stairs all the time.) It was good Gary didn't need me around much, because I would hate for him to get this cold, especially given the extra problem such a cold would cause a paraplegic. So far, he has escaped it.

On Tuesday enough of Mom Gruenhage's house had been sorted through so that she could move her into her new place. After Tuesday's dinner, Gary and I went to see it for the first time. At this time, paving stones lead from the parking lot to the back entrance, but she is having a sidewalk put in, so that will make it much more wheelchair accessible – especially in leaving, when going downhill, Gary's wheels kept getting caught between the stones. The apartment is one-bedroom, with a living room/ dining room area, and a semi-enclosed kitchen off of that. The previous owner had put up something to block the view out of the kitchen into the living room area (and out the sliding glass doors of the back entrance), and we all agreed that was claustrophobic for anyone in the kitchen! So that was taken down and it really opened up the room. (And it would have been weird to be a guest sitting in the living room and talking to your host in the kitchen who you couldn't see.) What I guess would be called the front door led to a hallway, down which were the entrances to the other residences and to common areas, like the laundry room, mail room, and dining room. A dinner is served around noontime every day (for something like $4, I think). Her apartment seems ideal for one person. But she sure had to get rid of a lot of stuff! (You would think that would motivate me to get rid of all the junk I keep, but . . . .)

I think on Wednesday they pretty much finished with the upstairs of her house and started in on the downstairs, and got that finished on Thursday. I rejoined them for a time on Friday so they would know I was still alive, hoping I didn't give them my germs. Actually, I missed seeing Norma and her family off on Friday, because they left early. Bye, guys.

One nice thing that happened is Phyllis showed Gary (I wasn't there) a photo of a sculpture that Carissa did for an art class. Gary told me her art class assignment had been to pick a person inspirational to her and make a piece representative of that. Carissa had chosen Gary and her piece had in it a wheel and a chain attached to a shoe. Gary said Phyllis explained it much better, but that it was supposed to represent how he wasn't letting his disability prevent him from leading a full life. I asked to have the image emailed to me so I could put it up on the blog, but evidently Carissa doesn't feel it's finished, even though Gary thought it marvelous (and cried over it). So, when I get an image of it from her, I will put it up on the blog.

We left on Saturday morning. The people at the airport were very helpful. The Avis people dropped me off at the terminal (they had to drive, and with our luggage, it wasn't going to work for both the guy and Gary and me to be in the car, and since Gary had been driving, for him to now be the passenger would have meant putting together his chair so he could transfer into the bucket seat on the passenger side, then breaking the chair back down and loading it in the car, and I would walk – much easier for him to wheel!). We met up on the curb outside door 2 of the Omaha airport. Gary went inside to get a porter, but meanwhile a porter showed up to help. The guy got our boarding passes for us and our luggage checked – we didn't even have to wait in the long line that had formed! Gary did an IC, then we had lunch. In security, they again didn't check the pouch under the front of Gary's chair. I did discover when I got home that they went through my checked-in bag (they left a note saying so). I'm not surprised – it was oddly shaped. Wonder what they thought when they opened it and found a slow cooker, a large tin of rice, and other foodstuffs.

When we got to our gate, we found the plane was going to be delayed an hour and a half! Grrr! They didn't give us "a tug fell over in front of the plane" excuse, so I don't know what the delay was about. This time Gary did all the transfers involving the aisle wheelchair himself! (Instead of having two people lift him.)

Gary was thrilled to have been able to make this trip. He fared far better than I did.

When we got home, our cats let us know they really missed us. It's been funny. For the past three days they keep making all this noise, keep checking to make sure we're still in the house, and Tigger ran out anxiously to the car when Gary and I made to go to the grocery store on Sunday as if he didn't want us to leave. It's hard to be too mad at Blackjack, but he keeps making all these strange, loud ululations that we've never heard before (Gary told him to put a sock in it, but the cat didn't accede to the request). They didn't make this much of a fuss after our trip to Missouri or to Day Program, nor did Blackjack act up like this when we came back that first time from Shepherd. Have no idea why this seems to have been so traumatic for them!

And to finish this entry:

Throughout Gary's stay at Shepherd, he would say he could never repay me. I told him yes he could. He could read my stories and give me his honest feedback on them, but he had to be honest because my critique group certainly would be, and he wouldn't be doing me any favor by not being forthright – even if that might be hard on us both. Well, he finished reading my novel while on the trip, and said it is absolutely his favorite of the fiction I've written. I will spare you from giving you the details of all the nice things he had to say ;-) I hope everyone (or at least, lots of people ;-)) will feel the same way as he does about it. :-D

(Which is not to say I am perfectly satisfied with it yet. And, as didn't surprise me, he had a couple sections he thought should be shortened "to get back to the main story.")

Jul 7, 2007

Just thought I'd point out today is 07/07/07. Hey, I only get to point such things out 12 times during a century. Thirteen, I guess, if I count 05/06/07 (or if you're from some country where they the order is other than month/day/year, you would have some other variant of that).

Gary is going on a daily antibiotic, as the leaking problem continues unabated.

He practiced another floor-to-futon transfer tonight. Strange how the one time he accidently fell onto the floor while doing a transfer went more smoothly than the three times he's tried to get out of his chair to the floor on purpose! Instead of going straight down and landing on his tummy, he ends up going to the side and landing on his hip. At least he didn't fall on his head this time (and I didn't give him any support under his chest like I did last time). Plus I put a piece of foam to the side in case he *did* go sideways (as well as an exercise mat straight out for him to hopefully land on), so when he did go sideways, he was cushioned. He tried to get up on the futon without any help at all from me, but from his up-on-his-knees position he sank back onto his butt and then he didn't have any leverage to go forward, so I gave him a little boost until he had his chest on the futon. He did the rest himself. So, he still needs more practice.

His sister Norma called (right when we pulled into the parking lot of Kroger :-)). He told her about the trip back. She mentioned that she is planning on putting a lot of the photos that their dad took over the years onto a DVD. He was quite a good photographer – lots of cute pictures of "the kids" and also nice scenery shots from their vacations. Norma mentioned that she would try to cut down the number of pictures somewhat – they probably don't need three of a dog they had when they were kids. Gary said he thought of pointing out to her that in terms of the pictures of "the kids," there is a disproportionally large number of her (because she is the only girl) and Donne (because he is the first-born), whereas Gary and Bob got short shrift. So Gary really thinks she could work at evening out the number of photos of the four of them. :-)

Jul 12, 2007

A man is lucky to get any woman who will have him.

So, where we meeting for Christmas. (Better be independent by then, cuz I'm not hauling him around anywhere, particularly not thru 3 feet of snow in Boise.)

Donne's and Phyllis's story – giving the bird an MRI.

Jul 21, 2007

Jail break

Opelika performing arts accommodation lack

acupuncture

Gary's adventure.

Tigger taking up with Gary lately.

Cat's sense of smell.

Monday, Jul 23, 2007

Well, Gary is off on his big adventure tonight. He says he feels like a little boy who's getting to camp out on his own in the backyard for the first time – excited, and a little nervous.

And what is this big adventure? He is ten minutes away in a motel, where for the first time since his accident he will stay overnight without me being feet away. I guess this means he'll be skipping his bath tonight ;-) We are both really, really hoping he doesn't drop something vital on the floor after he's gotten into bed (or for that matter, dropped *himself* on the floor *before* getting into bed). The walkie-talkies won't work at this distance, so I will be keeping my cell phone on overnight. Sounds like a real relaxing prospect, doesn't it? :-)

Actually, I'm sure he'll do fine. Well, almost sure.

My latest "adventure" is I'm trying out a local acupuncturist. I've seen her twice, and last Saturday night I had practically zero pain in both legs for the first time in a couple years (I had seen her on Friday). It was so nice going around thinking, Gosh, I don't hurt! I slept great, best in a couple years. Unfortunately, the next night I was back to the usual. I am going to give her a try for a while to see if it can help.

Okay, more random stuff.

On Saturday morning while I was still grasping onto those last tendrils of sleep, Gary came to my room and announced there had been a jailbreak – for the first time, he'd got his bed rails down himself so he could get out of bed. I thought this meant he was going to do this all the time, but no such luck – only shower days, because on those days he does his skin checks after his shower so he doesn't need the light on until after that (after he's gotten out of the bed), whereas the other days he needs the light on before he's gotten out of the bed and I am still enough of a pushover not to make him get out of the bed himself, turn the light on, then get back in the bed and do his skin checks (we keep saying we're going to look into some kind of remote control for the lights). You would think my groaning response into the walkie-talkie when he asks to be let out of jail would be incentive enough for him to do it on his own, but apparently not. Actually, he has told me it would be more enjoyable if I were a little more upbeat in the morning, so I have taken to responding to his request with a "Zip-a-Dee-Doo-Dah." I'm afraid it comes out a little sarcastically, however.

Well, as an acquaintance of mine says, a man is lucky to get any woman who will have him, so Gary probably realizes this and knows not to complain to loudly.

Recently we got a brochure from the local performing arts center and were debating getting season tickets. But apparently they only have four places for wheelchairs, and only two regular seats (total) would be next to these four slots. People with season tickets already have both those regular seats, which means we'd most likely be sitting apart during the various events. I think we'll go see Garrison Keillor, anyway, but I'm not sure we'll get the season tickets. Seems like they should have better accommodation.

Gary still never got the bolt for the push handle that came off of his wheelchair when he was at his mom's – for some reason his equipment supplier can't figure out which one he needs, claiming there's lots of different bolts for that place, even on the same make of chair. They suggested we take the other handle apart and figure out what bolt we need and go to a local home center to buy one. We're now pretty sure the bolt got stripped off because of the pressure of Donne picking up Gary's chair by those handles to get him up the stairs at his mom's. Recently Gary came across an article that said the person behind the chair should only be there to tilt it, and it is the person in front who does the lifting. That may be better on the push handles, but it is definitely harder on the back of the person doing the lifting! That is also not the way they taught us at Shepherd.

Well, Gary just called. He's settled in his room but not in bed yet. He plans to wash his upper body while sitting in his chair (though he won't be able to reach his back), and then he'll take wash cloths over to the bed and get into bed and wash his lower body while in bed. He says the hard part is going to be getting into bed – the bed is higher than the motel ones he's stayed in before. So he says if I get a call it will be because he was unsuccessful at that transfer (and is therefore now on the floor). He did take his transfer board and thinks to be safe he will use that for the transfer.

I told him to call me after he got into bed and was ready to turn off the lights for sleep so I don't have to have my imagination going wild wondering if he's on the floor and his cell phone has dropped somewhere out of reach.

More randomness. Just this past week Tigger has become Gary's "faithful kitty." When we first got home, Tigger used to get in the hospital bed with him all the time, but after Gary started doing his stretching on the futon and not on the bed, Tigger stopped coming in. We then realized this was because Tigger was wanting to be where *I* was, not Gary, that is, Tigger was only on the hospital bed because I was in there stretching Gary's legs. We figured this out because it soon became obvious that every time I go into Gary's room to do something for Gary while he's in bed (bring the washcloths, give him his pillows), Tigger comes in demanding my attention. We knew he was jealous of Blackjack ever getting any attention, but now it became obvious he was jealous every time I gave *Gary* any attention in the bed! We have to laugh at that.

But maybe Tigger is expanding his affections somewhat. This past week he has been jumping into bed with Gary when Gary goes there to wash and do his bedtime IC and so forth, and I'm not in the room.

And now for your edification. I came across a note about how, though dogs are used in forensics for tracking smells, they do not have the most acute sense of smell in the animal kingdom. Cats are much better, and so are ferrets and pigs (think truffles). The trainer being interviewed said pigs don't mind working but can't always be brought into the area needing investigating, and besides, they get distracted by food. Ferrets apparently have zip attention span. Dogs like to work, respond to praise, and see themselves as people partners. Cats don't like to work, and certainly don't see themselves as people partners. The forensic trainer finished by saying the only time a cat would be useful in this regard would be if he was looking for a half-rotted fish and the cat was really, really hungry.

Smart cat.

Another call from Gary. He made a soft landing (onto the bed), but forgot to turn the hall light out, so now he has to transfer out of bed, turn off the light, transfer back into bed, and call me again.

Gary called again. All’s well ;-)

Jul 24, 2007

Gary came home this morning and I took his report ;-). He said everything went pretty good, overall. He didn’t sleep that great while proning because although the pillows were those thick ones like the ones at the Holiday Inn Express in Columbus, he didn’t check whether he had put a firm one or a soft one underneath his chest beforehand, and it turned out to be a soft one and didn’t give him the support he needed. He was fine after he turned to his side though (about 3 am). He said the people at the hotel were happy to bring in his big suitcase for him and take it back out in the morning (at least, they were happy once he tipped them ;-)), so that was no problem. Maybe I should’ve had them do that for us in Columbus. Not sure if that works if you don’t look handicapped.

His first transfer into the bed took some planning on his part, because the bed was so high, and he said it didn’t go very smoothly. Because of the height of the bed, his feet didn’t reach the floor when he got into a sitting position on the bed, and whenever his legs are dangling without his feet being supported, his legs start spasming – literally kicking out – which makes it harder for him to balance. But since he forgot to turn out the hall light and had to transfer back out of the bed and then back in, he got extra practice on the transfer, and the second time went smoother. So now he feels confident he can transfer into a motel bed, at least if using the transfer board, with no problem.

He had another problem-solving situation arise at breakfast. In Columbus, I had gone to the breakfast area and brought him back bowl, spoon, banana, and milk, but here there was no way that he could carry back one of those 6 oz glasses of milk without spilling it on himself (normally he carries liquids in a big glass set between his legs while he wheels). Fortunately he had an empty 16 oz cranberry juice bottle, so he used that.

I didn’t worry too much about him during the night – woke up a couple extra times, I think. Worst thing was some ding-dong called my cell phone at 11:30 pm, and I shot for the phone, thinking it was Gary. Wrong number. Grrr. This is why I usually turn my phone off at bedtime.

Meant to mention with the random stuff yesterday, they had the auction of Gary’s mom’s household items last weekend. Mom Gruenhage wasn’t going to go – found it overwhelming, I think (Donne came up to oversee things). But she did go to it, and it turned out she was glad she did. She knew quite a few people there – including some cousins of Gary’s, who were bidding on stuff. And after people would win things, they would ask her for the history, so it turned she enjoyed it. The antique pedal organ didn’t go for as much as expected – about $250, I think. Gary’s erector set went for $35. :-)

Jul 28, 2007

Sad news. Gary did a websearch for one of his roommates at Shepherd, to see if he could find any recent information on the man – Gary had tried emailing him last fall, and never got a reply. Gary turned up an obituary during the websearch. The man died this past June, the obituary saying his death was caused by complications due to his spinal cord injury. He seemed in good health (other than the SCI, of course) when we were at Shepherd together, and his spirits had always been good. He was congenial and witty. He went around wearing a Superman T-shirt. We had met his mother and sister and one of his sons, and Gary had met his wife of 41 years. The man became a quadriplegic, I believe close to the time Gary became a paraplegic. The man's injury was caused by a drunk running a stop sign.

The news of his death made us cry.

Jul 30, 2007

Wayne Flynnt: guess in a way it’s a matter of doing what you have to, but you two have handled this with such grace and dignity it’s a testimony to the human spirit.

Aug 1, 2007

Gary drove by himself to Atlanta and back (!), for his check-up with the doctor. We joked that it was all right for him to go without my help, because for the first time they wouldn’t need to check his butt (flap) and so he doesn’t need to get up on one of those examination tables. It still amazes us that Shepherd, geared toward spinal cord and brain injuries, has examination tables that are so difficult for the patients to get on by themselves (high and narrow), particularly the newly injured. But of course the staff has sufficient training to aid in the transfers!

Gary talked to the doctor about his never-ending urinary tract infections, and they did a “KUB” while he was there – that’s a radiograph of the kidneys, ureters, bladder, and urethra – to see if they could determine any reason for the infections. He is also going to finally have the urodynamics study done in about three weeks. Because of the radiograph, the day went much longer for Gary –he left about 9:30 and didn’t get home until after 7:30. His trip there took the usual two-and-a-half hours, but the trip home took four: two-and-a-half for the time moving on the road; a half-hour to eat (he would need a third hand to eat in the car); fifteen extra minutes to account for rush-hour traffic; and a half-hour of crawling along because of an accident. So he was one pooped puppy by the time he got home, but I think he was pretty proud of himself for doing it himself. I know I’m proud of him.

I checked his flap after he got in bed (and so did he), and it looks pretty good -- a bit redder than usual but nothing like what it looked like after one day of our journey to Mo. last spring. Since he was in that car seat for six hours today, we thought this was pretty good! I told him he had finally developed a tough butt.

Tomorrow is our wedding anniversary. He says I can pick out a new car. He then said I am the only person he knows who would not be excited by this (too much trouble deciding what to get ;-)).

Aug 2, 2007

We had a nice anniversary. We gave each other cards and flower arrangements. Gary gave me a car (well, virtually) and I gave him chocolates and a gift certificate for shirts and made him a pizza and bought him a pint of Dove Chocolate and Brownie ice cream, which he says is now his favorite ice cream, so I think we had a fair exchange.

Blackjack also gave him a present – since the accident, Blackjack has not been venturing into Gary's room, but this afternoon he plopped himself down on Gary's hospital bed and has pretty much been there since! Wonder if he'll continue this behavior. Weird cat!

Aug 11, 2007

Gary had a math visitor all week, Kenichi Tamano, of Japan. Kenichi has been coming for a visit at least the past three years, and they made some progress in a problem they've been working on. They also went out to eat lots, and Gary discovered facts about the accessibility of local restaurants. They first tried a fairly new sushi restaurant. After parking (near the old post office, for those who know where that is), Gary first had to negotiate a long uphill – Kenichi pushed his chair for him. Then it turned out at the restaurant there was a huge step one had to get up in order to get into the restaurant proper. Gary was told he could get in at the back, but that would mean going back down that long hill, over a block, and around to the back. A young strong guy volunteered to help him up the step in the front, and he, Kenichi, and Narendra Govil, who had gone with them for lunch, ended up picking up the wheelchair with Gary in it to get up the step. The young guy warned he might not be there when Gary was finished with lunch, and he wasn't, so Gary went out the back of the restaurant – after they cleared stuff away from the back door (evidently it isn't used much). At least that way was closer to where they parked!

When Gary and Kenichi tried the Chinese place nearby the sushi place, they went to the back first. There they discovered a step down, which they weren't comfortable in negotiating themselves. So they went in the back entrance of the nearby pizza place. More problems. To get to most of the seating area, they would have to get up a step, plus the tables were too high – they'd come to Gary's chin if he were seated at them. There were three table he could've gotten to at the front, but they were full and so Gary and Kenichi would've had to wait. They ended up ordering a pizza to go.

Another day they tried another Chinese restaurant. The problem there was more minor – the buffet table had only a tiny ledge so Gary couldn't set his plate on it to serve himself. Kenichi had to get Gary's food for him.

I went out to eat with them Thursday night (at Outback), and we had no accessibility problems. We found out Kenichi has visited only four places in the U.S.: New York, Washington, San Francisco, and Auburn. Well, he's hit all the hot spots. He gave me a beautiful Japanese paper lantern at the end of the meal. He left Friday.

Gary has also recently gotten some other research results, so I think he is happy about that.

On Friday, he met an exercise goal: 1.5 miles in five minutes on the hand cycle. His trainer said next they will increase the duration to 6 minutes. They also got a new exercise machine in, one that simulates rope climbing (so, Gary doesn't go anywhere, but the rope moves). Gary said he could tell it's exercising different muscles – he's sore!

We test-drove a Prius last Saturday, and although I liked the concept of it, I could not get comfortable in the seat, and indeed it set off my leg symptoms. Gary thinks maybe a power seat would be better for me. Today he plans to haul me off to look at some Hondas.

Aug 19, 2007

Yesterday Gary and I went to check out Toyotas: RAV 4, Camry, Corolla. Previous week it was the Honda Accord and Honda Civic. By the time I get into the next car I've forgotten what the previous car was like, unless it caused me obvious discomfort, like the Prius. I did decide I'd rather go for a car than a SUV (RAV). I hate car shopping. I think I'll just flip a coin.

My birthday is coming up. Gary asked me what I wanted. I told him he could get installed whatever technology is needed so he can flip on the overhead light in his bedroom himself when he is in bed, so that it what he is doing (this way, he doesn't have to get me out of bed to turn his light on, which is why it is *my* birthday present) . Jo Heath gave us a doohickey that screws onto a lamp so you can turn the lamp on and off with a touch of the hand on the lamp, but, at least with the lamps we have, that doesn't make the room bright enough for him to do his skin checks.

Aug 27, 2007

Happy Birthday to me!

Well, no car fairy appeared to me and told me which car would be perfect for me, so I went ahead and got a Honda Civic. I had test driven the Hondas a week ago, and two weeks before that. This time the dealer brought for me to test drive a red Civic with two thin gold stripes running along its sides. I raised an eyebrow. I test drove an Accord after the Civic, then settled on the Civic as having the more comfortable seat for me. It was kind of funny how no matter which car I was in, the dealer made it sound like that one was the best choice for me. After settling on the Civic came the choice of color. The dealer said they had the red one, a beige one, and a white one. White would show dirt too easily. As I went to look at the beige one, another dealer said they had a dark blue one on the other side of the lot. The beige one didn’t thrill me, and blue is my favorite color, so I thought I’d get that one. Gary suggested I go sit in it. The seat didn’t feel as comfortable. Being suspicious, I felt like to get that one I was going to have to test drive it and make sure I could get the seat where I wanted it. I was reluctant to do so, however, being pooped from the test driving I had already done. Gary asked me why I didn’t want the red one. I said because I don't think of myself as a "red" person and, besides, I’d heard that cops keep a special eye out for red cars. He asked me just what it was I was going to be doing in it that would draw the attention of cops. He then said I’d look cute in a red car with stripes. That settled it, I got the red one.

At least I probably won’t forget what color my car is, as I’ve tended to do in the past.

But wouldn’t you know it, within an hour already something needed to be fixed. After buying the car, we went to Kroger, me in the Civic, Gary in the Sienna, and upon coming out I couldn’t get the trunk of the car to pop open (tho it works with the key). Took it back to Honda today because it was too late to do so Saturday, and I had to schedule an appointment for Thursday to have them look at it.

Anyway, anniversary gift solved, it was on to my birthday presents. Gary gave me gift certificates to amazon.com and half.com so I can indulge myself with books. He also got me flowers and said there is something else which he will give me tonight. He tried to put in the doohickey that would enable him to turn on the overhead light in his bedroom while using a key chain remote control (so he can do this himself while in bed in the morning without relying on me) but he ended up doing something so that now his overhead light doesn’t work at all. :-(He called an electrician about a week ago, and the guy said he wouldn’t even be able to call to schedule something with us until this week.

Tigger cost us over $350 last week. I thought he’d been looking too bony lately, so I took him into the vet, and he’d lost 1 ½ lbs. The vet did all sorts of tests, including thyroid, and turned up that Tigger has a raging urinary tract infection. So he’s on antibiotics for three weeks. Thank God for the person who invented pill pockets, as so far Tigger had been gobbling down his pills when they are hidden inside the little salmon pockets. In the past, however, there has come a point where he loses his sense of taste from the antibiotics. Then it will be exciting seeing how Gary and I manage in getting the pills shoved down him – this wasn’t an easy task when Gary was fully able-bodied! It always took the two of us, one holding onto the cat for dear life, the other prying that little cat jaw open (I did the holding). I’m not sure if the UTI accounts for Tigger’s loss of weight. If not, maybe it’s time for a change of diet. I’m sure if he got fresh fish and chicken and steak, as he’s indicated he’d like, he’d put the weight right back on.

Speaking of UTIs, Gary hasn’t leaked in three weeks now. He took a more powerful antibiotic – given to him by his Shepherd doctor – to knock out the infection he had, and since then he has been on a daily antibiotic PLUS he decided to use a new catheter each time instead of cleaning out the old one and re-using it for a month. At five catheters per day, this gets expensive, but oh well. While he was in the hospital he never had a UTI and this is what they did then. When people go home, tho, they usually just do the “clean technique,” re-using the catheters, but maybe that isn’t good enough for Gary.

He is teaching a full load – has an undergraduate linear algebra course and a graduate topology class. He says things are going fine. At the student rec center they’ve gotten another new exercise machine in, to replace the cable pulley machine, so he is looking forward to that. Or at least his trainer is. Evidently it has finer gradations of weight than obtainable on the pulley machine.

My computer made me very nervous last week. Monday it simply wouldn’t start up. Gary didn’t think it was on warranty, and it was too bad we didn’t realize we could go online to check that out, because I ended spending $40 for a local computer repair guy to look at it, tell me it was probably the mother board which would probably cost me $300, and then he went online and told me we had gotten the extended warranty and I still had 99 days left on it! So I shipped it off to Dell on Tuesday, and they had it fixed and returned to me by Friday! Seems to be fine, fingers crossed.

Sep 2, 2007

Well, I just mentioned to Gary today that I didn’t have much to blog about lately (or at least, that I am willing to blog about ;-)) so evidently Gary decided to provide me with something. After our evening routine of him stretching and me doing my knee and back rehab exercises while watching TV, Gary trundled off to his room to undress and get ready for his evening bath while I went to my room to work on my novel some more, when all of a sudden I hear an unusual creaking sound from his room and a rather strained call of “Peg!” That definitely didn’t sound good. I feared I’d find him on the floor, and I did – he said he landed on the edge of his bed during his transfer and was unable to do anything about it and so slipped off. Fortunately, he fell slowly, he said. I went and got my exercise mat for him to use as a pad when he got himself into a kneeling position, and after a little thinking we figured out what might be the best way to orient himself to the bed. He used the bed rails to help and got himself to his knees, me hanging onto his belt so he wouldn’t slip back down or to one side. Then he pulled himself onto the bed without me supplying any muscle, so he did real good! He commented that he *knew* he should’ve been practicing that floor-to-bed or floor-to-futon transfer more (and we won’t even mention the floor-to-wheelchair transfer that we’ve never practiced since Day Program), but he says it’s hard to make himself do those kind of transfers deliberately.

So, that was exciting.

Other news of the week. The electrician came out and fixed Gary’s light so it now works by a key chain remote. So does his desk lamp. Pretty cool! The overhead light even works as a dimmer. The system is callled “X10.” I love this birthday present, since it gives me more time in bed ;-)

Got the trunk on the Honda fixed. It pops open fine now.

Gary and Peg's movie recommendations based on their recent viewings, all foreign films: "The Lives of Others," "Tsotsi," "Sophie Scholl: The Final Days (Sophie Scholl - Die letzten Tage)."

So far, we love Netflix!

Sep 16, 2007

On Wednesday the 13th, Gary made his first independent trip (not counting the trial run overnight stay at the motel ten minutes from our house), a success! He left for Atlanta and stayed overnight in order to make an early morning appointment Thursday at Shepherd for his urodynamics test. He stayed at Holiday Inn Express, and they were very nice to him. One of the employees not only carried his bag in for him, but on seeing that there wasn't a place for him to park that would allow the ramp of the Sienna to come down, told Gary he could park in a no-parking spot, and that it would be no problem because it was the inn that had put up the sign and he would pass along the word that it was okay for Gary to park there. The employee then got Gary changed to an accessible room close to this new parking spot. He also refused to take a tip, even after Gary insisted.

Gary said the room was reasonable. He wouldn't have been able to take a shower had he wanted to, since there was only a tub and no roll-in shower. (Tub transfers – there's something we've completely forgot about!). He wanted to use the coffee table to put the bowel and bladder supplies on that he would need during the night, so had to drag it from the living room area to the bedroom area (he was in a suite), but was able to do this by himself. The bed was a couple inches lower than his chair, so the transfer into it was easy, and to transfer out he had the coffee table near enough "Just in case" he lost his balance and needed to grab something, so he was confident of that as well. He had no problems. For dinner he had stopped in at Fresh Market and got take-out to bring back to the hotel.

He had to get up at 5 in order to make his 8 am appointment. They hoyered him onto the table and took his pants down for him, saving him some work. The test found that the bladder isn't as elastic as it should be, but that the pressure in it is fine (if too high it could cause urine to be forced back into the kidney and cause kidney disease). They also found there was some spasming in the bladder when it got close being 500 cc full, that 500 the number they always want you to regulate your ICs and fluid intake etc. so you stay under it.

Since Gary hasn't leaked in over a month, his doctor told him to continue with what he's been doing: the daily antibiotic and the Vesicare (for bladder spasming). Gary said he'll also continue using a new catheter for each IC – they aren't terribly expensive, under a dollar each (so about $5 a day), and he figures the peace of mind is worth it – he is now convinced he had a urinary tract infection for over a year, ever since leaving Shepherd, except for a few brief intermissions when he was on an antibiotic, up until the time he started on the daily antibiotic (first knocking out the existing UTI with a stronger antibiotic).

His Shepherd doctor told him that unless there was any special problem, he didn't need to see him again for a year. He told Gary that as far as tests went, he should have a kidney ultrasound every year, and the urodynamics every 3-5 years. Hopefully the local doc will agree to doing the kidney ultrasound; the local doc wanted to do a KUB every year, but the Shepherd doc said the results of that were unreliable unless one is "cleaned out" beforehand, and being "cleaned out" is a real drag for paras and quads (diarrhea isn't fun for any of us, but you can imagine how worse it'd be for someone who doesn't know an episode is coming on and would have to go through a rigamarole to get pants down and onto a toilet or into bed and use underpads).

After the exam, his doc was the chattiest he's ever been. He asked how the university was treating Gary, and Gary told him about how Phil had changed offices with him so he wouldn't be dependent on the elevator and how the university had had a sidewalk put in so he could reach the handicapped parking spots without endangering life and limb. The doc, whose injury is similar to Gary's (he's a T2), said his university hadn't been nearly as accommodating. Of course, he had been a student. His achievement was quite phenomenal, actually. He only missed one semester of work due to his injury, and when he returned, he took a double load. He told Gary that every morning he had to wheel up a big hill to get to his 8 am chemistry class, and that often it was raining! And of course as a student he would've had to have wheeled all around campus for his classes, not just be in one building all the time like Gary is. Given how much time "maintenance" takes, for the doc to have been able to handle a double load seems almost inconceivable.

The doc finished their appointment by asking Gary what the square root of pi is. Gary told him to plug it into his calculator.

Gary then went to visit the Bridge Program Coordinator. She was pleased to see him and said he is one of their success stories. That was probably to soap him into being a peer supporter for his area (JUST kidding about the soaping part). She did succeed in that goal. She also tried to convince him to go on a snow ski trip, but fortunately ;-) she failed in that. Gary gave her the excuse that the dates fell while he was in school, but it'd be a long trip and he's not fond of being out in the cold (and I'm even less so, and I'm sure at this point I'd need to go with him).

Gary also ran into his favorite PT, the one who made him feel like he could do anything. She gave him a big hug and showed him pictures of her new baby.

Gary said the traffic on the way home was again terrible, slowing to a crawl at times, but at least it wasn't as bad as last time.

To sum up, a successful independent foray!

Sep 22, 2007

UTI back. I've won Spanish and Irish email lotteries this past week.

What were they thinking? 20/20 spot. Starts off heartwarming. Newly injured young guy viewing this. Horrible. Comes home from hospital after 10 months, and she informs him she's leaving him.

Oct 7, 2007

About a week ago, another person was killed in the exact same intersection Gary had his accident, and because of the same problem: someone coming from the golf course didn't see an oncoming car on the highway and pulled in front of them. As Gary said when he heard this, choking up, "How many people are going to have to die or be seriously injured there?" The yellow blinking light they put in after his accident clearly is not enough, but the law is the traffic count has to be a certain amount for them to consider a stoplight.

A couple weeks ago, Gary found a 20/20 (TV show) spot on the internet, about someone who recently suffered a spinal cord injury as a result of a motorcycle stunt. Gary called me to watch it with him. The segment starts out heartwarming, about how the young guy's girlfriend devoted herself to his care for the 10 months he was in the hospital. The segment ends when she brings him home from the hospital. And at that same time informs him she is leaving him!!! Gary and I looked at each other, appalled. Jeez, thanks for sharing that clip, 20/20. I know that kind of thing happens, but how horrible it would be to be newly injured and see that.

Gary's UTI came back (rats), but he knocked it out with a stronger antibiotic.

Well, so that this entry isn't entirely a downer, I would like to inform you that I have won both the Irish and the Spanish lotteries, according to my email.

Oct 10, 2007

Another accident on US 280, this time at the intersection just east to the one where Gary had his. Fortunately no one killed or maimed this time. You can go to http://www.oanow.com/ and click on the "Citizens Make Call for Action" link to see an article about it (listed as one of the "top stories for October 10th "). The mayor is going to ask the governor to directly intervene and get stoplights put up at these troublesome intersections. At the intersection where Gary had his accident, there have been 34 accidents (for some reason, the police reports divided those into 9 on the north side, 25 on the south side, tho it is the same intersection) since 2004, and there have been another 10 accidents at the intersection just east of that. Gary got a phone call this morning regarding this. The Community Relations Specialist in the mayor's office is getting together a citizen's group to call for action. Apparently her own son was killed at one of those intersections.

Oct 19, 2007

Success! The Community Relations Specialist in the mayor's office emailed Gary with the following information: the governor called the mayor this morning to say that traffic lights will be installed at both intersections (see the blog entries of October 10 and 7) by Thanksgiving.

Oct 26, 2007

I got a call this evening from Gary. He said, "Would you come here and pick something up off the floor I dropped?" Funny guy. He is three-and-a-half hours away north of Atlanta. I told him only if the something was him and even then I would have to think very very hard about it. He said not to worry, if it'd actually been him on the floor, he would call his former graduate student Brad to help, seeing that Brad lived only five minutes away. I said that was good, because I really wouldn't have come up there – I'd call 911 to get him first!

But actually, Gary is experiencing another turn of the wheel in independence.

He left yesterday for a college a bit north of Atlanta, where he'd been invited to give a talk to some graduate students. The drive, he said, wasn't bad until he hit north of Atlanta. Evidently a lot of people were going to the mountains of north Georgia to view the changing of the color of the leaves that is happening this time of year, and perhaps also to some festival Gary heard was going on in the area. But, he made it fine – although once at the motel one of the employees ended up running and grabbing him to make sure he didn't fall out of his chair! This is what happened: Gary checked into the motel, and he and an employee were going to the parking lot to get his suitcase out of the van. The parking lot sloped down rather steeply, and there was a bump at the bottom of the incline; Gary hadn't noticed it when he'd gone uphill, so he wasn't going particularly slowly while going downhill, and his wheels caught, his chair stopped dead, and he started to tip forward out of the chair. Gary doesn't think he would've actually fallen out of the chair, but I am glad the other person was there to make sure of that!

The only other challenge he faced at the motel was he needed a lamp he could reach from the bed. This meant he had to move around some heavy antique furniture in order to drag a floor lamp bedside. Too bad the motel was so nicely furnished with antiques and didn't have the modern cheapo lightweight furniture ;-) I'm sure he could've asked for help from the motel employees, but being the independent sort he managed himself.

He had to get up about an hour-an-a-half earlier than usual in order to get his routine done in time to make his talk. He said his talk (on independence and undecidability questions in topology and set theory) went well, the students seeming to enjoy it. He went out to eat with them at a Mexican restaurant for lunch, and went to the same restaurant that evening with Brad, who is the person who invited him up for the talk, now being on the faculty of the college. Brad's wife, whose name I am sorry to admit I forget, also came, as well as his sixteen-month-old daughter. This little girl "visited" Gary soon after she was born, when Brad and his wife came to visit Gary at Shepherd.

Gary also spent some time in a little café across the street from his motel, and again experienced the problems of negotiating the hillier terrain of the area of that city (it is in the foothills of the Appalachians). Getting across the street involved going up a rather steep section of sidewalk. Gary was struggling with it, and a passerby offered to give him a push. Gary told the person he thought he could do it, but it turned out to be too difficult, so he ended up accepting the push. When he told me this, I was reminded that just this afternoon I had caught the last few minutes of a segment on Georgia Public radio that was about the accessibility of Savannah, Georgia to those in wheelchairs. The person they were interviewing said he'd lived in that city his entire life, and that he was pleased that in recent years the situation had improved – though there was still much room for improvement. He said, for instance, a lot of curb cuts were useless, being too steep for those in wheelchairs to negotiate. But he's seen progress. He said in years past he would try to go out with his family to shop or eat or whatever, but they would end up splitting up because he couldn't get around to all the places they could. He mentioned how nice it was to be able to pretty much go anywhere he wanted now, just like the able-bodied (or whatever the politically correct word is there that I should use) take for granted. I know Gary can relate to the satisfaction of being able to get around by himself.

He will be driving back tomorrow, making this his first two-night stay alone. I am very proud of him.

Nov 21, 2007

Yesterday we left to spend the Thanksgiving holiday with my mom. Took us a little over 8 hrs. to drive to Florida, Gary doing much of the driving. (We decided it would be easier to drive straight there rather than go through the rigamarole of unpacking and re-packing the minivan for an overnight stay at a motel on the way.) So, it took maybe about 45 minutes longer than if Gary hadn't had to lift up for a minute every 25 minutes.

We're staying at a Holiday Inn Express, and oddly, we are practically the only ones checked in – feels like we have the run of it! This motel chain seems to be a pretty good one in terms of accessibility, except sometimes, as with this one, the bed is higher than Gary would like; his feet don't touch the ground after he makes the transfer onto it, which makes it harder for him to keep his balance. This particular motel probably does have the best roll-in shower, however – it's the first one he could actually use. (The last place he was at was really a head-shaker in this regard: not only was there a bump he'd have to navigate to get into the shower, but the shower seat was clear over on the far wall – the combination meant he would've had to fly over to get to the seat.)

Someone mentioned that lately I haven't said much in the blog about my own health. That's because I figured you were tired of hearing me whine about the same thing ;-). In case you aren't here goes: back and knee aren't all that much improved; they hated the trip and let me know that, particularly during the night; but I think so far the trip has been easier than the previous couple. I really wish they'd hurry up and invent the transporter beam (as in, "Beam me up, Scotty").

After Gary's bed bath last night, he had me check out his flap. We were curious how it would be, because this was the first time he's taken such a long drive since Missouri, at which time I'd yelled out "Jeez O'Pete" at seeing the state of his flap. We were fairly confident it would be okay this time, because he's done shorter trips with no problem and because we figured the flap area had probably toughened up some by now. This time after I checked it out, he asked me how it looked, and I was happy to inform him he had a cute butt, no problem with the flap.

We moseyed over to mom's about noon her time today, and spent the day talking, reminiscing (although I'm not sure I believe all mom's recollections – come on, did I really tell my kindergarten teacher she wasn't a very good teacher and that I wasn't going to waste my time doing the assignments because they were too easy? Too bad I lost such impudence about middle school), relaxing, and trying to ward off mom's attempts to get us to eat more. Oh, and we had Christmas. Probably the only people to ever have celebrated Christmas the day before Thanksgiving. Actually, we hadn't gotten mom her gift yet, but she had gifts for us: two sweaters for Gary, pajamas and a dressy shirt for me.

As we left for the motel, mom said we had given her the best gift we could've: seeing us behaving "back to normal." The last time she'd seen Gary was that first week after his accident, up at the hospital in Birmingham. Despite the fact she gets all the news of the blog, she still had in her head that Gary was going to be debilitated, and therefore that it was going to be emotionally hard for her to see how difficult life was for him now, and that she was going to have to put up a brave front and not let us see how this affected her. But then after being around us for a time, she said she realized, "Why, it's just the same ol' Gary!" Okay, not quite the same ol', but you know what she means. She was fascinated to watch how he did his transfer into the driver's seat of the van and to see how he could operate the controls. As typical, however, she said he ought to put his seat up higher (a trait I know I've inherited to some extent – always thinking you know a better way somebody should be doing something other than what they're doing). As was also typical, Gary ignored her advice and continued to do it his way.

Jan 6, 2008

Happy New Year!

Late, I know. And yes, we still exist. Jo Heath pointed out to Gary that though I had told all about the journey to my mom's for Thanksgiving, I didn't say a thing about making it back. Well, we did. To help pass the time of the trip, we listened to a recorded book we'd checked out from the library. James Joyce's "Portrait of the Artist as a Young Man." That was a mistake, because we found it mostly boring :-) An entire disk (if not more) was devoted to the description of hell – even hellish descriptions can be boring after a while – and another disk was devoted to a discussion by the book's characters of the definitions of aesthetics and beauty. Gary still said he'd be interested in seeing the movie version of the book, so we got that from Netflix. We thought it better than the book, but only because it was shorter. :-). We must be literary neanderthals. On the "Modern Library" website, they list the top 100 novels of all time. #1 is Ulysses, #2 is The Great Gatsby, and #3 is Portrait of the Artist. We had earlier rented out the movie version of Ulysses. Gary couldn't finish it he found it so uninteresting, but I stuck it out (just to say I had). I wasn't motivated to try the book. And all I remember about Gatsby is there's a rich guy in it, and a tragedy, and Gatsby was played by Robert Redford :-) (never read the book).

We took a trip to Gary's sister's (Norma) in Houston for Christmas, his entire family descending on her, so that there were twelve of us altogether (plus Jake, the cat, whom I finally got to meet. Sorta. He pretty much stayed in the bedroom or out in the garage; my cats would've been out in the back woods except to sneak in at night for food). We drove to Houston, taking two days. The only real traffic problem was that we ran into a jam east of Baton Rouge, due to big traffic accident. Gary did seem to always manage to time it so *I* was the one driving through the big cities (Mobile, Baton Rouge). While Gary was driving, I, as usual, worked on my novel on my laptop, but while I was driving we listened to a recorded book. But we had learned our lesson. We went for a Dick Francis mystery novel. After Thanksgiving I had taken to listening to recorded books while doing my therapy exercises for my knee, and had gone through Francis's "Dead Cert," which I enjoyed. So, I picked out another one of his for the trip, "Decider." It wasn't nearly as quickly paced (thought it could use some editing), but Francis writes in such an interesting way that I was content. Also on the trip I also listened to Frank McCourt's "Teacher Man" on audio book while doing therapy exercises at the motels. I had mixed feelings about the book. His honest account definitely made me wonder how a person could stand to be a public school teacher in a large city (he was in NYC). Sometimes he came off as very much the drifter through life, but occasionally he'd say something that indicated his students were inspired by him. Perhaps part of the problem was that he was performing the audio reading himself, and maybe he found that awkward. I also kept getting the feeling that there were gaps in the narrative, that it jumped too much, and I later realized it was an abridged recording. I regretted renting the audio book, as I would've liked the whole picture but am now not sure whether I'll spend the time reading the book, knowing there are parts of it I've already heard. I did very much enjoyed his previous book "Angela's Ashes," though.

I also finished Joan Didion's "The Year of Magical Thinking" while on the trip, and started on a book called "Between, Georgia," a humorous novel dotted with eccentric southern characters (two feuding families) – I read those books while taking my walks and when in the bathtub. Speaking of those walks, next to the motel in Houston was a short length of road. At its end, to one side was some kind of factory and to the other was an enclosed field with an iron gate. The metal at the entrance to the gate was formed into the words, "Old Settlers Cemetery." I guess I must've been blind, or maybe all the tombstones were off in the distance behind an old white structure I saw, because I didn't see any of the tombstones. All I saw was a "trees donated in memory of" marker and the white structure, yet when I checked on the web, I came across a bunch of pictures of the place. See http://www.webspawner.com/users/brooksidekate137/index.html
(I only saw views encompassed in the first three and the last pictures.)

I enjoyed the book "Between," but I'm not sure Didion's book was a good one for me to read at this point in my life. It brought back all those feelings I had about wanting to encase Gary in bubble wrap and keep him safe on my shelf, since Didion's book is all about her first year after the death of her beloved husband (the "magical thinking" part is that even though she knew it irrational, she would behave in certain ways because at some level she expected her husband to return at any moment).

Enough literature for now :-). When we first arrived in Houston (never promised this would be chronological), Gary was slightly lost and we stopped for directions. Good thing, because we were traveling down a road in the opposite direction we should've been. As we got closer to Norma's, I sang, "It's a long way to Tipperary," Tipperary being the name of the street we had just turned onto. All the streets in Norma's area apparently have the names either of counties in Ireland or of golfing terms. (Gary investigated, and no one has a street address on Bogie Way – only the backs or sides of houses are on that short street.) Upon arrival at Norma's, Gary's brother Donne bumped Gary up the step into Norma's house (as either he, Wayne, or David did all during our stay). Norma had cooked a delicious welcome meal, and she also cooked a superb Christmas meal (turkey and all the trimmings, finishing with that famous southern dessert, rhubarb pie, and for anyone who doesn't know, the "southern" is a joke; midwestern, definitely; anywhere else?). I can even attest to the greatness of the meals with authority, because I have found that in the last year I have been able to eat small amounts of foods other than the rice and zukes I lived on for about a decade. The other mealtimes while we were in Houston we either had leftovers at Norma's or we went to restaurants – Mexican, Italian, fish cooked Louisiana style. I would generally split something with Mom Gruenhage and supplement with "safe foods" I'd brought for the trip (aside: I always get a kick out of Mom G. She takes everything literally, making it impossible to tease her or to make a joke at another person's expense in her presence.) On those evenings we'd go to restaurants, Gary and I would head straight to the motel afterwards. The other evenings in leaving Norma's place we'd have to trail this long line of Christmas light gawkers to get out of Norma's neighborhood. That is, we trailed them until Norma told us a back route. Her area is famous for its Christmas lights (or should that be "Holiday lights"?), and it was quite a show. Norma and Wayne had their place all lighted up too.

The Gruenhages are into games. Gary gave Norma a game I think was called "Memory Madness," if I'm remembering correctly. I liked it because my team (me and Gary) won. A category was named (for example, vegetables that start with "P"), and we would go around a circle, each team having to name an example until a team got stumped (30 sec time limit). The pressure was on when your team had to start – it seemed much easier to think of something when you didn't have to go right away, and even easier after the category was over! Gary and I once had to start off with "names of U.S. cities that have a color in it." We couldn't think of a one! Until way after time was up. Gary thought of one about 18 hours later. Auburn, Al. Duh.

My favorite answer was when the category was "dogs with 'hound' in their name," and Norma said Huckleberry Hound. There's thinking outside the box. In general, though, Norma gave up too easily when challenged on an answer. Had I been her, I would've been upstairs at the computer searching on the internet to justify my answer, no matter how long the others had to wait while I searched ;-). A couple of times, I should've been more gracious and not challenged an answer, but my competitive juices were roused (amusing Gary with my hopping around). And, by the way, there are such things as dried nectarines. Sorry I challenged you, Megan.

The next day we played a different game, called Outburst. It was similar, but we divided into just two teams. One team selects a topic card, and everyone on the opposite team yells out simultaneously everything they can think of that might be listed on the card under that topic (in some cases, the responses were unlikely but hilarious, as for example "sushi" being "a food item found at a sporting event"; apparently the sporting event was sumo wrestling). My team lost on this. I know I personally found it hard to think with everyone yelling out stuff!

They played another game another day, named something like "Man Laws and Woman Rules," but I was gamed out (might've had something to do with having an aversion to the title).

Oh, I forgot -- there was another game. A very sadistic one, it would seem. Up to four players each have a hand control. You watch a little button that is flashing red, and when it flashes green, you press your hand control. The last one to press their hand control gets a nasty shock! Yes, Gary and I actually played this (Norma said her estimation of the intelligence of those gathered went sharply downwards) -- I was, perhaps unjustifiable, confident of the speed of my reflexes. Remember, I am the one who made the amazing catch of a flying frozen fish went it went sailing over the fish counter at the grocery store. Anyway, I went through two rounds without getting shocked, but the way those who got shocked cried out and dropped their hand controls persuaded me not to press my luck any further.

At some time during this holiday get-together there was a conversation about California community colleges (Donne is the chair of a guidance department at one such). Evidently someone's decided too many people are failing out of California's community colleges, so the answer is to fund basic classes. Which means, college professors would be teaching these community college students courses that are grade school level English and math. Yikes!

In recent years for Christmas each member of the Gruenhage clan would draw a name from a hat (in reality, someone else would draw it for Gary and me or anyone else who wasn't in the presence of the hat) and that would be the person you would get a present for. But this year we went back to the tradition of getting something for everyone. That was fun. Many gifts were serious, but some were humorous – like the T-shirts and sweatshirts Donne and Phyllis and Carissa and Justin gave. Bob and Gary got "CSI BOISE" and "CSI AUBURN" respectively. I got a sweatshirt that read, "Careful, or you'll end up in my novel," which I thought hysterical as well as appropriate. I opened it up soon after I had opened one of Gary's gifts, the equally appropriate sleep mask with the words "Working on my novel" written on it. But when Norma got a beautiful watch from Wayne, I teased Gary by hitting him on the arm and saying, "And all I got was a lousy sleep mask." (I personally didn't want a watch, I then assured him.)

(We of course took in a second Christmas haul from my side of the family.)

Nephew David, Norma and Wayne's son, decided to do something extra special, and he got us all tickets to the play "A Christmas Carol." So we trooped off to the center of Houston for that on the day after Christmas. It was an enjoyable production. We did have a bit of a problem in that the air conditioning was blowing on us. I was cold, but Gary was even colder (might have helped me that I had three layers of shirts on). Gary was shivering away next to me (their "handicapped seating" meant sitting in the aisle in the last row, but that was fine because we had a good view), so at intermission I went to our van and got my poncho and two sweaters I had. We put the poncho on him, draped one of the sweaters around his shoulders and put the other on his lap. He said he probably looked dumb but was too cold to care. He didn't really warm up until we went to the restaurant afterwards (which, conveniently, was across the street) and he got something hot in him.

I also kind of worried about where he was sitting during the play. He had his brakes on, of course, but I had this little worry that someone would stumble over him in the dark and his chair would get pushed down the step. So I had one ear cocked for someone moving in our direction. Call me paranoid ;-).

Speaking of heat and cold, it took us a couple days to figure out that to work the temperature control in our motel room, we needed to flip open this little box on the wall, not just push the button on the outside (which obviously wasn't doing anything). I was okay because I had brought my portable heater (always be prepared) but Gary was on the cool side until this discovery, him being a man and not wanting to come right out and ask the motel staff if there was some way to adjust the heat in his room ;-)

The entire trip lasted a week – 4 days of it traveling – and the weather most of the time was on the cool side with some rain (sheesh, if I'm going to go to the effort of traveling, the weather can at least cooperate and be nicer than back at home). I was happy get back to my own bed. Had the usual motel disturbances while away, of course ;-), Santa and his reindeer having a good ol' time up on the rooftops. A couple nights during the trip I was so tired that I forgot to turn Gary's lights out after getting him settled in bed (I was in a separate room), and he had to yell at me to come back. Fortunately, my ears are good, so I heard him (I feared the entire hotel had ;-)) and came back from down the hall to rectify the situation. My other motel mishap was that a blew up a peeled hard-boiled egg in the motel microwave. I guess heating it for an entire minute was too long. Naturally I didn't do this in the privacy of my room but in the hotel dining area, so all the other guests could jump at the "Boom!" and stare at me. I said, "Oops, I blew up an egg." They did not seemed amused. Bah, humbug. Which reminds me of another motel story, a different morning of the trip, a different motel. A woman was seated at a dining table with her husband. I had waited at the elevator with him earlier, and he seemed a nice gentle old guy. Turned out I had also met his wife at the elevator after that, she going out, me going in (I was loading up stuff into the car), and for some unknown reason she'd scowled at me. So now I see her with her husband at the table, she talking on her cell phone. She spoke sharply. She ended the call, made another one. More sharp words, then an ending to the call, the another one made. After a few brief introductory words, she said, "You're the third of my children who isn't coming. Is this how I raised you? What did I do wrong?" I bet they could give her an ear-load if she really wanted to know ;-) (And why do people on their cell phones think the rest of us want to hear their conversation? Although, I admit, this one had entertainment value.)

It was a bit of a bummer that Gary got another UTI during the trip. Not sure why – it's been three months since he's had one. Maybe the stress of travel or the change in diet (he ate more sweets than usual)? He was out of practice in keeping the condom catheter secure, and as a result we had to change his trousers a couple of extra times.

The UTI has cleared up now.

My knee and back did better on this trip than they did on the previous ones, so that's progress. I fear I am going to end up having to have surgery on the knee though. It's not healing, and it prevents me from doing so much. I dread surgery.

We're continuing to enjoy Netflix. Recent movies have been the Irish movies "Once" and "Intermission." The first is a story about a male Dublin street musician and a female Czech immigrant who meet and have an eventful week, dancing about on the edges of love. Very interesting, the story moved along by songs – and there are some really good ones there. The second is a dark comedy, also set in Dublin, the plot involving romance, betrayal, kidnapping, bank robbery. It mixed romance, crime, and farce. We enjoyed it. But don't forget we labeled it "dark." Also recent was "Black Book," a German-language WWII thriller about the last days of the war with a protagonist of a Jewish singer who hooks up with the Dutch Resistance.

We do love our English subtitles or "for the deaf" options on the DVDs. Right now we are taking a break from Netflix and watching a PBS Masterpiece Theater production I taped over the holidays, "Prime Suspect," a British police procedural. The first night we watched, especially, we had to keep stopping the tape and ask each other, "What did s/he say?" Do wish those Brits would speak English. :-)

The kitties were glad to see us when we got back. Or at least Tigger was. I suspect Blackjack only cares he has someone to fill his bowl. As a result of Tigger's bout of UTI problems, we (read "I") am supposed to feed him special food. He is not thrilled with it. Four times a day I have to stand near him while he eats. When he starts to walk away, I go over to the bowl of (canned) food and stir it with my finger. This magically makes it taste better to him (my massage therapist theorizes that this releases the aroma of the food, and says she does something similar to get her cat to eat the food that's been sitting in his bowl a while). After I stir it, Tigger starts in on it again. Stops. Peg stirs food again. Cycle repeats. Occasionally Peg tried to spice things up with added blue cheese salad dressing or canned sardines or Gary's homemade chicken curry or bits of fish or meat (the cod liver oil and the oyster sauce were utter failures). The length of the cycle shortens with each repetition until it reaches zero (at which time Tigger is going out the cat door to escape my next attempt to put the bowl in front of him; I worried that my trying to "force" him to eat more in this fashion would completely turn him off to the food, but it hasn't seemed to have had that effect). This encouragement of his eating is done because we are having trouble keeping his weight up.

I usually try to feed him while next to my laptop or with a book in my hand so I'm not simply "wasting" my time watching him for the length of time it takes him to eat. One problem with this special treatment of Tigger is that Blackjack feels deprived (HE doesn't get the expensive food coming out of a can which surely is better than his ol' dry food and HE doesn't have his mommy encouraging him to eat more), and if Tigger wanders off and I'm too absorbed in my other activity, the next thing I know there's a black cat devouring the food. Blackjack does not need more food. He is a bottomless pit and I fear the next time I bring him in to the vet she is going to say he needs to lose weight. I tried putting him behind the locked cat barrier when feeding Tigger on the other side of the house, but he scratches and yells. I think I will try my older sister's technique and feed Tigger up on my desk, which Blackjack can't jump up on (he can barely make it up the bed sometimes). I don't know if this will be much of an improvement, for I am sure Blackjack will probably still holler and look betrayed. My sister, by the way, has a cat with severe allergies who is on a diet of special food. Before, it was kangaroo meat. But when there was that tainted cat food scare, it turned out the kangaroo meat was affected, so now he's on untainted duck meat. What we do for our pets. Reminds me of the story Donne (Gary's brother) and Phyllis (Donne's wife) told last summer of the vet telling them they could have an MRI done on their parakeet to see why it kept falling off its perch. They declined. (If I remember correctly, a diagnosis would've in any case been unlikely to save the bird.)

I made two New Year's resolutions. One was to go back to eating only fresh food. After Gary's accident, I got in the habit of eating soup out of a can (I'd found one "health food" soup I could tolerate without much food reaction) and I picked up a rice cake addiction. So now I'm making my veggie soup fresh. It may take me longer to wean myself off the rice cakes. My second, related, resolution is to see if I can tolerate more foods. This hasn't been quite as successful, as I've ended up with some tremendous allergy headaches from reacting to something I've eaten. As yet I haven't been disciplined enough in my testing to only add one ingredient at a time. Still, I know I'm doing better that a few years back – I don't feel like ripping my guts out at night, every night.

Because my knee doesn't allow me to walk very fast, I finally decided to get in some aerobic activity by taking up the hand cycle, which is what Gary has been doing. I started in late November. I'm following the program Gary has been following, trying to maximize my distance in a certain time, and after three times of reaching it, increasing by one minute. I started at five minutes, got to six, but then the school break closed the exercise room. I tried starting right in at six minutes again yesterday, and it went all right. I am really puffing at the end. Afterwards, I go to the track, which is a very short distance away, and walk for a half-hour. That's MWF. The other days I walk in our neighborhood for fifteen minutes (I tried going up to thirty minutes on those day, but got shin splints, it being hillier around our place).

Gary is continuing to progress in his exercises, both the weight and the hand cycling (I think he is at nine minutes, maybe ten, on that). He has his trainers all impressed. And he's got great delts. He plans on going to the Spring Topology conference in Milwaukee, making the trip without me. Piotr Minc has, unasked, volunteered to accompany him during the trip (they will take a plane). Gary is one of the keynote speakers :-)

Gary is also planning on changing the company that services his wheelchair. The one he has been using has moved their branch out of the area. Gary spoke to a different company about an hour away, and they seem knowledgeable enough. He will try them the next time he needs service.

I continue to spend my time (when I'm not going to therapy <G>) working on my novel. I am going to give it another pass (to further develop the female lead; I've got the male lead pretty much where I want him). Then I will look into the arcane world of agents and publishers. After or during that, I plan to try to turn part of this blog into a book. The spinal cord injury part, I mean. Don't know if anyone wants to read about my kitties.

Mar 16, 2008

The Mighty Hero has come home.

March 12-16 Gary went to the Spring Topology Conference up in Milwaukee unaccompanied by me. He picked up Peter Minc in our van and then drove him to Atlanta, where the two caught a plane. The plane trip went without a hitch, the only problem being they had to wait an hour (!) in Milwaukee for a handicapped-accessible shuttle (the airport made some excuse about being particularly busy or something). Gary made all the transfers to and from the airplane's aisle chair (the narrow wheelchair they use to get him from his own wheelchair to an airplane seat) by himself, though he admits sometimes awkwardly, as he doesn't get much practice at that – but, no two-man lifts were required!

Gary also needed no help from skycaps, because Peter took over that job, lugging both his own two bags and Gary's two bags (and one of Gary's bags is huge!). Thanks, Peter!

The conference was held at the Hyatt Regency, which also housed the participants, so that was very convenient – no hassling with transportation. (Gary says the Summer Conference in Mexico City is out for that reason. He doesn't speak Spanish, and he thinks there might be a problem with communicating to taxi drivers how to break down his wheelchair – and given my knee, I don't particularly want to be breaking it down for him (not to mention the other reasons I'm not fond of traveling!)) His room at the Hyatt was satisfactory, except that he couldn't reach the wall lamps from his bed (which he needs in order to see to do his 3 am ICs, for example), so he prevailed upon Peter to do some furniture rearranging. The room had a roll-in shower, but no shower bench. When he called room service they brought him a bench, but it turned out he had no time to try out the shower anyway! (Instead, he bathed his upper body with washcloths while sitting in his wheelchair in the bathroom, then took washcloths in a basin over to his bed, transferred to the bed, and did his legs while in bed; at home he does his entire body while in bed (except I do parts of his back he can't reach), except on Saturdays when he takes a shower and washes his hair. Which reminds me, he's got his shower routine down so that it takes him only twenty minutes from the time he transfers to the shower bench to the time he transfers back into bed so he can dress after the shower. When he first was taking showers, it would take him double that.)

Another point about the Hyatt – the computers in the business center were set up too high for someone in a wheelchair.

They had a dinner for the conference participants the first evening, but Gary had to skip it. He needed the time to get his room organized, to do his routine, and to plan out things like "what was he going to do for breakfast." The conference breakfasts were too early for him, ending when the talks began at 8:15. So he found out he could buy a small carton of milk at the gift shop/coffee shop. This he kept in his ice bucket over night, and poured it on the high-fiber cereal he'd brought with him. That first evening he had a room service meal; they told him he could leave the tray outside his room when he was finished, but it turned out he couldn't. He didn't eat everything, and the tray was heavy, and he didn't want to attempt trying to set it outside. The maid got it the next morning.

He said he was dead tired that night – probably having to do all that pushing through the Atlanta and Milwaukee airports contributed to that – and he slept just fine.

He enjoyed the talks at the conference, and his own talk went well – he gave a half-hour invited talk. Meals were sometimes an adventure, and in going out to them he found the weather was far colder than he was used to at home, sometimes below freezing! Gary notes that he can handle cold far better than he could while at Shepherd center.

He went to a micro-brewery with some of his former grad students on Thursday night, and Mirko Popvassilev pushed him back from that – Gary said his muscles were unusually sore, no doubt from the airport pushes he'd done. On Friday night there was a conference reception 12 blocks from the hotel, and Ronnie Levy pushed him both to and from that (Gary said he did some of the pushing back on his own, it being the easier direction). Saturday night he went to a Cuban restaurant, about 6-8 blocks away, and Alan Dow pushed him to that. Then Alan and Sheldon Davies shared in the pushing on the way back. The restaurant had a high-step up at its entrance. Gary could've gone around to the back, where there was a wheelchair-accessible entrance, but since there were more than a dozen in his dinner party, three or four of them simply lifted him in his chair up the step. Thanks to everyone who helped Gary out in various ways!

So, as you can see, Gary is getting along great. As you can also see, these blog entries have dribbled off. I guess that means we've reached "our new normal." I will probably still make entries if there is something of note (or not, depending on your perspective ;-)). Thanks to all who've ever read entries. Your support certainly got us through some tough times.

Now I guess it's getting time for the book and movie versions of the blog to come out ;-)

May 5, 2008

Gary made it up and down our steep driveway for the very first time, accomplishing goal number one on his list of summer goals. Though he had to take a little rest when he reached the top, he said it wasn't hard at all. He noted he wouldn't have been able to do it last year. He has much more upper body strength now.

So now he can go get the mail! ;-)

May 11, 2008

Gary did a wheelchair-to-floor transfer (“wheelbarrow” style). I did hang onto his belt buckle, so he vows to try it again soon without me touching him. But I didn’t give him any help at all getting onto the futon from the floor. So this the first time he’s done that entirely by himself!

May 16-17, 2008

Time for another Adventure Skills workshop, at Camp ASCCA in Jackson’s Gap, Al! The first thing Gary noticed was that getting up that big long hill to get to registration wasn’t as bad as last year – though not a piece of cake. We got him signed up for confidence course (wall climbing and zipline), water skiing, jet skiing, and scuba. No sign-up sheet to ride an ATV, you just show up at the site. We hadn’t rushed to arrive, so after sign-up, Gary did an IC and then it was time for lunch! It was interesting being back in an environment where the typical conversation starters were “What’s your level of injury?” and “How did it happen?” One of the guys we had lunch with was one of the drivers of a boat for the waterskiers. I remembered him from last year. He is a C-6, C-7 quadriplegic and (as you would hope in a driver) has some gross use of his hands, but cannot do fine manipulations. We learned he is the World Champion in 2 water ski events! The jump event and the slalom event (there is a third event, “trick”). In the jump, with the boat going 32 mph, he sailed over 50 feet! For the slalom, the skiers must wend their way around buoys. The maximum speed the boat is allowed to go is 36 mph. The man, Bill, said that there are many people of a similar skill level, so to determine the winner, they keep shortening the rope the skiers are being pulled on. He won by making it around 3 buoys on a 38 ft. rope, half the length of the usual rope. He said the rope was shorter than the distance from the buoy to the boat, so that to get around the buoy he had to use his body to make up the difference in length.

The waterski he used was similar to the one Gary was on, but narrower, so more maneuverable (and less stable). You can scroll down to the next blog entry to see pictures of Gary in his waterski.

But, waterskiing wasn’t Gary’s first event; the confidence course was. First we lost confidence in the map they gave us to find the site: Gary said the map was like a Rorschach test. We turned left when we were supposed to go right, and started down a long steep hill. Gary had to go pretty slow, keeping his hands on his wheels to brake him, so I went ahead to see if I could find out where we were supposed to be. I ran into a volunteer who was supposed to be one of the people running the course, and she told us to go back the other way. Well, that meant Gary had to go UP that long steep hill. I went ahead, and I discovered that there was another even steeper, though shorter, hill coming up. But I found another path that would be easier, though longer in distance (as opposed to the time it would probably take him to travel it). I told Gary this, but he told me he had just passed another volunteer who said the hill coming up wasn’t as steep as it looked, and that it was less steep than what he’d just come up. Right, I said, she’s on two feet, what does she know. Well, Gary decided to try the hill. And guess what? . . . As Gary inched his way up the hill, he grunted out, “She’s nuts.”

So now that Gary’s all warmed up for exercise ;-) it’s time for the confidence course. And here I lost confidence in the staff running this particular event! After he got all decked out in harnesses and kneepads and helmet, they gave him a rope with a movable horizontal bar on it (sorry, I’m sure there’s a name for it, but I don’t know it). You curl your wrists down and push the bar up the rope, then you flex your wrists back and that locks the bar and you pull yourself up using it. Nice theory. After about 5 minutes of him vigorously working away at this, he’d gone about 6 inches. Only about another 30 feet to go. Obviously they didn’t have something right, and they told him to forget the bar and pull himself up hand over hand. Well, he did make his way up the rope that way, but . . . somehow they had something else screwed up, and he wasn’t balanced right in the harnesses. His body started angling so that soon he was horizontal instead of vertical, and then he was declined to the horizontal! I was just about freaking. I suppose he was safe enough with all those harnesses on, but I kept having visions of him falling out of the harnesses and landing on his head! I’m sure the volunteers didn’t appreciate my anxiety-ridden voice squeaking, “Why is he going up upside down? That didn’t happen last year!”

But at last he was on the tower. I ran to the other tower where he’d finish and took pictures of him ziplining (see pics below). And then what does he do after these death-defying feats? He gets back in his wheelchair, goes down a short steep ramp that is the first part of this exit tower, and slides out of his wheelchair! He said he had so many straps on him, he forgot he hadn’t put his seat belt on. Oops! Fortunately, there wasn’t enough room for him to slide all the way out of the chair, and four volunteers got him back into it. They then suggested he let them back him down the rest of the ramp. He took them up on it :-D

Next up was jet skiing, but to do that he first had to pass a water test (that he passed it last year didn’t count). So they took him in his wheelchair close to the lake and then several volunteers lifted him out of the chair into the water (see pic). He passed, turning himself from a face-down position to face-up after they touched him on the shoulder after 20 secs. Most everybody who tried, passed – only saw a few bodies floating on the lake.

So then they got him on the jet ski (see pic), and he and a volunteer went around the lake to get him “checked off” so he could take me out. But, I didn’t like the jet ski we were on. No strap to hang onto. There was a depression way below the seat I was supposed to hang onto. Well, my arms weren’t really long enough, so I had to ride with my back all hunched over and my head banging into Gary’s back (I was afraid I was either going to bruise him or knock some of my neck vertebrae out of alignment; he said he didn’t feel a thing – dark humor) and unable to see a thing. :-(

Next came water skiing, Gary’s favorite event! I got a bunch of shots of it, see below. The driver, a different quad than the one we’d had lunch with, was very impressed with Gary’s skills, said he had great starts and kept a good skiing position. Right after he said he was letting Gary ski longer than he had anyone else, Gary wiped out! Gary was probably getting a little tired about that point, because shortly after that, he wiped out again – though he was being more dare-devilish this year, going over the wake instead of staying right behind the boat. When he went down, he nearly lost his suit! He said it came down to his knees and the volunteer from the jet ski (who was following behind him) had to help him pull the trunks up. I didn't see any little white butt floating by from my vantage point in the boat, however.

Naturally he got some war wounds – after they got him back into his wheelchair they discovered a gash on his leg and one of his little toenails had been ripped right out! Guess that's a good time not to be able to feel such things. And just tonight (May 22) we discovered his big toe is all black and blue. Despite that, he had a blast and is thinking of going to one of the water ski clinics this summer at a lake near the Atlanta airport.

Well, that was enough for the day. So we went back to the van to change, then Gary did his IC, we had dinner there, and then we left for home.

Late the next morning (Saturday), Gary went to the ATV site. They had a new one this year, and he got to ride that. He said he could tell it was much more stable and he felt a lot more confident. A little too confident, evidently. He said the volunteer riding with him told him several times to slow down. He asked her if she was scared. She said, a little. :-D

Pics of him on the ATV are also below.

Next we had lunch, then it was time for scuba! He went to the van to change into his suit, and he got his swimsuit on all by himself! (Getting pants on while sitting in the wheelchair is something he still hasn't mastered, and this was the first time he'd gotten any type of pants all the way on entirely by himself. Long pants will be harder, of course, and when he went to put on his long pants after the days activities, I helped with the last little bit.)

At the pool, the volunteers seemed to be trying to talk him into letting them just pick him up and carry him into the water, but he wanted to do a wheelchair to deck transfer, and he did (see pic below). Then they got him in mask and tanks, gave him some basic instruction and made sure he was comfortable in the water, then let him go swim underwater; he could raise and lower the level he was swimming at by using an air pump connected to the tanks. After a while, someone brought him an "underwater scooter" (a Seadoo) to try. All he had to do was hang on and it pulled him around under the water. Only, at one point he somehow got partway flipped over and was practically zooming around underwater on his back. First the confidence course now this – had some thing during this workshop about being upside down, I guess. (James Bond, he's not.)

Next, we went back to the jet skis, and this time they had one with a strap available, and I had a blast too, being able to hang onto the strap and look (blindly, without glasses) over his shoulder and galloping over the waves (the fast trotting was the hard part). He got up over 50 mph! We later wondered how stable those things were and how fast we dared take it. When we got back to the launching pad, a volunteer told Gary he had hair that said, “I just had a really really good time!” Because of the wind and water spray, it was sticking straight up like a troll’s. He wouldn’t let me take a picture of it, though ;-)

Well, that was enough gallivanting for the day. We went back to the van for a break. Gary did some research, read in the Readers Digest, I worked on my novel (2/3 of the way through this revision). Then came IC time and dinnertime and time to go home.

Tigger was unhappy that we’d both been gone for most of the past couple days, and he climbed into Gary’s hospital bed with Gary and stayed there throughout Gary’s bedtime routine – he hasn’t gotten into bed with Gary in ages. Blackjack was just happy to see his meal tickets were home. (Speaking of Tigger, we are still struggling to get his weight up. At the vet’s suggestion, we supplement his cat food diet with people food – or is it vice versa? So daily he gets grilled salmon or tuna steak or scallops or steak, and the occasional filet mignon or chilean sea bass. He is not nearly as appreciative of this as he should be.)

Thus ended Adventure Skills! You da man, Gary!

On Monday, we traveled to Birmingham where I got a second opinion on my knee (torn meniscus (cartilage)). I am resigned to having surgery on it. I tried for 13 months to get it to improve by rehab. I make slight improvement, then the slightest thing can set it back. I can’t go up and down more than a few stairs, can’t walk faster than a mosey, etc. So, I give up. Am trying to decide whether to go back and forth to Birmingham three more times (for the surgery and 2 follow up appointments), a 2+ hour trip each way, to this guy who regularly does a significant number of these surgeries, or to stay local to a competent surgeon. The surgery is, on the scale of these things, one of the simplest ones (arthroscopic, where they cut out the part of the cartilage that is torn and being pinched in the joint). I feel like getting it over soon.

Anyway, had to wait for 2 hours before seeing this guy. I swear they make you wait that long so you’re tired and your resistance is worn down so you’ll agree to anything they want. But actually, I did like the guy once I got in to see him.

Today, I had an appointment with my family doctor. The previous two visits, he had found me very low in vitamin D (7 and 14) and hypothyroid (4+ and 5.6). This time my D was at 28. Normal is 32 to 100, so at least I’m making progress on that front. Besides the vit D supplement I’ve been taking, I’ve recently been able to tolerate soy milk, and at least the Silk brand is enhanced with vit D, so I think that is helping. The thyroid was a 4.0. Still low, but improved. I’m going to wait and see what it is next time to see if this is a positive trend before going on a thyroid med.

One of these past few days, Gary discovered that going backwards down the steep part of the driveway is easier than facing front (I was with him when he tried this, of course), so that will be the way he does it.

Okay, now you can scroll down and look at the pics! ;-) If you click on them, they will enlarge.

TITLE FOR BLOOK? “ALWAYS FORWARD”

Aug 29, 2008

Gary and I "completed" my birthday celebration this evening. First we went out for Japanese -- sushi, yum! Then I got up the nerve to ask if he'd like to play with me (I'll let you work that out). We had fun until he fell out of my bed (first time he's been in it). Fortunately, we had thrown all the pillows onto the floor on that side, so he had a cushy landing. He briefly worried I'd have to call 911, because he was stuck in a tiny space between bed and wall, and I couldn't lift him. But, we finally managed to make enough room for him to maneuver and get back onto the bed. Then we laughed.

I am flabbergasted and appalled. The accident was on Saturday and they pull the plug Tuesday? Sorry to sound crass, but I find that upsetting. That is hardly enough time for her to know how much functionality she will regain, what she can still accomplish in her life -- think Christopher Reeve, not the fictional Million Dollar Baby. My husband's car accident rendered him totally paralyzed from chest down, and I was closely involved in his rehab. I KNOW quadriplegics can go on to live full lives.

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It is no surprise one's first reaction to finding oneself in this situation would be shock, hopelessness, and depression (yes, even psychologists can experience those). I fear the decision to die was made out of ignorance of the possibilities – I hope I am wrong. But I truly do not see how she and her family could have a comprehension of the possibilities only three days into the injury. I am so grateful my husband had knowledgeable people guiding him like those at the Shepherd Center in Atlanta.

Aug 31, 2008

I am shocked and appalled by a news article I came across on Yahoo! News the other day. A 65-year-old triathlete, Barbara Warren, fell off her bike and broke her neck during a competition last Saturday (the 23rd). Last Tuesday, the 26th, her family – twin sister, husband, two grown daughters – took her off the ventilator because Barbara repeatedly blinked her eyes and nodded when asked if she wanted to die.

3 days after her accident they pull the plug! Sorry to sound crass, but I find that upsetting! That is hardly enough time for her to know how much functionality she will regain, what she can still accomplish in her life. Was she a victim of the fictional Million Dollar Baby? Her family certainly wasn't thinking Christopher Reeve.

Those of you who followed this blog, particularly in its first four months, April-July 2006, know how closely I was involved in Gary's rehab after the car accident that severed his spine (at the T4 level, which left him completely paralyzed from nipple-level down). And hopefully in relating our experiences at the Shepherd Center in Atlanta, it came across that both paraplegics and quadriplegics can make great strides during their rehabilitation and go on to live full, meaningful, fulfilling lives. But goodness, it took Gary 2 months to recover from the accident to the point where he could even begin rehab. And I'd like to here mention again that some of the quads at Shepherd recovered functioning they were never expected to have. You just can't know what your ultimate situation with your injuries is going to be after 3 days. And if you have the worst possible injury, C1 complete, then you can look to Christopher Reeve as your role model.

It is no surprise one's first reaction to finding oneself in this situation would be shock, hopelessness, and depression. But Barbara's decision to die, and her family's quick follow-through only three days in, seems to me to have been made out of ignorance of the possibilities.

I am so grateful Gary had knowledgeable people guiding him like those at the Shepherd Center in Atlanta.

To see the article on Barbara, here are some links. I'm giving you the links that I found that allow you to leave a comment (you may have to sign up for a free account to post your own comment). Most of the people seemed to think it was just fine for her to make this rapid decision, some even compare it to the Schiavo case. Ignorance, to my mind!

http://www.sfgate.com/cgi-bin/article/article?f=/n/a/2008/08/28/sports/s101058D00.DTL

and

http://ca.news.yahoo.com/s/capress/obit_track_warren

In other news, Gary recently went for his check-up in Atlanta. He's doing well, except his doctor (who you may recall is also a paraplegic with a higher level of injury than Gary, being T1 complete) made fun of Gary for still having his "training wheels" on – meaning the tip bars. I told Gary he should have told the doctor that I wouldn't let him take them off (though Gary has no desire too). And speaking of falling . . . they said it WOULD happen, and it did. Gary managed to go for 2 ½ years without ever falling out of his chair, but recently he did. Fortunately, at home, so he slid his way over to the futon couch and got himself back up on that. Couldn't do the floor-to-wheelchair transfer, so he'll have to put that higher on his list of things to practice ;-). And I won't mention him falling out of my bed . . . . :-D

Gary has developed a bit of scoliosis and saw a spine specialist in Atlanta. It's not severe, though. He then went to the "seating clinic" at Shepherd, and they're going to get him a different kind of seat cushion that will hopefully enable him to sit straighter in his chair.

Sep 06, 2 008

Car rental – 25 minutes, down to 20.

May 31, 2009

Time for a little update. On May 15-17, we again went to Adventure Skills Workshop, at Camp ASCCA in Jackson's Gap, Al. The weather did not cooperate – thunder, lightning, rain. With the rule, "No activities until 30 minutes after the last thunder roll," activities were limited.

The weather didn't interfere with lunch, though :-D We really lucked out (I'm definitely not talking cuisine). Introverts, Gary and I are usually dependent on the others at the table to carry the conversation, and somehow we usually end up at a table with others who are similarly verbally-challenged. But at our table this time were a couple of Occupational Therapists from Kentucky, who were all enthusiastic about what goes on at Shepherd and want to create a "mini-Shepherd" in their small hospital. Enthusiastic is an understatement – these two were borderline ditzes :-D. Sorta reminded me of stereotypical pom-pom girls from high school (hope none of you reading this were/are stereotypical pom-pom girls), though one must've been at least mid-twenty and the other forties or fifties. They drew everyone at the table into conversation and kept things lively.

After lunch, Gary did "The Confidence Course." This year, we had more confidence in the attendants – they hooked him into the harness correctly, and he managed to ascend the climbing wall (via pulley system) right side up, instead of last year's upside down. On the blog, http://drpeg2003.blogspot.com/ I have inserted a picture at this point in the text.

Gary was a regular James Bond going up the wall – I couldn't believe how fast he got himself up that rope! He's so much stronger than he was three years ago. But, sitting on top of that thirty-foot tower with his legs spasming, he didn't want to attempt hopping himself to the other edge of the tower in preparation for the zip line, so got some help. They got him attached to the rope, and he flew! Unfortunately, someone stepped in front of my cell phone camera just as I snapped his picture (which I didn't realize until after I looked at it), so no pic this year of the zipline – you'll have to check last year's ;-)

Next came Gary's favorite: waterskiing! We went back to the van and Gary got himself changed into his swimsuit, then we were down to the docks. Gary as usual displayed superb form, keeping his arms low for balance, using his head (literally) to control his balance and direction. After staying right behind the boat for a while, he felt confident to go over the wake. He said he had planned to be more adventurous and move about behind the boat, but the driver only took him around the lake circuit once, whereas last year I'm sure he went around at least three times. Maybe they were trying to get in as many people as they could before the rain hit.

Though I snapped a couple shots of him waterskiing, the volunteers in the boat got better ones. You can see 11 snaps of him at http://picasaweb.google.com/adaptiveaquaticspictures/ASW2009# He is in rows 20-22. Click on a photo to get an enlarged view. Notice the buff arms, the determination in those steely eyes.

(Oops, I checked and only the waterskiing pictures seem to enlarge. Don't know why. But the waterski ones are great!)

I will download a couple of those snaps to the blog here. The jetski following behind him is in case he wipes out.

After the waterkiing came the highlight of the weekend: For the first time ever, Gary got his long pants on entirely by himself while sitting in his wheelchair. Only took him fifteen minutes – plus, he joked, three years. But since the only time he's practiced this skill since Shepherd is when he's been at Adventure Skills (meaning he's only practiced 3 times in the last 3 years!), we thought this a historic accomplishment. Not that I've seen him practicing any more since – still quicker to dress in bed.

Speaking of routine, he noted that "shower mornings" now only take him about 2 ½ hours, whereas when we came home from Shepherd, they were taking 4 hours. Shower morning is only Saturday, though – the rest of the time, it's bed baths.

After dinner, Gary played golf! Well, sorta. They had a tee set up on a dock, where you could hit balls into the water. They had a special club designed for hitting from a sitting position. I was impressed that he could hit it so far, but Gary didn't seem all that impressed. I guess he was getting it about 50 yards with that club – said he couldn't lift the club back any farther. Seeing that the one time I played golf (in high school), I'd either miss the ball entirely or it'd go about three inches, *I* thought it pretty cool the ball was going that far! I am inserting a picture of him playing golf at this point in the blog.

After that, we left for home and got caught in a torrential rain during the drive!

On Saturday, the only activity Gary got in was the ATV, and I will upload a picture of that here. Gary said there was a little excitement on the trail – the person on the vehicle that had left just before him fell off! So Gary and the Shepherd person accompanying him stopped, so the volunteer could help the other volunteer get the guy back on the ATV. The bad thing about that, Gary said, was his volunteer made him drive slower after that. :-(

Then the rain started in again. We had hoped the rain would clear up so Gary could go jetskiing, but, no go. While we waited, a young guy (maybe around twenty) talked our ears off. I found his story interesting, but he did go on (then, so do I, don't I?). His injury is C-level, and when he woke up in the hospital (motorcycle accident), all he could move one was one finger. Then in time, another, and another . . . He's now got about 80% of functioning back in one leg, maybe 50% of the other, and fairly good use of arms and fingers. Anyway, he filled us in on every single detail of his recovery, including how he demanded to learn how to again pee while standing upright, "because he's an outdoorsy kind of guy."

In mid-afternoon, we gave up on the weather, so that was the end of Adventure Skills this year.

The following week, Gary took his first plane ride entirely by himself, and went international – to Toronto! He said the trip was smooth – did a Park and Ride at the Atlanta Airport, and at Toronto was picked up by a taxi service specializing in accessible services. Gary said the only problem was, the taxi guy evidently took his tip bars off to get the chair into the taxi van, and when the guy put them back on, he put them in too far. You may recall this is what led Gary to land on the back of his head one day at Shepherd! Fortunately, for the entire day that Gary didn't notice his tip bars weren't correctly placed, he didn't practice any wheelies.

However, he fell over into the gutter of a street, attached to his chair. (He informed me of this just as we were ending one of our phone conversations, as if I'm going to say, "Oh, really? Well, bye, honey.") Evidently some of the curb cuts he encountered in Toronto aren't well designed. He found them too steep, and as the cut enters the street, there's a crack that runs the entire width of the cut – and his wheel tended to get caught in the cut. So, the first time that happened, his chair got stuck, while momentum carried him forward. His response was to lean to the side, which caused the chair to go over on its side. Fortunately, a husky woman was crossing the street toward him, and she simply picked up the entire chair with him in it (he had his seat belt on) and set it upright. He wasn't hurt. His chair got stuck yet another time, but he kept his weight forward instead of to the side, and the chair didn't tip (as he told me this, I of course am picturing him landing on his face!).

For the entire week Gary worked with another mathematician (Paul Szeptycki) at the Fields Institute, and as well shared meals with other of our Toronto math friends (Juris Steprans, Steve and Karen Watson, Frank Tall, Bill Weiss). On Wednesday, Gary gave an hour and a half seminar, and he said it went well.

On Thursday, he tried out the subway – about half the stops are accessible to those in wheelchairs. His particular stop wasn't, but the next one down was. Other than that instance of the subway and using services to get him to and from the airport, he pushed himself in his wheelchair to his various destinations. He said he could see why many paraplegics develop shoulder problems. In our small town, he doesn't have much need for frequent extended pushes. In Toronto, it'd take him twenty minutes to get from his hotel to Fields, and in addition he'd be pushing himself around to the various restaurants for meals. (One night, he wanted to get pizza from the place next to his hotel. He called, and they said they didn't deliver. He said he was staying right next door and couldn't get into their restaurant because they had a step up into it. They told him if he waited outside their door, they'd hand the pizza to him :-D). On Thursday night, Bill Weiss hosted a party at his place.

Gary underestimated how long it'd take him to push there – and it ended up taking 50 minutes! Gary couldn't get into the house because of the steps, but people came outside into the backyard and chatted with him, and he had a meal out there. Because the weather looked stormy, Gary decided he'd better leave. People offered to drive him back to his hotel, but he hadn't brought his slide board to transfer into a regular car, and he wasn't comfortable having untrained people help him into a car. So he began his push back to his hotel. And got caught in the rain. He said the wind was so strong his rain poncho was nearly being whipped right off him. He pulled in under the eaves of an Indian restaurant to (hopefully) wait out the storm, and the proprietor invited him in and chatted with him for about twenty minutes until the rain died down. Then Gary made a beeline for the hotel.

So, Gary was wheeling around "a hell of a lot," as he put it, and he said he was reminded of the very first time he pushed himself in a chair at Shepherd. We were going from his hospital room to the auditorium in the connecting building. Gary had to take numerous rest stops.

On Friday and Saturday, the Appalachian Set Theory Conference was held at the Institute, and Gary said the schedule was quite grueling: went from 9:30 to 6:30 with a half hour break for lunch and a couple additional 10-minute breaks. Gary enjoyed the conference, however.

Gary's trip home also went very smoothly. Something kind of funny happened at airport security in Toronto, however. This guy was patting Gary down, and he asks, "What's that?" Gary felt where the guy had been touching and said, "My ribs. I'd like to take them with me." Guess the security guy wasn't used to feeling up many thin people.

Once back at home, he unfortunately came down with an other UTI, complete with fever and chills. When he sees his Shepherd doctor in July, he's going to ask if there's anything he can do about these UTIs, which flare up almost always right after his trips. (He is on a daily antibiotic to keep the UTIs under control, but it isn't good enough for the trips. I suspect the doctor will tell him to take a stronger antibiotic while he's on the trip.)

Okay, I think I've caught you up on Gary news. I've still been working on my novel. My previous drafts were likely too long for publication, and I've managed to cut it down from 367,000 words to about 135,000. Then I had to go through and make sure I didn't cut out anything vital (and I did end up adding small bits back in). Gary is reading it now, and after he finishes, I'll give it to my writing group, and hopefully they too won't think I've cut anything vital and will like it even better than they liked the first draft. In late September, I'm going to a writers conference taking place about an hour a way in Columbus, Ga. There, I'm having the first 15 pages of the manuscript critiqued by an agent who also is the president of FinePrint Literary Agency. Keep your fingers crossed that that leads to something.

I sat in on a Fiction Writing course at AU in the spring, and wrote my first literary short story (I suppose Remington Steele fanfic doesn't count ;-)). It's a good story, I believe, and I have sent it to a highly competitive lit magazine. I think I should hear back from them by August. If they don't accept it, I'll send it around to other places. I also wrote my first "short short" story, aka, "micro fiction." It's a complete short story in under 200 words. It also was well received by local writers (and by the couple "email" readers who I've been sending stuff to for years for their comments), and I've sent that out to be considered for publication as well.

This past Friday, I did an "open mike" at our local used book store. Former topologist and current writer Jo Heath conned me into this. She and I both read 5-minute excerpts from our novels, and in addition I read my short short. Gary said I done good, but I have never experienced such stage fright! I have been attending a monthly writers workshop for the last half year (and Jo joined it more recently), and it was at the workshop leader's instigation that Jo and I were giving readings. I expected the audience to be maybe four of us from the workshop, our spouses, a few friends. Well, damn, there must've been about forty people there! I suppose it was some combination of not speaking in front of groups of people for the last 15 years, plus it not being math talk (after all, presumably in math talks people are listening for the facts and aren't there primarily for entertainment) that caused my nervous system to go haywire. I had to keep taking small steps around, because I was literally afraid that if I didn't, I was going to pass out, and my heart was about to burst my chest. Jeez!

After the entire session was over, the store owner asked if I'd read at future such events, and I hesitated, and the workshop leader, who was standing right there, said "Yes." Hmm. It is true that that which doesn't kill you makes you stronger, right?

Jo and then I were the first presenters of the evening – getting it over with – and then the rest of the evening was quite enjoyable, listening to two other readers and two musical acts.

One last writing note. While letting my novel sit awhile, I tried to write another short story, this one based on Gary and my "most frustrating day" in the course of his recovery, the day he got checked out of Shepherd. I though it'd be easy to write, since it was so closely based on experience, but it's turned out to be very difficult to write, and I haven't gotten anything I like yet, though I've been working on it since April. It got me thinking about "the blog book" – the project I've had in mind of turning this blog into a book. I'm not quite ready to tackle that, but am getting closer to the day, and now I'm wondering, how exactly will I organize it? Why type of book will it be? I imagine it'll mostly focus on the year of accident, recovery, rehab, with other milestones noted. But what of this blog of those months should be included, what deleted (besides all my complaints of my noisy hotel neighbors)? Anyway, if any of you reading this have thoughts on this subject, I'd appreciate hearing from you. If you're getting this missive by blog and not email, just go to "View my complete profile" on the right-hand side of the page (yes, I know it's not very complete) and then click the email tab on the left. Thanks!

All for now!

Jun 10, 2009

Gary on campus at restaurant in Student Union: Au Ban Pin, or something. Counter so high couldn’t see where to place his order slip and had to get someone else to get his order for him.

At bookstore, found pens, but couldn’t reach them. Went off to get some notebooks. Salesclerk asked him if he’s finding everything he needs. He said he’s finding it, but can’t reach it.

Gary’s on the Shepherd video, on the ATV at about 4:01 and 1:04.

http://shepherdtv.org/WhatsNewatShepherdCenter/SkillsWorkshop/