

Randy's brother Alan's e-mail updates to family and friends, 2001-2005

(email to Alan from Francine, a second cousin from Greece, and Eric, a first cousin, who called Randy on his birthday in 2001)

Dear Alan,

I received both e-mails you sent to Eric, thank you! I wasn't sure whether Randy was happy or not .. or enjoyed my monologue. I was hearing the nurse, I think, telling him "Randy if you want to talk, just go ahead" but I wasn't sure, I tried to encourage him.. and then I tried to encourage him that it will come very soon, if only he wants to. I reminded him, also, of his promise to take me to Vegas. Don't know what the reaction was but as today is his birthday I will call him and sing to him.. hopefully it won't start raining there.

Thank you once again and give him a big kiss from us.. I could send you a picture by e-mail and you could show it to him.. some funny ones too...

Keep in touch.. and I wish I could be more helpful

Take care, your "cousin"

Francine

December 3, 2001, 10:48am

Dear Francine,

Yesterday we had Randy's (birthday) party. Many people showed up and it was a lot of fun. Randy was smiling and very animated. I gave him a gun that shoots "silly string" and he was shooting it at everyone. He was also throwing and catching a ball. His physical therapist Dave was there and he said that he was with Randy when you called. He said that Randy was very happy to receive your call. In fact, Dave was trying to do therapy on Randy and Randy wanted him to stop so he could concentrate on your call and he was trying to push Dave away with his foot. This made Dave very excited because it was a good advance. Dave now wants to try calling people to talk to Randy while he is working because he gets such a good reaction out of him.



Randy's birthday party, December 2001

Please send the pictures. My father took some pictures, too, and I will send them to you and Eric when I get them. Next time you call, if you don't talk too long, you may want to try asking the nurse to wait and watch his reaction and then ask Randy to hand the phone to her so she can tell you.

Randy cannot talk unless they put a special device on the tube in his throat. But I am trying to get him to practice moving his lips so that they will put the device on.

Take care, Alan

PS: Thank you and Eric for the beautiful flowers!

February 22, 2002, 11:07am

Hi All,

As you know, Randy's surgery to replace his skull was a complete success in that there were no complications or infections. However, I had hoped that it would also help his brain recover to some degree. What has happened is beyond my wildest hopes! It is like the left side of his brain is suddenly turned on again after two years. Randy is talking all day long, in complete sentences. It is hard to understand him because he sounds like he is mumbling, but he will be starting speech therapy today to help improve his enunciation. He is moving the right side of his body now and he is vigorously exercising his left side. I have ordered the staff to put him in a chair each day to get him used to sitting in an upright position. After a few days of that, he should hopefully be allowed to feed himself. I prepared a list of foods that he might want to try first such as apple sauce, mashed potatoes, etc. He thought guacamole and yogurt sounded interesting, but frowned at cottage cheese. Then he instructed me to add a BIG STEAK to the list. He asked me to bring a mirror so he can look at himself and he puts on his black cap to cover his recently shaved head. Yesterday, he looked down at himself and asked me what the tube was and I explained it was his feeding tube. Then, he asked about the plastic thing taped on his waist. When I told him it was a diaper, he was aghast! So, this morning, he promptly climbed out of bed to go to the bathroom! The nurses found him with a bruised foot and leg. He told them in a surprised voice "I can't walk!" Now he is kept in bed with the side rails up, but will start using the bed pan.

On the down side, he is extremely frustrated and angry that he can't do everything normally RIGHT NOW! He is swatting at people that don't understand or deliver what he wants. I am instructing the staff that they need to explain what they want from him and why, in terms that he will see that benefit him--upon which he complies, otherwise he fights them.

Randy is going through so much right now and needs some time without visitors or callers. He needs to adjust and calm down. I have been helping him to de-stress and relax and deal with things, but he is still focused on what he has lost. (When I told him he was a lucky man, he frowned cynically and said "Lucky? Why? Why am I lucky?" I told him God has given him a second chance at life. He should forget about everything prior to today and start dreaming of what kind of new life he wants to have now--and there are no restrictions on his choices).

Randy needs to focus on what he has gained and to be willing to do the hard work and cooperate with the staff in order to recover fully. He is also having

problems with his memory and frequently interrupts me to ask me who someone is or other things he doesn't remember. His memories should improve soon. When he has calmed down and can speak more clearly, I will let you all know when he is ready for visits and phone calls.

Thank you for all your prayers and best wishes, which have clearly paid off.

Alan

March 1, 2002, 1:08am

Hi All,

I'm back from NY. Thanks for all your wonderful replies to my last email. Wait to see the attached picture after you have read this email.

Randy continues to improve. Before I left, he was refusing to wear anything but his street clothes, but today, he was wearing a hospital gown. When I asked him why, he got quite upset and said they took them all away (apparently, they were being washed). I brought him some more clothes and he pointed out that the jeans would be too tight even though he had lost a lot of weight and that one of the shirts would be too warm. When I offered to bring some other things to replace these, he said "You have more?" I said yes, lots. He said "Bring them all!"

In some ways Randy is his old self, but in others, he is off. He remembered that he has several pair of silk PJs and mentioned that he didn't think it would be a good idea for me to bring them, because the hospital staff wouldn't be able to wash them properly without damaging them. On the other hand, he can't seem to remember his therapist's name or some of his old friends. Last week he said he didn't remember having a birthday party, but this week he said he was starting to remember some of it.

I held up a pair of shorts directly in front of him but he was reaching out with his left hand about 2 feet to the left of them. When I asked him if he was trying to reach out and take them, he responded as if I was some sort of idiot. Then he got mad at me because he thought I was holding them out of his reach. Apparently, he is having some problems with his eye/hand coordination. He kept trying to grab the shorts, reaching all around, well away from them. He wears an eye patch, which he shifts from eye to eye as he experiments with his vision. The fact that his eyes don't look out in the same direction is giving him problems. Funny, though, that he can see the TV very well. He changed the channel to Star Trek, turned up the volume and proceeded to ignore me as he watched Captain Kirk fight his evil duplicate. He was able to tell me minute details about what he was viewing on the TV, which shows he can see the screen very clearly. He also mentioned that he had seen the new "Enterprise" show, but he didn't think it was as good as the original series.

Emotionally, he keeps thinking other people are "dumb" or not cooperating with him or are intentionally trying to hurt or anger him. He gets very angry, but when

I explain things to him he understands and calms down. For instance, he was getting very angry with me and couldn't understand why I didn't seem to always understand what he was saying. I finally had to demonstrate how his voice sounded to me by mimicking him. He appeared shocked at the revelation, then got sad and refused to talk, but eventually got used to the idea and accepted that the problem was his and started talking again, this time more tolerant of my difficulty in understanding him. In general, he is much calmer and handles frustration much better than last week. I believe he is still having problems dealing with the world and his situation, especially that his brain just woke up after almost 2 years and he needs more time to get used to things. I have said before that he is like a baby that has to learn how to do everything. Well, I think that also applies to his emotional state.

Randy is very concerned about his appearance. When I tried to take his picture to include with this email he carefully covered up the trach tube with his shirt and adjusted his eye patch. Then he insisted that he be able to view the picture on my digital camera and "approve" the picture prior to it being sent out. He also wanted to know the names of every person I was going to send it to. I couldn't get much of a smile out of him though. After two disappointing pictures, I was bugging him to give me a real smile for one more picture when he gave me the bird instead. His sense of humor is still there too. In the past, when he drooled, I had been nagging him to attempt to both swallow his spit and to wipe it off with a paper towel. So, this time, when I said "swallow it" he started to stuff the paper towel in his mouth and chew it up. Alarmed, I asked him what he was doing. He said "Well, you told me to swallow it!" and gave me his old sly grin.



Alan

March 3, 2002, 1:09pm

Hi Everyone,

Here's the latest on Randy.

His personality and general recovery are accelerating. I can hardly believe the improvement in only the last two days. He now has his old iron grip on the TV remote and will actually transfer it to his right hand (a miracle) rather than put it down when he needs to free up his left hand. He will be starting regular physical therapy next week. I believe he is now over the difficult adjustment phase of his awakening and is ready to start work. Two days ago, he was apprehensive about the therapy and worried it would hurt and cost too much money. Now he

says he wants it—that he realizes it will be uncomfortable and tiring, but he will do it because he wants to get better.

I believe it is now OK for everyone to contact Randy to the degree that you like, but you need to know a few things first. He is still very upset and agitated with the growing realization that his mental faculties are impaired. Randy is very proud and his self image cannot yet fully deal with the idea that anything is wrong with him. He tends to blame everyone else for not understanding what he is saying or knowing what he wants. If he thinks something is not right, it is because someone screwed up or deliberately did something to hurt him or make him upset. He may hit you if you touch him without asking first. He may yell at you and act like you are an idiot if you disagree with him. It is pointless to argue with him on the facts, but with tact and a caring approach he is open to the idea that his memory is “rusty” and he needs to exercise it to get it back to speed. [He got very angry with me and insisted that I was trying to teach him insulting kindergarten things he already knew like the days of the week and months of the year.] In helping him regain his memory I have found that rather than ask him something and then tell him the correct answer after he got it wrong or couldn't respond, I give him hints and lots of time to think about it. I ask him if he wants me to tell him the answer before telling him. It is not so important that he regains the memory as it is that he gets the mental exercise and develops the ability to remember on his own.

The most important thing is not to overreact to his obvious memory and reasoning dysfunctions. There is a very good chance that these are temporary anyway. Some mental impairments may be permanent, but only time will tell. Researchers know that the brain atrophies over time just like muscles, especially the ability to imprint and retrieve new memories. So it is normal for him to remember some obscure things from his past very well and other everyday things not at all. Both his long-term memory and his new short-term memories are like swiss cheese—full of holes. If he doesn't remember you, you should certainly NOT take it personally. It is not a matter of caring or interest—he didn't choose which memories were lost. Anyway, I haven't seen any indication that any of his memories are permanently lost, I think they are just hard to get to and sort out for the time being. So, when he says something crazy, just ignore it. If you want to correct him, do it in a friendly, matter-of-fact, non-patronizing way. Please—most definitely avoid acting in any way like it is “sad or tragic that the poor guy is mentally disabled.”

Here are some examples: He sometimes mixes up his memories, both in fact and in time. He insists he has never had his teeth cleaned and feels that it is too expensive. When I told him his insurance was paying for it he was very surprised. I believe he is confusing it with the teeth whitening procedure which, two years ago, he told me he was looking into. He insisted that the movie “An Officer and a Gentleman” he was watching was called “Jake and the Fatman.” When I corrected him he got angry and said that I was confusing this movie with another one. He also insisted that Jack Lemmon in “Grumpy Old Men” was Steven Seagal—I believe because he saw Lemmon crash through a window.

He is not yet fully aware of his present situation and may think he did something yesterday that he really did several years ago. He told me that in the morning one of the therapists drove him around to look at houses to buy and he found one, but it needs a lot of work—apparently he is confusing a therapist with a real estate agent. He also insisted that I let him know precisely what time his new therapy was going to start on Monday because he was very busy and had a lot of things to do and places to go—he couldn't possibly be stuck at home all day waiting for them. I could not convince him otherwise and finally told him I could only give him an approximate time frame just like the cable repair guy. Since Randy used to be a cable guy, he found this acceptable.

I eventually got him to remember the date and place of his birth without telling him, but he insisted I was wasting his time because he would never need such trivial information. He does not remember much of anything that has happened over the last couple years and so had a hard time believing it was actually 2002 and not 1999. He also insisted he was 39 and not 41, although he eventually accepted both facts. If you ask him, he will probably tell you he is 35, but that has nothing to do with his memory.

So, I hope you see that what might appear to be “crazy” is actually just disorientation after being asleep for 2 years combined with a rusty memory retrieval process. I hope you do find the time to call or visit Randy when it is convenient and please don't be nervous about it. If anything unusual or interesting happens, please let me know.

Regards,

Alan

(email from Alan and Randy's Uncle Karl, March 3, 2002)

Dear Alan,

One of the problems about his grasping things in front of him might be because he has no binocular vision i.e., sees only with one eye at a time. I can sympathize with him as I have lost fine depth perception and when putting clothes on the line to dry, I have to watch the clothespin as it goes over the line and damp clothes. If he has not lost the use of one of the nerves that govern the motion of his left eye he MIGHT benefit from an operation that they use to help children who have crossed and divergent eye problems.

[re: Muscle recession or advancement.] Only an ophthalmologist can tell you.

Aren't you glad you didn't use botox on his legs? Is there a phone number that connects directly to his room?

Uncle Karl

March 3, 2002, 9:21pm

Dear Karl,

To contact Randy, call (949) 499-7113 and ask the nurse to transfer the line to Randy Hall.

I'm thinking that with the right side of his body suddenly "active" again, he will eventually be able to regain full control over the muscles that control the movement in his right eye. With therapy he may fully bring that eye back on track with the left one. There has been remarkable increase in his ability to see out of his right eye over the last 2 weeks, as well as increased movement in his right eye, leg and hand. I think the problem is that his right brain may have gotten used to operating on its own and so the two halves are not yet communicating/coordinating with each other adequately. I will explore the surgery option if needed after several months of therapy. When he uses his eye patch to cover his left eye, he does not seem to have the perception shift problem. Also, over larger distances, he is able to see well, i.e., the TV. I know he has severe double vision. I believe he is associating his left image with what he is trying to touch while focusing on the object with his right eye--hence the reaching to the far left of the object and not understanding why he can't grab it. I am trying to teach Randy to use your "clothespin" technique--looking at his hand and the object with the same eye and then moving them together. Currently, he will only reluctantly move his hand to the right based on my prodding. He is very skeptical of my advice and tends to insist that his hand is reaching in the correct place and it is I that am playing a trick on him somehow.

Yes, thank you again for the advice on the Botox. Sometimes it seems like modern medicine is still in the stone age.

Alan

May 22, 2002, 9:25pm

Good news everyone!

Randy has been improving in many ways recently.

His trach tube was removed from his throat a few days ago. He will have a little difficulty speaking for a while until the hole heals shut. His feeding tube will be removed soon.

He is eating regular food and feeds himself without any assistance.

His memory is gradually getting better and he doesn't get as upset when he can't remember something. He has had some time now to accept his situation and he is committed to improvement.

His eyes are starting to focus together a little instead of looking in completely different directions all the time.

His hand/eye coordination is greatly improved in his left arm and the right is getting better too.

His legs are getting more and more stretched out and stronger. Yesterday he actually stood up briefly on his left leg!

Randy was transferred to another facility today. It is a nursing home. He will stay there until his legs are fully stretched out and then hopefully be transferred to a full-fledged rehab hospital. He doesn't have a phone yet, but when I get it set up, I will let you know the number.

Hope all is well with you.

Alan

May 26, 2002, 1:07pm

Hi everyone,

Randy is staying at Lake Forest Nursing Center, 25652 Old Trabuco Road, Lake Forest, CA 92630, Room 511. From the 5 freeway (south of the 405 intersection) take Lake Forest north (left) a few miles until you pass Trabuco Road. Immediately turn right into the little street Old Trabuco Road. The facility is on the left side. Visiting hours are 24 hours, but requested 9am to 8pm.

The main phone number is (949) 380-9380. Randy's number is (949) 951-3367. He is now able to pick up his phone and return it to its base by himself. It may take him awhile to get to it, though (give it no more than 20 rings out of consideration for his roommate).

Randy continues to improve. His memory is coming back slowly, but some of his memories and skills are gone for good.

His strength is returning, he is more alert and has more energy. He can do things like write his name and correctly dial a number on the telephone. I handed him a new TV remote and a new telephone and he was able to read the buttons and use them quite well without any assistance at all.

The physical therapists at Lake Forest are pretty good and Randy likes them. He is anxious to start up again next week. He is upset that his legs have contracted some during the transition.

On the down side, the facility is all elderly, many long-term. Many of the patients wander the hallways in a daze. Randy is rather graphic in his negative opinion of his roommate (a really sweet old character named "Red") and the other patients.

Because of the brain injury, some of the worst aspects of Randy's personality are manifesting themselves. He is unable to handle any kind of stress because of the injury and his personality is generating most of it. When everything is going just right, he is happy. If anything is wrong, he can become extremely angry and agitated. More often than not, he imagines something is wrong. He has memories of things that needed to be taken care of and does not remember that they were resolved, so he gets very upset about them. He also imagines problems that never existed and becomes hysterical when no one believes him, pleading with them angrily that the problem needs to be taken care of. Perhaps because of the financial problems he had when he had the heart attack without any health insurance, he is concerned about money and questions the cost of

everything. His math skills are weak to non-existent and he has trouble judging appropriate costs for things.

His short-term memory is seriously affected and he is unable to remember names or numbers. His memories from before his injury are often quite good, but he has a lot of difficulty making new memories. I have requested he receive therapy to improve his memory. This consists of games and memory aids such as pictures with names written next to them. It is much like the stuff used in primary school to teach children. I have also requested a psychological evaluation to see if he would benefit from that kind of therapy. I believe he would. He needs to be reminded to use stress reduction techniques, to try to calm down and not get out of control. He is often paranoid, believes people are stealing things from him, and feels some of the people trying to help him are "assholes." He needs help in regaining a grip on reality and to re-center himself on the things that matter most in life. Please do what you can when calling or visiting. Also, if he should act in an inappropriate manner, do not hesitate to correct him sternly. I don't believe anyone should cater to him or make any allowances, or ignore things. He is like a child and is now learning what is appropriate behavior. Putting up with anything inappropriate or worse, showing him that yelling will get him what he wants faster, will not be doing him a favor.

Take care,

Alan

May 31, 2002, 3:28pm

Hi All,

Randy has been moved to another room (125A) and has a new phone number (949) 206-6927.

Apparently, he was agitating his roommate, Red. He may be moved again soon if he doesn't get along with his new roommate. Apparently, he has been throwing his TV remote controls and breaking them. He told me that it was his roommate that was throwing them, but that is highly unlikely. I got him some wireless headphones so he can turn up the TV loud without bothering others and hopefully, they will muffle the sounds of people in the hallway that really gets on Randy's nerves.

I talked with a friend whose "twentysomething" son was in a coma for over 3 years. She said he also went through a similar angry/frustrated phase for about a year. She said it is quite common with people that have been injured on the right side of the brain, but less common and/or not as bad with left brain injured patients (like Randy). Her son was biting people and she was even afraid for her and her daughter's safety on several occasions. Her son got so bad, word got out and she wasn't able to find any hospitals in Southern California that would take him. Fortunately for her, her ex-husband found a place back east (where he lived) that would take him. There, they drugged him up with tranquilizers all the time. He eventually got over it and today her son is a real sweetheart.

The resident doctor at Lake Forest told me yesterday that she is going to try to find another hospital that will be able to provide "more intensive" therapy, but I suspect the nursing staff just don't want to deal with him.

The hospital has also stopped allowing Randy's private rehab therapist to practice there for "legal" reasons. I believe it is really due to some internal politics and the fact they are not making anything off of his work there. I am meeting with the hospital administrator next week to discuss the issue.

On the plus side, over the past week Randy has been showing tremendous improvements in his cognitive abilities--thinking, reasoning, and remembering.

Take care,

Alan

July 3, 2002, 8:54pm

Good news everyone!

I have managed to find a rehab hospital that will take Randy. He is very excited about it and can hardly wait. There, he will get three hours of therapy a day instead of one. He will be around younger patients working on similar problems. The staff will be more used to brain injured patients. The whole atmosphere will be more focused on getting better toward going home. This facility even has an outpatient outing program where disabled people can go sailing, jet skiing, horseback riding, etc. using special harnesses and trained assistants. I'll let you know the details after the move.

Randy continues to improve. After fighting with the insurance company for months, I finally got him the expensive special splints for his legs and he is using them daily. It really hurts and he hates them so much that he has them taken out of the room when he is not using them because he can't stand the sight of them. But, he is using them, and they are working. He is gaining more flexibility and his legs are even starting to get bigger and stronger. I ordered both the tubes (throat and stomach) removed and the holes are gradually healing shut (like a pierced ear hole will grow shut if you remove the earring).

Randy's ability to handle stress without getting angry and agitated is improving with the administration of a mood-altering drug called valproic acid. I am teaching him techniques to stay calm and collected when things don't go his way, to put minor issues in perspective, to not see everyone as an "asshole," and reminding him that being nice is often a better way to get what you want than yelling and demanding.

He still has some vision problems as his eyes don't point to the same thing, but they are getting better. From what I have learned, the surgical technique of correcting this problem is far from perfected, so I hope that we won't have to resort to that.

Randy has been asking about what happened while he was in the coma and was shocked to learn how bad off he was and how many times he came very close to dying. He asked what happened to him that caused the coma, but I refused to tell him what I know because I want him to remember what happened and not confuse my theory and evidence with real memories. To show how far he has come, he understood and accepted this reasoning immediately upon hearing it. Randy swears he has learned his lesson, and that he will have a better life this time around and will not indulge in the self destructive habits that led him to his present condition. Time will tell.

His coordination is also improving. The other day, I brought him some sushi for dinner. He not only ate more than I thought he would be able to, he actually carefully ate each piece one at a time, first dipping briefly in the soy sauce and then popping them into his mouth, USING CHOPSTICKS!! He never once used his fingers. He is able to call me (several times a day) on his own telephone without any assistance with the dialing. Next time I see him, I need to remind him not to call me after midnight!

His ability to make and recall new memories is getting better and he is remembering more and more. He recently asked if I had kept the battery charged in his Mercedes parked in his garage. I had to tell him the lease expired last year and I had already returned it to the dealer two years ago in any case. He was utterly heartbroken and expressed that that was the most tragic aspect of his injury by far! Randy is definitely back.

Take care,

Alan

July 31, 2002, 8:52pm

Hi everyone,

Randy continues to improve. He is getting 3 hours of rehab a day: Occupational (daily chores), Physical (stretching and strengthening), and Speech (social skills, memory, problem solving). Although he only has the use of one arm, I taught him how to use his left foot to steer his wheelchair while he pushes the wheel with his left arm. Although he tires after a short time, he is able to go down the hall and turn corners by himself! He is able to put his own shirt on (mostly) and fully shave himself with his electric razor.

He is still in a lot of pain from his contracted right leg and I am working on getting him Botox. Botox deadens the nerves where injected, allowing the muscles to relax and stretch out. The muscles recover after a few months. He is getting better at using his right arm and hand just by working them during therapy. I believe that when they get well enough to use for simple tasks, Randy will use them and the recovery will speed up considerably.

I am concerned about his mental state. He is getting more and more aware. While this is good, generally, there is also a downside. For example, he is more

aware of others around him and is even starting to offer help and encouragement to others in his group sessions! But he is also becoming compliant with his situation. He seems more calm and content to lay in bed and watch TV. He has expressed anxiety about leaving the hospital and going home. He does not believe he is going to be able to take care of himself. He refuses to wear his braces unless I am there to twist his arm and he often refuses to fully participate in therapy. Just a few weeks ago, he would often demand to be taken home immediately and try to walk out himself. He used to say he would be walking in 4 weeks--tops and throw himself wholeheartedly into therapy. He is still openly sarcastic with his caregivers (and me) but has toned down his verbal abuse a little. He no longer yells at and openly makes fun of the other brain injured patients (in front of them), but does occasionally makes jokes about them to me. Yesterday, he made a positive comment about someone being a "funny character." This is a great improvement.

Randy went through a phase where he would refuse to take any medicines. I found out he was afraid someone was going to give him something to dope him up like a zombie (like in the bad psychiatric wards on TV) because he was always acting up and insulting the nurses. I solved the problem by giving him a list of the approved medicines. Each time they would give him his meds, he would check the list and verify they were ok. After a while of doing that, his memory got better and he is able to do it without the list!

Of course, Randy's mental improvement is a good thing overall. He said that he is actually glad that his injury happened because it was a big warning sign that his life was not right, that he was on a self-destructive path. He has sworn off alcohol for life and when friends call and joke around about the good old times "partying" he tells them he doesn't want to be reminded of all the drinking he used to indulge in.

Attached are pictures of Randy taken yesterday. The first is Randy pedaling the arm cycle machine. This teaches his arms to work together.

Alan





A lot of Randy's day is taken up with physical therapy. It's painful, but he's coming along very well.

August 28, 2002, 4:01am

Good news everyone!

Randy is getting amazingly better, especially his mental processing. He is pushing himself around the hospital by himself. He looks up his schedule posted on the wall and takes himself to his therapies at the appropriate times. His right arm and hand are really getting better, almost normal. The other day he made tacos in the kitchen in the OT room (that was something the two of us thought up to do since the hospital food is so bad). His math skills are basically normal. He has been questioning me about the business and all the changes I've made. At the rate he is going, he may return to completely normal mental functionality. Ironically, he is getting increasingly negative about his condition the better he gets. The hospital shrink says that is exactly what you want to see because that shows he really understands his limitations, and that is the last step in his recovery. He does need more work to focus on the positive, however.

Ok, now the hard part. Warning: if you don't want to hear upsetting news, don't read any further.

He went in for his test today. The doctors had already decided that Botox would not work and that the only recourse was to "release" the muscles in his leg and allow it to straighten. After my pleading they finally agreed to try a test to determine if maybe Botox might work after all--or prove that I was wrong and it would not work. The purpose of the test was to simulate the effects of Botox by "paralyzing" his legs so that it could be determined how much of his leg contractures are caused by the active signal from his brain to contract the muscles versus an actual "permanent" shortening of the muscles and ligaments resulting from long-term contracted positioning. By anesthetizing his legs, the doctor could pull on them and see how far they would straighten.

The drug may have migrated too far up his spine and paralyzed too much. For whatever reason, he complained he "felt weird," then he said something weakly but I couldn't hear him so I bent forward and asked to repeat it. He said he couldn't see anything. Everything was black. I noticed that his pupils were dilated and then he stopped breathing. I told the doctor immediately that he had stopped breathing, but it seemed like ages that he lay there motionless with his black eyes open, staring at the ceiling. The doctor lifted his jaw to open the airway and he started breathing again. His blood pressure had fallen to critical levels. They brought the crash cart over and got the defibrillator ready, but with some IV fluid and an injection of neonefrain to constrict his blood vessels, his blood pressure gradually came back up.

Then, as he became more conscious, he realized he couldn't feel anything or move anything from his waist down. He forgot about the purpose of the test, and even though I repeated it again and again, he got panicky and scared that he was somehow permanently paralyzed. His upper body started twitching and shaking uncontrollably. His skin was cold and clammy. He was crying. It was tough, but he (and I) eventually got through it.

When we got back to the rehab hospital, I treated him to take-out tacos and he seemed to forget all about it. As far as the test result is concerned, it indicated that the majority of the contracture is "permanent." This is not what we hoped for, however, I believe the doctor is willing to order the Botox anyway. Even if we can get his right leg only partially straightened, I believe it will be enough to allow some functionality and will be better than permanently cutting the muscles away from the bone and rendering the leg limp and useless. Now begins the long hard fight for approval from the health insurance company.

Wish us luck. Alan

September 7, 2002, 12:21pm

Good News Everyone!

After more than 2 months, I finally pinned down the ENT doctor to set up a firm appointment to seal up the hole in Randy's throat so that he can talk normally without having to use his one good hand to hold it closed. It has been very frustrating for him to try to talk on the phone because he could not cover the hole and hold the phone at the same time. I couldn't really make out much of what he was trying to say over the phone and he would cry in frustration. The surgery is next Thursday. I think it will make a big improvement on his morale.

Randy's memories are gradually coming back and he is re-learning the appropriate choice of words as he interacts with people that are smart enough to understand what he means and considerate enough to point out the appropriate way to say it. He is also starting to restrain himself from inappropriate behaviors, especially commenting about how he feels about people in front of them. I am enjoying his unrestrained favorable comments however, and hope he doesn't

stop any time soon. He told someone yesterday that he wants to learn to be a better person, a nice, kind person—just like his brother!

Randy has progressed to the point where he is able to be somewhat mobile. I bought a used Toyota Camry at an auction (at about \$3,000 below market value and \$1,800 below average dealer cost as listed in the Kelley Blue Book) and brought it over to the hospital yesterday. The hospital had told me these were good cars because they are easy to get in and out of and the wheel chairs fit in the trunk well. Anyway, we took a short training on how to transfer from the wheelchair to the car seat and back using a flat board as a bridge. I had to track down the doctor to get permission for a "10 minute test drive" and we took off. Randy was very apprehensive about leaving, but once we got on the road, he, of course, insisted we stay out as long as possible. We went to an inexpensive sushi place that I like to frequent, but when we got inside, Randy would have none of it, so we went to a fancy all-you-can-eat Japanese restaurant. There, we spent over 4 hours sampling every kind of delicacy you can imagine.

As always, I took every opportunity I could to make a therapy session/learning experience out of it. For some time now, I have been really working with him a lot on his negativity--getting him to recognize when he is thinking negative thoughts and then to replace them with positive ones. Last night, when he said "The table is too low, I can't get my legs under it!" I told him that was negative and to say "The table is lower than the ones in the hospital, but I'm going to try to fit under it." He said that and then he tried and he did it. He looked so surprised, then turned around and shook my hand.

In addition to what Randy considered excessive lecturing he also got upset with me about my nagging him about his eating a lot of fried foods and my refusal to allow him to have wine, but we still had a lot of fun in spite of it. It was, after all, a celebration of the milestone of his first time out of the hospital since his injury. We had a few logistical problems, but we got through them with excellence. I intend to take him on more trips and will use this as an incentive to get him to work harder on this grooming habits, behavior, and use of his right arm and leg.

Let me know if you have any ideas for day trips for Randy. I found an internet site on this disabled lady artist that has an incurable disease. She set up a program to provide special stainless steel wheelchairs with big round tires that can be used to take people on the sand and even in the water at the beach. The lifeguard stations have them. You just have to call ahead and reserve one.

Take care,

Alan

September 20, 2002, 5:07pm

Good News Everyone!

I took Randy over to see his house in Laguna Niguel on Sunday, September 8, 2002.

He told me he did not remember his house at all, but as we drove closer, he said he recognized stores and other landmarks. Then, as we drove up his street, he was able to pick out his house from the others on the block.

He toured the house and kept telling me that everything looked so much like his old house. He was amazed at how “similar” this house looked compared to the one he used to have. He was very impressed with my construction skills that I was able to build a house so much like his—down to the fine details. I kept telling him that this WAS his old house, but it didn’t sink in until after about a half hour. When he finally grasped the concept he said it felt very strange, very weird. Apparently, being there must have been like going back in time or reliving an old memory that he wasn’t sure was real or just a dream.

He was utterly blown away by simple kitchen utensils that he remembered using. He got very excited when he picked up a kitchen timer and turned the dial. He said “This is mine, it rings, it rings!” and then when it did he practically jumped out of his skin in excitement.

We played a game where he had to tell me which things were the same and which things I changed while he was in the hospital. He got it right almost every time. Since I made a lot of changes to the bathrooms, he didn’t recognize them at all. He knew the windows were all new. He thought I installed the tile floors just like he had planned to do them, although he actually did them himself. He remembered his refrigerator, but was confused about the stove. It looked like the one he had purchased, but he thought his was a different brand, so he concluded this one must be something new I put in.

He remembered his den the best, with his sofa and bookcase and especially his cigar cabinet. He was very excited to see it again, but very upset and angry when I told him I doubted the cigars were any good after so long.

His bedroom invoked the most intense emotions. He was very excited to see one of his old paintings on the wall and could not believe that his little night stand next to his bed was still there, just as he remembered it. He didn’t remember the bed spread or sheets at all, but he remembered the bed frame very well. He said he had it for many years and it was a good bed, but he wanted me to get rid of it. He said he didn’t think he could ever stand to sleep in it again. As he sat there next to the bed he actually shuddered. [Note: This section deleted due to police investigation.]

In the garage, he stared longingly at his wine cabinet, but agreed it needed to be sold. He also agreed that we should get rid of all the wine paraphernalia.

After visiting his house, we went over to see the new store in Laguna Beach. On the way, he pointed out landmarks and mentioned that I needed to get him a nice convertible sports car—not right away, but when he moves back home.

He liked the new store and especially the name, Muse. Although, he was very sad that he had missed out on fixing up and opening the new store himself.

Strangely, when he recognized some of the fixtures in the store had come out of his attic at home, he got angry at me for “stealing” them. He also showed some jealousy toward me and made some spiteful comments about the store, but the next day he called me to apologize for it. He said he thought I was doing a good job with the business.

We ate dinner at a restaurant down the street from the store. Unfortunately, they sat us next to the bar. Randy stared at the bar and the bar patrons for a long time. He told me he wanted a drink very much, but he agreed that it was not a good idea. He had some difficulty with eating at the table and dropped his food a few times. This made him cry very loudly and then he said he was sorry he was acting so badly in front of everyone, but I told him not to worry, he wasn't embarrassing me at all. I told him not to be concerned about what other people thought of him or what he thought others were thinking of him.

On September 12, I took Randy to the hospital to have the hole in his throat sewn up. It was supposed to take an hour, but took two and a half instead. He seemed fine when he came out. He was happy and relieved. He said they put him out and when he woke up it was all done. However, about a half hour later, the right side of his face started to get puffy looking. I thought he might be having a reaction to the anesthetic, but it seemed like a long time after the surgery for that. By the time I got the nurse to come, his face was really looking swollen. He looked similar to when he was first brought into the hospital almost three years ago, and that really stressed me out. When we finally got a hold of the doctor, he said that the inner stitches must not have sealed his trachea completely, and because the outer stitches in his skin were sealed air tight, air must be leaking under his skin. Apparently, Randy had gotten used to blowing out of his throat over the last few years. Now, every time he exhaled, air was pumped into his face under his skin. While the doctor was coming over, Randy's neck, face and head grew to nearly the size and shape of a basketball. His eyelids were as big and round as golf balls. He couldn't open his eyes at all. I was very upset and angry and wanted the doctor there NOW. Just before the doctor came, Randy started complaining he couldn't breathe. His voice was getting very high pitched, I guess from the pressure. He got panicky and then said his chest was hurting really bad, like a heart attack. The nurse ran an EKG. Then, the doctor finally came. He quickly pulled the bandage off and started pulling some of the stitches out. Randy was writhing in pain because there wasn't time for anesthetic. Then the doctor did something that I will never forget as long as I live: he put his hands on Randy's face and squeezed. The red air started bubbling out of the wound in his throat like he was burping a Tupperware container. He kept squeezing his face and neck and his eyelids to get the air out. It didn't seem real—it was like some kind of weird Hollywood special effect. With most of the air out, the doctor bandaged up his throat and said he would be fine. Although his face was still swollen, he said the remaining air would be reabsorbed within a couple of weeks. The EKG turned out to be normal. Apparently, some air had accumulated under the skin in his chest, causing him to feel painful pressure similar to a heart attack. Randy looked and sounded just like the aged Marlon Brando with a lisp. He says it didn't hurt, but the experience

wiped him out and he slept the whole next day. I'm pretty wiped out too. But, we finally did get his hole sealed up, so that's one less thing bothering him.

Whenever I used to talk with him on the phone, the hole in his throat would hiss so bad, I couldn't understand him. He used to cry in frustration. Now that is fixed. Next, his legs. I have also asked the doctor to refer him to a neuro-ophthamologist to examine his eyes.

Randy no longer has to wear diapers and he intends to ask the hospital staff if they will let him use the Jacuzzi or pool as part of his therapy.

Randy has recently decided that my name is Steve and he has trouble remembering my real name when I tell him it isn't. He has a lot of problems with names as well as picking out specific words. If you are able, it would be great if you could send me a digital photo of yourself, preferably a head shot. I will compile the photos into a "directory" with names for Randy to study and refer to. If you can't send a digital photo, then please mail a photo and I will scan it in myself. My address is 4236 West 166th Street, Lawndale, CA 90260.

This weekend, I plan to take Randy to the zoo. I'll let you know how it turns out.

Thank you all for your words of encouragement. I'm sorry I don't always have time to respond. But I do appreciate it. It helps me keep going.

Take care, Alan

September 25, 2002, 3:25pm

Good News Everyone!

The pain management doctor finally wrote a letter recommending Botox and sent it to the case manager at the hospital. The case manager was very surprised because he had told her previously that he would not recommend it. He told me that too. But I got him to agree to do the test anyway. When Randy failed the test, it seemed to put the last nail in the coffin. But, I can be very persistent and persuasive and I eventually succeeded. Now, the case manager will try to get the insurance to approve it too, but she says it is almost certain that they will deny it. No problem, just more work for me.

Randy and I went to the San Diego Zoo last Sunday. We rented a motorized scooter and Randy was able to ride it all by himself. He did very well--he only ran into me three times. He was not shy about asking (telling) people to move out of the way so that he could see the exhibits--taking full advantage of his handicap. We also hit on some ladies we met there. I think that was an ego boost for him. He had been worrying about his appearance and thought maybe people would laugh at him.



We only saw about half the zoo because of all the logistical problems (bathroom/eating), but we had a good time nonetheless. It was a little frustrating for Randy in not being able to make out many of the smaller animals (his eyes). But, we did see the pandas and the



usual assortment of lions and tigers and bears. Of course, Randy was overjoyed with the time he spent in the petting zoo section. The attached files show Randy petting goats

and sheep. Having baby chicks eat out of his hand was just pure heaven.



Take care,
Alan

(Alan's response to his Uncle Karl)

October 26, 2002, 12:03pm

Yes, Karl, Randy is suffering from disuse shortening which will not (fully and immediately) respond to Botox. His right leg also suffers from continued cramping and spasms--I believe from disuse. He also has a lot of pain in his right knee, but there is no evidence of any calcification. His right arm used to be the same way, but now he uses it regularly and has no more pain or spasms in it, although he still has limited range of motion and control.

He can voluntarily move his right foot about 6 inches back and forth, but it can be stretched about 18 inches (with some pain) when he is able to relax it. There is severe pain and limited flexibility when he fights the stretching, which he does as a result of the pain--a vicious circle. He receives regular doses of Vicodin for pain control but he is becoming increasingly desensitized to it, requiring larger and larger doses. The pain killer also affects him mentally, interfering with his cognitive therapies.

His left leg has three times the range of motion and he can stand on it for up to 3 minutes if he has something to hold on to for balance.

I believe with localized pain control and relief from continued spasms and active contractions that he will tolerate traditional physical therapy techniques of manual stretching and wearing a spring-loaded brace while sleeping. It may take a couple of years, but I believe he could regain full or nearly full range of motion with such treatment. The doctor pushing for more radical surgery (permanently cutting the tendons from the bone) argued that my idea would cause Randy to "waste" 2 years of his life in therapy.

Randy was there in the meeting and responded that he would be willing to do therapy for even more years rather than spend the rest of his life "crippled."

I am, however, looking at surgery to partially lengthen key tendons and ligaments as part of the solution. The idea is to use this to allow him to place his right leg all the way down onto his wheel chair and his foot down fully on the ground while sitting. Theoretically, this will allow him to gain some functionality with his leg and encourage him to use it, just as he did with his right arm. Also, because his right leg is suspended up in the air while sitting, his muscles and tendons must bear the weight of his leg all the time in order to avoid the pain of stretching.

Thus, he is actually contributing to the pain from fatigue and also increasing the contractures. Being able to rest his right leg down on the wheelchair and relax the muscles should significantly help the situation.

Thanks for all your help.

Alan

November 13, 2002, 8:20pm

Hi All,

I just got a call from my father. It seems Randy has been complaining to him about me. Of course, my father was very happy for the opportunity to criticize me, as he believes that is the most important function of a parent. Funny though, that none of what he said had anything to do with what Randy has said to me. It all sounded exactly like the same things he has been criticizing me about for the last 40 years. It is a shame that when I report that Randy and I are having difficulties, instead of getting support or help, I am told that I am the problem.

Randy doesn't like being told what to do. He doesn't like being dependent on anyone he can't control. He certainly doesn't like it when he is told that his view of things is incorrect. Given that I am his principle point of contact with his affairs—the one that takes care of everything—I'm not surprised that he sees me as the source of all his problems. However, it is unacceptable for anyone *e/se* to tell me that I am not doing a good enough job.

I have been fighting the "system" on Randy's behalf for almost three years. I have begged, pleaded, nagged, pushed, and even harassed many professionals along the way. I have been told that I am delusional, that what I am striving for

is clearly impossible, and that I am a compulsive perfectionist. Perhaps all comments are true. But, damn it, I have also been willing to do the work and make the personal sacrifices to see the impossible happen. Had I gone along with half of what I was told was the "correct" and "customary" thing to do, Randy would still be in a coma or worse. His business and home would be gone and all of his assets would have been used to pay medical bills. I feel like I have paid for it all by prematurely aging. Randy gets a good laugh every time a nurse or doctor assumes I am his father or that my father and I are brothers. It happens a lot. I haven't taken the time to take adequate care of myself. I have been trying to nurture a support network for Randy, but let mine die off. I am working on the edge.

The hardest struggle is getting Randy to do what he has to do. It is very stressful to be trying to help someone and have them not only not appreciate it, but also treat you badly for your efforts. The director of rehab therapy at the last hospital freely admitted that she had stopped trying to stretch his leg out some time ago. She said that he refused to do it and she frankly didn't feel like going the extra step to motivate him when he was subjecting her to verbal abuse--specifically, being called a "fucking bitch." At the time, I didn't appreciate what she was saying. I told her he was brain damaged and couldn't help it. I asked her to ignore his behavior. She said I was not in a position to judge her. I now understand. Randy must modify his behavior if he is to function well in this world. The world will not cater to him as he wishes. It just doesn't work that way. For example, some of Randy's problems with his leg are his own fault. He was telling me all the while that he was doing the therapy. He lied. He admitted later that he thought that it was all just some "bull shit" I made up. He was convinced that there was some surgery or drug that would make it all better, so why do the work? The meeting with the orthopedic surgeon (the one where he was told he would never walk again) got through to him. He now says he will do the work and I believe him.

I am trying very hard to motivate Randy to do what he needs to do and teach him what he needs to learn. Am I tough on him? Yes, at times, when I feel it is necessary. I also admit I am not perfect, but I AM doing the best I can. I don't need and I don't have the energy to both take care of Randy and deal with well intentioned, but unconstructive comments.

Thanks for letting me get this off my chest.

Alan

(Alan's response to his cousin's encouragement)

November 15, 2002, 8:45pm

Hi Eric,

Thanks for your kind words of encouragement. I really don't feel like I've wasted the time spent looking after my brother. It has been gratifying, even if Randy doesn't always appreciate it. When he gets home, he will have an attendant to

take care of his daily chores. My workload won't decrease because he is already getting this level of care at the hospital, it will actually *increase* because he will be more mobile (ask any mother if her workload decreased when her toddler first learned to walk!). The good news is that he will have more freedom. His attendant will drive him around wherever and whenever he wants. Randy will buy his own food and prepare it with assistance. He will be able to entertain guests and visit friends. I intend to gradually give him work to do and responsibilities as he is able to handle them. It will be a struggle, because he will want to take on everything immediately.

I am learning to avoid saying things to him about certain important matters rather than argue with him about it. For instance, yesterday he told me he absolutely did not want the Botox injections because he believed he was going to be able to stretch out his leg all by himself within a few weeks (he said that based on one successful day of therapy). I said "fine," and continued to plan for the Botox anyway. Today, his leg was sore from the prior day and actually pulled back. He changed his thinking completely and now wants the Botox. I used to feel uncomfortable about this sort of "scamming" as he would put it, but it is necessary. He is, after all, brain injured. I have a tendency to put that out of my mind and treat him as you would any other adult. He is somewhat paranoid, and often accuses me of holding back information. He demands to see everything I sign on his behalf and wants to know everything I do all the time everyday. The funny thing is, I always told him the complete truth and opened everything up for discussion before. Now, in order to avoid an argument, I intend to avoid some of his queries and make unilateral decisions as appropriate.

On the other hand, for matters not so important, I intend to let him make more decisions and learn from his mistakes. For example, we recently spent an entire day driving around to various furniture stores looking for two beds and chests for his two bedrooms. He didn't see anything he liked except for a decorative piece with no practical value. I suggested that since we only had two days before he went home with the attendant, perhaps I could find something myself. He got very angry and announced that if he didn't like what I got he would throw it out into the street. Fortunately, I lucked out and got him into another hospital. If this situation were to come up again (very likely) I intend to tell him he can use the couch, a cot, and some cardboard boxes until he goes out with the attendant and gets something himself. Hopefully, he'll pick out something on our next trip, but I'm not going to sweat it.

BTW, on our last furniture buying trip, I made a deal with one of the sales people at an exclusive store to sell Randy's wine collection for a commission. She had just broken up with her long-time boyfriend and moved to the area looking for some fun and a new life. She was very friendly and extremely attractive. Randy insisted I let him hold her card and then later, when we got back to the hospital, refused to give it to me or to copy the information from it. Some things never change.

Latest update: Randy is very happy with the new facility and the people there. I had coached him to make a very good first impression and he was amazed at

how well it worked. I told him that if he was even nicer to the people there that they would be even nicer to him. His eyes got big and with a wide grin said that was "the greatest scam in the world!" His therapy is going very well and he goes to sleep every night very tired and feeling like he really accomplished something. Yesterday, he was asked to do some volunteer work helping to teach an elderly woman to play a senior version of volleyball. She was very grateful and Randy felt so good about the experience he said he would like to make a career out of helping people like that.

Always open to suggestions,

Alan

December 24, 2002, 10:03pm

Hi All,

Randy and I wish you all a merry Christmas and a happy new year. Randy wants to remind everyone that his phone number is (949) 295-9448 (hint, hint).

I finally got Randy his Botox shots. The shots are supposed to begin to work on Christmas day (amazing coincidence), so that is Randy's gift from me this year. His right leg has already started to drop down and drag on the floor when he is in his wheel chair. Despite his irritation at this, we have high hopes this means the Botox will work.

I also took him to the eye doctor recently. Unfortunately, Randy is not a candidate for corrective surgery at this time. The neuro-ophthalmologist said that he could adjust his eyes to point to the same spot when Randy looks directly ahead, but if he moves his eyes off center at all, then the eyes will no longer be in sync and he will experience "visual confusion." The solution for now is to get him glasses and put scotch tape over the right lens. This will make the view fuzzy and his brain will quickly learn to ignore what he sees from the right eye. This will allow him to have normal vision in his left eye without having to wear an eye patch, which can cause an eye infection. Randy spent a considerable amount of time picking out just the right pair of frames, of course, and he should be able to see much better by the end of the year.

Randy should be going home around the middle of February. We hope that the Botox will have started working by then so the insurance will continue to pay for outpatient therapy to get him to walk. If it doesn't work, we will try to find something else, possibly surgery, and pay for it ourselves. Either way, he goes home at that time, if not sooner.

Randy's memory and logical thought processes are improving daily. It really is a miracle how well he has gotten recently. Randy and I are getting along much better now that he has mellowed out a bit and become more considerate of others.

I have resolved to start taking better care of myself, so I will be joining a gym shortly, and am looking to buy a nice car befitting a single man of my status. I

have also started to plant some flowers in my front yard, which has languished as a large pile of dirt for the last few years. Life is good.

Happy Holidays!

Alan

February 7, 2003, 12:57am

Good news everyone!

Randy is now home. His home phone number is 949-661-7604. I built handicap ramps and took the doors off the inner rooms so he is able to get around quite well. He is busy opening up his boxes of stuff and putting things away. He has an attendant, and therein has been a problem. He doesn't feel he needs an attendant and is very mean and grouchy to the two that he has had in the last three days. He yells obscenities at them and treats them like slaves. The first one quit right away. The second is a very seasoned southern black woman who doesn't put up with much. She had me saying "yes um" to her within a few minutes of arriving!

Randy is very disappointed that his return home, which he dreamed of for so long, is not what he expected. He had this fantasy that when he finally got out of the hospital (the "prison" he woke up in) that his life would somehow be just like it was before his injury. He is angry that it isn't. He has been treating me very badly too, yelling and hitting me and he does not feel that I should have any say in any of his affairs any more. At the same time, he has been demanding that I make his house perfect and hang up all his paintings immediately. I have been going to his house almost every day for the last 2 weeks and am very, very burnt out. Every time I think I can have a day off to work on the huge backlog of business that was put off over the last several months, something comes up, like having to fix the toilet or take Randy to the doctor or fix a medication problem. The idea was that the attendant was supposed to handle these types of things, but this has proven unrealistic. Legally, the attendants are not even allowed to dispense medications, but this is widely ignored in practice.

My father has made the problem worse by telling Randy that he does not have to do anything I tell him, unless of course, it is really important, like taking his medicine. However, he feels that it is up to Randy to decide what is important and what is not, so the end affect is the same. He got Randy worked up against me so bad I couldn't handle him at all. I told my father if the second attendant quit and I couldn't find another, I was going to leave Randy on his door step. He got upset and said he would call the police and have Randy taken away if I did, and then charge me with abandonment. My father also does not have the time to do anything to help me, but likes to pop in unannounced to disrupt my plans. He has wasted several days of my time so far. He refuses to coordinate anything with me and has no respect whatsoever for what I am trying to do. For instance, the second day Randy was home, there was not enough food in the house for lunch. (My father prevented a trip to the grocery store the night before.) I arrived

around 11:30am to take Randy and the attendant out to lunch and then the market as planned, but Randy refused to go, saying that his father was coming over. I called Abby and he was adamant that I stay until he arrived. He didn't arrive until 1pm and then spent a half hour slowly putting some groceries he brought away, taking the time to hold up and describe each item. When he was finally done, he berated me nastily for "letting Randy starve well past his lunch time" and then said thank god he had showed up to feed him as he made a grand spectacle of bringing a take-out lunch out of the car.

Another example was last night, when I couldn't leave with Randy and the attendant because Randy said his father was coming over. I needed them to take me home so that they would have the car I bought for Randy at Randy's house for the attendant to drive. So, I still have the car. Because of this I told my father that he would have to take Randy to the lab for a blood test the next morning instead of me. [I drove through 2 hours of rush hour traffic the day before to take Randy to the blood test so he wouldn't have to go too long without eating (12hour fast required), but when I arrived he had just finished breakfast!] My father agreed to take him, but called later and told me it would not be possible and I would have to come over to do it because his wife had refused to allow him to use the new car my father had bought her to transport Randy because he might damage it in some way! Give me a break! My father lives only 4 miles away from Randy and the lab is only 2.4 miles from Randy's house. I live 65 miles away.

When the second attendant, Wanda, declared she was quitting this morning, I was at my wit's end. There were no other attendants available, so I was going to have to move in with him until one could be found.

Even if one was found, it would still take me a day to train them and watch them long enough to be sure they were ok. Either way, I was literally too fatigued to make the drive, let alone do the job. The business has also been starting to tank without my attention. I told Randy he HAD to get along with Wanda and to stop treating her so badly or he would be left there alone. He said he wanted to be alone and he would be happy to treat her even more badly if it meant she would quit sooner.

I cried and God heard me and He gave me an idea. I asked Wanda if she would stay another day if she didn't have to do anything except give Randy his medicine on time and make sure he didn't get hurt. Otherwise she wouldn't have to lift a finger and could goof off. She said OK. I told Randy that I agreed with him that maybe he really didn't need an attendant, but the court would not approve unless we could offer evidence that he was able to live home alone. I told him that if he could go for 24 hours without ever once needing the attendant to help him that I would see what I could do to make it permanent. He agreed. He no longer had someone to do things for him every other minute. He suddenly had to do things for himself. It was very hard for him, but he managed to change his pants by himself for the first time. He did, of course have to ask for help to go up a ramp and to help him up after he fell out of his wheelchair. But he also managed to feed himself lunch too! He was disappointed to discover that,

contrary to his prior belief, he really did need someone to help him. You see, he was holding on to the belief that, if he really tried, he could do everything by himself and this fantasy had comforted him even as he demanded that everyone around him do every little thing for him. Now, hopefully, he will be able let go of the fantasy and start seriously working to gain his independence. Hopefully too, he will appreciate the things I and his attendant do for him a little? We will see.

Alan

February 12, 2003, 4:47pm

Hi Everyone,

Well, it worked. Randy now agrees that he needs an attendant. The problem is that they are unable to deal with his behavior. Wanda quit suddenly, forcing me to go over and spend the day with him until someone else could come over. He got another older woman that was really great. She would laugh and joke around with Randy all the time. Randy told me he wanted me to hire her on a long-term basis. However, after a few days, she couldn't take it any more and she has now quit too. She told me that based upon her 20+ years experience, she didn't think anyone would be willing to put up with him for more than a day or two. Randy's thinking process is warped, and he changes his mind frequently. Although I am able to understand the "logic" of his actions, others are not able to and to them, he acts "crazy"--which is exasperating to them as they try to do his bidding.

Even with the attendant there, I have to intercede over the phone several times a day to deal with some sort of crisis or argument--usually something petty. For example, the third attendant moved some stereo equipment I had haphazardly scattered on the floor in the corner of his room. She just wanted to clean the floor and carefully replaced the equipment in basically the same way. However, when Randy noticed it was arranged differently, he threw a screaming fit because she "touched his stuff." I was not able to calm him down over the phone and he hung up on me. A short time later, a repentant Randy called me to tell me she had quit. He said he apologized several times, but she was too angry and wouldn't listen.

Randy has the judgment and temperament of a 5 year old with the force, determination, and mannerisms of a scowling 42 year old man. He is easily insulted if he is talked to in any way that he feels is treating him like a child. He lacks a basic level of common sense. He does not think through the likely consequences of his actions before acting or saying something. He also doesn't think of anyone but himself unless he is reminded to do so. The worst problem is that he refuses to admit to anyone or even himself that he might have forgotten something or maybe remembers something incorrectly. He refuses to acknowledge he might be wrong and will not listen to logic. Bottom line, he says he doesn't care if he is wrong. What he wants is what he wants and it's as simple as that. He became sensitive to having people do things he didn't ask for at the hospital and now that he is at home (in his castle) he finds it hard to deal

with anyone there. He feels like a piece of the hospital nightmare has followed him home to invade his privacy and generally torment him. Because of his injury, he is unable to handle the stress of arguments or anything or any situation that differs from what he wants.

Well, I have to rush off now. The attendant had promised me she would wait in her room with a locked door until morning for the new person to show up. But she just called and said that Randy was shouting "bitch" and "whore" through the door, so she is leaving now. I have to drive through an hour and a half of rain to spend the night there and then meet the new person in the morning.

If anyone has any suggestions as to what can be done to improve the situation, I am very open to hear them--please!

Alan

March 13, 2003, 7:19pm

Hi Everyone,

I found this article on brain injured people that really describes Randy better than I could. If you have the time, it is interesting and easy to read. I would say Randy is in the anger/depression stage with bouts of denial and testing. He is sometimes able to make fun of himself, which is a very good sign. I look forward to him getting to the acceptance stage. To that end, we will be attending a support group where he can meet other brain injured people.

Randy continues to improve. He is learning to do many new physical things. His leg is not responding to therapy as well as we had hoped, although it is improving. Randy has decided that he doesn't want to wait any longer and now feels that he wants surgery for his leg. He says that he would rather walk "like a cripple" than be confined to a wheelchair.

Alan

[Link to Article: Emotional Stages of Recovery](#)

April 11, 2003, 6:48pm

Good News Everyone!

Randy continues to improve. He goes to physical therapy every day and his right arm is much better. His left leg is straighter and stronger and he is now able to "walk" several feet using a walker for support. I am trying to get another, larger, dosage of Botox for his right leg. The first two treatments did help improve his flexibility. It is still too early to tell if surgery will be necessary. At times, Randy has been getting impatient and has been demanding that he have his tendons cut. But he is thinking that it is some magical procedure that will make him instantly whole again. When I tell him of the downside of the procedure, he gets discouraged and says he doesn't want it.

Randy still vacillates between two extremes of either relaxing in luxury and having people do every little thing for him, and working to improve his abilities toward more independence. He gets very angry when I bug him about eating less (he is very overweight) or doing things for himself. It's stressful and draining. He yells at me a lot and it seems he is angry at me and unappreciative most of the time. Yet, when I ask him if he wants me to stop and let him do as he pleases, he pleads with me not to stop. He says he wants me to push him because he wants to get better. I got very upset recently when I found out that his last attendant had disregarded my order to not "baby" Randy and had been doing way too much for him. Randy actually lost some of his former abilities, mentally and physically, like getting out of the car by himself—because of too much assistance. The problem is that they try, but he throws such a fit when they tell him to do things for himself that they always end up treating him like a little baby and do every little thing for him. People on the street also tend to want to help him do everything, like opening doors and even pushing his wheelchair for him. This makes him feel that he needs the help and can't do anything for himself. In his mind there are two kinds of people. Those that are nice and offer to do his every whim and bidding, and those "assholes" that tell him the only way he is going to get better and eventually be independent is to do things for himself.

Randy is mostly bored during the day. He goes to therapy, doctor appointments, and grocery shopping (every day). He has too many groceries at home as he buys way more than he uses. I have him take the car in for maintenance and cleaning and other chores. I need more ideas of things he can do by himself with his attendant driving. I've tried suggesting things to do, like shopping for new furniture, but he doesn't take the initiative to do things unless I set it all up and remind him about it.

I have taken him into the pool on several occasions. He was very afraid at first to let go of the hand bar by the stairs, but now he is fairly confident. He is able to walk using the water to hold him up and he can even swim. I make him swim or walk 4 lengths of the pool before I let him relax in the hot Jacuzzi. He always complains that he can't do it, but he always does it and is happy for it. The pool work is helping him with his balance as well as improving his overall strength.



Recently, I took him kayaking in the harbor canals in Belmont Shore and two days ago we went sailing out in the ocean off the coast of Long Beach. See pictures. I am planning other activities soon. We also want to go to Disneyland again, with some other friends (hint, hint) to share the time with. It's great to be able to get on all the rides without ever having to

wait in line. I believe Randy's awareness of other peoples' feelings and to understand things from their standpoint (empathy) is much improved since the last time we went.



Randy still has a problem with his self image. He is getting along with his attendant much better, and that is a big relief to me. But he still has this feeling that not being able to walk and having memory problems means he is a "cripple" and he believes people are laughing at him behind his back. I am taking him to a brain injury support group twice a month and he has met several other survivors of brain injury. They tell him that he is going through denial just like they did and



he needs to move on. I believe he is encouraged by these people because many of them were in a wheelchair like him and now can walk. Some can drive, but most still live with their parents. One brain-injured lady told him the reason that he thinks others are laughing at him is because that is the way he feels about brain injured survivors. She feels he needs to get past his prejudices in order to accept himself. Randy will start seeing a psychologist within the next couple of weeks. Hopefully, that will help.

I signed Randy up for a special program for brain injured survivors at the local community college ([ink to Coastline Community College's ABI Program](#)). It is a nationally recognized program that helps improve memory and teaches other daily skills for living. I hope he is accepted. Most of the survivors at the support group are graduates of this program and they appear to have benefited very much from it. Randy was surprised to learn that some of the "normal human people" he met there were actually brain injured.

Randy has now decided that he is ready to take care of a cat. Earlier, he had turned down my offer to get one because he wanted to "fix his leg" first, but he has changed his mind. We are going to visit the local shelters in May (kitten season). He can hardly wait and cries at the thought of having one. We need one that is a tough cookie to keep away from the coyotes—and its tail out from under the wheelchair. It also needs to not be shy about reminding Randy of its needs.

Take care,
Alan

June 29, 2003, 10:57am

Good News Everyone!

Randy continues to improve. He has been living at home now for a few months and has adjusted well. He spends his days in physical therapy, shopping, going out to interesting places, and entertaining friends. He will soon be starting a special college program designed to teach brain-damaged students better occupational skills, like reading, writing, cooking, personal finances, memory skills, etc. It is 4 hours per day, 5 days a week for 2 years. I met several graduates and they were very enthusiastic about the program. Randy is very

excited to start. I have cut his medicine down to less than half with his doctors' blessing. He now only has to take pills twice a day, which is much more manageable, and he is much less impaired by the side effects, one of which is being hungry all the time.

I have mixed feelings about Randy "getting used to his disabilities." He no longer cares about doing the physical therapy to stretch out his right leg and prefers not to use his right arm. He was walking for awhile using a walker, but he won't touch it now. He has dropped out of going to the gym as he used to and no longer cares to swim in the pool. He prefers to have people do things for him rather than do them for himself. I believe he equates it to receiving love and attention. When I try to tell his attendant not to do as many things for him or when I insist he do things for himself, he feels I am just being mean to him. Of course, I do it out of love. When Randy lets others do things for him, he not only doesn't get better, he actually loses his ability to do things. First, he forgets how and then his body forgets and loses its strength to do the task. After awhile, he claims he was never able to do the task without assistance. It has proven impossible to stop this situation, as most people around him feel they are helping him by doing things for him. It makes both of them feel good, but meanwhile, he slowly loses sight of his original goal of self sufficiency. Perhaps the school will help. Perhaps I just have to let go and accept whatever happens.

Randy had been nagging me angrily and unmercifully to turn control of the business back to him. I told him he had to take it one step at a time. To get him started, I had him take over his personal checking account and pay his bills for awhile. He did a good job, but complained that it took him too long and he wasn't pleased with his handwriting. He insisted I take the job back. When he called me in the middle of the night complaining of chest pains and claimed he was having a heart attack because of the stress of the task, I relented. He then decided that the only part of the job running the company he really wanted was having the keys to the cash boxes! Yeah, right! I already give him a 6 figure income and he burns through it like an internet startup. He has very expensive tastes.

I have had to learn to stop bugging him about things / feel are important, like his eating habits. He has gotten worse without my pressure, but found his own equilibrium. For instance, I used to bug him all the time about eating greasy foods and candy bars. He simply hid the candy from me and ate his cheeseburgers away from home. When I gave up, he ate more for awhile until he realized himself it was excessive and cut back on his own. I am concerned about his health, but nagging only worsened his health from stress, and mine too.

Randy has decided that he wants the surgery which will cut some of the muscles away from the bone and let his right leg pull out straight. With therapy and exercise, he should eventually walk, albeit with a cane and a limp. The doctors say he probably won't walk, but that is ridiculous. Randy previously was not willing to accept any type of limp, but now realizes that people don't automatically look down upon "gimps" and "cripples." He has even found that he can use his

disabilities to get whatever he wants from people and does not hesitate to put on an act of helplessness to gain attention.

One bit of good luck. Six months ago his neuro-ophthalmologist told me that he was not a candidate for corrective eye surgery. His right eye, affected by the coma like his right leg, will not move in sync with his left and gives him a “crazy eye” appearance. He also cannot use both eyes because of double vision. However, contrary to the doctor’s prediction, his eye did improve as I insisted and he is now eligible. In the simple, one-hour procedure, the horizontal muscles which hold the eyeball in place (and move it side to side) are cut away from the outside of the eyeball. They are reattached in different places, so that the eyes are pointing in the same direction. It is essentially the same procedure as having the two front wheels or headlights on your car aligned. The muscles quickly reattach themselves to the eyeball and the sutures dissolve. If the alignment needs to be fine-tuned in the future, the procedure can be re-performed without undue complication. At first, when he looks to the far right or left, he will get double vision again, but his brain will be able to work on the problem once the surgery has resolved most of it, and he will tend to see better over time. He has also been getting his teeth fixed, which were messed up by the blows of the attacker. The eye surgery is scheduled for this Monday.

I am very proud that Randy has been able to resist the urge to drink alcohol. This is a common problem of brain damaged people who didn’t even drink that much before their injury. There have been a few times when he tried to convince his attendant and me to let him have some “feel good” pills, but he didn’t get them and he learned he could make it without them. Randy has been seeing a psychiatrist and a therapist for a few weeks now. The therapist has been able to get through to him where I had not about seeing life in a positive, rather than negative way. It is frustrating to me to have him believe it when she tells him something, where he would not accept it from me, but I am also very glad he is finally getting it. He still feels in his heart that I am the enemy, that there is some sort of competition and that anything bad that happens to him is automatically good for me, and vice versa. Accordingly, he believes he should do the opposite of whatever I tell him to do and assumes whatever facts I tell him are most likely a lie. Any kind of logic or evidence I care to offer is just some sort of trick to deceive him. He told me that he remembers as a little boy that his parents were constantly showering me with love and attention while he was always ignored, or worse, considered a loser, a pain in the neck obligation to be tolerated. He believes it was my fault, that I engineered it to get all the attention he should have gotten.

Secretly, without my knowledge, Randy visited his old friend, Lisa. He wanted to get more information from her about what happened to him just before and after his injury (she was the last person to see him before and the first to see him after his injury). Randy had just dumped her a few hours before the attack. She has no alibi for the time he was injured. She convinced the police that she was his loving fiancé and that they had planned to be married soon and that she was the hero that rescued Randy and took him to the hospital. When the hospital told her

the police would investigate, she claimed Randy did not want an investigation, that he had in fact been doing something wrong at the time and was not a victim of a crime. When she was told that the police *had* to investigate, she went to his home and cleaned up all the blood and discarded or laundered all the bloody bedding and clothes. She used Randy's cash, which was still spattered with his own blood, to buy new bedding. She deliberately avoided contacting any of Randy's family or friends for the first three days he was in the hospital and then later told the family that she tried to call, but she didn't have anyone's phone number (she had Randy's cell phone with all of the family's numbers in it; the hospital staff themselves finally called the family). She used her position as "fiancé" and "hero" to deliberately lie about several key aspects of the events to the police and led them on a wild goose chase following up on things that never actually happened. Hers were the only fingerprints found at the crime scene other than Randy's. She told several people that Randy "had it coming" and that "when he is drunk, he makes you so angry, no one could help but hit him." She also told someone recently that she thinks Randy "faked the whole coma thing to get attention." The lead detective refused to investigate Lisa and refused to consider any evidence against her. He said that she was the fiancé and the one that saved his life by taking him to the hospital, so she could not possibly have any motive to harm him. He added that it was physically not possible for a petite young lady like Lisa to have cracked Randy's skull with her fists. (He said my idea about a sudden, rage-filled drunken bedroom attack with a convenient large glass ashtray was a crazy, far-out idea. (Randy's big art glass ash tray, the one he kept by his bed, is still missing). He said the most likely scenario is that Randy was in a bar fight that he himself started (Lisa's story). When I found evidence that Randy was home all night, he said Randy most likely was trying to rape someone that he picked up at a bar when he was hit in self defense. (Hello! Randy was home the whole evening, you idiot!)

Then he said that Randy was most likely the victim of a random attack by a "one-time" serial killer that followed him home from a bar. (Hey, moron, how could he have been at a bar IF HE WAS HOME ALL EVENING????!!!!) Ok, then, the serial killer randomly selected his house to go to and then somehow convinced Randy to let him in at 2am (and *my* theory is crazy and far-out????!!!!). The investigator refused to release any information to a private detective, making that option impossible. He refused to close the case which would have made the files accessible public records.

He has since been demoted to jail guard, for undisclosed reasons.

Randy did not believe anything I told him about it and wanted to hear it from a trusted friend: Lisa. Apparently, their meetings did not go well. According to Randy, Lisa told him she had been conducting her own investigation and had a lot of evidence that pointed the finger at someone else, but she did not have the time to show it to him then. When he insisted on seeing it later, she told him she did not like the way he was talking to her and he should not contact her again. He has given the whole matter a lot of thought and come to the conclusion on his own that Lisa is most likely responsible for his injury. He also realizes that he did

indeed treat many people very badly and that this was most certainly a contributing cause of the attack. When I asked him to think of people that might have a grudge against him, he came up with Lisa first, but also too many other people and too many other reasons, and this scared him. He keeps the burglar alarm on at night and sincerely desires to be the kind of person that everyone will like and want to be around.

As for me, I am currently working, seriously, in excess of 110 hours a week as I had to fire one of the store managers in April for embezzlement. I was hoping to promote the assistant manager, but she quit (she was a close friend of the manager). So, I had to do both their jobs myself. Then the lead sales person I wanted to promote to assistant manager got another job because I didn't promote her to manager. However, in spite of all this, with me running the store, sales are up 53%. I will start training the new manager tomorrow. In a few months, she should be fine and I will be able to tackle the backlog of my regular work. Having Randy home from the hospital has also been very stressful for me. It's been one crisis after another. I have to be ready to drop everything and deal with the latest disaster at any time, night or day. I am a physical and mental wreck, but I think I can see the light at the end of the tunnel.

On the lighter side, Randy picked up a new kitten from the local shelter. She has



very unusual coloring, has huge ears, and rarely makes a sound. She has gone through a few names and currently lacks one, but she is a happy little ball of fur and claws. She trained herself to use the sand box, and has quickly assumed her God-given role of master of the house. Randy loves her very much.

Randy's friend, the music director of the Pacific Symphony, invited us to attend a performance recently, which was very nice. Randy got us past the guards in to the back stage area to meet the performers afterward.

I took Randy fishing recently and he caught 5 fish, although none were legal size. He will quickly, and truthfully, add that his brother caught none. We enjoyed it and will go again soon.

Wish Randy luck with his eye surgery. I'll report back on how it went.



Alan

September 12, 2003, 10:12pm

Hi All,

I apologize for not writing sooner. It has been very tough on me recently, with the huge work load from having to work three jobs in the business and dealing with Randy out of the hospital and getting into some sort of disaster every other minute. Also, my computer crashed and I had to do without for awhile, plus I lost some very important data that had to be recreated. I am now up and running on a new computer and after converting my living room into an additional office, plan to hire some office help. Perhaps I may even have time for some fun at some point??

Randy continues to improve. He started a special school recently. There were a lot of forms to fill out, medical records to obtain, a long waiting list and lots of tests, and, of course, Randy was adamant about not going, but it all came together and.....he loves it!

Before, he was surrounded by "normal" people and he just kept comparing himself to them and feeling screwed and angry about it. Now, he is around others like himself and he realizes just how lucky he really is. The first week, everyone took their turn talking about themselves and how they came to be there. Some would talk about being in a coma for a few days, a few as long as a few weeks and one, a couple of months! To this, the rest of the class and the instructors would ooooooh and aaaaah in amazement. When Randy casually mentioned being in a coma for two YEARS, everyone's eyes opened wide and mouths dropped. Several told him he was mistaken, that it was impossible. Randy told me that all of the people in the school that were in a coma for more than a couple of weeks are much worse off than him. He is really amazed at how well off he is. He is now also very much more appreciative of me and what I do for him. It is a real pleasure to be around him.

Randy is very excited about getting better in the school. The first day, several graduates came by to talk about how much they benefited from the two-year program. The existing students also rave about what they are getting out of it. Randy is very hopeful for the future now that he is on a formal path to improvement. He is also more aware of the world around him and is not so suspicious of everyone. He is not so distrustful of me anymore either. On the other hand, he is more appropriately skeptical of strangers. His judgment is also improved.

As you know, Randy went into surgery for his eyes a while back. The muscles that move his right eyeball side-to-side were cut off and sewn back on in different positions so his eyes would point in the same direction. The alignment was much improved, but not so he could see one image. A few days ago, he went in for the left eye and now, his eyes are almost completely in sync. However, his eyes have not had any practice focusing on the same image for three and a half years. He needs to strain a little to focus his eyes together on one spot so he can see clearly, but with practice, he should have normal vision soon. It was a little funny at first, because he was terribly disappointed with his vision when he took the bandages off after the second surgery. I told him over the phone that he would have to try to focus on an object and that the double vision wouldn't go away by itself. But, he said he tried and tried but could not do it. Apparently,

before he removed the bandages, Randy had replaced the scotch tape over the right side of his glasses that I had removed during his second surgery! When he took the tape off it was a "miracle"! Randy felt quite foolish at his blunder, but was very happy indeed at the outcome.

As I mentioned in the last email, Randy had given up on the physical therapy. I did not bring up the other option (cutting) as I wanted him to reach that conclusion on his own. He did, and I even tried to talk him out of it. He has decided that he is willing to be cut and knows that it will permanently weaken the muscles in his leg. The Botox injections and physical therapy did wonders for most of his body, but his right leg is still partially contracted. Surgery will involve partially cutting the muscles and tendons, stretching them out and then casting til they heal in the longer position. Also, some full cutting may be necessary. Randy's leg will be weakened, but he should be able to stretch his right leg out enough to walk, even if he has a limp. So far, none of the surgeons has expressed much hope for him to actually walk, but then, they don't know him very well, do they?

One last thing, after a first attempt aborted when he fried his computer with a well aimed glass of orange juice, Randy now has an email account and would like it very much if you could send him an email. Pictures are especially welcome. Randy has not yet mastered reading the email and you should not expect him to be able to send email back for awhile. But, all in good time. His email account is: ComaDude@aol.com

Cheers,

Alan

November 12, 2003, 11:31am

Hi everybody,

Randy was complaining of soreness in the right side of his neck. He has two shunts (plastic tubes), one on the left and one on the right side of his head. They allow excess cerebral-spinal fluid in his brain to drain out and run down into tissues in his abdomen where it is absorbed by his body. When I checked the right one it was swollen. Then he showed me the large bump on his chest which had appeared the day before. It was at the end of the shunt and was bright red.

Well, I took him to the emergency ward immediately and we found out it was, indeed, infected. This is very serious because the infection can travel through the tube and get into his brain. It was precisely such an event that caused Randy to go into a long-term coma in the first place. The doctor tested the fluid coming out of the left shunt and we are waiting for the results now. If the fluid is infected, then the left shunt, the 6 inch diameter piece of his skull, and the metal plates holding the skull piece in will all have to come out and be replaced. That is very serious. However, I believe that the infection is confined to the right shunt. I think he will be fine. I will let you know when the results come back.

The surgery to remove the right shunt went very well. They had to make a quarter-sized hole to get it out, but that won't be a problem as long as he doesn't get poked there. The tube was full of pus and it is obvious that it wasn't working anyway; that is, no fluids were draining out for some time. The doctor feels that the bacteria must have been present in the shunt from when it was installed three years ago and it just took this long to get as bad as it was. This right shunt was in fact the fourth one to be installed as the previous three had to be removed shortly after installation because of infection. It was during the course of all those surgeries that the infection got into his brain and caused the coma. Randy is doing fine, but of course not at all happy about being back in the hospital. He was afraid that when they knocked him out for the surgery that he might go back into the coma, so he was very relieved when he came out and it was still 2003.

He is staying at St. Joseph Hospital in Orange. His number is 714-771-8000 ext. 3202

He will be there for a week or so for observation and to take massive doses of antibiotics. Please wish him luck!

Thanks, take care.

Alan

November 21, 2003, 11:02pm

Hello Everyone,

To continue from my last report on Randy, he returned from the hospital and was put on a 6-week course of antibiotics. I was frustrated, because they still hadn't been able to identify what the microorganism was. I asked how they could know what antibiotic to use if they didn't know what the bug was. The infection specialist got upset and told me I didn't know anything about it, so I had to put him in his place. Anyway, a nurse came to the house every day for an hour to apply the infusion.

After a few days, Randy started to act very strange. He was becoming increasingly agitated and incoherent. He began to complain that he couldn't see very well. His memory was worsening. He got to the point where he was violent, throwing things, yelling obscenities, and he trashed his house out of anger and frustration. He was paranoid and completely out of touch with reality. He threatened to kill me on several occasions. I was distraught. All the work and progress over the last year were melting away in a few days. It got a lot worse. If you placed something in his left (good) hand, he would continue to yell at you that he wanted the thing, not recognizing that he was holding it right in front of his face. He complained that it was too cold—because he didn't realize he was running around naked. He forgot how to go to the bathroom. He lost the ability to recognize where his arms and legs and other body parts were in space. He complained that his phone didn't work because he was holding it so the speaker and microphone were pointing away from his head. He was not able to feed himself and had to be spoon fed. To help him, I tried to point out the things he

was doing wrong, but he would just go berserk because he didn't believe me. His attendant took off without notifying me. Randy said she left because she was sick and had to go to the doctor, but I know she was lying. She just couldn't handle it and abandoned him.

I called the doctors, but they insisted that he must have had one or more brain seizures and there was nothing that could be done. They said it would clear up soon. But, it didn't seem that he had had seizures from what I knew of them. I examined him over time and noticed that the left side of his body—the good side—was becoming increasingly paralyzed. I figured out the reason he couldn't see was because his left eye had become bad (he said he could see with it, but he didn't seem to understand what he saw through it). I told the doctor that had removed the shunt on the right side of his head that the infection from the shunt must have come out during the surgery and penetrated into his brain through the hole in his skull. There must be infection or swelling or both on the right side of his brain that was causing the problems. It seemed to me that Randy's symptoms were identical to the ones he had when he first went into the coma four years ago, only on the other side. He said that was impossible and that I was overreacting.

I called his old neurologist, and got him to do an emergency EEG. The EEG showed that the right hemisphere brain waves were abnormally slow, but there was no indication of seizures. At that point, I told the neurosurgeon that I was going to take Randy to the emergency ward. He then agreed to schedule CAT scans and said if I went to the emergency room, it would actually take longer for him to get the scans. I didn't want to wait til the afternoon for the scheduled scans, so I took him to have it done in the morning. I pleaded with the lady at the desk and got him in right away.

The doctor examined the scans and was very surprised. The worst had happened: infection had taken over about half of his right hemisphere. As I had insisted, the antibiotics were not working. I suggested that the doctor inject the antibiotics directly into his brain, but he said that was much too radical and risky; the antibiotics were too toxic for direct infusion into the brain. However, three hours later, he had MRI photos of Randy's brain and they showed an abscess about the size of a tennis ball on the right side had formed in those three hours. It was clear that the bacteria must be a "superbug," resistant to antibiotics, and it was growing fast. Despite the risk of kidney damage, the doctor put him on large doses of several different kinds of antibiotics. He scheduled an emergency surgery for the next morning. He had to cut open another hole on the right side of his skull and suck out the pus and dead tissue. He also flushed the area with antibiotics. There was a good chance Randy wouldn't make it through the surgery, would go back into a coma, or the brain damage would be permanent....

When Randy came to a few hours later, he was much better. His functionality had improved even beyond what it had been prior to the infection. He is now better, functionally, than he has been since he was originally injured four years ago. The infection, however, is still there. The infection doctor had still not been able to identify the bug, but I figured that the bug was probably the same one that

had infected Randy's brain years ago and had just been hiding in the shunt all that time. So, I got the lab records from 2000 and faxed them to the doctor. It was an antibiotic-resistant strain of staphylococcus. Time will tell if the infection will or has spread to the left side and infected his metal plates, the dead piece of his skull, or the left shunt. If so, they will have to come out. These things are outside the reach of his blood stream, so there is no way to absolutely get the antibiotics to them, short of removing and sterilizing them. Another MRI scan will be performed soon.

Randy will remain in the hospital for a few days and then most likely be transferred to a nursing home for awhile. He is in good spirits, but will likely be extremely upset and angry about not being allowed to go home when I tell him. I, personally, feel like I have been on an emotional roller coaster of extreme proportions. Every part of my body aches from stress. My head and jaw ache and spasm from clenching my teeth at night. I am fatigued and burnt out. But I am also very proud of myself and relieved that Randy has survived yet another chapter.

Alan

November 24, 2003, 4:32pm

Good News Everybody!

Randy is doing very well. The infection specialist said the lab results I faxed him were very helpful. It appears that the antibiotic they were giving him was likely the best one. He felt the infection must have been working away on his brain for awhile before the antibiotics were started. I am not sure I buy into that, but he will get another MRI tomorrow and that will show whether the infection is growing or not. The doctor reiterated that a good-sized portion of his right hemisphere was "liquefied" and removed; however, I can't seem to find any disability showing in Randy's behavior or skills. He seems better now than he has been since he was originally injured. I am trying to find him an attendant right now. He will be going home Wednesday morning.

I am not doing that well. I had felt really tired and fatigued since taking Randy into the hospital. Yesterday, while getting my haircut, I got really hot and dizzy and I thought I was going to throw up. I'm not sure what happened after that, but a nurse that was getting her hair done helped me to the couch. My whole body was tingling and shaking and I couldn't feel or move my legs or arms. My skin was at first very sweaty, then dry. My muscles ached and there was pressure on my chest. The paramedics came and they carted me off to the emergency room. I feel bad that I didn't get to thank the nurse before she left. One of the paramedics joked that "some guys will do anything to get a free haircut!"

At the hospital, they hooked me up to an EEG and put me on an IV. The EEG showed no heart problems—thank God! But my blood pressure was a little low. They concluded that I probably passed out from excessive stress. I am supposed to avoid stress or physical exercise until I can get a cardiac treadmill

stress test. I do, however, intend to go back and finish my haircut. My head looks kinda funny—every day is a bad hair day right now!

Alan

February 21, 2004, 11:42am

Hi Everyone,

I took Randy to a new orthopedic surgeon yesterday. It turns out that over the last year his right hip has frozen to his pelvis with a lot of excess bone growth. Some main nerves run through it so the surgery to remove the bone will be tricky, but his leg should gain a lot of movement once it is freed. He will have to take a drug that prevents bone growth for 6 months to prevent the bone from growing back, and this will make his other bones fragile for a year or so. His tendons will require a lot of cutting to lengthen them which will weaken them, but with straightened legs, he should be walking again within a year. He will need a steady dose of Baclofen, a muscle relaxer, to help the stretching and this will make him act a little like he is on Valium (he likes Baclofen very much). The doctor feels that after a couple of years, he might be able to walk without a limp. Of course, now Randy is already trying to decide what color his convertible Mercedes should be!

Randy has been insisting on more independence and I have been giving it to him. He now has his checkbook and must pay his own bills. Despite him calling me constantly to help him with it and the occasional times he doesn't (and pays something that he shouldn't) he is doing a good job. He is doing well in his special school and has gotten the hang of calling the special bus service to take him places when his attendant is not available. It is trying on me as he wants to do things on his own, but tends to blame me for "not helping him" when things don't go right. However, I am so relieved at the idea that my work load might actually be going down that my spirits remain high.

Randy's new cat is mellowing out as it grows older and doesn't scratch him as much now. I have been trying to teach him how to use kindness as a way to manage the cat and allow for clipping her claws as opposed to exerting brute force to dominate her (she always wins in this case). She has grown into a really beautiful cat. Randy has decided to get another kitten to keep her company when he is away at school. I'll send pictures when he gets her.

Take care,

Alan

February 8, 2005, 10:37pm

Good News Everyone!

After over a year of preparation, Randy finally got to have the surgery for his leg today. During the 3.5 hour operation, excess bone growth from his right hip and

knee was removed and his tendons and muscles were sliced and nicked to allow them to be stretched. The surgery was risky because the nerves running through tiny holes in the bone could have been cut, resulting in permanent paralysis. In fact, the doctor had to remove less bone than planned, because it was too "tricky." However, there should be enough removed to allow adequate movement.

The surgery was a success, with minimal blood loss and Randy is now recovering just fine. Tomorrow, his leg will be stretched on a special machine and may be set in a cast. After a couple of days, assuming there is no infection, he should be OK to go home. Then, over the next 6 to 12 months or so, he will go through physical therapy to regain his ability to walk. He will have to use a walker, then a cane, and will likely always have a limp, but who cares, as long as he can walk and perhaps drive himself!

Alan

February 11, 2005, 1:12pm

Hi Everybody,

Randy needs to go back into surgery again tomorrow. Apparently, in removing the excess bone growth that had fused his leg and hip bones together, the doctor was not able get inside the ball-and-socket hip joint completely and the ball was not shaped just right. So when they stretched his leg out in physical therapy, the joint got stuck and the ball at the top of his femur cracked. They could try to fix the ball, but the doctor feels the quickest and best solution is to replace the ball with an artificial one. Randy is in a lot of pain and waiting for the bone to heal would greatly delay his recovery. They also need to keep stretching the leg to make sure the muscles don't heal in a contracted position. He may have a problem with the new ball joint popping out if he is not careful, but otherwise, it should last for the rest of his life. The surgery is scheduled for early tomorrow morning at St. Joseph Hospital. He will stay in the hospital for another couple of days and then transfer to a rehab hospital for a couple of weeks. The insurance has not yet approved that, however. Randy can be reached at (714) 633-9111 room, 508, bed 2. He would appreciate a call.

Take care,

Alan