

Stroke Diary

*Documenting my journey
from stroke to recovery*

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Chapter One

The Stroke

I had my stroke on Monday, September 26, 2011. It happened at about 8:30 PM. Laura, my wife, and I were walking on Main Street in Waltham, Massachusetts. We crossed together, with Laura a few feet ahead of me. I was still in the road when I felt something like a “click.” I stared at my foot for what seemed like a long time. After that, nothing.

The next thing I could remember was holding on to a peeling white pole next to the street. My face was crushed into the pole and I could smell the rust. But I didn’t know how I got there. Laura told me later that I had moved from the street to a traffic light and then to the white pole, a few feet away.

Laura looked back and saw what had happened. She ran back and grabbed me. She must have known I had a stroke immediately. My right side was paralyzed. I was dazed and couldn’t talk. Apparently I tried to talk, but Laura said it was just gibberish.

She got under my right arm and propelled me (I don’t know how else to say it) across the parking lot and into the CVS store. I missed that entire trip. We took pictures later of the street, the poles and the lot. It looked like she dragged me about 300 feet into the store and to the pharmacy in the back.

The next thing I could consciously remember was sitting on a chair at the pharmacy. I could see a line of people at the cashier. My right arm dangled. I saw it there but had no control over it. I really didn’t know what it was. I just picked it up and put it on my lap. It fell off a couple of times. And I kept picking it up, like a dog with a stick.

I did remember brushing at my pants as if it was lint that needed cleaning. That was my recollection at the time. Laura told me later that that was exactly what she thought I was doing ... “picking lint.” I had no concept of what was happening to me but it seemed like I didn’t want to be embarrassed. Laura got that impression too. I was apparently trying to “make things right” with whatever might have gone wrong.

It must have taken only a few minutes for us to get from the street to the pharmacy at CVS. And Laura called immediately for someone to call 911. The fire & emergency station was literally right around the block, so the ambulance arrived quickly.

The next thing I remembered was lying on a gurney. I had no idea how I got there from the chair. There were two EMTs next to me. One was on my left and spoke to me. I can’t remember any words but he soothed me and put in a saline line (not that I knew what it was at the time). There was another person on my right. He talked over me (I assume, to his partner). I could hear him. I could feel his breath on my face. But I could not see him. I assumed he was right behind me.

While “working on me” (again, I had no idea what was going on) the person on my right side reached across me to do something. That was the first time I was shocked enough to notice what

had happened. A right arm appeared in front of me. It was doing something, but there was no body attached to it. It appeared to be an arm that was sliced off cleanly, waving in the air. It disappeared quickly, but was there long enough for me to wonder what it was. Seconds later it happened again. I was barely conscious, but this got my attention.

The next thing that happened was enough for me to start worrying. And I didn't even know enough to *be* worried. But two disembodied arms were the beginning of knowing something. When my right-side guy's head moved into view—his head sliced off at the neck—it was time for me to sit up and take notice. He was only there for a few seconds. He had a beard. It looked like a balloon bobbing on a string. A balloon with a beard.

I could not think in any concentrated way. But the two arms and a head made an impression that stuck with me. I couldn't see with my right eye. It was the beginning of understanding that something was wrong. Before that, you didn't know what you didn't know. That night in the ambulance I still had no idea. But I saved the scraps of memory—the street, the pole, the chair, the EMTs. I remembered them. For quite a while, though, I couldn't tell anyone else what I had seen.

The ambulance trip was uneventful. It was dark. There were some murmurings. But that was all. No more spectral apparitions.

I was clocked in at the Emergency Room at MGH in Boston at 9:35 PM. Thank goodness for the speed of the local EMT people. I made it from the stroke in the street to the hospital in about an hour. It was 12 miles to MGH. I didn't remember the transition from the gurney to a bed in the ER either. But I did remember it was very bright ... not much more.

Laura had arrived at the hospital. The ER staff were talking with her about my status. They talked about my blood clot and the drug (tPA). They concluded that I had the kind of stroke (and in the right amount of time) that would allow me to take tPA. They administered the drug at 10:30 PM: "*TPA infusing, wife by bedside*" from the MGH medical records.

Not having heard or seen anything up to that point, (although I was there, just not terribly conscious), I was given the drug. The next thing I remembered was what sounded like popcorn popping off in my brain. I heard the sound and put my hand up to my left temple, patting it. Apparently I had tried to speak, but Laura said that I couldn't even make words just word-like sounds. I didn't know what I tried to say either, but weeks later I told Laura about the "popcorn popping." Laura remembered seeing me touching my head that night, but didn't know why. Apparently, at the time I *did* try to talk. At 11:02 PM, the nurse reported: "*pt remains with word salad speech and r sided weakness.*"

The "popcorn popping" was the last episodic memory of the day. It appeared that I had remembered only the most intense events that had pierced my otherwise dazed consciousness. That night was the end of it. The popping subsided, and I was transported to a Neuro ICU room at 1:28 AM on Tuesday, September 27, 2011.

The nurses told me to rest as best I could. They told me they would check my vitals every couple of hours but otherwise wanted me to sleep. They asked lots of questions about my vision, pills,

nausea, pain and balance. Apparently, I could only say “Yes” or “No” to their questions. The nurse put me to bed, and Laura left at 3 AM.

I spent all of Tuesday, September 27, 2011, in the Neuro ICU room and as far as I knew, I could not remember anything that day. I was moved to a new room, Lunder Building, Room 732, on Wednesday, September 28, 2011, in the afternoon. I only knew that it happened because I took a picture of my Neuro ICU room bed with my iPhone at 1:00 PM that day and took another picture of my Lunder Room (Rm. 732) at 1:26 PM. Thank goodness for technology. I only wished I had taken more pictures.

Before I left the Neuro ICU room for my new room, a speech pathologist came by that morning. She talked to me about the possibility of having a problem with my language. That is to say, she explained things to me that I still didn’t understand. I asked (and truly, I don’t remember if I asked) whether I had a problem or not. I didn’t even know that I had had an assessment that morning until I got a report saying that I had. I certainly didn’t understand my deficits at the time. It was not until I received the medical records from MGH (two and a half years later) that I discovered the conversation between us. Of course, it was hardly a conversation. She talked and I imagine I blabbered. Here is the report.

Exam:

Cog: Alert, oriented, focused and attentive. Social pragmatics WNL. Demonstrates insight into deficits and emerging understanding of the implications of his new disabilities.

The doctor related that I appeared to be aware of all those things. If that was the case, I was *trying* to focus; I was *trying* to express myself; I was *trying* to understand. But if I knew them in the moment, I certainly couldn’t remember them later.

Communication: Auditory Comprehensive: Asks for repetition and clarifications at times. Picture ID 4/4. Color ID 0/2. Letter ID 0/2. Number 0/2 (though semantically understands the number values and can do basic math.) 1 step commands 2/3. Repetition: 1/5 single word level. Phonemic paraphasic errors. **Written comprehensive:** 6/6 word-object matching. Reads simple sentence with 100% comprehension, but reading aloud is neologistic. *Verbal output:* Spontaneous speech is largely fluent and paraphasic (neologistic, phonemic) with intermittent intelligible words and phrases, and some hesitation for word finding. Names 0/5 BNT pictures. Names 0/5 letters correctly (errors are neologistic & phonemic paraphasias, i.e.,: “serithmekit” for BENCH.) *Written output:* Attempts to spell aloud “A-T-O-M” for COMB. Phoneme/grapheme conversion is impaired for basic words. Is at times successful at writing words, i.e.,: Brandeis, though cannot supply appropriate letters that have been left out of basic words, i.e.,: O_TOPUS.

I seemed to remember the doctor pulling out a comb from her pocket. But I don’t remember anything else. I did find a connection between what she said based on the recent records from MGH. I had saved everything from my hospital room when I left. This included two sheets of scrap paper. There were a number of words in my own handwriting. They were scratched out, lined out and misspelled.

There were also other words, not written by me. I had seen them over the years but had no idea what they meant. It was not until I found the MGH records mentioned above that I made the connection. On the scrap pages were the words “ATOM, COMB, OCTOPUS and BENCH.” Speech-Language Pathologist Rebecca Santos must have written those words on a blank page on Wednesday, September 28, the day of my earlier assessment. Among other words, I wrote “BRANDEIS” and “REBECCA.” (She had left her business card on the table.)

Also, there appeared to be in her handwriting, the word “APHASIA” and a crude diagram connecting the words “WORD” to “READING” to “UNDERSTAND” to “SEMANTIC” and back to “WORD.”

The speech-language pathologist also provided a memo with short definitions of a variety of pathologies including aphasia, cognitive-linguistics disorders, dysphagia, dysarthria, verbal apraxia and voice disorders. The words were there, but I couldn’t understand them or even pronounce them. That was all I knew. There was a phone number and the name of a therapist, with a note “booking mid-October.” The page was printed out from the Newton-Wellesley Hospital website with the date of September 28, 2011. This confirmed the date between me and the speech-language pathologist at a meeting I could barely remember.

The speech-language pathologist told me I would get a full assessment at Newton-Wellesley Hospital in a couple of weeks. She said it would take some time to rest and for my brain to “settle down” before taking the next step.

I wish I had taken more pictures that week. But even the written notes by doctors and nurses (and occasional notes by me) were as close to taking a picture as anything. They were messages launched in a bottle. I found them eventually. But not until they washed up in St. Augustine, Florida. I had written my first “real” sentence (but hardly real at all) on the back of a note from the hospital’s clinical social worker. This is what I wrote on what appeared to be Saturday, October 1, 2011, the day of my discharge. And I didn’t see it, either, until St. Augustine.

“Didn’t at CVS that on more Mon, at time on time hire smart thru right—smart that person at the window hire how officially.”

I had written it down without knowing what it meant or even remembering that I had written it. It was only by seeing it with my own handwriting that I could tell it was mine. It turned out that most of the diary had the same “problem.” Those words were real words. And I wrote them. At the time, though, I didn’t know that the rules of grammar were gone. The words were there but they couldn’t carry their weight measured in meaning.

I had sent a number of texts and emails to friends, family and colleagues even while still at the hospital. I didn’t know what I had sent or to whom, but I looked through my files and found what few I could find. This set of emails between me, Laura and each of my kids bracketed the times and events of Wednesday, September 28, 2011.

I sent a note to Laura with nothing except the title at 10:33 AM,

“Hi, there here you breath?”

She replied at 10:50 AM to all of our kids,

“I came in to work for a little while, and look what I just got from Dad!!! He even knew to copy himself (as he usually does) and he’s trying to communicate. Wow... so I’ll go there after lunch and stay tomorrow and maybe Friday.”

My son, Will, emailed at 11:08 AM,

“Hey, That sounds great. It certainly is strange that he can spell words correctly, but their meaning/syntax is incorrect. I hope that this is corrected soon enough. Talk to you soon, Mom!”

My other son, Dave, emailed at 11:18 AM,

“Does he want to call so he can hear you?”

Laura emailed at 11:44 AM to all,

“Funny, he just called me!! I think you were right, he wanted to hear my voice!! Anyway, he said he met with speech therapy and they tell him 3 to 6 months before he regains to full capacity speaking. He told me they’re moving him to another room soon, and I told him I’ll find him. So good he’s doing so well!!”

My daughter, Josiane, emailed at 1:24 PM,

“I called dad and then he called me back, too! Sometimes it is really clear, but other times he messes up the words. And he tried to spell but all the letters were wrong. It was sad, but he doesn’t care it seems like—just knows he will have to work on it. Sounds like he will be OK pretty quickly. Maybe even sooner than 3 mos? I asked him what they said about the scan and he said everything looked fine, so hopefully it just needs time to recover, no real damage.”

I didn’t find that email for a long time. But when I did, it established dates, times, events and meaning at a time when it was difficult to remember anything other than a hazy memory that week. My memory did get better. However, without some physical presence proving that I actually did do one thing or another, those first few weeks were a blur.

Later that afternoon, my daughter wrote to her father-in-law at 4:00 PM,

“Thanks for your email. It’s so crazy, I can’t believe my dad is in the hospital again. I talked with him today and it was OK, but it is hard for him to say some words and it’s sad for me to hear. But, he met with the speech therapist and it sounds like he will get back to 100% after a few months of speech therapy. I hope that is true. Physically, it seems like he is totally fine and healthy again, but now just this disconnect between what he is thinking and what he can say. He said that inside his head he is 100%, he just can’t quite express everything right now. I hope that each day he will get better and better!”

I was so glad that someone on the “outside” could articulate what I meant to say on the “inside” but couldn’t. Those notes were gold. No matter how small, or insignificant to others, every clue led me down a trail I was yet to see. But it was there for the taking.

I was moved to the Lunder Room (Rm. 732) shortly after lunch on Wednesday. My shift nurse asked me to take a walk around the floor. She walked with me to make sure I could walk without stumbling. After being sure I was OK, she told me to walk as much as I wanted. Laura and I had walked every day (we were in the middle of a walk the night of the stroke), so walking the floor was helpful. Plus I had nothing else to do. So I went walking around and around the floor. It took a minute or two to pass the nurses’ station. As I recalled, I counted laps as I circled Lunder.

It did get boring soon enough. I looked everywhere I could. I looked at every open door. Many were closed. I discovered additional corridors, stairs, elevators and exit signs. I went down each corridor. I was worried about being lost so I didn’t go too far. There was a small conference room with windows. It appeared that there were doctors or medical students studying at computers. Some worked together while others worked alone with massive tabbed printouts.

I found a small exercise room two doors over from my room. Room 730 was next to me and then the exercise room. The sign read: “Rehabilitation, Room 728.” It was a beautiful, bright room with stepping stairs, a treadmill and uneven bars. It was located at the corner of the building, with big windows and an amazing view looking out in both directions.

Other nurses assisted patients who needed help walking. I saw a number of patients in their rooms or being moved from one place to another. Some could not talk; some were paralyzed. Some were transported in beds and others in wheelchairs. I assumed they had a stroke or something like it. And after watching them every lap or two, I concluded that many patients (if not all) were much worse than anything that had happened to me. I didn’t know what had happened to them. But for all of that, at least I was talking and able to walk. Given what had happened the night before, it started to feel like a bad dream.

I still could not tell if I had sustained any other damage or not. But given the physical damage that I could see in other patients, I really thought I was fine and ready to go home.

Other than walking, there was nothing else to do but watch TV (which I didn’t watch much) or look outside. It was a beautiful day for watching, so I did. I pushed a big chair between the bed and the window and watched. Walking and watching were the activities of the day.

Laura went back to work full-time on Thursday, September 29. She came to see me early in the morning and later in the day, after rush hour.

There were no additional conversations with the speech pathologist. I wanted to know more, but I had been informed more than once: physical injuries at this hospital; the next hospital would treat any additional neurological issues.

As the days went by, I was anxious. I was certainly beginning to tell that something was wrong. I had begun to see things outside my window that I could not name. I knew what they were. I knew their names. But I could not say them out loud.

I looked at, pointed at and named or tried to name everything I could see out there. I spent a lot of time doing exactly that. Since there was no one else to talk with, I started talking to myself. Basically, I whispered to myself. I pointed at clouds, windows, people and cars, and could hear myself say what appeared to be the right words. But there were other things (with the associated words) that I could not say. *Skyscraper*, *skyline* and *buildings* were among those I could not “find.” I distinctly remember seeing those things and being unable to find them in my brain. I didn’t have anything to write with. I wonder what I would have done if I had been able to write them down. But at least I was lucky to remember what I could.

Of course, only later did I finally understand that I couldn’t read, write or speak well. So much for pen and paper. Again, because I did not take many pictures, I was so happy later to find that I had taken a picture on Friday, September 30, 2011, at 1:10 PM. It was a picture of a building on the right, with skyscrapers and a skyline in the distance. Like finding a dollar bill in an old book—what a surprise.

I only found one more set of emails while at the hospital. This set of emails was between me, Laura and one of my sons throughout the day of Friday, September 30, 2011.

I sent a note to Laura with nothing except the title at 9:34 AM,

“Would the sunshine will be better?”

She replied immediately,

“Hi DAddIO!!!!!!!!!! Was just going to send you a note!! Hope you are well....”

I replied to Laura at 12:53 PM,

“Hi Laura,

Soon Yani and Cece.,,come visit!”

She replied immediately,

“WOW, Cece is coming to visit? GREAT!!! I talked to Humberto and Steve Fournier. They will visit too.”

I replied again at 1:33 PM,

“Hi Laura,

You tired tire turned tire turned time simply...seem type to seem type insert.,,turn has to turn in Sat at 12:00 simply time turns.

Tom”

Laura sent her last email at 1:54 PM to our son, David,

“What do you think he means by this?”

There might have been other responses, but I couldn't find them. It was clear to everyone in the family that this thing called "aphasia" was real. These emails were as real as they could be.

My discharge day had shifted from Thursday to Friday. On Friday I was told I would be discharged on Saturday, October 1, 2011. I wanted to get home. And I certainly wanted to start on whatever was going to happen next.

My discharge papers, including a "non-medication prescription," were printed at 3:29 PM on Saturday, October 1, 2011. The prescription was titled "Outpatient Speech Therapy – evaluation and treatment." I wrote some notes on it. I wrote individual words and fragments, but no sentences. In retrospect, I thought I had done well with those notes. There were misspellings, cross-outs and wrong grammar. But at the time I still had no idea about what was right or wrong. Those notes were the beginning of the need for documentation for therapy's sake.

My Discharge Summary was printed at 4:40 PM. The fourth picture I took during my time at the hospital was a picture of the Lunder Building, looking up at my seventh-floor room. I took it at 5:07 PM that evening. My last picture before leaving for home was the main entrance at MGH, taken at the same time. I arrived home by about 6:00 PM on Saturday.

I saved every note, every picture and every report. There weren't many at the beginning. But I saved them carefully and organized them for later. No matter how small, they had to have been part of a larger picture. I still had no idea what that picture might look like. I am glad I kept everything.

With those few notes, there were many more gaps in the record. There were only a few facts. Memories were hardly memories at all. There were times when I had missed parts of conversations. Some memories that I was sure were real, turned out to be wrong.

For example, I was *sure* that Laura and I went to the "walking farm" the day after I was discharged. I was discharged on Saturday and was sure we had gone there *the next day*. I had no other reason to think otherwise. Even the pictures of Laura and me at that farm appeared in my iPhone after the picture of the MGH entrance at my discharge on Saturday, October 1.

It was not until years later, after I found and organized the facts, did I discover that the day/time of the picture at the farm was Sunday, October 9, 2011, at 5:04 PM, not the Sunday before. It seemed like I had lost an entire week. I guess in some ways, I did.