Living After Brain Changes: From the Patient's Perspective

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Life with Multiple Sclerosis

Meg Balter

I am a 54-year-old woman who has had MS for 33 years. I was diagnosed at age 21, in the prime of my life. Life has taken me through many challenges, but this was not a challenge I was ready to take, not one I was not prepared for at the age of 21. I was a recent graduate of nursing school and was at my first job as a Registered Nurse in a large suburban hospital. I traveled, skied, rode a motorcycle, played softball for the hospital, and was generally glad to be living life. I had my own apartment … was on my own … life was good. All I ever wanted to be was a nurse—my friends were jealous, I knew what I wanted out of life.

I was the second oldest of six children in a close Catholic, Italian, Irish, German, Polish family! My mother had Lupus most of my life so I knew what responsibility was at an early age. I knew that I wanted to be a nurse.

While working at the hospital I met my husband David, a Pharmacist. He is a patient and loving man. While we were dating I was diagnosed. He was there from day 1. We were playing tennis and I could not feel my legs, they went numb…the more we played, the worse it got. He knew there was something grossly wrong.

This chapter is a compilation of vignettes from various patients living with neurological illness and injury. It is included to afford the patient or caregiver an opportunity to hear of the challenges faced by others and how they overcame many of these challenges. We hope this chapter will motivate patients and caregivers to work to maximize their functioning and live the highest possible quality of life. Most of all, we hope this chapter helps persons living with brain illness and injury to not lose hope.

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First we went to an orthopedist, then a neurologist, to a specialist in New York City, more tests, and finally a diagnosis, Multiple Sclerosis. Back then there were no MRIs or CAT scans, it was lumbar punctures and myelograms.

Given the prognosis, David married me, knowing what might come.

The first year of marriage was bliss, until paresthesia from the waist down. How does this work? Not fun. With time it resolved. We went through genetic research for future plans for children, we were told to go ahead. With God's help we had three beautiful boys, the pregnancies were good. With David's help at midnight feeding's we made it through. I still had numbness, spasticity, fatigue. I had exacerbations and remissions. I was an assistant coach for little league baseball and soccer, taught CCD for 17 years. I still work on a local access Cable TV show for "A Dominican Way," participated in all the elementary and high school duties and kept to my workout routine.

David was always researching to find ways to make my life easier, to find answers and minimize the impact it had on our lives.

MS has changed my life. I set out to be a nurse. I was a charge nurse at a hospital until I could no longer function at a safe capacity for my patients. Memory impairment halted my career. Leg pain and incoordination ended my career.

I studied very hard and I really hate the fact that a disease ended my aspirations for a fulfilling career in nursing.

But here I am now, happily married 29 years with three grown men. My children and my husband know me well. At times I confuse words, numbers and often I do not realize this. My family is supportive of my "style of speaking" and my "style of memory" (DO NOT ask me about the checkbook incident when I was so sure all the numbers ADDED UP!)

Through involvement in research, I learned techniques that help me with daily living. I can now remember more of what I need from the grocery store because my son knows to say "I need super foamy shaving cream because I have a class picture tomorrow" instead of saying "I need shaving cream."

I can ask him ten times if he has homework tonight and not remember. It is just as frustrating for him as for me!

Life has changed because of fatigue. I have learned to pace my day and take needed rests. I almost never stay out late; it makes the next day a disaster for me. David and I will go to a party and if it starts getting late we leave, whether dinner was served yet or not. I do not go on any thrilling rides at Disney, or watch scary movies, it only makes me tingly and weak for a few days; it is not worth it. Avoiding heat can be a challenge, but it absolutely is a must. No hot tubs, baths, or long days on the beach. If I am out in the sun during the summer I am in the pool or the ocean.

Life has changed because even though I am a chatterbox, I am quiet in crowds or at meetings because I cannot express what I want to say, my words come out mixed up and people look at me strangely.

I may be in that exercise class at the gym, I may be giving it my all, but thanks to supportive friends and instructors, they look the other way when I am doing half. Hey, it is MY best!

Meditation, biofeedback, and self hypnosis, all help with pain control. I learned them from a doctor in NYC and they have all helped me at various times in my life, especially during labor and delivery. I could not have an epidural, so without these tools, it would have been a whole different experience.

Through over 30 years of having MS, it is a challenge finding a balance. There are sometimes new scientific findings that could impact my life … what to do, what not to do … what to eat, what not to eat … how to take vitamins or the newest cure or remedy. I have found that the best for me is to stay on a balanced low fat diet, exercise, rest and to try to minimize stress. Reducing stress is not always easy with a household full of boys, but it is a fun house none the less.

Someone once told me never stand if you can sit, never sit when you can lie down, and when you see a bathroom, use it!

When I get symptoms, I shut down! If I do not, the symptoms worsen and I know from past experience that means medication, physical therapy, and an alteration of my life.

My goals have definitely changed since I was 21, overcoming difficulties is definitely a challenge, but the joy of life is present every day, in the faces of my husband David, and my sons Christopher, Evan, and Brett.

Life After Stroke

Bob McGee

On July 17th, 2009 I was chasing my small dream. I was trying to win the club championship at my golf club. I arrived at the course "juiced" to say the least. I had lost a very close match the year before and I was determined not to let that happen again this year. I had practiced all week even going so far as to take a lesson from my local pro. I arrived at the first tee literally shaking from nerves and anticipation. I was determined to win. I got off to a shaky start, going, one down fairly early in the match. By the sixth hole, I had completely reserved my fortunes and was now one up. Because of the format of the match this was the eighteenth hole on the golf course and fortunately for me it was right next to the clubhouse. I putted out on 18 and pulled the flagstick for another gentleman in our foursome.

It was at that moment that I felt as if I had stuck my finger in a light socket. My entire left side felt as if it were buzzing. I felt no pain at all, I heard the someone say "OK you can move away from the hole now" I didn't know where I was. I was buzzing and totally disoriented. I walked under my own power to the golf cart some 50–100 yards away. I became aware of the fact that my left eye wasn't blinking. It was as though it was wide open and there was nothing I could do to shut it. I sat down in the cart in the seat usually occupied by the driver. When my partner came to get in the cart he asked me to move over, I tried but I couldn't move. I felt as though my left side were a block of granite. He literally shoved me over so that he could get into the cart. I was then brought to the clubhouse. Paramedics were summoned. They sat me down in a large chair in the Pros' office and gave me water to drink and began to towel me down. I was sweating profusely. I was starting to feel weak and my left eye was wide open and would not blink. I could hear sirens.

As the ambulance pulled up I could hear people speaking in a very hurried fashion, doors opening and slamming shut I heard more sirens, police were arriving now. Paramedics came in with their first aid kits. One paramedic sat down in front of me and asked me to smile. I struggled to do so but the left side of my face wouldn't cooperate. He then asked me to shrug my shoulders again my left side wouldn't move much. He then asked me to squeeze his hand, which I did, quite weakly. I had no strength in my left hand. I recall being put on the stretcher and loaded into the ambulance. As we rode to the hospital, I could see out the back of the ambulance and I remember thinking,

> *"of all these people out here, why me? I had been doing all the right things. I had lost 25lbs since 2001. I was working out at least three days a week. I was playing golf two-three days a week. I hadn't had a drink or a drug in 18 years. I hadn't smoked in 16 years. My eating habits had improved over the years. Why me?"*

In the ambulance I was totally aware of my surroundings. The first thing I remember was when the paramedic inserted the needle in my left hand. The gravity of the situation began to overcome me and the feelings of helplessness and hopelessness began to set in. I asked the paramedic if I was having a stroke. He told me to lay back and relax. I took that as a yes. Isn't that what they always tell you when you are in deep trouble? The anger began to set in. Why couldn't I just get in my car and go home and be among the masses of people fighting the traffic on this otherwise beautiful July day? The Paramedics were communicating with the hospital. I began to hear things like "blood pressure 220 over 110. No involuntary responses left side" My heart sank, would I die?

I thought of my beautiful girlfriend Rona, if ever I needed her, it was now. I had never "needed" her until this moment. I had met her only 21/2 months prior. I made sure the paramedics had her number. I thought of my children. I had left them and their mother only months prior. I thought of my mother and that little smile she would don, to try and convince me she was going to be okay in the months leading up to her death, she never did succeed in convincing me. I smiled at the memory of her feeble attempt to help me through the process. When they wheeled me into the hospital I was still aware that my eye wasn't functioning, not having blinked in some time it was becoming sore from the dryness. I was wheeled up to a large intake area. I could see the paramedic was growing impatient. Finally I heard him say in an irritated fashion "What do you want me to do with this stroke" A very attractive Asian woman dressed in green scrubs, wheeled around and with a look of both horror and incredulity asked "That's a stroke?" She then ordered the paramedics to bring me in to a room not far from the intake area. People came in and began to remove my clothes, which was difficult because my body was soaked with sweat. I remember them taking off my golf shoes.

I must have lost consciousness soon after this point. I spent 10 days in ICU, I remember some very brief glimpses of people. I remember seeing my brother very briefly with tears in his eyes, which moved me quite deeply because my brother is quite stoic. I also remember my good friend visiting and joking about how many strokes he wanted from me when we hit the golf course after I got better. I remember the day Rona came in and needed to know the numbers on the keypad of my car because the battery had died and no one could get in it. I remember someone shoving a toothbrush in my mouth and hitting my teeth and being very rough. I recall some sort of skullcap with soap being applied to my head to wash my hair.

From ICU I was transferred to rehabilitation. I was given a room on the brain injury unit. Early on I was in a diaper because I could not control my bladder or my bowels. They would shower me on a gurney lying down. I remember being wheeled in to the shower room and seeing myself for the first time in a mirror, my eye was still not closing. It was alarming to say the least to see myself as such. I had come been in fairly good physical shape prior to my stroke, but now my body was lifeless with no muscle tone. I was angry and irritated to say the least. I was not at all happy to be alive. I wished that I hadn't survived, not wanting to deal with any of this. At times I would think about ways that I could commit suicide. I would dwell on it at times. Although I was forced to do therapy I had no interest in participating in my recovery at all. My mind and body were ravaged by this event I wanted to die or at least sleep. But the aides would come in early in the morning and would pull the curtains back, which sounded like a flock of screeching sea birds, That is how the day would begin and at the onset the fear and sadness would begin. Psychologically, it was hell.

I was what they call a hemi. Apparently so much damage had occurred in the right frontal lobe that my left side had a severe deficit. I couldn't sit up without falling over. I was literally like jello. I had no control to hold myself up at all. I would flop to the side when they put me on the mat in therapy; they couldn't leave me unattended. The first day I remember sitting in a wheel chair in the therapy room waiting for my therapist to come get me and I started to topple over nearly coming out of the wheelchair, I could feel myself falling. I started to bang on my wheelchair and began yelling, afraid I would wind up on the floor. My therapist was able to save me, catching me in time as I was headed downward. I was terrified. The next day I was put on the antianxiety medication. I don't recall ever being as agitated and fearful in my life. The medicine seemed to help. I started to feel somewhat calm, my mind started to clear up as well, up till this point my brain seemed very foggy. It was brought to my attention later that I wasn't looking at people on my left side at all. Though I could read I wasn't scanning the page at all to the left. So these were the things they began to work on in therapy.

At some point I began to turn around. I went from being negative and irritable to willing and cooperative and much of that I owe to the incredible therapists who continually pushed me when I didn't want to be pushed. Many told me I could do it when I doubted I could. I went from an outlook of sorrow and pity to gratitude and appreciation. As I started really participate in my own therapy I realized how fortunate I really was. I would see people in the therapy room who were so much less fortunate than I was. I knew I would at some point get out of my wheel chair and walk again, there were so many that wouldn't. I realized how fortunate I was to not have lost my speech or my cognitive ability.

There were times when I thought that I would never regain my ability to control my bodily functions. Fortunately that was not the case. I was taught to dress myself. I dreaded my therapists appearance at 8:00 AM every morning when she would come in to show me how to get dressed; it was one of the most difficult things I ever did, but certainly one of the most valuable. After I left rehabilitation I went to live with my girlfriend Rona. I remember the day she brought me home, it was cold and rainy and I was in an old wheelchair that she had obtained from someone she knew. To get to her apartment from the parking lot we had to go down a steep hill. Rona was literally slipping out of her shoes. I thought we would both topple over. I was terrified.

The first couple days in her home were difficult. She would go off to work and I would get up with her. I would move to the living room and usually sleep for several more hours. My brain and body were beat up. I was tired. I was scared. Her apartment was very remote. I felt if anything were to happen no one would get to me in time. Rona had just started a new job about ten miles east of where we were living. Rona would leave food for me, which she would make the night before. She was always very helpful with my medication and making sure I had the right pills at the right time. She would also run around and pick up prescriptions for me. At times it would wear on her however. While I was in rehab, Rona would complain about how much she had to do and how time consuming it was and how she was ignoring her own life. She would speak often about needing to do things for herself and how she needed her space. It was a constant struggle for both of us. Rona is an extremely bright woman with a terrific and at times “stinging” sense of humor. Since the stroke I became more sensitive. My inability to not feel slighted by comments she claimed were made to be humorous was a source of difficulty for us and the relationship suffered.

My confidence was not what it had been before the stroke. I could hardly walk. My body was out of shape due to my inability to participate in any kind of exercise. I suffered some strange effects from the stroke. I would laugh or cry uncontrollably at times, depending which emotion happened to be prevalent at that particular time. This made me feel strange, adding to my low self esteem. At times Rona would even mock my laughter which made me feel worse. No doubt caretakers face tremendous difficulties especially because of the dependency of the ill person, which places a tremendous burden on the caretaker.

It seems to me, that any emotion I feel is intensified as a result of the stroke. Anger seems to be an emotion that raises its ugly head quite frequently, accompanied by frustration. I tend to get confused quite easily. My memory is noticeably affected. I forget where I put things. I forget to return phone calls. I forget appointments unless I write them down. I have constant tinnitus. I find myself depressed quite a bit and engage in self-pity. Although, I would say that my attitude toward recovery is good. I am determined to get better and am willing to work hard toward that goal. I try to stay busy. I engage in a lot of social events. I stay very close to my friends, go to the movies and out to concerts. I go to a lot of AA meetings and Al-anon. I have joined a professional networking group. I feel quite a bit of stress now, wondering if I will have another stroke at some point. It is also more difficult to handle my daily activities such as bill paying, cooking, and cleaning. My girlfriend and I are no longer together, which is difficult emotionally. I live alone and that is challenging in terms of keeping my life organized. I feel quite stressed with regard to the future. Prior to the stroke I was in sales, but I have no interest in going back to that line of work, nor do I have an idea of what it is I would like to do. Though I am collecting a monthly disability check. I worry if I will have enough money. I wonder if I will ever be 100 % physically and emotionally. I hope to go back to driving in the coming weeks and that is a source of concern for me.

The questions that we all face seem more immediate as I recover. I feel quite a bit of pressure in my life. I improve physically but emotionally and mentally I am not as confident. I have trouble speaking in a group I don't feel as confident as I used to. I have a degree of insecurity that I didn't have prior to the stroke. Every time I feel a slight bit off kilter I worry. If every I feel any pain in my head I immediately worry that a stroke is imminent. I don't know if I have another recovery in me. I don't believe I could summon the courage or the strength to go through this again.