

My Story of Striving in the Post Stroke World

By Mitch Raymond

When most people think of stroke, they think of it happening to people 50+ years of age in the latter half of life due to a blood clot or hemorrhage in the brain. People are absolutely shocked when I tell them that it can happen at any age of life. Take me for example, I had my stroke during my childhood and in the beginning, I was very debilitated. It was an uphill battle filled with many twists and turns but I was able to make it from being a debilitated child to being a fully functioning adult with a wife, two children, and a successful career to support them by the time I got around to typing up/voice dictating this story 30 years later. The career that I chose, and currently practice today is Physical Therapy. This allows me to integrate my personal stroke rehab experience with my PT knowledge and clinical experience. In turn, that allows me to better help my clients improve their functional abilities. Some may ask how I was able to achieve this level of success. Well, it did take open-mindedness, curiosity, will power, perseverance, determination, research, and a lot of life experience, but I did not achieve this alone. With the guidance of therapists, teachers, friends, colleagues, fellow people with disabilities, and of course my loving family, I was able to overcome many of the obstacles that stood in my way toward success.

I had my stroke back on January, 17th 1989 when I was 6 years old. I had a benign brain tumor that was a birth defect. By the time I was five, the tumor was golf ball sized and it had made itself one with my left middle cerebral artery. Up until the tumor was found, I was having seizures that were getting worse and worse. In the beginning, they were just daydreaming spells. But they gradually became more involved. My mom eventually took me to the local doctor when I was four years old. It was determined that I was allergic to milk without anything more than the most superficial of diagnostic observations. By the time I was five, the seizures consisted of the following. I would be playing with my older brother when all of the sudden I would go into a trance. I would then proceed to walk toward my mother and sit in her lap, stand by her side, or walk in

circles for a minute or two. She would frantically try to get me to respond during that time, but I could not answer or I would answer in incoherent babble. I would then proceed to walk toward the bathroom, vomit and collapse. Allergic to milk... right.

My parents could only trust the original doctor so far and then decided to get a second, third and even fourth opinion to make sure the real diagnosis was found and sound. When the tumor diagnosis was confirmed at UMass Medical via CT scan and MRI, I was sent to Boston Children's Hospital for surgery. Anyone who knows arteries knows how fragile they are, especially when a tumor has to be extruded off of one. Thus, when the tumor was surgically extruded, my left middle cerebral artery hemorrhaged leading to my stroke.

When I exited out of the OR (I don't remember this, mind you), I stared up at my parents and then to the surgeon who had just saved my life and said "I... hhate... yooou." He smiled up at my parents and said "no big deal, I get that all the time." He was a doctor with a great sense of humor, along with just being a great doctor in general, because he saved my life.

My affected side (right side), was totally flaccid (paralyzed) post-operation. I could not even support my own posture to sit in a regular wheelchair. They ended up having to put me into a special wheelchair that put me into a propped up but laying down position. On top of that, I had double vision and anomic aphasia.

Textbook characteristics of anomic aphasia include trouble using correct names for people, places or things; speaking hesitantly because of difficulty naming words; difficulty finding words may be evident in writing as well as speech; reading ability may be impaired; and having knowledge of what to do with an object, but still unable to name the object. I had every one of these characteristics at first, but I was able to work



through most of them through speech therapy, which I had for six years after the stroke. After that 6 year period of speech therapy, word retrieval fluency was the only residual deficit from the anomic aphasia.

After the tumor extrusion surgery, the doctors told my parents that I may never walk again. The keyword there was "MAY," but my parents took it as "Will." That was until I started rehab. My PT was the first therapist I saw and my parents told her that the doctor said I WILL never walk again. The PT smiled and said "we'll see about that; no prognosis is set in stone when it comes to stroke rehab." This was by report from my parents later in life when I could comprehend such things.

It was through PT that within three months I could walk again and within six months I could run and play with the other kids with a significant limp. I kept having PT until sixth grade, when my playing sports took priority over PT.

In school sports, I always felt subpar due to my weak right side. That was until I joined the Vermont Special Olympics (VTSO). It was through the swimming and skiing competitions that I realized that it was possible for people/kids to be more disabled than I was and still outperform someone like me through hard work, through a significant amount of practice, and determination. I practiced for, and competed in, the VTSO from 1992 to 1997. By 1997, I was competing well and had built up enough confidence in the sport of downhill skiing that I started coaching other kids with disabilities to compete in the winter VTSO games. I credit the VTSO with giving me the confidence boost I needed to become a successful adult.



In school from elementary school into high school, writing/typing narratives for school assignments was agonizing due to my residual word retrieval fluency problems on top of having to write with my formerly non-dominant left hand and type with only one

hand as well. I had this difficulty right up until high school when a new piece of technology came my way.

In sophomore year of high school, I was introduced to Dragon Naturally Speaking voice dictation software. At first, it was terribly difficult to train and use due to the accuracy issues of the program combined with my difficulty efficiently retrieving words. However, after a year or two of using it, two remarkable things happened. One was the program became more used to my speech patterns and two was that the residual word retrieval fluency problems that I had were significantly reduced. This occurred due to the need to speak in complete sentences in order to get the program to transcribe the correct words on to the document that I am writing. To this day I still use Dragon Naturally Speaking and other voice dictation software to more efficiently perform word processing projects and it has made a world of difference.



My biggest regret from my childhood was in regards to my neglect of my right hand. I did have one period of late in the game progress when my mom signed me up for Constraint Induced Movement Therapy for two weeks one summer while in high school. I retained my thumb and forefinger pincher grasp through this therapy, but I still neglected the use of my hand into my first year at college.

I went to Boston University for one semester of Aerospace Engineering and then one semester Astrophysics. All the while spasticity was actually increasing in my elbow, forearm/wrist and hand muscles out of neglect. I saw this and also saw that my life wasn't going the way I wanted it to. I ended up withdrawing from BU and taking a year off to re-assess my life.

That summer, I began to design my own therapy regimen with everyday household items (PVC Pipe, a basketball, pen and paper, cups, utensils, etc). With this I start-

ed to see some of my control returning and started to develop an interest for the first time in the rationale behind the rehabilitative therapy interventions I had been through. I then started shadowing local Physical Therapists to see what rehab was like from the perspective of the therapist. I was fascinated by their descriptions of the rationales behind their interventions. I wanted to know more both for myself and potentially for others to see if I was able to accomplish what it took to become a therapist. Thus, I started applying to and visiting colleges again and finally got into the Quinnipiac University Master of Physical Therapy (MPT) program.

PT school was one of the most difficult challenges that I have ever put myself through. Not only was it mentally challenging due to the amount of information that I had to cram into my memory

banks for each test, but it was physically challenging as well on a neuromuscular level. Almost every single hands on technique that we learned and practiced needed to be adapted to my physical capabilities with my stroke affected right upper ex-

tremity. In the beginning, this was

hard not only mentally, but socially and emotionally as well due to the fact that my adaptive techniques made me stand out amongst my peers with my different approaches to the text book ways we were learning each technique. This made me feel somewhat of an outcast amongst my fellow students because a lot of them did not want to get confused by my alternative approaches to the text book techniques that they were trying to master.

I even dealt with a select few of my instructors who were hesitant to allow me hands on experience with clients in the field due to being insecure about my physical capabilities. One time, one of my neurorehab professors allowed every single member

Physical
Therapy
Rewiring
the Brain
After a
Stroke



of my lab group to get hands on with a stroke survivor from facilitating balance work to transfer, gait and stair training; everyone except for me of course. I know now that I could have been hands on with that client in the field lab and been totally safe with him if I had been given a chance to be hands on. I was so put off by this experience that I reported this incident to the heads of my department and vowed to never let it happen again.

Being a student of PT also had its perks. I got to learn from some of the greatest PT minds in the field with regard to their educated and well researched perspective to my case as a stroke survivor. I also had the privilege of being a subject of a graduate PT study on the application of Saebo Splint products. I even got Botox injections to tone down my spasticity in my

forearm and hand so that it could be easier to stretch and work my hand with the Saebo stretch and the Saebo flex splints that I got to practice with. Unfortunately, the project was cut short due to my catching Mono during my week trip down to New Orleans in 2005 to be a part of the Katrina Relief effort. After 5 years of schooling, a year of clinical affiliations, and hundreds of hours studying PT baseline knowledge and skill sets, I finally sat down to the PT Board exams and passed 1st time around.

Today, I am a PT licensed in the state of New York, a husband to my wonderful soul mate, and father to my 2 loving sons. Since 2010, I have worked in all aspects of inpatient rehab as well as in home care. I currently work in a home care agency in up-state New York. I also lead a local stroke support group called Friends and Family Stroke Recovery Group. It is through PT that I have accomplished many of my life's



goals. It is also through PT that I still work on my ongoing goal of continuing to regain the control and use of my right hand. As a PT, I work hard every day to help people achieve their goals of regaining their functional mobility through applied evidence based practice, education given to each patient about my approaches to each of their cases, and empathy. Some people believe stroke is a curse. For me, my stroke was a blessing because it made me who I am today, a Physical Therapist who can truly empathize with the hard but rewarding work of rehabilitation through my life as a Physical Therapy patient and professional status post stroke.



If anyone has questions or comments, you can send them to the following email and I will reply when I can. Email: mitchraymond614@gmail.com