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Life Revised

Martha A. Parker

I was nineteen, scared and alone, and in an ER for the first time when a nurse suggested that I might have multiple sclerosis (MS). She then proceeded to stick me with an IV of steroids to combat the inflammation in my eye, the apparent cause of my partial blindness. It was my first time in a hospital, my first time in an MRI tube, and my first time getting an IV. Saying I was scared is an understatement. I flew home to Utah (I was working for Disney World in Florida at the time) and was diagnosed with MS shortly thereafter.

Happily, I did not go completely blind, and my eye healed after several weeks, but I am not ashamed to say that I spent several years in denial that I had a debilitating disease. After a time, I found the right doctor and right medication. It worked for about four years. During that time, I never had another exacerbation (an MS version of an attack). Life was grand. I sang and danced and walked and talked and jumped and did everything a person with a regular body could do.

Then the unthinkable happened. In February 2012, I started to notice a change in my ability to walk. In April 2012, I could walk only with somebody to lean on. (I had fallen four times at home when I was left alone.) I like to say I walked like a drunk person. I've never been drunk, so I don't know for sure, but there was a lot of staggering involved. By May 2012, I had lost all ability to walk and moved back to my parents' house. I had several MRIs, and the doctors could find nothing wrong with me, but something was very wrong, and I knew it. On July 31, my doctor discovered that I was one of only 350 out of 110,000 people currently taking Tysabri worldwide who had developed a condition called Progressive

Multifocal Leukoencephalopathy (PML), a brain infection. My cerebellum (the powerhouse in your brain for all things balance related) was slowly being eaten alive. Of those 350 people, only 15 percent had survived.

I entered the hospital, blissfully unaware of what would happen to me there. I had heard of plasmapheresis before, but I didn't know it would require a PICC line in my aorta. A PICC line is simply a tube doctors stick in a vein that allows them to pump blood out of your body. The PICC line in my neck was supposed to allow them to filter the blood contaminated with Tysabri to clear the drug out of my system.

The picture plasmapheresis painted of me was not pretty. I couldn't eat by myself. I couldn't walk. I had no focus, so I couldn't read, and watching TV gave me a headache. My muscles moved in weird and unexpected ways. I flailed around so badly that I had to be seat-belted into my wheelchair and strapped to the toilet so I wouldn't fall onto the cold tile floor. I had a catheter, an IV, and leg cuffs that inflated and deflated to keep my blood circulating. They call this lack of coordination *ataxia*, which is just the scientific way of saying no muscle control.

I felt like a marionette with some unknown puppeteer pulling the strings that would make my arms, legs, and head move. "Let's make her head loll back and forth like a chicken." "Pull," said the puppeteer. "Let's make her clock herself in the face with her fist every time she tries to raise her arm." "Pull," said the puppeteer. "Let's make her legs spaz out in all directions whenever she tries to stand." "Pull," said the puppeteer. My attempt at controlling my hands and feet was to name them and call upon them whenever I wanted to move. I christened my feet Ralph and Wanda, and my hands Phoebe and Phil. I don't know if that worked very well, but it did make my life far more entertaining.

I should have been dead. Two or three times, I wished I was. All my doctors expected me to die. Who could blame them, since every other PML patient they had seen had ended up in the morgue? That just seemed easier; I had no husband or kids to worry about, and it seemed at the time that I was causing my family pain. If I died, I would walk again and dance and sing. This seemed like the better existence, but I didn't die, and I think I know why.

People around the world and of different religious backgrounds were praying for me and uniting in the spirit of fasting. My dad and brothers and even my cousins had all given me priesthood blessings. The blessings said nothing about healing from my troubles, but they gave me peace, comfort, and patience enough to wait on the Lord's timetable.

My circumstances allowed me to serve in ridiculously unexpected ways. My therapists served me most of the time, but I served them by

having a good attitude. My mom served me by coming up to the hospital on a daily basis, but I served her by smiling and holding her hand. I always thought giving service meant I was doing something for someone else. Many people served me, but I could also find a way to serve them. It was a two-way street that I had forgotten existed.

“Faith is knowing the Lord will hear my prayers each time I pray.”¹ I sang those words in Primary. I sang them growing up. I probably now sing them as an adult. Those words haunted me during my hospital stay. I prayed. I prayed every day. Healing was still elusive. All of my life I had been taught about spiritual gifts. One stood out at this time, more than any others. And that was faith to be healed. There was only one explanation. I didn’t like it, but it was the only conclusion I could fathom. I must not have had sufficient faith for healing to happen. This thought depressed me more than any other thought I had had in my life. The days during plasmapheresis were tedious and usually long. There was little anyone else could do to lift my spirits. Then about halfway through my hospital stay, I thought of Jesus Christ and Joseph Smith. They certainly had faith, but their troubles didn’t disappear. Not that I am equating my struggles with their struggles, but just maybe they shared a spiritual gift with me and countless others. We had faith not to be healed, or said another way, when we were not healed, we could still have faith. Faith is not dependent on circumstances. I had to learn that the hard way, but at least I learned it.

I surprised everyone by continuing to live. After six weeks in the hospital, I moved to a rehab center. I thought I knew what to expect. I thought I had had enough physical therapists (by that time I’d had four) to know what to expect in therapy. I was wrong. I tried to sing songs with my speech therapist each day to work on my pitch and endurance. I certainly didn’t expect that. Occupational therapy had me do word searches and make salsa. That was unexpected. The most unexpected thing was in PT. They had a gym that rivaled the hospital’s any day. My physical therapist had me walking up stairs, riding every bike imaginable, and squatting on a piece of gym equipment.

The most fantastic and unexpected machine ever was the antigravity treadmill. You put on a pair of super snazzy shorts, and they zipped you into the machine. It then blew up like a balloon. The therapist could control how much of your own body weight you felt and how fast the treadmill moved. That allowed me to walk relatively unassisted. From my

1. Beatrice Goff Jackson, “Faith,” *Children’s Songbook* (Salt Lake City: Deseret Book, 1991), no. 96.

new vantage point, I could see the outside world through the windows and, drum roll please . . . the parallel bars. They never stopped haunting me, even when I left the hospital. I wanted to walk between them, but I was scared to death that my hips would attack the sides like they had once before. Such a thing would not only mean I had failed in my endeavor, but it would also confirm my suspicions that I had not improved at all. I looked at the parallel bars and continued to walk on the antigravity treadmill.

On my last day of therapy, I finally built up enough courage to ask my PT if I could attempt to walk in the parallel bars. He said, “Why not?” and what was once a dream became a reality. It became a reality in a big way. I walked without crashing my hips from beginning to end. I even walked backwards. It was the finest moment of my rehab experience.

Plasmapheresis left me unable to talk. I could make my desires known more or less, but speaking in long sentences of any kind made me pant for air. Singing, once the love of my life, wasn’t even on my radar. One day, a friend visited me and insisted that squawk or not, I could sing, and she wrote on my hospital daily goal board that I had to sing at least ten songs a day. My voice teacher also visited me in the hospital. She insisted that I sing any song I like. I had a hard time believing both of them. I could hear me. My mouth and throat couldn’t form the words or pitches that I heard in my head. Some days I would sing to myself, but mostly I would just give up.

When darkness masked the night sky and the world was alight with stars, when the moon was shining brightly across the earth and I heard quiet footsteps of nurses and CNAs in the hallway, only then was I completely alone. I could snuggle in my blankets and feel the gentle breeze from the ceiling fan on my face. The dark of the night was the only time when I didn’t have to have someone next to me (and considering I face-planted on my living room floor, that is probably a good thing). In the sweet silence of the night, sometimes I could forget that my legs didn’t work and that my hands would never be still. I could forget that my hair was gone, that my eyes couldn’t focus. For a moment, I could be “normal” again. And I was singing. I was dancing, and jumping, and walking. But then the darkness would cast another spell, and I would fall asleep and wake up with legs that didn’t work and hands that would never be still. And I would have to wait through another day before I could feel free again.

None of us are really what we appear to be in the mortal frame. I am as guilty as the next person when it comes to judging people with a disability of some kind. I am ashamed to say I probably made judgments on their intellect and their abilities and their contribution to the world and their families. Now I can’t stand it when people assume I am a certain way because I am in

a wheelchair. I hate it when they think I am stupid or don't have an opinion. What goes around comes around, I guess. I sure as heck plan on never judging others again.

After many days of rehab and after about a hundred grilled cheese sandwiches and so many hours in my wheelchair, I finally got to go home. "Home is where the heart is," and don't I know it! I could sleep in my own bed, associate with my own family, and eat my mom's home-cooked meals. Coming home was the best medicine I could possibly have asked for.

Under Medicaid, I was allowed to have occupational and physical therapists come to my home for a preapproved number of visits (I guess speech therapy had gone the way of the dodo). These were not the same therapists I had in the rehab center, but I loved these guys all the same. I remember the day when I stood up on my own with my new OT. It was surreal and kind of scary, but I stood as long as I could. When the therapist finally departed, I may have collapsed in a puddle of tears while my friend danced around the room like a crazy lunatic. It had been close to a year since I had stood up by myself. It was a very happy day.

The approved number of visits came and went. I was left without a therapist in my pursuit of regaining my abilities. I am my own therapist now. I have weights that someone else can strap to my hands or feet. I have a recumbent exercise bike, and I have a special treadmill. I use them as often as I can. It's not as good as the PT, but it's as good as I can do on my own.

I mourn my femininity. My curling iron is gathering dust. So are my hot rollers, my straightener, and my hair dryer. Even if I could wield a curling iron now, it would be beside the point because my hair is not long enough to curl anyway. My clothes are gone, sold. My sister planned three yard sales so that I could make enough money to keep credit card companies or the collection agency of their choice from calling.

I think snakes shed their skins a few times while they're alive. In some ways, I feel like I'm shedding a skin. I'm not the girl I used to be, I'm somebody different. Maybe it's a good thing, and I'm version 2.0. Good or bad, I just feel different. My hobbies have changed. How I spend my time has changed. What I wear has changed. I may still be the girl I once was on the inside, but there is so much that is different now.

Everyone I know hates this analogy, but I'll say it nonetheless. A swan's feather on an ugly duckling doesn't do much good. It's still an ugly duckling. I am an ugly duckling now—at least it feels that way with my cropped haircut and lack of anything remotely feminine.

My niece watches intently as her mom takes care of me. Then she insists on trying to help. She'll hold up my water bottle so I can take a

drink. She tries to put my shoes on when I'm not wearing them, and if we're ever putting weights on my feet or my arms, she either helps or puts weights on herself so she can be like her auntie. She reminds her mom when it's time for lunch and makes sure that I am wearing a bib to match her own. She also pushes my wheelchair. My nephew does that too, so I guess he's a nursemaid as well. Have I mentioned that my niece and nephew are two and three years old? I thought I should mention that vital piece of information. I'm being babysat by babies.

On a Wednesday in October 2013, I went to the temple with my sister. During the course of the night, she had me hold the car keys. These weren't just any car keys; they were *my* car keys—once upon a time, when I could drive. I hadn't held my keys for probably a year and a half. Needless to say, I started bawling. But it wasn't just the keys. It was everything the keys represented. If I had car keys, that meant I had a job to go to, and I made enough money to have a car, and pay rent, and live on my own. They represented everything I thought I had lost, and I wasn't getting it back anytime soon.

I had lost many things. They seemed so irreplaceable at the time. But what had I gained? I gained perspective on life, compassion, increased love, better relationships with my family, better relationships with my nephew and niece, and a personal drive to get better unlike anything I had ever seen in myself before. I gained much more than I thought I had lost.

My future is hazy at best. I don't know what will happen to me or how long I'll live or what abilities, if any, I will regain. I'm full of questions, and nobody on this earth seems to have the answers. But I have a confession: I make my own answers. My hazy future will include hours on my exercise bike, lots of listening to books on tape, lots of singing along with CDs, and lots of attempts to walk.

I could choose to be angry or bitter or helpless. Pathways fork in every direction, but I don't like where those paths lead. What does my future hold? I don't know, but I will write new editions every day and include them in my book of life. Sure, some pages will have angry outbursts or heaving sobs, but I hope even more have stories about my niece and nephew and about me defying odds. As for me, I will choose how my story in the book of life is written instead of having someone write it for me.

Martha A. Parker earned a bachelor's degree in English from BYU in 2005 and worked as an editorial assistant and assistant managing editor at BYU Studies from 2005 to 2007.