Accepting MS

by LIBBY SELINSKY

Learning to Accept Multiple Sclerosis

How do we accept that our lives are out of our control? How do we accept that multiple sclerosis is going to be calling some unforgivable shots?

MS is an incredibly insulting disease. It waltzes into your home and takes any number of your most precious things and crushes them right in front of you without any warning or apology.

My MS relapses always seem to occur while I am sleeping so they can reveal themselves as soon as I wake; sitting there proudly, mocking me, and no one else can see or feel what this latest relapse has done. I am alone in the experience, and I have to go to bed every night knowing that the next morning I could wake up paralyzed or blind.

I was not, am not, ever going to be the person who accepts this disease quietly without complaint. I am loud and I am angry. I fought its existence in the beginning. I would not, could not accept that this disease was actually a part of me that I could not remove. It was just so alien.

I knew nothing about this kind of torture and I fully believed, as I do today, that it has absolutely no business coming into my life and stealing from me EVERYTHING that I have built, everything that I have earned. The trouble is though; I can't get rid of this disease. It is my body that is doing this to me. My immune system is working too hard and it is out of my control. I hate being helpless to this fate.

Meeting a Hero

In the beginning, I was quiet and terrified. I was so alone. My husband loved me so much, but his ability to speak to me about my MS was about as deep as my shallow understanding of the disease itself. We were both trapped and unable to reach each other. The two of us would lie in bed at night, without much to say.

Around the same time that I was diagnosed with MS, a man named Denny was diagnosed with ALS. Denny was an old friend of one of my husband's coworkers. My husband, Kier, works in technology as a career, but is also an incredible photographer. Denny wanted to document his progression with ALS so he could share his experience with the public, and he chose my husband to be his photographer. He didn't want to hire someone who would exploit his disease and he believed that Kier would be sensitive to his needs, in large part because he knew of my situation — MS and ALS are similar diseases.

I believe Kier felt good about meeting with Denny and diving into a project that could provoke strength and goodness within a tragedy. Denny was a character! The day I met him, he was so full of life and insistent on meeting me. I was so removed that I had separated myself from the large group of people and I was sitting at a picnic table across the park from Denny. He beckoned me from afar and insisted that I stand in the group photo with him and his friends, marking the beginning of his journey with ALS and the end of his Harley days.

That day was his last ride. His hand had already begun to decay and he would no longer be able to control his bike safely. My hands were still numb from my first large relapse. We were two strangers missing the strength of our hands, standing within a group of people who would never understand our similar struggles.

I looked at Denny with such deference. He was going to die and yet he was incredibly loud and funny. He had a strong and raspy laugh. Denny became one of my biggest heroes in life. His road with his disease was going to be shorter and more predictable than mine would be with MS. He had to live every day knowing that he would never watch his grandchildren grow up.

Next page: standing on the edge of a well, and being grateful.

Standing on the Edge of a Well

I have always felt like we were two people standing on the edge of a well. We both got pushed in, and it was only because of where I was standing that I was capable of catching the edge. I was left watching him tumble down to the bottom and drown while I hung onto the edge, not knowing if I would fall in or climb out. It seemed so unfair that he had no chance of survival from life’s early push of fate.

Denny and I talked a lot every time I would visit. He always wanted to listen to me. He always had a lot of questions about who I was. Somehow I found inner peace within those visits. My fear of MS subsided in a way. I was not going to die from this. I was not decaying with speed that Denny was. I was still very young and I still had many years ahead me. Denny was my friend. Denny taught me how to give selflessly to others that need someone talk to. Denny taught me that it's alright to let people see my sickness.

He also taught my son how to do a wheelie in a wheelchair. I love him for that because he taught my son not to fear or ignore people with disabilities. My son was seven years old when Denny died, but he still remembers riding around on the back of Denny's wheelchair. My son also still remembers Denny's laugh after all these years.

Denny died about three years after I met him. The documentary had dwindled when he lost the support of his friends. They had tired of him and he was left in a care center. His daughters loved him very much but they were still too young to have the resources to support him when his girlfriend left him. In the end, my visits with Denny became solely about hanging out with a friend.

To this day, I still believe that we needed each other very much; but I know that I got the better end of the bargain. I was given the gift of his strength and guidance and I was also blessed with time. I have been given such irreplaceable gifts in this life.

Being Grateful

I am grateful. I am grateful for Kier bringing me and Denny together. I am grateful for the many hours that Kier sat and listened to the two of us talk. I am grateful that my son learned the deep lessons of love and loss, at such a young age, and with such grace. I am grateful that Denny wanted to help me while he was suffering.

I learned that I am not alone. I learned that love can come from strangers and settle within your soul for life. I learned that this world does terrible things to wonderful people all of the time – that is just life. Grace comes from finding the beauty within the pain.

I learned that I am not special in regards to suffering. My suffering is unique to me, but I am not unique for my suffering. It is the human plight. I learned that I need people, and that's OK. Most importantly, I learned that today might be hard, but I still have a tomorrow and not everybody can say that. I am thankful for today.

No one can or should tell you how to accept this disease. Everyone has their own path. I've never wanted to accept that I am stuck with MS. I hate this disease. I still get furious about it and that's OK, because it motivates me to stay healthy and strong.

Acceptance found its way to me through my release of control over my fate, and my realization that living with this uncertainty and loss has also given me bountiful blessings.

A friend of mine asked me early on, “How are you doing?” My answer was simple: “I am physically on the mend, but I will not be fully healed until I am grateful for getting multiple sclerosis.” I really never knew if that day would come, but when I take stock in my life, I realize that my whole family is the better for it.