

The Challenges of an MS Warrior



MS sometimes makes it feel as though I'm the unwilling star in my own action movie. Falls, blurred vision, excruciating dystonic spasms and bowel and bladder issues are all part of the obstacles to overcome in my adventure. I never know when I get up in the morning what will be in the "script" that day.

I remember feeling relieved when I was finally given an MS diagnosis, which was followed immediately by fear of an unknown future. My job as a certified health unit coordinator at a large hospital was becoming more and more difficult to perform. I agonized about what I was going to do, but the decision was made for me when I had a heart attack and subsequent robotic coronary artery bypass surgery six months after my MS diagnosis. After the eight-hour surgery, I was very weak, and recovery took much longer than expected. It became obvious that my work days were over. I spent hours researching treatments, outcomes, etc. and deciding on a path for my own care. Just as every person is unique, MS is unique in each person, which makes it a very personal quest.

I have completely removed the word "hurry" from my vocabulary. Just getting dressed some mornings is a comical battle between limbs and clothes. I have more than once found myself tangled in a top or so consumed with trying to cope with a spasm; I once walked around all day wearing two obviously mismatched socks.

Oh, yes, I have had some very embarrassing things happen and twists and turns along the way. One time my sister-in-law and her husband came for an unexpected visit, and we went out to dinner at a restaurant that was a remodeled blacksmith shop. The restaurant was very crowded and the only table available was on the second floor - only accessible by a steep

open staircase. The wait staff was literally running up and down the stairs with their full trays propped on their arms. The manager halted all action and completely cleared the stairs. I could feel all eyes upon me as I held my cane in one hand and the railing with a death grip in the other and slowly climbed the stairs one step at a time.

One of my least favorite (and funniest) memories is of using the restroom in a Hobby Lobby. When I flushed the toilet, a pipe broke producing a geyser sending water up to the 12-foot ceiling! I tried as best I could to “run” out of the room with a huge gush of water following me. With my cane slipping and sliding and my difficulty walking, I was soaked from head to toe, and two women took one look at me and hurriedly walked the other way.

But a more serious issue is that once MS is diagnosed, it can become too easy to think everything is a consequence of this disease. I awoke one morning to such severe difficulty walking that I could barely make it from the bedroom to a chair in another room. I discovered when I reached our computer that my left hand could type, but my right couldn't. A small portion of my face was numb. The consensus was that it was “MS,” but my neurologist ordered an MRI just to be sure and it showed that I had had a thalamic stroke!

MS has definitely been both a challenge and a learning experience. It has taught me not to take myself or things that happen to me too seriously. But sometimes it does feel like way too much to handle and on those days there are more tears in my shower than tap water. On a day like that, I am blessed to be able to phone my sister who was diagnosed with MS years before me. Together we laugh at having to hold onto walls in stores when we became dizzy or commiserate on how we are feeling. I am so blessed to have my sister - but for those of you who are alone in your battle, there are support groups and resources so that no one ever need feel isolated and alone. The advances in both knowledge of the disease and in treatment have been and continue to be life-altering for many.

We are all MS warriors walking, wobbling or rolling into a much brighter MS future.