

Meeting Halfway

Living with multiple sclerosis requires an independent spirit as well as the support of others.

BY NICOLE ROLFES

I was diagnosed with multiple sclerosis (MS) in January 2012. It seemed like a long road to the diagnosis, but some people live with their symptoms for many years before figuring out the cause.

Back in 2009, half of my face went numb. It felt like I had just walked out of the dentist's office. In fact, I kept checking to see if I was drooling. My doctors thought I might have experienced a stroke, but after a computed tomography (CT) scan and a number of other tests, they diagnosed me with MS.

In addition to facial numbness, my symptoms include tingling sensations in my legs and feet, headaches, fatigue, vertigo and balance problems. Vertigo has been the most difficult of all the symptoms to deal with. It has made me very ill and caused me to miss many days of work. I have had to change jobs numerous times, but I finally found an understanding employer and the right medication for me, which is interferon beta-1a (Rebif).

Scientists used to think MS was not genetic, but now they know there is a genetic component. My brother has been diagnosed with the condition as well as two of my cousins.

The day after my diagnosis, I reached out to the local chapter of the National Multiple Sclerosis Society (nationalmssociety.org) to see what was available as support and information, and I bought a number of books to read. Exercise and eating healthy have helped me manage my MS symptoms. I tried eating vegan and was able to stick with it for six months. I felt great, but it was difficult to follow this type of diet, and cooking two different meals—one for me and one for my husband and children—hurt the pocket book.

In addition, I have been attending a support group

every month in order to surround myself with other people who understand what I'm going through. We share our experiences and tips for managing MS, talk about the different medications we're taking, and find a way to laugh no matter what life brings. Meeting with the group reduces my stress level, which seems to reduce the number of exacerbations that I have. A majority of the time my spouse attends these groups with me, and at times our children do as well. The entire family should have support, not just the person who was diagnosed.

It's also important to feel safe enough to discuss the symptoms of the disease with our loved ones. For example, MS can affect sexual relationships. Our spouses and partners may not know that we are experiencing pain or numbness. Those symptoms can be "invisible" but negatively affect our desire for intimacy.

At the same time, I appreciate when my friends and family don't remind me that I have MS all the time. I tell them, "If I stumble or fall but don't ask for help, then don't worry about me—I'll ask for help if I need it." You have to strike a balance between feeling independent and leaning on other people for assistance.

I'm confident that no matter how the disease progresses, I'll find a way to manage. Emotionally it will be difficult, but no one said life would be easy. My attitude is even if I end up in a wheelchair, my father is a great welder and he'll mount a shovel on the front so I can still clear the snow off my driveway. That's my idea of meeting halfway.

Nicole Rolfes lives in Lloydminster, Alberta, Canada, with her husband and blended family of four children. She is the office manager for a company that provides computer technical support to the surrounding area.

