

My Elusive MS Diagnosis



I know multiple sclerosis is sometimes called one of the “invisible illnesses,” but I call it my “ghost illness” because it is always there haunting me. For so many years I had strange, frustrating symptoms that went undiagnosed. To name only a few: tingling in my extremities and vision changes, bladder and bowel problems, and fatigue that confused the myriad of specialists that I visited.

I am an adoptee, so for many years, my medical history had been a mystery. About 20 years ago, I was able to find my birth mother’s family and discovered that one of my sisters has MS as well as an uncle and a cousin – a veritable small cluster! I had many of the symptoms that they had, but it took 10 more years for my diagnosis.

On one occasion, I was training puppies at our local Humane Society when my vision suddenly changed. I looked across the training arena and it was as though I was seeing things through a strange telescope where everything was miniaturized. I drove myself to a local ER where an MRI showed odd white lesions in my brain and not the stroke that the doctor had thought she would find.

On another occasion, I was in a store when I suddenly had a horrific, painful sensation in my leg which was worse than any Charlie horse. It wouldn’t let up and was accompanied by a burning sensation down my back and extreme difficulty ambulating.

When I worked in the medical unit at a large hospital, I would go into the restroom and hang onto the railing and try not to scream in pain when a spasm started. My nurse friends noticed the excruciating pain I was in. Then the episode would pass and I could get on with my job.

The symptoms eventually worsened. My arms would suddenly go into a severely painful spasm, and I couldn't unclench my hands. I began to wobble when I walked and looked like I had way too much to drink. And I was beginning to experience what I later found out is known as the MS hug with crushing pain around the perimeter of my upper abdomen.

My husband drove me to an ER where a nurse told me: "There isn't anything wrong with you. You need to go home!" But I was admitted and taken to my room - the nurse that was assigned to me had been given a report by the ER nurse from earlier and adapted the same attitude. I started spasming in the room and when I asked her to look at what I meant, she would look the other way.

After many tests, the neurologist said that I may really have MS, but that he wasn't ready to make a definitive diagnosis. So very frustrated and scared, I was sent home and began my quest to find my own answers. I made an appointment with a renowned orthopedic specialist, but that appointment didn't go anywhere. I did make one more appointment with another orthopedist. While I was sitting in a chair listening to him tell me "he just didn't know," I suddenly began to have another dystonic spasm. The doctor muttered "Oh my God," and I could tell from the expression on his face that this had both shocked and surprised him. I asked him to please phone my neurologist because he had never seen one of my spasms. My neurologist ordered a spinal tap which showed abnormal oligoclonal bands. These can also show up in Lyme disease, but numerous tests for that had been negative in my case. And so, my MS diagnosis was finally made.

It's been over 10 years now and thankfully, I have seen positive changes in the diagnosis and treatment of MS. There are so many resources and blogs, so no one needs to feel alone and overwhelmed. There is also a greater awareness of others, including medical professionals, of the different presentations of this disease. Looking to the horizon, there is always hope.