

stiff person syndrome: a rare disease

By Anna B.

"If you can't fly, then run. If you can't run, then walk. If you can't walk, then crawl. But, whatever you do, you have to keep moving forward." Martin Luther King Jr.

My entire world was turned upside down when, at the age of 38, I was diagnosed with Stiff Person Syndrome (SPS), a very rare neurological disorder with features of an autoimmune disease that affects about one million people worldwide. SPS causes muscle rigidity of the body's trunk and limbs, and heightened sensitivity to stimuli such as noise, touch, and even emotional distress, which can trigger excruciatingly painful muscle spasms. SPS also causes people to have abnormal postures, appearing hunched over and stiffened, and often unable to walk or move. Many SPS patients remain at home, fearing that a spasm or fall could result in serious injuries.

I, too, experience many of these symptoms, including sensitivity to stress, touch, bright lights, vibrations, quick reactions, too much physical activity, and car or train rides. Prior to my diagnosis, I was a hard-working and successful operations director who thrived on being challenged, who exercised five days a week, and who enjoyed traveling, hiking, camping, skiing, and golfing.

According to the National Institutes of Health, SPS affects twice as many women as men, and is often associated with other autoimmune diseases such as diabetes, thyroiditis, vitiligo, and pernicious anemia. Scientists don't yet understand SPS, but research indicates that it is the result of an autoimmune response gone awry in the brain and spinal cord. Like me, SPS patients are often misdiagnosed as having Parkinson's disease, multiple sclerosis, fibromyalgia, mental illness, or told their symptoms are psychosomatic.

I have adopted a multi-faceted approach to managing my symptoms and improving my quality of life. This includes oral medicine, immunoglobulin therapy, medical marijuana, physical therapy, heating pads, hot baths, proper sleep, meditation, low stress environments and relationships, proper hydration, a healthy diet, and taking part in support groups and therapy.

I always knew I was a tough person, but I didn't know how tough until I SPS crippled my body. Using my upper body for any activity was difficult, and I had to relearn how to walk after terrible pelvic spasms. I am determined to live my life to the fullest extent possible. SPS is sometimes referred to as an "invisible illness." This ex-

plains why, when people see me on good days, they often can't see the effects of SPS on my body and mind. To them, I appear to be a healthy woman. I'm not, but I work hard to stay positive, and advocate for myself and others as I build connections with other SPS patients to help spread awareness.

In the meantime, I enjoy the simple, funny moments in life that I used to take for granted, and have become more compassionate and empathetic toward others. I have also learned that people's disabilities aren't always readily visible, and that we can all be a lot more caring in our interactions with others.

To learn more about the disease and donate to research, please visit www.stiffperson.org.



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