

A Flower Grows in Stone

My life with Stiff Person Syndrome.

BY ANISAH HASSAN

It happened once while I was on the phone with a friend. We were talking about love, spirituality, and the good things to come in our lives. I was overcome with emotion, and suddenly my legs froze and became like stone. I told my girlfriend that I needed help, then hung up and dialed 911. Looking down, I saw my legs and torso in the throes of violent spasms, as if I had been struck by lightning. It was the most excruciating pain I've ever felt. After a few minutes my body exhausted itself and I fell backward, drenched in sweat. I heard and felt the back of my head hitting the floor, and wiggled my fingers to make sure I was still alive.

I suffer from Stiff Person Syndrome (also called Moersch-Woltmann Syndrome), a rare and progressive neurological disorder that causes muscle stiffness and a heightened sensitivity to stimuli such as noise, touch, and even strong emotions. These stimuli can set off muscle spasms like the one I had on the phone.

My symptoms started in 1992, when I was 22 years old and had just graduated college. I was first misdiagnosed with multiple sclerosis and treated for six years but continued to experience symptoms. I then found a new general practitioner and a new neurologist, who told me I have Parkinson's disease. The next diagnosis was Rigid Spine Syndrome. I was treated—unsuccessfully, for the most part—with diazepam, muscle relaxers, pain meds, and botulinum toxin.

Fourteen years later, in 2006, I was finally evaluated for Stiff Person Syndrome. The disorder is often misdiagnosed as Parkinson's disease, multiple sclerosis, fibromyalgia, psychosomatic illness, or anxiety and phobia. Sometimes people with Stiff Person Syndrome become too disabled to walk or move. The condition can also make you too afraid to leave the house because street noises, such as the sound of a horn, can trigger spasms and falls. Even something as small as the wind brushing my hair across my shoulders can trigger a spasm for me.

Scientists aren't sure of what causes the disease, but they think it's the result of an autoimmune response gone awry in the brain and spinal cord. Stiff Person Syndrome affects gamma aminobutyric acid (GABA). This inhibitory neurotransmitter helps neurons determine what signals will be selected for response, so it influences your reaction to stimuli.

A definitive diagnosis can be made with a blood test that measures the level of glutamic acid decarboxylase antibodies in the blood. People with the disease have elevated levels of these antibodies, which work against an enzyme involved in the synthesis of GABA.

Thanks to knowledge and proper diet, I am now in a better place. I have begun monthly IVIG infusions and take a number of medications. Nevertheless, stress, weather, and emotional stimuli remain major triggers. I'm also starting to notice a change in posture (kyphosis) and have developed "swayback" (loradosis), which is very uncomfortable.

At times, isolation and loneliness threaten to consume me, but I'm always pulled back by my own laughter. Alone time doesn't seem so bad anymore. I have a vivid imagination, a greater appreciation of the good times, and the power to make something beautiful out of suffering. I've always dedicated my skills to social service, by working as a caseworker in a transitional housing facility, assisting families

with securing permanent housing, and working with abused and neglected children. Now, I'm also an author hoping to raise funds for the Stiff Person Syndrome Research Fund with the National Organization for Rare Diseases (rarediseases.org). By using my energy this way, a flower is growing out of the stone. NN



Anisah Hassan hails from St. Louis, MO. Her mission is to raise awareness and research funds for a cure for Stiff Person Syndrome. Her book is titled A Flower Grows in Stone: The Diary of a Life in Progress.