

Walk a Mile in My Brace
Diane Hoover Bechtler

Could I have danced all night?

My Russian ballroom dance instructor pulled me toward him. We counted beats -- Cha, cha, cha, rock back. 1 and 2 and 3 and 4 and. He led; I followed. Then I was down. I'd fallen again. Sergio hoisted me upright as usual. We started the routine over. He walked me methodically through a turn. My pink satin strappy stilettos made my unreliable legs look long, lean, and feminine. But I moved as though my left foot were embedded in the slick hardwood floor. Around me teachers and students gracefully swirled in Viennese waltzes or jived World War II style. I headed for a chair and my comfortable purple suede shoes.

A friend with Parkinson's disease remarked that I fell more often than he did and suggested I go for a checkup. After examining six huge bruises on my legs, I agreed. I thought I was out of balance because I was drinking too much, staying out too late, and stressing about school. I worried about money, my inability to keep a relationship together, and my future in general. But, that I couldn't stay on my feet during my two-hour weekly dance lesson concerned me the most. I paid the studio \$80 an hour to teach me to walk a straight line. Heel, toe, heel, toe. I referred to the lessons as taking the sobriety test.

I often dropped books or papers. I caught my heels on the backs of the stairs, and my left foot didn't always land where I intended. I slipped in the shower. I tripped on the sidewalk. My foot stayed in place seconds after I told it to move. I dragged the same foot. I shuffled and limped. People mentioned that I was listing to the left. Balancing on high heel shoes became difficult then impossible. I needed sand dollar-sized heels rather than dime-sized.

I continued falling. I made excuses for my tripping; my hitching gait, and my complete inability to do ballroom dance turns.

If someone remarked "shoes too tight?" I answered, "yes."

Or "back trouble?" "Yes."

Nonetheless, at 54, I entered grad school, and scheduled extra dance lessons to overcome my clumsiness. I did more leg presses and calf-raises at the gym.

Heel, toe, heel, toe, I walked through my condo with bare feet endlessly practicing, but my dance steps didn't improve. I walked near a wall so that when I lost my balance I could catch myself. People asked me if I was dizzy. I wasn't dizzy. But I answered, "Yes. I'm dizzy."

Finally, I stopped the expensive dance lessons, counted 10 large bruises, and marveled at my black and blue knees.

I called my internist to get a check-up. I'd avoided dealing with the problem for more than seven months. The constant embarrassment of making excuses for my awkward walking and my bruises sent me to the doctor. I wore blue Velcro tennis shoes hoping to appear steady.

The medicine men and women started with the easiest explanations; however, my case became complex.

What it wasn't:

My internist examined me, drew blood and concluded that I did not have a vitamin B-12 deficiency, nor did I have an obvious inner ear infection. She had me do a battery of neurological tests.

I thought such tests would be complex. No. I touched her finger then my nose, then with the other hand. I lifted one heel and ran it down the other shin. I counted from 100 backwards by threes. I fell after standing on one leg less for less than 30 seconds. When I closed my eyes, I swayed. Dr. Matlock watched me walk down the hallway and concluded that I planted or plopped my feet. Her diagnosis? I had a balance problem and proprioception difficulty. Proprioception is the body's innate ability to locate itself in space. Mine was skewed. Example: When I stepped, I was not certain where my foot would land, which explained why I missed a stair or caught a heel. When I reached for a cup, I might overreach and knock it off the table. My doctor could not say what was causing these problems but she was concerned. She sent me for my first brain MRI.

Your MRI was the title of the paper they gave me. It explained the process. Magnetic Resonance Imaging takes pictures of the affected body part in a more thorough way than X-rays. Magnets project waves that are read by a computer. In the end, I had a stack of large films that segmented my brain. Its deep recesses were shown as discrete images. I thought of onion slices and tree rings.

I removed my watch, locked it in a drawer, and put on a skimpy hospital gown. I kicked off my brown crocodile loafers.

"Did I suffer claustrophobia?" The technicians asked.

"No." The technicians questioned me about shrapnel in my body or other metals such as joint replacements.

"None."

Since the magnets are strong, I asked if there'd be problems with my root canals. I pictured my nicely capped front teeth ripped from my gums and stuck in formation to the curved metal above my head. The assistants assured me that would not happen. The woman gave me earplugs; the guy started an IV of contrast dye that would run through my brain to enhance the pictures. He gave me a ball to squeeze in case I needed to be rescued.

"Too late," I thought.

I lay on a cold, thinly padded table, which moved on a track into the tight tube. Clacking, clanging, and buzzing began. My head was stuck in a washing machine with an off-balance load. The nurses left me in that washing machine for about a week.

Dr. Matlock called on Wednesday. That she called rather than wrote was a bad sign. While she talked I examined my black Prada flats with their red stripe.

"I've got your MRI results." Matlock let out a big sigh. "You have confluent lesions on the right side of your brain. They're not presenting like MS because they run together. I've never seen anything like this. You have a lot of brain damage. I'll get you to a neurologist and find out what this is." Then she said something one never wants to hear a doctor say. "Diane, I am so sorry."

Friends indulged my "balance" problem, quite certain it was caused by an inner ear infection. A lot of people "knew" exactly what was wrong with me. I drank beverages with Aspartame. I didn't exercise enough. I exercised too much. I ate foods with preservatives. I lived near electrical cables. I used a cell phone. Their cures ranged from chewing certain types of Chinese bark to sleeping on a pillow parallel with the flow of the Catawba River.

Dr. Matlock sent me to Dr. Andrea Richardson, a neurologist. She was a young pretty doctor full of energy and determination. She referred me to an MS specialist who bounced me back to her.

Mystified by my MRI results and the MS evaluation, Dr. Richardson referred me to Mayo Clinic in Minnesota. It was time to see the big boys. I had become an interesting case.

Since I was in a low-residency Masters of Fine Arts grad school creative writing program, online access was necessary for me to continue my studies wherever I was. During my trips to the Mayo Clinic in Rochester Minnesota, I stayed at the Kahler Grand. The hotel offered high-speed wireless Internet access and had a stately European look to it. It connected to the Mayo Clinic by underground passages lined with nice shops selling shoes I could no longer wear. Having Internet access let me research every test they gave me. Keeping in touch with school grounded me. It helped me realize more was happening in my life than sickness. I wanted to keep some goals on my horizon.

The best doctors in the world searched for the cause of my mysterious illness. They squinted at the wavy patches and holes on the films of my brain. They referenced French neurological journals. They teleconferenced with India. I sat quietly on a sofa wearing low-heeled black lace ballerina shoes with ties wound up my calves.

While at Mayo, I kept current with my school submissions via the Internet. Between the MRIs, skin biopsies, and blood draws, I could also see what fashionable lace-up shoes Saks Fifth Avenue.com had on sale. In white athletic shoes, I missed my lovely footwear collection.

I mostly wore flats with straps or laces to stabilize my left foot trapped in its new brace that kept the foot at a right angle so it no longer dragged. Shoe styles other than lace-ups, either fell off my feet or wouldn't hold me upright. Footwear came one way for me now – sturdy. And it had to accommodate the brace. Orthopedic catalogs gave me many ugly choices. I began a quest to find attractive, stylish, special needs shoes. I would become the Carrie Bradshaw of orthopedic footwear. Mentally I began designing appropriately sturdy but pretty shoes.

Before I left home, I had packed away 24 pairs of shoes I would most likely never wear again. I had that many more to put away. I had to let go of my former life in stages.

Before I left for my second Mayo trip, as a farewell to heels, I wanted to choose the most painful, the most beautiful, shoes I owned, put them in a bag and take them on a date with my boyfriend, Lawrence, who would deposit me at the front door of an upscale restaurant. Using Citizen Cane (my new third leg) I could lurch to the door and barrel in. The Maitre'd knew me and could do the gentlemanly routine of crooking his arm to escort me to our table while Lawrence parked the car. I'd slip out of my flats and make a ceremony of putting on those shoes perched on pinpoints; the shoes hook at the ankle with metal chains; they have brass dragons crawling up the fronts of my feet. They are heartbreakingly gorgeous and sexy. They are art. I will have a vitrine made for them since they have become only decorative objects.

Fear of falling and breaking my leg kept the restaurant/shoe date a fantasy. However I did wear my heels in the relative safety of my home where I sat in a stable chair and kicked out my little feet.

My second trip to Mayo was much more demanding than my first trip. I had many more exceptionally painful tests. On the first trip I took my sister. I needed her on the second trip and she was home in North Carolina. I knew I'd take her on the third trip...

The original trip seemed a warm-up. The second trip, an exercise in pain, the third a further exploration of pain with an added dash of more impaired mobility. My trips blended into a quilt hiding my life.

Coda: As of today, I have lived with this condition for seven years. The doctors at Mayo and elsewhere do not have a name for it. I finished my Masters degree while I was sick and I think that is significant. I am monitored every year to see if my brain proteins are proliferating. Over the past seven years they have not moved. That is a good thing. I continue to write and am published under the name Diane Hoover Bechtler. Most of my work appears on the web. Much of my work is about illness and survival. I have written a memoir about my illness but so far have not been able to place it with an agent or publishing house. I am working on a new book will be a fantasy about a woman who travels through time. Although a fantasy, it will include parts of my life because that is the only life I know. Some of my life has been unbelievable and some has been horrible. In other words, my life is perfectly normal. I continue forward with the hope that some miracle will happen or some cure will present itself, perhaps through studies about Alzheimer's.

I am happily married to a man who is not afraid of my illness or anything else. I have my feline companion "call me IshMeow, Ishy for short.

some days are better than none...

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