

# *CIDP: EIGHT YEARS AND WALKING*

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"I don't think this is musculoskeletal," the physio said, "Otherwise I wouldn't be able to bend your leg like this. You'd be screaming. I think you should ask your doctor for a nerve conduction test. You should be able to get one pretty quickly."

I did have two mildly deteriorating disks. But I had been having increasing difficulty walking. I climbed stairs by using the railings to pull myself up. I fell twice going up curbs. Once I was unable to get out of my bathtub. I was tired. My back hurt – a lot – whenever I moved. I didn't bother buying tickets for the Toronto Film Festival, although I always went. I walked through my house with one hand on a piece of furniture or on the wall. The medical term, I learned later, was "cruising the furniture." I phoned my family doctor, who thought the test a good idea. The next morning, I received a call asking if I could get to an office at the hospital in two hours. A friend said she could take me. Two months later that same friend would bring me home.

First: Diagnosis

Not long into that nerve test, the doctor said, "You need an MRI. I'm going to find you a bed." I felt a huge sense of relief. There was something wrong with me, and now they were going to find out what it was. I gave myself up to the system. The pain medication worked but there wasn't much sleep. Someone kept waking me up to breathe into some contraption. Others came and took vials of blood. And the lead neurologist and the residents and students congregated around my bed and asked me questions. I came to think of them as Dr. Mama Duck and all the doctor ducklings. Had I had an infection of any kind? A vaccination? Where had I been? When did I start to get weak? How? Where was the pain? What was it on a scale from one to ten? And they tapped my arms and legs and had me resist as they tried to pull them. Arms were normal; legs had no reflexes and barely any movement. I did not feel the tuning fork or pricks on my toes, feet or legs. I'd had no vaccination and no infection that I could remember - but they were asking about the past six or eight months. The next day I had the MRI. I had no idea they were so noisy, like trucks picking up garbage.

The MRI showed something. Next day's brain scan came up normal. Then it was the weekend and the lumbar puncture would have to wait until Monday. I had too much time to think. What if I had cancer, one of the possibilities mentioned, and died? What if I never walked again? I lived in a house with stairs. I owned it with another woman who lived in the other half. If I could never go home what would happen to her if I had to sell? I had a two-person communications business that operated from the house. How would I be able to serve our clients, get new business and keep enough money coming in? I was 61, not willing or able to retire. I was executor and decision-maker for a friend who had terminal cancer. I had three cats. I wasn't prepared for this. On Monday two ducklings came to do the lumbar puncture. One duckling appeared a couple of hours later, grinning. "Well, we know it's not cancer," she announced. "We'll know more later, but I wanted you to know that." I thanked her. Late that afternoon, Dr. Mama Duck and all her brood appeared. My autoimmune system was working overtime and destroying the myelin that is the sheath that covers the nerves, in my legs. Thus, the messages from my brain couldn't get through and the legs weren't working. The now deconditioned muscles in my legs and core were probably the cause of the pain in my back. They would give me a dose of immune globulin intravenously each day for the next five days. The immune globulin, which comes from other people's blood, would make my own antibodies stop attacking the myelin. Then I could leave hospital. I'd be able to walk again, no problem. I was lucky. I had a mild

case of this CIDP, or perhaps it was Guillan-Barré Syndrome. The time of onset was not clear. But the treatment was exactly the same, so we'd find out in time. They left, pleased with the good news. They may have said more, but if so, I was unable to take it in. I was lying in a hospital bed, unable to use my legs, and it's a mild case? It didn't feel mild.

IVIg started that night. A physiotherapist showed up every day to start exercises. It was only from him that I learned I would go to a rehab hospital for a couple of months. The ducklings had done their job and diagnosed me, and I was tolerating the treatment. They did take me as a subject to grand rounds. It was satisfying to know that several experienced neurologists had seen my file. I learned that if it came back, it would only come back to what it had originally attacked. My arms would remain unaffected. And I finally learned to pronounce the full name - chronic inflammatory demyelinating polyradiculoneuropathy. After 10 days in acute care, an ambulance transferred me to a rehab hospital.

#### Second: Recovery

Then followed days of physiotherapy in the morning, occupational therapy in the afternoon, and walks through the hallways. In between I tried to keep up with my regular work. Writing and editing needed a laptop, a phone and internet access, but not legs. Progress was slow, but steady. My first taste of independence came when I got my own wheelchair and I could get myself into it. Now I could go to the bathroom by myself. I could go for coffee. I learned to do a wheelie. I got blisters on my hands. My first step wasn't as exciting. It was more of a lurch. After the six-step walk, a nap. I was exhausted. The back pain diminished. I learned to use a walker, then two four-footed canes. I learned to climb a curb with a walker and to climb stairs with a cane. We had to get up and down a flight of steep stairs before we were allowed to go home.

I came home in early November with a walker and made it up the front stairs into my house, grinning. Although there was a hospital bed waiting for me on the main floor, I made it down the stairs into my own bed, reveling in the quiet and the dark - and my very own private bathroom.

I had several weeks of physiotherapy as an outpatient, working to improve leg and core strength. A major step was learning to get up off the floor - that meant I could take a bath.

The increased exercise brought leg cramps, often while sleeping. Standing relieved them, but it was a scramble to get up. I left a four-footed cane by the bed. They stand up by themselves so you can find them immediately. The myelin comes back, although not entirely as good as new, but it takes a long time. For me, it was almost two years. For the first year, the advice was not to push past exhaustion so as not to damage the nerves. So, when I was tired, I sat. I worked at home exclusively during the first year, not doing any on-site projects although I did manage two business trips, accompanied.

One year exactly after the hospital stay, I went to the film festival, using two canes and seeing only a few films. The following year I used only one cane, and saw my usual quota of 20 films in 10 days.

#### Accepting help

A long-time friend visited me in rehab on Thanksgiving weekend, with some turkey. We walked down the hall, I using my walker and she wheeling my chair behind me. I sat down for a little rest at the window at the end of the hall. She sat in a regular chair. We ate the turkey. She said, "You have always been so fiercely independent. It must be really hard to accept help, let alone ask for it." "Well, I've learned that people really do want to help," I replied. "You just have to tell them what you need." One, who lived near my vet, brought me cat food. Another shopped for clothes for me. Another regularly took my walker and me to the movies. Others took me shopping. One accompanied me to medical appointments and took fastidious notes. Many came for lunch or dinner, bringing the meal. A client who lived near the rehab hospital printed things for me and dropped them off. My assistant paid my personal bills as well as the business ones. She even renegotiated my cell

phone plan. My neighbours did my laundry. And my housemate looked after the cats. I hope I always remembered to say thank you.

### Third: Living with CIDP

Now, eight years after diagnosis, I need to use railings most days. I use a cane outside of my neighbourhood. It also gets me a seat on transit, and it's useful when I encounter stairs that have no railing. And it helps when it's a long walk or a long time standing. I still hesitate at the top of down escalators. And I'm a beat slow catching my balance when I turn, trip or slip. I avoid ice and I pay attention to where I put my feet. I have done one European vacation on my own. I attend a weekly exercise class that concentrates on the basics of sitting, standing and walking, and I still go to the physio who first noticed it was nerves. Almost all my reflexes are back. And I can feel the tuning fork on my toes and that horrid steel instrument the neurologist uses on the soles of my feet. It takes me a while to unkink if I sit for more than an hour. I catch more colds. I get tired more often. (Some of these things might be due to aging, I'll admit.) I still get leg cramps, but not as often. I can't wait in line for more than 20 minutes or walk for more than 45. However, I can add to that if I sit for a few minutes.

I get my IVIg for two days every five weeks and do not schedule anything major for the day after. The treatment leaves me tired. The biggest worry is finding a good vein. We tried to extend the time between infusions but only a couple of days beyond the five weeks I got that walking-through-hardening-concrete feeling. We also tried lowering the dose, which also didn't work. The present schedule does.

The doctors were right. My case was mild, and it remains only in my legs. Life is organized around my IVIg schedule. But, as I tell myself, all my friends of similar age have something to live with too, like arthritis or high blood pressure. CIDP is just a little more dramatic, and certainly far more rare.