

A disease that tested, an outcome that surprised

By Rob Kelly

There are basically two types of serious illnesses. The ones that run over you like a freight train and the ones that sneak up on you with a sinister tingle or niggling ache that grows slowly at first and then spreads faster than wildfire.

I had the latter in the summer of 2018. And like a forest blaze this disease burned hot and fast, and for a while it was deeply uncertain how much damage would be done.

It began with unpleasant foot pinpricks and a slight right leg weakness, which I attributed to an old back injury that flares up once in a while. But then walking became more of a chore. Soon after I wasn't really walking at all, at least not in the way most of us understand it. Instead I was swinging my hips and then planting my legs, as people do when manoeuvring on stilts.

This all took a couple of days, from a Monday to a Wednesday, to fall from bothersome ailment to genuinely disabling phenomenon. Meanwhile I tried to go about my business. That didn't work out so well.

On the Monday I had an appointment at a Toronto high-rise office building. So, I took the train in and planned to walk the 15 minutes north from Union Station. It took me about an hour. I was having trouble getting over the pedestrian crosswalks before lights changed. The short escalator in the building was broken. I struggled with the nearby small set of stairs, so much so that a kind young woman offered to help me.

Walking back to the lakeshore later things deteriorated. People were staring. A middle-aged lady came up to me as I leaned on a lamp post to rest a few seconds before pushing on. She asked what was wrong. I said it was an old nagging back injury. She firmly told me that was not the case, that she was a nurse at a nearby hospital, and I needed to go there or to another one, very soon.

Back at Union Station, I knew I had to get a little help and one of the employees guided me to a commuter bus and pushed me up its steps. I fell on the second stair despite her assistance. When the bus got to my stop at the end of the line, the driver had to help me off.

I soldiered on for the next day or so. It was a bit of a blur, frankly. The next morning, Tuesday, I had an appointment with my financial guy. A beautiful summer day was breaking when I arrived at the bank. Two women were waiting at the front door for it to open as I crabbed my way up the staircase, both my arms wrapped around the broad wooden bannister while I pulled myself along as if on a rope, my mostly useless legs dragging below. They looked at me, puzzled and uncomfortable. To ease their tension I said, "Good morning, ladies. Lovely day isn't it?"

Long story short, by Wednesday my doctor was telling me to go to the hospital. I thought I would stop by there to figure out what the problem was and then get treated as an out-patient. I called a taxi for the short ride. When the driver came, despite using a makeshift cane, I collapsed into the back seat of his cab as my legs gave out. He yelled in alarm and quickly drove to the emergency entrance.

The doctors were initially puzzled. They asked me to both tell them and show them what was wrong. "When you walk, you think about other things, like 'what am I going to have for dinner,'" I said. "When I walk, I think 'how I am going to plant my leg so I don't fall over?'" Then I showed them, stilt-walking a few steps by swinging my hips and then grounding my uncooperative legs. "That is not the gait of a normal person," one emergency room physician said. Doctors came and went. They were all business. They ran through the gamut of potential ailments. One possibility was a virulent, fast-acting cancer that was somehow chewing up my insides and blowing through my motor functions. Then one said there was something else that dovetailed with the symptoms, but it was a remote possibility since the disease was so rare. It was a reach, but they called in a neurologist anyway. Bingo.

It was Guillain-Barre Syndrome, which is basically an immune system response run amok. The thinking is that you can have just a minor ailment and your immune system over-reacts. It then attacks and damages your nerves, causing numbness, weakness and not much later, paralysis.

They booked me into the hospital immediately. Things went downhill. I couldn't walk at all and my hands and arms weakened drastically as well. They tried to move me at one point from a bench the two feet to my bed but I collapsed on the floor and the nurses couldn't lift me, so they had to get a portable hoist/crane gizmo that they have in all hospitals, but that hardly anybody ever notices.

Two days later, on the Canada Day weekend, I began what is called immunoglobulin therapy, delivered intravenously for three hours on each of two consecutive nights. That was the turning point, although I didn't know it at the time. The antibodies from the donated blood used to make the treatment beat back the spreading illness.

I spent the next two weeks in my hometown hospital and the following two weeks at a nearby one, which had more extensive rehabilitation facilities. When they transferred me from one to the other, it was in a wheelchair clamped to the floor of a disabled transport bus.

I went from bedridden to wheelchair, and then from wheelchair to a walker with no wheels, then to one of those walkers with wheels, which they call a rollator. I did circuits with it, plodding slowly around the perimeter of the intensive care ward. When I finally got out of the hospital, I was so weak I could not throw the very light rollator into the back of the SUV a friend brought to pick me up.

Over the next couple of months, as the summer heat beat down, I continued the routine I had begun at the second hospital, adding on to it as my strength grew. I did a few errands with the rollator, minor shopping. I used it to complete endless parking lot loops around the building where I live. I screwed up my determination and attempted to mount a single step on an outdoor staircase, yelling in agony to the winds as I did so. Later on, I went to a challenging therapy program for several weeks. I slept for hours in the middle of the day after most exercise periods.

But it paid off. By the fall I had ditched the rollator for a cane. I began lifting light weights. That November I went to a seminar organized by the resourceful small group that runs the Guillain-Barre Syndrome Foundation of Canada. A security guard at Hamilton's Mohawk College assisted me down a long staircase after the event, but that was the last time anyone had to help me get around.

I started a more serious exercise program, which was discouraging at first. I could not do one push-up. Dumbbells that I used to handle easily lay stubbornly unmoving in the racks of my building gym, as if they had been welded there, when I vainly grasped and pulled on them.

That changed, slowly at first. One push-up became five, then 10 sloppy, shaky but consecutive ones. I started gaining back the weight I had lost, and the muscle. I gradually increased the exercise tempo and volume until I got to 500 repetitions per workout, including 200-300 push-ups.

There are a few long-term consequences to the disease, but they are minor. My thumbs and index fingers tingle, and the feeling in them is less than it was. My torso, from just below the neck to the waist, has a lot of numb areas, front and back. Those lingering effects may go away in time or they may not, and to tell you the truth I am fine either way.

Because today I can climb stairs again, lift heavier objects than most people would care to tackle again, move physically through life with purpose again. And there is one more thing, which surprised me to no end when I got out of the hospital. It was a feeling that overwhelmed me, so deeply that I was stunned by its depth and breadth. It was gratitude.

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