

A patient's experience with chronic inflammatory demyelinating polyradiculoneuropathy

■ Cite as: *CMAJ* 2023 February 13;195:E239. doi: 10.1503/cmaj.230085

See related review at www.cmaj.ca/lookup/doi/10.1503/cmaj.220936

It started with tingling and numbness in my feet when I was 45 or 46 years old. I was no Wayne Gretzky, but I coached my son's hockey team. I went out for a practice and my skating was severely affected; I fell down. My family doctor referred me to a neurologist. When I walked in with my two walking sticks, she immediately wondered about CIDP (chronic inflammatory distal polyradiculoneuropathy).

I was admitted to hospital, where I had a battery of tests and plasmapheresis (the standard treatment at the time), and was put on a high dose of prednisone. I had muscle wasting in my hands and feet. I was in a wheelchair and was off work for about six weeks. I improved to the point where I was walking reasonably normally, but I've had relapses since then. Energy-wise, I am

10 mg of the drug to hold me. I still have paresthesia. I cope with the muscle wasting and problems with my balance. Because it doesn't take much to send me down, I use a walking stick. I sometimes have problems going to sleep because of spasms in both feet. I try to control that with medications, but it can take me a few hours to fall asleep.

As a doctor who became a patient (I am retired now), I became more aware of some things that make a difference. I certainly made more eye contact with patients afterward. I was more aware of how, when a patient becomes sick, it affects their extended family. I have also realized that there's a short leap between humour and compassion. When I shared a laugh with a patient, that helped me bond with them and

I have made accommodations in my living space, anticipating that I might get weaker. The house I'm in now has wide doors, a wheel-in shower and the ability to put a chair lift in if needed. Some people put off travelling and think, "We'll do all this when we retire." I often suggest people go and do these things because you don't know what's coming around the corner. Exercise has been important, as has having a supportive family. I always try to have something to look forward to. If I have bleak days, having something planned that I am looking forward to helps me get through it. — Interviewee wished to be anonymous

As told to Victoria Saigle MSc

Lead, Patient involvement, *CMAJ*

This article has not been peer reviewed.

Consent has been given for these perspectives to be shared.

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the kind of character that pops out of bed in the morning saying, "Good morning! How are we doing today?" When I'm tired and don't do that, it sometimes signals that I'm in a relapse.

I've been stable for two or three years. I'm on a standard dose of prednisone, I take mycophenolic acid and I'm followed every six months. We have tried to get the prednisone down, but I seem to need

then I could sit down and deal with their serious issues. I'm still seeing the same nurse practitioner after 35 years. Being assessed by someone I've known for that long makes a big difference. She picks up changes in my condition and can answer questions quickly because she knows my history so well — on my last visit she was unhappy with my change in gait.

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