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Photos by Seema Marwaha

I'm 25 years old. In my fourth year of university, I started to get numbness and tingling on the soles of my feet. It slowly progressed up my legs. Getting to a diagnosis took months. I went from a sports clinic to my family doctor and then for an extensive work up by a neurologist — everything from magnetic resonance imaging to nerve conduction studies. Each appointment took time and there was usually a 2-month gap from 1 test to another.

I was distracted by mid-terms and didn't have time to focus on my progressive symptoms. But by June, the numbness was up past my knees and I could see my calf muscles wasting. Lupus, multiple sclerosis and Lyme disease had been ruled out, but my diagnosis was still a mystery. My specialist told me if things progressed to the point where I could not get up from a chair, I should go to the emergency department.

I'm an athletic person and I was struggling to keep up with my 2 active jobs over the summer. The day I could not get up from a chair, I called my parents and we went to the hospital.

It took 3 days and many more tests, but I was finally diagnosed with chronic inflammatory demyelinating polyneuropathy and

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started on intravenous immunoglobulin and then prednisone.

I have a love-hate relationship with prednisone. I lost hair and got a moon face. I had heartburn every night at 2 am. I couldn't sleep, yet was somehow full of energy. But the numbness slowly dissipated. Today, I have no neurologic deficits.

I'm lucky. My background in kinesiology really helped me during this experience. I was able to explain my symptoms clearly in a language doctors understood and to navigate my own recovery.

My parents, having had their own health care experiences, understood the "system" and coached me to be a model patient. They said to be clear and concise when describing my symptoms, to never go to appointments alone and bring someone to take notes, and to refrain from expressing overt frustration with the long, inflexible process. Without this coaching, I'm not sure I would have ever gotten a diagnosis.



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