

Media Release

Employment security, misunderstanding of disease add to the daily challenges of living with MS

TORONTO, May 14, 2025 – The fact that only 90,000 Canadians have multiple sclerosis makes it harder for those who do have it to navigate its challenges in part because there is such limited awareness of it. MS is relatively rare compared to diseases like diabetes and cancer, and highly variable and sometimes invisible. Receiving an MS diagnosis can be a one-two punch: first you have to face the sudden harsh reality of it, then you have to deal with a universal misunderstanding of it at every turn.

Misunderstanding of MS abounds everywhere: in the workplace, in front-line medical interactions, even while out and about and engaging in daily life.

All of the above has been experienced by Toronto resident Richard Fabregui, 39, who was shocked on learning he had the progressive, disabling disease. He had initially felt a pulling sensation in his left arm, and at the same time, the right side of his face went numb. Assuming it was something minor, he visited a walk-in clinic. The doctor wasn't familiar with his symptoms and referred him to a neurologist. A CT scan didn't offer an explanation, so he was sent to an MS specialist who ordered MRI scans that finally confirmed the diagnosis.

Post-diagnosis, the former runner's symptoms escalated with numbness, tingling, and pain emerging in his arms and legs. He developed double vision, and balance issues that led to frequent falls. He started using a cane. His seizures have proven to be the most frightening. They've occurred at work and social events, and he has no memory of them - only of waking up to people around him.

Like many people with MS, he is prone to heat sensitivity, which triggers flare-ups and can make everyday activities during warmer months daunting. Even small elevations in the core body temperature can be detrimental to the demyelinated fibres (MS damages the myelin sheath that protects nerve fibres) in the central nervous system. Common symptoms that may intensify in hot weather include fatigue, problems with concentrating, muscle weakness, numbness, and impaired balance. For those who experience heat intolerance, any MS symptom may be exacerbated by heat.

For Fabregui, battling profound MS fatigue is an ongoing struggle. He says it's like hitting a wall. No matter how much he rests, his body still feels drained. He finds it frustrating to feel capable, but physically unable. The toll of his MS symptoms is further compounded by the misunderstandings he encounters from those around him when he is involved in daily activities.

"A major difficulty is that most of my symptoms are invisible. I can appear healthy, but internally I'm struggling. This makes it hard for others to truly understand what I'm experiencing, especially in public settings like transit or casual outings," said Fabregui.

His career as an online e-commerce specialist was to some degree a casualty of that misunderstanding, employment security being a significant issue for people living with MS.

On hearing Fabregui's disclosure of his diagnosis, his employers weren't dismissive, but it seemed that, like so many people, they didn't have the necessary familiarity with MS to have a complete understanding of it or how it could affect his work. A COVID work-from-home mandate was beneficial for the short term, but that mandate was eventually lifted and the office relocated.

Even with accommodations made by his employer, he would have had to commute to the office a few times a month, which was two hours away. The transit commute - especially during cold winter and hot-and-humid summer months - was too much to physically manage given his MS symptoms and heat sensitivity. In the end, he decided to prioritize his health and resign.

According to MS Canada, more than 60 per cent of people living with MS eventually reach unemployment, indicating that more needs to be done to assist those who live with it.

Fabregui's long-term plan is to return to the workforce under the right conditions with accommodations that set him up for success. Ideally, he'd like a remote or hybrid role with an office that's readily accessible via public transportation. Commuting is problematic, so location matters. He's hopeful that there's a job out there that suits his needs. He also considers himself fortunate to have a husband who's very supportive and wants him to find something that's right for him and his health limitations.

In the meantime, he is finding some improvement in his health with a low-stress lifestyle and a change in diet, including eliminating gluten, dairy and alcohol.

MS Facts

Common symptoms can include, but are not limited to: fatigue, lack of coordination, weakness, tingling, impaired sensation, vision problems, bladder and bowel problems, and cognitive and mood changes.

Globally, the most common barrier to getting an early diagnosis is a lack of awareness of MS symptoms among the public and healthcare professionals.

By learning more about this disease, fundraising, donating or volunteering you are making a difference in someone's life today and tomorrow. Learn more at mscanada.ca/msawarenessmonth.

About MS Canada

At MS Canada, we are inspired by the vision of a world free of multiple sclerosis. We focus on support, advocacy and research that will positively impact the lives of people living with, and affected by MS. For over 75 years, we have been a trusted connection for the MS community to valuable resources and programs needed on their unique MS journey. We advocate for policy change that removes barriers and improves the well-being of persons affected by MS in Canada. We invest in life-changing research that will advance treatment and care, enhance well-being, help to understand and halt disease progression, and ultimately prevent MS. For more information visit mscanada.ca.

Media Contact: Michele Penz, Calico Communications for MS Canada
1-778-888-2249, calicocomm@telus.net