

A patient's perspective on finding treatment for migraine and a provider who believed her

■ Cite as: *CMAJ* 2023 January 30;195:E161. doi: 10.1503/cmaj.221813

See related review article at www.cmaj.ca/lookup/doi/10.1503/cmaj.211969

My migraines started in 2005. They cause intense pain on 1 side, and nausea, photophobia and sound sensitivity. They last anywhere from 8 hours to 9 days in a row. Until recently, I averaged 20 migraine days a month.

Migraines affect every facet of my life and the journey trying to get treatment has been frustrating. I was working at my dream job in New York City, which involved 12-hour days and lots of business travel, and suddenly I could no longer do it. Doing household chores could trigger a migraine attack. My social life changed dramatically — I went from a fast-paced environment to being home almost 24/7, in bed. I had to let go of a lot of my dreams. I'm fortunate not to have any comorbid mental health conditions. I trained myself early on to focus and be grateful any time my pain went down. My life became about living in the moment and adapting because I might be okay, and then, 2 hours later, in terrible pain.

I work a lot on managing my triggers and paying attention to SEEDS (sleep, exercise, eating, using a diary to track migraines, and stress). I also work on pacing myself, because the fatigue that comes with chronic migraine is intense and physical exertion is a trigger for me. I constantly have to balance my happiness and sanity with the cost on my body. All these limitations make it an isolating disease.

One of the hardest things is that I have a rare trigger: tactile, thermal and mechanical allodynia. Wearing a necklace or earrings triggers a migraine, as does exposure to any cool air, wind or a breeze on my face. Thermal allodynia is my most debilitating trigger because it's hard for me to be out in the world — I can't control the air.

My experience with headache specialists hasn't been great. I don't present the same way that I feel, and I have felt a lot of judgment because of that. In an effort to

be helpful, I would bring an Excel spreadsheet with all my medications and treatment history to my appointments. But it backfired because often, rather than seeing me as organized and self-motivated, physicians assumed the pain wasn't that bad — which would be an incredibly discouraging and upsetting experience. When medications didn't work for me, my physician would start blaming me. I've seen written in my medical notes, "The patient arrived very fashionably dressed," as though that somehow negated my pain. I think that is archaic and sexist.

I've seen 4 headache specialists since the diagnosis. I've often felt like I could not say to the physician, "I hear your perspective and I disagree with it and here's why..." I live with this disease every day and I should have some input into my treatment.

When I tried to explain my allodynia trigger to my first specialist, I was treated like a weak, complaining, hysterical woman. I began taking my husband to appointments so he could corroborate my symptoms, but my specialist still wouldn't believe us (I found out later they thought I might be agoraphobic — I'm not). At the last appointment I had with them, I was told no medication would ever help me, I would not improve, and I had to accept a life of constant pain. This spurred me to take my migraine care into my own hands.

I did research and found out about the first calcitonin gene-related peptide (CGRP) inhibitor coming to Canada in December 2018, erenumab, and I went to new headache specialists to convince them to give it to me. My next specialist erroneously told me it wasn't coming to Canada, and that I should give up on it. I knew this wasn't true, so I found another specialist who agreed to prescribe it. CGRP inhibitors have helped me a great deal. If I had listened to my first

headache specialist, I would have given up. I'm not recommending patients manage their own care but, given my experience, it was the best way forward.

I think there needs to be a perspective shift in the medical profession, to stop thinking treating migraine is not urgent because it's "just pain." More than anything, I would have liked to be believed. If at any point a doctor had said, "I won't give up on you — let's work together to improve your quality of life," that would have made all the difference in the world. Nobody has ever said to me, "Wow, you're incredibly strong to withstand pain 24/7." Having a physician tell you there is no hope for you is not an appropriate response to a complex disease that requires persistent effort to find the right treatment. — Interviewee wished to remain anonymous

As told to Victoria Saigle MSc

Lead, Patient Involvement, *CMAJ*

This article has not been peer reviewed.

Consent has been given for this perspective to be shared.

Content licence: This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY-NC-ND 4.0) licence, which permits use, distribution and reproduction in any medium, provided that the original publication is properly cited, the use is noncommercial (i.e., research or educational use) and no modifications or adaptations are made. See: <https://creativecommons.org/licenses/by-nc-nd/4.0/>

In Their Own Words provide extracts of interviews held between *CMAJ* staff and patients, families or clinicians. They are usually linked to an article appearing in the Practice section and are intended to provide complementary perspectives.