

“It’s hard trying to explain yourself when you’ve fainted”: a patient’s experience with Takayasu arteritis

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I started getting dizzy when I stood up. A couple of months later, I passed out. I got more symptoms after that — my arms were weak when showering or doing my hair, so I had to take breaks. I started falling frequently, and my jaw got tired when I ate. I stopped driving because everything would go fuzzy.

that I wasn’t crazy and that I wasn’t doing it to myself.

After I went home, I got worse. I was told the steroids would take a while to kick in, so I assumed that was what was happening. It got to the point where I couldn’t walk. A vascular surgeon I saw two and a half weeks after diagnosis told

back, which is nice. Going to the emergency department or a walk-in worries me. I’d rather talk to a doctor or nurse that knows my history.

Fighting to make sure someone helped me was the hardest thing. People have heard about what happened and they’re like, “Oh, how are you doing?” I just kind of say, “Oh, I’m good.” But I know this is a lifelong thing. I’ll be on meds forever. I have scans fairly often. I have to see a rheumatologist for the rest of my life. I was, I thought, young and healthy. I didn’t expect this to happen, but there’s nothing I can do about it. — Caitlin Jacques

Three months after surgery, I felt something pop in my head and became blind in one eye.

I think I went to the emergency department 6 times before they admitted me. My husband and I made a pact that I would keep going until they’d help me. They would say things like, “Young girls don’t eat enough,” or, after I threw up five days in a row, “You probably have a flu.” I was on a postpartum medication so, for a while, they said the medication was the problem. But when I went off it, I wasn’t any better. This was during COVID time, so my husband couldn’t go in with me. It’s hard trying to explain yourself when you’ve fainted. I got told repeatedly that nothing was wrong.

Once I was admitted to the hospital, everyone was really nice. They saw me fainting and my blood pressure dropping. When they diagnosed Takayasu arteritis, I was happy because I finally had an answer. I had been convinced I was crazy for so long. I didn’t think about what would happen after — I was just relieved

me I wasn’t getting enough blood to my head. Three weeks after meeting him, I had a thoracotomy and a bypass from my aorta to my left subclavian and carotid arteries. After the surgery, I felt a lot better.

A few months after surgery, I had a number of mini strokes (transient ischemic attacks). Three months after surgery, I felt something pop in my head and became blind in one eye. That’s when I knew something was *really* wrong. I’d had a stroke.

I was off work for one and a half years and couldn’t drive for a year. Now, I don’t have any major issues from the stroke, so obviously I’m lucky that it didn’t affect me that much. I’m still on steroids and I also take etanercept, warfarin and a number of heart medications. It’s a lot of meds.

My main doctor is the rheumatologist. I talk with the nurses in his office often. I can leave a message and they call me

As told to Victoria Saigle MSc

Lead, Patient involvement, *CMAJ*

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Consent has been given for these perspectives to be shared.

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