"My family doctor didn't know how to help me": a teenager's perspective on being diagnosed with long COVID

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I started having COVID symptoms in April 2021. When I found out I tested positive, I felt really disgusting and worried that I was going to get everyone sick. My dad's really high risk and if he got COVID it could possibly kill him. I had my first ever anxiety attack in the bathroom. Most of my symptoms lasted for 8 days but the fatigue and loss of taste and smell lasted much longer. I didn't have the energy to even leave my room. I was out of quarantine after 10 days but did not feel 100%.

I was able to go to work, but I came home almost every day and had to take a 4-to-5-hour nap. Then, I noticed that a lot of my hair was coming out. My mom started noticing cognitive problems, like we'd talk and 2 minutes later, I'd have forgotten the conversation. Our family doctor wasn't sure if there was actually anything wrong. She just kind of said, "Maybe your body's stressed." After that, my mom took me to a naturopath, who gave me supplements to help with my immune system and fatigue, and sent me for blood work. When the results came back, I was told I was anemic and vitamin D deficient, and that I had high levels of inflammation.

I completely understood that COVID was new and I didn't expect doctors to know what to do, but it was very scary that my family doctor didn't know how to

help me. The naturopath, was at least trying to help me and wasn't just telling me, "I don't know." She also explained things both in medical terms and then in a way that I understood.

Around the 3-month mark, my mom found a study that was enrolling long COVID patients. We had a phone call with the study group and did blood work. When we saw the [study] doctor in person, they said I had symptoms that a lot of long COVID patients have. The study was one of the only ones that would accept me — I was 16 at the time. I liked knowing that there was something they could help me with; it wasn't just like, "Oh, you're sick." It was, "We'll help you through it." The long COVID team is great. They listen.

For a while, I had been crashing every 4 days. I'd feel good for a few days and then, by around day 4, I'd need to sleep for 18 hours. The long COVID clinic explained that, as I started feeling better, I'd have to take baby steps. If I didn't, I'd get so fatigued that my body would start to shut down and tell me I needed to stop and rest. They also recommended that I take a higher dose of ferritin because my levels were still low.

Long COVID affected me a lot last year and a bit this year. I stopped doing basically everything — fastpitch, rugby and school. I didn't see anybody. The only thing that I did was work, but I wasn't working as much as I used to. Now, I'm still tired but I don't need to take a nap every few days. However, I'm not at the level that I was before having COVID. — Interviewee preferred to remain anonymous

As told to Victoria Saigle MSc

Lead, Patient involvement, CMAJ

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Consent has been given for this perspective to be shared.

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