

A patient's perspective on long COVID: improvement month to month not week to week

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I got COVID in early January of 2022. It lasted 10 days and then in mid-to-late February, I got additional symptoms. It started with a lack of appetite, dizziness and extreme fatigue, and then psychological symptoms, like anxiety and depression. The nausea, lack of appetite and weight loss were the most concerning. At its worst, walking around the house or to the end of the driveway was difficult. I slept 16–18 hours a day. In mid-to-late March, I saw my primary care doctor and other specialists to try to figure out what was wrong.

Initially, they were thinking something else was going on, maybe an autoimmune disease or cancer. I had lost 30 pounds in 3 to 4 weeks. I saw a gastroenterologist and an internal medicine specialist, had a CT scan of my chest and abdomen, an upper GI scope and a whole bunch of blood work, as well as an abdominal ultrasound and an echocardiogram. After all of the tests were done, long COVID kind of became a diagnosis of exclusion.

In early May 2022, I got an appointment at a long COVID clinic. My wife had heard of the clinic and we emailed them directly. No one that I had seen up to that point was willing to do anything else. I felt like I was stuck.

The long COVID clinic had the benefit of a 3 and a half month history and all the medical tests that showed essentially nothing. They took a thorough history, did some more tests and said it fit with long COVID. One thing they talked about was the importance of pacing and setting

a level of activity I could achieve without pushing myself. It was relearning what I could manage and then slowly building up my activity. Other than time and rest, that's probably the most important concept that I had to get my head around. I see improvement month to month, not week to week, which I'm still coming to terms with.

The nausea and the poor appetite disappeared first, and after 4 or 5 months my weight returned. The fatigue, lightheadedness, dizziness and my exercise tolerance are still works in progress.

I was off work for 4 or 5 months. I work as a large animal vet. It's a physically demanding job with long hours. At that time, my work involved night work and getting called in at irregular hours. I have not returned to that, but I now work about 60% of a normal week. My employer was super supportive and I couldn't ask for more. My work, my wife and my family are my rocks that helped me get through this. Before this, I had no significant problems and took no medications. I felt like a healthy 52-year-old man.

It's been really difficult to be that sick and not have an accepted hypothesis about what's going on. I understand that sometimes we don't know, but it's important to see a path forward. In the summer, I spoke with people who also went through long COVID. Finding a way for patients to talk to others with the disease would be a huge help. The psychological part of long COVID could also be discussed more. I am on medication now,

but at times I got the feeling that there was a temptation to explain all of my symptoms as being psychological. The uncertainty, lack of experience with long COVID and the dearth of clinicians to treat me resulted in extreme difficulty accessing any disability insurance. It has been very hard to get the details of my symptoms and their effects into my records in sufficient measure for insurers to feel it is worthy of a claim. — Patient wished to remain anonymous

As told to Victoria Saigle MSc

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Consent has been given for this perspective to be shared.

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