

Long Covid Case Study

I'm a 40-year-old journalist. I live with my partner, who's an academic. We have a three-year-old son and six-month-old daughter.

Towards the end of February 2021, I caught a cough. I tested negative for COVID and the illness was mild so I tried to carry on working, but I couldn't shift the cough and I had to take several days off work. I had no pre-existing conditions, aside from persistent hayfever, so I wasn't especially concerned.

Then on 19 March, I woke up and everything was different. I was tired - overwhelmingly, crushingly tired, as if I'd been up for days, when in fact I'd slept all night - and I couldn't think straight. When I tried to text my boss to tell him I wasn't going to be able to make it into work, it took me more than an hour to string a sentence together.

This crushing tiredness abated after a few weeks, so I was able to leave the house and walk around, but from then on my energy was limited and if I pushed myself at all either physically or cognitively - even a long phone conversation - I would suffer intense post-exertional malaise, which could knock me out for a week or more.

My GP prescribed graded exercise therapy, which made my condition worse, and I stopped pursuing it. In general, my problem wasn't taken that seriously by the health service. After 15 months, I was eventually referred to a long covid clinic where I was advised to look at CBT, another treatment which didn't feel appropriate to my condition. That was my last interaction with official NHS support.

Although I am better than I was, I have not returned to my pre-COVID levels of health. My energy is still limited, and I can't accelerate or "do more". This basic problem means I haven't been able to return to work for more than half the time; even that is very inconsistent because of my crashes, when I can't work at all. I'm also unable to contribute at home in the way I used to, so the burden of childcare falls heavily on my partner.

My main symptoms are fatigue and post-exertional malaise. I also suffer from brain fog, memory failures, nausea, headaches and persistent diarrhoea, although fatigue is by far and away my most significant symptom. The fatigue is not constant and although I have good weeks, I am unable to do anything but the most basic tasks roughly half the time.

I have tried a large number of treatments, including hyperbaric oxygen therapy and low dose naltrexone, as well as a huge range of supplements, all prescribed by private practitioners. Overall I estimate I've spent about £7,000 on treatments – strangely, this doesn't feel like that much, given the intense pressure to spend on treatments. However, the cost hasn't helped the financial pressure caused by being off work for such a long period.

The only thing that has definitely helped has been carefully managing my energy. I have been helped in this by a dedicated workplace vocational rehabilitation specialist, who was assigned to me by the insurance company which has been covering a portion of my salary through my work's insurance scheme. She stopped me trying to go back to work and crashing when I did too much, which helped me recover enough to get back to limited hours.

I have also been helped by a physio at a long covid clinic, who sees me in her free time. She has encouraged me to rest completely at regular intervals during the day, which produced a notable improvement, although I have since had a significant setback. This shows that there is potentially life-changing practical support available, if only it can be communicated to patients.

I have had numerous tests which have all been negative, aside from one - a finding of very low vitamin D in my first blood test. In a formal sense, therefore, I have not had an issue with access to the NHS. My issue is the ignorance and fatalism of the clinicians. I changed GP recently and when I informed the new doctor of my condition he told me that there was nothing that could be done but that I should increase my activity gradually. This is typical.

My aim is to return to life as it was.

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