Trying times: an experience of early pandemic COVID-19 diagnosis and enduring long COVID

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COVID-19 has affected us all, but for those with long COVID there is a need for patience and compassion as we learn to treat this emerging condition. https://bit.ly/3A7JCpZ

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Helen caught coronavirus disease 2019 (COVID-19) at the beginning of the pandemic. Here she speaks about this and her ongoing experiences with long COVID.

In mid-March 2020 my husband took ill with a high temperature, sore throat and fatigue. With underlying health conditions, including severe asthma, I was worried that I too would fall ill. At this stage testing for COVID-19 wasn't available to the public. Within a few days I had symptoms, the worst of which was a choking cough. I spoke to my general practitioner (GP) on 23 March 2020 who advised rest and fluids. By Friday 27 March 2020, I was really suffering with fits of coughing that lasted 3 h and a temperature of 39°C. I called my GP again and this time I was told it was highly likely I had COVID-19 and was prescribed a strong antibiotic, as was the protocol at the time. My GP advised me that if I deteriorated, I would have to go to hospital. I spent the weekend in bed hoping I could avoid hospital mainly because I was frightened that if I went in, I would not come out again.

Over the weekend, a GP friend dropped off an old oximeter to keep a check on how I was doing after we had tried counting my breaths on a FaceTime call. On 30 March 2020, my breathing continued to get worse, and my oxygen saturation dropped to 91. At this point I was admitted to hospital. When the doctor came in, he checked my breathing, listened to my lungs and took bloods, advising me that I was unlikely to be going home as my X-ray showed significant changes. My bloods came back around 4 h later and this time a consultant came in to explain what would happen next: ECG, swab tests and then I'd be taken up to the COVID-19 ward. He described it as "the war zone"!

On the ward I was put into a private room until my swab tests came back. Once they confirmed COVID-19, I was moved to join a ward with three other COVID-19 patients. This was the hardest part, seeing others slightly further on than me, who struggled to breathe. I was the youngest on the ward at this point. At this very early stage, fear was one of the most common feelings on the ward and it was palpable – even amongst the staff. It's amazing how quickly you come to rely on the other patients to comfort and support you. The ward was eerily quiet apart from coughing and machines beeping. The staff only came into the ward for short periods, so we were alone for long periods and it's a lonely place to be.

Thankfully, unlike many others I was able to return home to recover and I thought I was over the worst. Well, that's what I was told by the consultant. However, 2 weeks later I was back in hospital. I felt I had gone right back to the start. Thankfully, this was a short stay. My GP sent me to the Accident and Emergency Department as I was having pain in my lungs and was very short of breath. As well as that my heart rate was going as high as 170 beats per minute at rest. An X-ray, ECG and blood tests followed, and at this point I was told these symptoms were likely to be linked to COVID-19. I was prescribed antibiotics as a precaution and referred on to the COVID-19 clinic. I was advised to listen to calming music – this would help my anxiety and settle my heart rate! Not quite what I had expected to hear.

Helen Parks.

This seems to be the reality of COVID-19: it lingers, it keeps biting back, it attacks your whole body. I felt that even my brain hurt when I tried to read. The recovery has been incredibly slow. The symptoms keep emerging: heart racing, temperature spikes, sore throat, hoarse voice, no smell or taste. The fatigue just hits you and feels like a heavy weight on your head. There is no medication to help, no speedy tips to get you back on your feet. You feel slightly better one day and you do a walk, some cooking, catch up on emails and then thump! Back down again, crashing for another 3 days when you can't get out of bed. As one doctor put it: your body has a been involved in a head on collision and you are now trying to slowly put it back to what it was before.

It was at this point that I started to look at Twitter to see if others were suffering like me. That's where I found a tweet looking to engage with people who had COVID-19. I sent a message to the person who had left the message and soon I was chatting to Professor Chalmers and became a patient voice for European Lung Foundation (ELF), who at that time were looking at the medications that could be offered to inpatients with COVID-19. I was keen to help anyone coming after me and facing the long road ahead. I felt incredibly privileged to be part the ELF patient advisory group (PAG) and felt that the I was contributing in a way that might help others. I have continued to work with the ELF PAG and a study on long COVID.

I felt very alone during this period with no one to explain why I felt so awful. When I left hospital, I thought the worst was over, when in fact it wasn't. I was fortunate to get an appointment with the newly formed COVID-19 Recovery Team in July. This involved a range of breathing tests and a range of specialists saw me: psychologist, physiotherapist, ear nose and throat (ENT) and cardiologist. The one common thing that they were saying was that COVID-19 lasts long beyond your time in hospital. No one was talking about long COVID at this point, no one was saying that the effects would be long term. Twitter was my go-to for answers or fellow sufferers. I certainly wasn't getting ongoing medical support. I was desperate to understand what was happening to me. I wanted someone to believe me when I said I was still fatigued, still sick, still had screaming in my ears. I didn't want to be told to listen to a meditation app or play relaxing music.

This illness is not in my imagination – it is real! I fully understand the pressures on hospital resources, but I feel that a whole section of society, which is growing every day, has been very much let down. I also get that this has been a steep learning curve for medics and research is still very much in its infancy. What I need is to be believed. I needed support, understanding, a listening ear and someone who can say we will try to help you. I can see frustration creeping in with doctors who don't have the answers. I share their frustration. 2 years on and I can't say that I have had a day without a headache, pains, fatigue or tears! 2 years on and I still can't believe that support is minimal. Long COVID clinics don't exist in Northern Ireland. No one is treating my symptoms. I fear that no one knows how to treat long COVID. Support doesn't always need to be medication or cost a fortune. However, the cost of doing nothing is a greater price in the longer term.

One long COVID sufferer commented on Twitter: "To my fellow sufferers at home: say good-bye to kick starting the system… We all need kindness at these times, and employers need to understand, be sympathetic, and allow their staff time to convalesce. My guess is that there are a lot of us out there, and none of us know how long this recovery will take". And this is my advice to you, please be patient and kind as we are all trying our best.

Conflict of interest: J. Denning is an employee of the European Lung Foundation.