

Living with long COVID and its impact on family and society: a couple's view

My name is Karlie, and I am now 56 years old. I contracted coronavirus disease 2019 (COVID-19) in July 2020. I was working in aged and disability care as a human resources (HR) manager, mentor and trainer. I have endured long COVID symptoms for four years since my COVID-19 infection.

My health before COVID-19

For a perspective of my health before the COVID-19 pandemic, my medical history can be summarised as follows. I have had severe acute asthma since the age of 14 years, treated with multiple medications including ongoing prednisolone. I have had several respiratory arrests and yearly hospital admissions due to severe asthma. I have psoriatic arthritis, which is treated with methotrexate, and was diagnosed with supraventricular tachycardia, requiring two corrective procedures. In 2017, I had a multilobar abdominal tumour from endometriosis and adenomyosis which resulted in a radical hysterectomy. About 20 years ago, I had a workplace accident that caused a Colles fracture, which required multiple reconstructive procedures for my left wrist and arm, and had multiple anterior cruciate ligament and cartilage repair surgeries.

Contracting COVID-19

In the early stages of the pandemic, I must admit I was extremely fearful of having COVID-19. Given my severe acute asthma, I was fully cognisant of the implications of surviving it. At the time, I was an HR manager for an aged care provider. It was the day before masks were mandated, but my office adhered to physical distancing practices. My employer had done everything possible to ensure we were in a safe working environment; however, a team member had come into work without telling anyone they were unwell.

I was in a room providing instruction to that team member and two other people. We were physically distanced from each other according to the practice at the time. The following evening, I was advised by my manager that I was a close contact to a person who tested positive to COVID-19, who was the team member who was unwell, and that I needed to have a polymerase chain reaction (PCR) test as soon as possible. I did not have a positive result on that first test, but, early the next day, I was symptomatic and began feeling very unwell. I did another PCR test and it was positive for COVID-19.

Hospital admission with COVID-19

Two days after the positive test result, I was admitted to hospital and received oxygen. At that stage, I could only speak two words before being completely breathless; I relied on texting family and friends to

communicate. Very quickly, I was placed on high flow oxygen, and, within a week of admission, I was transferred to the intensive care unit.

By that stage, I was unable to roll myself over in bed. I was asked if I had an advanced care directive and who to contact when I needed to be intubated. I developed secondary pneumonia and spent five weeks in hospital, with a total of 54 days in isolation (including at home).

During my whole time in hospital, my husband and youngest son also had COVID-19. They were in home isolation for 26 days. Only my two sisters were told about the situation as my husband and son did not want to burden me with the thought that I had infected them.

Recovery after COVID-19

Once home, my recovery was extremely slow. Numerous symptoms started to develop, some almost immediately, while others manifested slowly over the next few months. I began to have chronic fatigue with muscle fatigue, weakness and headaches, as well as insomnia. When I did manage to sleep, it was only for a few hours at a time. Conversations became difficult as I found myself stumbling trying to find words in the middle of a discussion, as well as remembering things in general.

I had hair loss, whereby clumps of hair would fall out, and I also developed light sensitivity and eyesight deterioration. This aspect was exacerbating as I was being told by doctors these symptoms were not related to COVID-19.

I had difficulty in swallowing and talking. I had been referred to a speech therapist who did not understand that my issues were caused by COVID-19. They later apologised after reading some research describing all the same concerns I had raised with them. Even to this day, when I get tired my voice deteriorates.

For over two years, I had digestive issues, including reflux, indigestion, vomiting and being limited to fluids and soft foods. I have had several surgeries to correct these problems.

Additional issues that manifested shortly after my infection are fibromyalgia, which caused pain in my hands and legs; blood pressure that would vary from low to high; and balance issues with no apparent cause. I have not had any falls but had trouble walking a straight line. I constantly bumped into doorways and needed to hold onto furniture for stability.

Aspects that developed from my hospital admission include blood clots in both arms which were being monitored. I could not take anti-inflammatory medication as I am anaphylactic to them. I also developed extended spectrum β -lactamases from being in intensive care.

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Seeking care for long COVID

Both my husband and I attempted to get assistance through our general practitioner but were constantly being told they did not know anyone else who had ongoing issues, or who had been admitted to hospital with COVID-19. The general practitioner did not know how to treat the symptoms.

After visits with the COVID-19 team at Austin Health, I was placed in their ReCOVeRY Program in late 2021, which gave us access to physiotherapists and neuropsychologists. Funding for this program was cut after 12 months. At present, neither of us are receiving any clinical support for long COVID symptoms as we do not know where to get the help we need.

Together, my husband and I also sought counselling due to the trauma COVID-19 caused us and our family. Some clinicians that were engaged were dismissive of ailments that manifested. This was disheartening as the problems were present and became part of the mental battle, along with the physical battle. However, an important aspect that was helpful in working towards recuperation was having clinicians accept that the issues raised were real.

Impact of long COVID on work and income

I couldn't return to work for six months, and, even then, it was very graduated. My employer was very accommodating in my return-to-work program. I mainly worked from home, as the drive to and from the office was physically and mentally draining. However, due to my ongoing health issues, I resigned from work. I found it difficult to keep working in a full-time management role. I felt that all I did was go to work, come home, and go straight to bed and then repeat it the next day. Weekends were spent recovering from the working week.

I am now in what I call my "resignationment", hoping I can return to the workforce one day. My husband has opted for early retirement specifically due to his ongoing long COVID issues. We have had a dramatic income drop, down by about 40%, which could have been more severe if not for my husband's defined benefits superannuation scheme. We acknowledge that we are getting by, but our current lifestyle bears no resemblance to our previous one.

Impact of long COVID on our lifestyle

We recently sold our home of 29 years. It was a large house on a third of an acre and we have found it extremely difficult to maintain the property due to our fatigue. We have moved to an over-55s community and into a brand new home with no maintenance. We may have considered this move many years down the track if it wasn't for our long COVID issues; however, we realised we had to make the move to enable a relaxing and low energy lifestyle. The move has meant we are further away from family and friends as there are no similar communities where we used to live.

Together, my husband and I have lost contact with friends, stopped social activities, and resigned from local community groups. We have minimal engagement with people now. We are cautious when shopping or in crowds. We carefully plan our trips to any shopping centre to ensure we have somewhere to rest part way through.

We struggled to maintain our previous home, but, most importantly, we struggled to care for ourselves, which has had an impact on our self-worth. On reflection, we are grateful that we have some functionality when we compare ourselves with many other people with long COVID who are confined to their bed or a wheelchair.

Given that physical activities have completely diminished, there now hangs a significant question over our heads: has our decline in health shortened our life expectancy? My husband was healthy; he had to undergo medical assessments every year for his work and his results were exceptionally good for his age. He now feels he has the body of someone in his 70s even though he just turned 63.

Contributing to long COVID research

We both spend time reading about long COVID issues. Likewise, shortly after our initial infection, we volunteered for a COVID-19 study at the Walter and Eliza Hall Institute of Medical Research.¹ We volunteered knowing it was not going to help with our long COVID issues that had already developed; we volunteered to be part of what we believe may be a solution to the problem.

My husband has sat as a consumer representative on three committees about long COVID. We also spoke at the scientific conference for long COVID hosted by the Victorian Department of Health and shared our experience of living with long COVID. It has been the only work-like activity in which my husband has been involved.

We learnt from the Victorian Department of Health's survey on long COVID that 14% of respondents had long COVID.² It begs the question of the impact of long COVID on the workforce in general and its impact on voluntary roles — something in which we both passionately immersed ourselves. How many other community groups now suffer due the withdrawal of assistance by people with long COVID? Long COVID affects society in many ways.

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- 1 Walter and Eliza Hall Institute of Medical Research. COVID PROFILE: studying immunity to COVID-19. <https://www.wehi.edu.au/research/clinical-trials/covid-profile/> (viewed Sept 2024).
- 2 Holmes A, Emerson L, Irving LB, et al. Persistent symptoms after COVID-19: an Australian stratified random health survey on long COVID. *Med J Aust* 2024; 221 (Suppl): S12-S17. ■