

Background (pre-covid)

I am in my early 40s, married and live with my husband and step-son, who is 12. I have qualifications in health and legal disciplines including an honours degree, a masters, and a doctor. I am a senior public servant who has dedicated my 20+ years in the public sector focused on supporting people with disability and people living with mental illness.

Prior to my infection I was leading an active life which included: working a minimum of 60 hours per week; doing moderate exercise of walking and yoga for about 3 hours a week; regularly socialising with friends and family including games nights, dinners, attending the theater and concerts, and trips away; and enjoying my hobbies including reading, sewing and painting.

Covid

I was double vaccinated in May/July 2021. I experienced immediate and prolonged side effects from the vaccines which led to me needing several weeks off work. These symptoms included fits (where I would collapse and shake), fogginess, severe headaches, racing heart, nausea and extreme fatigue. Despite investigations by various specialists including cardiology and neurology, no underlying condition was detected. I returned to work in August 2021. I gradually built up my activities and felt that I had returned somewhat to 'normal' in December 2021.

I was booked in to receive my booster vaccine in mid-January 2022. The week prior to this appointment I tested positive to COVID by RAT.

I experienced relatively mild symptoms which were managed at home with paracetamol and rest. These symptoms included a mild fever, sore throat, aches and pains, fatigue, and fogginess.

Post-Covid

Initial experience

I had two weeks off work during the acute phase of my illness. While my fever and sore throat resolved during that period, the fatigue, aches and pains, and fogginess never lifted. Given I still had some lingering symptoms, I returned to work on a half time basis. Over the next two weeks my symptoms gradually became more severe and new symptoms began to emerge. The most concerning of these was my heart racing with even the most minor of activities such as sitting for any length of time or doing simple tasks such as making a cup of tea.

About four weeks after I first tested positive for COVID I experienced my first 'crash'. This was characterised by: an overwhelming level of fatigue where I could do little else but sleep; a severe headache; nausea where I could only tolerate very plain food such as boiled rice; dizziness; fogginess; and a feeling of heaviness accompanied with pain in my limbs. This initial 'crash' kept me bed bound for about 10 days with it being extremely difficult to even go to the bathroom by myself.

Diagnosis

I initially reached out to my GP with whom I have a long and trusting relationship. My GP believed the severity of my symptoms and immediately referred me to a number of specialists to rule out more serious causes. The results of further tests and investigations over several months showed a sustained elevated inflammation response. This was suggestive of either an active ongoing infection, or that my immune system was stuck 'on'. However, no underlying condition was identified by the specialists I saw including cardiology, neurology, and immunology. This ultimately led to a diagnosis of post-viral fatigue or 'long COVID'.

My experience over the three months of investigations that led to this diagnosis was varied. First, I am fortunate that I am in the financial position to afford to have the investigations done and see the specialists privately. The process cost me a few thousand dollars and I am aware for too many people this would be unaffordable leading to lengthy delays in clarifying what may be causing their symptoms.

Second, I am very familiar with the health system from my professional career and I was able to navigate it relatively easily to access the different specialities. However, this was not without an impact on my condition. The effort required to reach out and make appointments, gather together the information requested, and attend the appointments was overwhelming. I inevitably experienced a 'crash' following appointments, even though I attempted to spread them out to manage my energy levels and other symptoms.

Third, given my training I was keen to ensure I was well informed and used what little energy I had to read relevant journal articles and information issued by health organisations such as the NHS and CDC. This protected me somewhat from the poor information I received from the various specialists that I saw. At best the advice was benign. For example, comments such as 'You don't have an underlying more serious condition. It is most likely post-viral fatigue and should resolve with rest.' More often the advice was ill-informed. For example, multiple doctors advised that it was a fitness issue and my symptoms would resolve with more vigorous exercise and encouraged me to get a personal trainer. This is despite the literature stating that this is contra-indicated for long COVID due to post-exertional malaise which I would point out to the doctors with mixed results. At worst the interaction with the specialists was disrespectful and insulting with suggestions that I was malingering given that the tests did not show an underlying condition or that I was depressed and should go on antidepressants. One doctor literally laughed at the suggestion that there was such a thing as post-viral fatigue.

Even with the research under my belt these interactions still took a toll on me. I took on board comments to the effect that I simply wasn't trying hard enough and pushed myself to do more. This was precisely the wrong thing to do I soon discovered and contributed to an exacerbation of my cycle of 'crashes'.

Treatment

I was fortunate to be referred to a specialist clinic and waited about 6 weeks for my first appointment. The clinic supported me to understand the 'boom and bust' cycle I had been experiencing and taught me the importance of listening to my body and pacing to manage my energy levels. Over a series of months I learnt that even though I had considerably reduced what I did in a day, I had still been doing far too much. The clinic supported me to find what my true baseline capacity was both for individual activities, and in combination my capacity for activity across a day, or a week. The clinic guided me on how to gradually build on that baseline in small increments over an extended period of time and helped me set goals on the key areas I wanted to focus on rebuilding.

10 months on from COVID

My level of functioning remains severely limited. I can be 'active' for 2-3 hours per day depending on the mix of activities and provided that I have rest breaks between activities. Physical activity tires me very quickly, with a current limit of about 5 minutes of walking at a slow pace. I can read for about 18 minutes and carry on a conversation with someone for a little over half an hour. I even have to be careful as to what I watch on TV as I have difficulty following more complex storylines. I find it difficult to be in public spaces as I find the noise overwhelming. I also now find it difficult to manage basic navigation around the local area independently even with directions guiding me such as from google maps. It has also been difficult to keep up to date with routine screening and health checks with such appointments triggering a 'crash' due to the mental and physical effort required to attend.

Well-meaning friends and acquaintances have said that at least I have had a year to catch up on my back-log of books and TV shows or enjoy my hobbies. However, this is simply not my reality. I spend the vast majority of my day lying down and resting my mind and body. A 'treat' is when I have the energy to do this in the lounge room rather than staying in bed.

I have virtually no social life. I stay in contact with family and friends by messaging apps but in-person socialising has been rare. When it does occur, it is brief and small due to the difficulties I have in processing lots of noise and how quickly I fatigue when in conversation.

In terms of employment, I have been fortunate to have accrued lengthy leave over the course of my career which I have been utilising since my first 'crash'. With the support of the clinic and an incredibly understanding and supportive workplace, I started a graduated return to work plan in September. This started at 1 hour, 3 days per week working from home with a plan to gradually build to 3 full days over about 18 months.

I have found returning to work fulfilling and my husband has commented on me having my 'spark' back when I get excited by an idea or project we are working on. However, the return has not been smooth. Even the first small increment of adding 15 minutes per day was followed by a series of crashes I had to rebuild from. Whether I will ever be able to return to full-time work is unclear.

Recommendations

Public Health messaging

The messaging from governments over the course of this year has focussed on a 'return to normal', an end to 'covid exceptionalism' and the need for 'individual responsibility'. These messages appear to be primarily driven by political and economic reasons rather than considering the full health impact of COVID. Even when health information has been shared the focus appears to be on mortality (e.g. the relatively reduced risk of serious disease and death compared to earlier in the pandemic) rather than morbidity (e.g. the long term detrimental health impacts).

People got used to doing things because they were told they had to during earlier phases of the pandemic. The corollary of this is that many think unless they are told they have to, they don't need to. I do not support a return to mandates, but if we are to have 'individual responsibility' then individuals need honest, consistent, and transparent information about the full range of risks and what options are available to them to protect themselves and those around them.

In the public discussions I have seen by politicians at both state and federal level, the risk and impact of long-COVID has been minimised and/or dismissed. The lack of action by governments to address long COVID reinforces this perception, including the lack of research funding and treatment centres (detailed further in later recommendations). This appears short-sighted on the part of governments given the growing disease burden which brings with it significant social and economic impacts, as well as increasing the long-term demand on the already strained health system.

Research funding for long COVID

It was notable that the federal budget did not contain any funding for research for long COVID. This is a departure from other nations including the US and UK, which have funded research programs on the cause and treatment of long COVID. These other nations have recognised long COVID as a 'mass disabling' event and the urgent need to better understand and develop treatments for those affected. Given the continuous growth of people impacted by long COVID in Australia, it is critical that funding is invested into researching the cause, prevention, and treatment of long COVID. As an immediate priority, funding should support establishing and tracking the burden of disease associated with long COVID to provide clear information and guide policy and program decisions.

Education of Medical Professionals

As long COVID is currently a diagnosis by elimination, it will remain the case for the foreseeable future that individuals will see a range of specialists and other medical professionals in their journey. Too much harm can be done by these professionals in providing ill-informed advice to patients due to a lack of understanding of long COVID and the emerging evidence. It is critical that as part of the professional education required of medical professionals to retain registration that this includes education on long COVID. In particular, it is vital that where long COVID is suspected, patients are treated respectfully and believed. They should also be provided with

early advice as to pacing and appropriate management of post-exertional malaise so as not to exacerbate the condition pending confirmation of the diagnosis and accessing treatment.

Increased availability of treatment

Australia has been relatively slow to establish long COVID clinics compared to other jurisdictions. This is particularly disappointing given the comparatively long lead time Australia had and the ability to foresee the need based on overseas experience. This should have been part of the planning for what 'living with COVID' would look like. The onus remains on governments to rapidly address this gap and ensure that all Australians, regardless of where they live, have timely access to appropriate treatment for this serious condition. The delivery of this treatment needs to be flexible having regard to the nature of the condition, including allowing for telemedicine.

Connection to employers

I am all too conscious of the privileged position I hold that I continue to utilise leave from my employer to support me as I learn how to manage living with long COVID. This means that I have not had the added stress of suddenly finding myself unemployed due to my illness. For far too many Australians, this would not be the case. Indeed, given the diagnosis by exception takes some months, I imagine too many would become disconnected from employment prior to even receiving a formal diagnosis.

The hope of returning to my work has been a goal I have steadily been working towards during my months of rest, recovery and treatment. The fact that I am now able to commence a graduated return has had an enormously positive impact on my wellbeing. This should be possible for everyone. A program should be put in place to keep individuals connected to employers. I understand that this will be difficult given the length of time it takes to confirm a diagnosis of long COVID. However, the long term economic and social benefits of sufferers being able to maintain employment I am sure would outweigh the cost of any such program.

Financial assistance

In the absence of, or depending on the nature of any program to keep sufferers connected to employers, clarity needs to be provided on what financial assistance those with long COVID are able to access. Of the current options the most likely appear to be the Disability Support Pension or JobSeeker Payment. However, the DSP requires that the condition be 'permanent'. Given how much is still unknown about long COVID it is likely it will be difficult for sufferers to meet the 'permanent' criteria. The opposite problem occurs for JobSeeker which states that it's for 'when you're sick or injured and can't do your usual work or study for a short time'. Again, it is unclear how this would apply to long COVID given it is by definition continuing for a long period of time.

Navigating and gathering the necessary documentation to access financial assistance is difficult at any time, particularly for those suffering from an illness which is characterised by fatigue and difficulty concentrating. This is only exacerbated by the lack of clarity on the appropriate path for long COVID sufferers.