

The Long COVID and Repeated COVID Infections Committee

Personal Submission from:

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Prior to having Covid I was a very fit 65 year old who walked daily, did 5 or more high intensity aerobics classes a week, managed the family company and undertook website and communications work as a volunteer for a not for profit organisation. I was also an active member of three Community Committees and ran a household.

I caught covid -despite having been ultra careful and fully vaccinated- in early December 2021. While I was very unwell during my infectious period I didn't require hospitalisation, but I was unable to work or manage any household tasks until early January. During this time I completely lost my sense of smell and taste.

My recovery was slow but steady through January however despite following Doctors advice to rest as much as possible for 8 weeks, in early-February I suddenly developed tachycardia with a resting heart rate of over 100 bpm. I also developed a crushing and immovable fatigue that wasn't (and still isn't) improved by sleep or rest as well as mild vertigo and nausea.

My very supportive GP immediately arranged for me to see a Cardiologist who organised tests, monitoring and scans. The scans showed some minor valve damage and I was prescribed medication which very much helped with the heart rate issues. I was also sent for lung tests and given breathing exercises.

At this point I was unable to drive or manage day to day tasks. Reading more than a page of text was exhausting and a phone call of more than a few minutes left me needing to lie down for an hour.

I had gone from a person who had a full and busy life, ran communications and a web site, spent at least 2 days a week on several community committees as well as managing the administration for our family company and managed a household - to someone who could barely hold a conversation and couldn't manage paying bills.

Total rest was the only option.

In early March I then noticed that I had developed a mix of Parosmia and Anosmia with many things either smelling overwhelmingly of chemicals or having no smell at all. This is still the case. I have either zero smell/taste or I am left reeling and nauseous from the fumes of everyday foods and objects.

Having decided that total rest and minimal mental exertion was the necessary path to any sort of recovery I spent four months almost totally resting. I handed over everything to others – and am incredibly fortunate that my husband, neighbours, the organisation I volunteer for, my accountant and many others stepped up and helped. I am also very fortunate that I could financially afford to do this – most can't.

The only things I did undertake were Doctors appointments – and even those had to be carefully scheduled so as not to cause me to crash. I also needed someone to come with me as I often couldn't remember what I was told – or in one case the following day I had no recollection that I'd even been to the appointment.

There has been a slow progress towards improvement. But it is one with many plateaus and many backward steps along the way.

I am now able to drive short distances safely. I can focus for an hour at a time. And I have been able to resume most basic daily tasks as long as I can do them as I feel able – not to any fixed schedule.

As just one small example, just last week I did 30 minutes of hydrotherapy (my only manageable exercise), had a shower and then had coffee for an hour with two friends. I crashed that afternoon with fatigue and vertigo and was mainly in bed for 3 days. This meant that other commitments were cancelled. So it's now back to only doing one thing per day.

While I am in the very fortunate situation of not needing financially to work, I have always contributed to the community. Losing the ability to say "I'll help" is devastating and depressing. I have sadly had to massively scale back my volunteer work and resign from my community committees as I can no longer contribute.

I also realise that there are many who are not in my fortunate situation.

- There are many who are far more debilitated by Long Covid than I am
- Most have families to support, and need their jobs.
- Many employ others.
- Those who cannot afford to access specialists outside the public health system
- And those who (like me) who have been on the waiting list for a Long Covid clinic appointment for months and months with no appointment in sight.

While I do not expect a 'magic-bullet' cure I do hope that the Government will recognise the urgency and desperate need for research and world-wide collaboration as well as more accessible and relevant support for those suffering.

I also hope the Government will recognise and act upon the very urgent need for education of the public that every single person who catches Covid is at risk of Long Covid.

The ongoing effects of Long Covid are likely to be felt for decades and this will have an enormous impact on all areas of our lives and economy. There is going to be a significant cost to health-services, business and taxpayers and this needs to be planned for now.

Logically it would seem sensible and prudent to prevent as many cases of Long Covid going forward by preventing as many cases of Covid as possible.

I also hope that the medical profession and researchers will take an open and receptive view of new and emerging research around the world. And that they will respond to it in an urgent manner.

While I have been fortunate in having a GP who believes in Long Covid, and perhaps also fortunate that I had a measurable symptom with my heart issues, the stories of patients not being believed are legion.

There is no point in saying 'talk to your GP' unless all GP's are provided with information and education about Long Covid as well as precise, current and continuing updated information about what help is available and where patients can access help.

GP's do an amazing job, but they are pushed beyond reasonable limits currently and are unable to undertake any meaningful research into this issue themselves.

And I would really like to stress that now is not the time for maintaining past positions and prejudices about post-viral illness.

We have all had to adapt and change our minds about a lot of things during the past few years and everyone involved in this needs to be open to new and emerging data, research and ideas.