

To: [Committee, Health \(REPS\)](#)
Subject: Form Submission - Inquiry into Long Covid and Repeated Infection Submission
Date: Friday, 18 November 2022 11:57:05 PM

What is your experience of being a patient in Australia of long COVID and/or repeated COVID infections, particularly regarding diagnosis and treatment?: I had my second Pfizer vaccination by choice. I believed everything we were told. I listened to Dr Norman Swan's Coronacast. I was very afraid of covid and even moreso, long covid. So I 'did the right thing' and had my shots. The day after that second fateful shot on July 20th 2021, I slept 29 out of the next 36 hours.

I'd just started a new job, got just 3 weeks into it & was then rendered incapable of working. I was excessively & unusually confused, my brain was buzzing with a vibration, I couldn't understand what people were saying to me, it was like I had to translate. I fell asleep at the wheel of my car. Woke to horn blasts, called my husband & he drove me home. I was unable to drive for many months. I lost my job. I was having uncontrollable sleep attacks, paralysis episodes, muscle spasms, screaming banshee tinnitus and massive cognitive dysfunction and I just wasn't myself any more. I lost my 3D depth perception and developed a horizontal nystagmus.

This went on for at least 9 months until I started to see improvement and the sleep attacks, hypnogogic and hypnopompic hallucinations and paralysis episodes eased. The rest of my symptoms remain, 16 months on. The cognitive dysfunction still remains, as does a whole host of other new diagnoses. I've been diagnosed with FND - Functional Neurological Disorder with Non-Epileptic Seizures, Dysautonomia - causing my heart rate to fluctuate wildly with multiple episodes of atrial tachycardia every day.

I then got covid in April 2022. The illness itself wasn't too bad. But a couple of weeks afterwards I was slammed with the heaviest fatigue you could possibly imagine. I felt like I was wearing lead weights, walking through syrup up a mountain dragging a truck tyre behind me. And that was just going to the letterbox and back. I've become very sedentary, I sleep on average 15 hours every day. I can't think straight, I'm often confused. When tired I now stutter. I can't find my words, or I say completely the wrong thing. None of this existed prior to that vaccination & covid.

There is a lot more, but I'm weary & this has taken a long time to write already so it will have to do.

Losing my job (it was part time) has cost my family in the vicinity of \$41,000. I was not financially rewarded (bribed) to get the vaccination. I was not covered for losing my job. I don't quite qualify for disability because we don't know how much of the damage done to me is permanent. My husband is just a touch over the threshold so we can claim no benefits at all. I can't get centrelink because I couldn't look for work. Every day is unpredictable for me - I don't know if I'll be able to hold a conversation for an hour one day, or if I'll just need to sleep most of the day and stay in bed. I can't stand up long

enough to cook for my family. I have just been told I can apply for NDIS, but I'm so confused by it, I haven't been able to read all the information or work it out and I don't have the energy to jump through your hoops.

We have two teenage children. One has ADHD, the other Autism & dyslexia. They are in a private school because public schooling was seeing them slip through the cracks. My job was supposed to pay for their schooling. Now my husband is working two jobs to try to make ends meet.

There is no compensation option for me for my injury because the neurological damage so many have experienced is not included. People who have had myocarditis or pericarditis generally recover and can go back to work. It's been 16 months for me & I may never be able to work again.

I have fallen through all the cracks. We have had to pay for the school bus at \$20 per day because we live 2kms away from the village centre with the nearest bus stop & I couldn't drive safely. Our children have had to buy lunches because I can't stand long enough to prepare food for them.

And then there are the Doctors fees. I have seen multiple specialists. I've seen the following:

My GP - visits every 2-3 weeks

Sleep & Respiratory Specialist

Immunologist (AEFI) - who gave me exemptions from further shots

Neurologists x 2

ENT

Gastroenterologist

General Physician

Psychotherapist (to help deal with the massive devastating changes to my life)

I'm sure there's more but I can't think now. I am soon to see a neuropsychiatrist to do full cognitive function testing.

I've had MRI's, CT's with contrast on my lungs, heart, brain, ECG, EEG, sleep studies, brain wave studies, blood tests - enough to fill a bath tub, urine tests, hearing tests, and so much more. I'm having an endoscopy next week & a nerve conduction study the week after. I only leave the house to go to medical appointments.

These have cost us something like \$10,000 - \$15,000 so far and counting. And still I get nothing.

The answers I have are not definitive. They are multi-systemic. They do not explain what and how all of this has happened to me. I have seen studies overseas using fMRI, SPECT, PET scans and various other things that are not considered diagnostic here. So we can't get any actual answers. It's frustrating & my body continues to fall apart. As my life has. I use a wheelchair now. This is devastating.

Why was there not clinics and research facilities and groups set up to deal with the 'rare' (not) vaccine reactions when you rolled out the vaccines? Why is there no compensation for my injuries? Why do

I not matter? Why have I been ignored, gaslit, blocked, banned, shut down every place I turned to for help? The global shut down of anyone who talks about these things is horrible. It's been so hurtful and damaging. If you wanted people to have faith in the vaccines, why did you not say simply "if you have an adverse reaction, we've got your back?" and take part in the global ability to work out what can and was going wrong for

some people? And how to help them/us/me?

What have the health, social, educational and economic impacts been for you, in relation to long COVID or repeated infection? Has there been an impact on your family or community?: I'm scared of future infections with covid. How much worse will I get next time? Why is nobody wearing masks any more? I trusted you & you let me down in the worst possible way & now you turn your back & give me no support or help or answers.

I have missed events for my children. I have missed events with our families. I have missed just going for a walk. I have missed my brain. I have missed my ability to draw and write. I have missed my friends. I have missed 16 months of my life so far. I'm not sure there's an end to this.

This has been very hard & at times traumatic for our children. The stress and pressure on my husband has been enormous. He's had a stroke and heart issues himself this year as well.

What specific actions would you like to be taken in relation to Long Covid and Repeated infection, that would positively impact the situations you have outlined above? : I want financial support - disability, NDIS, medical fees covered. I want answers. I want to be heard; taken seriously; considered as a valuable human being.

Why are doctors not reading the studies being done all over the world? Why do so many of them not know anything about it all? This should not be covered up & considered taboo. Be open, find answers, do the right thing.

I would like the Inquiry to contact me to discuss privacy and confidentiality options for my submission: No