Inquiry into Long COVID and Repeated COVID Infections Submission 51

To: Committee, Health (REPS)

Subject: Form Submission - Inquiry into Long Covid and Repeated Infection Submission

Date: Monday, 24 October 2022 7:38:34 PM

What is your experience of being a patient in Australia of long COVID and/or repeated COVID infections, particularly regarding diagnosis and treatment?: Being gaslighted by neurologist who said I had functional neurological disorder following covid due to the trauma of it. When I had right sided numbness and had and continue to have constant tinunitis. The long covid clinic at st Vincent's hospital in Sydney knocked my referral back because I live in western Sydney and there does not seem to be a local equivalent. GP doesn't get it either. I have reduced hours at work to 4 days a week from full time but struggling with that. I was diagnosed with pots after covid vaccine. That worsened after first then second infection and now I have constant chest pain, but issues and severe headaches and fatigue and regular bouts of stomach pain and diarhoea. I need to see an immunologist, cardiologist and will go back to GP to try and get a referral for Nepean hospital that might get accepted because I'm employed by the local health district. I'm struggling with my mental health and activities of daily living. I'm trying to pace myself, but I struggle to even walk for 5 minutes as I get light headed and feel unwell. I'm aware that even if I can get referrals, I might be waiting months to see specialists and am concerned some of them will write it off as psychological

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?: Needing to reduce hours at work by one day a week and likely needing to reduce further due to worsening symptoms

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?: GPs and specialists to have mandatory training about long covid and dysautonomia and how to manage long covid including having access to clear and easily accessible information (ie not needing to read 100 page documents) with regards to referral pathways. There needs to be long covid clinics set up across all Local health districts in NSW and nationwide. State and federal governments to reimplement masks and mandatory isolation to protect vulnerable community members. In my own experience, each bout of covid has worsened symptoms and has caused worsening disability despite taking significant precautions when I am at Work and in the community, others have brought the virus home. Improvements to ventilation in workplaces must be made and enforced and set in place for new buildings. The state and several governments need to consider long term impacts to the workforce and the economy being impacted by the scourge of disability long covid is causing by allowing "let It rip" policies that are putting votes ahead of protecting people's health. Selfish people or causally employed people don't follow NSW Recommendations of staying home when sick if it's not mandated and they're not getting paid to isolate.

I would like the Inquiry to contact me to discuss privacy and confidentiality options

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for my submission: Yes