

## Long Covid Diagnosis

I am 47 years old. I got COVID on 10<sup>th</sup> Jan 2022 in Melbourne in the middle of the big wave. I started on Prednisolone before I even tested positive as with my Asthma Plan for a serious flare up 50mg for 3 days, 37.5mg for 3 days, 25mg for 3 days & 17.5mg for 3 days. I got all symptoms started with dizziness, then sore throat, cough, fever, vomiting, diarrhea. On Day 5 my back pain started felt like bad sciatica – something I haven't experienced for 20 years. Within 2 days I was in 10/10 pain and rang the covid nurses at Eastern Health. They called me an ambulance and said I would be going to Box Hill Hospital; the ambulance drivers changed their mind and sent me to Maroondah a non-covid hospital this is where the start of the public hospital system failed me. I was left waiting in the corridor with a towel over my face waiting for a bed. Trying very hard not to cough on anyone going past. Once I saw a doctor, he was very alarmed that I had been sent to a non-covid hospital. He stood a fair distance from me asked me to point to where my pain was said there was a very long wait for MRI – like weeks and that I just needed stronger pain medication. I also had some muscle weakness in my leg which he would have seen if he had assessed me. I was sent home with strong pain killers that didn't help.

The nerve pain travelled – down my left leg, and down from the left side of my face. I could no longer lift my leg up even a small lip in a door way. I could not stand up if I was on the floor as I had no strength in my legs. My GP was very unsure what was happening. I called my Neurologist who I saw from Trigeminal Neuralgia and migraines and left a message for her to help. She called me a few days later and by this time I was on 17.5mg of prednisolone. She was able to track over the phone that my neurological symptoms were getting worse with the reducing of the steroids and that I had to get back on the 50mg. By this time I had numbness in my left side of my face and head, no feeling in my tongue and no taste, ringing in my ears and numbness that was spreading down my neck. No feeling in my left arm and hand, from my waist down I was unable to feel anything and felt like I had a tight band around my hips. Really painful muscle spasms in my left thigh and shooting pain down my legs, total numbness in my shin and a pins and needles feeling that come and went. It was a few more days until I hit day 14 and was able to see my GP in person the covid nurses discharged me as my breathing was getting better but nerve pain and numbness just continued to get worse.

On assessment my GP said that I had muscle weakness in my legs, and reduced reflexes in my left leg. I was unable to use my legs to get out of a chair and when standing up from the floor would often fall over. GP instructed me that I needed to buy a walking stick as I was not strong enough in my legs. My neurologist was able to get me an MRI within 8 days – I couldn't get in anywhere when I called around for 6 weeks. Neurologist wanted to rule out Transverse Myelitis.

On the Day of my MRI everything got worse, I now had numbness in my right leg muscle weakness and now needed a 4 wheel walker as I was falling with a walking stick and I could no longer drive. Every step was like nerve pains shooting down my legs and I cried all the way to the MRI. I should have gone to emergency but after my last experience I was scared that I would lose my MRI spot. MRI of brain and spine came back clear and my right leg had started to improve. But my neurologist wanted me to go back to emergency as she was concerned that I could no longer feel the need to use my bladder or bowels and I couldn't feel my vagina. So she wanted to rule out Guillain Barre.

When I arrived at Box Hill hospital after 7 hours of waiting, I saw a doctor who did an assessment and said that there was a condition that overweight middle aged women get that causes nerve pain in the hips – I said and how does nerve pain in my hips cause numbness in my face and arm and muscle

weakness in my legs and reduced reflexes. Eventually I saw the neurology team, they did an assessment and said there wasn't much they could do for me except giving me stronger pain meds. I got upset and he said he could admit me but they wouldn't be doing anything else for me except continuing on the prednisolone. I asked about the IV steroids that are stronger and they said no as there was no lesions on my scan that they wouldn't do that. I told him I wasn't taking stronger pain killers I wanted to be able to use my legs again, drive my car, have sex with my husband. I am 47 years old and I am using a walking cane. They said there was nothing they could do but book me in for a nerve conduction test in 2 weeks time at the hospital. This also came back clear.

I also saw my cardiologist in January as I had gotten pericarditis from the vaccine – so she did a check and I still had a high heart rate on standing over 120 beats but when sitting it dropped back to 80. She organised a echo for me in September, but was shocked that I hadn't gotten pericarditis from the virus.

I have been rejected from the Long Covid clinic as I am in the Eastern Health catchment, and they don't have a LC clinic and the other clinics won't take patients outside of the catchment. I have seen a Cardiologist, a Rheumatoid ologist, a Gastroenterologist who have all cleared me of having any other diseases that can cause these problems. For the first 4 months I spoke to my neurologist fortnightly, and she communicated with my GP and if my GP had concerns she would contact the neurologist. But this has been at a great financial expense to me as this has all been done privately and could only happen because I already had a neurologist that I saw yearly and a cardiologist since I got pericarditis from the vaccine in August 2021. So I didn't have to wait on a long waiting list, and my neurologist was compassionate in helping me. I also paid for weekly osteopath appointments to regain my strength in my legs and re taught me to walk up and down stairs and to give me back balance. Which is only good when I don't have fatigue – once I am tired I struggle to walk, talk or think.

I am 10 months in and I still have debilitating brain fog, fatigue that doesn't get better with sleep. I used to be able to walk 30,000 steps easily – now more than 5000 and I will pay for it the next day. I have only just been able to complete a full supermarket shop, 3 months ago I would have only been able to do 3 or 4 isles with my heart rate spiking up to 170 beats per minute by resting heart rate is 60 to 70 beats. I was able to do 3 x 20min sessions in a hydro pool. I started with 1 x 10min session which I needed to sleep in the car before I could drive home. I went to the Royal Melbourne Show in September, I was able to make to 2hrs I did nothing but walk to an exhibition and I would sit and wait while everyone else participated within 20mins of standing I am looking for my next seat. By the time that I got to the train, I was unable to talk properly slurring my words and missing words out of sentences and my husband had to come and get me out of my sisters car. I went to the theatre and by the end of the 2hr show I could barely walk, or communicate and again my husband needed to come get me from the car. Then after both of these I stayed in bed for 2 days unable to get out as I was exhausted. I have always been able to drive long distances – not unheard of for me to drive to see my aunt and uncle in NSW 14hr drive and drive back the next day with no fatigue I love driving. Now I can only drive 30 to 40mins and then I need a sleep. When I am exhausted, I am very forgetful. A few months ago, I was driving along and I couldn't remember where I was going, I was able to pull over look at my maps and realise I was in my estate so

maybe I was just driving home. When I got home I realised I had wet swimwear with me so I was obviously on my way home.

I have a 14 year old foster child in my care who has been with us for 18 months and who is in our care long term. It is common practice for people to assume I should just give him up because he can be hard work some days. But if I had given birth to him no one would expect this. We have given him stability that he has never had in his life and now he worries every day that I am going to get covid again and that he may give it to me. And that I may get to sick to care for him. We are his 5<sup>th</sup> family in 14 years and like every kid he deserves stability, and this is something that long covid has taken from him. The unknown is difficult and it is not something that I can hide from him. He sees me struggle everyday, and that small things like taking him to basketball takes everything out of me.

My husband is on the spectrum, and he has been expected to take on more as I can no longer mop the floor, vacuum, most days I cant cook dinner as I don't have any energy left and I certainly cant cook anything that requires me to stand in the kitchen and stir. Every activity we want to do as a family means that I am going to spend 2 days in bed.

I am the main income earner in my family and at work I am known as the person who just makes things happen. I worked as a HRIS System Manager – I managed a small group of 3 people, and I also did most of the complicated configuration of the system is was not unusual for me to do 70 hours a week. My salary was around \$130k. I have income protection insurance in my superannuation, but it is at the bottom level of maximum of \$3,000 a month. My husband earns a base wage in retail setting. My work were great at the start I only had a few weeks leave as I had taken all my sick pay when I got pericarditis twice from the vaccine. So, I was on unpaid leave for approx. 6 weeks. I was not entitled to any job seeker allowance as I had \$10k in the bank. When I was able to start returning I came back initially for 2 days x 2hrs and slowly worked my way up to 12 hours a week 3 x 4hrs. Then they decided to replace me as they realised I was not going to return as quickly as they would like. So the pressure started from the safety team and return to work co Ordinator. She started prefilling my hours that I would be returning to work, she wanted me to try a 6 hour shift. So I did and by the time I got to 5hrs I was exhausted – kept going 5.5hrs I was really struggling to type, to understand what I was reading so it took me another 20mins to finish what I was doing and to get off. My husband came home and had to help me from my work from home desk to the couch I could not talk, I couldn't walk properly it was like my brain at totally shut off for the day. He put me to bed because I was unable too. I couldn't get out of bed for 3 days and I went backwards in what I could do physically I was working 14hours at that stage and had to go back to 12. I tell my work and they said we didn't ask you to do that you should have seek doctors advice. But they continued to pre fill in my hours increasing my hours that I could not do.

Then they suggested that they could find me a long covid specialist that could help me. I was so excited and told everyone. When I got the email through I googled the doctor and he was a GP that specialised in Occupational Therapy. So I questioned this as I was now concerned that they were trying to get evidence that I couldn't do my job. I was told no no no we are just trying to help you get better and he has sat on the long covid board. So I went into the city on the train and I asked him his experience with LC and he said that he had done a report on a few and there ability to do there job. So I walked out. I

was devastated it was R U OK Day? I was sitting in the park shattered that my business was obviously trying to force me out. I called my boss on the way home as he is the HR General Manager and he said no we are not trying to do that. I talked to the Return to Work Co Ordinator a few days later as she was really busy organising all the business events for R U OK? And didn't have time to call me back as she was exhausted. Two weeks later I was called and they were sending me to another GP – I said cant you talk to one of my specialists Neurologist and I was waiting to see a Infectious Disease Specialist. I was told no, its in your contract. I spoke to a psychologist about how upset I was feeling. My manager had stopped having meetings with and I was feeling very isolated. She said that I was so desperately looking for answers to get better of course I would be so upset that someone had tricked me by praying on my vulnerability.

I went to see the doctor that they were forcing me to see, it was horrible he made comments about my treating specialists and GP and that they hadn't done enough and that I was a google doctor and that he didn't seem to believe in LC and that he thought I needed a psychiatric review as I obviously had anxiety issues and needed to see a psychiatrist. I left that doctors surgery shattered and I sat in the middle of the CBD curled in a foetal position sobbing. From the moment that this doctor review was initiated I have gone backwards in my recovery, my anxiety and increased heart rate is as bad as it was 6mths ago. I am no longer able to do any rehab exercises – I work and I sleep. I asked my employers for an open conversation about 2 months ago I would have preferred them to just say we cant hold your position. My GP felt that my work environment was no longer safe place for me to increase my hours. She said that I needed to cease my increasing of hours at that stage I was trying to increase 15mins per shift every fortnight. I even offered that maybe if I came back to the office one day a fortnight (something that is important to my employer) that was given to the co Ordinator and then she was demanding 15mins increases each shift each week and weekly shifts in the office.

I went a saw a Infectious Disease Specialist and she advised that if it had taken me 10 months to get to 12.5hrs then it would probably take the same to 25hrs. I took this information to my employer and said I was open to a conversation about other opportunities that were part time 12hrs or casual. And I was advised that there were no positions for me, that unless I could provide evidence that I would be able to return to full time they would be terminating my employment a week before Christmas. This was not a workers comp claim, I have no idea where I got covid. I was only getting paid for the hours I worked, and in the whole 7 months since I started working again I have missed one shift. There has been days I have had to have a break due to exhaustion. I have worked late afternoons even though that is not my best time. How do I get employment with Long covid for 12hrs a week. For me 12hrs a week paid me around \$3k a month and then the insurance was about \$1900 a month. But this is only half of what I used to get paid.

This termination will mean we will have to move to another rental as we cant afford the rent during a rental crisis. I will not be able to pay for weekly osteopath which is what has been helping me get stronger so I can do more hours. My specialists have been able to start bulk billing me which helps but the medication is experimental so its not all covered by the PBS. And stress will make this worse, it was very clearly stated to me that if work continued to stress me that I would continue to get worse and that I may never work again. So potentially another person on job seeker, adding to our rental crisis, and having to give up our foster child because we wont have a place to raise him. This is more than just an illness this is a crisis where employers can throw you to the curb and there is no assistance to assist to

find another job and no support for businesses willing to give LC people ago. A bigger burden on our health care system