Long COVID is a debilitating condition that presents after a COVID infection.

Long Covid is still relatively new, there is no diagnostic test, and it's likely it's a mixture of different conditions with different underlying causes. Affected people have described many symptoms, the most common being shortness of breath, fatigue, fever, headaches, and “brain fog.”

Many clinicians are unfamiliar with Long Covid post-viral or post-infectious syndromes. Doctors may not have experienced Long Covid firsthand, haven't recognized it, or have not had appropriate training in identifying or supporting people with long COVID.

According to the Australian Department of Health, a person experiences long COVID when their symptoms remain four weeks after they first had COVID.

The World Health Organisation says long COVID is usually three months from infection, lasts at least two months, and cannot be explained by another diagnosis.

1.PERSONAL EXPERIENCE (based over 6 month time line)

I woke on the seventh of April 2022 with an itchy throat that developed into a sore throat; the next day, I tested positive for covid. I registered my test with NSW Health online services.

In the next few days, my children also tested positive and started to show symptoms. My 10-year-old daughter had mild symptoms, and my son and I were bedbound with flu-like symptoms, muscle weakness, loss of appetite, shortness of breath, and fatigue.

My partner came down with a temperature and was only tired for two days, though he had insomnia that followed for weeks. He returned to work after the 7-day isolation period.

In the following week, I continued to be bed bound. I noticed my heart rate would increase each time I got out of bed to go to the toilet or shower my smart watch would alarm to tell me the rate was high. I knew that wasn't good before I had covid I would need to be running to get that kind of heart rate.

I was unable to eat much, it was difficult to swallow. I felt very weak my veins bulged and I had small internal bleeds on my hands. My feet and hands were tight, became red and burnt like a gout-type inflammation.I was often dizzy and had a tight chest, it felt like I had a belt around my ribs. My skin was blotchy,I was short of breath, I started to wake up at night gasping for air, sleep apnea, chronic diarrhoea, new food sensitivities and a rash.

I started having intrusive thoughts and hearing things I had a feeling of impending doom and thought I was going to die.

In the following weeks I ended up at ER 3 times I had also called the Ambulance with heart and breathing difficulties. The chronic chest pain felt like I was having a heart attack. Shortness of breath and a constant squeezing band around my ribs. Each time I was given a different diagnosis post viral malaise, gastritis,possible autoimmune, maybe long covid, nonspecific chest pain, shortness of breath and chronic diarrhoea the recurring response was you seem anxious. Tests were done and with the pain resolved I was clear to go home.

I would like to highlight that if you were sick for weeks and had difficulty breathing, you would be anxious!

The general response on exertion was that my oxygen levels would drop into the 80s but would return to normal at rest. Unable to take deep, satisfying breaths at rest, my anxiety increased. I tried to seek anxiety medication and counseling three times without success. Suffering from weeks of insomnia this post viral condition started to get the better of me. I called the mental health line completely exhaused and at my wits end. I wanted to admit myself as mentally unwell, as the doctors at the ER kept saying there was nothing physically wrong with me.

The mental health care workers were the best. They reassured me it was probably long covid that some of them had experienced it themselves, the first time I had heard of it.

My 16 year old son seemed to be improving,he was still coughing and tired though he was getting up and starting to eat again, play for short periods on his computer and shower. My daughter was having increased sensory issues, tinnitus, complaining of stomach pain, muscle aches, chest pain, breathlessness on exertion, and pins, and needles.

I returned again to the medical centre with no improvement. I had chronic diarrhoea for weeks that turned into months. I was losing a kilo a week. It felt like my health was rapidly declining. I had lost a lot of weight, had chronic fatigue, muscle pain and weakness. The doctor found a postural drop and the ER doctor noticed something on my echo suggesting I see a cardiologist. Everything looked fine structurally. The cardiologist did not test for pots stating he knew nothing about covid related conditions that hopefully things would just settle down as I recovered.

The following week I went back to My GP and spoke about the recurring issues and begged for a referral to a immunoligist as I felt there was something odd going on with my immune system and I was clearly not improving. He ran some more blood tests and everything looked fine. I was just told to keep resting and come back in two weeks if symptoms persist. At this point I feel education about long covid would have been helpful. I was too sick to drive, my partner and my parents were taking days off work to take myself and my son to medical testing appointments.

At the same time as my decline it was clear something wasn't right with my son. He was walking to the fridge and fainted, hitting the floor heavily right in front of me. It was clear his heart was racing upon standing. He would shake and sweat. He complained of chest pains and shortness of breath, and started to develop anxiety. We attended the hospital. They checked him out and said to follow up with the GP. The following week he had an echo and wore a holter all fine. He was clearly not fine, was still light headed, had chronic fatigue, muscle weakness and was losing weight rapidly. He could not concentrate on school work and spent a lot of time sleeping.

DIAGNOSIS and TREATMENT

ON multiple visits to the ER and presentation to Ambulance staff, I complained of these ongoing issues they are symptoms of lung inflammation that could of been treated at a early stage by my GP**,** I have struggled for 6months with this.

- A general sense of fatigue.
- Wheezing.
- Dry or productive cough.
- Trouble breathing.
- Chest discomfort or tightness.
- A sense of lung pain.
- Gasping for air.

It was clear after months of multiple tests that our GP didn't know how or feel comfortable to make a diagnosis nor did any other GP we saw. They said it would need to be diagnosed by a specialist. I asked the GP for my son and I to be referred to St Vincent's covid clinic, We were then redirected to the JHH rehab clinic.

Frustratingly after referral to the clinic with a possibility of LC (see referral) the Rehab Clinic sent us a letter saying that they do not diagnose Long Covid that we must have a diagnosis before we come to the clinic. I tried to talk to my GP about this he said no one wants the responsibility of diagnosis. They are all passing the ball.

I spoke to the St Vincent's Clinic, they said some DRS are comfortable diagnosing Long Covid some are not, this places a huge strain on the patient looking for answers they are bounced around from Dr to Dr without diagnosis. Without diagnosis patients are placed in the psychosomatic category; this is when family and friends retract support, no support quickly leads to poor self esteem and mental health.

There is no public pathway for teens in the Hunter Valley. My son , being 16, was too old for the local hospital paediatric clinic and too young for the JHH rehab clinic. I reached out to our Local politician to draw attention to the difficulty we were having.

At the five month mark I was prescribed montelukast in combination with an antihistamine it was a breakthrough finally my breathing started to improve my energy levels and cognition returned to near normal. Montelukast is a tricky medication/ a mast cell stabilisers anti-inflammatory often used in childhood asthma. Some people have difficulty with nasty side effects, I had some, but they subsided when I reduced my dose.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8673734/

Moving forward, Accessing Treatment

I have found private doctors specialising in areas that are affecting our family.

My son is currently waiting on a private paediatrician and pots specialist as we could not get treatment through the public system. The first appointment will be the combined cost of $1000.

A Private Integrative Gp is treating me at $450 per hr. My immune system is overactive. Medication for mast cell activation syndrome (MCAS) is not on PBS. The cost is $215 a month plus $200 for supplements, I still have shortness of breath and chest pain when active or standing. This has made it difficult to engage in many activities.

Public paediatrician for daughter on waiting list, continuing to have difficulties. she is homeschooled and it has been difficult to maintain school work with our current health.

The new added financial burden for our family has added extra stress to my partner at a time where we are facing high costs of living. As well as the emotional stress that has come watching my kids suffer. My son has missed out on achieving his year 11 grade as he has been unable to attend school due to longcovid/pots. Muscle weakness is an issue with him getting around on his own and the possibility of fainting on standing has made leaving him alone difficult , he is 10kg underweight for his height, struggling to eat and gain any weight.

2.The Experience of Healthcare Services

Over the last six months my family has endured significant stress that could have been avoided due to a poorly recognised post covid condition. We have encountered numerous health professionals with no knowledge and bad attitudes towards people who have struggled to recover after covid.

No acknowledgement of the post viral condition

Financial pressure for private doctors/limited access to public services

We have had a significant delay in treatment

We have suffered gaslighting been told many times that our symptoms are from anxiety

We have been refused help and turned away from doctors and the hospital

We have been unable to access counselling

We have been unable to access affordable long term care publicly in our area.

There is a breakdown in the system from our experience, I have spoken to many Australians and also people Internationally struggling with the same issues. The current theme is that GPs aren't taking on the role of recognising long covid and ruling out other conditions in a timely manner. This is placing a burden on the healthcare system creating a rebound effect. The patient becomes desprerate for answers and starts to Doctor shop, often the patient ending up in the ER due to a poorly managed conditions. It took a long time before my lung inflammation was recognised and treated. We saw three Gps before one would listen to me in regards to my son's post covid condition It should not be that hard to get medical help.

The Current NSW Health recommendations are to see your GP for help with long COVID. Our experience was poor, no GP wasn't able to provide education, and had no interest in researching this area.The multiple doctors we saw had no awareness of RACGP guidelines or interest in reading it. There are tools that would be very useful to the patient such as a symptom Diary.

https://www.racgp.org.au/clinical-resources/covid-19-resources/patient-resources/patient-resource-managing-post-covid-19-symptoms/introduction

I have read many personal accounts from attendance to different Australian Long covid Clinics. The overall opinion is that the clinics are unhelpful, useless and a bad experience. They seem to be focussed on lung issues, covid is a systemic virus that causes a multitude of issues that need investigating such chronic fatigue, PEM,MCAS, POTS, ANXIETY,DYSAUTONOMIA and MICRO CLOTTING none of these post covid conditions can be treated with an exercise program.

3 Research and Risk Factors

A recent Monash University study has found six months after recovering from COVID-19 critical illness, one in five people had died, and almost 40 percent of survivors had a new disability.

https://www.monash.edu/news/articles/the-long-term-effects-of-covid-19#:~:text=A%20recent%20Monash%20University%20study,survivors%20had%20a%20new%20disability.

There is an allergic type response causing shortness of breath discovered by Dr Shankara Chetty his finding urgently needs to be highlighted for doctors and the general public so they can act in a timely way to reduce the reaction. An overactive immune system triggered by the virus can cause a release of chemicals called histamines, which can cause inflammation throughout the body . In that situation, the release of histamines can cause tearing of the eyes, congestion in the nose, swelling, difficulty breathing, and even vomiting, diarrhea and sensitivity to food.

https://www.health.com/condition/infectious-diseases/coronavirus/allergic-reaction-covid-19

https://www.parliament.nz/en/pb/petitions/document/PET_118399/petition-of-emile-van-der-merwe-investigate-the-covid-19

As Well as an overactive immune response much like or possibly Mast Cell Activation Syndrome.

Dr. Tina Peers explaining MCAS

https://www.youtube.com/watch?v=sICD0Kn6pR4

According to this document below frequently reported symptoms persist for 6 months or longer after acute infection. COVID-19 survivors complain of recurring fatigue or muscle weakness, being out of breath, sleep difficulties, and suffer from anxiety or depression. Symptoms noted in Long COVID/PASC patients show numerous similarities to those seen in chronic illnesses, including Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Postural Orthostatic

Tachycardia Syndrome and Mast Cell Activation Syndrome. In a large global survey of 3762 Long COVID/PASC patients from 56 countries it was found that nearly half still could not work full-time 6 months post-infection, due mainly to fatigue, post-exertional malaise, and cognitive dysfunction.

https://cardiab.biomedcentral.com/articles/10.1186/s12933-022-01579-5

People with Long Covid have a higher risk of developing further health problems from repeat infections access to AntiVirals needs ro be considered to shorten the intensity of viral exposure. Even a mild COVID-19 infection may increase your chances of developing type 2 diabetes.

https://www.health.com/condition/infectious-diseases/coronavirus/mild-covid-type-2-diabetes-study

6 Best Practice Responses

Access to Antiviral medication for people with post covid syndrome

It is paramount that support must be offered to people experiencing Long Covid as there are many areas that can impact people's lives, burdened with new barriers to education,homelessness, employment and increased risk of mental health.

Referral pathways need to happen from ER and Gp office

If a person presents to ER with post covid issues they need to be flagged to be followed up on and a plan put in place re long covid clinic and counselling

Responsible timely diagnosis from GP

Treatment options for chronic inflammation such as montelukast,steroids, ssri’s, and antihistamines for allergic responses

Post-Covid positive patients presenting with breathing issues could benefit from an arterial blood gas test. There seems to be a biological issue happening in oxygen transfer.

New tests used in ER such as cortisol levels and micro clotting/not just the D Dimer.

Mandatory training and resources for frontline workers and GPs to be able to respond to long COVID

Specialist long COVID clinics with up-to-date research for those with lasting complex problems

Disability supports for people whose problems become long-lasting

NO more gaslighting as an anxiety condition, anxiety can be a symptom it is not the diagnosis of the condtion.

Education and timely counselling

Tracking and surveillance of long COVID patients will prevent them from falling through the gap and will benefit research ourcomes. Learning about the condition in the long term, how it may add to or affect other health outcomes such as growth and development in children,fertility and cardiovascular disease is essential for the human race.