

SUBMISSION:

Inquiry into Long COVID & Repeated COVID Infections

Date: 9/9/2022

This submission directly addresses numerous Terms of Reference set out by the Committee overseeing the “Inquiry into Long COVID and Repeated COVID Infections”.

This submission includes attachments, links to online content and supporting documents.

This submission will also include suggestions & recommendations to the Committee with respect to best practice in the prevention of repeated COVID infections, and by extension prevention of Long COVID.

1. I submit to the Committee a real-world example of the negative health, social and economic impact on an individual FAMILY MEMBER who developed Long COVID – and the impact on them, their family and the broader community.

In early May 2022 a family member, who works in Aged Care in Regional Victoria, contracted COVID-19 following the rampant spread of COVID within the Aged Care facility in which they worked.

At the time of their infection, the majority of staff working in this particular Aged Care facility were NOT being provided fit-tested N95 Respirators/Masks by their employer – despite it being identified as the “gold standard” Face Mask which should be used to mitigate the spread of SARS-CoV-2 (which was recognised as an Airborne Pathogen by the World Health Organisation, the CDC in the United States and AHPPC in Australia, et al).

Following their COVID infection, my family member sought access to COVID Antivirals (such as Pfizer Paxlovid), but was deemed NOT ELIGIBLE under the PBS to access these Antivirals. They never received any antiviral treatment.

It is worth noting that Paxlovid was/is available to anyone over 18 years of age in countries such as Singapore, The United States of America (et al); and had my family member become infected with COVID in one of those countries they would have been able to access Paxlovid to aide their recovery – but not in Australia.

My family member’s COVID infection progressed to moderate severity, resulting in the need to take more than 10 business days of Sick Leave from their workplace. They regularly Rapid Tested and continued to test COVID POSITIVE at Day 8 & 9 after infection – despite mandatory COVID isolation being set at only 7-days by the Federal Government.

As a casually employed staff member in Aged Care they did not have access to any paid sick leave. As a casually employed staff member, they were unable to earn his usual income for over 2-weeks, and as a result needed to seek out support from friends and family to cover urgent expenses.

Following partial recovery from COVID, my family member returned to work but found themselves unable to work a full shift over the coming few days due to ongoing fatigue, headaches, coughing, breathing problems and difficulties focusing on tasks in their role in Aged Care. Following this, they sought additional advice & support from their General Practitioner, who essentially informed them that fully recovery could take weeks or months (or even years for some people) – but recommended additional rest.

Following GP advice, further time was taken off work – again with no income or paid sick leave my family member faced financial hardship.

After additional rest they returned to work, despite not feeling fully recovered – and this was primarily due to pressure and a lack of understanding from their employer, plus the pressure of staff to return due to chronic staff shortages in Aged Care.

Today, in early September 2022, my family member has been enduring Long COVID symptoms for over 4-months – with no end in sight.

Their Long COVID symptoms include ongoing fatigue, headaches, coughing, breathing problems, trouble sleeping, difficulties focusing on tasks due to fatigue and an ongoing feeling of ill health.

My family member has no access to any Long COVID specialised treatment clinics in their area in regional Victoria, with most being located in city/metropolitan areas.

My family member has repeatedly visited their GP, requesting further treatment for crippling symptoms. However they were told: “There’s no effective treatment for Long COVID and so many people are going through what you’re going through. This is going to keep happening to a lot of people unless something is done.”

As a result of my family member’s Long COVID they can no longer work the hours they did previously, nor offer to complete extra shifts in Aged Care that they were able to offer before. This has impacted their income and it has impacted their Employer as they have lost staffing capacity. In my family member’s workplace they advised that SEVEN staff members have since left their workplace, permanently, because of Long COVID illness – with many of these people under 45yo. It was relayed to me that sick leave requests had increased over 350% in their workplace in 2022 compared to 2019.

My family member’s quality of life has been very negatively impacted, with them spending most of their out-of-work time trying to recuperate and recovery from Long COVID symptoms that are exacerbated by the demands of their work. They spend additional time sleeping, resting, and can no longer participate in the social activities that they did previously due to an urgent need to conserve energy wherever possible due to their Long COVID symptoms. The situation is also impacting their mental health and income.

2. I submit to the Committee a real-world example of the negative health, social and economic impact on an individual who developed long COVID, their family and the broader community.

In June 2020, before any Vaccines for SARS-CoV-2/COVID were available, a close friend of mine contracted COVID-19. His name is Mr Jayson Cuming (Aged 35-yo). The Australian Broadcasting Corp. (ABC) publicly published a story about Mr Cuming that expands on what I'm about to write, below, and I include this as an attachment & link.

Jayson and his partner's income has been cut in half by Jayson's condition, causing them financial and emotional stress. Whilst Australians with disability or chronic illnesses who cannot work can apply for support via the National Disability Insurance Scheme (NDIS) or Disability Support Pension (DSP), those with long COVID, like many others with invisible disabilities, struggle to prove they fit the detailed criteria. He receives limited support, and there are no medical treatments available at present to eliminate his Long COVID symptoms.

I attached a copy of Jayson's story as published by the ABC, which can also be found online here:

<https://www.abc.net.au/news/2022-07-12/long-covid-limbo-disability-support/101170148>

The previous two pages outline the situation and plight of just two individuals in my immediate circle of family and friends. In actual fact, there are a dozen more colleagues, friends and family members who I know that are experiencing and dealing with Long COVID to varying degrees. Some have ongoing headaches, but are otherwise functional whilst others have fatigue to varying degrees. Some have lost their usual sense of smell and taste on an ongoing basis.

Many are reluctant to seek help because:

- (i) they know the Health System is overwhelmed;
- (ii) there are limited Long COVID clinics and/or openings available to clinics, and;
- (iii) there is a feeling of hopelessness because most are aware there are no effective treatments at present, and so many are resigned that they may never be themselves again.
- (iv) The State and Federal Governments are minimising the impact of COVID and Long COVID by “gaslighting” the population with the false narrative that COVID is “mild” and that the “Pandemic is over” – despite hundreds of people dying every few days from COVID in Australian Hospitals.

It is clear to many that COVID and Long COVID is creating mass disability in Australia.

COVID and Long COVID is negatively impacting our economy. It is reducing income and quality of life for those impacted, and placing an excessive burden on some families and the workplaces of those afflicted.

Australia can and should take immediate steps to reduce the spread of COVID, and these steps need not negatively impact individuals or the economy.

We can live better with COVID-19 and reduce the burden of infection, illness and death and the effect on workplaces, schools and daily life. We have achieved elimination of measles and polio through vaccination in Australia, but still have occasional outbreaks of measles.

It may be possible to do the same for SARS-CoV-2 with high rates of boosters and/or vaccinations matched to variants, supported by other measures such as safe indoor air, masks and ventilation. The economy will fare better when COVID-19 is well controlled.

I will tender some recommendations, over page, as to how Australia can reduce COVID, reduce LONG COVID and not negatively impact the function of our society.

CONCLUSION & RECOMMENDATIONS

COVID (SARS-CoV-2) is AIRBORNE. There is no question about this fact.

Airborne transmission of COVID-19 via aerosols is the main route of infection, far outweighing infection from surfaces. As such, clean air and Masks are going to be the main mitigation measures that will be effective in reducing spread of COVID.

Less COVID = Less Long COVID = Less Impact on People & Economy.

I tender the following recommendations for reducing COVID transmission and reducing cases of Long COVID in Australia, as well as impact on businesses:

a) **VENTILATION, CLEAN AIR, SAFE AIR, HEPA FILTERS.**

Because the primary vector for COVID infection is via the breathing of aerosolised virus, it is imperative that we pursue an approach that ensures that the air we breathe is safe, in order to reduce infections.

SARS-CoV-2 is airborne and therefore floats/hovers in indoor air very easily for long periods. As such, indoor environments with poor ventilation are the greatest risk.

Safe Indoor Air (via improved National Ventilation Standards) is one of several critical steps that must be taken for every indoor environment, whether it be for schools, workplaces or even homes.

There is a substantial body of scientific evidence on Safe Indoor Air (Ventilation) and the risk of airborne infections, generated by engineering, science and medical researchers - but much of it not known to medical experts.

Involving engineering experts in ventilation solutions for Australia is essential, as is the modernisation of our Building Standards. I would highlight work by PROFESSOR JASON MONTY who is Head of Mechanical Engineering at the University of Melbourne, as well as many others from Universities across Australia.

References:

REDUCING COVID-19 TRANSMISSION WITHOUT COSTING THE EARTH
<https://pursuit.unimelb.edu.au/articles/reducing-covid-19-transmission-without-costing-the-earth>

VICTORIAN GOVERNMENT: VENTILATION
How ventilation helps you lower the spread of COVID-19
<https://www.coronavirus.vic.gov.au/ventilation>

b) **VACCINE PLUS STRATEGY – Masks, Education, Ventilation, Testing etc.**

In January 2022, over 100 public health experts, clinicians, and scientists signed an open letter urgently calling for the World Health Organization (WHO) to adopt something called a “Vaccines-Plus” strategy in the fight against COVID-19.

Ref: <https://www.bmj.com/content/376/bmj.o1>

This type of strategy utilizes a combination of Vaccines, Education, Masks, Testing, Tracing and other non-pharmaceutical interventions to put downward pressure on COVID infections and reduce caseloads hitting Hospitals.

The global strategy involves acknowledging the SARS-CoV-2 virus is airborne, promoting the use of high-quality face masks, effective ventilation, establishing consistent safety measures, and providing support to achieve global vaccine equity.

The “Vaccines-Plus” strategy is robust medical science – and it is science that Governments around the world need to adopt urgently to reduce ongoing mass disability. **COVID Vaccines DO NOT provide sterilising immunity – as such people still get infected with COVID despite vaccination. Vaccines DO reduce illness severity in most cases - but they DO NOT prevent Long COVID, though they minimise the risk of it.**

The specialists who wrote to the WHO warn that vaccines alone will not get us out of the Pandemic. They are absolutely correct in this assertion.

Many countries have strong education campaigns that outline how N95 Masks prevent spread of illnesses such as Flu, COVID, RSV etc. In many Asian countries, the wearing of Face Masks indoors is mandated, resulting in obvious decreases in the spread of COVID. Australia does not pursue this. It should.

Many countries hand out FREE N95 Face Masks. The United States of America is one such country where you can walk in to almost any Pharmacy and obtain a FREE N95 Masks. Australia does not offer this. It should.

Testing for COVID should be a common occurrence, but due to the cost of COVID Rapid Antigen Tests many people don't test when they should. Employers also don't test when they should and thus cases are missed in the workplace and COVID increasingly spreads.

Australia needs to recommend and invest in the most sensitive and accurate rapid testing, and remove poor quality Rapid Tests from the shelves of Pharmacies. We need to encourage a culture of regular testing in high risk environments and in workplaces.

c) **WORKING FROM HOME**

“Working From Home” (WFH) is one of the cheapest and easiest ways to reduce COVID spread, whilst not impacting the operations of businesses or economic productivity.

In fact, worker performance can increase up to 13% percent by working from home.

A study by Stanford University of 16,000 workers over 9 months found that working from home increased productivity by at least 13%.

Ref: <https://www.gsb.stanford.edu/faculty-research/working-papers/does-working-home-work-evidence-chinese-experiment>

Imagine a 13% boost to productivity across all sectors which can leverage WFH, and what positive economic impact it can have for Australia.

Other benefits to Australia with increased WFH adoption include:

- Better work-life balance
- Improved productivity
- Increased job satisfaction
- Increased economic output
- Reduced use of roads & public transport, resulting in environmental gains
- Reduced cost to businesses in that office space can be reduced, and equipment/power costs can be shared with Employees.

Less COVID = Less Long COVID = Healthier Workforce = Stronger Economy

IN CLOSING:

It's an absolute false-economy to allow COVID to continue to run rampant in our society. Less illness results in greater productivity for our economy, less demand for Hospital and healthcare services, and less Long COVID – which benefits Australia.

Improved ventilation and indoor N95 Mask wearing can reduce Flu, RSV, COVID and other respiratory illnesses. The gains to society & economy from less illness are immense; and the Australian Government has a role to play in changing the narrative and attitudes in society so we PROTECT the most vulnerable amongst us (i.e.: the elderly, immunocompromised, the disabled) rather than throwing them under the bus as has occurred since the end of 2021 with the rampant spread of COVID.

Several attachments are over page.

Thank you for reading this submission.

Long-COVID sufferers unable to access disability payments say they need more support

By the Specialist Reporting Team's [Evan Young](#)

Posted Tue 12 Jul 2022 at 4:58am, updated Tue 12 Jul 2022 at 12:52pm



Jayson Cuming says he feels forgotten by the government (ABC News: Patrick Stone)

Jayson Cuming feels like he is living in limbo.

Mr Cuming contracted COVID-19 in June 2020 — well before he had a chance to be vaccinated — and two years on, still wakes every day to severe exhaustion, pain and brain fog.

The 35-year-old spends his days moving between bed and couch. Occasionally, if he can manage it, he will get up to walk around his rental house in Melbourne's north.

Life has crashed to a halt — and there is no indication it will start up again any time soon.

"Most days, it's just a wait and see if there's any new medical advice coming out for possible treatments or ... hoping the government does something that might help," he said.

Key points:

- There is limited immediate support or relief for long-COVID sufferers as they wait for research to progress
- Some are facing financial stress but are unable to access disability support
- Experts say further waves of COVID-19 are likely to come and exacerbate the impacts of long COVID



Jayson Cuming says "nothing has changed" since he first developed long COVID two years ago (*ABC News: Patrick Stone*)

Just speaking on the phone leaves Mr Cuming breathless and sometimes he will sit dripping wet in a dressing gown after a shower, too exhausted to dry himself.

He has chosen not to shave his thick beard for over a year, allowing him to spend the little energy he does have on other "more important" activities, such as making lunch.

Not knowing what his future holds is "heartbreaking".

"This happened over two years ago, and nothing has changed," he said.

"If anything, the government has made it easier for people to get COVID now."

Do you have a story to share? Email Specialist.Team@abc.net.au.

While many studies on long COVID are happening across the world, researchers expect it to take years to unlock the mysteries of the condition.

In the meantime, sufferers with severe, longer-term symptoms, like Jayson, have little relief available to them and are struggling to access disability support.

'Incredibly disabling'

Figuring out the exact number of people in Australia with long COVID is difficult as [there is no official tally](#), nor is there a universal definition of it.

The Australian government defines long COVID as symptoms that persist for more than four weeks after an initial COVID-19 infection, which cannot be explained by other factors.

Research published last month suggested women, along with people who are older and had poor health pre-pandemic, [may be more likely to report long COVID symptoms](#).

Many long COVID patients improve over time — but many do not.

A study last year found 5 per cent of people who got COVID-19 during New South Wales' first wave in 2020 [were still experiencing symptoms three months later](#).

Australia has officially recorded more than 8 million COVID-19 infections — so even if just 5 per cent of those become long COVID, that could still be hundreds of thousands of cases.

Similarly, it is unknown exactly how many people have severe, lasting long COVID, which has been likened to another mysterious, multi-system condition, [myalgic encephalomyelitis/chronic fatigue syndrome](#).

But what is known, is that those with severe forms of long COVID struggle to perform basic daily activities.



The AMA's Chris Moy says a lack of diagnostic criteria has hampered long COVID patients in getting support *(ABC News: Claire Campbell)*

"Long COVID is incredibly disabling when people have severe symptoms," Australian Medical Association vice-president Chris Moy said.

"It's very multi-system and it's very hard to know what percentage [of cases] are really severe at the moment. Part of the reason why we may have patients in limbo would be to some degree the lack of clarity about diagnosis [of long COVID]."

Too unwell to work, 'not unwell enough' for disability support

Mr Cuming wants a number of more immediate actions taken to support people with long COVID while the science catches up, including more training for GPs.

But he said the number one thing that would help him live more comfortably would be financial support.

Mr Cuming attempted to start work again in 2021 before his symptoms got even worse, and he's now fully financially dependent on his wife.



Jayson Cuming says it's "heartbreaking" not knowing what his future holds (ABC News: Patrick Stone)

The couple's income has been cut in half by Jayson's condition, causing financial and emotional stress.

While Australians with disability or chronic illnesses who cannot work can apply for support via the National Disability Insurance Scheme (NDIS) or Disability Support Pension (DSP), those with long COVID, like many others with invisible disabilities, [struggle to prove they fit the detailed criteria](#).

NDIS participants need to prove they have a disability caused by an impairment, that the impairment is likely to be permanent, and that the impairment reduces their functional capacity to perform everyday tasks, and work, study or take part in social life.

When it comes to the DSP, an applicant's condition needs to be diagnosed, treated and stabilised.

Mr Cuming, like others who have contacted the ABC, has not been able to prove he fits either criteria.

He said extra financial support would help with medical costs, bills, rent, hiring a cleaner and paying for a wheelchair.

While he was too unwell to work, he said it felt like he was not "unwell enough" in the eyes of the government to access disability support.

"At times it makes it feel like the government thinks I'm either lying or exaggerating what I'm going through ... or they consider the illness not really worth their money or time," he said.

"It just makes me feel forgotten."

'No real difference yet'

While research is underway on possible treatments, such as anti-inflammatories or antivirals, there is little currently available that can help patients return to pre-COVID capacity.

[Long COVID clinics](#) have been popping up across the country to help patients manage their symptoms, but most are in metropolitan areas and demand is much higher than the places available.

"We've been blown away by the amount of people that have sought us out," said Anthony Byrne, co-lead of the long COVID clinic at Sydney's St Vincent's Hospital.

"But there are limitations – there's only a certain number of patients we can see and there are waiting times of weeks and months."

Mr Cuming has been attending a public long COVID recovery unit in Melbourne for the past few months but has seen "no real difference" yet.

Soon after joining, he was prescribed light, seated exercise, which he said made his condition worse.

Professor Byrne said it was important long COVID information and support was also available outside of the clinics.

"We shouldn't be doing things in silos," he said.

'A bunch of waves' coming

COVID-19 is showing no signs of dissipating — Australia is on the verge of [another Omicron wave](#), with [Queensland](#) and [NSW particularly on high alert](#).

Dr Moy said he expected the prevalence and impact of long COVID to continue to balloon as time goes on.

"It's worrying," he said.

Some researchers and disability advocates have termed the pandemic a "[mass disabling event](#)" and warned long COVID could cause significant disruptions to the workforce and demand for support to skyrocket.

"We're on the beach and there's a bunch of waves coming, not just one. COVID is not going away in the foreseeable future," Professor Byrne said.

"Most people will get over their COVID and not have long COVID. But there is a percentage that will ... so we need to be thinking about resourcing."



Jayson Cuming is calling for greater financial assistance (ABC News: Patrick Stone)

Professor Byrne said preventing further acute COVID-19 infections would go a long way to keeping a handle on long COVID.

"If we can limit severe disease, then we will limit long COVID," he said.

New Health Minister Mark Butler did not respond to questions from the ABC.

Mr Butler acknowledged [last month](#) that long COVID would likely be a "major health challenge for the coming couple of years at least".

"I'm very keen to talk with clinicians, with researchers, have a look at the international research as well, and start to make sure that our health system is prepared for what will be a very big wave of people experiencing these very long symptoms," he told the Seven Network.

But that's of little comfort for Mr Cuming, whose life is on hold as he attempts to navigate a system not ready to help him yet.

"This is not something you would wish on anyone ever," he said.



Mutations in the COVID-19 virus continue to pose a risk

What you need to know about coronavirus:

- [The symptoms](#)
- [The number of cases in Australia](#)
- [Tracking Australia's vaccine rollout](#)
- [Which masks are best and is it OK to reuse them?](#)