# Inquiry into LONG COVID AND REPEATED COVID INFECTIONS PARLIAMENT OF AUSTRALIA

<u>Inquiry into Long COVID and Repeated COVID Infections – Parliament of Australia</u>

The Committee will inquiry into and report on Long COVID and Repeated COVID Infections. Submissions for this inquiry will close on **18 November 2022**.

Submission by Professor Kerryn Phelps AM Conjoint Professor, NICM Health Research Institute Executive Member, OzSAGE

CHAIR: Dr Mike Freelander

### TERMS OF REFERENCE

The House of Representatives Standing Committee on Health, Aged Care and Sport will inquire into and report on:

- 1. The patient experience in Australia of long COVID and/or repeated COVID infections, particularly diagnosis and treatment;
- 2. The experience of healthcare services providers supporting patients with long COVID and/or repeated COVID infections;
- 3. Research into the potential and known effects, causes, risk factors, prevalence, management, and treatment of long COVID and/or repeated COVID infections in Australia;
- 4. The health, social, educational and economic impacts in Australia on individuals who develop long COVID and/or have repeated COVID infections, their families, and the broader community, including for groups that face a greater risk of serious illness due to factors such as age, existing health conditions, disability and background;
- 5. The impact of long COVID and/or repeated COVID infections on Australia's overall health system, particularly in relation to deferred treatment, reduced health screening, postponed elective surgery, and increased risk of various conditions including cardiovascular, neurological and immunological conditions in the general population; and
- 6. Best practice responses regarding the prevention, diagnosis and treatment of long COVID and/or repeated COVID infections, both in Australia and internationally.

I am a general practitioner with over forty years of clinical experience.

I have been responsible for overseeing COVID safety protocols in two general practice clinics.

I have been a health communicator in mainstream media for 37 years.

I have also been a President of the <u>Australian Medical Association</u> at State and Federal levels, and past President of Australasian Integrative Medicine Association.

I am a former MP for Wentworth and a former City of Sydney Deputy Lord Mayor and councillor.

I am an Executive Member of the expert group OzSAGE <a href="https://ozsage.org/">https://ozsage.org/</a> and a Conjoint Professor at the NICM Health Research Institute, Western Sydney University

I am making this submission in my private capacity out of concern for the direction that has been taken by Australia's public health system in the response to the COVID19 pandemic, the implications of Long COVID and COVID19 reinfection, particularly for medically vulnerable people, the community and the health system, and the way that the risks and preventive measures have been communicated.

Long COVID is a multi-system disease which may occur after a relatively mild initial infection with the SARS CoV2 virus. If someone is unlucky enough to develop Long COVID or post-COVID syndrome after the initial COVID infection it can linger for months or longer. We don't yet know how long the condition may persist, or whether in some people the impairment might be permanent. It can affect any age: children, young adults, the elderly.

Official estimates of SARS CoV2 infection numbers in Australia are over ten million cases, however this is likely to be an underestimate as many cases are now going unreported. <sup>i</sup> To date there have been over 15700 reported deaths.

It is a death toll that in 2022 has been ten times greater in magnitude than the road toll. To reduce the road toll, we build safer roads, insist on drivers being licenced, enforce speed limits and road rules, mandate wearing of seat belts and prohibit driving while under the influence of drugs or alcohol.

To reduce cardiovascular disease, we have introduced plain packaging and package warnings on cigarettes, invested in public health campaigns, encouraged people to exercise, banned smoking in indoor environments where passive smoking is likely to be a danger to others. The long-term cardiovascular effects of COVID19 are unravelling those decades of public health efforts.

Yet there are currently few public health measures in place and little effective public heath communication to prevent transmission of SARS CoV2 or the potential seriousness of its consequences.

The World Health Organisation has estimated that between 10 and 20 percent of COVID 19 survivors will be left with lasting symptoms such as extreme exhaustion, cognitive impairment, breathlessness, palpitations and more<sup>ii</sup>. Current research suggested approximately one in eight people who get COVID19 go on to develop Long COVID, post-infection symptoms lasting for at least a month.<sup>iii</sup>

It may be seen referred to as post-COVID syndrome where symptoms persist beyond twelve weeks<sup>iv</sup>. The terms *long COVID* and *post COVID syndrome* are sometimes used interchangeably.

A recent study published in JAMA<sup>v</sup> found that approximately 10 percent of individuals with acute COVID19 infection still had symptoms after one year of follow-up, highlighting this as a current and future "public health concern".

Dr Anthony Fauci labelled Long COVID an "insidious public health emergency for millions of people"vi. I tend to agree.

We have no way of knowing how long this pandemic will last, or the long-term impact of infection and reinfection, but the early signs are disturbing. The science demonstrates that reinfection worsens Long COVID, even in people who have been vaccinated.

Meanwhile more and more people become vulnerable as they develop Long COVID from their first, second or subsequent reinfection. We are facing a catastrophic toll of disability due to Long COVID with broad implications for families, community, the health system, the workforce, the economy and all levels of government.

Despite knowing about Long COVID for over two years now, Australia does not have reliable data on the numbers of people affected, or how they are impacted. There is no apparent comprehensive plan for its management.

I welcome this inquiry as a step in developing such a plan.

### RECOGNISING LONG COVID

There are more than two hundred symptoms of Long COVID now recognised<sup>vii</sup>, and they relate to effects of the virus on the brain, lungs, heart and blood vessels, the immune system and other organs or body systems or a combination.

The most common symptoms are shortness of breath, fatigue, and trouble thinking clearly or concentrating (also called brain fog.)

People also complain of loss of taste or smell or an altered sense of taste and smell, chest pain, poor exercise tolerance, insomnia, anxiety, impaired vision, depression, and mood swings, digestive problems, joint and muscle pains, headaches, and other neurological symptoms. There may be impaired immunity<sup>viii</sup> and signs of premature ageing<sup>ix</sup>. Some develop a condition called dysautonomia with symptoms that include rapid or pounding heartbeat, blood pressure surges, or blood pressure drops with dizziness when they stand up and unstable body temperature.<sup>x</sup>

There are reports of a significant increase in diabetes diagnosis<sup>xi</sup> after a COVID infection<sup>xii</sup>, as well as a doubling of the risk of heart attack or stroke in the year after the infection. There are also reports of cardiac arrests and sudden death in young adults.

People suffering the symptoms of Long COVID may present to an emergency department or to their GP complaining of chest pain or breathlessness, extreme fatigue, nerve pain or cognitive difficulties. They may have the standard tests like Xrays and ECGs and CT scans and MRIs and blood tests which come back normal, so they are told there is "nothing to find".

The problem is that we don't have specific tests, partly because we do not yet fully understand the underlying pathophysiology(-ies) of Long COVID.

### WHY DOES IT HAPPEN?

So why does it happen? There are theories that the virus persists in the body, or the virus triggers an immune dysfunction, reactivation of other latent viruses, vascular endothelial injury or persistent inflammatory response. The truth is, the causes are likely to be multifactorial and we just don't have the answers yet.

#### HOW BIG A PROBLEM IS LONG COVID?

The other thing we do not know is how many Australians are currently suffering the effects of Long COVID, how it is impacting them or how we might project future disability with existing cases of Long COVID and additional future COVID infections and reinfections. Part of the problem with assessing the prevalence of Long COVID is an absence of consistent

terminology or specific diagnostic tests for the condition.

Confirming the initial COVID infection is another growing challenge.

People with initially mild symptoms from their acute infection may not have confirmed that they had COVID infection at all, so this becomes a barrier to diagnosis of Long COVID. It is difficult to make a diagnosis of Long COVID on clinical history if you do not have confirmation of whether or when a patient had an initial COVID infection.

PCR testing has been wound back, and rapid antigen testing expensive for many individuals and families, or unreliable, and no longer required to be reported.

With reduced access to PCR testing and the abandonment of mandatory reporting of rapid antigen testing, accurate data on COVID infections will be even less reliable, and collection of data on long COVID even more challenging.

The other barrier to diagnosis of Long COVID is the current lack of any definitive diagnostic tests.

This is particularly problematic for people whose post-COVID symptoms are not recognised as being related to prior COVID infection, or where the onset of symptoms is delayed so that a temporal and therefore causal association is more difficult to determine.

### WHAT ABOUT TREATMENTS?

Of course, if a person suspects they have a COVID infection, they will ideally make sure they confirm it and document the result.

If they develop persistent symptoms, they will present to their doctor(s) for medical assessment and investigations to rule out other causes for these symptoms.

Health practitioners may or may not recognise Long COVID. It becomes a diagnosis of exclusion, or a diagnosis of assumption.

Even if their doctors do recognise the condition as Long COVID, they may only be able to give general advice about pacing of activity, rehabilitation and mental health. They may be offered symptomatic management such as pain relief.

But so far there is no current consensus on specific treatment protocols that have been developed because we just do not yet fully understand the mechanisms that are causing Long COVID.

There are long waiting times for the few established Long COVID clinics and treatment at this stage is very much trial-and-error.

Patients are relying on patient support groups for advice on what supplements and other interventions might have anecdotally shown benefits for others.

General practitioners diagnose and manage most chronic disease in the community, and GPs who are recognising Long COVID are relying on small clinical trials and anecdotal reports from colleagues and patients about what is likely to help patients, and recommending a range of pharmaceutical interventions and supplements to try to help patients to manage their symptoms.

## MIXED MESSAGES, MISSTEPS AND MISINFORMATION

Effective health communication from trusted sources is an indispensable element of public health.

Very early in the pandemic, I was asked by media to provide advice to try to make sense of the confusion and to counter some of the misinformation that was being promulgated.

Examples of misinformation in the early days, and some still in circulation include:

"COVID is not airborne"xiii. Wrong.

"Wash your hands to prevent transmission". Ignored airborne transmission.

"Masks don't work, in fact they might increase your risk"xiv. Wrong.

"Children under 12 have been proven not to be carriers or transmitters of the disease"xv Wrong.

"It is necessary and inevitable for everyone to get COVID"xvi. No it isn't.

"Herd immunity from mass infection is a good idea."xvii No it isn't.

"It's just a cold". No it is not.

"COVID will evolve to be milder". There is no evidence to support this.

"COVID is not as bad as the flu". Yes it is.

"At least I got it over and done with". No you haven't.

"Children are sicker this year because of immunity debt"xviii. Immunity debt is a made-up term to excuse exposing children to a dangerous virus.

"The pandemic will end in 2022"xix. Unlikely.

Daily press conferences by public health officials emphasised that of the people who died, many had "underlying health issues", as if that made the premature deaths of those people any less tragic.

A forum of medical practitioners was told by the Secretary of the Department of Health in late 2021 that they had "stopped trying to prevent transmission". So removing all public health safeguards was a conscious and deliberate decision by health advisors to government.

Given how little we knew about the potential long-term consequences of COVID19 illness, I was alarmed. We certainly already knew about the potential for Long COVID.

I perceived this as a disregard for the precautionary principle and the potential impact of the virus on the health and quality of life of many individuals, particularly the elderly, the disabled, children, medically vulnerable and indigenous Australians.

I joined OzSAGE <a href="https://ozsage.org/">https://ozsage.org/</a> in late 2021 when it was formed by Professor Raina MacIntyre. This group has been instrumental in providing expert apolitical consensus on current issues related to COVID19. The group has provided much needed professional and intellectual support for doctors and other professionals who are trying to work our way through the morass of misinformation and false reassurance.

Many of my colleagues warned about an over reliance on a "vaccines-only strategy" when it became apparent that high levels of vaccinations were not going to be sufficient to contain the pandemic or prevent long-term damage.

I was also deeply concerned about the as-yet-unknown future impact on children exposed to repeated infection with a neurotropic virus in their early developmental years.

Many of my colleagues and I tried to warn that children would be at risk and that opening schools before mitigation plans such as ventilation improvements in classrooms were in place was an unacceptable risk to teachers and students.

Masks act as a barrier and reduce the aerosol spread and inhaled viral load of SARS CoV2, and hence the severity of COVID19 if exposed. Some of my colleagues and I tried to encourage to use of face masks from the early days of the pandemic, but there was a strange ideological rather than a reasoned evidence-based resistance. Unfortunately, that resistance came from people in positions of greatest influence over government decisions, despite the research findings<sup>xx</sup> or indeed basic logic.

Workers have been forced back into unsafe work environments or risk losing their jobs if they want to work from home to protect themselves or others in their household. Mask requirements in airports were removed, then planes and other forms of public transport.

People have been reporting on social media that they have been mocked or ridiculed for wearing a mask in public.

The mandatory isolation period for infectious people was reduced from seven days to five days, and then completely removed. The five-day isolation period was inadequate in any event, as over half of people will still be infectious at five days.

When governments removed all isolation requirements on 14 October 2022, in health communication terms it sent a message that it was acceptable to be out and about while infectious, at school, at work, in public transport, in theatres and restaurants, in sports teams, in supermarkets.

This sent a signal to the public that either the risk was so minimal as to not require safeguards, or that the government's intention was to allow or indeed encourage the COVID19 virus to spread through the community.

Without government funded support to isolate, people with suspected or confirmed COVID infection may feel a financial pressure to return to work despite still being infectious.

Referring to the pandemic in the past tense gave many people the impression that it was over, and they could go back to "normal" life. "Urgency of normal" was a campaign driven by short term thinking.

Patients I speak to still have the mistaken impression that currently available COVID vaccines will stop them getting COVID and that is all they need to do. This over-reliance on vaccines has come from a misconception that "effective" means "you will not get COVID", on a background of generations of experience with vaccines which have been able to practically eliminate or vastly reduce the incidence of most preventable childhood diseases like measles, rubella, pertussis and chickenpox. This is not the case with current COVID vaccines

Most people have no idea that they can still become very sick with COVID, even if "up to date" with booster vaccines. Overall, studies demonstrate that vaccine effectiveness wanes over about four to six months after completing the two-dose primary schedule and subsequent booster doses.

Most have no idea about the risk or implications of long COVID. I still hear people expressing relief that they got COVID, not realising that they can still be susceptible to reinfection, and to the risk of developing Long COVID if they are reinfected.

That awareness is starting to emerge despite the lack of a government funded public health information to warn of that risk.

Framing COVID19 as "unexceptional" is in my view dangerous and misleading. This is an exceptional virus and it continues to circulate in the Australian community. I will leave it to the virologists to explain why it is exceptional from a virology point of view, but emerging information on long COVID tells us that we should be proceeding with far greater caution, as this virus is starting to demonstrate the extent of the risk of long-term effects on the body especially the immune system, lungs, brain, and cardiovascular system.

The absence of an honest, effective and trustworthy public health campaign has left a space for misinformation fuelled by vested interests and has generated a lot of confusion, aided and abetted by many of the mainstream media.

As a result, many people including health professionals no longer trust government sources of public health information.

Some health "commentators" who have repeatedly been wrong about facts and predictions continue to be given a platform in media because they are saying what the media want people to hear, not what the public needs to know if they are to avoid the long-term consequences of repeated COVID infection.

## THE IMPACT OF ABANDONING SAFEGUARDS

PCR testing has become less accessible, and few people are routinely testing with rapid antigen tests when they have symptoms suggestive of COVID infection. These results are not required to be reported, and as mandatory isolation of people in their infectious period has been lifted, infectious people are going about their usual business while infecting others. Without a change in the government's current approach, the number of people being infected and reinfected, and therefore developing Long COVID will continue to rise for as long as the virus continues to circulate, and new variants continue to emerge.

### WORKPLACE HEALTH AND SAFETY

LONG COVID is currently affecting the Australian workforce. It will become an increasingly significant Workplace Health and Safety issue for several reasons.

The symptoms of Long COVID, including fatigue and cognitive impairment make it difficult for workers to deliver the same productivity as when they were well. People with Long COVID say they are so exhausted and unwell that they just can't concentrate or do what they used to be able to do, the sports they love, even activities of daily living become difficult.

Another crucial issue is that workers should be able to expect that they will be safe at work. The abandonment of almost all public health safeguards including mandated masks on public transport and lack of air quality initiatives in shared indoor workplaces increases the risk of work-related COVID infection and Long COVID. Nonetheless, with widespread

community transmission, it will be extremely difficult for a worker to prove that they were infected in the workplace, so the usual compensation arrangements for a workplace injury will be difficult to obtain.

Along with lost productivity, there will be shortages in key sectors.

Several sectors have borne the brunt of exposure risk. With exposure risk comes increased infection numbers, increased reinfection and increased long COVID. It is likely that childcare, healthcare, education and other essential services will increasingly face significant worker shortages. There are already reports of workers in these sectors reconsidering their career choices.\*\*xii, xxiii

I personally know medical colleagues who have had to cease practice or substantially reduce their hours because of concern about being exposed to the infection, or the effects of Long COVID.

Most chronic disease is diagnosed and managed in general practice, yet we have a dwindling number of medical graduates choosing general practice as a speciality. With infectious people no longer being required to test or isolate, general practitioners and their staff and other patients are at increased risk of exposure and therefore infection and reinfection from patients. This will further strain the GP workforce.

### "MEDICALLY VULNERABLE"

"Learning to live with the virus" is some dystopian term that has been generated to deceive the population into carrying on as usual. Until they can't.

Medically vulnerable people will be further disenfranchised and marginalised, forced to live in relative isolation.

As more people become infected and reinfected, there will be more cases of Long COVID leading to widespread long-term disability and more medically vulnerable people who should not be forced to take an increased risk of reinfection because public health has failed them.

As always, the major burden of disease will fall on disadvantaged persons, including the elderly, chronically ill, poor, people living with disability or caring for a person with disability, and First Nations people, groups we know already have worse health outcomes than the rest of the population.

### ADVERSE EVENTS FOLOWING IMMUNISATION

COVID19 vaccination has been central to Australia's response to the COVID pandemic with the stated aim of reducing the risk of severe disease, hospitalisations and death. The initial urgency of the vaccine rollout was considered necessary to limit the numbers of deaths and hospitalisations that were being experienced in other countries.

A subset of medically vulnerable people includes those who have suffered adverse events following immunisation (AEFI) with COVID vaccines.

I stress at the outset that these people are NOT ANTIVAXXERS.

They clearly all presented for immunisation as recommended or because their occupation required it, and would have continued to have doses of vaccine if they have not been so significantly affected by the vaccine they willingly had.

# Why is AEFI or "VACCINE INJURY" relevant to an inquiry into Long COVID and Reinfection? There are several reasons.

People who have suffered significant damage to their health from a COVID vaccine are unlikely to be able to safely have further vaccines or booster doses with current vaccines. If vaccination does confer some protection against Long COVID and reinfection, people who are unable to have further vaccinations or boosters become more vulnerable to Long COVID and to the consequences of reinfection including severe illness, complications of COVID, hospitalisation and death.

The organisation of which I am a member, OzSAGE, produced a position statement IMPORTANCE OF COVID-19 VACCINATION & DEVELOPMENT OF BETTER SYSTEMS FOR MANAGEMENT OF UNCOMMON SUBSEQUENT ADVERSE EVENTS.\*\*Xiii

This important document outlines the main issues and areas of the health system in need of attention, including reporting of uncommon adverse events following immunisation, follow up of reports of AEFIs, confusion about the safety of future vaccines for people affected, recognition of the impact of vaccine injury on individuals affected, the importance of research and the need for treatment protocols to be developed. It was the result of eight months of discussions and consultation.

The OzSAGE document outlines the scope but not the scale of the problem because we do not know the scale of the problem. This is partly because of under-reporting and under-recognition.

This is an issue that I have witnessed first-hand with my wife who suffered a severe neurological reaction to her first Pfizer vaccine within minutes, including burning face and gums, paraesethesiae, and numb hands and feet, while under observation by myself, another doctor and a registered nurse at the time of immunisation. I continue to observe the devastating effects a year and a half later with the addition of fatigue and additional neurological symptoms including nerve pains, altered sense of smell, visual disturbance and musculoskeletal inflammation. The diagnosis and causation has been confirmed by several specialists who have told me that they have seen "a lot" of patients in a similar situation. Jackie asked me to include her story to raise awareness for others.

We did a lot of homework before having the vaccine, particularly about choice of vaccine at the time. In asking about adverse side effects, we were told that "the worst thing that could happen would be anaphylaxis" and that severe reactions such as myocarditis and pericarditis were "rare".

I was also diagnosed with a vaccine injury from my second dose of Pfizer vaccine in July 2021, with the diagnosis and causation confirmed by specialist colleagues. I have had CT pulmonary angiogram, ECG, blood tests, cardiac echogram, transthoracic cardiac stress echo, Holter monitor, blood pressure monitoring and autonomic testing.

In my case the injury resulted in dysautonomia with intermittent fevers and cardiovascular implications including breathlessness, inappropriate sinus tachycardia and blood pressure fluctuations.

These reactions were reported to the TGA at the time, but never followed up.

I have spoken with other doctors who have themselves experienced a serious and persistent adverse event including cardiological, rheumatological, autoimmune reactions and neurological consequences. Patients and other members of the community have told me about their stories.

They have had to search for answers, find GPs and specialists who are interested and able to help them, spend large amounts of money on medical investigations, isolate from friends and family, reduce work hours, lose work if they are required to attend in person and avoid social and cultural events.

Within this group of vaccine injured individuals, there is a diminishing cohort of people who have symptoms following immunisation, many of which are similar to Long COVID (such as fatigue and brain fog), but who have not had a COVID infection. These people would be an important subset or control group for studies looking into the pathophysiology, causes of and treatments for Long COVID.

It is possible that there is at least some shared pathophysiology between vaccine injury and Long COVID, possibly due to the effects of spike protein.

A group of **Greek scientists** publish a good summary on the "spike", which points to a possible mechanism of causality. xxiv

Vaccine injury is a subject that few in the medical profession have wanted to talk about. Regulators of the medical profession have censored public discussion about adverse events following immunisation, with threats to doctors not to make any public statements about anything that "might undermine the government's vaccine rollout" or risk suspension or loss of their registration.\*\*\*

"Any promotion of anti-vaccination statements or health advice which contradicts the best available scientific evidence **or** seeks to actively undermine the national immunisation campaign (including via social media) is not supported by National Boards and may be in breach of the codes of conduct and subject to investigation and possible regulatory action." -Ahpra

In trying to convince people in positions of influence to pay attention to the risks of Long COVID and reinfection for people with vaccine injury, I have personally been met with obstruction and resistance to openly discuss this issue. There has been a delay in recognition of vaccine injury, partly because of under-reporting, concerns about vaccine hesitancy in the context of managing a global pandemic, and needing to find the balance between risks and benefits on a population level.

Reactions were said to be "rare" without data to confirm how common or otherwise these reactions were. In general practice I was seeing cases, which meant other GPs and specialists were seeing cases too. Without diagnostic tests, we have to rely largely on clinical history.

Germany's Ministry for Health (Bundesgesundheitsministerium) has referred to "Post-Vac Syndrom". xxvi

The **Paul Ehrlich Institute** (PEI) Germany's pharmacovigilance body, has undertaken ongoing surveys of vaccine recipients (as opposed to the TGA which only accepts passive reports, or AusVaxSafety whose survey stopped at 6 weeks). They have found that the incidence of serious reactions occurs in 0.3 per 1000 shots (not people). Considering that the majority of Australian adults have now had at least one booster, this suggests that the incidence of serious adverse reactions per vaccinated person could be more than 1-in-1,000. PEI admits that under-reporting is a problem, and observers suggest that an order of magnitude of under-reporting is not unreasonable to consider (most estimates put underreporting at much worse than this). XXVIII

Without acknowledgment and recognition of post-vaccination syndrome or vaccine injury, there can be no progress in developing protocols for diagnosis and treatment and it is difficult to be included in research projects or treatment programs. It has also meant a long and frustrating search for acknowledgment and an attempt at treatment for many individual patients.

### SPECTRUM OF ADVERSE EVENTS FOLLOWING IMMUNISATION (AEFIS)

People who suffer COVID vaccine injury may present with a range of symptoms, and results of standard medical tests often come back normal. And like patients with Long COVID, they too are also asking the medical profession and public health systems for help.

In the early days of the vaccine rollout, the Astra Zeneca vaccine received attention for the reports of unusual blood clotting.xxviii

Less generally recognised are the reported adverse reactions after mRNA vaccines by Pfizer and Moderna beyond myocarditis and pericarditis. Even then, there has been a misconception that myocarditis is "mild", "transient" and "mostly in young males", when there are many cases where myocarditis is manifestly not mild, not transient and not confined to the young male demographic.

The international literature has documented many case reports of AEFIs.

The US patient advocacy group REACT19 <a href="https://react19.org/">https://react19.org/</a> has compiled links to published peer-reviewed reports <a href="xxix">xxix</a> and patient-led survey results painting a picture of the impact on patients.

An Australian advocacy group COVERSE <a href="https://coverse.org.au/">https://coverse.org.au/</a> has also been established and is providing support for people who have had their lives affected by vaccine injury.

Some adverse events are acute and self-limiting. Acute reactions include allergy and anaphylaxis, cardiovascular, neurological, haematological and autoimmune adverse effects.

Of concern is that some AEFIs become persistent and go on to cause long term illness and disability. As the vaccines are relatively new, the data on how long these adverse effects may persist will take time to emerge.

Unfortunately, the science is at an early stage because we are just over two years into the pandemic and the global focus has been on vaccinating as many people as quickly as

possible with a novel vaccine for a novel coronavirus. Because of this, all of the studies that have been published so far are either small, or case studies only.

The burden of proof seems to have been placed on the vaccine injured rather than the neutral scientific position of placing suspicion on the vaccine in the absence of any other cause and the temporal correlation with the administration of the vaccine.

However, some countries have gathered significant databases of adverse events following immunisation (AEFI)

Some of the published studies or case reports in relation to COVID vaccine injury are listed and referenced below:

### **CARDIOVASCULAR**

Hypertension or exacerbation of existing hypertension (possibly neurological/autonomic)<sup>xxx</sup> Symptomatic tachycardia

Chest pain of indeterminate origin

Myocarditis/ Pericarditis xxxi

Immune thrombocytopenic purpura<sup>xxxii</sup>

Deep vein thrombosis and pulmonary embolism

Vaccine induced Thrombocytopenia syndromexxxiii

## NEUROLOGICAL XXXIV

Paraesthesiae and other sensory disturbances<sup>xxxv</sup>

Dysautonomiaxxxvi

POTS-like syndromexxxvii

Bell's palsy

Acute transverse myelitis

Dizziness/ Vertigo

Sensorineural hearing lossxxxviii (including Sudden Sensorineural loss)

Stroke or transient ischaemic attack xxxix

Headachexl

Gullain-Barré syndromexli

Central nervous system demyelinationxlii

Brain fog/ Poor concentration

Altered visionxliii, xliv

Sudden sharp neuralgia-like pains

Facial Nerve palsyxlv

Autoimmune neurological syndromesxlvi

Herpes Zoster reactivation xlvii

## AUTOIMMUNE / RHEUMATOLOGICAL

Exacerbation of existing or previous autoimmune conditions xlviii

Arthralgiaxlix; 1

Enthesitis, bursitis, myalgia
Relapse of inflammatory bowel disease, Crohn's disease, ulcerative colitis<sup>li</sup>, <sup>lii</sup>
Immune thrombocytopenia purpura<sup>liii</sup>
Thyroid disorder <sup>liv</sup>

DERMATOLOGICAL Alopecia areata<sup>lv</sup> Skin rashes

GENERALISED/OTHER
Fatigue, hair loss, reduced exercise tolerance

### AN UNFAIR BURDEN

People who are suffering from Long COVID, people who are medically vulnerable despite vaccination and people who are unable to have further vaccines are bearing an unfair burden of the pandemic as it is allowed to spread through the community in the absence of effective public health measures.

With the removal of isolation requirements and mask mandates or inadequate recommendations for masking and air filtration and ventilation, those at greater risk of the consequences of infection or reinfection have to make a risk assessment for every potential interaction, including their work environment, medical appointments, investigations and procedures, family events and celebrations or even doing their supermarket shopping. Grandparents are having to make the heart-breaking decision to choose between protecting themselves from COVID infection and reinfection vs regular contact with their grandchildren.

This leads to a disproportionate disadvantage for these groups who are forced to limit social and professional interaction, who cannot safely take public transport, who cannot safely work in person and may not have working from home options.

Teachers and childcare workers are unable to protect themselves now, and risk repeated reinfection if they continue to work with children.

There is no State-wide or national approach to zero COVID transmission in hospitals and healthcare facilities, where medically vulnerable people should be able to feel safe. I am aware of people who are delaying dental care, skin cancer checks, mammograms or colonoscopy and other screening tests because of the risk of encountering someone who is contagious, either in transit or in the waiting room or procedure room.

Healthcare workers are burnt out and frustrated and face a higher risk of infection at work without a "zero COVID" approach.

New COVID variants are already emerging and with open borders and no quarantine or detection measures in place, these variants will continue to emerge in Australia. Over time we will see wave after wave of Long COVID cases presenting to their doctors who currently have limited options to help them while patients bear a financial burden in the search for answers.

#### **PREVENTION**

Immunisation does not stop transmission of SARS CoV2. While current COVID vaccines may reduce the risk of developing Long COVID by an estimated 15% (possibly up to 41%) recent data tell us that the risk remains for most people after immunisation and increases with subsequent reinfection.

Repeated COVID infection appears to increase the risk of post-COVID symptoms whether the symptoms of the acute infection were "mild" or severe.

There is recent evidence that antiviral treatment early in the course of an infection may reduce the incidence of Long COVID. However, antiviral medications do not eliminate the risk in most people.

Access to affordable antiviral medication in Australia is very limited. Unless a patient fits the very strict criteria for a prescription under the Pharmaceutical benefits Scheme, they are required to pay over \$1000 for a five day course.

The upshot is.. the only way to prevent Long COVID is to not get infected in the first place, or not to get reinfected.

"Personal responsibility" has become a political cop-out and this failed strategy will lead to more and more cases of COVID19, reinfection and Long COVID.

This is the antithesis of the principle of public health, which is to ensure that community-wide actions are needed to protect the health of all people in the community in a way that respects the rights of individuals, for mutual benefit.

The public health strategies to achieve this are in the hands of Federal and State governments.

## WHAT NEEDS TO HAPPEN

Government has the levers to help all people in the Australian community to live safer lives until there are better vaccines capable of preventing transmission, better treatments for SARS CoV2 infection and until Long COVID treatment protocols are developed.

Australia needs a long-term, comprehensive plan NOW to minimise transmission, Long COVID and reinfection.

This does not mean a return to draconian lockdowns.

A return to the PRECAUTIONARY PRINCIPLE and the FUNDAMENTALS OF PUBLIC HEALTH and DISEASE PREVENTION, a COMPREHENSIVE PLAN for RESEARCH, and DEVELOPMENT OF TREATMENTS to include:

- Effective PUBLIC HEALTH MESSAGING about the risk of Long COVID, including the limitations of a "vaccines only" approach in preventing Long COVID.
- Access to high quality N95 or equivalent masks with evidence-based targeted mandates
- A national approach to improving indoor air quality including ventilation standards with CO2 monitoring and target levels.

- A national approach to reduce COVID transmission in schools to protect students (especially medically vulnerable children and children with medically vulnerable household members), teachers and school support staff.
- A return to mandated isolation of infected individuals through the infectious period
- Expansion of hybrid work and education options
- Encouragement and funding for research into future preventive interventions including alternate vaccines that stop transmission or different formulations where spike-protein based vaccines are contraindicated.
- Expanded availability of affordable evidence-based antivirals.
- A national approach to aim for zero COVID transmission in hospitals and healthcare facilities
- Research into the underlying mechanisms of Long COVID
- Research and development of diagnostic tests and targeted treatments for Long COVID.
- Development of specific information packages for GPs and medical specialists on Long COVID recognition and treatment options.
- Identification of barriers to reporting of adverse vaccine reactions and streamlining of processes.
- Follow up of adverse COVID vaccine events reported to the TGA
- Streamlining of the reporting process for adverse events following immunisation
- Development of specific information packages for GPs and medical specialists on the spectrum of vaccine adverse events so that patients receive full and accurate informed consent prior to vaccination, and wider recognition of vaccine injury.
- Development of Consumer Medicines Information resources about COVID19 vaccine adverse events
- Development of specific information packages for GPs and medical specialists on how to manage patients with suspected or likely vaccine injuries.
- Research into the underlying mechanisms of vaccine injury
- Research and development of targeted treatments for vaccine injury.
- Recognition of long term Long COVID and vaccine injury disability under the NDIS.
- Adoption of the principle "no-one left behind".

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