

INQUIRY INTO LONG COVID AND REPEATED COVID INFECTIONS
House of Representatives Standing Committee on Health, Aged Care and Sport

4 December 2022

Late Submission (by invitation) from Brimbank Long COVID support group

To: Health.Reps@aph.gov.au

The Brimbank Long COVID support group is an unincorporated community-led support group, recently formed, for sufferers of long covid in the local municipality, to lend support to each other for this debilitating disease that US long COVID researcher Ziyad Al-Aly phrased a "serious, serious public health crisis".

A number of our members wish to make this late submission by invitation to the Inquiry in response to the Terms of Reference, and specifically in relation to Long COVID and our experience as sufferers (not in relation to repeated COVID infections).

1. The patient experience in Australia of long COVID, particularly diagnosis and treatment;

We have found the patient experience in Australia to be generally poor, with many general practitioners ill-equipped to deal with the illness, lacking accurate, up to date information to understand the disease, diagnose, or guide patients in living with this condition.

It is concern to us to read that Federal funding in this area is ceasing in December (*Cloud over Victoria's long COVID clinics as federal funding dries up*, The Age, Nov 24, 2022).

There is little assurance that the States will or have the capacity to pick up this shortfall with an already compromised, stretched health system - and with current long COVID clinics experiencing year-long wait lists in some cases according to news reports. This wait list reflects our personal experiences as well. This article above also states that "GP and hospital services for those living with the debilitating chronic condition are not being adequately funded."

Recommendations: Federal government to sustain or increase (match) funding to support long COVID diagnose and treatment, especially for standalone long COVID clinics in each State and Territory – to reduce wait times, and to push for a diagnostic and treatment approach based on latest research, not simply a "well-being" or management approach to "living with" the disease.

2. The experience of healthcare services providers supporting patients with long COVID;

The abovementioned article also states that “patients are being told to access alternative support through their GP”.

Most commonly, the advice has been “try to live more healthily”, and others have been told that “we don’t understand it yet, as it’s so new”.

Recommendation: Specialist Long COVID clinics rather than GPs or the already stretched hospital system are best placed to provide a dedicated, caring and specialist approach and a significant source of important community data on his disease, that in our opinion must be maintained. Wait lists need to be shortened for these clinics.

3. Research into the potential and known effects, causes, risk factors, prevalence, management, and treatment of long COVID;

While of course long COVID can affect sufferers differently including for example cardiac or respiratory symptoms, for many of us it is the brain impacts (brain fog, fatigue, headaches, tinnitus) that seem to be the most alarming and misunderstood. There may be a time critical element here in respect to the long term or permanent impacts of this disease on the brain.

There are of course many researchers and clinicians a home and abroad looking into this disease, many in Australia of whom will have had input into this enquiry:

Dr/s Anthony Byrne and David Darley, St Vincent's Hospital

Dr. Beate Jaeger

Dr Dirk De Ridder (tinnitus treatment, not long COVID)

Professor Greg Dore, Kirby Institute

Professor Jason Kovacic, Victor Chang Cardiac Research Institute

Professor Jason Kovavic, Victor Chang Cardiac Research Institute

Dr John Campbell (U.K.)

Dr. Katarzyna Sklinda, Polish Medical Society of Radiology

Dr. Kirsty Short, University of Queensland

Adjunct Professor Knut Stavem (Norway)

Associate Professor Louis Irving, Royal Melbourne Hospital

Associate professor Lucette Cysique, St Michaels Hospital

Dr Nick Reynolds, La Trobe University

Assistant Professor Yuhai Zhao, Louisiana State University Health Sciences Centre

Long COVID patients are desperate for answers and diagnosis, but it can be a struggle with cognitive impairment to even comprehend this research, where answers within the medical system are lacking.

On a related note, we are certainly not taking an anti-vaccination stance and acknowledge the political sensitivity around ensuring the vast majority of the healthy public are vaccinated as best protection against COVID. However we also endorse the ongoing need

for accountability and transparency in looking into any potential relationship between vaccination and long COVID, or related symptoms. No door should be shut in terms of this research. We note that the U.K. has decided not to pursue a parliamentary Inquiry and instead to look at the safety of vaccines as part of a broader analysis of the pandemic, despite a parliamentary statement from one member that “there has been a significant increase in heart attacks and other related illnesses since the COVID-19 vaccinations started to be distributed in 2021”.

Recommendation: One of the most frustrating things for people with this condition is the “not knowing”. A coordinated network of Long COVID researchers in Australia and globally to expedite the push for answers into the potential and known effects, causes, risk factors, prevalence, management, and treatment of Long COVID – greater connection to patient research through long COVID clinics to this network, and for diagnostic information to be available more easily (and in a way that can be comprehended) to sufferers as new treatment pathways are found through research. Second, to look into both COVID and reinfection, Long COVID, and vaccines collectively in respect to long-term health impacts of the pandemic and its control measures.

4. The health, social, educational and economic impacts in Australia on individuals who develop long COVID, 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;

For many of us, the impacts of long covid go beyond the immediate physical, mental and emotional health impacts and extend to things like relationship stress and inability to work.

While it might be politically unpopular to talk about COVID in late 2022, and the vast majority of the general public return to “life as normal” or a “living with the virus” state of mind, it is important those still suffering from the long term and largely unknown impacts of this disease are not left behind. This also acknowledges that many groups face a greater risk of serious illness due to factors such as age, existing health conditions, disability and background.

When you have long COVID, everything changes, and becomes harder including for example the writing of this submission. Concentration and focus, memory, stamina, cohesion, general cognitive function are all impaired. There is no certainty as to whether the issue will subside will be more long-lasting which adds to the stress for individuals of the health impacts.

Everyone suggest solutions to try and help (from medication, to alternative therapies, to general health and well-being, meditation etc.) but lack of definitive medical certainty is the most stressful factor, added the multitude of information on the internet, and the lack of brain function to decipher the information that is available.

A “living with covid” government health policy stance does not work for those of us with long COVID. A chronic 24/7 enduring illness cannot simply be “passed through” like a cold or flu, which is how most experience COVID and view the virus. This has been life changing for

those of us affected, and we also live in fear of the risk of being reinfected and potentially worsening systems. This is a highly debilitating disease to both health and lifestyle.

Long COVID impacts social, family and friendship groups. Sufferers may want to be alone, maybe emotionally short tempered to things like headaches or confusion. They might avoid events because of “the noise” or fatigue, or the risk of reinfection. This is more isolating, and can cause a spiral into mental health conditions.

There is a social stigma in declaring one has Long COVID to others. There are reports that many in the general population can be dismissiveness of these complaints, “It’s just ageing”, or “you’re just tired”, or ‘COVID was nothing for me’. This can be very wearing to hear.

Educational impacts include difficult in learning and concentration.

That roughly 75 per cent of people living with long COVID will have cognitive impairment poses a huge burden on the global economy, and this burden is only likely to increase as time goes on with new waves of COVID.

Economic impacts on a personal level including inability to work (or work same number of hours). For some it is even looking to retrain entirely into the type of work that is able to be done is impaired - for example mentally stressful work or work requiring concentration (administration) or safety risk related work may become difficult or impossible.

And of course, this impacts families, communities, and the Australian economy and workforce in general.

Recommendation: Centrelink special Income support for GP diagnosed long COVID sufferers, non-means-tested, for at least up to 12 months, while sufferers are unable to work due to this disease, to alleviate immediate family and financial stress, and support services to help suffers adjust to new work or wok approaches, or potential pathway to disability support for those severely impacted and unable to work at all. (In the United States, long COVID is recognised as a disability if it substantially limits one or more major activities.)

5. The impact of long COVID 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;

We are not medical professionals and unable to comment on this point, but it is clear that there are significant ripple effects of Long COVID on Australia’s overall health system.

6. Best practice responses regarding the prevention, diagnosis and treatment of long COVID, both in Australia and internationally.

We are not medical professionals and unable to comment on best practice responses regarding the prevention, diagnosis and treatment of long COVID, both in Australia and internationally. However sufferers already struggling to understand this disease on their own, need access to best practice responses through specialist centres.

Recommendation: As discussed earlier, reinstatement and maintenance or increase of Federal long COVID clinic funding, a taskforce dedication to ongoing analysis of latest research and diagnosis and treatment pathways. Long COVID added to the list of high-risk groups to expedite access to preventative therapies, antivirals and treatment.

In summary

The existing Federal-State existing hospital agreement, provides no guarantee standard public hospital services are adequately set up to support the needs of this specific disease, and these are services already under extreme pressure in terms of staffing and resources as a result of the past few years.

Long COVID sufferers have felt forgotten, and we welcome this Inquiry and hope that it leads to a commitment by all levels of government to protect the health of all Australians into the future, and to provide the best possible support to current long COVID sufferers in relation to diagnose and treatment based on continuing and best practice research, through specialist Long COVID clinics.

We thank you for your consideration of this important matter,

Signed

(Long COVID since March 2022)
(Long COVID for two years)
(Long COVID since April 2022)