

Parliamentary Inquiry into Long Covid and Repeat Infections of Covid-19

Written Opening Statement of the Australian Long Covid Community Facebook Support Group

for the Public Hearing on 17 February 2023

Thank you. We are a patient-led group representing three and a half thousand members (and steadily growing) who are sick with Long COVID and are there to support each other. We include many essential workers such as doctors, nurses and teachers, come from occupations across the board and include a wide range of expertise. We are all volunteering our time despite being unwell with Long COVID ourselves.

We have twice surveyed our members to guide our input to this Inquiry and have just submitted some additional findings. Key members of our Parliamentary Inquiry team could not be here today because they are too unwell. But the three of us are happy to answer questions relating to the group experience, as well as our personal experience.

We are here to help you understand our predicament and what we would like to get our health back on track. We wish to work cooperatively with those developing policy because we believe that our unique perspective of lived experience has an important role to play in the development of best practice responses. So we really appreciate this opportunity to address you in person.

Broad issues and how our members have been impacted

1. A Major Global Challenge

The world faces a major new epidemic of Long Covid with far reaching social and economic implications. It has been spoken of as the next big global health challenge. And the current estimates suggest that Australia 's Long Covid rate is catching up with the worst affected countries. We recognise that the cost of acting quickly will be high but the cost of not doing so will be far greater.

It is estimated that Australia already has several hundred thousand long COVID cases, and that the latest Covid-19 wave alone will lead to, conservatively, 250-300,000 new Long Covid cases, with yet another wave expected next month - more members for us, sadly. And vaccination has not stemmed the tide.

2. Economic Impact

As well as the health and social cost to our members Long COVID has a major economic impact, at both personal and country wide levels. The economic cost of Long COVID to Australia has been estimated as \$100 million a week and \$5 billion a year¹.

For 3500 of us, we estimate our loss earnings per year from the reduction in work hours to be between \$100 million (lower bound) and \$166 million (upper bound). The cost in loss earnings from losing our jobs (over the next five years) is estimated as \$16.5 million, using the estimate of the cost of job loss from the RBA². We also estimate that we have spent roughly \$10.5 million ourselves on treatment per year (very conservative estimate of \$3000

¹ [The effect of COVID-19 on the Australian economy so far | AMP Capital](#)

² <https://www.rba.gov.au/publications/bulletin/2021/sep/the-financial-cost-of-job-loss-in-australia.html>

per person for 3500 members). We are aware these are very back-of-envelope and rough estimates but this is the best we can get with the data we have.

3. **Complex, Serious, Mysterious, Challenging**

Long Covid is a highly complex and not yet properly understood, yet often very serious condition which is severely challenging our health services.

For our members and tens of thousands of others, maybe more, the impact is very significant: jobs, careers, incomes, community involvements, friendships, relationships, homes, hopes for a recovery, mental health, are literally being destroyed. For many our former lives are gone, with no sense of when, or even if, we will get them back.

See also 'Summary of Member's Experience' below and for more detail Submission 309 and recent Supplementary Submissions A & B

4. **Health System Unprepared and Inadequate**

Our health system is woefully unprepared and inadequate and very few professionals in either primary or secondary care know enough to offer much.

Those with Long Covid, including our members, are often being told by their general practitioners that they simply cannot help. If they get a referral to a specialist, even at a Long Covid Clinic, many of them say there is little they can offer. It is too new, very complex and still too mysterious. The waiting time for a Long Covid Clinic is typically several months, or more. The care and support available has too often been very limited.

5. **Social Support Inadequate**

Our social support systems have been largely unable to meet the need for practical assistance

Those with Long Covid have found it almost impossible to access appropriate financial and other practical government support because they do not 'fit the guidelines' for Disability Support Payments, NDIS, etc

6. **Insufficient Research**

Research in Australia has been very limited. A recent University of Tasmania/Deakin report stated 'Australia is an outlier among similar countries in not having instituted large scale national surveys and surveillance of Long Covid. As a result Australia lacks strong data on which to base its Long Covid policy response; this information deficit risks becoming an increasingly significant policy failure.'³

This lack of knowledge to guide appropriate policy responses is already impacting hundreds of thousands of lives, across this country since 2020. Until we have more and better research, treatment options will be limited, and continue to be only for symptoms.

7. **Minimal Understanding in the Community**

Throughout the community the understanding about Long Covid is still very limited.

As a result, what so many of our members feel is that wherever they turn they are not understood, have been forgotten, are ignored, even dismissed by family, friends, work colleagues, employers, Government support systems, even within the health system. This is what they are telling us.

³ [New modelling shows the scale and impact of Long COVID across Australia | Institute for Health Transformation \(deakin.edu.au\)](https://www.deakin.edu.au/news/new-modelling-shows-the-scale-and-impact-of-long-covid-across-australia)

When so many people post on our Facebook page that it is the only place they feel safe to share, the only place they feel understood, accepted, supported, we have to be concerned.

An effective response to these, which we know you are well aware of, will require some radical changes in approach and direction and policy. We have attached a list of specific proposals which build on those in our original Submission 309 in October 2022.

Summary of Members' Experience

Each of us have on average 20 Long COVID symptoms. Our most severe symptoms are such as fatigue, cognitive impairment are also the symptoms that are less likely to be resolved quickly. Our median duration of Long COVID was 200 days, so it is definitely lasting longer than the 3-6 months time frame.

Our first survey of 607 respondents show we experience multiple barriers to accessing healthcare and treatment, including stigma, disbelief, lack of knowledge by professionals and a lack of support. Many of us have lost jobs or had to take months off from work. We have also lost our identity, our financial security, the ability to care for ourselves and our loved ones. We are unable to carry out activities of daily living and every aspect of our lives is affected by Long COVID. And there is very little support available to us.

Over 90% of us were healthy before Long COVID, now the figure is less than 10%. 80% of us were working before Long COVID compared to 68% now. Nine in ten of us with a job are unable to do our expected work hours. Meanwhile the Government and the media are always talking about the importance of the economy and skills shortages.

If we do not address Long COVID, there will be a huge impact on our workforce and the economy and on our healthcare system. If we use the conservative Long COVID prevalence estimate of 5% with the data that 65% of Australians have been infected with COVID-19 as of August 2022⁴ we get 850,766 Australians with Long COVID. This estimate does not include the latest Omicron wave.

We have this week forwarded Supplementary Submission A, which provides additional findings from the October survey not included in Submission 309.

We have also this week forwarded Supplementary Submission B, which gives the results of the second member survey, which closed earlier this month.

Additional Recommendations

Prevention is better than cure!

1. Prevent future Long COVID by reducing and minimising exposure to COVID-19 and prevent further health harms to people with Long COVID

- Vaccine plus strategy including ventilation, masks in essential settings, isolation and testing
- We need safe hospitals, clinics, workplaces and schools
- Make antivirals readily accessible to people with Long COVID
- Priority PCR testing for people with Long COVID as reinfection worsens symptoms

2. Improve support for people with Long COVID

⁴ [RACGP - Vast majority of Australian population has had COVID: Seroprevalence survey](#)

- We need multidisciplinary Long COVID clinics, not just mainly rehab based clinics. These should offer telehealth options.
- Long COVID treatment is very siloed. We are being passed around between health professionals with no coordination of care.
- Mandatory education and training about Long COVID care, including Post Exertional Malaise and risks of cardiovascular exertion.
We have run two Webinars through the Long Covid Australia Collaboration group. Have emailed GP groups (RACGP, AMA etc) to invite their members to attend, unfortunately with limited success. RACGP Guidelines for LC were too generic to give Doctors much guidance. Better communication between LC Lived Experience & GP groups.
- Current chronic disease management items are not widely used and case conferencing is not common even for existing chronic illnesses
- GPs are doing their best but we need a single point of contact/case managers as highlighted in our submission.
- Leave no one behind
 - i. those who have had Long COVID for three years now, and remote and Regional Australians
 - ii. Vulnerable Australians (e.g. those living in poverty, CALD and First Nations people, people with disability and chronic illnesses)
 - iii. Telehealth is absolutely essential for those that are housebound with Long COVID and those in remote and regional Australia. Current telehealth rules are not working for us. We also need long telehealth consults for Long COVID patients.

3. We need more research and access to the latest research and treatment options

- We need Centres of Excellence for Long COVID, with the best minds working together and collaborating with overseas counterparts.
- We need researchers to partner with us on all types of research from clinical trial design, trial and other research priorities, surveillance of long COVID and in allocation of Long COVID research (either by NHMRC, ARC or Future Fund)

4. Improve education and public health messaging

- Better public messaging to the public/community. We need to change attitudes in the community and increase awareness that Long COVID is a very serious disease and it has an enormous impact on individuals and the society. We also need to increase our vaccination rates and make people aware that reinfection is harmful. COVID is just not a cold.
- Better public health education to patients, professionals, employers, educators and the wider community. We need easily accessible information online and in hard copy.
- Protection from misinformation. Many patients are being sold unproven and expensive treatments and are very vulnerable to exploitation.