

Submission to the Commonwealth Government COVID-19 Response Inquiry

by the Australia Long COVID Community (ALCC)

The ALCC

- An online peer led support group for people with, and caring for people with, Long COVID (LC).
- The largest Australian Long COVID support group, with 4,560 members and sadly still growing.
- Strong record of advocacy and working cooperatively with experts and other groups.
- Made submission to Parliamentary Inquiry into Long COVID and Repeat Infections of COVID-19 and invited to appear at one of its public hearings.

This submission

- addresses Terms of Reference 1, 2, 3 and 6, focusing on the specific concerns of those with Long COVID and what our particular experience can bring to the Inquiry:
 - impact on our members as Long COVID sufferers
 - their experience of seeking help for their Long COVID
 - overall pandemic response since higher infection rates lead to higher rates of Long COVID
- is based on the results of a recent survey completed by 619 members, plus three years of informal feedback through online written comments. Permission has been given for public attribution of names to quotes. (For a detailed report on the survey results see Attachment A.)

How our members have been impacted

"I feel invisible. Forgotten by work. Forgotten by friends. Forgotten by family. Forgotten by society." (██████) "It is life destroying living with Long COVID" (Anon)

These few words sum up what our lives are like now and how our members feel, not knowing when, or whether, it will end. The subject of this submission is how the Commonwealth Government's response to the pandemic has contributed to this and the consequences for the many thousands very seriously affected by Long COVID, and the hundreds of thousands less seriously affected. (See Attachment B for more quotes from our members regarding impact)

The Commonwealth's overall pandemic response

- 72% of respondents rated **the Commonwealth's early response** *adequate* to *very good*.
- However, **this support declined seriously over time** as restrictions were eased then removed. The messaging changed to downplay the risks, even as hospitalisations and deaths rose rapidly and the mantra became 'back to normal'. This was interpreted as the political imperative very quickly taking over from the scientific and health one as the population tired of restrictions and votes seemed to be at risk. By then the warnings of respected experts seemed to be being almost completely ignored. By 2022 61% of our survey respondents rated the Commonwealth response as *poor* or *very poor* and for 2023, that had risen to 86% of respondents.
- **Even the basic facts seem to have been ignored**, swept under the carpet to hide the ongoing seriousness of the pandemic: the nearly 10,000 deaths attributed to COVID-19 in 2022, 20,000 excess deaths in total, with COVID the third most common cause of death in that year; the first time in living memory that an infectious disease had been in the top five, seem not to have caused a ripple in public political discourse. Even in 2023, numbers are about two thirds of 2022. Life expectancy is expected to fall for the first time in decades because of

COVID-19. Where is the response, even the recognition of a continuing health and human crisis?

- It could have been predicted, and probably was, that **higher infection rates** would lead to **higher rates of Long COVID** and that **repeat infections, sometimes several times**, would **put those with LC at much greater risk** of both further infection and worsening of their LC symptoms. The explosion of COVID-19 cases has therefore been of enormous concern to our members. Yet this has simply not been addressed in the Commonwealth's response.
- It has also been reflected in **the messaging and the information provided**: Only 33% rated the Government's messaging as *adequate* and 51% as *poor* or *very poor* (32% and 64% to medical professionals). The 'back to normal' messaging through 2022-23 has been very concerning. It is as if the issue of LC has continued to be almost completely ignored.
- Because of the lack of official information about the real risks from COVID-19 (hospital, death, LC), **many people now treat it as 'just another cold'** - ignoring it, putting many at serious risk.
- Specific measures:
 - **Vaccination**: rated reasonably, but significant concerns
 - **PPE, testing, antivirals and quarantine**: all rated poorly (mainly lack of availability, early, late or both), with only 1-6% *excellent*
 - **Data collection and research**: rated even more poorly: 86% *less than adequate*
 - Support measures (income/practical/mental health: all rated 70%-80% *very poor* and almost none *adequate* or better)
- **Airborne transmission**: there has been an almost complete failure to act on, or even acknowledge this, and therefore the importance of clean indoor air and respiratory masks.
- **Relying on vaccines alone** for the last year or two, despite limited effectiveness, does not seem to have been medically sound or logical. Worse than that, the public message about COVID works against the vaccination message, so no wonder vaccination rates are low, as Prof ██████████ has recently pointed out (ABC Life Matters, 21.11.23). This again puts more people at risk.

More broadly, in the view of our survey respondents:

- Accepting that many health roles belong constitutionally to the states, the Commonwealth should have shown **stronger national leadership & co-ordination of the overall pandemic response**.
- **The Australian health system** has been shown up as not having:
 - the capacity to respond adequately to the scale of need in a pandemic,
 - the expertise in or focus on chronic illnesses to properly address any consequent long term post acute illness syndrome,
 - the agility to make timely use of emerging treatments for novel illnesses.

The Commonwealth's response to Long COVID specifically

- **The overall response** rated only 2.5% *adequate* or better and 79% *very poor*. As with so many chronic illnesses, Long COVID seems to have been sidelined, given no real priority.
- **The major issues raised** were the lack of information to doctors, lack of public messaging about LC, lack of individual support from Government, and lack of timely research into LC.
- **Information** provided by the Commonwealth to GPs, other medical professionals (even to LC Clinics) and the public about LC has been minimal, unhelpful and sometimes damaging. There are still doctors who dismiss people's LC as psychological, even some still denying LC exists.
- **Messaging** rated just 1.5% *adequate* or better (2.2% to medics) and 82% (74%) *very poor*.

- Almost no mention of the risk of developing LC, its potential seriousness or the very large numbers affected. In fact it is almost never even mentioned.
- Parliamentary Inquiry recommendations were published 9 months ago. Not a word since.
- Most members of the public know almost nothing about LC. The result has been widespread lack of understanding/recognition/support/empathy.
- **Practical, financial & other Commonwealth support** for those with LC has been very hard to obtain, particularly income support. Most pharmaceuticals prescribed are not PBS and there is a desperate need to adapt existing support programs (eg DSP, NDIS) or develop new ones.
- We feel largely, often almost completely, unsupported, ignored and in some cases, dismissed when pandemic policy has been discussed and determined. We are part of the collateral damage from getting life and the economy 'back to normal'. We do not count. At every level we have not been listened to or understood.
- **No LC data collection/tracking.** The country cannot have appropriate policies without it.
- The \$50m for **Long COVID research** is welcome but we will not see any benefits for several years and we have not heard of any other current Commonwealth funding for LC.
- **The LC Clinics** (supported with Commonwealth funding) have been a huge disappointment.
 - Woefully small capacity, very long waiting lists and several have now closed. Ending Commonwealth funding has made the situation worse.
 - Some have been helped but for many others the experience was largely a waste of time: limited testing, very limited support, sometimes misguided.
- **The decision to rely on primary care** for LC was always unrealistic. GPs lack the capacity (including for long appointments) and cannot be expected to have the knowledge required.
- **Lack of access to antivirals** when reinfected has been a huge issue for our members.
- **LC from vaccination.** Quite a few of our members appear to have developed LC as a result of a vaccination, but find it almost impossible to get this acknowledged officially.
- Finally, over the last couple of years the Federal Health Minister's office has been approached by this group and several members of the group individually for a **meeting with the Minister** to discuss these issues. Every request has been declined. Again, we conclude we don't count.

Recommendations

1. Urgently improve Long COVID information and education for GPs and other medical professionals.
2. Urgently update all public messaging to be open, transparent and science based, to correct the current narrative in the community and to adequately address long term health impacts.
3. Urgently improve support, for those with serious long term effects: health, practical, financial.
4. Restore a science based approach to policy, including quality data collection, ongoing research and promotion of strong public health action for as long as needed to combat the health threat.
5. Provide adequate funding for all aspects of the ongoing response to the continuing COVID-19 pandemic and Long COVID.
6. Involve those with lived experience in developing future responses to Long COVID.
7. For future pandemics:
 - 7.1 Develop a nationally agreed, co-ordinated and united approach to pandemic response,
 - 7.2 Establish an Australian Centre for Disease Control.
 - 7.3 Ensure all interventions are science based, timely and transparent.