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Suicide Prevention Australia

# Inquiry into Long COVID and Repeated COVID Infections

## Submission

**For general enquiries:**
02 9262 1130 | policy@suicidepreventionaust.org | www.suicidepreventionaust.org

## Introduction

Suicide Prevention Australia welcomes the opportunity to provide input to the Inquiry into Long COVID and/or repeated COVID infections.

Suicide Prevention Australia is the national peak body for the suicide prevention sector. We have over 350 members representing more than 140,000 employees, workers, and volunteers across Australia. We provide a collective voice for service providers, practitioners, researchers, local collaboratives, and people with lived experience.

Over 3,000 people tragically die by suicide and an estimated 65,000 people attempt suicide each year. Over 7.5 million Australians have been close to someone who has taken or attempt suicide. Our shared vision is a world without suicide and with our members, we work to inform through data and evidence; influence systemic changes that drive down suicide rates and build capability and capacity for suicide prevention.

We are concerned about the potential increased risk of suicide for long COVID and repeat infection sufferers. Despite research still emerging on the significance and severity of long COVID, we know that in general chronic health conditions can have an all-encompassing impact on people's mental well-being alongside having far-reaching negative social and economic consequences. Worryingly, there is a clear link between suicide and chronic illness, and research suggests that one in 10 people who take their life are suffering from a chronic or terminal illness.[1]

On this basis we would like to provide input relating to one of the terms of reference for this enquiry:

*(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.*

In preparing this submission we have consulted with those who have had lived experience of suicidal ideation and chronic health complaints, as well as relevant published research.

## Summary of Recommendations

1. The Commonwealth Government collect data on long COVID cases and repeat infection in the community to identify patterns, and communities and population groups most at risk.
2. The Commonwealth Government should work with State and Territory Governments, Coroners and the National Coronial Information Service to identify and report on any future suicide deaths where long COVID-19 may have been a contributing factor
3. The Commonwealth Government extend supports such as the National Disability Insurance Scheme and the Disability Support Pension to individuals severely impacted with long COVID and/or repeat infection.

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| 4. | The Commonwealth Government should provide individuals severely impacted with long COVID and/or repeat infection with a $50 a week Disability and Illness Supplement as part of broader welfare reform to provide this to all people with a disability or illness. |
| 5. | The Commonwealth Government train and upskill community connectors such as general practitioners in suicide prevention. |
| 6. | The Commonwealth Government invest in a national public awareness campaign to educate the public on long COVID and repeat infection to reduce stigma and discrimination. |
| 7. | The Commonwealth Government should work with State and Territory Governments to invest in peer-led local support groups across Australia in primary care settings integrating support to address suicide risk factors and behaviours for individuals and families impacted by long COVID and/or repeated COVID infections. |

## The link between suicide and long COVID and repeat infection

To date, Australia has not seen an increase in suicide rates due to the COVID-19 pandemic.[2] This may in part be due to the significant levels of support given by governments to alleviate the impacts of the pandemic and associated necessary health measures.[3] But it is critical to understand, as we emerge from the pandemic and compounding natural disasters, that research shows suicide rates can peak 2-3 years after a crisis.[4]

Concerning indicators of this potential future increased risk of suicides are that other measures of distress, such as mental health service usage, self-harm and suicide attempts increased during the pandemic.[5] In particular, use of mental health support website Head to Health grew by 184% over the 3-years of the pandemic.[6] Average calls to crisis support service Lifeline rose by 24%, and Beyond Blue by 23%.[6] Ambulance attendances related to suicide also increased[7] and worryingly, within the State of Victoria there was an 11% rise in callouts for suicidal ideation.[8] This data indicates that record numbers of Australians are seeking support and demonstrates that there are ongoing suicide risks in the community.

Suicide is a complex, multifactorial human behaviour with many varied risk factors. Increasingly, the evidence is clear that the social determinants of health and wellbeing, including social, economic, and physical environments, play a critical role in suicide rates. The impact of chronic illness on physical and mental health can be significant.

Common symptoms of long COVID such as fatigue, weakness, and brain fog can severely disrupt people's lives and limit ability to participate in daily activities.[9] For Australians aged 65 and over, limitations on activity due to disability is the most identified risk factor for suicide.[10] Also, continually feeling unwell can be deeply upsetting and unsettling. Likewise experiencing repeat COVID infection can be physically and emotionally demanding. On study has found that 14% of Australians had long COVID symptoms lasting for more than 4 weeks.[11] Another study, tracking NSW residents diagnosed with COVID-19, found that 5% experience ongoing

symptoms for three months or more.[12] This is supported by international research which indicates that 6% of people do not recover 6-18 months post infection.[13] It has been indicated that long COVID could possibly develop into one of Australia's most significant causes of longer-term disability.[14]

Unfortunately, research shows that chronic illness rates are substantially higher among the most vulnerable and disadvantaged in society,[15] including groups disproportionately impacted by suicide. We know that socioeconomic status can affect health outcomes and that risk of suicide is heightened for those living in more disadvantaged areas.[16] People with low socioeconomic positions are overrepresented in suicide statistics. Data indicates that the highest rates of suicide occur in the lowest socioeconomic areas.[15] Concerningly, research has also found that suicide rates increase by 3.5% per year in low socioeconomic areas while the highest socioeconomic areas experience minimal change.[17]

*'The prospect of having ongoing pain is terrifying. People can get very depressed and there is a real risk people end up taking their lives as they can't stand it anymore.'*
*Person with lived experience*

Research with patients who attended long COVID clinics in Israel and Europe found that long COVID is more common in older adults aged 65 years and over.[18] This finding was supported by research conducted in the United States.[19] There is an increased risk of suicide for older adults,[20] and Australian data indicates that deaths by suicide often occur in older aged groups.[21] Sadly, for Australian males, the highest suicide rate occurs in men aged 85 and over.[20] Common flow-on effects of chronic illness such as isolation, physical illness and pain heightens this risk.[20]

*'I just want to feel normal, and I don't want to feel so sleepy during the day. Sometimes I won't eat as I don't have the energy to cook.'*
*Person with lived experience*

It is concerning that there are no clear figures which report how many people are experiencing long COVID or repeat infection in Australia. Considering the unequal distribution of chronic illness risk, and disproportionate prevalence in certain demographics, the government should be aware of long COVID rates in the community. This is vital for identifying vulnerable and high-risk groups to ensure they are supported and to mitigate the health consequences for individuals suffering from ongoing symptoms. Armed with the right data, the government will be more effective at allocating resources to create better outcomes for Australians with long COVID or repeat infection.

**Recommendations**

1. The Commonwealth Government collect data on long COVID cases and repeat infection in the community to identify patterns, and communities and population groups most at risk.
2. The Commonwealth Government should work with State and Territory Governments, Coroners and the National Coronial Information Service to identify and report on any future suicide deaths where long COVID-19 may have been a contributing factor.

## The employment and financial implications of long COVID and repeat infection

For a growing number of Australians long COVID has affected their ability to resume normal life, or even ability to work. In Australia, working-aged individuals with chronic illness are less likely to be employed, while those who are mature-aged (45-64) are twice as likely to be out of the labour force.[22] Unfortunately, the connection between suicide and unemployment is well established. Unemployment is associated with a two-to threefold increased risk of death by suicide.[23] For people who experience longer periods of unemployment there is an even greater risk of suicide.[24]

*'In everyone's mind COVID is over, no one is thinking about the ongoing impacts. But people need support dealing with an unpredictable long-term illness. Without support from the government and organisations about how to deal with repeat infection and long COVID, people feel abandoned and are finding support where they can. Chronically ill people should have somewhere to go for support – it's a feeling of huge grief and betrayal'*
*Person with lived experience*

Worryingly, long COVID and repeat infection not only adds to ongoing pressures caused by the pandemic, but also places further strain on people already struggling as cost-of-living increases across Australia. These life changing impacts and repercussions for families, and communities is of key interest to our sector which is concerned with the connection between the social determinants of health and risk factors for suicide.

For individuals who have a chronic health condition such as long COVID and are unable to work or require reduced working hours, loss of employment can be devastating. Unemployment or underemployment can contribute to overwhelming feelings of hopelessness, helplessness, and loss. Australian research indicates there is a heightened risk of suicide for individuals who are unemployed,[25] and this is supported by international data.[26] Loss of employment can result in financial hardship making it impossible for those affected to continue living a normal life. Income loss is particularly difficult for people dealing with the financial implications of serious illness, as medical bills can be a substantial expense. A study found that more than half of people with long COVID report an increase in family expenses.[27]

While it may be instinctive to think of the short-term consequences, it is critical to acknowledge that chronic illness can lead to chronic unemployment and financial hardship. In our consultations for this submission, it was stated that when chronic illness affected their ability to work, they felt constantly worried about keeping a roof overhead and affording necessities. They emphasized the importance of understanding that for some individuals long COVID will trigger enduring life-long problems, and while additional support is needed now, it will also be required in the future. It is concerning that young Australians with long COVID who are unable to work may suffer at retirement age due to loss of superannuation and savings.

Along with the exhaustion and stress that can accompany illness, the additional pressure of income loss and financial stress can be overwhelming. Both unemployment and financial hardship are potential risk factors for suicide. With cost-of-living pressures building in Australia

the additional financial stress caused by long COVID and/or repeated infection should be addressed.

Suicide Prevention Australia advocates that there is a need for individuals who have long COVID, or whose lives have been repeatedly disrupted by ongoing COVID infection have access to greater support, such as the National Disability Insurance Scheme (NDIS) and the Disability Support Pension (DSP). In addition, they should have access to a $50 a week Disability and Illness Supplement in line with the recommendations of the *Raise the Rate for Good* campaign.[28] This is based on modelling which indicates that a person with disability needs an extra $50 per week to achieve the same standard of living as someone without a disability.[29] At this stage, as there is no diagnostic test it is difficult for individuals to prove their symptoms are caused by long COVID and demonstrate they fit the criteria to access disability support. Other Countries such as the United States are working to make long COVID care as accessible as possible.[30] Long COVID is considered a disability under the Americans with Disabilities Act, Section 504, and Section 1557.[31]

Broadening access to disability payment to include individuals with long COVID or individuals who have been impacted by repeat infection who are unable to work would help with medical costs, bills, and rent. This would act to reduce financial hardship a potential risk factor for suicide and help ease cost-of-living pressures for vulnerable Australians with chronic illness. This would be particularly helpful for Australians from lower-income households as research suggests this socioeconomic group are more likely to experience long COVID.[32]

It is critical that people with chronic illness have access to health services for support. Sadly, several people we consulted with expressed that there is little support available in the community and stressed that there is an immediate need to expand health services to prevent the mental health and physical health of individuals suffering from long COVID deteriorating further. While there are long COVID clinics available in major hospitals in many states, there is feedback of long waitlists and that it is difficult and time-consuming to get a referral. The government should work alongside health organisations to make sure they are equipped to better support people suffering from long COVID and repeat infection.

**Recommendations**

3. The Commonwealth Government extend supports such as the National Disability Insurance Scheme and the Disability Support Pension to individuals severely impacted with long COVID and/or repeat infection.
4. The Commonwealth Government should provide individuals severely impacted with long COVID and/or repeat infection with a $50 a week Disability and Illness Supplement as part of broader welfare reform to provide this to all people with a disability or illness.

## The mental health consequences of long COVID and repeat infection

When thinking about the impacts of long COVID, or recurrent COVID infection, it is critical to examine the mental health ramifications. Data suggests individuals with long COVID fare worse across numerous indicators including anxiety and loneliness.[33] Alarmingly one study

indicates that as many as 23% of individuals with long COVID experience anxiety or depression.[34]

Other research which examined the electronic health records of patients across the United States of America found that within six-months of contracting COVID-19, one-third of individuals were diagnosed with psychological or neurological symptoms including anxiety, depression, post-traumatic stress disorder (PTSD) and psychosis.[35] These neurological consequences have been explained by data which indicates that brain inflammation and nerve cell damage in long COVID patients may be associated with the development of anxiety.[36]

Research also indicates that individuals with pre-existing poor mental health are more likely to experience long COVID. Experiencing depression, anxiety, perceived stress, and loneliness pre-COVID is linked to an increased risk of long-term illness.[37] For some Australians long COVID may have exacerbated existing mental health symptoms, heightening risk of suicide. For others, long COVID has taken away their usual coping strategies due to physical limitations associated with the illness leading to a decline in mental health.

*'What I struggle with the most is that nobody will say my symptoms are COVID-related.'*
*Person with lived experience*

Feedback from one of the individuals we consulted with who lost their sense of taste and smell, demonstrates that long COVID can prevent people from using their normal coping strategies. Due to the loss of their tastebuds, they were unable to get enjoyment out of eating or cooking food. In their own words they expressed that 'being unable to taste things was depressing.' In addition, they are a chef by trade, and in their profession being unable to smell or taste food can be career-ending.

Another person we consulted for this submission expressed that due to debilitating fatigue and weakness caused by long COVID they were unable to enjoy hikes or exercise. There are far-reaching benefits of physical activity,[38] so the ramifications of being unable to exercise are enormous. For individuals with chronic illness, it is particularly important to participate in physical activity, as exercise is linked to improved quality of life.[39] Research indicates that people who are unable to exercise are at greater risk of experiencing depressive symptoms,[40] so may have a higher risk of experiencing suicidal ideation.

*'One of my self-care strategies is cooking. Having that stripped away and not getting enjoyment out of things you normally get enjoyment out of made it a highly anxious time for me.'*
*Person with lived experience*

People we consulted with said that they believe general practitioners are not doing enough to meet the needs of people with long COVID or repeat infection. It was indicated that during doctor's appointment to discuss symptoms members were not asked about their feelings or mood. By the time these members had sought medical assistance several had experienced a decline in their mental health and required additional support. They wished they had been asked about their mental health and offered a referral to a mental health service.

For suicide prevention to be effective, it is vital that key people in the community such as general practitioners receive suicide prevention training. Connector training, also referred to as gatekeeper training, ensures that individuals who are in regular contact with people at risk of suicide are equipped with suicide prevention skills and can respond effectively to those in need. Individuals who act in this capacity fulfill an important role in the community and are often the first to recognise the warning signs of suicide. With the right training, connectors within communities can have a conversation with a patient that could shift their mental health, wellbeing, or suicide risk.[41]

**Recommendation**

5. The Commonwealth Government train and upskill community connectors such as general practitioners in suicide prevention.

## Common experiences of stigma in people living with long COVID and repeat infection

Even though we know long COVID is real, many questions remain, and this presents a significant challenge for individuals who have this complex, chronic illness. Lack of clarity around diagnosis can mean that many individuals suffering from ongoing debilitating symptoms are in limbo. Feedback from a person we consulted with indicated that they felt that seeing a GP made them feel more anxious. The GP had no understanding of long COVID and advised the member that they were unclear how long symptoms would last.

*'When you have a chronic illness and feel disillusioned and scared having support around you helps you stay strong, focused and feel resilient. You also need to believe that society cares about you to fight to get well and reach for support. Chronically ill and disabled folk, including those with long COVID, are being given a strong message that our lives aren't valuable. That's devastating to both your physical and mental health.'*
*Person with lived experience*

For individuals and their families, experiencing long-term symptoms such as ongoing pain or fatigue without a treatment or cure available is particularly difficult and often traumatic. People may experience intense grief due to loss of identity or a career they thought they'd have as they adapt to a new way of living.

A person we consulted with likened long COVID to an invisible illness and voiced that there is considerable stigma associated with illness not outwardly visible to others. This was reinforced by other people we consulted with who said they believed there was a general lack of understanding about long COVID and its severity, and that this extends to the medical community. There was feedback that work colleagues, health professionals, friends and even family members expressed disbelief that long COVID, or associated symptoms were real.

A person we consulted with explained that their employer did not understand the severity of their symptoms or accept it was COVID-related. They stated that they were made to feel that it was 'all in their head'

and felt that their symptoms were trivialized and dismissed. From this conversation it was clear that they experienced significant opposition, and when employers are unaccommodating this amplifies stress. Another person we consulted with explained that due to serious fatigue they had to take time off work and had used up all their sick leave. They are churning through their annual leave and are worried about what they will do when it runs out. It is evident that more needs to be done so that the community including employers are aware that long COVID can cause debilitating symptoms and negatively impact ability to work.

Concerningly, due to the lack of public information, health care providers can also fail to recognise long-COVID symptoms and how it presents in patients. Shockingly, a person we consulted with said they had to stop saying they had long COVID. They felt ashamed and were concerned that others thought they were making it up. Worryingly, they articulated that they felt like they could not trust themselves and wondered if it was all in their head. Public health messaging about the pandemic has ignored long COVID and this is harmful as it deprives people of a shared language and the ability to communicate experiences and access medical health.

Stigma can cause social isolation, and lead to feelings of hopelessness and is linked to increased risk of suicide.[42] It is vital the government act to change attitudes towards long COVID and encourage open conversation about post-covid symptoms to reduce discrimination against sufferers. Long COVID is a new illness, and there are many people within Australia who are not aware of the symptoms associated with long COVID or the disruptive impact it can have on people's lives.

To counteract stigma, people we consulted with suggested the government launch a nation-wide public awareness campaign about long COVID and repeat infection. This will build public recognition and may change attitudes and beliefs related to long COVID and repeat infection.

*'I saw myself spiralling and having depressive thoughts. I went to see my GP to see how long my symptoms would last and was told you just have to 'wait and see'.'*
*Person with lived experience*

**Recommendation**

6. The Commonwealth Government invest in a national public awareness campaign to educate the public on long COVID and repeat infection to reduce stigma and discrimination.

## The impact of long COVID and repeat infection on families and relationships

Long COVID can have a domino effect on the wellbeing of others. Partners and family members of individuals with long COVID indicate it impacts family activities and report feeling worried, sad, and frustrated.[26] In Australia many caregivers are women and as research suggests females are more likely to have long COVID,[43] this can have significant spillover effects on other family members and children.

While research led by the Murdoch Children's Research Institute indicates children are less likely to get long COVID than adults,[44] other data suggests 25% of children and adolescents experience ongoing symptoms.[45] Children experience similar symptoms to adults and have verbalised long COVID as 'exhausting, painful and lonely'.[46] It is well-documented that caring for chronically or continually unwell children can be isolating and considerably stressful for caregivers. Parents of chronically ill children can experience poorer mental health.[47]

It is important to recognise that suicide rates are elevated in individuals with chronic illness,[48] and in those with a mental health condition.[49] Living with a long-term illness can have a negative impact on social relationships and this extends to feelings of belonging.

Sadly, a person we consulted with expressed that they do not get invited out as much anymore as they don't have the energy to go out. People can isolate themselves when feeling unwell and lack the energy to socialise so social disconnection can occur. Another person we consulted with explained that chronic illness had a considerable impact on their social standing and that their friendship circle had drastically shrunk. Social support a key protective factor for suicide is vital for physical health and mental wellbeing yet compromised by ill health.

To better support Australians or families affected by long COVID or repeat infection Suicide Prevention Australia suggests establishing government funded peer support groups. A peer support group allows people to connect with others who share a similar experience in a group setting either online or face-to-face to discuss their knowledge and learn coping skills with others in a safe space. Peer support groups are particularly helpful for reducing isolation, and distress and improving resilience, self-esteem, and wellbeing.

Local peer support groups could be offered in primary care settings and facilitated by a trained mental health practitioner who has received suicide prevention first aid training and is able to recognise suicidal indications. Different peer support groups can be offered for children and young people who have a parent, carer or family member living with long COVID or repeat infection. Considering little is known about the long-term effects of COVID-19 the peer support group could work closely with policymakers, researchers, and other bodies to increase understanding.

**Recommendation**

7. The Commonwealth Government should work with State and Territory Governments to invest in peer-led local support groups across Australia in primary care settings integrating support to address suicide risk factors and behaviours for individuals and families impacted by long COVID and/or repeated COVID infections.

## Acknowledgements Statement

Suicide Prevention Australia acknowledges the unique and important understanding provided by people with lived and living experience. This knowledge and insight is critical in all aspects of suicide prevention policy, practice and research. Advice from individuals with lived experience helped guide the analysis and recommendations outlined in this policy position.

Our Lived Experience Panel helped guide the development of this submission including through advice on physical and mental health repercussions of living with long COVID and chronic illness; the far-reaching impact of long COVID on relationships, work and life; and the significant need to increase support now and in the long-term for people living with long COVID or repeat infection.

As the national peak body for suicide prevention, our members are central to all that we do. Advice from our members, including the largest and many of the smallest organisations working in suicide prevention, as well as practitioners, researchers and community leaders is key to the development of our policy positions. Suicide Prevention Australia thanks all involved in the development of this policy position.



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