



COVID-19: A roadmap for recovery



Lung
Foundation
Australia

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Lung Foundation Australia is the nation's leading peak body for respiratory health and lung disease. Lung Foundation Australia funds life-changing research and delivers support services to enable Australians with lung disease and lung cancer to live their best life.

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Acknowledgement of Country

Lung Foundation Australia acknowledges Australia's First Nations People and pay our respect to Aboriginal and Torres Strait Islander Elders, past, present and emerging. We do so in a spirit of reconciliation recognising that Aboriginal and Torres Strait Islander people across Australia are significantly overrepresented in lung disease and lung cancer. We commit to partnering with communities to address this and Close the Gap.

Executive summary

The emergence of COVID-19 has transformed the lives of all Australians, with the nation continuing to manage the biggest public health emergency of the twenty first century, so far. The number of COVID-19 cases in the country has exceeded 10 million and there have been more than 15,000 COVID-related deaths. As we transition to the endemic phase of the disease, the nation has a unique and important opportunity to learn how COVID-19 has affected the Australian community. We can also deepen our knowledge of how the pandemic impacted all Australians and the unique experience of people living with lung disease including lung cancer, and gain a deeper understanding of the prevalence and impact of ongoing COVID-19 symptoms (often referred to as long COVID). National estimates of long COVID prevalence range from 10 to 30% of those who have acquired COVID-19. This means that millions of Australians may be suffering from ongoing symptoms or may be at risk of developing such symptoms following a COVID-19 infection. Ongoing COVID-19 symptoms can severely impact an individual's life, reducing their ability to work and their quality of life. Research suggests ongoing symptoms may include fatigue and post-exertional malaise, respiratory and heart symptoms, neurological symptoms, and digestive symptoms.

Our collective lack of understanding of COVID-19 impacts in Australia opens the way for critical gaps in our health services, leaving those experiencing ongoing COVID-19 symptoms unsupported and without tailored care. In order to gauge the extent of these gaps, Lung Foundation Australia recently surveyed Australians, including those who have had COVID-19, those who have not had COVID-19, and carers, finding both similarities and significant differences in their experiences. We explored and noted the differences in experience between the general population and those living with a chronic condition, lung disease or lung cancer, and we reported the various challenges faced by different population groups.

Lung Foundation Australia's survey and accompanying report provides new and important data for government and non-government organisations to consider. The impacts of COVID-19 on Australians will continue to be felt, and we must address the needs of the community and acknowledge that our response to COVID-19 will have a lasting impact on the lives of our population. We also have a unique opportunity to reshape the narrative and to make significant improvements to health and to advance the health system.

Based on the current evidence and the findings from Lung Foundation Australia's survey, it is clear that a holistic approach is needed and we have made the following recommendations as a roadmap for change:

- 1. Fund respiratory nurses to support people with ongoing symptoms**
- 2. Ensure access to quality information and tailored support to manage COVID-19 symptoms and recovery**
- 3. Enhance physical activity and self-management through pulmonary rehabilitation**
- 4. Address the unique mental health needs of Australians living with a lung disease**
- 5. Transition long COVID clinics to multipurpose respiratory clinics**
- 6. Utilise and strengthen both telehealth and face-to-face healthcare**
- 7. Create a health-professional strategy and COVID-19 training**
- 8. Adopt a national long COVID definition to enhance data collection and research**
- 9. Harness acceptance of vaccinations now and expand the National Immunisation Program**
- 10. Invest in the National Preventive Health Strategy**

Now more than ever, it is time to leverage the enhanced awareness of lung health and the importance of being able to breathe freely. By reshaping the anxiety around respiratory health and harnessing the optimism of Australians, we can create positive, proactive change to improve the health of Australians now and into the future.



Professor Lucy Morgan
Chairperson



Mark Brooke
Chief Executive Officer

About Lung Foundation Australia

Lung Foundation Australia is Australia's only national charity and leading peak body dedicated to supporting people with a lung disease, including lung cancer. For over 31 years we have been a trusted, national touch point on matters of lung health for people living with lung disease, their families, carers, health professionals and the general community. There are over 30 different types of lung disease and together these impact one in three Australians.

Our mission is to improve lung health and to reduce the impacts of lung disease on all Australians. We are working to ensure that lung health remains a community priority through activities including promoting lung health and early diagnosis, and advocating for policy change and research investment. We raise awareness about the symptoms and prevalence of lung disease, and we champion equitable access to treatment and care. As a patient-representative charity, we partner with people living with lung disease, health professionals, researchers, medical organisations, and the Australian community. Together, we can drive reform in the delivery of health services across the country and assist the more than seven million Australians impacted by lung disease and lung cancer.

Lung Foundation Australia has offices across several Australian states. We are committed to achieving integration with state-based health systems so that the community has access to timely and accurate information and support.



Lung Foundation Australia and COVID-19

COVID-19 (SARS-CoV-2) is an infectious viral disease primarily impacting the upper airway and the lungs. It often results in respiratory symptoms such as a cough and sore throat, and, in severe cases, breathlessness, pneumonia, and acute respiratory failure. The respiratory nature of the illness has meant that Lung Foundation Australia has naturally played a critical role in supporting people living with lung disease and lung cancer throughout the pandemic.

We are regarded by the community as source of accurate and reliable information about respiratory illness. At the beginning of the pandemic, we delivered important, timely information to the lung disease and lung cancer community, and we continue to provide updates and information. In 2020, Lung Foundation Australia hosted a health professional COVID-19 webinar series, led by Professor Christine Jenkins AM, to provide COVID-19 updates to more than 1,000 health professionals across Australia as our understanding of COVID-19 evolved. Lung Foundation Australia also presented six webinars for those living with a lung disease and lung cancer in order to provide tailored information and support regarding COVID-19 and its interaction with specific lung diseases.

The need for information and support grew significantly through the pandemic with:

- **a 62% increase in Lung Foundation Australia website traffic during the peak of the pandemic**
- **over 134,000 visits to our digital COVID-19 resources and information**
- **an increase in calls and requests for information on COVID-19 and their disease, and**
- **a surge in reports of distress among both patients and carers.**

Lung Foundation Australia supports and advocates for improved lung health for all Australians. As the peak lung organisation, we are devoted to caring and supporting all Australians through the impacts of COVID-19. People living with a lung disease are particularly vulnerable to the effects of respiratory viruses such as COVID-19 and require tailored support, information, and care to ensure they understand how to manage their condition when experiencing a respiratory illness. Infection with the COVID-19 virus has created new health concerns for many Australians who are experiencing post-acute symptoms, such as breathlessness. Lung Foundation Australia is committed to addressing care gaps in the community by providing support for ongoing COVID-19-related respiratory impacts, providing evidence-based information and support, and enhancing our existing role of supporting Australians living with a lung disease or lung cancer. As the leading peak body in Australia, Lung Foundation Australia is equipped with the knowledge, structures and experience needed to provide continued support and information.

The long-term impacts of COVID-19 are not fully understood at this point in time, with some emerging evidence even suggesting an association between COVID-19 infection and the development of lung cancer.^{1,2,3} Further, the proportion of people experiencing ongoing symptoms is poorly understood. The Australian Department of Health and Aged Care states the figure may range from 10 to 30% of those who have been infected with COVID-19.⁴ International evidence varies, with self-reported data from United Kingdom estimating as of August 2022 that at least 3% of the population are experiencing ongoing COVID-19 symptoms.⁵

Australia experienced comparatively low COVID-19 infection rates for the first two years of the pandemic, with strong public health measures remaining in place until high vaccination rates were reached in December 2021. As Australia is only now experiencing the severe challenges many other countries have already encountered and responded to, it is vital that we consider international evidence and models such as the post-COVID Hub created by Asthma and Lung UK to support people with long COVID symptoms.⁶ Building on this international work, Lung Foundation Australia is committed to ensuring that all Australians, including those with and without a pre-existing lung disease, have their needs met when it comes to COVID-19 and COVID recovery.

Commissioned research

To gain a further understanding of the support required for the lung disease community, Lung Foundation Australia partnered with The George Institute for Global Health to try to identify the relationship between long COVID and lung disease. A rapid review titled *Characteristics and impact of long COVID-19 in people with lung disease* was prepared by Dr Agnivo Sengupta and Professor Christine Jenkins AM in August 2022. It will form the basis of the discussion and recommendations throughout this report.⁷

The rapid review analysed data from 84 studies, with the majority of the studies undertaken in European countries.⁸ The results showed that long COVID may cause a spectrum of symptoms, including fatigue, myalgia, palpitations, muscle or joint pain, chest pain or tightness, dyspnoea at rest or on exertion, sleep difficulties, loss of smell and taste, gastrointestinal complaints (diarrhoea, nausea), headache, and hair loss.⁹ People who were hospitalised, mechanically ventilated, or had a more severe infection in the acute phase were more likely to develop long COVID.¹⁰ Psychological symptoms associated with long COVID included anxiety and depression, with many indicating poorer self-reported quality of life.¹¹ Other symptoms often reported included poor sleep quality, cognitive impairment, lack of concentration and memory lapses.¹² People with long COVID symptoms reported mild to moderate limitations in undertaking activities, including an inability to perform their usual activities and experiencing pain and discomfort.¹³

Studies involving imaging and diagnostics have commonly identified Pulmonary Fibrosis (thickened and scarred lung tissue). However, the proportion of patients with radiological abnormalities varies from 0.01% in community-based populations to over 50% in patients who were followed up after hospital or ICU admission.¹⁴ Chest CT scans commonly identified abnormalities such as ground glass opacities and consolidation, with many lung studies concluding there was impaired diffusion capacity (gas transfer) in the lung four weeks post a COVID-19 infection.¹⁵ However, improvements in lung function tests at six months were reported for people who had moderate to severe COVID-19 infections.¹⁶

The rapid review concluded that people with an increased risk of long COVID include those over 40 years, females, people with higher BMIs, and people who were admitted to ICU due to COVID-19.¹⁷ **The prevalence of long COVID varies because of changing virus variants, testing requirements, severity of acute infection of COVID-19, and access to antivirals and vaccinations. However, Sengupta and Jenkins concluded that the prevalence of long COVID ranges from 3 to 12%.**¹⁸ The review determined that both hospitalised and non-hospitalised people may experience long COVID.¹⁹ Although an Italian study of hospitalised patients with COVID-19 showed longer resolution of abnormal diffusing capacity in those with asthma compared to those without, due to the lack of confirmatory data it could not be concluded if this represented a true indication of increased risk of long COVID or a susceptibility to persistent respiratory symptoms or new abnormalities for people living with a pre-existing lung disease.²⁰

This rapid review highlighted the need to distinguish between long COVID and slow recovery, and pointed to a lack of agreement in Australia around the clinical definition of long COVID. Clarity around these terms is critical in order for Australians to be able to understand the pathways that recovery can take and to access the support and services they need to get better. With this in mind, Lung Foundation Australia has adopted the term 'ongoing COVID-19 symptoms and COVID recovery' as a basis for the information and support it provides to people experiencing ongoing symptoms after an acute infection period of four weeks.

In the Lung Foundation Australia consumer COVID survey, the following definitions were utilised:

- **Acute infection:** refers to a period of up to four weeks following the initial COVID-19 infection.
- **Ongoing COVID-19 symptoms:** refers to symptoms continuing beyond the four weeks following initial infection.
- **COVID-19 recovery:** refers to the recovery period following the acute phase of a COVID-19 infection.

The term 'long COVID' was used in the public survey, in recognition of the fact that this name has been widely adopted around the world to signify ongoing symptoms.

Recommendation:

- ▶ **Create a national long COVID definition to enhance data collection and research**



Project overview

The survey developed by Lung Foundation Australia aimed to capture the experiences of a broad spectrum of Australians, with a particular focus on better understanding the impacts of the pandemic on the lung disease community and how they were impacted by ongoing COVID-19 symptoms. Analysis of the survey results has provided Lung Foundation Australia with a clear understanding of the types of healthcare, information and support that may be needed to help people manage ongoing symptoms and aid in their COVID-19 recovery. Along with a significant increase in COVID-19 case numbers in Australia has come an increase in the potential for people to experience ongoing COVID-19 symptoms, impacting their everyday lives.

The purpose of the survey was multi-faceted, aiming to understand:

- **The prevalence and severity of health impacts from COVID-19**
- **How often people are experiencing ongoing symptoms, what these symptoms are, and the impact they have**
- **Health system challenges and impacts throughout COVID-19 up until the survey date**
- **Any gaps in service provision, information and resources for people with ongoing symptoms**
- **The unique experiences of people living with a pre-existing chronic condition, including lung disease**
- **The experience of carers**
- **The community's current vaccination intentions**
- **The Australian perspective of the COVID-19 response and how Australians perceive their future with COVID-19.**

Demographics

The survey received **2,196 responses**. It ran between the 6 July 2022 and 27 July 2022, and was promoted through targeted paid posts on social media, direct communications with Lung Foundation Australia's database, and other avenues such as social networks.

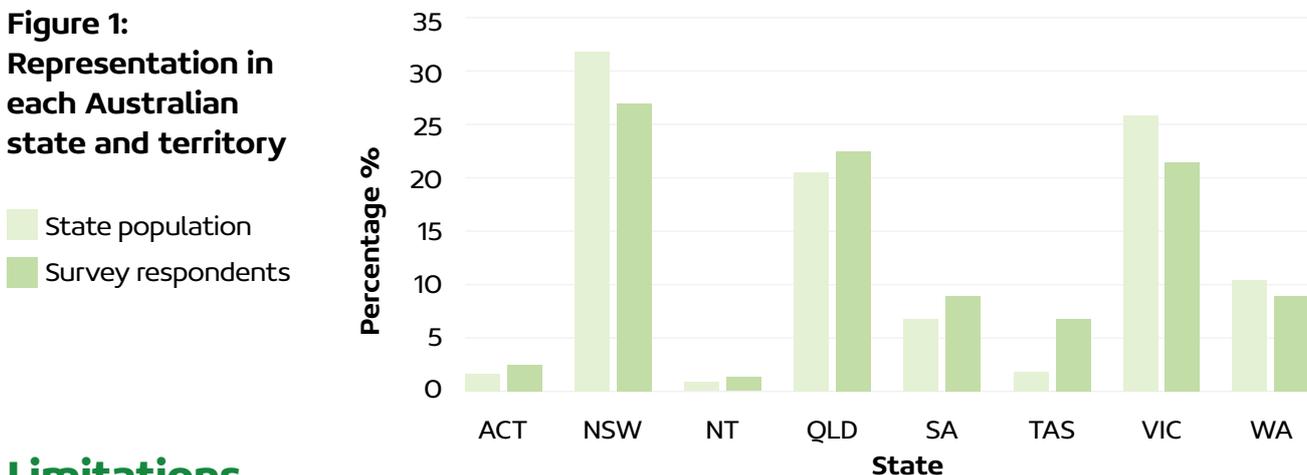
The survey was open to all Australians, and sought perspectives from:

- People who had experienced a COVID-19 infection and people who had not had COVID-19
- People who had cared for someone with COVID-19
- People living with a pre-existing lung condition or other chronic condition
- People who wished to share their experience of the health system from the start of the pandemic to the survey date.

The survey respondent population can be described as:

- Close to equally split between those who had not had COVID-19 (47%) and those who had (53%)
- Aged from 18 years, with representation higher in the survey for people aged 55 years and over (57%)
- Representing each Australian state and territory (Refer to Figure 1)
- More female (72%) than male
- Having a vaccination status representative of the Australian population. Some 95.5% of respondents had received two or more vaccine doses compared to the national rate of 96.2%²¹.
- In terms of diversity:
 - 8% of respondents identified as Aboriginal or Torres Strait Islander
 - 9% of respondents identified with being from a culturally and linguistically diverse background
- 9% of respondents cared or had in the past cared for someone with COVID-19
- 54% of respondents were living with a chronic health condition
- 46% of respondents were living with a lung disease or lung cancer.

Figure 1:
Representation in each Australian state and territory



Limitations

The survey relied on participants self-reporting their experiences. A reference to a long COVID diagnosis within a response does not necessarily reflect a medical diagnosis of long COVID. The data also reflects a specific period in time and thus cannot be used to accurately extrapolate the proportion of Australians impacted by ongoing symptoms in the future. This is due to the fact that long COVID rates have been shown to fluctuate in line with changing variants, immunisation, and access to antivirals.

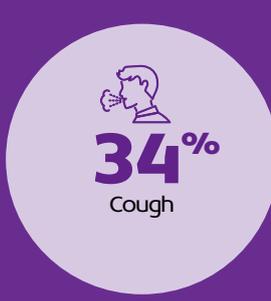
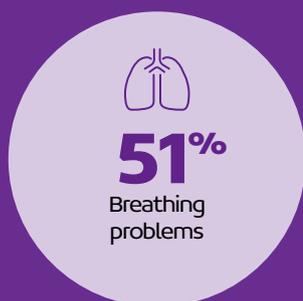
The survey was not entirely representative of the Australian population, with a low male response rate (27%) and a low young-adult response rate (3% 18-24 years old). This contrasts with the high case numbers experienced by this age group, as for the entire Omicron wave to date (15 December 2021 – 28 August 2022), the highest case rate has been in adults aged 18-29 years.²²

Experience of Australians through the pandemic



1 in 2 people experienced ongoing COVID-19 symptoms following an infection period of 4 weeks

Ongoing COVID-19 symptoms most impacting normal life:



3 in 5 individuals have sought medical advice or treatment for ongoing symptoms



Top professions medical advice was sought from:



3 in 4 people think the government should invest in increasing support and information for those with ongoing COVID-19 symptoms

Recommendations

- ▶ Fund respiratory nurses to support people with ongoing symptoms
- ▶ Ensure access to quality information and tailored support to manage COVID-19 symptoms and recovery
- ▶ Enhance physical activity and self-management through pulmonary rehabilitation
- ▶ Address the unique mental health needs of Australians living with a lung disease

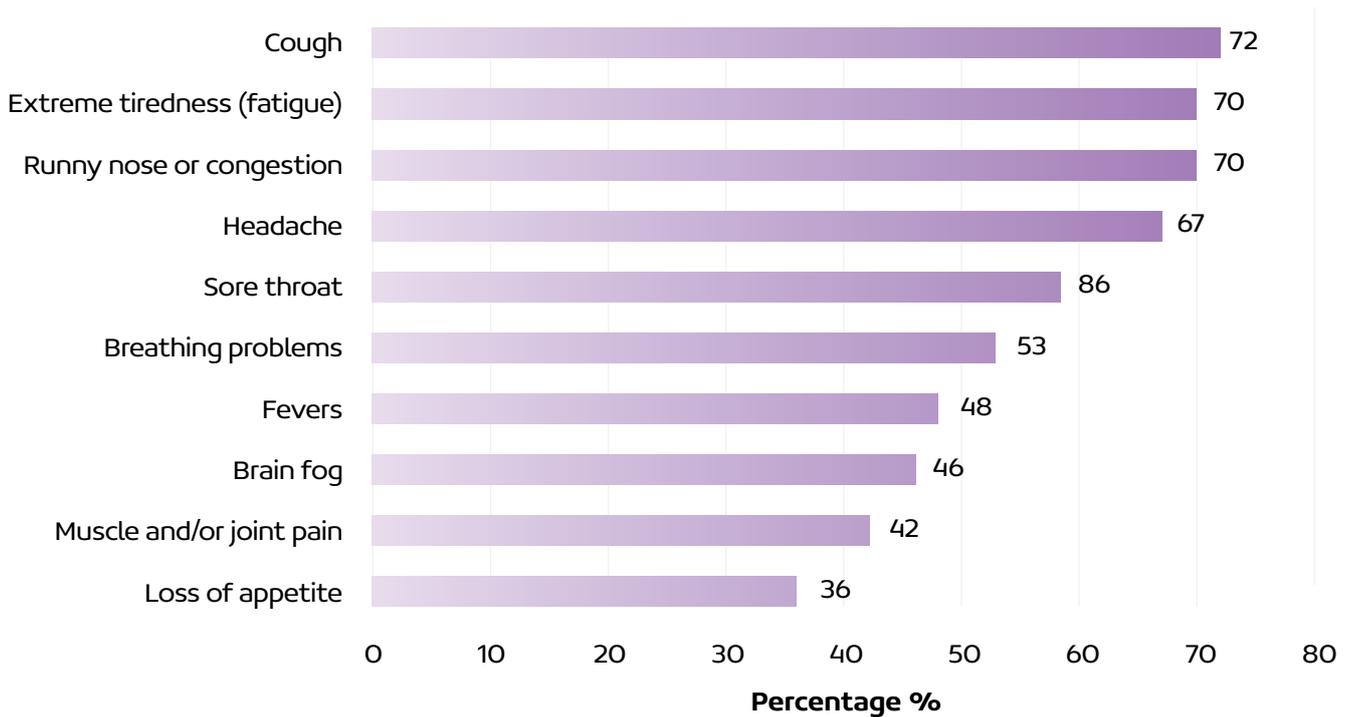


As of 1 September 2022, Australia had experienced several COVID-19 waves which had resulted in over 10 million infections and more than 14,000 deaths. As case numbers continue to rise, it is vital to understand how COVID-19 is impacting Australians and what support is likely to be required into the future.

The acute COVID-19 infection

Of survey respondents, 53% had experienced a COVID-19 infection. The most self-reported acute symptoms included a cough (72%), extreme tiredness/fatigue (70%), runny nose or congestion (70%), headache (67%) and a sore throat (58%) (Refer to Figure 2). Less than 1% of people reported having no symptoms.

Figure 2: Self-reported symptoms experienced in acute infection of COVID-19



Other symptoms experienced less frequently included sleep problems (29%), dizziness (28%), new loss of taste or smell (27%), diarrhoea or vomiting (20%), and nightmares or flashbacks (6%).

Close to one in two respondents (47%) reported that their symptoms from COVID-19 were more severe compared to other respiratory viruses experienced. Only one in four (25%) reported that they were milder. Compared to previous variants, Omicron appears to cause less severe disease and its symptoms are reported to be mild, particularly for people who have received at least two vaccinations.²³ And yet even with the milder Omicron variant circulating and vaccination rates for Australians at high levels, participants still reported symptoms that were as or more severe than other respiratory viruses.

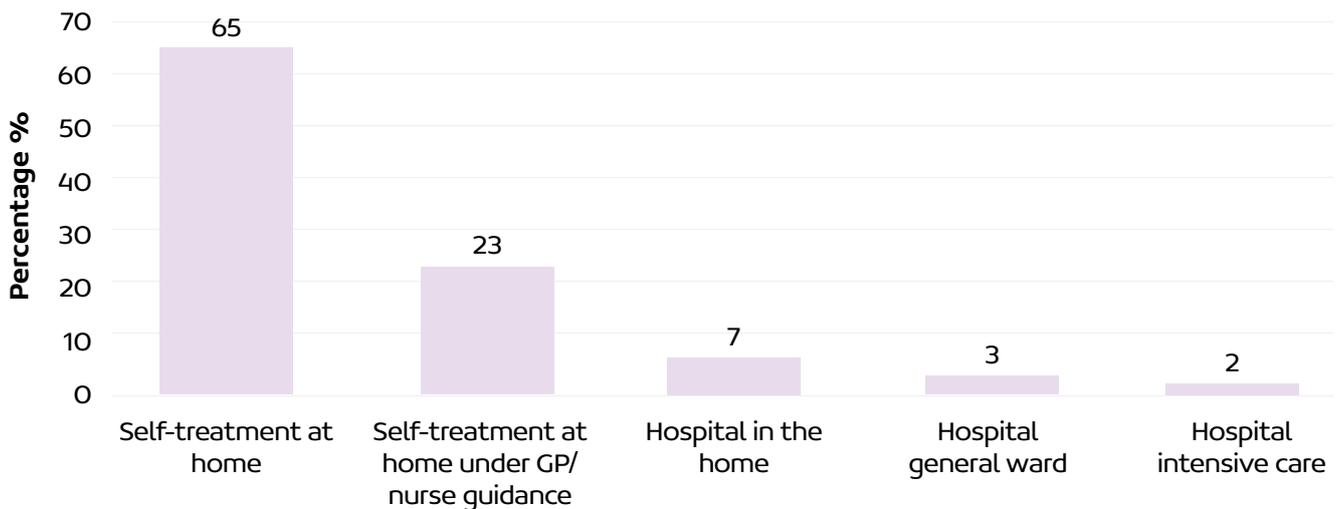


“Am very anxious of contracting another bout of COVID, fearful of getting so sick again!”

– VIC resident who had COVID-19

When it came to the treatment needed for those who had COVID-19, the survey identified 65% of people only required self-treatment at home. A further 23% received self-treatment at home with guidance of a GP/nurse, and 7% used hospital in the home service. Of the 5% who were hospitalised, 3% were hospitalised at a general ward and 2% were hospitalised in intensive care (Refer to Figure 3). The majority of respondents contracted COVID-19 less than four weeks prior to completing the survey.

Figure 3: Care received for acute COVID-19 infection



Ongoing COVID-19 symptoms

People who experience a COVID-19 infection generally reported a full recovery. However, some people experienced ongoing symptoms. Importantly, studies have demonstrated that regardless of the severity of the acute COVID-19 infection, people can experience ongoing symptoms.



“My COVID was very mild, literally two days, that’s why I was so surprised to get breathless and long COVID symptoms.”

- WA resident who had COVID-19

As previously mentioned, for the purposes of this survey, we defined ongoing symptoms as symptoms lasting beyond four weeks. More than one in two respondents (54%) who had experienced COVID-19 reported ongoing symptoms. The reported symptoms which most impacted normal life included breathing problems (51%), fatigue (50%), cough (34%), brain fog (31%) and being less able to do physical activity (23%) (Refer to Figure 4). The survey found ongoing symptoms had clear impacts on everyday life, strengthening the need to have greater recognition of the respiratory impacts and additional challenges that Australians are experiencing due to physical activity limitations after COVID-19 infection.

Exercise and educational programs, such as pulmonary rehabilitation (PR), can teach people the skills needed to exercise safely and manage breathlessness. This, in turn, can improve their ability to complete daily tasks such as showering, walking and undertaking household chores. PR is currently used for people with a lung disease. However, the program may also be effective in supporting people with ongoing COVID-19 symptoms and COVID-19 recovery. People who experience post-exertional symptom exacerbation, may require adjustments to PR programs to accommodate careful monitoring of symptoms, activity and energy management. A PR audit facilitated by Lung Foundation Australia in 2022, indicated 59% of PR services are supporting patients with long COVID.



“[I had] reduced exercise tolerance and ability to work as much or exercise as much. Support for people with long COVID. Fear of the future, if I can no longer work full time. Loss of enjoyment of life due to fatigue and breathlessness.”

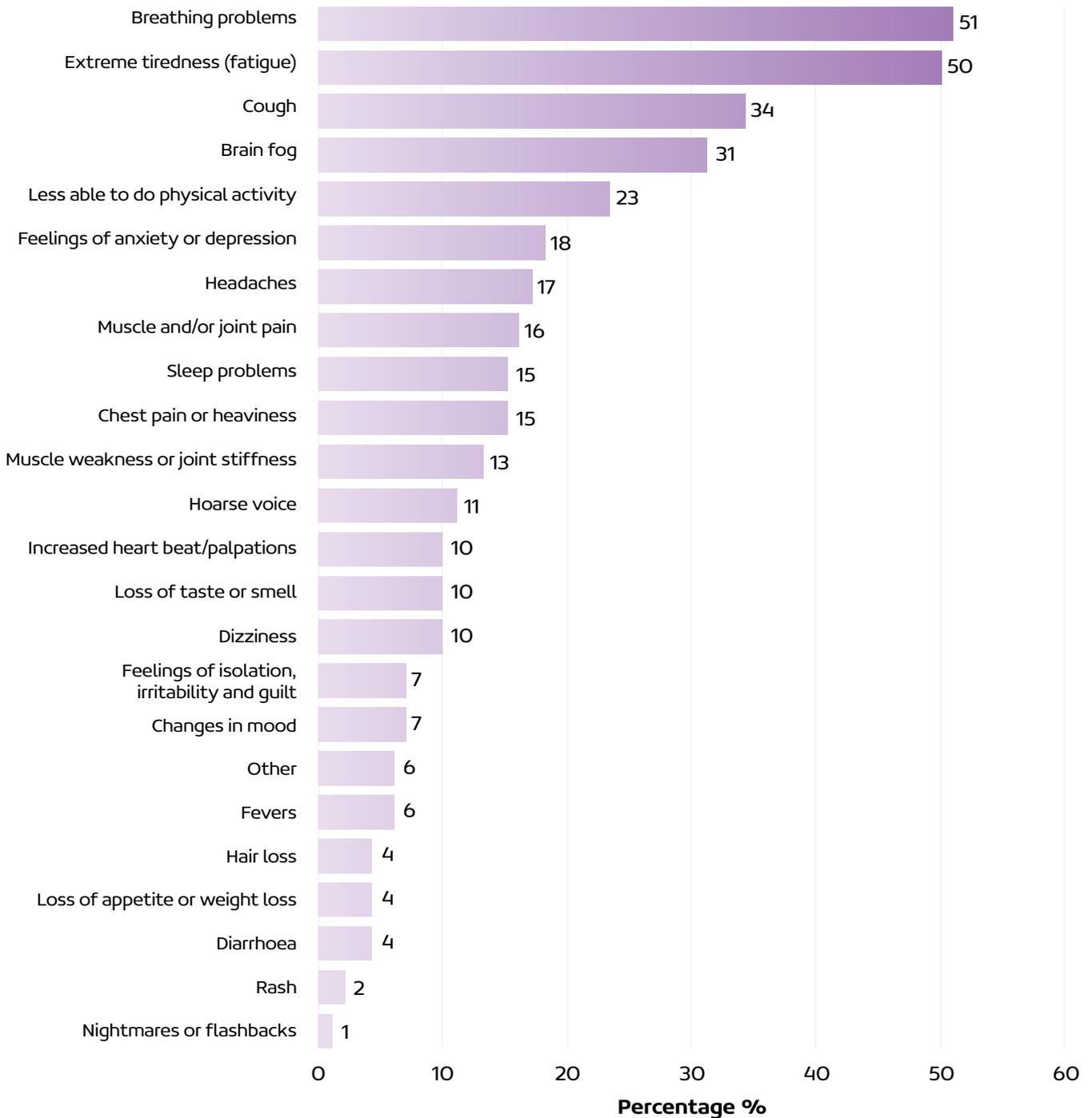
- QLD resident who had COVID-19



“[I had] reduced exercise due to [the] need to recover. Loss of income. Reduced quality diet during illness due to [the] inability to cook. Hope more people take it more seriously when there is a surge in infections in the community.”

- NSW resident who had COVID-19

Figure 4: Ongoing COVID-19 symptoms that have most impacted normal life



The survey further found people experiencing ongoing COVID-19 symptoms were severely impacted in their everyday lives, highlighting the need for further support. Among the 54% of people who reported having ongoing symptoms more than four weeks post COVID, some 46% said that their ability to do household chores and activities was always or often impacted. This impact on regular activities is certain to have flow-on effects, and add to the impacts on physical wellbeing (with the ability to exercise being impacted at 63%) and emotional wellbeing (42%). The need for further supports for Australians who are experiencing ongoing COVID-19 symptoms is clear.



“Our life has not been the same since the kids became unwell seven months ago. I’ve been unable to work, they’ve been unable to participate properly in school or any other aspects of their former lives. The lack of knowledge about children and long COVID is very poor, and some medical professionals have proven to have limited understanding of invisible illnesses.”

– VIC resident who had COVID-19



“I am looking at doing work that has less emotional and physical exertion. I hope that there will be more public education about what to do if you have COVID, what to do if you have long COVID.”

- ACT resident



“It has had a huge impact on my life as a health care worker and a person with long COVID symptoms now. I have lost hope that work will get easier and that the pandemic will ever be over. Every new strain fills me with dread. I am considering leaving my profession which I love but cannot go on working under those conditions.”

- VIC resident who had COVID-19

Managing ongoing COVID-19 symptoms

The management of ongoing COVID-19 symptoms is a difficult path for many to navigate. The novelty of the virus means that there is a general lack of resources and information. In the survey, only three in five respondents (58%) had sought medical advice or treatment for ongoing symptoms. Of those who had, this advice was mainly being acquired from a general practitioner GP (65%), allied health professional (15%), psychologist or other mental health professional (8%) and pharmacist (8%). This means that 40% of respondents experiencing ongoing symptoms are not seeking medical advice or treatment. The true burden of people requiring support and care for ongoing symptoms, therefore, may be underestimated.

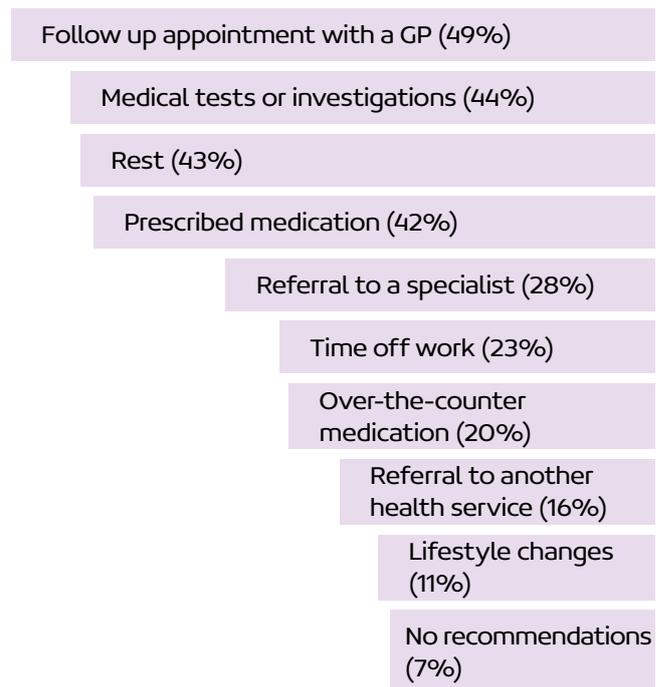
Almost one in two respondents with ongoing symptoms (44%) had a health professional refer to their ongoing symptoms as long COVID. A follow-up appointment with a GP was the most reported recommendation (49%) followed by medical tests or investigations (44%) (Refer to Figure 5). The information provided was noted as easy to understand by 55%, and provided verbally (48%). However, less than one in three (27%) reported the information gave them confidence to manage their symptoms. Around one in ten of this group (12%) received information in writing to which they could later refer to.

In response to the presence of ongoing COVID-19 symptoms in the community, Lung Foundation Australia in 2022 presented a webinar for health professionals on the issue of post-acute and long COVID care.²⁴ Given the more than 650 registrations received for the event, it is clear that health professionals are seeking guidance and information on how to provide the best care possible for patients with ongoing COVID-19 symptoms.

Following an appointment with a health professional, more than two in five respondents (43%) looked elsewhere for information to help manage or understand their ongoing COVID-19 symptoms. Additional information was sought via the Department of Health (45%), another medical practitioner (38%), international health websites (30%) and another website (30%). When asked what type of information would be helpful to manage ongoing COVID-19 symptoms, people reported: treatment options (74%); stories from others experiencing ongoing symptoms (43%); a written management plan (43%); mental health support (42%); and lifestyle changes (36%).

65%
of survey respondents expressed very high levels of trust in medical professionals for accurate and unbiased health information, services and support.

Figure 5: Recommendations from health professionals received by respondents with ongoing symptoms



Supporting people with ongoing COVID-19 symptoms

Ongoing COVID-19 symptoms may impact a significant proportion of Australia's population, leaving many unable to live a healthy, productive and fulfilling life for varying periods of time after having COVID-19. Nearly three in four respondents (73%) think that the government should invest in increasing support and information for people experiencing ongoing COVID symptoms, indicating that many believe the government is not currently meeting support and care needs. Australians experiencing ongoing COVID-19 symptoms need access to clear information and tailored support. This should acknowledge the changing environment of symptom management and treatment and the fact that further research is needed to fully understand ongoing symptoms.

The growing body of international evidence and research regarding ongoing symptoms can be used to guide and inform the Australian response.



“Accessing specialists post-infection has been impossible. It’s a 12-month wait to access a respiratory specialist on the Gold Coast. There are no long COVID clinics in Qld.”

- QLD resident who had COVID-19



“My life has been turned upside down. Long COVID support in regional Victoria needs to be improved.”

- VIC resident who had COVID-19



“[I want] easier and more access to long COVID support, more information from reliable sources provided for people.”

- VIC resident who had COVID-19



“The pandemic brought on new feelings of anxiety. After having COVID, I struggled for a while with shortness of breath and brain fog and as did many of the people I knew. However, we had no information on this and when it would clear. I hope for the future more research is available.”

- NSW resident who had COVID-19

Some seven in ten respondents (70%) reported they would be interested in accessing a free, COVID-19-specific telephone-based respiratory nurse to help manage symptoms following COVID-19. We note that the existing telephone-based respiratory nurse model of care is evidence-based and led by Lung Foundation Australia through its initiative for Australians living with Chronic Obstructive Pulmonary Disease (COPD) and bronchiectasis. This service has clearly proven its value in supporting patients through their symptoms and their disease journeys. Self-reported evaluation data indicated that prior to using the service individuals were 1.8 times more likely to present to an emergency department and 1.4 times more likely to be admitted to hospital than those who were involved in the service for 12 months.

Nearly half (46%) of survey respondents would consider joining a Lung Foundation Australia peer-support group to connect with others who were going through similar experiences. Given the current pressure on the health system and the access challenges that Australians are facing, this concept of a telehealth COVID-19 respiratory care nurse offers a novel solution. There is a clear interest in both services, which emphasises the need for further support options to be available.

7 in 10 people reported they **would be interested in accessing a free COVID-19 telephone-based respiratory nurse** to help manage ongoing COVID-19 symptoms

Experience of Australians living with a lung disease or other chronic condition

People experiencing ongoing symptoms had



57%

A lung disease



58%

A chronic condition



51%

No chronic health condition



44% of people who were living with a chronic condition other than a lung disease, reported ongoing breathing problems impacted their life the most



Nearly 3 in 5 people living with a lung disease sought medical advice or treatment for ongoing symptoms



44% of people living with a lung disease or other chronic condition reported that ongoing symptoms have mostly or completely resolved



95% of people mainly sought GP advice

Recommendations

- ▶ Fund respiratory nurses to support people with ongoing symptoms
- ▶ Ensure access to quality information and tailored support to manage COVID-19 symptoms and recovery
- ▶ Address the unique mental health needs of Australians living with a lung disease
- ▶ Transition long COVID clinics to multipurpose respiratory clinics



Pre-existing chronic health conditions can increase the severity of illness from a COVID-19 infection. People with chronic health conditions, such as those living with a lung disease or lung cancer, are considered vulnerable, and this increases the need for their conditions to be well managed prior to an infection²⁵. Acute respiratory infections often exacerbate symptoms for people living with a lung disease. This creates a need to understand how COVID-19 is impacting the community of people living with a lung disease. Of the survey respondents, 60% indicated they had an underlying chronic health condition, with 85% of these people living with a lung disease such as COPD, Idiopathic Pulmonary Fibrosis (IPF), bronchiectasis, asthma, silicosis, rarer lung diseases and lung cancer. Other chronic co-existing conditions include but are not limited to arthritis, heart disease/blood pressure problems, back pain, mental health conditions and osteoporosis.

The acute COVID-19 infection

People with a chronic condition are said to be vulnerable to the effects of COVID-19. Research has shown that individuals living with respiratory and non-respiratory comorbidities are more vulnerable to acquiring COVID-19 and experience more severe disease.²⁶ A systematic review of 33 studies identified the higher prevalence of respiratory disease in fatal COVID-19 cases, supporting the high levels of concern felt by the community living with or caring for someone with a respiratory disease.²⁷ However, survey respondents with a chronic (46%) and no chronic (48%) health condition reported similar disease severity levels to those living with a lung disease (46%), thus many reported the virus was more severe compared to other respiratory viruses they had previously experienced.

Survey respondents with a pre-existing lung disease reported increased rates of treatment under the guidance of a GP/nurse (45%) compared to those respondents with other chronic diseases for whom the rate was 28%. The rate of treatment in hospital was similar for both groups at 7%, compared to people with no chronic disease at 3%. Furthermore, the rate of self-treatment at home was highest for respondents with no underlying chronic health condition (78%) followed by other chronic conditions (65%) and lung disease (48%). The occurrence of higher hospitalisation rates for people with chronic health conditions is to be expected, as evidence suggests underlying health conditions can lead to severe disease, resulting in the need for additional treatment and care in hospital.²⁸



“[I want] more follow-up from GP, hospital or Health Dept. if they know you are living with a lung disease... I am still testing positive after four weeks and I can't physically see my GP to get my lungs and breathing checked - both of which I feel have been hit hard... coughing is more laboured, constant and sleeping more.”

- NSW resident living with a lung disease

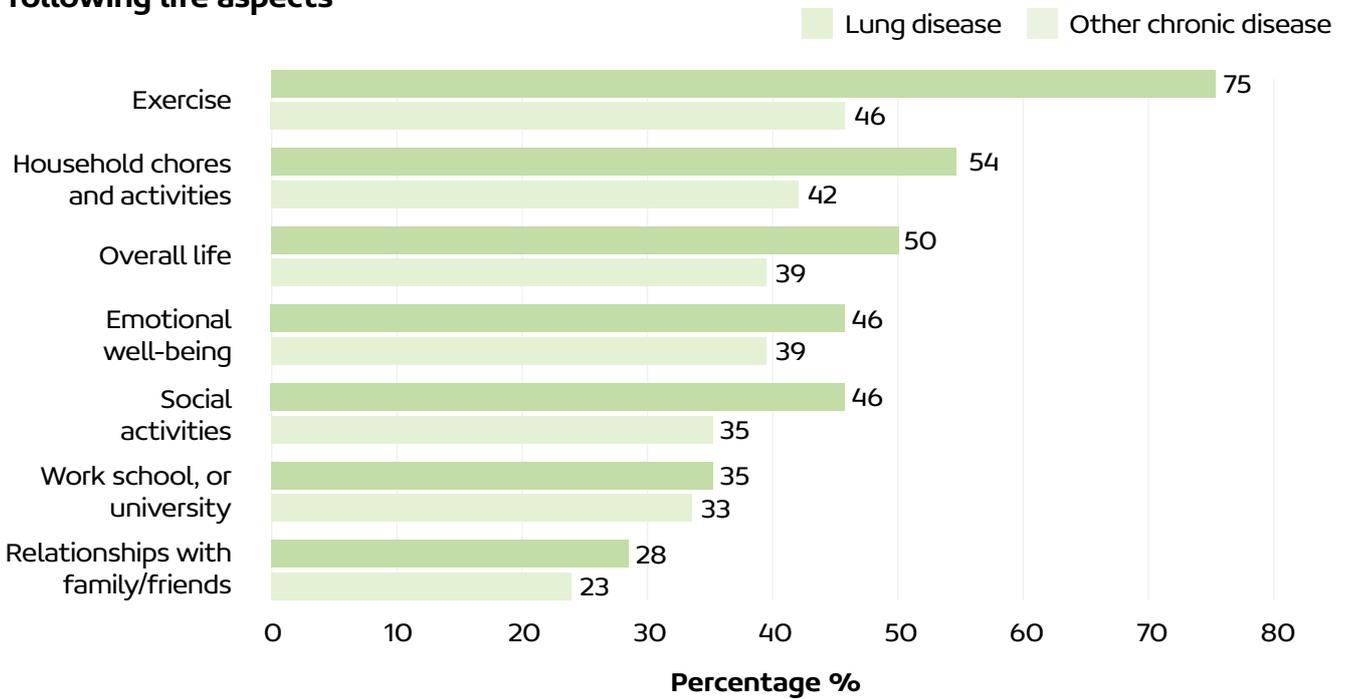
Ongoing COVID-19 symptoms

The survey found that people living with a lung disease or chronic health condition had a higher reported incidence of ongoing COVID-19 symptoms, with rates of 57% and 58% respectively. The rate for those without a chronic health condition was 51%. Fewer than one in two people living with a lung disease or another chronic condition (44%) reported that their ongoing symptoms had mostly or completely resolved. In comparison, respondents with no chronic disease were less likely to report current ongoing symptoms, with 56% reporting symptoms had mostly or completely resolved. Research has demonstrated that people who experience a more severe acute COVID-19 infection are more likely to develop ongoing COVID symptoms. However, it is important to note that such people – who more become more unwell and require further treatment – are likely to take longer to recover than someone with a mild illness.²⁹ **The rapid literature review concluded that currently there is not a consistent link between ongoing COVID-19 symptoms and underlying respiratory disease. However, people living with a lung disease may experience ongoing symptoms for a longer time before returning to their initial baseline.**³⁰

Ongoing symptoms can differ widely between individuals. However, three in five people living with a lung disease (61%) reported that breathing problems were the most significant ongoing symptom affecting

their life. Furthermore, ongoing COVID-19 symptoms affected the ability to exercise for three in four people living with a lung disease (75%), and the ability to complete household chores for more than one in two (54%) (Refer to Figure 6).

Figure 6: Ongoing COVID-19 symptoms that have always or often impacted the following life aspects



For almost one in two people living with a chronic condition other than a lung disease (44%), breathing problems were reported as the ongoing symptom most impacting normal life. Ongoing symptoms greatly impacted the ability to exercise as reported by nearly one in two respondents (46%) (Refer to Figure 6).

“As I have mild COPD that I take a medication for every day I have found since having COVID my breathing has become worse and I had all the vaccines. This has affected my ability to do physical chores and meal preparation etc.”
 - VIC resident living with a lung disease

“I’m still very tired and have no energy I’m finding it so hard to do things around the house.”
 - QLD resident living with a lung disease

“I fared quite well during the pandemic until I caught COVID-19. Since then, my health has been a real struggle. I had COPD and asthma prior to being infected. I had to have CT scan to check my lungs after my illness due to shortness of breath, more so than usual.”
 - VIC resident living with a lung disease

Managing ongoing COVID-19 symptoms

Nearly three in five respondents living with a lung disease (59%) sought medical advice or treatment for their ongoing symptoms, with 95% of those mainly seeking medical advice from a GP. In 92% of cases, the health professional recommended follow-up. By comparison, 68% of respondents with other chronic health conditions sought medical advice or treatment for their ongoing symptoms, with 54% mainly seeking advice from a GP. For 97% of these respondents, the health professional recommended some sort of follow-up.

The experience of Australians living with a lung disease or other chronic condition

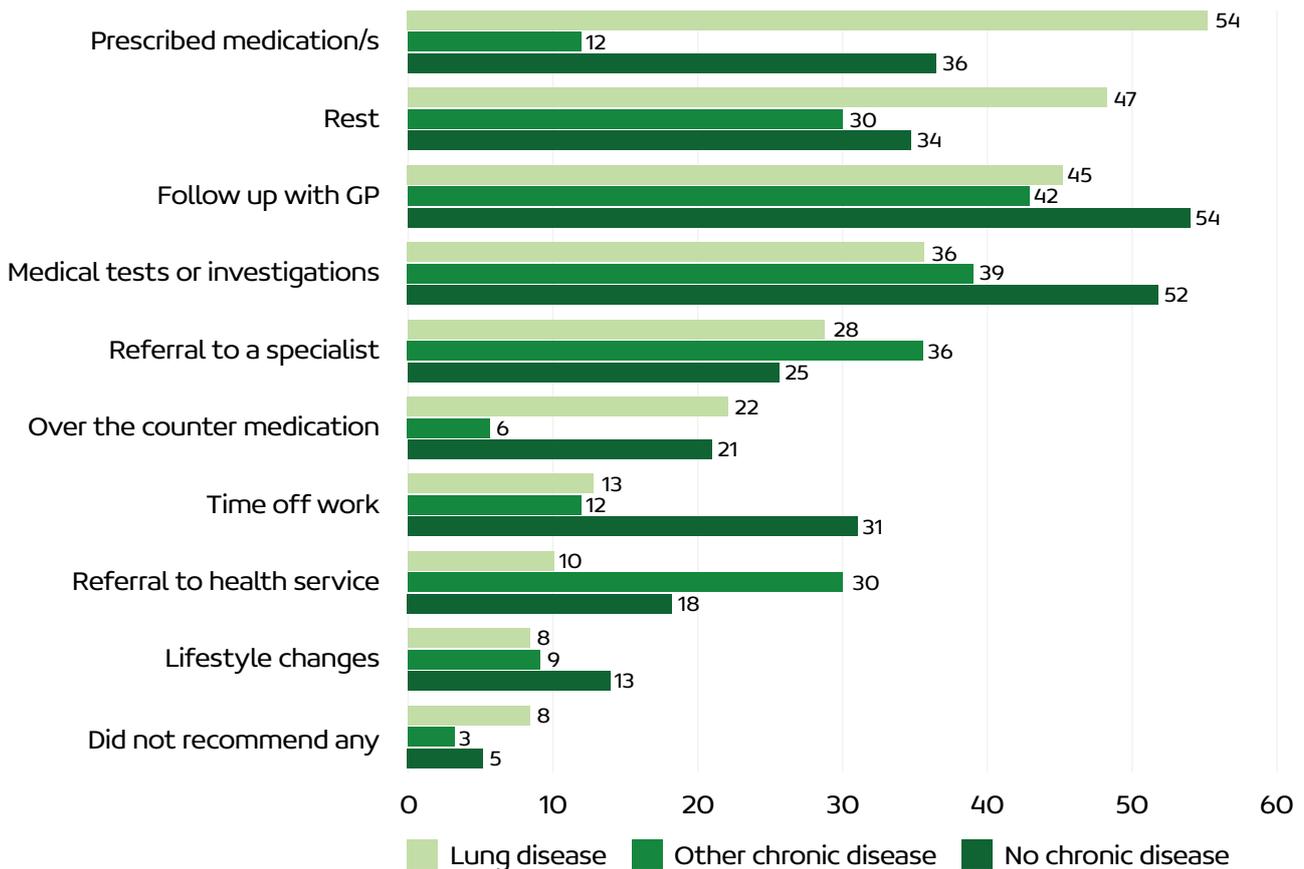
Health professionals recommended a variety of management and treatment options. However, follow-up with a GP was the most common recommendation (Refer to Figure 7).



“I think people who are experiencing long COVID need better monitoring of their ongoing symptoms, and ongoing testing including lung X-rays need to be done. I still have a partially collapsed lung nine weeks after diagnosis.”

- QLD resident living with chronic health conditions

Figure 7: Comparison of recommendations from health professionals



For one in three of people living with a lung disease (33%), a health professional referred to their ongoing symptoms as long COVID. Some 30% looked for further information elsewhere to help them manage or understand their ongoing COVID-19 symptoms following a discussion with a health professional. For respondents with other chronic disease, two in three (67%) looked elsewhere to help them manage or understand their ongoing COVID-19 symptoms. In 2022, Lung Foundation Australia created a short video providing expert tips on recovering from COVID-19. The video is now the most popular COVID-19 on-demand short video on the Lung Foundation Australia website. Management of ongoing symptoms can be difficult to navigate when an individual is living with a lung disease. As mentioned previously, people living with a lung disease can experience symptoms for a longer period of time compared to a healthy individual, and this demonstrates the need to develop tailored resources and information to assist with symptom management.

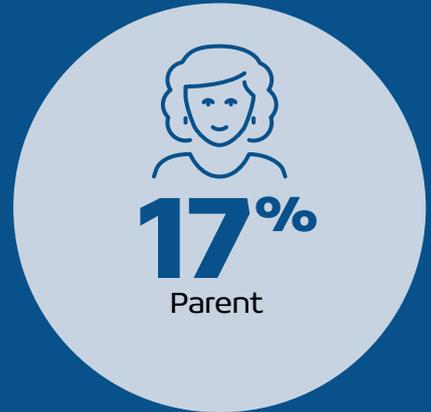


“I really don’t think that I had enough information about the possible effects of ‘long COVID’. I was not very sick during my isolation period with COVID so I did not request home care. However, when long COVID hit after, I was left struggling for breath and didn’t feel that I was receiving any help. My respiratory consults were over the phone and I don’t think they understood just how much I had been impacted.”

- TAS resident living with a lung disease

Experience of Carers

Primary caregiver roles reported



46% of carers

are extremely or very anxious about future COVID-19 infections, long-COVID and the potential impact on:

- their health
- ability to care for others
- impact on their life broadly

Main sources of COVID-19 information for carers:

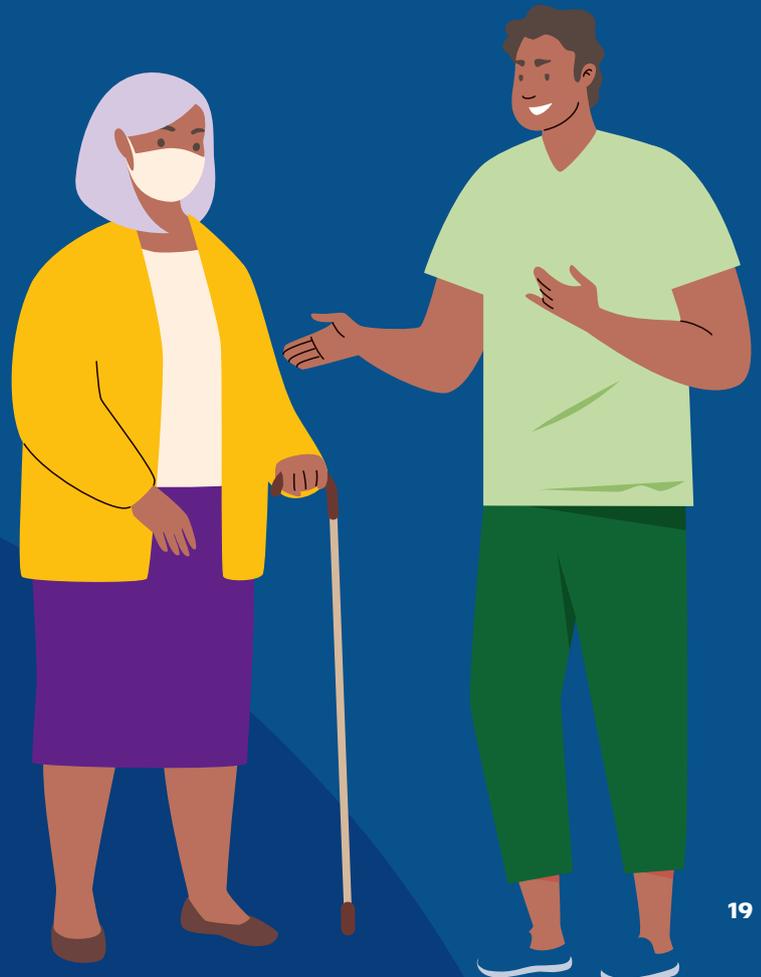


69% of carers

reported that information for treatment and how to improve symptoms would help in caring for someone with ongoing symptoms

Recommendations

- ▶ Ensure access to quality information and tailored support to manage COVID-19 symptoms and recovery



Experience of carers

Carers provide critical care and support to individuals managing health challenges. However, few organisations capture the experience of carers or are able to provide tailored information to guide them in their roles. Lung Foundation Australia is different in that it delivers a range of services and supports for individuals who care for people living with a lung disease or lung cancer. We understand how critical specifically tailored information and resources are to ensuring the best care possible.

Our COVID-19 survey received 206 responses from people identifying as caring for someone with COVID-19. Some 66 of these cared for someone with a pre-diagnosed chronic health condition, with 34 of these caring for a person with an underlying lung disease. People who are or were caring for someone with COVID-19 fell primarily into the categories of partners (33%), children (19%) and parents (17%).

Some 36% of carers reported a decrease in the level of care and support available for people living with an existing chronic health condition, when compared to before the pandemic. Over 50% of carers who were caring for a person with a lung disease or other chronic condition reported that the person they cared for had an appointment, test or procedure cancelled or delayed due to COVID-19. This caused an impact for four out of five of those affected, with specific impacts including worse mental health (47%), a worsening of condition or symptoms (36%) and additional physical pain (30%). Carers often provide crucial care and support for people living with a lung disease or other chronic condition. They need tailored information in order to provide the best care possible and to feel confident in doing so.



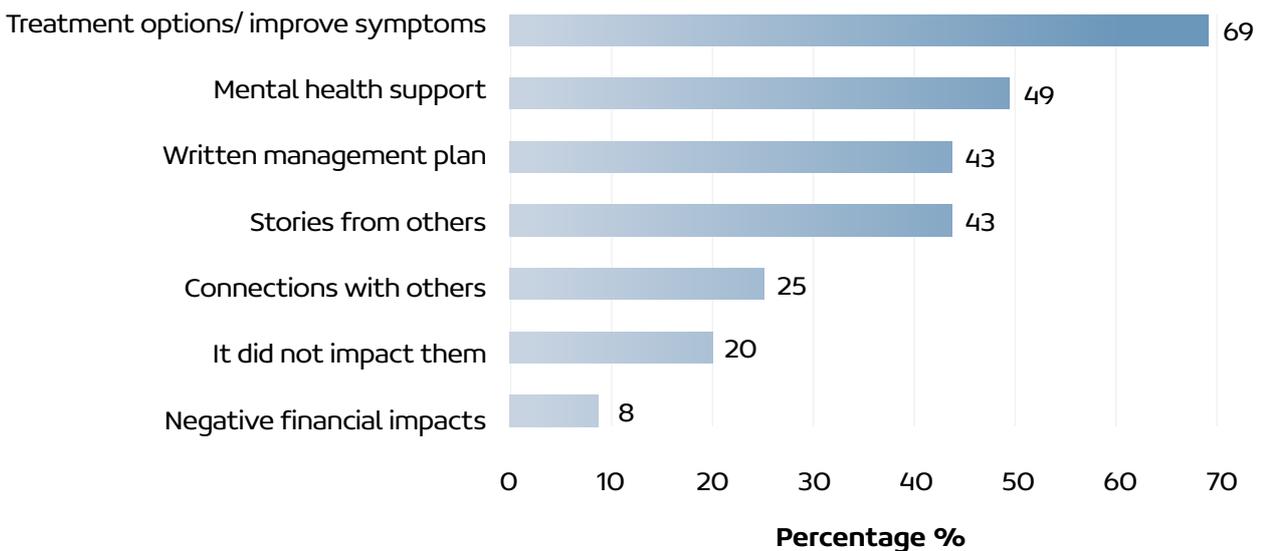
Experience of carers

The use of telehealth appointments was high, with almost three in four carers (74%) reporting that the person they care for had accessed such a service. With ongoing COVID-19 symptoms emerging as an area of need within healthcare, it is essential that carers have access to adequate information.

Carers identified the following information as being useful in assisting in caring for someone with ongoing COVID-19 symptoms:

- Treatment options/how to improve symptoms (69%)
- Mental health support (49%)
- Stories from others experiencing ongoing symptoms (43%)
- Written management plan (43%)
- Personal connections with others from individuals experiencing symptoms following COVID-19 (25%) (Refer to Figure 8).

Figure 8: Information that would assist carers in caring for someone with ongoing COVID-19 symptoms



Carers primarily refer to medical practitioners (52%) and the Department of Health (50%) as their main sources of information in caring for someone who is experiencing ongoing symptoms. It is clear carers want information from medical practitioners and the Department of Health, and it is thus important that they can access information to guide their care and support.



"[I] have researched sources unsuccessfully. Requested medical teams to inform us of treatments and plans but there has been very limited contact made. Doctors who we have seen have said they do not have access to the information we require."

- Carer QLD



"A lot of GP's don't know what is available to help their patients so then the patients don't know either."

- Carer NSW

Experience of carers

Almost one in two carers (46%) identified as being extremely or very anxious about future COVID-19 infections, long COVID, and the potential impact on their health and ability to care for others, as well as impact on their life more broadly. Only 8% of carers were not at all concerned. Carers provide vital care for people and correspondingly deserve information and services to guide them in their caring role.



“I have been impacted in every aspect of my life, I am constantly anxious and never go anywhere anymore as I don’t want to bring COVID home.”

- Carer NSW

Similar to those living with ongoing COVID-19 symptoms, carers require appropriate information, resources, and support in order for them to provide the best care possible and for them to feel empowered to care for individual needs. The survey identified a clear gap in the information available to carers caring for people with ongoing COVID-19 symptoms, with many carers reporting further information would assist with their roles.



“It was an energy and emotionally draining experience. I was constantly aware and alert to her needs and at the same time protecting myself from the virus.”

- Carer WA

Healthcare access



Almost

50%

of people living with a lung disease and 55% living with other chronic conditions had an appointment, test or procedure cancelled or delayed due to the pandemic



70%

of people living with a lung disease or other chronic condition

used telehealth services to access medical appointments during the pandemic

Those living with a lung disease reported higher rates of social isolation, worsened mental health and presentations to hospital



1 in 2 people living with a lung disease

or other chronic condition were unable to receive the same level of care and support compared to before the pandemic

Recommendations

- ▶ Fund respiratory nurses to support people with ongoing symptoms
- ▶ Enhance physical activity and self-management through pulmonary rehabilitation
- ▶ Transition long COVID clinics to multipurpose respiratory clinics
- ▶ Utilise and strengthen both telehealth and face-to-face healthcare
- ▶ Create a health professional strategy and COVID-19 training



Healthcare access

The COVID-19 pandemic tested the resilience of the Australian healthcare system and disrupted normal healthcare access and support. Australian federal, state and territory governments have thoroughly investigated the impacts of the pandemic on healthcare access and are continuing to examine the ongoing impacts. Many health services were suspended or were required to function in an altered manner, which unquestionably limited access and use. It is known that the suspension of non-urgent elective surgery for one month in March 2020 caused significant delays, however the long-term effects of cancelling or postponing non-urgent elective surgeries are not yet clear.³¹ Outside of health service disruptions, strong social distancing restrictions were put into force to discourage people from leaving their homes. These measures left many people in fear that they would contract or spread the virus if they moved about, particularly within health facilities.³²

The Australian Bureau of Statistics 2020-2021 Patient Experience Survey revealed that people with a long-term health condition were more likely to delay or not use health services they needed due to COVID-19, compared to those without a long-term health condition.³³ Importantly, significant changes in health service delivery models, policies, and programs allowed many to receive some form of care. The number of GP visits until the end of 2020 was similar to the two preceding years, with the introduction of Medicare-reimbursed telehealth allowing healthcare to be provided remotely.³⁴

It is clear that the general population of the nation was able to access healthcare when needed via alternative means. The experiences and challenges of individuals within this group have been well documented. However, Lung Foundation Australia wanted to ensure that the unique experiences of people living with a lung disease or chronic condition were also better understood. Australians living with a lung disease or other chronic condition often require continual healthcare and have more complex needs. Some people in this group experienced significant disruption in the management of their condition. The use of telehealth services throughout the pandemic ensured access to healthcare was maintained, and such services continue to play an integral role in the Australian healthcare system. However, it is important to acknowledge that telehealth will not be a suitable means of providing healthcare for every patient. Access to face-to-face services remains a vital model of care.

Health system challenges for people with a chronic disease

The inability to access face-to-face care was particularly challenging for people living with a lung disease. In some cases, they may have had symptoms that were difficult to distinguish from their baseline or other respiratory infections. At times during the pandemic when negative COVID-19 tests were required before attending medical appointments, some Australians may not have been able to access care even though they had a negative rapid antigen test. A potential outcome of this situation is poorer physical and/or mental health. Additionally, some Australians were scared to leave their homes out of fear of contracting COVID-19 in the community or in a waiting room. This may have resulted in some accessing telehealth alone, despite a face-to-face consultation being potentially more effective, given certain signs and symptoms can't be easily ascertained over the phone. Alternatively, this cohort may have delayed appointments.

It is critical that healthcare approaches to this group be strengthened, keeping in mind that both telehealth and face-to-face care provide benefits to patients.



"[I want] improved access to GP for face-to-face appointment when presenting with respiratory conditions and are PCR negative."

- SA resident living with a lung disease



"Keep access to lung specialist open. No testing or physio available in Townsville for a long time, all appointments are on hold or long overdue."

- QLD resident living with a lung disease

Healthcare access



“... I had some phone consults but still had to have a few face-to-face appointments, spending up to four hours in a waiting room surrounding by people who were potentially COVID, flu or virally positive. Even a simple cold can be dangerous for me and hundreds of other Australians.”

- SA resident living with a lung disease



“[I want] more discussion, direction and advice for long COVID...”

- NSW resident living with a lung disease

Almost one in two people living with a lung disease or other chronic health condition in this survey (49%) reported that they were unable to receive the same level of care and support for their existing condition compared to before the pandemic. This is likely due to restrictions, lockdowns, and burden on the healthcare system. However, this may also be due to hesitancy on the part of individuals to seek care due to fear of contracting COVID-19.

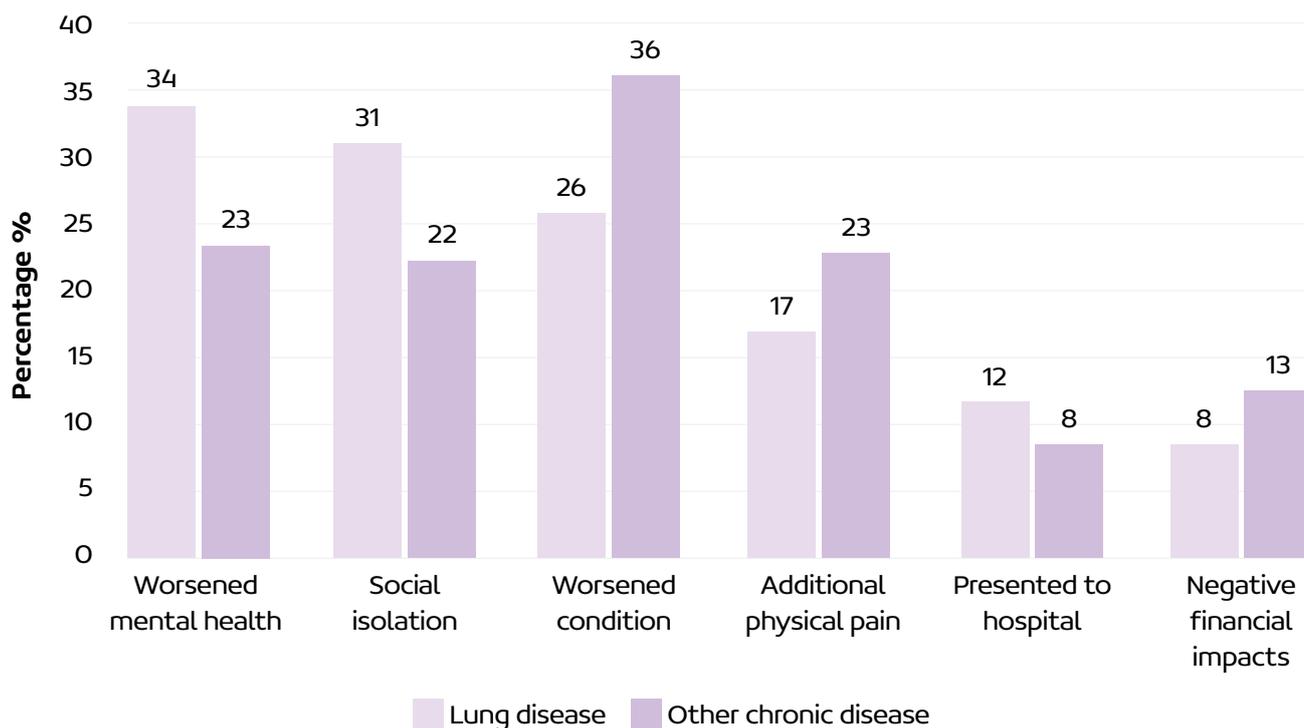


“I have end-stage COPD and I had a lot of trouble accessing appropriate help from a GP when I was feeling unwell. There has to be a better way...”

- SA resident living with a lung disease

The survey also found that 70% of people living with a lung disease or chronic condition used telehealth services to access medical appointments throughout the pandemic. Almost 50% of people living with a lung disease and 55% of people with other chronic conditions had an appointment, test or procedure cancelled or delayed due to COVID-19. This data aligns with statistics from the Australian Institute of Health and Welfare pointing to reduced consults for chronic diseases throughout 2021. Figures show the number of consults fell below 2018-2020 numbers for most of the months to October 2021 before recovering to similar numbers as in 2020.³⁵ The intervals of reduced consultations coincided with COVID-19 outbreaks and stay-at-home orders.³⁶ For two in three respondents (70%) the delay or cancellation had an impact. People living with a lung disease reported higher rates of worsened mental health, social isolation, and presentation to hospital (Refer to Figure 9).

Figure 9: Impact of an appointment, test or procedure being cancelled or delayed



Healthcare access

“I was unable to get a lung-function test for nearly two years as a result my lung function had dropped from 55% down to 46%, I have seen a physician recently and got it all sorted. Was very tired and had no social life.”

- VIC resident living with a lung disease

“Do not restrict or limit treatment for non-COVID related health issues. I could not get into a lung clinic because I didn't have COVID and this in my opinion exacerbated my breathing and hear- related crisis now controlled by medicines and under observation.”

- SA resident living with a lung disease

Telehealth has been fundamental for the continuation of healthcare for many Australians, and the prompt introduction of a telehealth Medical Benefits Schedule item in 2020 is to be highly commended. However, we note that there are some groups who feel telehealth is not a suitable tool for them, either due to health literacy, technological capabilities, personal preference or suitability based on health condition. Those living with a respiratory disease may experience further challenges in monitoring of their disease. Further consideration of their unique needs is warranted.

“Telehealth should be used more in the future especially to support regional populations.”

- WA resident who had COVID-19

“My respiratory health suffered because I had to have telephone appointments with my GP even when I had a negative PCR. It is impossible to auscultate lung sounds over the telephone! Greater access to lung health clinics in rural areas would help.”

- SA resident living with a lung disease

“More Telehealth so people can stay home and well.”

- TAS resident who had COVID-19

“Regional areas had greater access due to telehealth, this maybe should be continued. Also cuts out the travel issues for regional areas to access appointments and cost (specialists are expensive).”

- NSW resident living with a chronic condition

“Telehealth was not very useful as the site of my cancer could not be checked.”

- NSW resident living with a lung disease

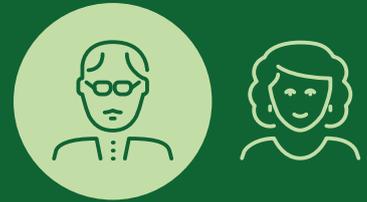
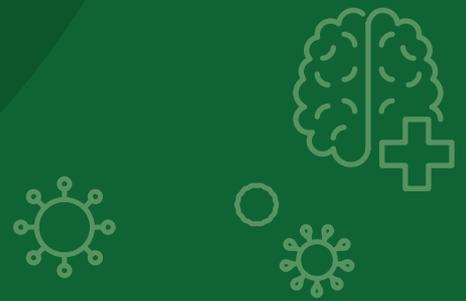
“Having Telehealth introduced was fantastic as that helped with anxiety of having to go to medical centres with other sick people.”

- VIC resident living with a lung disease

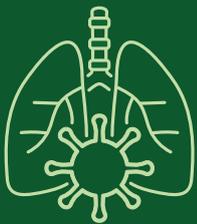
“Telehealth was a great improvement and should be available at all times.”

- NSW resident living with lung cancer

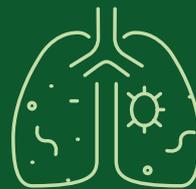
Mental health



Almost **50%** of people are **extremely or very anxious about future COVID-19 infections** and long COVID



People who have not had COVID-19 were more anxious about future COVID-19 infections and long COVID compared to people who have had COVID-19



People living with a lung disease are more concerned about COVID-19 infection and managing their condition compared to other chronic health conditions

Recommendations

- Address the unique mental health needs of Australians living with a lung disease



Mental health

The COVID-19 pandemic has greatly impacted the mental health of Australians. Members of the wider community have had to modify their normal way of living in the face of strong public health measures implemented to reduce disease spread. One unintended result is that the mental health of many people has suffered. A new crisis is now emerging, with Australians needing greater mental health support than ever before. The Australian Institute of Health and Wellbeing has reported on the rise in the use of mental health services and an increase in psychological distress during the COVID-19 pandemic.³⁷ Isolation, restrictions, and lockdowns prevented social connection between friends and families, and caused significant disruption to normal life such as work, hobbies and activities. In 2020, Lung Foundation Australia hosted the Understanding COVID-19 webinar series. To date, the most viewed webinar is *Looking after your mental health during coronavirus*, which continues to experience high interest since it was first published in 2020.³⁸ Lung Foundation Australia has also developed suite of digital resources known as Mind Matters to help those living with a lung disease and lung cancer manage their emotional wellbeing during the pandemic.

As we move into a new phase of the pandemic, there remain significant mental health challenges for many people. Infection rates higher than at any other time during the pandemic have increased many people's fears of contracting COVID-19. When asked how anxious they were about future COVID-19 infections and long COVID, 44% of respondents reported that they were **extremely or very anxious**.



"[I] am very anxious of contracting another bout of COVID, fearful of getting so sick again!"

- VIC resident who had COVID-19



"[COVID] made me feel very isolated and scared because I didn't want to pass the infection onto the vulnerable. The guilt of knowing I could make someone very sick made me feel very anxious."

- NSW resident who had COVID-19



"I feel anxious about getting COVID again. I have not returned to pre-COVID hours at work due to health issues and this means I am living week to week. Also, more discussion, direction and advice for long COVID."

- NSW resident who had COVID-19

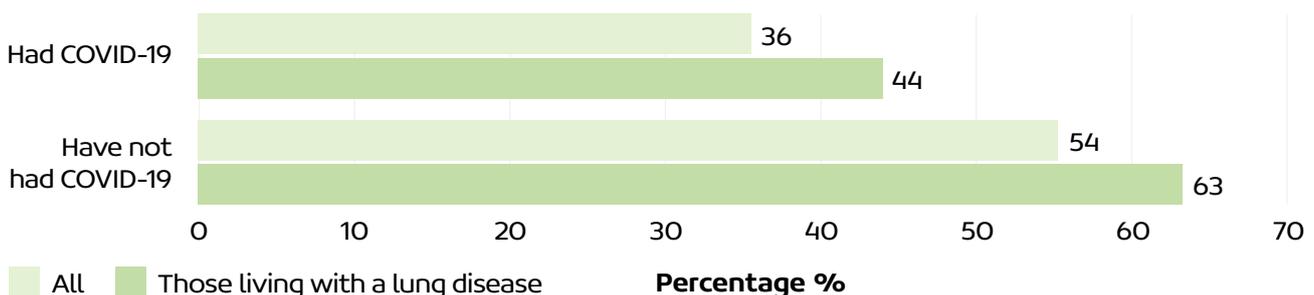
Interestingly, respondents who had not had COVID-19 were more anxious (54%) compared to people who had contracted COVID-19 (36%). Similarly, people living with a lung disease and who had not had COVID-19 were more anxious (63%) compared to those who had contracted COVID-19 (44%) (Refer to Figure 10). Thus, despite almost 50% of respondents reporting their COVID-19 infection was more severe than other respiratory illnesses, less than half expressed concern about future COVID-19 infections and long COVID. This indicates those who have yet to have COVID-19 are experiencing high levels of anxiety and fear about getting COVID-19, and this may be exacerbated due to high infection rates and the lifting of public health measures.



"I am quite cautious about where I go and anxious about the number of people still being infected and dying."

- VIC resident living with a lung disease

Figure 10: How anxious you are about future COVID-19 infections and long COVID



Mental health



“[COVID] changed life...far less social and I am anxious in social settings now because A) worried about getting COVID and B) getting too used to staying home and not socialising.”

- VIC resident living with a lung disease



“[COVID] made our lives more anxious, I honestly wish for a return to a more normal life. The anxiety is wearing mentally and physically.”

- NSW resident living with a lung disease



“I became quite anxious as to how bad I was going to be infected and affected, particularly given my scleroderma and PAH.”

- ACT resident living with a lung disease



“We don’t go out much, we have really reduced our socialisation and we are very picky where we do and don’t go. We have managed to avoid COVID so far but are realistic that it’s a numbers game and our number will come up some day. I am very anxious about contracting long COVID.”

- QLD resident

For people living with lung disease or lung cancer, maintaining mental health and emotional wellbeing is an important aspect of managing their condition. Research has shown poor mental health can have a significant impact on physical health.

People who experience chronic health conditions commonly experience poor mental health. Evidence demonstrates a clear link between poor mental health and comorbidity with other physical conditions. Many chronic health conditions, including lung disease and lung cancer, are physically debilitating, particularly as the condition or disease progresses. People who live with COPD are vulnerable to depression and anxiety and have a higher prevalence of panic disorder – up to 10 times the rate of the general public. They commonly experience panic attacks due to the inability to breathe.³⁹ The prevalence of anxiety and depression in people living with lung cancer is also relatively high when compared with other major cancers. Some 49% of people with lung cancer experience anxiety and depression, compared to 24% of those with breast cancer, 20% of those with colon cancer and 18.5% of those with head and neck cancer.⁴⁰ Australian Institute of Health and Welfare data suggests only 1.6% of people with cancer and 1.8% of people living with COPD do not have a mental health illness.

The survey found people living with a lung disease have higher rates of being very or moderately concerned about managing their condition and the risk of COVID-19 infections (56%), in comparison to those with other chronic health conditions (37%). Our Information and Support Centre and our Respiratory Care and Lung Cancer Support Nurse service received very strong messages about people’s fears of contracting COVID-19 during 2020 and 2021, and these fears have continued in 2022 as COVID-19 has spread rapidly in Australia, prompting many to remain at home to protect themselves. This was also a strong theme in the qualitative feedback received through the survey. This trend reiterates the need to better understand the mental health impact of COVID-19 on people living with a lung disease and to gain insights into how to best support this community into the future. Furthermore, nearly nine in ten respondents (88%) who are living with a lung disease reported being more aware/concerned about their lung health and the importance of breathing well, compared to those with other chronic health conditions at 74% and those with no underlying health condition at 69%. Over 50% of people living with a lung disease reported being extremely or very anxious about future COVID-19 infections and long COVID, compared to those with other chronic health conditions at 41% and those with no underlying health conditions at 30%.

Overall, people living with a lung disease reported being more concerned about managing their condition, were more aware/concerned about lung health and breathing well, and were more anxious about future COVID-19 infections and long COVID.

This highlights the need for specific messaging, information and support to ensure that people living with a lung condition not only have confidence in being able to manage their condition while having COVID-19 but, importantly, understand the support and care that is available.



“As a COPD patient, I have to be especially careful. COVID has, at times, forced me to live in near-seclusion, drastically impacting my family, social life, and mental health.”

- SA resident living with a lung disease



“I worry I will get COVID despite all the precautions we and our family are taking to keep us, my husband and I, safe.”

- NT resident living with a lung disease



“A lot of isolation as my family work in healthcare and education and are mindful of my condition. As I have Pulmonary Fibrosis, I feel destined to spend a lot more time alone into the future and not much to look forward to.”

- WA resident living with a lung disease

Federal, state and territory governments have made significant investments into supporting the mental health of Australians through the development of new programs and increased service accessibility. We acknowledge the continual mental health impact of the pandemic and the need to ensure funding within this sector remains strong into the future. There is a need for special considerations and supports for Australians who have a lung disease and who experience poorer mental health overall.



“It has been a very distressing experience. Because of my chronic lung disease, I do not socialise, fear that my wife will bring it home from shopping or socialising with friends, cannot see my new grandson, depression etc.”

- NSW resident living with a lung disease

Immunisation



Over 4 in 5 people are more likely
to keep up to date with vaccinations due to the pandemic



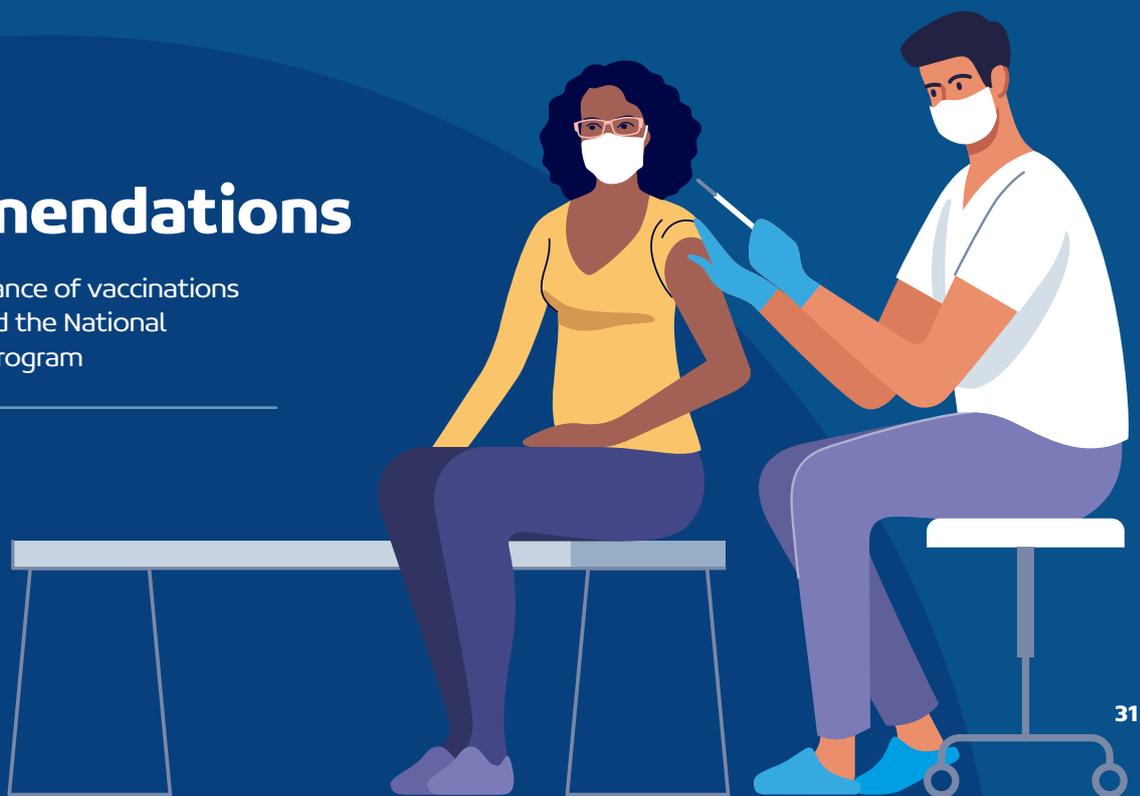
89% of people living with a lung disease were likely to keep up to date with vaccinations compared to
76% of people with other chronic health conditions
75% of people without any underlying health conditions



People who have not had COVID-19 are more likely to keep up to date with vaccinations compared to people who have had COVID-19

Recommendations

- ▶ Harness acceptance of vaccinations now and expand the National Immunisation Program



Immunisation

The development of an effective COVID-19 vaccine has paved the way for Australia to return to a 'new normal' and find ways to live with COVID-19.

The National Immunisation Program (NIP) allows Australians to access free vaccinations that provide individual immunity and support the nation in achieving herd immunity with a view of reducing the burden of illness from preventable disease. Increased awareness and encouragement of childhood vaccinations has resulted in vaccination rates reaching over 90% of children, although the use of vaccinations beyond and into adulthood tends to decline.⁴¹ Additionally, other vaccinations such as the influenza vaccine are promoted annually, with states and territories in 2022 offering free influenza vaccines in response to increased flu transmission and strain on the health system. As demonstrated with the COVID-19 vaccination program, increasing awareness and improving access by removing barriers such as cost can assist in raising vaccination rates and protect vulnerable populations from severe illness.

Governments on all levels have provided a resounding message around the importance of being vaccinated against COVID-19 and vaccination remains the key intervention required in order to open the country safely. Australia has one of the highest COVID-19 vaccination rates in the world, and our high vaccination rate is recognised as the reason for overall reduced disease severity upon infection. This has resulted in a broader understanding of, and more positive opinion on, the benefit of vaccinations even in adulthood.

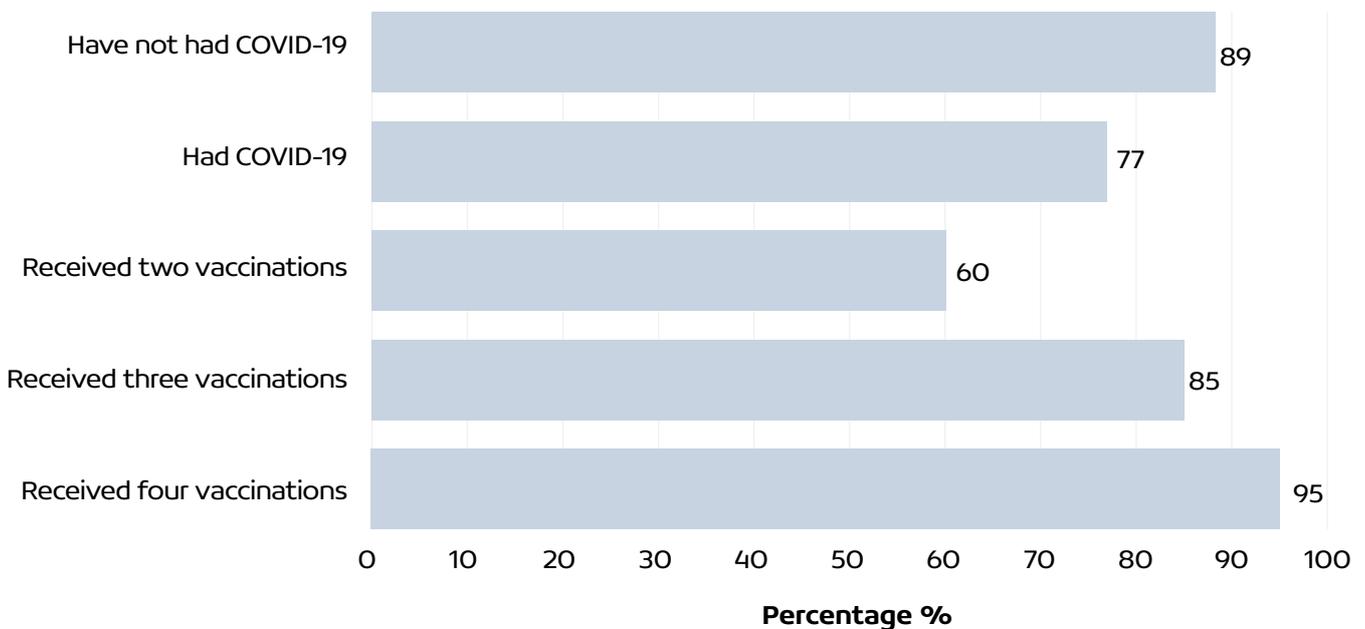


"The importance of vaccination must be stressed."

- VIC resident living with a lung disease

This improvement in public opinion on vaccinations is supported by our survey, with **over four in five respondents (83%) saying they are more likely to keep up to date with vaccinations due to the COVID-19 pandemic**. The survey found people who had received three or four vaccinations were more likely to keep up to date (85% and 95% respectively). Interestingly, people who had not had COVID-19 were more likely to keep up-to-date with vaccinations (89%), compared to people who had had COVID-19 at (77%)(Refer to Figure 11).

Figure 11: More likely to keep up to date with vaccinations



Immunisation



“[I am] much more inclined to make sure my family and I are all up-to-date with vaccines for respiratory conditions including flu. I hope there’s a decrease in vaccine hesitancy in the future.”

- QLD resident living with a chronic health condition

The pandemic response has generated increased awareness of vaccines and their ability to prevent severe disease. This has subsequently highlighted the importance of vaccination to protect not only one’s own health but the health of the community. While many of the impacts of COVID-19 have been challenging and to the detriment of health, the increased trust and acceptance of the importance of vaccines should be leveraged and cemented into usual care.



“[I want] continued positive promotion of free vaccines to the community. It’s the only way to keep everyone safe and hospital able to respond to those with other serious conditions.”

- VIC resident living with a lung disease



Immunisations are particularly important for Australians who are at risk of or are currently living with a lung disease.

Immunisations are often essential for people living with a lung disease, offering them increased protection from severe illness. The survey suggested people living with a lung disease were more likely to keep up-to-date with vaccinations (89%), compared to people with other chronic health conditions (76%) and people without any underlying health conditions (75%). The National Immunisation Program is able to provide increased access to vital vaccinations by removing cost to eligible people. However, because many vaccinations are only available to specific cohorts, many vulnerable people remain at risk.

The lung diseases below are listed as being conditions that increased the risk of pneumococcal disease. However, the NIP does not provide free pneumococcal vaccinations for them.

- COPD and chronic emphysema
- Severe asthma (defined as requiring frequent hospital visits or the use of multiple medications)
- Interstitial and fibrotic lung disease.⁴²

The results of this survey strongly support the current Australian government's support, promotion and communications regarding vaccination, however, more can be done to ensure vaccinations continue to be accessed at high levels.

“

“My experience with COVID made me hope for more effective vaccines that reduce the severity or the infectiousness of the disease.”

- QLD resident who had COVID-19

The view of Australians on **disease prevention, the future and government trust**

Percentage of people that reported high or extreme trust towards:



65%

Medical professionals



37%

International agencies



31%

State government



25%

Federal government



Increased understanding and value placed on disease prevention

Respect for others in the community and supporting one another



3 in 5 individuals have sought medical advice or treatment for ongoing symptoms

Recommendations

- ▶ Harness acceptance of vaccinations now and expand the National Immunisation Program
- ▶ Invest in the National Preventive Health Strategy



The COVID-19 pandemic has emphasised the importance of disease prevention and health promotion. It has also created greater awareness and understanding of the importance of preventive measures at the individual, community and national levels. This offers a unique opportunity to increase understanding of preventive health further with a view to keeping Australians healthy into the future.

The COVID-19 response was actioned, to a large degree, by each state and territory independently. This resulted in inconsistent messaging and differing regulations, which in turn led to mistrust of the government during a period of great confusion and uncertainty. The unique stories and experiences of Australians during this period provide us with crucial learnings for the future of public health in Australia. Despite the challenges and impacts experienced, many Australians remain hopeful for a brighter future where members of the community show respect and understanding for each other. This includes increased awareness and support of the need for emphasis to be placed on disease prevention.

Valuing health promotion and disease prevention

Prevention is defined by the World Health Organisation as ‘the approaches and activities aimed at reducing the likelihood that a disease or disorder will affect an individual, interrupting or slowing the progress of the disorder or reducing disability’.⁴³ Fundamental to any health system is the need to prevent disease and reduce ill health. This need formed the basis of the strong public health measures implemented by state governments for the containment of COVID-19.

Health promotion and disease prevention efforts support Australians to live healthy lives without disease and further reduce the economic burden on our health system. The National Preventive Health Strategy 2021-2030 acknowledges the need for further investment in preventive health, with total investment in this area to rise to be 5% of the total health expenditure across the Commonwealth, state, and territory governments by 2030.⁴⁴

The COVID-19 pandemic has increased awareness of respiratory viruses and the need for people to prioritise health, with the survey finding four in five people (80%) are more aware/concerned about their lung health and the importance of breathing well.

Fostering this enhanced awareness at the individual level provides new opportunities to raise understanding of preventive health and the benefits for individuals and communities. Behaviour-change concepts highlighted by the pandemic address the primary notions of preventive health. We believe that this awareness should be utilised and built upon to continue to reduce poor-health burden. The pandemic has additionally emphasised the role of vaccination programs. Immunisations have played an integral role within our health system by giving individuals immunity from severe disease, which is particularly important for those most vulnerable.



“I hope we see greater infectious disease readiness and greater kindness in communities.”

– VIC resident living with a lung disease

Unfortunately, while the risk of disease and illness can be reduced, they cannot always be prevented. This highlights the importance of regular health checks and screening programs. Early detection of disease and illness allows for enhanced treatment options, slowed disease progression and greater chances of survival.

Preventive health underpinned our response to COVID-19, including behaviour change and immunisation to early detection. These are approaches which can and should be implemented for both infectious and chronic diseases in order to reduce the health burden on Australians and the economic burden on governments. As of 2020-21, nearly 50% of Australians had at least one chronic health condition, with the National Strategic Framework for Chronic Conditions acknowledging, ‘a focus on prevention can significantly reduce the volume and severity of chronic conditions and provide long-term saving and better health outcomes.’⁴⁵



" [Governments] must encourage healthy lifestyle and preventative measures e.g., healthy eating, exercise, sunlight, reducing stress..."

- TAS resident



"There should be a much bigger focus of preventing disease because it's so expensive to treat."

- QLD resident who had COVID-19



"[COVID] made me become more aware of health and hygiene."

- TAS resident who had COVID-19



"I have become much more aware of my health and the health of those around me."

- NSW resident who had COVID-19

The COVID-19 pandemic and public trust

Building and maintaining high levels of trust in public health officials and governments was key for COVID-19 prevention and infection control. The preventive health strategies implemented – and the success of such strategies – relied on ensuring health messages were clearly communicated to the public, and the necessity of public health protection measures was conveyed and understood. The COVID-19 pandemic presented new and unique challenges, with a need for strong public health measures and agile policy changes that tested the public's trust and confidence in governments and institutions. The survey aimed to capture how the COVID-19 pandemic had influenced public trust to provide an insight into effective communication channels for future public health advice. Respondents indicated they were very or extremely likely to trust medical professionals (65%), international agencies (37%), state government (31%) and federal government (25%).

The pandemic presented unprecedented challenges for every country, and with the emergence of a novel virus we acknowledge the complexities of ever-changing views and evidence. In the face of the unknown, many nations, including Australia, reacted cautiously as the world came to understand the disease and the required measures to keep citizens safe and healthy. Differences in approaches to managing COVID-19 are already acknowledged by all levels of government as challenging, and, as a consequence, likely to have increased confusion for Australians.

Understanding how to effectively communicate risk by providing clarity and certainty will be essential for managing future COVID-19 variants and new disease outbreaks, to effectively protect public health.⁴⁶ Many Australian states faced some of the world's toughest public health restrictions, with rapidly changing health advice and government action. The delivery of public health messaging must be done carefully and consistently, ideally at a national level ensuring that information is accurate and clear to avoid the public questioning the government action. Studies indicate that a lack of trust drives vaccine hesitancy, and, with the outbreak far from over, rebuilding confidence is essential to protect vulnerable populations from severe disease.⁴⁷ While many Australians have received two or more COVID-19 vaccinations, challenges remain ahead, with data suggesting a waning of engagement in the COVID-19 vaccination program. Vaccination will remain the cornerstone for preventing severe disease from COVID-19, both now and into the future, and this underscores the importance of strengthening public trust in both governments and health research and prevention.



"We need to better fund basic science education and community building and empathy if we want to be the nation we say we are. We need to pull up our entitled socks if we want a smooth economy in troubled times, by caring for each other and using logic."

- TAS resident who had COVID-19



“The health messaging was quite poor at times throughout the period of lockdowns and regarding the vaccine. In future it would increase public trust if everything was more clear and honest.”

- NSW resident



“United leadership and actions across the country when it’s a global issue. Mixed messaging impacted trust and caused division and angst.”

- NSW resident



“Transparency and clarity in messaging, too many mixed messages from safety of vaccines to lockdown guidelines across the country. Need for unified federal and state governments, reduce inequities, increase speed in decision making that leads to action the public can see and trust.”

- VIC resident

The reflections of Australians on the pandemic and their hopes for the future

COVID-19 is continuing to cause widespread impacts for all Australians, and the future of COVID-19 is unknown. The learnings from this pandemic are extensive and integral in guiding not only how we respond to future pandemics when they arise, but, more importantly, how we learn to cope with and continue to respond to new COVID-19 waves and variants.

Every individual has a unique story and experience. However, some of the common experiences and hopes for the future expressed in Lung Foundation Australia’s survey included:

- Recognition that vulnerable populations, such as those living with a lung disease or other conditions, made great efforts to isolate themselves to prevent contracting COVID-19
- Positivity and hopefulness that the future would be better
- Recognition of the value of public health protection measures
- Acknowledgement of the need to be respectful of others and to protect vulnerable populations
- Acknowledgement of the importance of preventive health and looking after your health
- Recognition that telehealth provided necessary healthcare and the continuation of the service is highly supported
- Identification of negative mental health impacts due to lockdowns, restrictions, and isolation
- Highlighting of the need for a federal government approach to ensure clear, consistent health messaging and public health measures across state governments.

Governments, non-government organisations, professional bodies and researchers can all apply these views and hopes for the future in support of creating a healthier and more cohesive Australia.

Hopes for the future



I hope everyone is healthy
- NSW Resident

We (Australians) need to work together with unified approaches
- NT Resident

I hope that we can have equity to vaccines across the world
- TAS Resident

We should look after each other
- QLD Resident

I hope my family will be healthy and our living environment will be better in the future
- WA Resident

Full of hope for the future
- VIC Resident

Everyone would be more respectful of others particularly the elderly, children, people with illnesses that make them vulnerable
- ACT Resident

Take responsibility for our own health and understand the impact of our actions on those around us
- SA Resident

Recommendations

While the health system is dealing with an additional and ongoing burden, all Australians have a right to receive the information, support and services they need for COVID-19, COVID-19 recovery, and management of any co-morbidities, in an equitable and timely manner. To help achieve this, Lung Foundation Australia is making 10 key recommendations. These are spelled out below, with each recommendation underpinned by the need for equity. Significant disparities and challenges remain across Australia, including but not limited to an individual's geographical location, gender, health literacy, culture and language, and socio-economic status.

1

Fund respiratory nurses to support people with ongoing symptoms

With the community of people with ongoing symptoms increasing, additional resources, support and investment will be required. Respiratory nurses, available both on the ground and via telehealth (following Lung Foundation Australia's respiratory care nurse model) could provide assistance specifically for people with ongoing COVID-19 symptoms. They could assist people with recovery, information and management of their condition, including discussing treatment and medical tests with an individual's health professional. Such support alongside resources for symptom management and how to live with ongoing COVID-19 symptoms, would ensure people were receiving important care to aid in recovery. Some 70% of respondents reported that they would be interested in accessing a free Lung Foundation Australia COVID-19-specific telephone-based respiratory nurse to help manage symptoms following COVID-19. Expansion and promotion of this service to the community would ensure more people can access this free, evidence-based support.

2

Ensure access to quality information and tailored support to manage COVID-19 symptoms and recovery

There is a clear gap in the support, resources and information available to Australians experiencing ongoing COVID-19 symptoms. There is, therefore, an essential need for immediate action and investment to ensure Australians can access the care they deserve. Information and resources must be developed to support the increasing number of people experiencing ongoing COVID-19 symptoms and who suffer from ongoing respiratory symptoms such as breathlessness. Such resources should be designed in conjunction with this growing community. Australians experiencing ongoing COVID-19 symptoms need access to clear information and tailored support that acknowledges the changing environment of symptom management and treatment, given that further research is needed to fully understand ongoing symptoms. Furthermore, this will support carers who care for people with ongoing COVID-19 symptoms and guide their care.

As the peak lung health organisation in Australia, Lung Foundation Australia has established a website for COVID recovery information. This framework could be expanded to meet the needs of the affected community, identified by respondents to this survey. It is clear that Australians require evidence-based information on managing symptoms and the impact on everyday tasks after COVID-19, and currently find this difficult to access. With appropriate funding Lung Foundation Australia has the resources and mechanisms in place to meet the needs of people in this evolving area, in providing information and support and responding to emerging evidence in a timely way. Lung Foundation Australia engages key opinion leaders in respiratory disease as well as expert consumers to ensure that all information is accurate and relevant. A targeted campaign to promote these resources is essential to ensure that all Australians are aware and can access them readily.

Navigating the journey with ongoing COVID-19 symptoms can be challenging, and for this reason Asthma and Lung UK has developed a long COVID assessment tool to help guide people on what to do next and

what help is available. Australia currently provides limited information and support for citizens in this situation, and the development of a similar tool for the local setting is a necessary step to providing the support these individuals deserve. A similar model of referral and information could be implemented in Australia to provide further linkages for patients and carers.

3 Enhance physical activity and self-management through pulmonary rehabilitation

While research on the subject is limited, exercise may assist with COVID-19 recovery and reduce the burden of ongoing COVID-19 symptoms. For the clinical rehabilitation management of breathing impairment in adults with post COVID-19, the World Health Organisation suggest a combination of education and skills on self-management strategies including nasal breathing and pacing approaches alongside physical exercise training (for those without post-exertional symptom exacerbation).⁴⁸ Exercise completed under guidance of a medical professional – such as the pulmonary rehabilitation (PR) currently offered for people with respiratory conditions – aims to reverse an individual's cycle of inactivity and increase independence through daily activities and tasks, a fundamental of self-management. A PR audit completed by Lung Foundation Australia in September 2022 identified that 59% of PR programs were supporting patients with long COVID, with referrals primarily originating from long COVID clinics. This is a good example of using current practice to support people to be active. However, these services need to be consistently referred to, and funded, in order to ensure equitable support for Australians regardless of their location and financial position.

4 Address the unique mental health needs of Australians living with a lung disease

We found that people living with a lung disease have unique mental health needs and require tailored support to assist with anxiety prior to, during, and following a COVID-19 infection. With a growing number of people experiencing poor mental health, particularly due to the social and economic impacts of the COVID-19 pandemic, the federal, state, and territory governments are providing increased investment to enhance support and access to mental health services. Peer support services should be recognised as an important element of connecting Australians, along with dedicated social work programs for those with unique psychosocial and practical needs and challenges. Organisations such as Black Dog and Beyond Blue are leading significant support activities in this area. A partnership approach to ensure the nuances and intersects of lung disease specifically on mental health are addressed would be invaluable.

Peer support would assist by bringing people with ongoing COVID-19 symptoms together to share their experiences and help each other cope with the challenges they may experience. This would complement formal support services. Peer support provides the opportunity for people to share their lived experience with someone who 'gets it'. Being able to connect with others who can empathise and let you know you are not alone can be incredibly helpful.

Funding for social workers is crucial as they can help individuals to navigate the practical and emotional impacts of living with ongoing COVID-19 symptoms and provide emotional and mental health support. Ongoing COVID-19 symptoms can be debilitating, leaving many unable to resume work or needing to work at reduced capacity. This in turn can lead to severe financial strain and stress.⁴⁹ The Lung Cancer Social Work pilot program implemented at Lung Foundation Australia is a free telephone-based service to support people living with lung cancer to navigate the practical and emotional impacts. This model could be replicated for people living with ongoing COVID-19 symptoms and other lung diseases. It would provide the necessary support and help improve mental wellbeing for this group so that members experience significantly higher rates of social, practical and emotional wellbeing.

5 Transition long COVID clinics to multipurpose respiratory clinics

Long COVID clinics have been established around Australia with New South Wales, Victoria, Queensland and the Australian Capital Territory each having one clinic and South Australia having several. Western Australia and the Northern Territory have no dedicated long COVID clinics, and Tasmania is expected to launch a long COVID navigation and referral service. Long COVID clinics have the potential to provide support for a multitude of respiratory diseases outside of COVID-19, which becomes increasingly important as we move into the endemic phase. However, we note that current demand is high, with long wait times for appointments being reported. Appropriate consideration would need to be given to ensure current and then additional services provided through these clinics are accessible in a timely and affordable manner.

In addition, ensuring that appropriate data capture, linkages and learnings can be applied across jurisdictions and clinics will aid in ensuring that these services are fit for purpose and meet the broad needs of the community. Transitioning the long COVID clinics into multipurpose respiratory clinics would expand the reach and meet the needs of the broader respiratory disease community, who have struggled throughout the pandemic in managing their conditions. Placed-based respiratory nurses (linked with Recommendation 1) can be based at each clinic, expanding access to vital support and care and helping to create a network of respiratory care nurses.

6 Utilise and strengthen both telehealth and face-to-face healthcare

The Australian Government has recognised the importance of a robust healthcare system due to the impacts of COVID-19. Health equity has been a persistent challenge across the nation, as many Australians continue to face ongoing challenges in accessing the healthcare they need. Health services must ensure prompt diagnosis and address management of chronic disease – of which those living with a lung disease or lung cancer are a prime example. Telemedicine services have filled a substantial gap in healthcare delivery and have enabled healthcare access for those living in rural and remote communities. Returning to face-to-face healthcare poses challenges for many. As the health system grapples with ongoing high demand, many may be unable to access the support and care when needed. This is a particular concern for those living with a chronic condition, such as a lung disease or lung cancer. Telehealth services must be reviewed on an ongoing basis to gain an accurate understanding of the impacts and benefits such services provide and to evaluate whether the evolving health system is adequately and effectively meeting patients' needs. The evidence that telemedicine can be delivered with equal success to in-person consultations in achieving optimal clinical outcomes must be gathered especially as healthcare systems adopt it more widely.

7 Create a health-professional strategy and COVID-19 training

Australia needs to develop and implement a health professional engagement strategy to assist health professionals in understanding and providing evidence-based care, and to support to people with ongoing COVID-19 symptoms. With new research emerging and advice constantly evolving, it is important that health professionals understand how to effectively guide patients who have ongoing symptoms and know what services are available for referral. Because information, resources and services are constantly changing, the training and education needs of health professionals must be addressed as part of a health professional engagement strategy. The federally funded Lung Learning Hub curates the highest quality, evidence-based respiratory health training and education from a range of providers into one trusted, central website. It has been developed with wide stakeholder engagement, to help primary healthcare professionals easily find and complete training that will optimise their provision of care, their career and ultimately the outcomes for people living with a lung condition. Expanding this work to ensure COVID-19, ongoing symptoms, and emerging lung impacts are included is vital and is achievable through the strong partnerships already established as part of this program.

8 Adopt a national long COVID definition to enhance data collection and research

Internationally the definition of long COVID is contested, leading to a lack of consistency in long COVID reporting and understanding of the condition. In the rapid review by Sengupta and Jenkins, long COVID was defined as ‘a post COVID-19 condition occurring in individuals with a history of confirmed COVID-19 where signs and symptoms of COVID-19 last for more than 4 weeks and cannot be explained by any other diagnosis’.⁵⁰ Conversely, Healthdirect states, ‘a person is usually considered to have long COVID if their symptoms have continued for longer than 12 weeks after their initial infection’.⁵¹ As Australia currently does not have a working clinical definition for long COVID there is confusion amongst health professionals and downstream impacts on the communication, monitoring and reporting that can occur.

We commend the Australian Government for funding an Australian COVID-19 Register and linked data set, to be developed by the Australian Institute of Health and Wellbeing. This further strengthens the need to employ a consistent long COVID definition, to ensure consistent long COVID data is captured within the dataset. Clarity on the definition of long COVID must be provided and without such agreement, Australia may experience under-reporting of long COVID and a lack of support for Australians with ongoing symptoms. Ongoing COVID-19 symptoms remain poorly understood, prompting the need for enhanced research in this field to guide best practice and treatment into the future. With emerging evidence and research, it is important regular reviews are undertaken and sufficient funding is provided to ensure best-practice guidance and care can be delivered in a consistent manner.

9 Harness acceptance of vaccinations now and expand the National Immunisation Program

The COVID-19 pandemic has emphasised the importance of vaccinations in preventive health and protection. This increased awareness and understanding provides an integral opportunity to continue the momentum and expand the National Immunisation Program, removing barriers and increasing access to essential vaccinations. Despite their vulnerability, many people living with a lung disease are currently not covered under the National Immunisation Program and must pay out of pocket to access vaccines that would protect against severe respiratory disease, such as the pneumococcal vaccination. The National Immunisation Program identifies people with COPD, chronic emphysema, severe asthma, and interstitial and fibrotic lung disease, as being at increased risk of pneumococcal, however does not provide free pneumococcal vaccinations to these populations. Now is the time to review and amend the criteria for free vaccinations and the delivery model, which could encourage vaccination uptake and effectively utilise the enhanced awareness and support for vaccinations.

10 Invest in the National Preventive Health Strategy

Preventing disease creates a more productive society, reduces the burden on the health system, and reduces the cost to individuals and government, both directly and indirectly. The National Preventive Health Strategy highlights the need for further investment in preventive health, noting investment will be raised to 5% of the total health expenditure across the Commonwealth, state, and territory governments by 2030. This important national strategy outlines a range of evidence-based recommendations and policy priorities, of which Lung Foundation Australia is extremely supportive. Australians are more aware than ever of the benefits of preventing disease, with the emphasis of preventing COVID-19 infection being a focus for over a year. We need to harness this acceptance by implementing the policy priorities outlined in the National Preventive Health Strategy, which will require a greater investment in preventive health across the lifespan and a commitment to bold and innovative policy solutions.

Conclusion

COVID-19 has greatly affected the lives of all Australians and continues to place a profound burden on the nation. As we continue to assess and grapple with its lasting impacts, the lessons we learn from the pandemic will inform government policy for decades. Australia faced significant challenges throughout the pandemic, including overwhelming pressure on the Australian health system, with the mental health and wellbeing of many strained. We continue to observe the impacts as a result of the disruption to healthcare and existing disease management. COVID-19 will continue to impact Australians even in the endemic phase, and Australia needs a comprehensive strategy and strong investment to reduce further disease burden and health impacts. Ongoing COVID-19 symptoms are placing a significant burden on the mental and physical health of both the general Australian population and those living with a lung disease, as they struggle to get the support and care they need.

There has been substantial investment in the COVID-19 response including but not limited to pop-up testing clinics and targeted mental health workforce strategies. This report highlights that people experiencing ongoing COVID-19 symptoms are falling behind and are failing to receive vital support they believe they need. Much more can be done, as outlined in this report, to ensure these Australians receive the care they need. People living with a lung disease are likely to experience prolonged duration of ongoing COVID-19 symptoms and some have unique challenges in accessing normal care, creating a need for tailored resources and support. Further to this, mental health support for those living with ongoing COVID-19 symptoms is crucial to navigating the practical and emotional impacts. This is because the symptoms of ongoing COVID-19 can be debilitating and often result in individuals being unable to return to work and suffering severe financial stress. Australia has recognised the need to strengthen healthcare access to address health equity across the nation, and we highlight the need for continued enhancement of face-to-face and telehealth services to address needs in rural and remote communities.

As Australia moves into the endemic phase of COVID-19, we must acknowledge the growing number of Australians who are experiencing ongoing COVID-19 symptoms and the unique needs of the one in three Australians who are living with a lung disease. The need for robust, ongoing data collection cannot be understated, and we commend the Australian Government for funding an Australian COVID-19 Register and linked data set to ensure consistent and accurate reporting of COVID-19 and long COVID.

In addition to addressing health system and service challenges, governments must recognise the unique opportunity this provides, to enhance preventive health efforts with broad health promotion and disease prevention strategies. We are in a position to now, and into the future, leverage widespread recognition of the value and benefit of immunisation.



Conclusion

Preventive health care across the lifespan, to reduce the risk of developing multiple chronic diseases continues to be underfunded, despite the benefits for the individual, community, health system and economy.

As the peak lung health organisation in Australia, Lung Foundation Australia remains committed to supporting all Australians and becoming one of the world's most innovative and effective lung health charities and a fearless leader of lung health programs and research. We continually work with other non-government organisations and government to advocate for improved lung health for all Australians and to support the one in three Australians living with a lung disease or lung cancer.

Now, more than ever, it is the time to build on the enhanced awareness of lung health and the importance of being able to breathe, and harness the optimism of the population to create positive, proactive change that improves the health of Australians.



References

1. Shao-Lin Tao, Xue-mei Wang, Yong-geng Feng, Po-ming Kang, Qing-yuan Li, Tian-yu Sun, Qun-you Tan, Bo Deng, Is the presence of lung injury in COVID-19 an independent risk factor for secondary lung cancer?, *Medical Hypotheses*, Volume 143, 2020, <https://doi.org/10.1016/j.mehy.2020.110074>
2. Sadigov, A., Akhundov, S., Agaveva, A 2021, Risk Factors for Lung Cancer in Individuals With COVID-19 Without Cancer History, *Respiratory Care* Oct 2021, 66 (Suppl 10)
3. Sadhukhan P, Ugurlu MT, Hoque MO. Effect of COVID-19 on Lungs: Focusing on Prospective Malignant Phenotypes. *Cancers (Basel)*. 2020 Dec 18;12(12):3822. doi: 10.3390/cancers12123822. PMID: 33352869; PMCID: PMC7766284
4. Australian Department of Health and Aged Care 2022 Top 3 Questions - What is long COVID, is it becoming more common, do vaccines reduce your chance of getting it <https://www.health.gov.au/news/top-3-questions-what-is-long-covid-is-it-becoming-more-common-do-vaccines-reduce-your-chance-of-getting-it>
5. Office for National Statistics 2022, Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 4 August 2022, <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/4august2022#prevalence-of-ongoing-symptoms-following-coronavirus-infection-in-the-uk-data>
6. Asthma and Lung UK, 2022 Post-COVID HUB, <https://www.post-covid.org.uk/>
7. Sengupta, A and Jenkins, C, 2022 characteristics and impact of long COVID-19 in people with lung disease, The George Institute for Global Health
8. Ibid 7
9. Ibid 7
10. Ibid 7
11. Ibid 7
12. Ibid 7
13. Ibid 7
14. Ibid 7
15. Ibid 7
16. Ibid 7
17. Ibid 7
18. Ibid 7
19. Ibid 7
20. Ibid 7
21. Department of Health, 2022, Vaccination numbers and statistics, <https://www.health.gov.au/initiatives-and-programs/covid-19-vaccines/numbers-statistics#total-national-doses>
22. Australian Government Department of Health and Aged Care, 2022, Communicable diseases intelligence COVID-19 Australia: Epidemiology report 65, <https://doi.org/10.33321/cdi.2022.46.73>
23. Centers for Disease Control and Prevention 2022, Omicron Variant: What You Need to Know https://www.cdc.gov/coronavirus/2019-ncov/variants/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fvariants%2Fabout-variants.html
24. Lung Foundation Australia, 2022, Health professionals COVID-19, <https://lungfoundation.com.au/health-professionals/training-and-events/webinars-2/>
25. Healthdirect 2022, People with underlying health conditions and COVID-19 <https://www.healthdirect.gov.au/covid-19/underlying-health-conditions-and-covid-19>
26. Ibid 7
27. Ibid 7
28. Ibid 7

References

29. Ibid 7
30. Ibid 7
31. Australian Institute of Health and Welfare 2021, The first year of COVID-19 in Australia: direct and indirect health effects <https://www.aihw.gov.au/getmedia/a69ee08a-857f-412b-b617-a29acb66a475/aihw-phe-287.pdf.aspx?inline=true>
32. Scott, A 2022 The impact of COVID-19 on GPs and non-GP specialists in private practice https://melbourneinstitute.unimelb.edu.au/__data/assets/pdf_file/0003/3436014/UoM-MI-ANZ_Brochure-FV.pdf
33. ABS 2021, Patient Experiences in Australia: Summary of Findings, <https://www.abs.gov.au/statistics/health/health-services/patient-experiences-australia-summary-findings/latest-release>
34. Ibid 33
35. Australian Institute of Health and Welfare, 2022 Australia's health 2022 data insights <https://www.aihw.gov.au/getmedia/c91a05ef-307f-4c18-8ed3-dfe33d0c603d/aihw-aus-240.pdf.aspx?inline=true>
36. Ibid 35
37. Australian Institute of Health and Welfare, 2022, Australia's health in brief 2022, <https://www.aihw.gov.au/getmedia/c6c5dda9-4020-43b0-8ed6-a567cd660eaa/aihw-aus-241.pdf.aspx?inline=true>
38. Lung Foundation Australia 2020, looking after your mental health during the coronavirus pandemic, <https://www.youtube.com/watch?v=Y35qRIDLM2o&t=3s>
39. Nicole Livermore, Louise Sharpe and David McKenzie, 'Panic attacks and panic disorder in chronic obstructive pulmonary disease: a cognitive behavioral perspective' (2010) 104(9) *Respiratory Medicine* 1246
40. Lung Foundation Australia Making Lung Cancer A Fair Fight: A Blueprint for Reform, <https://lungfoundation.com.au/resources/making-lung-cancer-a-fair-fight-a-blueprint-for-reform/>
41. Australian Institute of Health and Wellbeing 2022, Immunisation and vaccination, <https://www.aihw.gov.au/reports/australias-health/immunisation-and-vaccination>
42. Australian Government 2022, List. Risk conditions for pneumococcal disease, <https://immunisationhandbook.health.gov.au/resources/tables/list-risk-conditions-for-pneumococcal-disease>
43. World Health Organisation 2014, Prevention for a healthier future [https://www.aihw.gov.au/getmedia/6c8ffb4a-a0f6-49f8-9b05-01f2157b822c/8_1-health-prevention.pdf.aspx#:~:text=The%20World%20Health%20Organization%20defines,disability'%20\(WHO%202004\)](https://www.aihw.gov.au/getmedia/6c8ffb4a-a0f6-49f8-9b05-01f2157b822c/8_1-health-prevention.pdf.aspx#:~:text=The%20World%20Health%20Organization%20defines,disability'%20(WHO%202004))
44. Australian Government, National Health Prevention Strategy 2021-2030, <https://www.health.gov.au/resources/publications/national-preventive-health-strategy-2021-2030>
45. Australian Health Minister s' Advisory Council 2017, National Strategic Framework for Chronic Conditions 2019, <https://www.health.gov.au/sites/default/files/documents/2019/09/national-strategic-framework-for-chronic-conditions.pdf>
46. Nutbeam, Don. (2020). COVID-19: Lessons in risk communication and public trust. *Public Health Research & Practice*. 30. 10.17061/phrp3022006
47. Nickel et al. 2022, Predictors of confidence and trust in government and institutions during the COVID-19 response in Australia, *The Lancet Regional Health - Western Pacific* 2022, vol 23, <https://doi.org/10.1016/j.lanwpc.2022.100490>
48. World Health Organisation 2022, Clinical management of COVID-19 patients: living guideline, <https://www.who.int/publications/i/item/WHO-2019-nCoV-Clinical-2022.2>
49. Davis, H et al., 2021, Characterizing long COVID in an international cohort: 7 months of symptoms and their impact, *Journal of EClinical Medicine*, 38 (101019), <https://doi.org/10.1016/j.eclinm.2021.101019>
50. Ibid 7
51. Health direct 2022, Understanding post-COVID-19 symptoms and long COVID, <https://www.healthdirect.gov.au/covid-19/post-covid-symptoms-long-covid>




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