



**Response to the House of Representatives Standing
Committee on Health, Aged Care and Sport**

‘Inquiry into long COVID and repeated COVID infections’

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About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail aged.

In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represent the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers should have the same rights, choices, and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment, and education.

This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including 'grandparent carers'
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI+)
- Who are living in rural and remote Australia, and
- Who are no longer in a caring role (former carers).

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples and communities as the traditional custodians of the land we work on and pays its respect to Elders past, present and emerging. As an inclusive organisation Carers Australia celebrates people of all backgrounds, genders, sexualities, cultures, bodies, and abilities.

Introduction

Carers Australia welcomes the opportunity to respond to the House of Representatives Standing Committee on Health, Aged Care and Sport (Committee) on the Inquiry into long COVID and repeated COVID infections (the Inquiry). We wish to relay several key points about Australia's 2.65 million carers¹, and would welcome the opportunity to provide further specific information to the Committee.

Becoming a carer is often not a choice, and the impacts of caring on carers can be profound, particularly on their own health and wellbeing. Never has this been more evident than in the experience of carers during the COVID-19 pandemic and ongoing. More than 1 in 10 Australians are carers² and in 2021, 72% of carers had an increase in intensity in their caring responsibilities due to COVID-19, with almost half (49.6%) reporting that this is long-term³.

What has been acknowledged in the COVID response to-date is that many of the people cared for are in a high-risk health or age category for COVID-19. The reality is that carers are also in high-risk categories themselves as individuals, or by the nature of the caring role.

In 2018⁴ more than one-third of primary carers lived with disability and more than half (54.8%) of those providing care to a spouse or partner were aged 65 years and over. Further, a high proportion of carers live with chronic conditions, and often report poor health, where in 2022 only 17.1% of carers responding to the Carers Wellbeing Survey⁵ reported that their health is very good or excellent, compared with 47.9% of Australian adults. Across all carers, more than 70% reduced their own social interaction due to one or more people they cared for being at high risk if they became ill with COVID-19.

It is essential to highlight that if carers are unable to continue their caring role at the same or increased intensity (as has been required during COVID), the health, aged care and disability care systems which are already stretched and struggling with workforce constraints, and in a tight fiscal environment, will have to provide more. Most hours of 'informal' care are provided by primary carers, who are estimated to spend an average of 35.2 hours per week, and up to 60 hours per week providing this care⁶. When you consider primary and non-primary carers combined, Australia's unpaid carers provided nearly 2.2 billion hours of care in 2020, at a replacement cost for formal paid care of \$77 billion.

The potential impact of long COVID and/or repeated infections on Australia's 2.65 million unpaid carers and the interplays cannot be understated – in addition to the individual impact of a carer having long COVID and/or repeated infections, there is the impact on the care recipient if their carer has long COVID and/or repeated infections, as well as the direct impact on the carer if the person they are caring for has long COVID and/or repeated infections.

An unwell carer will see an increased requirement for paid support for the care recipient, for example, through NDIS or My Aged Care, in an already stretched environment for these services and their workforces. It will place additional pressure on already scarce respite offerings across aged care, mental

¹ Carers Australia uses the term 'carer' as defined by the [Commonwealth Carer Recognition Act 2010](#) (the Act), where it should not be used broadly and without context to describe a paid care worker, volunteer, foster carer or a family member or friend who is not a carer. The terms 'informal carer', 'unpaid carer' or 'family and friend carer' are also often used by organisations, government and the community to describe a carer. Carers Australia may use these terms to assist in providing context and to differentiate between other types of care.

² Australian Institute of Health and Welfare, 'Australia's Welfare 2021' [\[accessed online\]](#)

³ The 2022 Carer Wellbeing Survey - a collaboration between Carers Australia and University of Canberra, and funded by the Australian Department of Social Services. The full report for 2022 is [available online](#)

⁴ Australian Bureau of Statistics' (ABS) '2018 Survey of Disability, Ageing and Carers' (SDAC), [\[accessed online\]](#)

⁵ Op.Cit (3)

⁶ Deloitte Access Economics, 'The Value of Informal Care in 2020', Commissioned by Carers Australia [\[accessed online\]](#).

health care, disability care and palliative care. In addition, the carer may require increased support and services, and in fact, need a carer for themselves in certain circumstances. They may be unable to return to their previous caring role at all, or with reduced capacity, with potential gaps in supports for the care recipient if funded supports are not available through long waiting lists, geographic restrictions, closed books, lack of workforce, cost, or issues navigating the NDIS, My Aged Care or mental health systems.

If the care recipient is unwell, this can increase the intensity of care required, which can exacerbate current issues with employment prospects, financial security, and the physical and mental health of the carer. This can also lead to the previously noted increased need for paid supports and respite care, and even result in the care recipient entering into residential care if the carer is unable to sustain an increased caring load whilst also trying to maintain employment, education and other functions within the family. In the context of COVID, this has included home learning of children, whilst at the same time working from home, continued caring and reduced access to much relied upon services.

This reduced access to services is also an important factor even without having long COVID or repeated infections in future responses. We have seen during COVID to date the intensity of caring has increased and is not yet reducing, coupled with the care recipients' condition, disability or mental health being impacted and exacerbated due to gaps in continuity of paid care and supports.

There is also the unknown demand for carers - more people may become a carer for the first time, or earlier than they may have anticipated for people living with chronic conditions, disability or who are ageing that otherwise did not require a carer prior to the full impacts of long COVID or repeated infections (as yet unrealised). A recent report⁷ by the International Alliance of Caring Organisations, of which Carers Australia is a member, found that nearly one in three (29%) carers in the Asia Pacific region started their responsibilities as a result of the pandemic, higher than the global average.

This will be exacerbated if there are no other family members or friends able to provide these roles, or there are many people impacted within the household. It should not be assumed that the community will 'step up' or that other family will step-in because 'it's what family should do' - the demands of the caring role often go beyond what would normally be expected of these relationships.

To note, the propensity to care is decreasing for many reasons, including changes in intergenerational attitudes, perceptions of caring, and the economic and financial impact caring can have. Modelling completed in early 2020 prior to the pandemic revealed the demand for informal carers in Australia will grow by 23% by 2030, however the supply is anticipated to rise by only 16%⁸. The widening carer gap already has significant policy implications for Australia's future, more so with the implications of ongoing COVID ramifications.

Response to the Terms of Reference

The patient experience in Australia of long COVID and/or repeated COVID infections, particularly diagnosis and treatment.

It is important to consider not only the patient (consumer) experience, but also that of unpaid carers in any response to long COVID or ongoing measures for repeated COVID infections. Carers are responsible for the wellbeing of some of the most at-risk people in our society and provide care for those with often poor health outcomes relating to underlying conditions or disability, and experience difficulties accessing

⁷ International Alliance of Caring Organisations, 'The Global Carer Well-Being Index Who Cares for Carers? Perspectives on COVID-19 Pressures and Lack of Support' (2021) [\[accessed online\]](#)

⁸ *Op.Cit* (6)

health and other services in normal circumstances. Carers often provided assistance to the care recipient related to:

- Understanding and enforcing where possible social distancing and other measures, as well as dealing with lockdowns and isolation period, particularly distressing for a person with dementia or other cognitive decline, mental health issues, or intellectual disability or delay.
- Understanding the vaccine regime and gaining consent (or supporting non-consent), as well as transport to and management of timings to receive the vaccine and boosters.
- Understanding testing, identifying when testing was required, gaining access to testing, and assistance with using RATs.

Carers, at the outset, were not provided with access to appropriate PPE, information or support. The lack of acknowledgment of carers role in supporting our health systems was evident where the Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19) did not mention carers at all, thus omitting them as a key component of any response. This is despite the Plan stating the importance of informing and supporting at-risk groups, where “additional strategies to support at-risk groups may be required” or that there are ‘specific needs’ groups for information.⁹

This resulted in an ongoing information gap for carers who needed to navigate multiple sites or sources to access relevant and up-to-date information dependent on the care recipients and their own needs, further increasing levels of stress. Many carers are also caring for multiple people, so needed to distil information related to aged care and/or disability care and/or mental health or other sectors. Young carers, culturally and ethnically diverse carers and First Nations carers also had an extra layer of disadvantage related to navigating systems for themselves and the person(s) they are caring for.

Regarding long COVID, carers will be assisting with monitoring symptoms, and there may be many people who will require their carers support with communication to describe their symptoms, exacerbated by the cognitive symptoms of long COVID such as 'brain fog', confusion and loss of memory. Carers Australia through our Member organisations, is also being informed of long waiting lists for Long COVID Clinics.

According the 2022 Carer Wellbeing Survey, the majority of carers reported delays or cancellations in treatment or therapy for care recipients, and difficulty accessing broader services and health professionals:

- 73.5% of carers reported it was sometimes or regularly harder to get health or social service appointments for the people they cared for due to COVID-19
- 71.3% reported treatment or therapy for care recipients being delayed or cancelled (37.4% regularly)
- 61.5% reported that access to some types of supports or services such as respite reduced for the people they cared for

⁹ Australian Department of Health, ‘Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19)’ (February 2020), page 40 [[accessed online](#)] states: “Provide specific information for groups at risk or with specific needs when identified.(e.g. culturally and linguistically diverse (CALD), aged care or Aboriginal and Torres Strait Islander people, schools, suspected cases, universities and vocational education training sector, hospitality and tourism industry, employers, airline and air/seaport, health professionals).”

- 55.8% reported that communication with medical professionals related to the care recipient increased in difficulty due to COVID-19 restrictions
- Only 60% of carers reported that telehealth appointments had been helpful during COVID-19
- 1 in 5 carers had difficulty in accessing the vaccine and vaccine certificates
- Only 52.9% of carers reported they had good access to information from the medical professionals who provided support to the people they cared for (35.0% had limited access and 12.2% no access to information from these medical professionals).

Further data is available on carers experiences of COVID-19, for example, the Carers Victoria '[Victorian COVID-19 Carer Survey](#)', Carers Tasmania '[COVID Impact Survey 2022](#)' and the Carers NSW biennial '[National Carers Survey](#)'.

While this response has primarily focused on carers who care for people within the home, it is important to note impacts on carers of people who live within residential aged care or disability accommodation, or those that were unable to perform their caring role due to other isolation practices and requirements such as cross-border issues or lockdowns.

This was recognised in the Royal Commission into Aged Care Quality and Safety Special Report on COVID-19¹⁰, which highlights significant negative impacts of public health orders restricting visitors to residential aged care, which meant that many carers were unable to spend time with their loved ones in a meaningful and fulfilling way, including to help with meals and personal care. During the pandemic carers who had been appointed Power of Attorney or Guardians were not permitted to enter residential care, and Carers Australia were collaborators in the development and subsequent reviews of the 'Industry Code for Visiting Residential Aged Care Homes During COVID-19'. Similar issues were experienced within residential settings for people living with disability, and have been explored by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.¹¹

We draw the Committee's attention to the 2022 Carer Wellbeing Survey which includes information specific to the impact of COVID on carers (data collected in February-March 2022). As a summary:

- Carers continue to be significantly more likely than other Australians to have concerning low levels of wellbeing, with 55.2% having low wellbeing compared to 25.4% of Australians.
- Carers also continued to be at higher risk of psychological distress, with 48.1% experiencing moderate to high levels of psychological distress – almost twice as many as the 25.0% of Australian adults who experience this. Rates of high psychological distress increased between 2021 and 2022 amongst carers aged 25-34 and those who had been a carer for five or more years.
- Rates of loneliness increased amongst carers between 2021 and 2022, with a rise in those reporting they were often or always lonely from 35.1% to 39.4%.
- Access to informal support also declined during the pandemic: 55.8% of carers reported that at some points during the pandemic, family and friends who usually assisted them could not provide support.

¹⁰ Commonwealth of Australia, Royal Commission into Aged Care Quality and Safety, Aged Care and COVID-19: a special report' (2020) page 6 [[accessed online](#)]

¹¹ Commonwealth of Australia, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 'Report - Public hearing 5 - Experiences of people with disability during the ongoing COVID-19 pandemic' (2020) [[accessed online](#)]

- Amongst carers who were in paid employment or enrolled in a course of study, just over half (50.9% and 51.8% respectively) reported they had taken time off work or study due to COVID19 related increases in their caring responsibilities

The experience of healthcare services providers supporting patients with long COVID and/or repeated COVID infections.

As highlighted, carers experienced increased difficulties in accessing and communicating with health and care service providers. The *Carer Recognition Act 2010* (Commonwealth) states that the relationship between carers and the persons for whom they care should be recognised and respected, and carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.

We highlight that the wellbeing of patients accessing healthcare services and their carers are interdependent. The healthcare system during COVID-19 did not proactively identify carers or include carers in appropriate discussions or decision-making, in effect ignoring the impact that a person's care needs have on the carer.

Research into the potential and known effects, causes, risk factors, prevalence, management, and treatment of long COVID and/or repeated COVID infections in Australia.

The COVID experience has highlighted the role of health and care provision in the home as direct medical and support services have become limited through lockdowns and workforce issues. With increased strain on health and medical settings during and post-COVID, carers have and will continue to play a key role in providing health and medical care to the people they care for with limited guidance or assistance.

Consequently, any research must include where appropriate, the impact, needs and role of carers in the context of long COVID and/or repeated infections, and should involve direct carer involvement in design of research.

The health, social, educational and economic impacts in Australia on individuals who develop long COVID and/or have repeated COVID infections, their families, and the broader community, including for groups that face a greater risk of serious illness due to factors such as age, existing health conditions, disability and background.

The long-term physical, emotional and financial effects on carers from disruption to services, loss of income and increased psychological stress during the ongoing pandemic are yet to be fully appreciated, but it is clear from the results of the 2021 and 2022 Carer Wellbeing Surveys that carers must be included explicitly in future planning and responses.

As noted above, 72% of carers had an increase in intensity in their caring responsibilities due to COVID-19, with almost half (49.6%) reporting that this is long-term. Further, for more than 50% of carer, access to informal support also declined where family and friends lost the ability to help. Social isolation is an everyday experience for carers, which dramatically increased during the pandemic and exacerbated carer stress and anxiety as they supported the person cared for confronting the very real possibility of becoming extremely unwell from COVID-19, and now from long COVID and/or repeat infections.

Their usual support networks and support services such as respite care, school, early intervention programs, social support programs, day centres, and home care were no longer available or could only provide support at reduced capacity.

It is noted that the National Mental Health and Wellbeing Pandemic Response Plan states *“The COVID-19 physical distancing requirements are having a significant impact on carers, both paid and unpaid, leading to increased stress, caring responsibility and financial losses. When formal supports are decreased or not accessible, unpaid carers are left to replace the support not being provided. In the current pandemic, they are also providing more support when the person for whom they are caring has increased anxiety while being unable to leave home for respite. Carers are already known to have poorer mental health than the general population and have lower household resources. Support for carers to sustain their loved one in their home environment is essential.”*¹²

However, there was no dedicated funding for the mental health needs of carers broadly, or increase in support provisions *for the carer*, despite carers being two and a half times more likely to have low wellbeing than a person who does not have a caring role¹³.

Carers Australia received funding for a 12-month ‘Caring through COVID’ project in 2020-21, which focused on carers of people living with mental ill-health, to enable carers to connect with other carers, assess and monitor their own mental health, and engage with online resources which promoted self-care and wellbeing. Between May and September 2021 more than 4,300 carers participated in 36 online mindfulness sessions and there were 2,188 listeners to a carer-specific podcast series.

Independent evaluation of the project determined a positive impact on carers’ wellbeing and more people identifying themselves as a carer to access supports. High engagement with the program increased social connectedness between participating carers and increased the number of carers accessing support pathways immediately after the program. Unfortunately, representations to have the project continued and expanded to support the wellbeing needs and experiences of all carers during the ongoing pandemic and recovery were unsuccessful.

Young carers as a particular population should be noted, where a young carer is aged 12-25 years. Young carers took on more caring responsibilities and experienced additional stress due to loss of support services and school closures during lockdowns across different states. Insufficient support for young carers, concerned about the COVID-19 virus, and increasingly isolated by lockdowns affected their mental health and wellbeing.

Many carers also experienced increased financial stress during the COVID-19 pandemic. While carers may need or want to work fewer hours to enable them to provide increased care, they still needed economic security. The reduction or loss of employment and social interaction, the added stressors of moving to remote work or schooling, and the impacts of sudden, localised lockdowns to prevent further outbreaks have impacted on carers disproportionately as they tried to also maintain their caring role.

Prior to COVID, primary carers were more likely to live in households with a lower equivalised gross household income, with 50.2% in a household in the lowest two quintiles, twice that of non-carers (25.6%)¹⁴. More than half the carers who responded to the 2022 Carer Wellbeing Survey reported that their household was either very poor, poor or just getting along financially, compared to 33.8% of Australians. 54% of carers had experienced at least one major financial stress event in the last 12 months, such as being unable to pay bills on time, going without heating or cooling, having to delay important

¹² Australian Department of Health, ‘National Mental Health and Wellbeing Pandemic Response Plan’ (May 2020), page.30 [\[accessed online\]](#)

¹³ Op.Cit (3)

¹⁴ Op.Cit (4)

purchases, or having to ask for financial help from friends and family, compared to 32% of Australians more generally in 2021. Many reported going without meals.

We also note that the Australian Government Coronavirus Supplement (introduced in March 2020) effectively doubled the amount of a range of social security payments, including JobSeeker, Youth Allowance and the Parenting Payment, cushioning the economic impacts of the pandemic. However, people receiving the Carer Payment, Disability Support Pension and the Age Pension were excluded from these extra payments.

Further, there were issues with other types of payments related to isolation for carers, which didn't consider that carers are often required to be out of the workforce as well with the person they are caring for, and the diversity of caring. For example, the Pandemic Leave Disaster Payment was targeted at families who were isolating with their children, who were only eligible if their child was 16 or under. So those whose children with a disability are 'adult' and over 17 years were missing out, even though they required supervision and support at home.

The impact of long COVID and/or repeated COVID infections on Australia's overall health system, particularly in relation to deferred treatment, reduced health screening, postponed elective surgery, and increased risk of various conditions including cardiovascular, neurological and immunological conditions in the general population.

Carers Australia reiterates the potential impact of a decrease in carers being able to maintain their caring responsibility, and the replacement cost of the 'informal' care being provided before the pandemic, and the anticipated increased reliance on health and support services for both the carer and care recipient if carers are not considered in future pandemic planning and responses.

Best practice responses regarding the prevention, diagnosis and treatment of long COVID and/or repeated COVID infections, both in Australia and internationally.

A pandemic response plan for carers was never developed. Future disaster preparedness and response planning for long COVID and/or repeated infections, as well as more broadly must be carer-inclusive and accessible to carers, underpinned by a clear recognition of the multiple layers of disadvantage that carers already experience. It must also recognise the expertise of carers and acknowledge their capabilities and unique knowledge about the person cared for, and that both people in the relationship have rights and responsibilities.

Lessons learned to improve support for carers during the pandemic are still emerging yet we know that carers were not provided with ease of access to PPE, or prioritised for COVID-19 testing or vaccination in initial risk management and contingency planning. Supports available in other countries for carers included: emergency support structures, financial support, health care providers tasked with supporting carers, support navigating restrictions, COVID-19 testing and provision of PPE¹⁵.

We note the 'Clinical Guidelines: Care of People after COVID'¹⁶ to support clinicians in the diagnosis and treatment of long COVID specifically references carers in communication with the primary health care team, however the guidelines and any further planning and documentation should embed carers further as appropriate, and explicitly support individuals to return to 'carer duties'.

¹⁵ Lorenz-Dant K. (2020) 'International examples of measures to support unpaid carers during the COVID-19 pandemic' Report in LTCcovid.org, International Long-Term Care Policy Network, CPEC-LSE, 20 May 2020 [[accessed online](#)].

¹⁶National COVID-19 Clinical Evidence Taskforce, Clinical Guidelines: Care of People after COVID' V.7.0 (10 November 2022) [[accessed online](#)]