



**Carers Tasmania's Submission on the Commonwealth
Government COVID-19 Response Inquiry**

November 2023



About Carers Tasmania

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers (hereafter carers) in the state.

Carers Tasmania's vision is for an Australia that values and supports carers.

Our mission is to work to improve the health, wellbeing, resilience and financial security of carers and to ensure that caring is a shared responsibility of family, community, and government.

Our values drive everything we think, say, and do.

- **Carers first** – we listen to what carers need, commit to their desired action plan, and deliver results that matter most to carers
- **Care in all we do** – we care for our work, about each other, about Tasmania's family and friend carers, and the bigger world we all share
- **Integrity always** – we are transparent, act ethically, own when things don't go to plan and do what we say we will
- **Quality every time** – we don't accept 'good enough' because carers deserve our very best every time
- **Speed that matters** – we are agile and don't put off what can be done today.

These values represent how we engage with and serve carers, how we work with each other, and our commitment to the broader community. Carers Tasmania encourages partnership with governments and health and community sectors to enhance service provision and improve conditions for family or friend carers through policy development, research and advocacy.

We acknowledge and support people of all genders, sexualities, cultural beliefs, and abilities and understand that carers in Tasmania, whilst sharing the common theme of caring for a family member or friend, are diverse individuals with varying beliefs, experiences, and identities. We value and respect the diversity of carers, their lived and living experiences, and recognise that carers are the experts in their own lives.

Carers Tasmania has offices in Moonah, Launceston, and Burnie.

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1. Background

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers within the state.

A carer is a person who provides unpaid care and support to a family member, or friend, with disability, mental ill health, a chronic or life-limiting condition, alcohol or other drug dependence, or who is frail or aged. Informal kinship carers who care for a child under the age of 18, because the parent is unable to, are also recognised as carers. Carers are predominantly family members, but may also be friends, neighbours, or colleagues. Informal carers are not to be confused with paid support workers who are often called 'carers', with the difference being that support workers are fully employed and remunerated with all the benefits of employment. On the contrary, informal carers perform their caring duties without remuneration, other than minimal carer payments and allowances from the Australian Government.

In addition to representing carers through the Peak Body activities, Carers Tasmania provides support to carers living in Tasmania through its service delivery arm, Care2Serve. The Commonwealth Carer Gateway program is delivered through Care2Serve in Tasmania, as are other supports and services, such as the Tasmanian Government's Home and Community Care program.

The Carer Gateway program provides a range of services and supports for carers which are designed to build resilience, increase wellbeing, improve quality of life, and sustain carers to effectively continue their caring roles. The available supports include the provision of information, advice and referrals, holistic identification of carer strengths and needs through a carer support planning process, professional counselling, peer support, and coaching which aims to support carers in achieving specific goals.

Care2Serve, through the Carer Gateway, has the capacity to fund certain instances of planned, practical support services such as in-home respite, personal care, domestic assistance, and meal preparation. Care2Serve may also fund items such as laptops to assist carers who are studying or trying to enter the workforce. Care2Serve also coordinates the provision of emergency support during instances where a carer may be unable to provide the care that they usually do, resulting from unexpected illness or injury of the carer.

2. Introduction

Carers Tasmania welcomes the opportunity to provide feedback on the Commonwealth Government's COVID-19 Inquiry (the Inquiry). The impacts of COVID-19 have been significant and wide-reaching; however, there have been many lessons learned. This Inquiry provides an opportunity to transform the negative experiences associated with COVID-19 into positive planning and safeguarding for the future. We must learn from these experiences and ensure that disaster preparedness plans are developed. These plans must specifically acknowledge at-risk cohorts, such as carers, who felt unrecognised during the pandemic despite their additional needs.

Carers Tasmania's response highlights some significant impacts experienced by carers and makes recommendations to be considered in any pandemic or disaster preparedness planning.

3. Significant impacts on carers

The following points have been collated from various surveys of carers and highlight the impacts and increased responsibilities carers faced during the pandemic.

Tasmanian COVID Impact Survey 2022

Carer responses:

- Most carers (43.5%) preferred TV or radio to keep them up to date with information about COVID-19. This was especially true for 54.9% of carers aged 65 or older.
- 50.4% of carers indicated there was nobody else who could step in for them in their caring role.
- 59.5% of carers chose to self-isolate to protect those they were caring for during the pandemic.
- 79.5% of carers reported feeling emotionally drained.
- 61% of carers reported their expenses increased following the opening of the Tasmanian borders.
- 13.8% of carers reported partial job loss and 2.7% completely lost their job during the pandemic.
- 8.3% of carers with a school-aged child indicated they intended to continue home-schooling their child despite schools re-opening.
- 75.8% of employed carers had not been provided the option to work from home.¹

Carer Wellbeing Survey 2022

Carer responses:

- 74.2% of carers reduced their social interaction to protect those they cared for during the pandemic.
- 72.2% of carers indicated their caring responsibilities increased.
- 63.9% of carers reported increased levels of isolation.
- 61.5% of carers had reduced access to formal support services.²

¹ Carers Tasmania. (2022). *Carers Tasmania COVID Impact Survey 2022*. <https://carerstas.org/wp-content/uploads/2023/08/Carers-Tasmania-COVID-Impact-Survey-2022-Report-.pdf>

² Schirmer, J., Mylek, M., & Miranti, R. (2022). *Caring for Others and Yourself: 2022 Carer Wellbeing Survey*. Full data report Carers Australia. https://www.carersaustralia.com.au/wp-content/uploads/2022/10/2022-CWS-Full-Report_221010_FINAL.pdf

National Carer Survey 2022

Carer responses:

- 44.8% of carers were separated from their loved ones for long periods of time during the pandemic (this was mostly within the context of hospitals or residential aged care facilities).
- 67.5% of carers of people with disability experienced a reduction or cessation of support during the pandemic. This was also the case for 42% of carers supporting someone accessing mental health services, and 40.4% of carers supporting someone accessing aged care services.³

Caring Fairly Coalition COVID-19 Survey 2020

Carer responses:

- 60% of carers lost the usual supports provided for the person they care for during the pandemic.
- 44% of carers indicated they spent an increased amount of time on unpaid care.
- 81% of carers reported their personal mental health had deteriorated.
- 52% of carers indicated their stress levels had increased either by a lot or an extreme amount.
- 37% of carers lost some or all of their income during the pandemic.⁴

Carers Victoria COVID-19 Survey 2022

Carer responses:

- 85% of carers reported feeling socially isolated during the pandemic.
- 51% of carers indicated their mental health was worse or a lot worse than prior to the pandemic.
- Over 80% of carers reported they spent more time providing care during the pandemic.
- More than 50% of carers were providing complex care that was usually provided by trained professionals.⁵

Despite carers being a high-risk group for catching COVID-19 due to their own health issues or because of caring for people who are high risk, the Carers Tasmania's 2022 report found that only 3.93% of respondents had tested positive for COVID-19. Whilst this low rate is pleasing, the survey found that the potential reason for this was that 59.5% of carers chose to self-isolate as a preventative measure. While low rates of COVID-19 amongst carers could result from self-chosen isolation, the consequences faced by self-isolating included exacerbated loneliness and loss of practical and/or emotional support. In addition, carers also experienced a loss of income, employment implications, difficulties in accessing essential items, and overall, a greater risk of carer burnout.

³ Carers NSW. (2023). *2022 National Carer Survey: Full report*. Available online at: <http://www.carersnsw.org.au/research/survey>

⁴ Caring Fairly. (2020). *COVID-19 Carer Survey*. <https://www.carersvictoria.org.au/media/2154/caring-fairly-covid19-survey-results.pdf>

⁵ Carers Victoria. (2022). *Overview of findings from the Victorian COVID-19 carer survey*. https://www.carersvictoria.org.au/media/4234/2754-carers-vic-overview-of-victorian-covid19-carer-survey_fa.pdf

4. Response to the Inquiry

Carers Tasmania's primary advocacy aim is for carers to be considered as a priority cohort alongside other specific priority cohorts in planning for any disaster or pandemic. There must be consideration and planning specifically for carers, to ensure their own safety, wellbeing, and to support them to sustain their caring roles. To date, several cohorts have been acknowledged as high-risk for COVID-19 due to health, age, or disability status. Unfortunately, carers have remained unrecognised despite the crucial role they play.

There are more than 80,000 carers in Tasmania and 2.65 million carers across Australia. Specific pieces of legislation aim to increase the recognition and support of carers both on a national level through the *Carer Recognition Act 2010* (Cth)⁶ and at the state level through legislation such as the *Tasmanian Carer Recognition Act 2023*.⁷ Despite these Acts outlining the importance of carer recognition, inclusion, and the right of carers to be supported themselves, carers were largely forgotten throughout COVID-19.

Throughout COVID-19, Care2Serve provided food and basic care packages to carers in Tasmania who couldn't leave their house. After the borders opened to Tasmania in December 2021, Carers Tasmania conducted a survey to examine the impact of COVID-19 on carers. This survey built on the findings from a previous survey that was conducted in 2020. The 2021 survey found that more than half of respondents (59.5%) chose to self-isolate as a preventative measure. This meant that many carers went without usual support from their service providers, and/or also struggled to access essentials. Most of the carers who chose to self-isolate (56.1%) were aged 65 years or older.

Several resources were circulated about what help was available to people with disability, but information specifically for carers was lacking. During the initial stages of COVID-19, Care2Serve completed check-in calls to carers to find out how they were coping. The feedback received from carers suggested that these calls were very much appreciated, and for many carers, this was the first time during the pandemic that someone asked how they were.

Some carers reported they were unable to access certain forms of respite. In-home supports such as domestic assistance, personal care, and respite became limited. Respite was even more restricted in residential aged care facilities. This resulted in carers not being able to access breaks or have time for themselves to rest and recharge. To ensure the wellbeing of carers, and sustain their capacity to continue providing care, carers must have opportunities to take time for themselves.

The *Royal Commission into Aged Care Quality and Safety Special Report on COVID-19*⁸ highlighted significant negative impacts that resulted from the public health orders that restricted visitors to residential aged care facilities. This meant that many carers were unable to spend time with their loved ones. Often, when a person enters residential aged care, either permanently or for respite, carers still find themselves assisting with meals, washing, appointments, personal care, and both social and emotional support. The restrictions on these activities caused great distress and confusion.

⁶ *Commonwealth Carer Recognition Act*. (2010). <https://www.legislation.gov.au/Details/C2010A00123>

⁷ *Tasmanian Carer Recognition Act* (2023). <https://www.legislation.tas.gov.au/view/whole/html/inforce/2023-04-20/act-2023-001>

⁸ Royal Commission into Aged Care Quality and Safety. (2020). *Aged care and COVID-19: a special report*. <https://www.royalcommission.gov.au/system/files/2021-03/aged-care-and-covid-19-a-special-report.pdf>

As highlighted by Carers Australia, the Australian Government Coronavirus Supplement that was introduced in March 2020 increased the amount of several social security payments, including JobSeeker, Youth Allowance, and Parenting Payment. However, people receiving the Carer Payment, Disability Support Pension, and Age Pension were excluded from these extra payments, despite the significant impacts that COVID-19 had on their finances.⁹

Carers Australia also highlighted issues regarding other COVID-19 payments that didn't consider carers. As an example, the Pandemic Leave Disaster Payment was available to eligible families who were isolating with their children if their child was 16 or under. Carers of older children with disability missed out, despite their need to stay at home and provide support during the pandemic.¹⁰

Carers shared many scenarios where they were not allowed in health settings when needed by the person they were caring for. These situations were stressful and challenging and at times led to poor outcomes for the people seeking treatment. The following case studies are just two examples:

Case Study:

Mr. A is a single father caring for his 9-year-old Autistic son. His son has an NDIS plan, but there is not enough funding in the plan for respite or activities. Recently, his son had to go to the emergency department in a North-West Tasmanian hospital and his father was told he was not allowed into the emergency room. Mr. A insisted that it was critical for him to be in the room and he would most definitely be accompanying his son. The hospital director eventually came to speak with Mr. A, which resulted in him being permitted to be present with his son in the emergency room. This is a distressing situation that could easily have been avoided.

Case Study:

A young carer who identifies as LGBTIQ+ shared their story about how their partner was admitted to a Southern Tasmanian hospital. Their partner has multiple health issues, but also co-occurring and complex mental ill health. The young carer was told they were not allowed to be at the hospital with their partner, despite being their only carer and support person. This was a very distressing situation for both the young carer and their partner who really needed their support during this time.

5. Recommendations

Carers Tasmania recommends the following:

- Embed the routine identification, referral, and support of carers, as required under the *Carer Recognition Act 2010*, as a central component of all Government and Government-funded services.
- Recognise carers as a priority cohort who must be considered in planning for disasters, pandemics, and other significant unforeseen circumstances.
- Ensure that policy, funding grants, and guidelines allow for flexibility in the delivery of support for carers in the case of any disasters, pandemic, or other significantly disruptive situations.

⁹ Carers Australia. (2022). *Carers Australia Response to Long COVID Inquiry*. <https://www.carersaustralia.com.au/wp-content/uploads/2022/11/FINAL-Carers-Australia-Response-to-Long-COVID-Inquiry-Nov-2022.pdf>

¹⁰ Ibid.

- Ensure that carers are recognised as a vulnerable cohort in need of additional government supplements in the case of any future disaster or pandemic due to the significant impacts on them and their need to provide increased care.
- Policy, particularly within healthcare settings, must be clear and inclusive of the rights and needs of carers.
- Given the low literacy rates and digital barriers experienced across communities, there must be strategically planned communications that are accessible and understandable for everyone during pandemics and natural disasters.
- Introduce increased protections and flexibility for employed carers, especially when unforeseen circumstances arise. There must also be adequate and accessible training pathways for carers who want to study, enter, or re-enter the workforce.