



**Response to the House of Representatives Standing
Committee on Health, Aged Care and Sport.
Inquiry into Long Covid and Repeated Infections**

February 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.

Carers Tasmania has offices in Moonah, Launceston and Burnie.

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Background

Carers Tasmania acknowledge the Aboriginal and Torres Strait Islander peoples as the traditional custodians of the land of lutruwita/Tasmania and we pay our respects to Elders past and present. 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.

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers in 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 are frail or aged. A carer may also be a kinship carer of a child under the age of 18. 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, 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 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.

Introduction

Carers Tasmania welcomes the opportunity to respond to the House of Representatives Standing Committee on Health, Aged Care and Sport (The Committee) on their inquiry (The Inquiry) into long COVID and repeated COVID infections. COVID has and is continuing to have significant impacts on carers and the people for whom they care.

It must be acknowledged that we are part of the National Carer Network of State and Territory Associations and that although Carers Australia has provided a collective response, we are submitting this state-based response with more specific information pertaining to carers in Tasmania.

To begin, we highlight that in Tasmania, there are more than 80,000 informal carers, according to The Australian Bureau of Statistics 2018 *Survey of Disability, Ageing and Carers* (SDAC)¹ which is representative of 15.5% of the Tasmanian population. Of these carers, females accounted for 41,400 (51.7%) and males accounted for 38,000 (47.4%). The report also found that there were 6,200 (11.6%) young carers aged under 25 years in Tasmania.

Tasmania, when compared with the rest of Australia fares very poorly in health outcomes, including greater rates of disease burden (arthritis, asthma, diabetes, cancer, heart disease) and high rates of mental ill health,² as well as an ageing population. So, the reality is that many carers in Tasmania, despite providing care to their family members or friends, experience poor health or disability themselves.

Our submission mostly focuses on the following items that are outlined in the Terms of Reference (ToR) of the Inquiry.

- **ToR item one:** The patient experience in Australia of long COVID and/or repeated COVID infections, particularly diagnosis and treatment;
- **ToR item four:** 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; and
- **ToR item five:** 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.³

¹ Australian Bureau of Statistics (2021) 44300DO006_2018 Disability, Ageing and Carers, Australia: Tasmania, 2018. Released at 11:30am Wednesday 5 February 2020

² <https://www.abs.gov.au/articles/snapshot-tas-2021#:~:text=In%20the%202021%20Census%2C%20the,city%20area%20of%20Greater%20Hobart.>

³

https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/LongandrepeatCOVID/Terms_of_Reference

Our response is mostly informed by results from the Carers Tasmania COVID Impact Survey 2022 Report⁴, which built on the 2020 Road to Recovery: COVID-19 Survey Results⁵ and other anecdotal feedback from Carers in Tasmania.

Response to the ToR

First and foremost, we consistently advocate for the recognition and inclusion of carers where patients or consumers are involved. In many instances, where there is a patient or consumer, there is also a carer.

Both carers and the people they care for should be considered as high-risk cohorts in relation to COVID. When carers become unwell, this can have significant flow-on effects for the person they care for due to changes in the level of support able to be provided. Aside from being able to access emergency support through Carer Gateway, (which is dependent on contracted support providers), there isn't a lot of additional support available if a carer is unwell.

Although aged care facilities are available for those who have been assessed by the Aged Care Assessment Team (ACAT) and meet the age requirements, it can be quite difficult to access emergency respite care with some facilities having long waitlists. The cost of the daily respite fee is currently \$56.87 which can also be prohibitive. On another note, those who have NDIS plans are quite often not able to access emergency respite due to the process involved in changing plan supports or lack of funding. This means that quite often, the carer must continue to provide support even when they are ill. This is not ideal for either the carer or the person being cared for.

When asking about contingency in the event of a carer not being able to provide the support they usually do, our 2022 survey found that 50.35% of respondents reported that there wasn't anyone else who could step in for them.⁶

Despite carers being a high-risk group of contracting COVID due to their own health issues or because of caring for people who are also high risk, our 2022 report found that only 3.93% of respondents had tested positive for COVID. Whilst this is good, the survey further found that the potential reason for this is that 59.5% of carers chose to self-isolate as a preventative measure. In addition, of these carers, 56.11% identified as aged 65 or older. These results could indicate that the low rates of COVID amongst carers could result from self-chosen isolation, however, the consequences faced by carers for self-isolating include an exacerbation of factors such as 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 higher risk of carer burnout.

In terms of the accessibility of specialist appointments, the 2022 survey found that 48.68% of carers reported that they or the person(s) they care for were waiting longer for specialist appointments. With time frames ranging from less than one month (29.22%), one to three months (36.07%), three to six months (13.24%), and more than six months (21.46%). Some carers (15.23%) experienced having medical or specialist appointments for themselves or the person(s) they care for cancelled with no rescheduled date.⁷

⁴ <https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-COVID-Impact-Survey-2022-Report-.pdf>

⁵ <https://www.carerstas.org/ctas-road-to-recovery-survey-report/>

⁶ <https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-COVID-Impact-Survey-2022-Report-.pdf>

⁷ Ibid.

COVID has also had significant impacts on the wellbeing of carers. In the 2019 survey, 51% of carers reported feeling emotionally drained, whilst 79.5% of carers in the 2022 survey⁸ reported experiencing this.

The following quotes outline further how COVID has impacted the lives of some carers:

- *“If the carer is immune suppressed, they are advised to self-isolate, but this means that they are at risk of losing financial support and have no access to housing, ability to self-care or care for the person we care for. Our support system is disabling, not enabling!”⁹*
- *“I have gone from having my son attend a specialist school 5 days a week. Now home full time with all his needs to be met by me. It is very overwhelming, the days are long and my mental health has suffered.”¹⁰*
- *“Support Services are already stretched beyond capacity and covid issues are compounding this. Wait times for specialist support is extreme and some have simply closed their books to new patients as they cannot keep up with demand. NDIS participants with complex support needs (under 18yrs) are already very difficult to manage on a number of levels, without covid issues making things worse.”¹¹*

Case study

The following is a true and de-identified case study outlining significant service gaps for a family affected by COVID. The person who is suffering the aftereffects of COVID is not eligible for NDIS or aged care support.

Mr. D (age 70) and his partner Mrs. N (age 55) shared their story at a recent Carers Tasmania consultation.

Mr. D has a heart condition, diabetes, and glaucoma. He reported feeling tired, frustrated with the system, and on the edge of burnout. They feel like they are falling through the cracks.

Mr. D cares for his Mother-in-law who has advanced Dementia, as Mrs. N no longer has the capacity to provide support now. Mrs. N was very well both physically and mentally until she experienced a severe asthma attack in June 2022. She was admitted to the RHH where she contracted COVID in ICU, and had a compartment haemorrhage in her leg. She spent 92 days in the hospital. Whilst in the hospital, she received some rehabilitation support such as speech therapy and physio.

Since this event, Mrs. N's life has never been the same. She presents with symptoms of someone who has had a stroke, but the medical professionals can't give her an actual diagnosis of a permanent disability. She is not able to access NDIS due to the lack of permanent disability diagnosis/evidence. Initially, specialists told her that she might have cerebella ataxia, but now they are saying there is no evidence of that and that she 'may' have functional neurological disorder.

⁸ Ibid.

⁹ Ibid.

¹⁰ <https://www.carerstas.org/ctas-road-to-recovery-survey-report/>

¹¹ <https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-COVID-Impact-Survey-2022-Report-.pdf>

Mrs. N now requires a walker, has very poor mobility, and does not drive. She has difficulty speaking and sometimes struggles to breathe when talking. She requires assistance showering and getting dressed. She can't get out into the garden anymore which she loved to do every day. She was also a successful gymnastics coach prior to this.

Mrs. N only has access to one hour per week of domestic assistance for herself. She can't get into a speech therapist and whilst she has some physio appointments, she has to travel to Hobart for these which is quite tiring and expensive with fuel. They live about 60 kms out of Hobart, in a particularly isolated place in terms of access to support.

Mr. D has a level 2 home care package and his Mother-in-law has a level 4 package. Mr. D and Mrs. N have used the majority of their savings to pay for equipment. Mrs. N is now unable to work but does not qualify for DSP due to the lack of diagnosis. They personally purchased a walker with a seat, a standard wheelchair, and a second-hand electric wheelchair for Mrs. N, as well as a trailer to transport it.

Care2Serve, the Tasmanian Carer Gateway provider funded some respite for their Mother whilst they had to travel to Sydney late last year for a funeral of an immediate family member, and have also funded a small amount of additional support, but this funding is limited. In the meantime, Care2serve has assisted with referrals to additional HACC support for Mrs. N, however, the impact of this event on Mrs. N's support needs is significant and the support available is not adequate.

As a result of covid, the caring dynamics in this family have changed, creating additional pressure on Mr. D who has his own health concerns. Mrs. N's quality of life has been severely diminished, as are her hobbies, social life, employment prospects, and financial security.