COVID Impact Survey 2022 Results

February 2022

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 the 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 government and the health and community sectors to enhance service provision and improve the conditions for family 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 owners 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.

Carers provide unpaid care and support to someone with disability, mental ill health, a chronic or life limiting condition, alcohol or drug dependence or who are frail or aged. 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. The term ‘informal carers’ also does not automatically include kinship or foster carers, unless they care for a child with disability, mental ill health or a condition as noted above.

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 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.

In addition, Care2Serve have capacity to fund certain instances of planned, practical support services such as, but not limited to, in home respite, personal care, domestic assistance, and meal preparation. Care2Serve may also fund various items such as laptops to assist carers who are studying or trying to enter the workforce. Care2Serve also coordinate 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 for the carer.

Introduction

In mid-2020, Carers Tasmania released findings from the '*Road to Recovery: COVID-19 Survey'*.[1] With high hopes for recovery from COVID, carers were asked to complete this survey with recovery in mind, providing responses on a series of questions regarding the impact of COVID on their caring roles, and what supports may be required as carers were planning to transition out of the restrictions. The '*Road to Recovery Survey'* highlighted the diverse experiences of carers throughout the early stages of the pandemic, with some carers not reporting much difficulty, whilst most struggled immensely.

The opening of the Tasmanian borders on 15 December 2021, resulted in a surge of COVID cases and associated consequences for the Tasmanian community. Carers Tasmania felt it was important to conduct another survey for carers to understand how the recent experience of COVID has impacted carers and what supports are required. The present survey is titled the '*Carers Tasmania COVID Impact survey 2022'* and was conducted online only. The survey was divided into the following sections:

- About you and your caring role
- Person or people being cared for
- Accessibility and understanding of information
- Medical or specialist appointments
- Covid status, isolation and support level
- Testing and other medical supplies
- Employment and schooling
- Finances
- Access to out of home supports/respite
- Your feelings and wellbeing
- Your needs and planning ahead

Carers Tasmania genuinely appreciate and value the time that carers took to participate in this survey, providing insight into their experiences of caring for someone whilst COVID is prevalent in the Tasmanian community.

The survey results highlight the experiences of carers and provide a valuable opportunity to understand the types of supports and changes that are required to be implemented to support carers in Tasmania, both moving forward from COVID and in preparation for any future adverse occurrences.

[1] https://www.carerstas.org/ctas-road-to-recovery-survey-report/

Carer information

A total of 323 responses to the survey were received as of 11 February 2022.

Responses were received from a broad age range of carers, including a small number of young carers. The majority of carers reported that they were 35 years or older (96.6%) and interestingly, 19.50% of carers reported that they were 75 years or older.

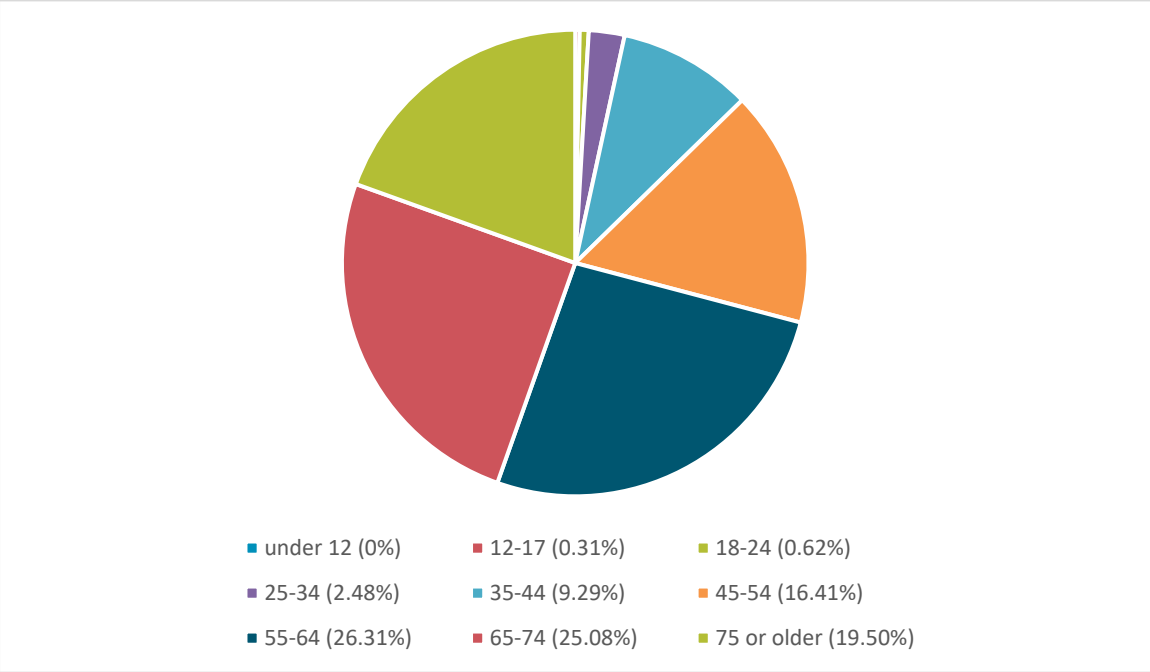

Figure 1: Carer's age range by percentage

We wanted to investigate whether there were any differences for carers based on their gender. A large proportion of respondents (80.75%) reported their gender as female. This is consistent with data showing that females are more likely to be carers than males.[2] One carer described their gender as fluid, and the remainder of carers (19.25%) reported their gender as male.

Carers Tasmania supports the diversity of all carers. People who identify as LGBTIQ+ can sometimes face additional barriers and stigma, therefore we wanted to identify whether carers who identify as LGBTIQ+ have experienced any differences in caring while dealing with COVID than people who do not identify as LGBTIQ+ to help us understand if there are things that can better support LGBTIQ+ carers. Fourteen carers who responded to the survey reported that they identify as LGBTIQ+.

[2] https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release

5.40% of carers reported that they identify as culturally or linguistically diverse (CALD) and 3.79% reported that they identify as Aboriginal or Torres Strait Islander. Aboriginal and Torres Strait Islander peoples are more likely than non-Indigenous people to experience poor health,[3] including increased prevalence and earlier onset of several of the health-related risk factors for COVID illness.[4]

Person(s) being cared for

We know that one in six people living in Tasmania are a carer, but we wanted to determine the number people each carer who responded to the survey was providing support for, as it is not always the case of caring for only one person. The majority of carers (77.57%) indicated that they provide care for one person, with 13.08% of carers reporting that they were caring for two people, whilst 6.54% were caring for three people, and 2.8% for four people.

Four carers who identified as Aboriginal or Torres Strait Islander reported they were caring for more than one person and five people who identified as culturally or linguistically diverse reported they were caring for more than one person.

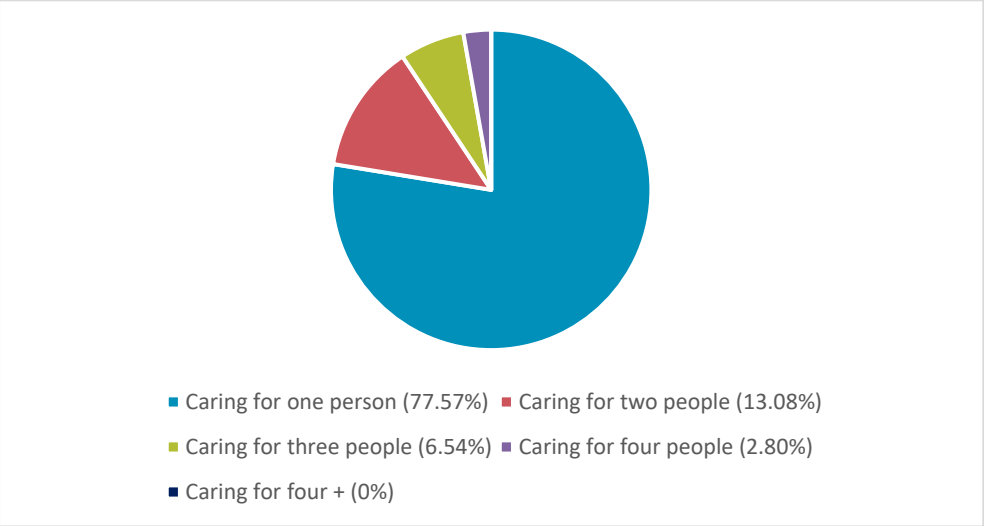

Figure 2: Percentage of carers by number of care recipients

There was a diverse age range of people being provided care. More than half of the carers surveyed reported caring for someone over 65 years old, with the majority of

3 Sherwood J. Colonisation–It's bad for your health: The context of Aboriginal health. ContemporaryNurse. 2013;46(1):28–40.

4 Thurber, K.A., Barrett, E.M., Agostino, J., Chamberlain, C., Ward, J., Wade, V., Belfrage, M., Maddox, R., Peiris, D., Walker, J., Baffour, B., Wenitong, M., Law, C., Senior, T., Priest, N., Freeman, K. and Schramm, T. (2021), Risk of severe illness from COVID-19 among Aboriginal and Torres Strait Islander adults: the construct of 'vulnerable populations' obscures the root causes of health inequities. Australian and New Zealand Journal of Public Health, 45: 658-663. https://doi.org/10.1111/1753-6405.13172

carers stating that they were caring for someone who is aged 75 years or older (46.18%).

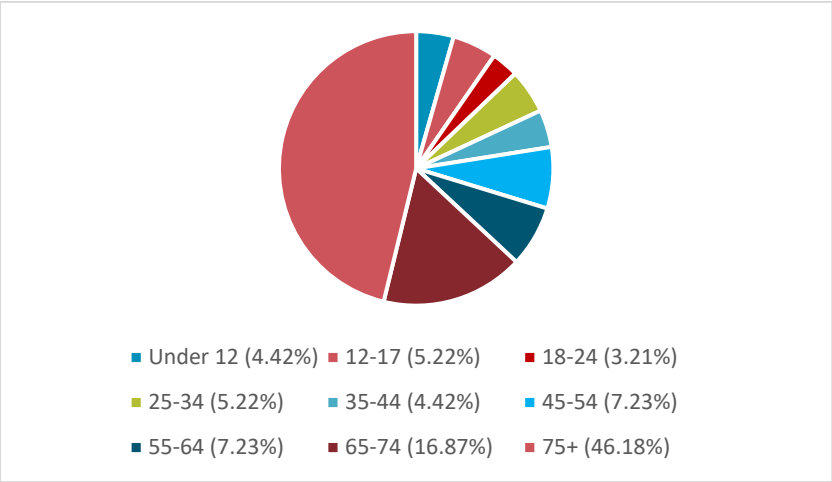

Figure 3: The age(s) of the person(s) I care for

The majority of carers reported caring for someone with an ongoing medical condition or a life limiting illness (54.44%). This was followed by a high percentage of carers providing care for a person with disability (43.15%). Often, there are comorbid health concerns for the person being cared for, which can increase the complexity of care needs, in turn increasing the supports required by the carer.

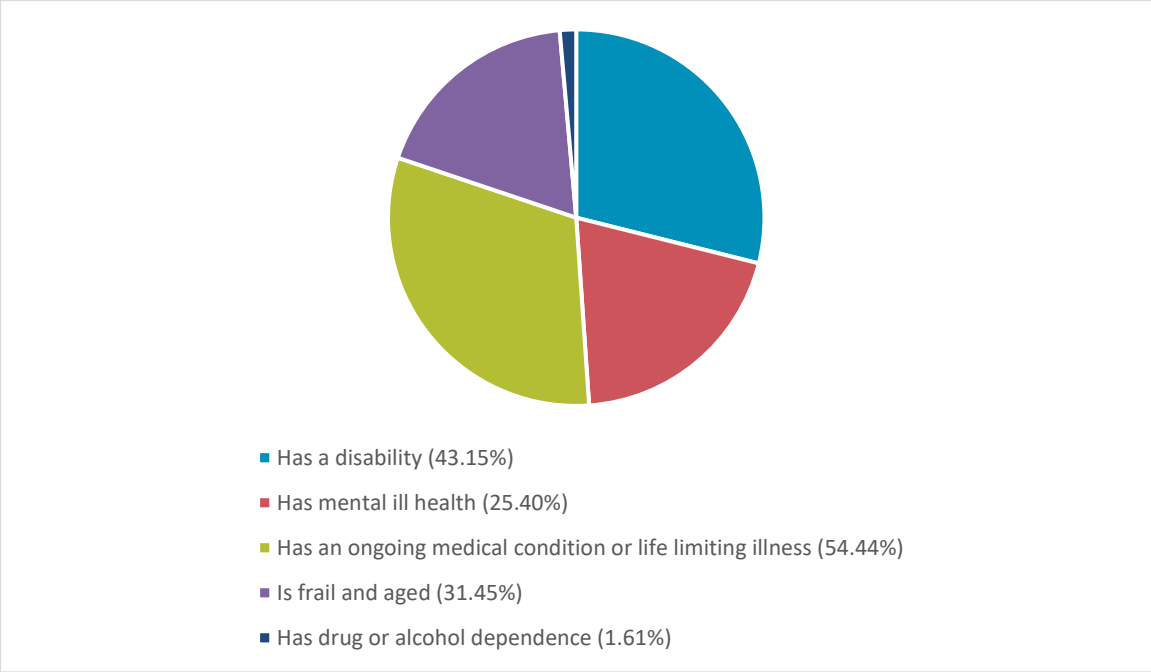

Figure 4: I care for someone who:

Accessibility and understanding of information

We wanted to investigate the experience of carers in being able to access appropriate and timely information. In addition, we wanted to explore what their preferred method of accessing this important information is. It is important to note that these results are reflective of carers who have a certain level of digital literacy as they completed this survey online.

The survey found that more than three quarters of carers were able to access information about COVID to an acceptable level, with 63.69% of carers reporting they were able to access information well enough and 18.15% able to access this information really well.

Just 2.23% (seven carers) reported that they were not able to understand the information about COVID well at all. Of these carers, one person identified as Aboriginal or Torres Strait Islander, two carers were males and five carers identified as female. Two carers were aged between 45-54 years of age, four were aged between 55-64 and one carer was aged 65-74 years.

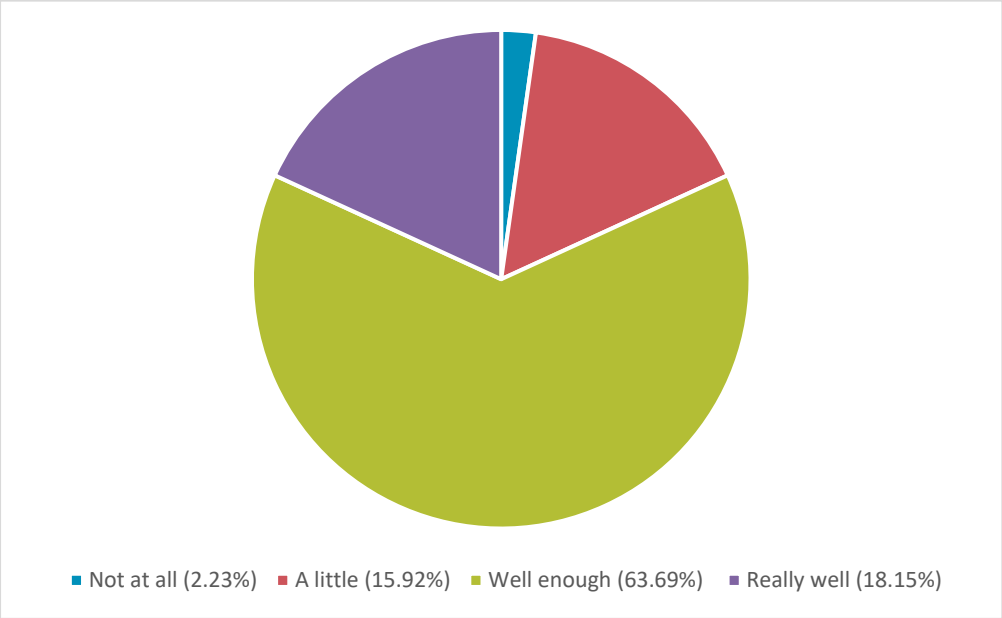

Figure 5: Number of carers who rate their ability to access information about COVID as:

When asked to report on the main methods used for keeping up to date with this information, we found that 43.5% of carers indicated that tv or radio was their primary method of accessing this information. This was followed by internet websites at 24.6%, and social media at 19.17%. The other methods each had responses of less than 10%, which were newspaper (5.11%), friends or family (3.19%) and service providers (3.83%).

For carers aged 65 years or more, the preferred method (at 54.86%) of accessing information was via the news (tv or radio). This was followed by the internet at

21.53%. For carers under the age of 65, the preferred method was news (tv and radio) at 33.14%. This was followed by social media at 29.65%.

Medical or specialist appointments

Alarmingly, more than half of carers reported experiencing some challenges in trying to obtain recent GP appointments, with 41.78% of carers expressing that it had been more difficult, and 11.84% reporting that it has been almost impossible. It is important to highlight that many carers have chronic health conditions or disability themselves for which they require GP or specialist support in addition to their caring role responsibilities.

Of the carers who shared their experience of trying to obtain a GP appointment as nearly impossible, two of these carers identified as Aboriginal or Torres Strait Islander, five of these carers were aged 75 years or over, six carers were aged between 65-74, and one carer was aged 55-64. Furthermore, five carers were aged between 45-54, four carers were 35-44 and one carer identified as aged between 25-34. The majority (eighteen) of these carers identified as female and the other four identified as male.

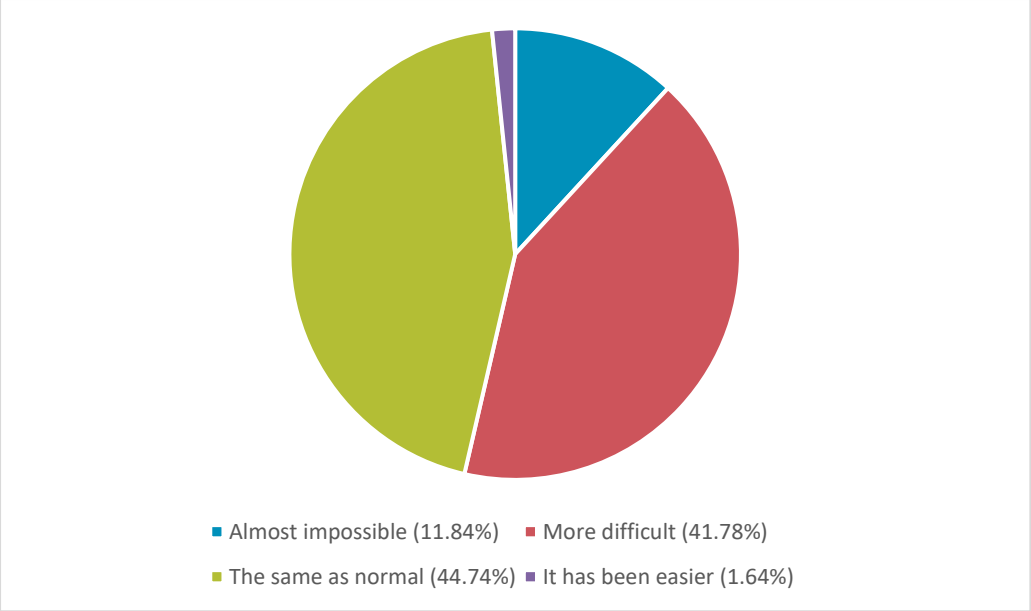

Figure 6: Number of carers and their experience trying to get a GP appointment

Carers were asked to report on whether they had used a telehealth appointment this year. Of 307 respondents, 61.56% reported that they had and 38.44% reported that they had not. Despite these responses only being reflective of experiences from carers with online access, it is quite consistent with the data from both online and paper respondents in the *'Road to Recovery survey'* which found that 60% of all carers said that they had used telehealth appointments throughout the pandemic.

In addition, of the twelve carers who identified as Aboriginal or Torres Strait Islander, seven reported that they have accessed telehealth this year. Of the seventeen carers who identify as CALD, eight reported that they have accessed telehealth this year.

When examining the results of carers who reported they had not used telehealth, the highest rates (28.81%) were by carers in the 55-64 year age group, which was closely followed by carers in the 65-74 age group (25.43%).

Members of the Tasmanian community have expressed their concerns about longer wait times to see a specialist since the rise of COVID cases in Tasmania. We wanted to explore whether carers have experienced this for themselves or the person they care for. Specialist appointments are crucial towards maintaining or improving wellbeing. In addition, results from specialist appointments can also sometimes determine the type of supports available to a person, particularly in the case of people who require an assessment to enable them to access support.

The results showed that 48.68% of carers said that they or the person(s) they care for have had to wait longer for a specialist appointment. Furthermore, for those who have been waiting longer, the time frames and prevalence range 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 have had medical or specialist appointments for themselves or the person(s) they care for cancelled with no rescheduled date. 15.23% reported that this had occurred in their situations.

What carers said:

> *"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."*

Covid status, isolation and support level

With the influx of COVID throughout Tasmania, we wanted to know if carers have had COVID themselves or been deemed as a close contact and forced to isolate.

The survey found that since borders have reopened, 9.48% of carers had been deemed a close contact and that 3.93% of carers have been COVID positive. In addition to mandatory isolation, 59.50% of carers reported that they had chosen to isolate as a preventative method, despite not being a close contact or having COVID. Of these carers, 56.11% reported their age as 65 years or over.

Furthermore, of the carers who chose to self-isolate,146 reported their gender as female and thirty-three as male. Twenty-eight carers reported that they were caring for two people, nine carers reported caring for three people and five carers reported caring for four people.

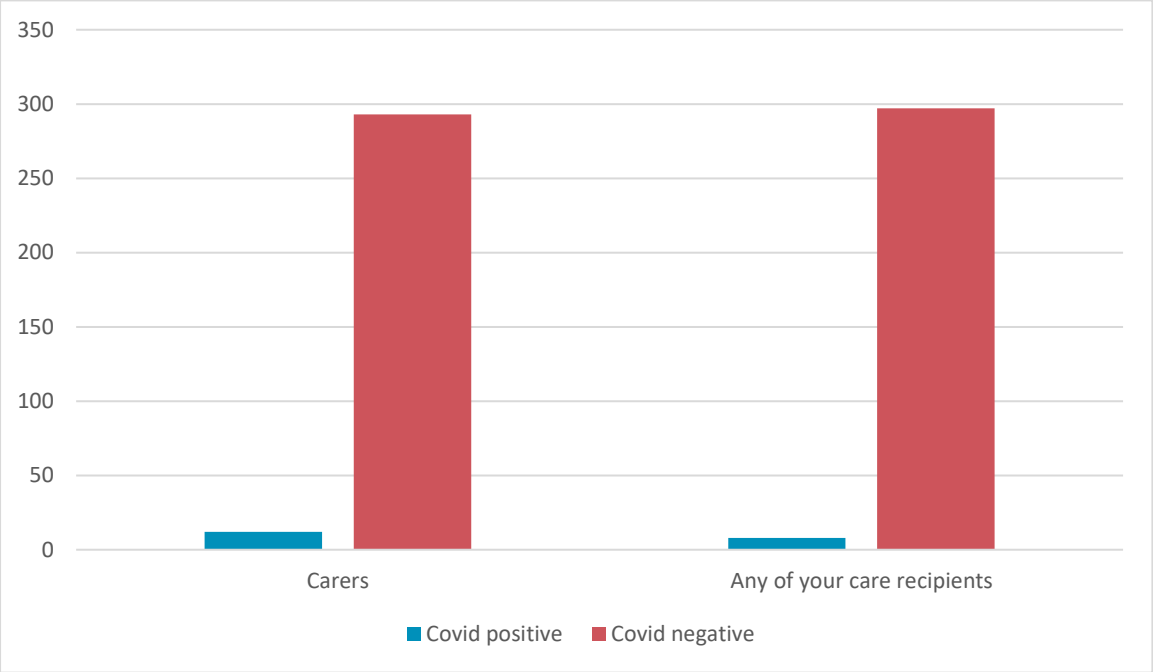

Figure 7: Carers and care recipient COVID status this year

The results could infer that the low rates of COVID amongst carers and care recipients might be due to the high rates of self-chosen isolation for carers and care recipients. Despite self-chosen isolation seemingly reducing the risk of catching COVID, there are other consequences potentially faced by carers as a result of this choice, such as loneliness, loss of practical and or emotional support, in some loss of income, employment implications, difficulties in accessing essential items, and overall, a higher risk of carer burnout.

What carers said:

> *"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!"*

As an impact of COVID, many carers have faced extra difficulty in accessing support for the person(s) they care for. 167 carers had experienced difficulties and reported

the service types they had experienced challenges in accessing. Some carers reported that they had experienced difficulty in accessing more than one of the following service types.

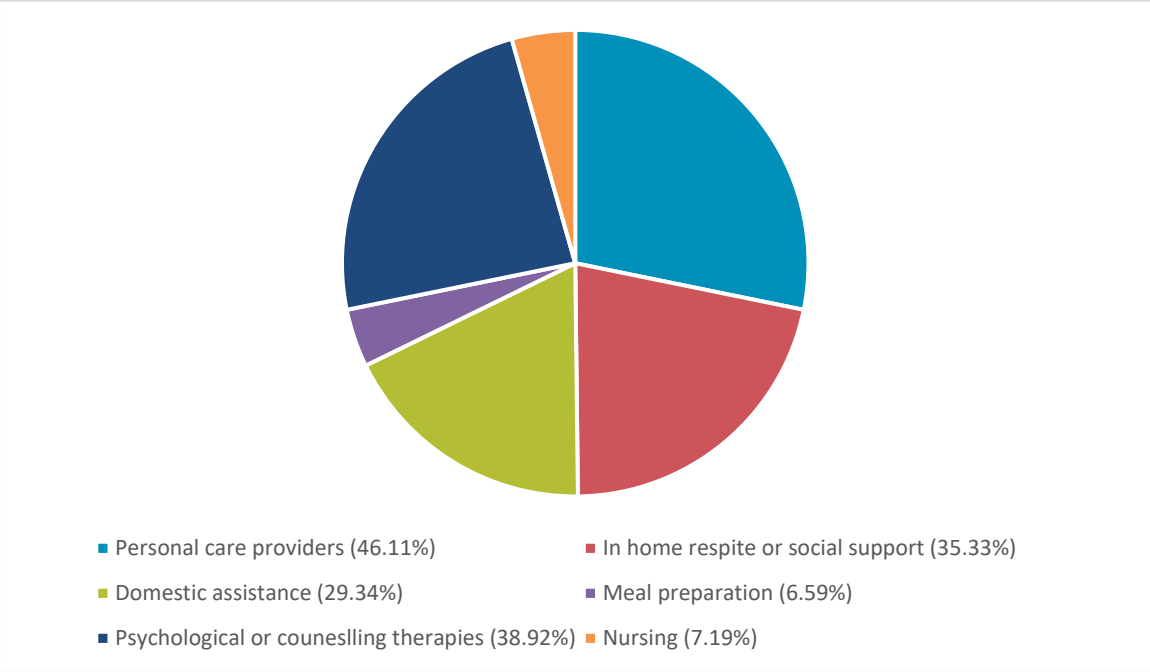

Figure 8: What have you had extra difficulty accessing?

We wanted to understand the reasons that carers had been provided for the difficulties they had experienced in accessing support services. The main reason that that had been provided was that there were a lack of workers due to isolation (60.12%). This was followed by 37.42% reporting there was a lack of availabiity of suitabilty experienced workers for the specific care needs. Only 2.45% of carers said that the reason for the difficulty was due to the person they care for having COVID. In cases where available support was reduced, or completely unavailable, the duties fall back on carers to manage amongst their many other responsibilities.

When asked if they had any family members that could assist at short notice, 59.60% of carers said that they did not. This is slighly higher that what was found in the '*Road to Recovery survey'*, which showed that 52% of carers did not have a family member who could assist at short notice. In situations where a carer becomes unwell or injured, they would have to rely on support services to assist or the carer may be at risk of futher injury or illness as well as increased possibility of neglect to occur for the person being cared for.

Testing and other medical supplies

There have been mixed experiences from the Tasmanian community around their ability to access Rapid Antigen Tests (RATs). The method to obtain these changed mid-January, but there are still some supply and accessibility issues. 21.21% of

carers said that they found the process of trying to obtain a RAT test very difficult and 10.89% difficult. Carers were not specifically considered a cohort who should have priority in accessing RATs despite the vulnerable circumstances and barriers that they and the people they care for face.

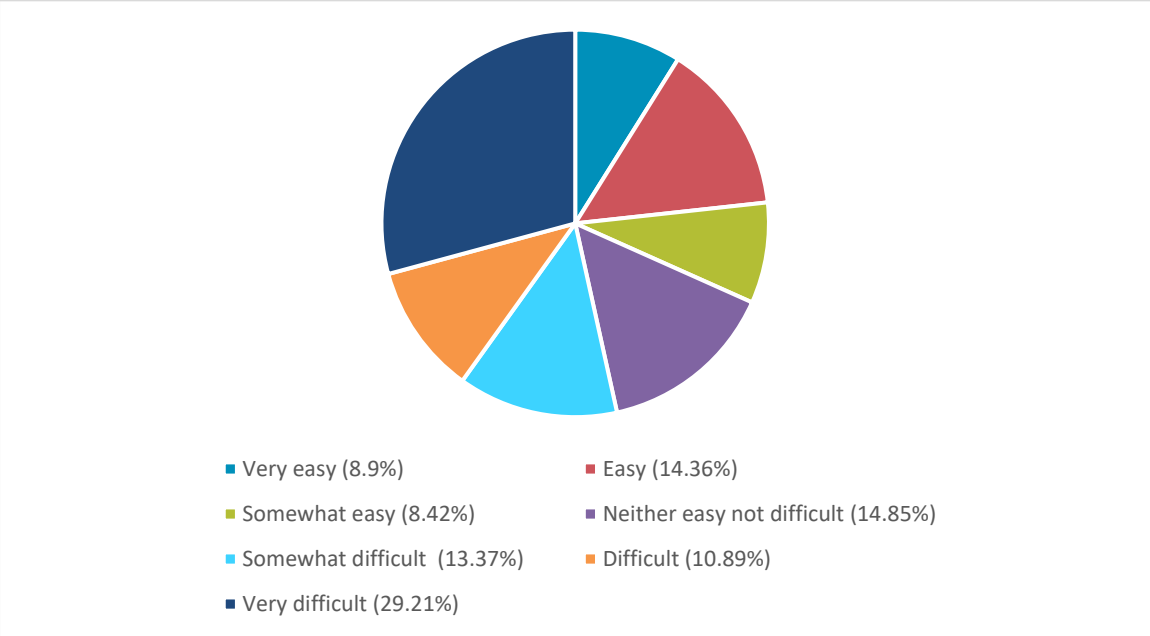

Figure 9: Process of accessing a RAT test

We asked carers to report on how they found the process of accessing a PCR test either for themselves or the person for whom they care. 15.52% of carers indicated that they found it very difficult to access a PCR test and 11.49% reported it was difficult. 29.21% of carers said they found the process of accessing a RAT test very difficult, and 10.89% difficult. The results showed that carers found the process of accessing a PCR test easier than a RAT test.

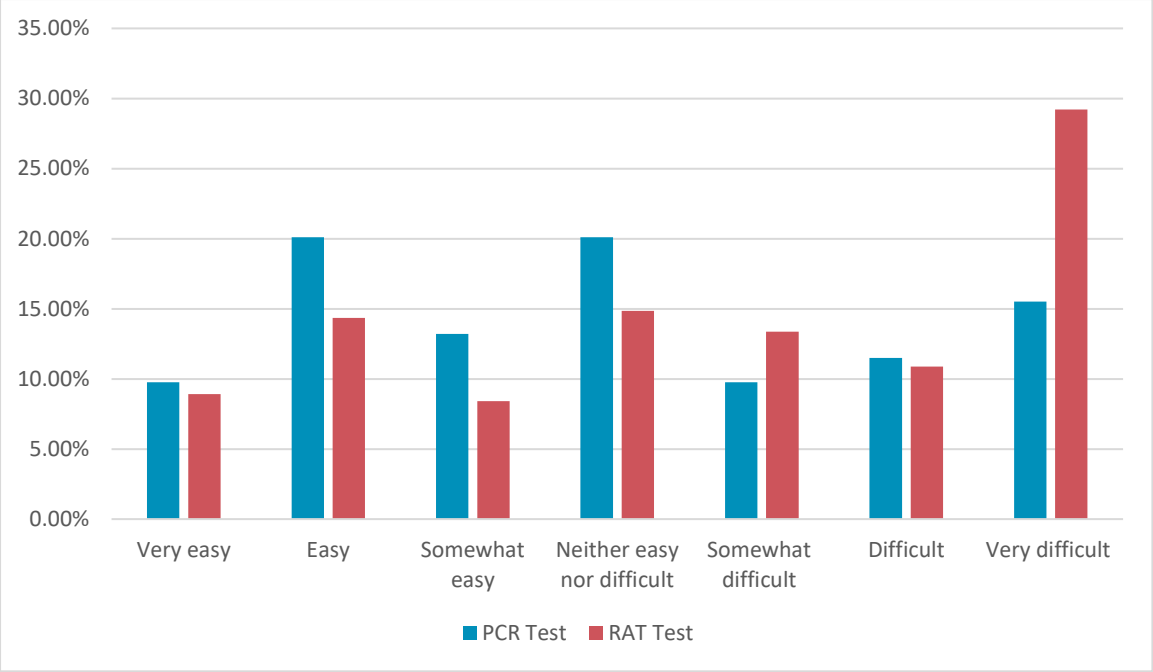

Figure 10: How did you find process to access a test?

We wanted to know if carers had experienced any difficulty in acessing medical supplies. We had heard of several situations upon where members of the Tasmanian community were stockpiling items such as panadol and other medicines. Furthermore, some pharmacies have had supply issues. To add an additional barrier, many carers reported that they were self isolating to protect themselves and their loved ones, which also made it difficult for some carers to access necessary supplies. The survey found that 21.81% of carers had experienced difficulty in accessing medical supplies.

Employment and schooling

Many businesses operating in Tasmania have changed their working conditions as a result of COVID. Some businesses have had the opportunity to allow and support their staff to work from home, whilst for some businesses this is not possible due to the nature of service they provide.

We wanted to know if carers who were employed had been provided the option to work from home. 75.78% of carers who responded said that they had not had the option or ability to work from home. It would be interesting to explore this further, to identify those who could not work at home due to their business type, and to those who possibly could have worked from home but were not provided with the option to. For some carers, it may also be inappropriate for them to complete their work tasks at home due to the nature of their caring role. Furthermore, 4.76% of carers reported that they had been ‘forced’ to work from home.

We sought to explore if COVID had impacted the number of employment hours for carers due to the need to provide extra support in their caring role. 12.18% of carers said that they had reduced their employment hours to provide extra support in their caring role and 10% of carers said that they would like to but cannot afford to.

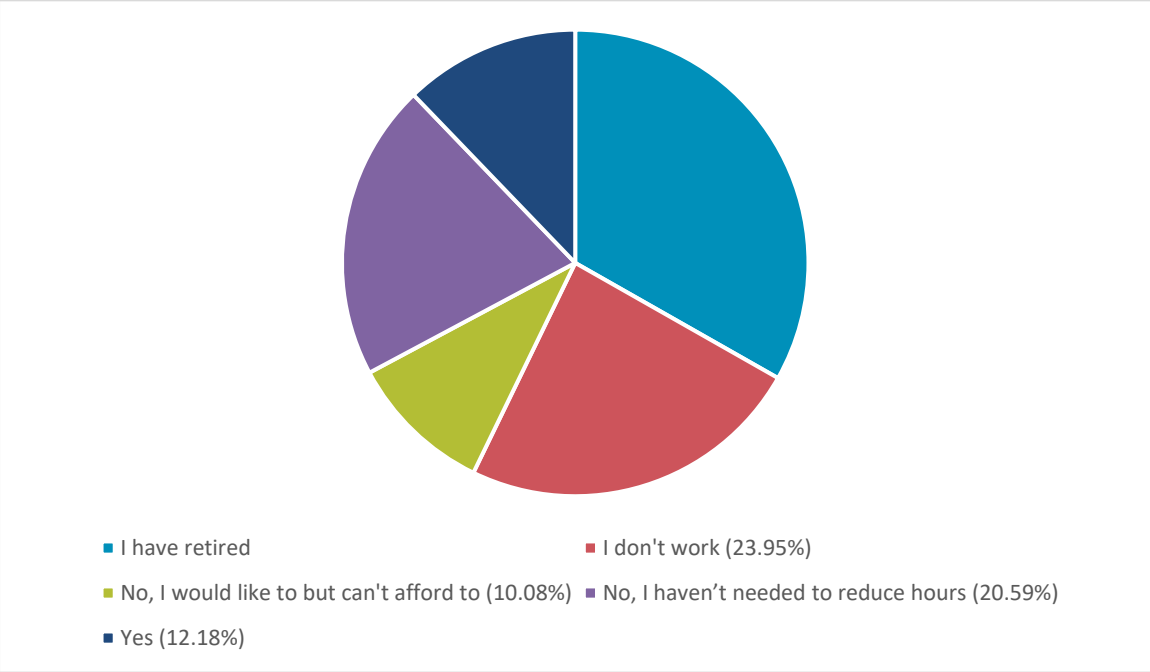

Figure 11: Percentage of carers who have reduced employment due to their caring role

13.8% of carers reported that they had partially lost their job due to COVID and 2.68% reported they had completely lost their job as a result of COVID. It is often difficult to find and maintain employment as a carer and it is evidenced by the survey results that COVID made this more challenging. Carers already face financial implications as a result of their caring role and adequate employment can assist in alleviating some of these challenges. Employment can also provide carers with avenues to enable a feeling of purpose, social connection, learning and a sense of achievement. Carers must be supported to find and maintain suitable employment as they wish.

There are mixed opinions on the safety of sending children back to school with high COVID rates in the community. 8.3% of carers who indicated they have a child reported that they plan on home schooling their child(ren) due to concerns about them contracting COVID at school. There is evidence to show that some parents and carers who have home-schooled their children during the COVID-19 pandemic have experienced significantly higher levels of psychological distress and work impairment compared to parents or carers who were not home-schooling or had no school-aged

children.[5] This extra stress and psychological burden can compound stress that is already existing due to the caring role, placing carers at greater risk of burnout or psychological injury.

Finances

Some people in the Tasmanian community have faced challenges in obtaining adequate supplies, with some people stockpiling certain items. There have also been challenges for retail businesses in obtaining and maintaining adequate stock levels. This has resulted in price rises for a lot of consumable items.

We explored whether carers have experienced increases in expenses, particularly since the opening of the Tasmanian borders. Many carers already experience financial difficulty or disadvantage as a result of their caring role, and the survey found that 61.03% of carers reported that their expenses had increased since the opening of the Tasmanian borders. This is an increase from the last survey, which found that only forty percent of all carers reported an increase in expenses which could be attributed to COVID.

Carers rated food as the category that they are spending more money on (85.42%), which was closely followed by fuel for transport (72.92%). Both of these categories are basic needs which are essential to wellbeing. A concerning find was that 36.46% of carers noted that their expenses had increased, but they were not able to spend more due to financial concerns. This is an indication that carers may be going without essential items as they cannot afford it.

[5] Calear, A.L., McCallum, S., Morse, A.R. *et al.* Psychosocial impacts of home-schooling on parents and caregivers during the COVID-19 pandemic. *BMC Public Health 22*, 119 (2022). https://doi.org/10.1186/s12889-022-12532-2.

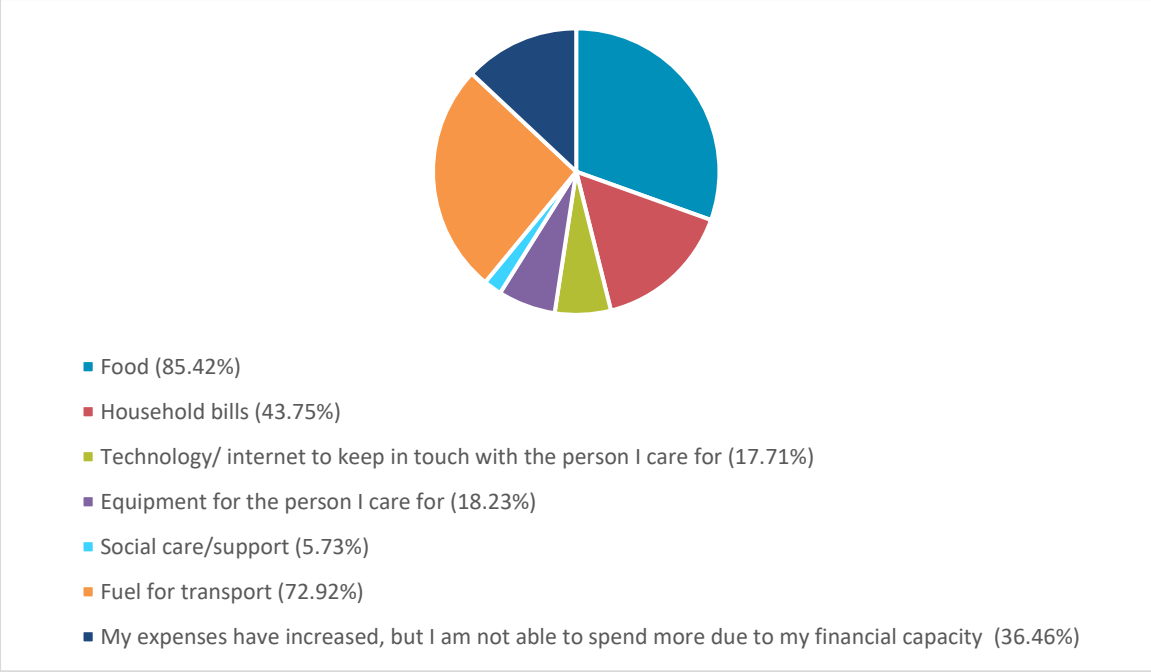

Figure 12: Increased expense by type

In addition to the extra expenses, some carers reported that they have needed to access emergency relief support because of their financial situation since the opening of the Tasmanian borders, with 6.86% of carers reporting that they have accessed emergency relief support within this timeframe.

Of the carers who responded yes to this question, one carer reported caring for four people, two carers reported caring for three people and nine carers reported that they were caring for two people. Furthermore, three of these carers identified as Aboriginal or Torres Strait Islander and two carers identified as CALD.

Two of these carers were in the age group of 75 years or older and one carer was aged between 65-74. The majority of carers (eight) were in the age group of 55-64 years. Four carers were in the 45-54 year age group, four were in the 35-44 year group and one carer was aged 25-34 years old. Four carers in this group identified as male and the remainder identified as female.

Access to out of home support/respite

Carers have had varying experiences with regards to lockdowns across several out-of-home respite service types. The service type that most carers reported having difficulty accessing were day centres for people with disability. A high rate of carers who responded to this survey reported that they care for someone with disability (43.15%). Of these, fifteen carers reported that they had experienced not being able to access day centre support for people with disability. Fifteen carers who were not

able to take a planned break or use that time for work or other errands. In addition, the people with disability missed out on being able to participate in a day centre, missing out on the associated benefits from that.

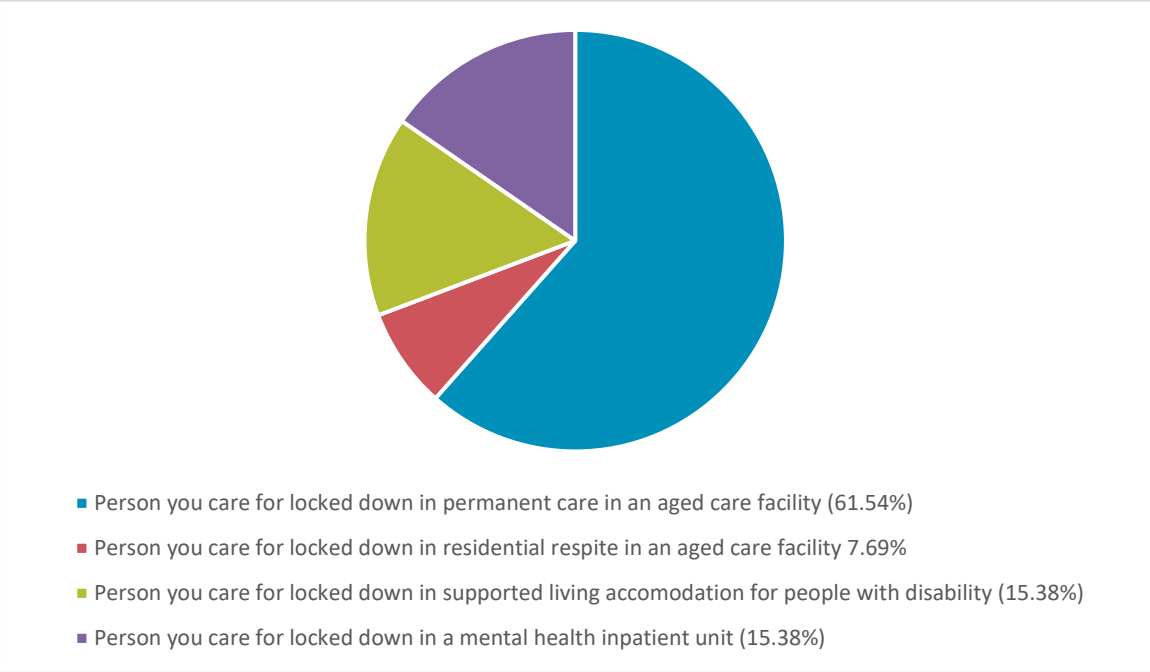

Figure 13: Have you experienced any of the following lockdowns due to COVID?

Sixteen carers said that they had experienced the person they care for being locked down in permanent care in a residential aged care facility. Two carers reported that the person that they care for was locked down whilst in residential respite in an aged care facility. Four carers indicated that the person they care for was locked down in supported living accommodation for people with disability and four carers had experienced the person they care for locked down in a mental health inpatient unit.

For those carers that had experienced a lockdown as mentioned, 34.8% said the lockdown lasted for a week or less, 31.03% reported that it lasted for a fortnight, 13.79% a month, 13.79% longer than a month and 6.9% longer than six months.

In addition to lockdown, some carers reported that they had not been able to access out of home supports for the person they care for. Of the carers who had experienced difficulty in accessing out of home supports, 37.50% of carers said that in their caring role, they had experienced not being able to access a day centre for people with disability. Planned out of home supports are crucial to enable carers a break from the caring role and time to recharge. Respite can also create opportunities for the person being cared for to make new social connections and experience new surroundings. Sometimes, out of home respite is not planned and is required quickly due to illness or injury for the carer. The survey results show that forty carers were not able to access out of home respite when they needed it.

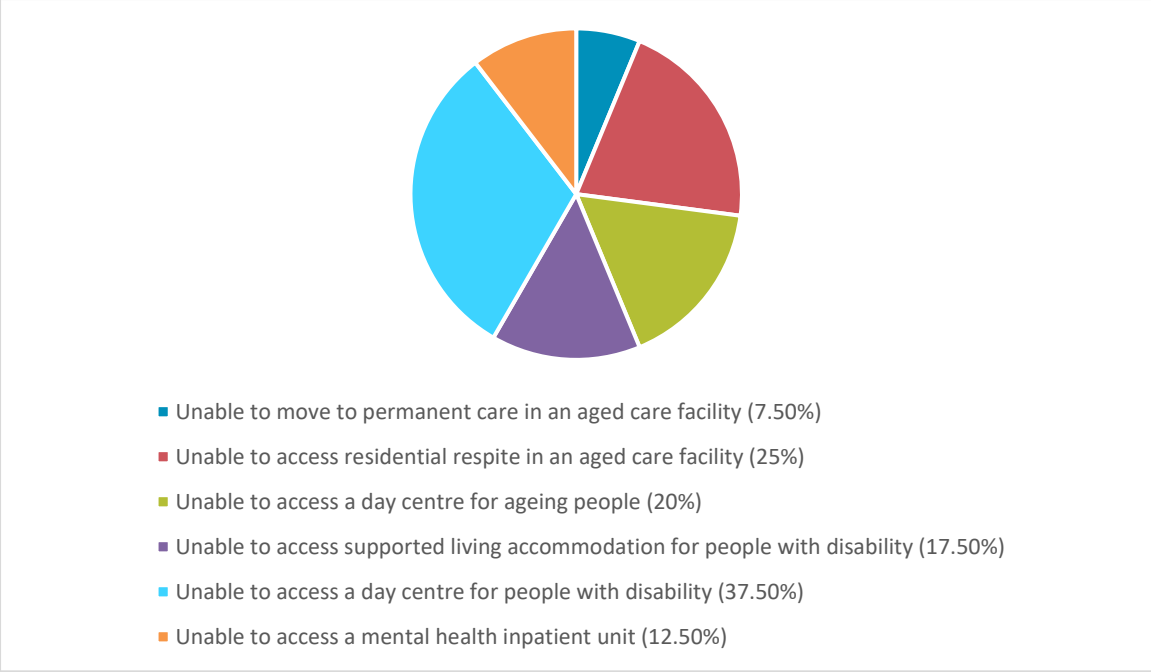

Figure 14: Inability to access out of home support for person(s) being cared for

What carers said:

> *"Issues with support staff at residential care becoming positive/few staff available which has led to daughter coming home for an extended period."*

Carer feelings and wellbeing

Carers were asked to report on a rating scale how worried they were about the effects of COVID, with number one being '*not worried at all'* to number ten being '*extremely worried'*. The average score reported was a six, showing most carers were somewhat worried about the effects of COVID. 35.05% of carers scored an eight or above, indicating that they were highly worried about the effects of COVID.

We wanted to explore this further and asked carers to report on their feelings by selecting as many options relevant from a list of feelings that carers often experience.

A large number of carers reported feeling *'emotionally drained'*, with 79.46% of carers reporting that they feel this. This percentage is higher than results from the *'Road to Recovery survey'* which found that 51% percent of all carers reported feeling emotionally drained at times. Eleven of these carers also indicated that they identify as LGBTIQ+. 27.80% of the carers who reported feeling emotionally drained were aged between 65-74 years. These results are not surprising, given that carers already carry significant responsibilities and burden as a result of their caring role. When that is topped with the additional effects of COVID, it is no surprise that carers

are experiencing increased negative impacts on their wellbeing. This is not sustainable.

Following *'emotionally drained',* the two next highest ranked items were *'unsupported'* (43.41%) and *'lonely'* (43.02%). It is important that carers have people that they can contact for support and social connection. Social connection is critical to maintaining good health and wellbeing. People with limited social connectedness have been found to have poorer mental and physical health, than those with increased social connection.[6]

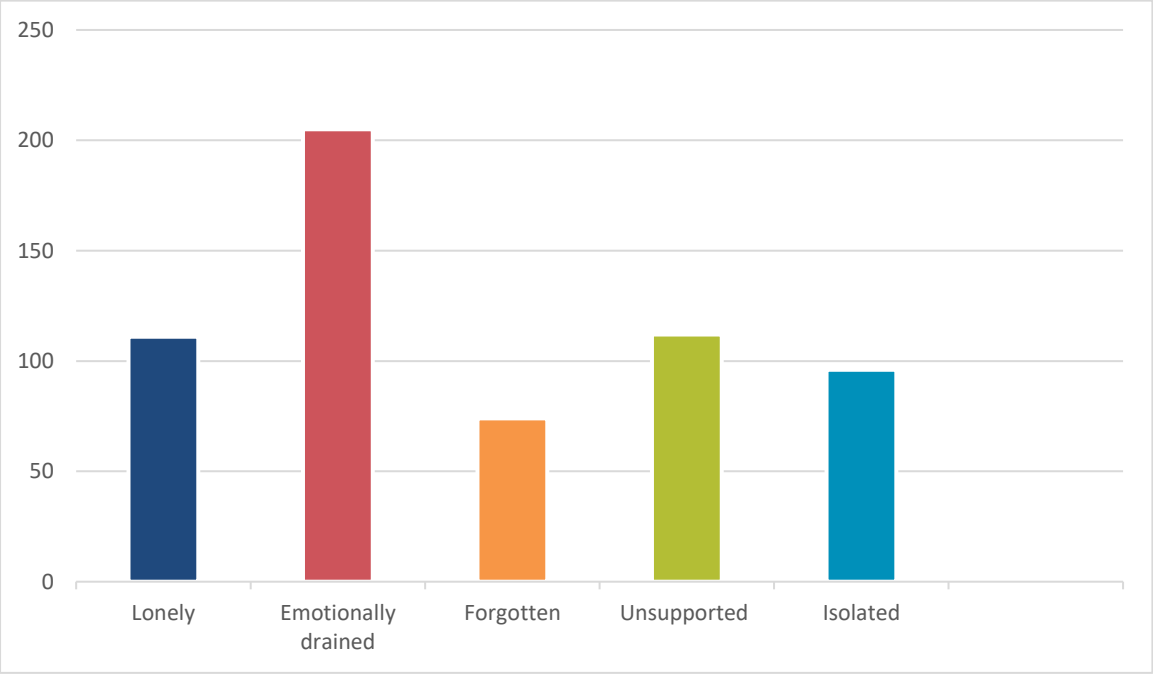

Figure 15:Number of carers who said at times they feel…

Achieving adequate and quality sleep on a regular basis is critical to both acute and long-term health and wellbeing.[7] We know that carers already have poor sleep due to factors such as worrying about the person they care for, listening out for the person they care for, their care recipient being upset and the effects of their own health concens.[8] We wanted to investigate whether COVID has had an additional impact on carer sleep. We found that 44.48% of carers indicated that their sleep has worsened due to COVID, 54.14% reported no change, and 1.38% reported improvements. It would be interesting to investigate further what the contributing factors towards this improvement were. Carers are already at high risk of burnout,

[6] Cruwys, T, Haslam, SA, Dingle, GA. (2014a) Depression and social identity: An integrative review. Personality and Social Psychology Review 18: 215–238.
[7] Adams RJ, Appleton SL, Taylor AW, Gill TK, Lang C, McEvoy RD, et al. Sleep health of Australian adults in 2016: results of the 2016 Sleep Health Foundation national survey. Sleep Health. 2017;3(1):35-42.
[8] https://www.carersaustralia.com.au/wp-content/uploads/2020/10/Sleep-Study-report_Final-004.pdf

with many carers juggling numerous responsibiltes, therefore futher disruption to carers already poor sleep quality can be really detrimental and has potential to put the carer and person being cared for unintentionally in unsafe circumstances.

Carer needs and planning ahead

Looking towards the future, we sought to understand how comfortable carers felt in their caring roles, and where they felt that they need assistance.

We asked carers if they have contingency plans in place for any instance where they are not able to provide care for the person they usually support. 64.41% of carers said that they did not have a contingency plan in place should they become ill. This is higher than the previous '*Road to Recovery survey'* which found that 55% of carers did not have a contingency plan. To explore this further, we wanted to understand what the barriers were that impact on not having a contingency plan. The most common answer was that '*there isn't anyone else that can step in for me'* (50.35%). In addition, 105/181 carers who reported that they did not have a contingency plan were aged 65 or over.

This acutely highlights the need for routine identification of carers and referral to appropriate supports. There is support available for carers where they can access assistance with future planning and discuss pathways to put in place practical support.

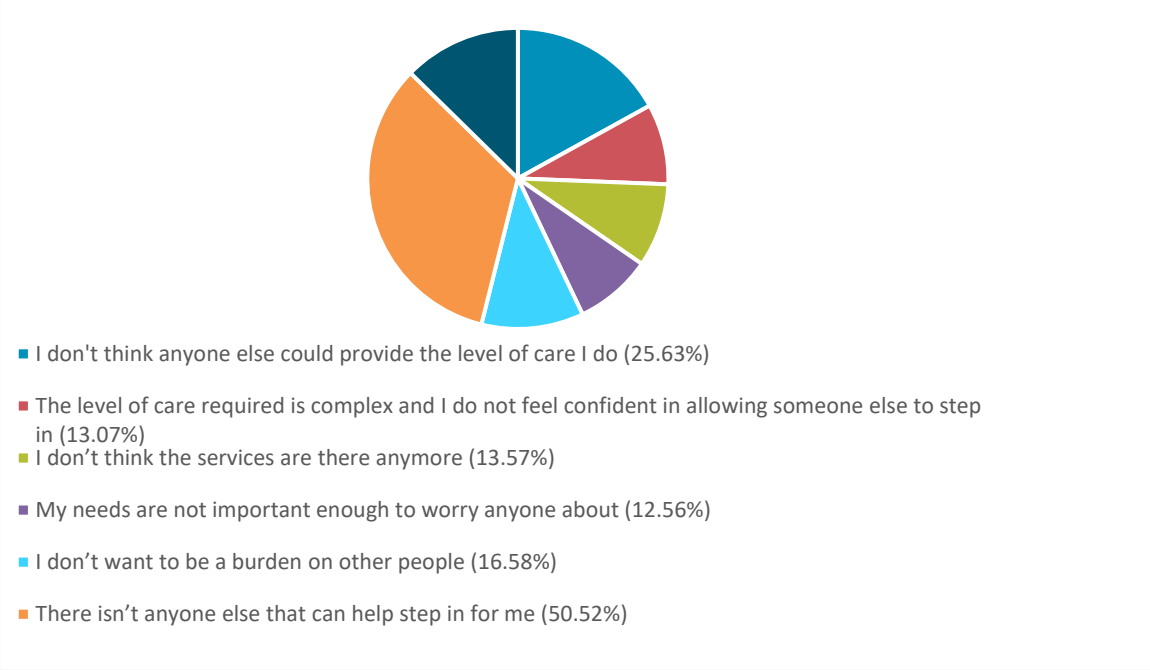

Figure 16: Main barrier for not having a contingency plan

We sought to understand what carers feel they need to be prepared for the future. The item that received the most responses was *'Have a better understanding of services I can access as a carer*' with 141 carers choosing this as an important item. This was followed by *'To have improved and inclusive communication processes in place between medical and/ or hospital staff* (30.95%). The item *'have a better understanding of services I can access as a carer'* was also a highly rated item in the '*Road to Recovery survey'*.

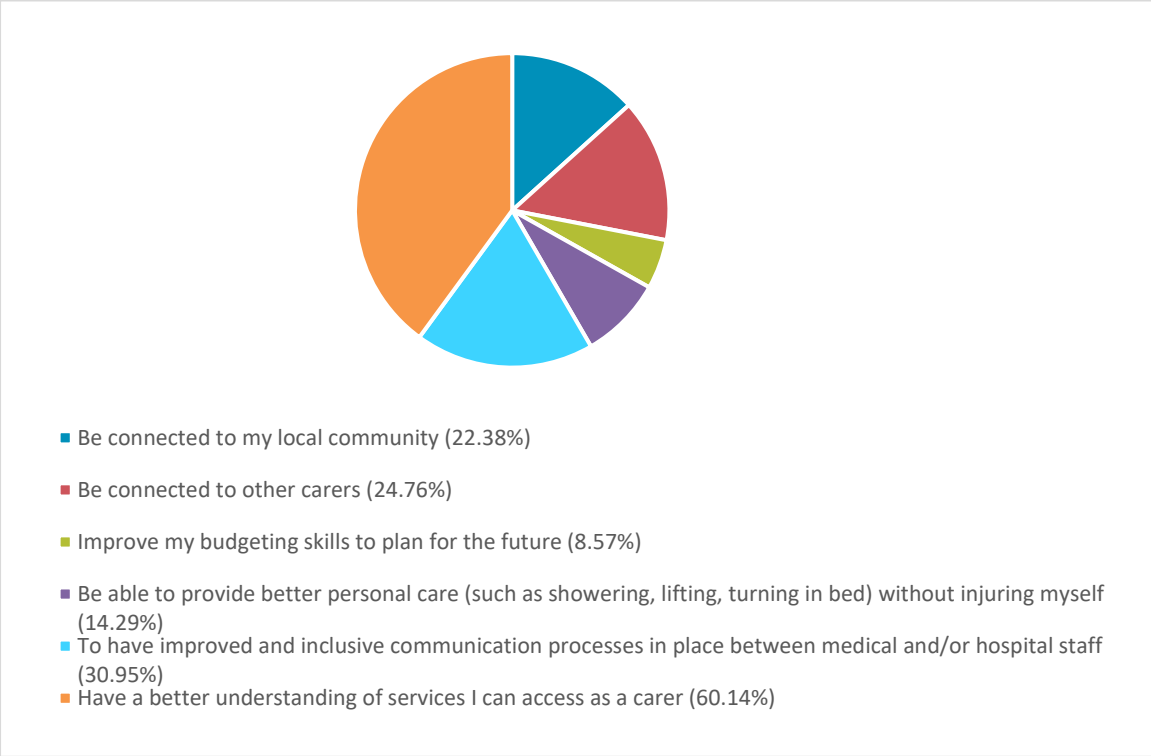

Figure 17: To be prepared for the future, I would like to:

The '*Road to Recovery survey'* found that the biggest thing carers thought would help them as the impacts of COVID began to reduce was '*confidence/reassurance in knowing that I can go out and the person I care for will be looked after',* with 40% choosing that option at least once.

In the present survey, the highest rated aspect at 44.83% was '*support to get services going for the person I care for',* followed by *confidence/reassurance in knowing that I can go out and the person I care for will be looked after'* at 42.36%. 37.44% of carers also rated talking with a counsellor that understands the caring role as something that would be helpful.

Care2Serve currently facilitate a free state-wide counselling service for carers which can be face to face, over the phone or via digital appointment, so it would be interesting to understand the reasons why those carers are not currently accessing this service. It could be that they prefer face to face but are currently isolating or may not have plans in place for someone to support the person they care for whilst they

attend counselling. This highlights one of the many instances where carers often go without support themselves to support the person that they care for.

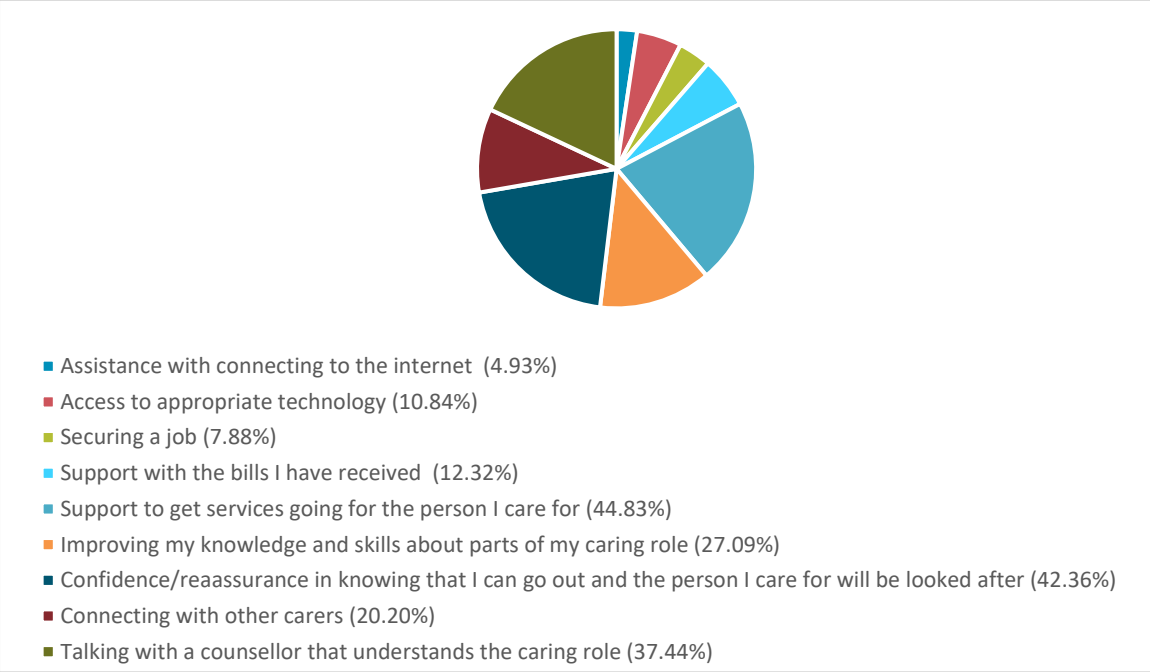

Figure 18: What would help you as the impacts of COVID begin to reduce?

Recommendations

The recommendations suggested are similar to those which were listed in the *'Road to Recovery survey'* as carers continue to face similar challenges. We highlight that these changes are required to support carers with adequate resources for their caring role(s), to enable them to move forward, and to have strategies in place that will prepare and support them for any future adverse events such as COVID.

- **Routine identification, recognition and priority** – Routinely identify and recognise carers as a priority cohort through routine practices of Government to enable streamlined access to the most appropriate supports for themselves and the person(s) for whom they care.
- **Carer Recognition Act** – Enshrine routine identification and support of carers as a central tenant of the legislation for Government, government-funded organisations and encouragement to the wider community.
- **Planning for the future** – Capability development activities funded by Government that support future planning by carers to ensure continuity of informal care.
- **Social connection** – Development, implementation and maintenance of innovative ways to provide flexible social connection options for carers, paired with adequate support for the care recipient to enable carers to participate.
- **Service connection** – This can be facilitated through increased carer identification, recognition and referral to appropriate services. Tasmanian Government services must adopt measures to increase identification and referral of carers. This will pave the way for the wider community to follow suit.
- **Funding for service innovation** – Funding for the development and implementation of innovative services to bridge identified service area gaps for carers, for example, individual carer advocacy.
- **Mental health and wellbeing support** – Support for carer specific programs across Tasmania which have a focus on improving the mental health and wellbeing of carers.
- **Additional supports towards the cost of living for carers, particularly in pandemic situations** – Prioritise carers for additional supports to assist with the cost of living.
- **Reducing negative impacts of the digital divide** – Specific and targeted support funded by the Tasmanian Government for those who are experiencing or at risk of experiencing digital exclusion.
- **Skills and employment** – Development and deployment of education, training and employment support for carers to maintain, access or re-enter paid employment.
- **Planning for further lockdowns or mass adverse events** – Carers must be identified as a priority cohort for accessing appropriate support in any future

Tasmanian Government planning for community emergencies or adverse events.

Conclusion

It is evident that COVID has had and is continuing to have a significant impact on carers and their families. Many carers have faced disruption, financial burden, isolation, and additional stress as a result of COVID. In instances where services have been unable to provide the support required, carers have had no choice but to manage, bearing the additional physical, financial, emotional, and social consequences to their own detriment. This toll is particularly evidenced by the high proportion of carers who indicated they are emotionally drained.

Upon undertaking the initial *'Road to Recovery survey'*, we were hopeful that recovery from COVID would occur in the near future. Little did we know that this was only the beginning and that we would experience COVID rates in Tasmania higher than ever before.

Carers, who already face several levels of challenge, stress and disadvantage, must be supported when things go pear shaped, so that any negative implications on their lives, and the lives of those for whom they care are minimised. Safeguards must be implemented to support some of the most vulnerable people in the community, the 85,000 carers and their families in Tasmania.

Tasmania needs to be proactive rather than reactive, identifying and recognising carers and assisting them to access relevant supports before their circumstances decline. Carers and the people they provide care should not have to go without essential life needs, items or support, no matter what the circumstances and they should be supported to live safe and fulfilling lives.