

Carers Tasmania's Response to the National Carer Strategy Discussion Paper

September 2024



About Carers Tasmania

Carers Tasmania is the Peak Body representing the more than 87,000 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.

Please direct any enquiries about this report to:

Dr Samantha Fox Chief Executive Officer Phone: (03) 6144 3700 Email: ceo@carerstasmania.org

Contents

1.	Background	4
2.	Introduction	5
3.	Response to the Discussion Paper Questions	6
١	National Carer Strategy principles	6
ŀ	A summary of caring in Tasmania	7
F	Primary carers and access to assistance from others such as extended family	10
٦	The supports and skills needed to support carers in their caring roles	11
F	Finding and accessing carer supports	12
A	Access to appropriate respite	16
(Carer-inclusive workplaces and education	20
E	Benefits of peer support	21
I	mproved carer recognition, especially in diverse or marginalised communities	22
F	Financial security	23
A	Additional items	24
4.	Conclusion	25

1. Background

Carers Tasmania is the Peak Body representing the more than 87,000 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 Australian Government 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 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 appreciates the opportunity to respond to the Australian Government's consultation on the development of the National Carer Strategy *(the Strategy).* We thank the Australian Government for their commitment to developing and implementing this Strategy with an aim to improve the quality of life for carers across Australia.

The main aim of this response is to provide a Tasmanian perspective on carer needs and considerations relevant to the National Strategy. However, we draw attention to and endorse the responses from Carers Australia and other organisations within the National Carer Network. The National Carer Network includes Carers Australia, and state and territory peak carer organisations who represent and advocate for carers within their jurisdictions, as well as for carers nationally.

This response addresses the National Carer Strategy Discussion Paper¹ questions and is categorised into the themes relevant to those questions.

Many of the key areas that are consistently highlighted by carers as needing improvement include:

- Identification and recognition of carers (enabling referral to the right types of support and inclusion)
- Flexible respite that meets the unique needs of various caring scenarios
- Support to access and participate in education and employment
- Navigation of service systems and processes
- The need to 'join up' relevant government service systems
- Access to support as and when needed, no matter where the carer lives or their circumstances
- Improving carer health, wellbeing and safety
- Financial security and wellbeing
- Reducing social isolation.

These are not new areas of concern, but longstanding issues for carers. Many of these issues have been highlighted on numerous occasions by the National Carer Network and through other avenues such as the *National Inquiry into Carer Recognition*. We highlight the 22 recommendations from that Inquiry,² which include some fantastic and tangible actions that the Australian Government could consider implementing into the National Carer Strategy.

 ¹ Australian Government. (2024). National Carer Strategy Discussion Paper. https://engage.dss.gov.au/wp-content/uploads/2024/08/English_DSS-Discussion-Paper-signed.pdf
² Commonwealth of Australia, House of Representatives Standing Committee on Social Policy and Legal Affairs. (2024). Recognising, valuing and supporting unpaid carers – Parliament of Australia (aph.gov.au)

3. Response to the Discussion Paper Questions

National Carer Strategy principles

Carers Tasmania suggests that the Strategy principles could include:

- 1. Carers are valued and recognised the Strategy promotes carer recognition and for the contributions of carers to be acknowledged and valued.
- 2. Carer-centred the impacts of policies and programs on carers and their families are considered when policies are designed, implemented and evaluated. The lived experience of carers is considered and valued.
- **3.** Evidence-based and safe policies and actions affecting carers are evidencebased and aim to uphold the safety of carers.
- 4. Gender equity the gender equity implications of policy changes and new policies are considered when assessing policies that affect carers.
- 5. Accessible, inclusive, and equitable carer policies and supports respond to the diverse needs of carers and the different life stages of caring.

The proposed principles could be based off the Statement for Australia's Carers and the *United Nations Universal Declaration of Human Rights (UNDHR)*,³ specifically noting that the principles of the Strategy should uphold and promote these rights for carers.

These principles are designed to promote equality, support, and inclusivity for carers, ensuring their rights and contributions are central to policymaking. In addition, these aim to ensure that improving carer wellbeing is a key focus of the Strategy, given the comprehensive evidence built over the years which shows the significant impacts on carer health and wellbeing as a result of their support for others. The various iterations of *Carer Wellbeing Survey*⁴ and *National Carer Survey*⁵ reports provide extensive information on carer experiences, health, and wellbeing in Australia.

³ UN General Assembly. (1948). Universal declaration of human rights (217 [III] A). Paris. <u>Universal Declaration</u> of Human Rights | United Nations

 ⁴ Carers Australia. (n.d). Carer Wellbeing Surveys. <u>https://www.carersaustralia.com.au/carer-wellbeing-survey/</u>
⁵ Carers NSW. (n.d). National Carer Surveys | Carers NSW

A summary of caring in Tasmania

The *2021 Census* found that Tasmania has a rapidly ageing population, and when compared to national statistics, has high rates of mental ill health, disability, and chronic health conditions.⁶ This may explain why the prevalence of carers is higher in Tasmania (one in six Tasmanians), compared to the nationally (one in eight Australians).

Figures one and two on pages nine and ten, provide an overview of Tasmanian carer experiences from respondents of the *2022 National Carer Survey*.⁷ This is just a sample of the Tasmanian carer experience, and not fully representative of all Tasmanian carers. For information about carers nationally, the *National Carer Surveys*⁸ and the *Carer Wellbeing Surveys*⁹ contain invaluable information about carers across Australia.

The Tasmanian findings from the 2022 National Carer Survey found that, of the 691 Tasmanian participants:

- Most respondents (75%) identified as female
- 58.7% of respondents were aged 65 or older
- Respondents were from various locations and cultural backgrounds, but most identified as Australian and lived in regional locations
- Three percent of respondents identified as Aboriginal or Torres Strait Islander
- Six percent indicated they also spoke another language aside from English
- Just under four percent (3.8%) identified as LGBTIQA+
- Ten carers identified as young carers
- The average length of caring roles was reported as 11.3 years
- The average amount of hours spent caring per week was 108
- 59% of respondents reported they were providing care on a 24/7 basis.¹⁰

⁶ Australian Bureau of Statistics. (2021). <u>2021 Tasmania, Census All persons QuickStats | Australian Bureau of</u> <u>Statistics (abs.gov.au)</u>

⁷ Carers Tasmania. (2023). Tasmanian Results from the 2022 National Carer Survey. <u>2022-National-Carer-</u> <u>Survey-Tasmanian-Report.pdf (carerstas.org)</u>

⁸ Carers NSW. (n.d). National Carer Surveys | Carers NSW

 ⁹ Carers Australia. (n.d). Carer Wellbeing Surveys. <u>https://www.carersaustralia.com.au/carer-wellbeing-survey/</u>
¹⁰ Carers Tasmania. (2023). Tasmanian Results from the 2022 National Carer Survey. <u>2022-National-Carer-Survey-Tasmanian-Report.pdf</u> (carerstas.org)

2022 National Carer Survey Tasmania Results



Highlights from Tasmania

This year's National Carer Survey heard from a total of 691 carers from Tasmania. The Survey results tell us a lot about carers' day to day experiences, support needs and perspectives on caring. Below are some of the key findings so far.

Carers from Tasmania represented a total of 10.1% of respondents to the 2022 National Carer Survey. They mainly responded to the Survey online and 53.3% were connected with Carers Tasmania.

About the carers who responded

The 2022 National Carer Survey was conducted from June to July 2022 and received a total of 6,825 valid responses from carers across Australia.

A carer is any individual who provides unpaid care and support to a family member or friend, who has disability, mental ill health, a chronic or life-limiting condition, alcohol or other drug dependence or is frail or aged.

Of the 691 carers who responded to the 2022 National Carer Survey from Tasmania, the majority identified as female and were aged 70 to 79. The average age was 65.5 years. They represented a range of locations and cultural backgrounds, but most identified as Australian and lived in regional locations. 21.1% of respondents were working while providing care.



About the people they care for

Most Tasmanian carers who responded to the Survey were caring for a partner, and the most commonly respondents were caring for someone living with a disability. The average age of the people they care for was 63.4 years. However, not everyone who responded to the Survey was still in a caring role; 47 respondents (6.8%) identified as former carers, and a further 150 (23.3%) had previously cared for someone, and were now caring for someone else.



About the caring experience

Most carers who responded from Tasmania cared for one person and most were the sole carer. They were most likely to living with the person they care for. Carers from Tasmania typically spent 108 hours per week caring, and had been caring for 11.3 years.



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Figure 1: Tasmanian 2022 Snapshot part one

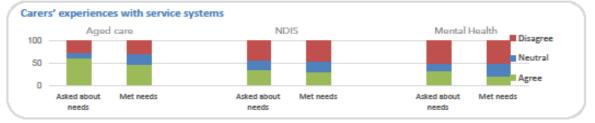
Carers' experiences with services

The 2022 National Carer Survey asked carers about their use of a range of services, and how included and supported they felt. Most carers from Tasmania were accessing the aged care services with or on behalf of the person they care for. Aged care services were more likely to ask carers about their own needs than health services, NDIS and mental health services

The 'typical' respondent from Tasmania was a woman in her 70s, caring for a partner living with disability, who was not in employment.

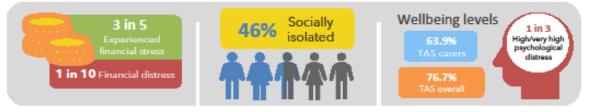


however, services didn't always meet carers' own needs or enable them to work or take breaks. Many carers also reported long waiting period to access services and reduced or interrupted services due to COVID-19.



Key challenges experienced by carers

In addition to the many challenges carers experienced when accessing formal services, many carers in Tasmania told us they were financially stressed and socially isolated. Compared to other Australians, carers in Tasmania were much more likely to be at risk of mental illness and had much lower wellbeing.



What carers told us

"Currently, I study at high school and my parents are blind. They always need someone to help them. After school I help them a lot."

"I love my son unconditionally even with all his little quirks, I worry every day of what will happen to him when I fall off the perch, who will care for him as I have done over the years without selfishness."

"I like being her carer and appreciate all the help we receive from services and our community. It is, however, the hardest thing I've ever done and requires me to give more than I have sometimes." Carers in Tasmania provide invaluable support to the people they care for and the community. And yet, recognition and timely support is lacking.

This National Carers Week, Carers Tasmania calls on the Tasmanian and Australian governments, service providers and communities to better support Australia's carers.

The National Carer Survey is an initiative of Carers NSW in partnership with Carers Tasmania and the other State and Territory Carer Organisations. The Survey is proudly funded by the NSW Department of Communities and Justice. More detailed results will be released in the coming months. For more information, visit www.carersnsw.org.au/research/survey or contact www.carersnsw.org.au/research/survey or (02) 9280 4744.

SUPPORTS ALL CARERS . AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS . AN

Figure 2: Tasmanian 2022 Snapshot part two

Primary carers and access to assistance from others such as extended family

The most recent *Survey of Disability, Ageing and Carers (SDAC)* reported that there were 3.0 million carers in Australia in 2022. Of these, 1.2 million people (or 4.5% of all Australians) were primary carers.¹¹ Furthermore, the data showed there were 383,600 secondary carers and almost 1.5 million other carers who were supplementing the 'normal' care provided by primary carers.¹² It is important to note that 'primary carers' for the purpose of the SDAC refers to carers who:

- "are aged 15 years or over; and
- provide the most informal assistance to a person with one or more disabilities, with one or more of the core activities of mobility, self-care or communication, and
- the assistance is ongoing or likely to be ongoing for 6 months or more."¹³

Therefore, the SDAC itself may exclude some primary carers, such as young carers who are aged 15 or below, carers who provide supports outside of those included within the definition, and those who provide care over varying, episodic time periods (for example, those supporting people experiencing mental ill health, or alcohol or other drug dependence). The SDAC also excludes carers who are supporting someone with a long-term health condition only (who does not have a disability and is under 65).¹⁴

The 2022 SDAC data estimated that there were 87,700 carers in Tasmania, and of these, 39,200 were a primary carer.¹⁵ Of note, the Tasmanian statutory definition of carers also includes informal kinship carers, carers supporting someone with a chronic or life-limiting illness, and carers supporting people who have alcohol or other drug dependence or are experiencing mental ill health (regardless of age). Due to the carer definition that the SDAC uses, informal kinship carers (of children who do not have disability), would not have been included within this data. In addition, carers of people with long term health conditions who are aged under 65 are excluded, and the survey could also exclude of people caring for someone with mental ill health or alcohol and drug dependence, if they don't also have disability or are aged under 65.¹⁶

Many carers from Tasmania report that they do not have other people who can provide them with adequate support to their caring role when they need it. Data from the Carers Tasmania *COVID Impact Survey 2022* found that 59.60% of carer respondents did not have any family members who could assist them at short notice.¹⁷ This rate is slightly higher that what was found in the previous *COVID Road to Recovery Survey*, where 52% of carers indicated they did not have a family member who could assist at short notice.¹⁸ This can increase the likelihood of carers ending up unwell, injured or burnt out, especially if they have limited access to external supports.

¹¹ Australian Bureau of Statistics. (2022). <u>Disability, Ageing and Carers, Australia: Summary of Findings, 2022</u> <u>Australian Bureau of Statistics (abs.gov.au)</u>

¹² Ibid.

 ¹³ Australian Bureau of Statistics. (2022). Methodologies. https://www.abs.gov.au/methodologies/disability-ageing-and-carers-australia-summary-findings-methodology/2022#disability-groups
¹⁴ Ibid.

¹⁵ Australian Bureau of Statistics. (2022). <u>Disability, Ageing and Carers, Australia: Summary of Findings, 2022</u> <u>Australian Bureau of Statistics (abs.gov.au)</u>

¹⁶ Ibid.

¹⁷ Carers Tasmania. (2022). COVID Impact Survey. https://carerstas.org/wp-content/uploads/2023/08/Carers-Tasmania-COVID-Impact-Survey-2022-Report-.pdf

¹⁸ Carers Tasmania. (2019). Road to Recovery Report. <u>Road to recovery: Covid-19 survey RESULTS</u> (carerstas.org)

The supports and skills needed to support carers in their caring roles

Carers often have difficulties accessing support and navigating systems. This frequently stems from a lack of carer recognition and awareness in government-funded services. Carers often describe situations in which the various government departments they speak with do not talk to each other. This adds to the often already high administrative burden on carers liaising with government services, arranging support, and navigating the information and services available.

In a submission on the *National Inquiry into Carer Recognition*, Carers Tasmania highlighted that:

"Across Australia, carers continue to go unrecognised. They are often excluded, and despite the significant support contributions to their family members and friends, they are considerably undervalued. Due to the lack of appropriate recognition and support, carers face poor health and wellbeing outcomes, social isolation, financial implications, and reduced capacity to undertake or sustain suitable employment or educational options."^{19,20}

The 2023 Carer Wellbeing Survey found that Australian "carers were almost twice as likely (58.3%) to report low wellbeing compared to non-carer adults living across Australia (30.4%)" ²¹ In addition, the survey found that some groups of carers experienced a larger decline in their levels of personal wellbeing between 2022 and 2023 compared to others. This was true for younger carers aged 15-24 years, carers who were studying, carers of people with low support needs, carers who identify as Aboriginal or Torres Strait Islander and carers who identify as LGBTIQA+.

Within the same survey, carers also reported higher than average rates of psychological distress compared to the general population. For example, 22.9% of adult Australians reported high levels of psychological distress in the first half of 2023, but the rate for carers was higher at 31.3%.²² Rates of psychological distress were highest amongst carers aged 25-44, carers who identify as LGBTIQA+, carers of three or more people, those caring for 40 or more hours per week, and carers of Autistic people, other developmental disorders, and alcohol or other drug dependence.²³

Furthermore, the survey found that loneliness was highest for carers of people with Autism and/or other developmental disorders, carers aged 35-44, carers with more than 40 hours per week caring commitments, carers of people with high or very high support needs, carers who are unemployed, carers of someone with mental ill health or psychological disability, and carers of children or grandchildren.²⁴

Additional or alternative methods of carer support for these specific groups who are experiencing increased levels of loneliness and/or psychological distress should be explored. Some carers have suggested that they would like to be able to access additional

¹⁹ University of Canberra for Carers Australia. (2022). Caring For Others and Yourself. The 2022 Carer Wellbeing Survey Full Data Report. https://www.carersaustralia.com.au/wp-content/uploads/2022/10/2022-CWS-Full-Report_221010_FINAL.pdf

 ²⁰ Carers Tasmania. (2023). Submission on the National Inquiry into Carer Recognition. <u>Carers-Tasmania-submission-on-the-National-Inquiry-into-Carer-Recognition.pdf (carerstas.org)</u>
²¹ University of Canberra for Carers Australia. (2023). Caring For Others and Yourself. The 2023 Carer Wellbeing

²¹ University of Canberra for Carers Australia. (2023). Caring For Others and Yourself. The 2023 Carer Wellbeing Survey Full Data Report. <u>2023-CWS-Report.pdf (carersaustralia.com.au)</u>

²² Ibid.

²³ Ibid.

²⁴ Ibid.

support for themselves through schemes such as the Better Access Scheme, but due to limitations on sessions, they are unable to access what they truly need.

Carer quote:

"I'm a carer for my son who is Autistic. Through the process of his diagnosis and supporting him as he's growing up, we've realised that I am Autistic and have ADHD myself. I have used Carer Gateway counselling before which is great in a counselling context, but I wish that Mental Health Care Plans could be increased for carers needing that additional layer of psychological support and therapy. I find that I use a lot of my subsidised psychology sessions talking about the impacts of constantly, and single-handedly supporting and advocating for my son, because I want the best for him. Then I don't have many sessions left for myself. I can't afford to pay the full price."²⁵

When facilitating consultation sessions with carers to inform the Carers Tasmania response towards the development of the *Tasmanian Carer Recognition Act*, the following were key items that carers indicated they needed or wanted improvements with:

- Practical support
- Financial support and economic security
- Time for self / respite
- Assistance with navigation of systems such as My Aged Care, NDIS, Services Australia
- Emotional or psychological support for self
- Transport
- Legal and advocacy support
- Social connection and companionship
- Ability to focus on own health and wellbeing, and
- Access to appropriate and timely support for the person being cared for. ²⁶

When reviewing or developing any new support programs for carers, authentic and accessible co-design must occur.

Finding and accessing carer supports

Many carers do not know what supports are available for themselves or the people they support. They often don't know how to access those supports or have limited time to investigate these as they are occupied providing and arranging care for the person they are supporting.

Across Australia, Carer Gateway provides a variety of services and supports for carers that are designed to build resilience, increase wellbeing, improve quality of life, and sustain carers to continue their caring roles. These supports include the provision of information, advice and referrals, holistic identification of carer strengths and needs through a carer support planning process, professional and confidential counselling, peer support groups, and coaching for carers who need support to achieve their goals.

²⁵ Carers Tasmania. (2024). Feedback on the Draft National Autism Strategy. <u>Carers-Tasmania-Feedback-on-the-draft-National-Autism-Strategy-1.pdf (carerstas.org)</u>

²⁶ Carers Tasmania. (2021). Response to the Carer Recognition Discussion Paper. <u>Carers-Tasmania-Response-</u> to-the-Carer-Recognition-Legislation-Discussion-Paper.pdf (carerstas.org)

Care2Serve is the Tasmanian provider of Carer Gateway supports and can fund instances of planned, short-term practical support services for carers such as in-home respite, personal care, domestic assistance, and meal preparation. Care2Serve may also fund one-off items to support carers, such as laptops for carers who are studying or trying to enter the workforce. Care2Serve also coordinates a 24/7 emergency respite service, which assists with arranging emergency support during instances where a carer may become unexpectedly ill or injured and unable to provide the care that they usually do.

While Carer Gateway is providing critical support to carers, it does not have capacity to provide ongoing support to carers, but rather is focussed on providing short-term support, whilst linking to ongoing external services. There is also limited funding available to promote Carer Gateway in Tasmania, meaning many carers are unaware of the services and support available.

Carers describe navigating systems, such aged care, disability and mental health services, as stressful, confusing, frustrating, and time-consuming. While Care2Serve assists registered carers with navigating systems, only a proportion of Tasmanian carers are registered with Care2Serve.

To improve the effectiveness and reach of Carer Gateway in supporting carers, the program should be expanded to enable long-term support to carers; increased support in navigating government services including aged care, disability and mental health services; and increased access to respite options (see below). Increased support is also needed to enable additional activities that improve carer's social connection and wellbeing (e.g. facilitating peer support groups, retreats, and workshops) through Carer Gateway and consideration given to brokering psychological services for carers, in addition to carer counselling. In addition, funding must be specifically provided in each region towards marketing Carer Gateway to ensure carers are aware of the support available.

On a national level, the *Carer Wellbeing Survey* provides information regarding the types and frequencies of supports that carers have reporting using.²⁷ The *National Carer Survey* asks carers about the types of supports that the person they care for uses, which are not necessarily directly carer supports, but may provide some assistance through services such as respite, social support, domestic assistance, meal preparation, and personal care. The Tasmanian results from the *2022 National Carer Survey* are presented in the following figures three to six.²⁸

 ²⁷ University of Canberra for Carers Australia. (2023). Caring For Others and Yourself. The 2023 Carer Wellbeing Survey Full Data Report. <u>2023-CWS-Report.pdf (carersaustralia.com.au)</u>
²⁸ Carers Tasmania. (2023). Tasmanian Results from the 2022 National Carer Survey. <u>2022-National-Carer-</u>

Survey-Tasmanian-Report.pdf (carerstas.org)

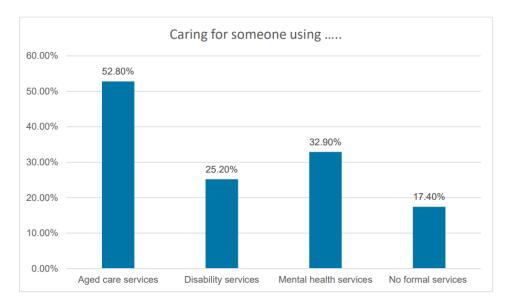


Figure 3: Tasmanian carers supporting people by service type

The survey results indicated that most carers were supporting a person accessing aged care services. Others reported they were caring for someone accessing disability or mental health supports, whilst a proportion (17.4%) of carers indicated they were supporting someone who was not accessing any formal services.²⁹

There are many potential reasons why a person may not wish to utilise formal services. Some of these reasons include cultural or religious reasons, difficulties finding the right provider, being informed and connected to support, personal choice, or lack of insight into care needs. For some people, finding the correct supports to assist with care needs at times that suit, is harder than providing constant care themselves. In some cases, arranging support is difficult or traumatic, meaning carers go without external supports.

Carers who are able to access external supports, still report challenges. Some of these include not being included in support planning or important conversations, and not being asked about their own needs as a carer.

Aged care services were the most likely to ask about carer needs than any of the other services. Mental health services were the least likely.³⁰

 ²⁹ Carers Tasmania. (2023). Tasmanian Results from the 2022 National Carer Survey. <u>2022-National-Carer-Survey-Tasmanian-Report.pdf (carerstas.org)</u>
³⁰ Ibid.

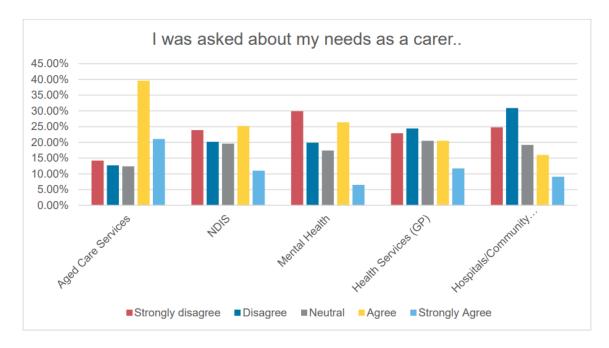


Figure 4: Services that asked about carer needs

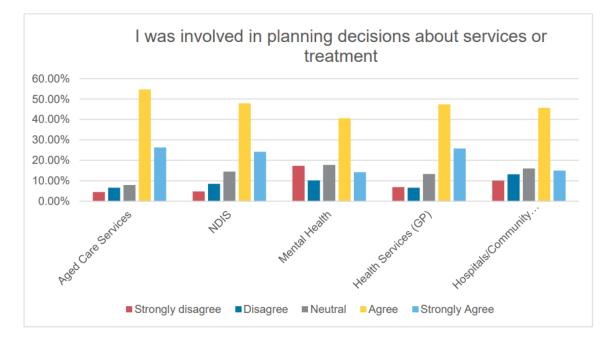


Figure 5: Services that involved carers in planning

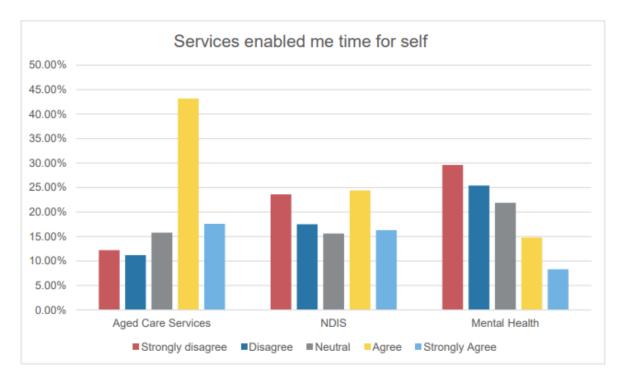


Figure 6: Services that enabled carers time for self

Some of these supports do not provide carers with adequate time for themselves. According to the survey results, in Tasmania, aged care services were the best enablers of time to self for carers, whilst mental health services were the least effective.³¹

The National Carer Strategy provides an opportunity to re-imagine how carers may be better supported to access time for themselves.

Access to appropriate respite

Carers report many barriers to accessing or benefiting from respite. For carers supporting someone in a 24/7 capacity, even with aged care or NDIS support, the funding allocated is often not enough to cover high support needs, long hours, overnight support, or support on weekends. In scenarios where there are high care needs, the funding is usually only allocated for the day-to-day needs, which makes it hard to access additional support when needed. In some of these situations, respite in a residential aged care facility or day centre may not be appropriate and may be more disruptive than beneficial.

There can also be barriers for carers who identify as Aboriginal or Torres Strait Islander or who are caring for someone who is. Aboriginal or Torres Strait Islander people often consider caring to be normal family responsibilities, so the concept of respite may be foreign or frowned upon. It can also be difficult for some families to build trust with outside service providers and they may not want people other than family involved in their personal lives.

This is also true in some culturally and linguistically diverse communities with people not considering themselves as carers, or not wanting to disclose there is someone within their family who has additional needs.

³¹ Carers Tasmania. (2023). Tasmanian Results from the 2022 National Carer Survey. <u>2022-National-Carer-</u> <u>Survey-Tasmanian-Report.pdf (carerstas.org)</u>

There may also be religious reasons as to why some people may not want to access respite or other forms of support. Some carers will not want to access respite through providers who are faith-based or affiliated with a particular religion. This can sometimes be the case for people who identify as LGBTIQA+.

There are significant workforce issues in Tasmania across the health, mental health, community, disability and child support and education sectors. These workforce shortages are exacerbated in some parts of Tasmania, making it extremely difficult to access support that suits individual needs.

Carers require different types of respite depending on the needs of who they are supporting. For example, carers of people experiencing mental ill health may be supporting a person who doesn't want others to come into the home, and accessing respite in a residential aged care facility may not be appropriate. In Tasmania, some mental health inpatient facilities can be accessed for people experiencing mental ill health who don't have an NDIS plan, but these facilities are primarily focused on either initial support for people in distress, or extended treatment and residential rehabilitation, and through the Statewide Mental Health Service, are only in Southern Tasmania. Due to the complexities of supporting a person with mental ill health, some carers may want to access respite for themselves away from their house.

Some activities that provide options of carer respite include attending carer peer support groups, carer retreats, wellness activities, or other carer events. Whilst these forms or respite do provide some level of support, these options are sometimes not accessible for carers who work during the week. Whilst feedback about carer retreats is generally positive, some carers want time completely for themselves to escape their caring role and have said that they would benefit from being able to stay somewhere local for a night or two on their own. Carers say that this wouldn't be a holiday, but their own form of respite. However, due to the financial impacts of caring, a lot of carers are not able to afford to pay for this sort of break themselves. Carer Gateway should be expanded to enable increased access to appropriate respite for carers, whether that be through attending retreats and events, or other options that are flexible to individual carer needs or family needs.

Although residential respite in an aged care facility may be an option for people who are aged over 65, or 50 if they identify as Aboriginal or Torres Strait Islander, there are challenges with accessing this option of respite. Many carers are not aware that the person they support requires an aged care assessment prior to being able to access this form of respite. Waiting for this assessment can be time consuming, making it difficult to access emergency residential respite. Once a person has been deemed eligible to access residential respite, there often significant waiting times in Tasmania due to limited beds. Most facilities in Tasmania are unable to take bookings too far ahead for carers needing to plan their respite. Some facilities don't have beds available for months at a time, and there are some facilities who will not take a person in for respite unless they intend to move in permanently.

Residential respite is also not an option for some carers if they are supporting a person who does not want to go into respite. There are also only a small number of facilities who are able to accommodate clients who have Dementia and need a secure ward. In addition, if a client is still receiving NDIS supports but has been assessed for residential respite, not all facilities have the processes in place to support these clients. Carers Tasmania has also been made aware of residential aged care facilities who would not accept clients who had an alcohol or other drug dependence, or extreme behaviours. Whilst the safety of workers and other residents is paramount, this places a significant burden on carers.

Carers Tasmania's Response to the National Carer Strategy Discussion Paper

The affordability of accessing residential respite is also an issue for some carers, where the daily fee is \$61.96 per day.³²

Many carers report that the NDIS is not able to facilitate respite for carers. Although through supporting NDIS participants to attend social activities or other outings, carers can sometimes have some form of a break, this isn't the type of respite that carers say they need. Carers also describe challenges where they may have a child in their household who does not have additional needs, and so even if a support worker could provide support to the person with additional needs, the carer will still not have a proper break as the other child is not supported.

Carers have also told us that when caring for multiple people who have NDIS plans, particularly children, that supports often don't align at the same time, meaning that carers never actually get a full break from all caring roles at once.

Case Study:

Ms. P is the sole parent and carer of four children with additional needs. Three of her children currently have NDIS plans due to various forms of disability, including intellectual disability, epilepsy, a genetic condition, and autism. Ms. *P* finds it challenging to keep up with the administrative burden of three NDIS plans on top of providing significant care to all of her children. One of her children has not received a formal diagnosis yet, so they do not have an NDIS plan, despite Ms. *P* describing clearly significant additional needs. The support across the three plans is not collaborative. The needs of Ms. *P* are not considered. She has little time for herself to enable her to sustain her caring role, and the support does not take into account that there is a child within the family not yet on the NDIS. Ms. *P* said that she feels this is just absurd. She said she feels like the supports are so siloed. She would love for supports to collaborate and see the whole family as integral to each other. As an example, she would love for the children to go out together on social activities that build their resilience, independence, and social skills. It would also provide her with some minimal time for rest and recuperation.³³

For carers who are supporting someone with alcohol or other drug dependence, it can be difficult to access any form of respite due to workplace health and safety regulations and a common requirement for detox prior to supports. Stigma is also a significant issue for carers within this cohort.

In Tasmania, it is estimated that there are approximately 9,300 young carers aged 25 and under supporting a family member or friend.³⁴ It is often difficult for young carers to access services to assist them. When respite is not an option, young carers must be supported to access other relevant supports so they can focus on school, work, sporting or other goals, or time for themselves.

Care2Serve, through Carer Gateway, aims to support carers to access emergency respite on a 24/7 basis. As this support relies on brokering local service providers, the significant workforce challenges within Tasmania can sometimes make this difficult. It can be difficult to find a provider to service a particular area at short notice, especially after-hours. There are also the aforementioned issues with accessing emergency respite in an aged care facility.

³² My Aged Care. (n.d). Short-term care costs and fees | My Aged Care

³³ Carers Tasmania. (2023). Submission to the NDIS Review. <u>Carers-Tasmania-submission-to-the-22-23-NDIS-Review-2.pdf (carerstas.org)</u>

³⁴ Department of Premier and Cabinet. (n,d). <u>https://www.dpac.tas.gov.au/divisions/cpp/community-policy-and</u> engagement/carer_policy_and_action_plan/carer-action-plan-2021-2025/what-the-data-tells-us-about-carers

Many carers tell us that NDIS plans don't allow flexibility to fund emergency situations. Some carers have told Carers Tasmania that they feel emergency respite would not work for them, especially when they are caring for multiple people at once, and/or children who do not have additional needs.

Carers Tasmania is also working with the Tasmanian Government, particularly the Tasmanian Department of Health, to improve identification and referral of carers within the health system. This will not only to help identify carers earlier in their caring roles, but also to identify carers who may be injured or unwell themselves, and support them to get emergency support in place, to ensure that care continues for the person they support. Carers Tasmania would like to see a similar approach occur with GP clinics.

Challenges with being able to access the right types of respite are not new. Although this is evidenced within more recent data such as that provided within the National Carer Surveys³⁵ and Carer Wellbeing Surveys,³⁶ historical reports such as the *Give Us a Break report*³⁷ by Carers NSW, and the Carers Australia, *Improving Access to Residential Aged Care Report*³⁸ illustrate these difficulties even prior to recent aged care, NDIS, and integrated carer support reforms.

It is important that carers can access true time for themselves, and this is a right that for all humans as outlined in the Universal Declaration of Human Rights. Article 24 states that "everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay," and Article 27 states "everyone has the right freely to participate in the cultural life of the community." ³⁹

The National Carer Strategy must address access to respite for carers. There needs to be consideration of flexible approaches to respite to suit individual circumstances, aged care facilities need to improve their capacity for residential respite beds, there needs to be more support accessible to those in vulnerable circumstances, respite provision should be provided for the family unit where relevant, and workforce issues must continue to be addressed. Consideration must also be taken to support those who don't easily fit into aged care services or NDIS, to ensure that carers of people in these circumstances can have time for themselves.

³⁵ Carers NSW. (n.d). <u>National Carer Surveys | Carers NSW</u>

³⁶ Carers Australia. (n.d). Carer Wellbeing Surveys. <u>https://www.carersaustralia.com.au/carer-wellbeing-survey/</u>

³⁷ Carers NSW. (n.d). Give us a Break. <u>Give-us-a-break_Evidence-that-Australian-carers-still-need-respite.pdf</u>

⁽carersnsw.org.au) ³⁸ Carers Australia. (2018). Improving Access to Residential Respite Care. <u>final-residential-respite-care-report-2-</u> <u>1.pdf</u> (carersaustralia.com.au)

³⁹ UN General Assembly. (1948). Universal declaration of human rights (217 [III] A). Paris. <u>Universal Declaration</u> of Human Rights | United Nations

Carer-inclusive workplaces and education

The *2023 Carer Wellbeing Survey* found that carers who were employed were more likely to have healthy levels of wellbeing (43.2%) compared to those who were unemployed (27.5%).⁴⁰ In 2022, Carers Tasmania conducted a survey on balancing caring and employment. Almost 42% of respondents reported that they were employed at the time of completing the survey.⁴¹



The employment statistics were similar to the 2018 Survey of Disability, Ageing and Carers, which found that in 2018, 46% of Tasmanian carers were employed.⁴²

The Carers Tasmania Survey asked carers about what they had found helpful in their workplaces. Some comments were:

- "Work has been great. However, now I am unable to work from home, therefore if mum and dad or myself or my child become unwell, then I cannot work at my place of work. Previously, I could make up the hours."
- "Work from home means I don't always have to access carers leave when my child requires additional care."
- "Currently working from home but needed to temporarily accept a lower-paid role to do this."
- "Some reduced hours (0.8 FTE) and flex time."
- "None, I'm currently in debt due to my incomings not matching my outgoings."
- "Held my position for me."
- "Reduced hours when needed, both short-term in response to crises and longer-term (months at a time) by negotiation."
- "None. Took a day off to take my 98 year old dad to an appointment and then had negativity."

⁴⁰ University of Canberra for Carers Australia. (2023). Caring For Others and Yourself. The 2023 Carer Wellbeing Survey Full Data Report. <u>2023-CWS-Report.pdf (carersaustralia.com.au)</u>

⁴¹ Carers Tasmania. (2022). Balancing Employment and Caring. <u>Carers-Tasmania-Report-on-Balancing-Employment-and-caring-2022.pdf (carerstas.org)</u> ⁴² Australian Bureau of Statistics. (2018). Disability. Againg and Carers. Australia: Summary of Eindings.

⁴² Australian Bureau of Statistics. (2018). <u>Disability, Ageing and Carers, Australia: Summary of Findings</u> methodology, 2018 | Australian Bureau of Statistics (abs.gov.au)

- "Annual leave, purchased leave, personal leave, carer's leave, flexible start and finish • times. flexible lunch times."
- "Currently on carers leave coming out of my sick leave bank." 43

The survey also asked carers what they needed from employers or prospective employers to support them to obtain and sustain employment. Some comments were:

- "For longer-term carers, an optional period of return to work confidence building • programs."
- "Training, employer understanding on why you had time out of the workforce." •
- "I think the government needs to assist either by assisting the employer or providing • more payment options for time of extended leave when you don't qualify for normal payments."
- "Help to get back into current upgrade of gualifications and help with study • technology. Supported respite to have time to study."
- "Why is it always about getting people into the workforce. How about recognising the work that we do ?? How about paying us to care for people?" 44

It is important that carers and former carers have accessible and tailored support to enable them to upskill, obtain, and maintain employment. For former carers who may have been out of employment, or never had the opportunity to undertake employment, starting this process can be quite daunting. Carers Tasmania suggests that the Australian Government look to expand programs that aim to support carers or former carers to obtain the confidence, skills and support they need to enable success. Carers Tasmania is supportive of programs such as the Carers Plus Employers⁴⁵ and Carer Inclusive Workplace Initiative,⁴⁶ which aim to assist employers to become more carer aware, inclusive and supportive to carers within their practices.

Education providers, such as schools, TAFE's, colleges and universities should ensure that they have relevant policies and procedures in place to ensure that young carers, and other carers have access to flexibility and support when needed.

Flexible support systems for young carers are critical to their future success, with research showing that school participation rates and educational attainment levels impact employment prospects not only for young people in general, but the impacts are particularly significant for young carers.47

Benefits of peer support

Caring for another person can be socially isolating for carers. Tasmanian data from the 2022 National Carer Survey found that approximately 46% of carers were socially isolated, with 23.9% of this proportion reporting high levels of social isolation. The COVID-19 period saw many peer support groups pause or completely dissipate. Care2Serve now provides more

⁴³ Carers Tasmania. (2022). Balancing Employment and Caring. Carers-Tasmania-Report-on-Balancing-Employment-and-caring-2022.pdf (carerstas.org) 44 Ibid.

⁴⁵ Carers + Employers. (n.d). <u>Homepage | Carers + Employers (carersandemployers.org.au)</u>

⁴⁶ Carers Australia. (2024). Carer Inclusive Workplace Initiative. carersaustralia.com.au/programs-projects/carerinclusive-workplace-initiative/

⁴⁷ Hutchings, K., Radford, K., Spencer, N., Harris, N., McMillan, S., Slattery, M., Wheeler, A. and Roche, E. (2023), "Addressing the challenge of engaging in paid work while undertaking unpaid caring: insights for improving employment inclusion of young carers", Equality, Diversity and Inclusion, Vol. ahead-of-print No. ahead-of-print. https://doi.org/10.1108/EDI-12-2022-0351

than 30 carer peer support groups across the state and the carers who attend find these groups very beneficial.

Comments from carers include:

- "Thank you for reminding me that I am not alone and for this resource. This is very reassuring."
- "I felt accepted and heard."
- "I have been in Carers Gateway peer support group for a while. As a member in our group and being in it helps me a lot knowing that we can talk and express what we have been through in our daily life experiences, by sharing our story to one another is helping us physically / mentally and comfort emotionally. The meeting once monthly is something to look forward to for myself and each one of the members of our group, as it gives ourselves a time even just an hour to relax and a peaceful mind. It feels we are not alone and knowing that there is someone who is willing to listen what we are going through. I fully appreciate and am thankful for all the help and supports you have given us."

Comments from carers on what they enjoyed about a peer support forest therapy walk, include:

- "Being able to completely relax"
- "The opportunity to stop and be present in a beautiful mindfulness activity"
- "How to engage with my body and breathe, be in the moment with nature"
- "Just wanted to say a big thank you to the counsellor for coming to Huonville Group to speak. Although we are a small group, we value the support from yourself and Care2Serve. Thankyou for organising him to speak to us about Self Care, I feel it was well rec'd by the group. Please let him know that his time was much appreciated. Hope we catch up with you again when you can make it down to the valley."

Consideration should be taken on expanding Carer Gateway to enable a greater focus on establishing and sustaining peer support groups and wellness activities that reduce carer's social isolation.

Improved carer recognition, especially in diverse or marginalised communities

The Strategy presents a good opportunity to consider how diverse carer groups could be better identified and supported. In some cultures, caring may not be recognised. Caring, in some cultures, is seen as normal family responsibility, whilst in other cultures, additional needs may not be fully recognised. The Strategy must support diverse caring needs and experiences, particularly for marginalised groups such as people who identify as LGBTIQA+, culturally and linguistically diverse carers, carers who have disability themselves, ageing carers and First Nations carers. The Strategy needs to be supportive of the needs and experiences of carers of different genders and young carers.

The Strategy must look at and support carers through an intersectionality lens, ensuring a person-centred, and trauma-informed approach is taken. The Strategy should foster an approach that encourages place-based approaches with target communities to identify what they need and what may work best for them.

Financial security

Caring for others has significant impacts. *The Caring Costs Us* report, commissioned by Carers Australia and the National Carer Network, found that in 2021, the Carer Payment was only equal to 28% of weekly ordinary earnings for singles in Australia and 21% of weekly ordinary earnings for couples in Australia.⁴⁸ When this payment was originally introduced as the Wife's Allowance (noting this was initially an allowance, not a pension) in 1943, this was equivalent to 15% of the average weekly earnings and 28% of the maximum rate of the pension. Furthermore, the report found that the Carer Allowance is equal to only 10% of the basic Aged Care Pension for a couple.⁴⁹

The Report also found that caring has significant impacts on superannuation, finding that Australian carers, by aged 67, will lose approximately \$392,500 in lifetime earnings and \$175,000 in superannuation. The losses are even more significant for those caring for extended periods of time, with the most affected losing at least \$940,000 in lifetime income, and \$444,500 in superannuation.⁵⁰

Carers are often financially disadvantaged as a result of paying for assessments, supports, medication, and other things required to support the people they care for. The National Carer Surveys provides more detail on this.⁵¹

For carers who are eligible to receive the Carer Payment, Carer Allowance, or both, they often describe the application process to be lengthy and frustrating. Some carers find it difficult to understand and obtain the documentation required, and sometimes experience medical professionals who do not fully understand their circumstances, which results in the forms being filled out incorrectly. It can be difficult, especially in Tasmania to access a GP appointment, especially if bulk-billing is required.

As of June 2024 in Tasmania, 9,445 people were in receipt of the Carer Payment and 17,615 people we receiving the Carer Allowance.⁵² This highlights a significant gap between the number of carers within Tasmania (87,000+) and those who receive any form of carer support payment or allowance, noting that the Carer Allowance has more lenient eligibility criteria around employment income and hours worked than the Carer Payment.

Some carers find it hard to leave the person they support for long enough to wait at Centrelink, and/or don't have a lot of time to wait on hold on the phone. The operating hours of Centrelink offices can also be prohibitive to working carers. Tasmania also faces also significant challenges with respect to literacy, digital literacy, and digital connectivity. Carers Tasmania and Care2Serve receive positive feedback about having the Centrelink Engagement Officers visit Care2Serve offices every month. This enables carers who otherwise could not get to a Centrelink office or are experiencing difficulties, to access support in person from a Centrelink Engagement Officer. This support appears to be highly valuable.

Carers Tasmania strongly recommends simplifying processes for applying for carer payments/allowances and providing superannuation on these payments to improve the

⁴⁸ Evaluate. (2022). Caring Costs Us: The Economic Impact on Lifetime Income and Retirement Savings for Informal Carers. A Report for Carers Australia. <u>Final-Economic-impact-income-and-retirement-Evaluate-Report-March-2022.pdf (carersaustralia.com.au)</u>

⁴⁹ Ibid.

⁵⁰ Ibid.

⁵¹ Carers NSW. (n.d). <u>National Carer Surveys | Carers NSW</u>

⁵² Department of Social Services. (2024). <u>DSS Benefit and Payment Recipient Demographics - quarterly data -</u> <u>Expanded DSS Benefit and Payment Recipient Demographics - June 2024 - data.gov.au</u>

financial wellbeing of carers. Carers Tasmania also encourages a better process for routine identification and referral of all eligible Carer Payment or Carer Allowance recipients to carer support. Although it is positive that the Carer Payment and Allowance outcome letters do provide reference to Carer Gateway, this information may be missed or forgotten by busy carers. Therefore, a method for routine referrable would be preferrable.

Additional items

The Strategy and any associated action plans must set out clear priorities with timeframes for actions and intended outcomes. It is important that review periods are specified governance and monitoring processes outlined. It must be made clear on who is responsible for each action, and how will it be monitored and measured. Carers must have adequate opportunities to be involved in the implementation, monitoring and review of the Strategy.

Carers Tasmania highlights that the Strategy should include some actions to support former carers. Given the impacts of caring on educational, employment, social and financial outcomes, the period of time after a caring role ends can be a particularly vulnerable time for carers. It can be a time of loss, confusion and further isolation. Former carers may still need information, emotional support, peer support, practical support, and support with housing, employment, education and finances. The transition out of a caring role can often be a complex, lonely and stressful time.

Individual advocacy is another area whereby carers often require support. It is often challenging when dealing with complex systems, or when things don't work out as planned. There are many scenarios in which a carer might require assistance with a formal advocacy service to support the needs or safety of the person they are caring for. Some of these instances may include:

- Dealing with challenges related to packages of support such as NDIS or Aged Care
- Difficulties within the school environment for young carers, or for carers supporting a child who has additional needs
- Guardianship, administration and other legal or financial scenarios
- Complex issues in families where there are multiple carers
- Elder abuse or other safety concerns
- Housing
- Obtaining information about government services or supports.

Many carers are not able to access advocacy support for themselves, as most advocacy services are funded primarily to support the person who has additional needs. Sometimes, carers just need a person in their corner, to help them feel supported and assist them to understand their rights. An individual carer advocate would not override the support by advocacy services for people being cared for, but it would ensure that all parties feel they have the support and representation they need.

Another area that could be considered within the Strategy development is updating the Commonwealth definition of a carer. In our submission to the National Inquiry Into Carer Recognition, Carers Tasmania proposed that the *Commonwealth Carer Recognition Act 2010* (Cth)⁵³ be amended, and that more specifically the carer definition be updated to use

⁵³ Commonwealth of Australia. (2010) Commonwealth *Carer Recognition Act 2010*. <u>Federal Register of</u> <u>Legislation - Carer Recognition Act 2010</u>

language that is more contemporary, best practice, inclusive.⁵⁴ We encourage this to be considered as a strategy item to ensure that the legislation can effectively support a broader range of carers.

Carers Tasmania also reinforces the need for adequate communication and ample time for the consultation when the draft strategy is released. It is important that as many carers as possible can read the proposed draft Strategy in a way that is accessible to them and provide their important feedback.

4. Conclusion

Noting that the vision for the proposed Strategy has been stated as:

"Our vision is for an Australian community in which all carers are recognised, valued and empowered with the support they need to participate fully in society and fulfil their caring role."

Carers Tasmania recommends that the Strategy:

- Enshrine and uphold carer's rights (as per the UNDHR)
- Be carer-centred
- Foster better recognition, referral, and inclusion of carers across Australian Government and Government-funded Services and encourage placed-based solutions
- Support relevant recommendations from the National Inquiry Into Carer Recognition⁵⁵
- Improve supports for carers, including by expanding Carer Gateway to provide long term supports; increased support in navigating government services; and increased access to respite options, as well as better marketing Carer Gateway to ensure carers are aware of the support available
- Improve access to appropriate respite for carers, including flexible approaches to respite to suit individual and family circumstances, and increases in residential respite beds
- Focus on reducing social isolation and improving the physical and mental wellbeing of carers, including increased support for activities that improve carer's social connection and wellbeing and considering brokering psychological services for carers, in addition to counselling, through Carer Gateway
- Update and amend the *Carer Recognition Act 2010*,⁵⁶ including updating the carer definition
- Streamline the process for carers to access carer payments and consider providing superannuation on these payments to improve the financial wellbeing of carers
- Promote carer-inclusive education and employment
- Champion authentic collaboration and co-design with carers
- Set out clear actions, responsibilities, timelines and monitoring mechanisms.

Carers Tasmania thanks the Australian Government for their commitment to improving life for carers across Australia and we look forward to receiving the draft Strategy for review.

 ⁵⁴ Carers Tasmania. (2023). Submission on the National Inquiry into Carer Recognition. <u>Carers-Tasmania-submission-on-the-National-Inquiry-into-Carer-Recognition.pdf (carerstas.org)</u>
⁵⁵ Commonwealth of Australia, House of Representatives Standing Committee on Social Policy and Legal Affairs.

 ⁵⁵ Commonwealth of Australia, House of Representatives Standing Committee on Social Policy and Legal Affairs.
(2024). <u>Recognising, valuing and supporting unpaid carers – Parliament of Australia (aph.gov.au)</u>
⁵⁶ Commonwealth of Australia. (2010) Commonwealth *Carer Recognition Act 2010*. <u>Federal Register of</u> Legislation - Carer Recognition Act 2010Federal Register of Legislation - Carer Recognition Act 2010