



**Response to the
Select Committee on Work and Care
Terms of Reference**

September 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 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 conditions for family or friend carers through policy development, research and advocacy.

Carers Tasmania has offices in Moonah, Launceston and Burnie.

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1. 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.

A carer is a person who provides unpaid care and support to a family member, or friend, with disability, mental ill health, a chronic or life-limiting condition, alcohol or other drug dependence or who are frail or aged. 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' does not automatically include kinship or foster carers, unless they care for a child with disability, mental ill health or other condition as previously noted.

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

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

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

2. Introduction

Carers Tasmania welcomes the opportunity to contribute to the Australian Government Select Committee on Work and Care Terms of Reference (TOR).¹ We acknowledge that the TOR seeks to explore a variety of questions to inform the understanding of the Select Committee on the extent, nature and the impacts of balancing work and care. Our response addresses some of the questions identified in the TOR, both nationally and through the lens of the Tasmanian carer experience.

Our response has been informed by drawing on evidence collected from various national and Tasmanian carer surveys which capture the voice and experience of carers as well as information from relevant and well-established data sources.

There are significant challenges that must be addressed regarding the challenge of trying to balance employment and caring. Due to the diverse and sometimes unpredictable nature of caring, a range of changes and supports are required to truly make a difference for working carers and carers or former carers who wish to re-enter the workforce. Supporting carers/former carers to gain employment and remain employed may have positive effects on the broader economy.

We urge the Federal Government to consider the introduction of a superannuation guarantee for carers who are in receipt of the carer payment as well as significantly increasing the carer payment and allowance. Whilst we are aware that pension rates have just increased, this is still not enough to keep up with cost of living pressures.

We support the current Productivity Commission inquiry which is exploring the possible introduction of additional leave entitlements for working carers. As noted in our response to the Productivity Commission,² we firmly believe that additional carer leave entitlements should be implemented for all working carers and provisions should incorporate a mixture of both shorter-term paid leave as well as longer unpaid leave options to suit the variety of caring circumstances.

Workplaces must be better educated to support their employees with flexible working arrangements when required because of their caring responsibilities. Carers or former carers who wish to re-enter the workforce must also be connected with adequate support services to enable them to refresh, update or obtain the skills they require for the workforce as well as assistance to build community connections and capacity to find appropriate employment.

In addition to supporting the uptake and sustainability of employment for carers, and improving the financial security of carers, a whole of government approach is required to address the widespread issues of service gaps and long waiting lists to access health services and practical supports.

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https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Work_and_Care/workandcare/Terms_of_Reference

² https://www.pc.gov.au/__data/assets/pdf_file/0007/345832/sub037-carer-leave.pdf

3. Terms of Reference Questions

3.1 Extent and nature of work and care

In Australia, there are an estimated 2.6 million people who provide informal care for a family member or friend.³ Anyone can become a carer at any time, and therefore many carers try to juggle employment and caring responsibilities. The 2018 Survey of Disability, Ageing, and Carers (SDAC)⁴ found that nationally, for carers who were aged between 15 and 64 years:

- 70.9% were in the labour force and
- 71.8% of all male carers were employed, compared with 63.2% of all female carers

Of working age primary carers (15-64 years), 55.5% were employed, however employment status varied with the hours of care provided per week by primary carers. Findings showed that:

- Less than one-third (28.6%) of primary carers providing greater than 40 hours of care a week were employed
- In comparison, over half (52.8%) of those caring for less than 20 hours a week were employed

Furthermore, the SDAC⁵ found that the most common reason primary carers took on a caring role was because of their sense of family responsibility, with 70.1% of all primary carers reporting this reason. Almost half of the primary carers who were parents and employed (45.5%) said they had reduced the number of weekly hours they worked in all jobs since commencing the caring role.

The 2020 National Carer Survey⁶ received 7,735 responses from carers living in Australia. Results showed that the most common group of people being cared for were people with physical disability, followed by people with a chronic condition and people with mental illness. The typical person being cared for was an adult son with physical disability who was not able to be left alone for more than a few hours.

The survey also found that on a national level:

- The 'average' carer worked 27 hours per week in a permanent role
- 50% of carers had used flexible start and finish times
- 44% used carers leave in the form of paid personal/carers leave
- 15% had taken unpaid leave and
- 16% had used paid carers leave

The most common impact of caring on employment, which was reported by 27.5% of respondents was resignation from employment due to caring obligations. Combined with retiring early to continue caring, 44.5% of carers reported leaving the workforce due to their

³ <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>

⁴ Ibid.

⁵ Ibid.

⁶ https://www.carersnsw.org.au/uploads/main/Files/5.About-us/Our-research/Summary_Report_HighRes.pdf
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caring responsibilities. The second most common impact that was reported by 27.4% of respondents was reducing working hours. This was followed by 17.4% of carers indicating they were unable to keep their skills and qualifications up to date.

The demands that caring responsibilities place on carers' time was also found to be a significant barrier to finding work. Approximately half of the carers participating in the labour force agreed that the demands on their time would have been too high and that it wouldn't be possible to take enough paid leave to meet the needs of the caring role.

The 2021 Caring for Others and Yourself - Carer Wellbeing survey⁷ illustrates findings from 5,800 carers across Australia during April and May 2021 and found that:

- Carers were less likely to be employed than other Australians
- Overall, 51.6% of Australian carers were employed, while 4.9% were unemployed and seeking work, and 43.5% were not in the labour force
- Carers were more likely to have paid employment if they were younger with less caring obligations
- Older carers or carers who have high caring obligations were less likely to be in employment
- The longer a person remains in a caring role, the less likely they are to be employed
- 47% of people who had been a carer for five years or more were employed compared to 61% of those who had been a carer for less than a year
- When asked if their employer was understanding of their caring obligations 17.2% reported they were not very understanding, 41.6% that they were somewhat understanding, and 41.3% that they were very understanding, and younger carers were more likely than other employed carers to report their employers as not very understanding of their situation

The report on Employment outcomes for families and carers of NDIS participants from 31 December 2020⁸ found that education was the most frequently reported employment industry for working families/carers of NDIS participants across all age groups. This was followed by employment in the health industry, care work, aged care, and retail.

It is significant to highlight that there may be particular challenges experienced by employed carers as a result of where they live. The 2021 Census⁹ found that the Tasmanian population was 558,000, with the median age being 41 years old. Tasmania is home to more than 80,000 carers, which equates to 1:6 people or 15.5% of the Tasmanian population. Of these carers, females accounted for 41,400 (51.7%) and males accounted for 38,000 (47.4%).¹⁰ As of June 2022, an estimated 263,700 people were employed in Tasmania.¹¹ The most current statistics from the SDAC 2018, reported that 46% of carers in Tasmania

⁷ https://www.carersaustralia.com.au/wp-content/uploads/2021/10/211011_Carer-Wellbeing-Survey-Executive-Summary_FINAL.pdf

⁸ <https://data.ndis.gov.au/reports-and-analyses/outcomes-and-goals/employment-outcomes-participants-their-families-and-carers#employment-outcomes-for-ndis-participants-as-at-31-december-2020>

⁹ <https://www.abs.gov.au/articles/snapshot-tas-2021#:~:text=In%20the%202021%20Census%2C%20the,the%20Census%20counted%20372%2C000%20people.>

¹⁰ Australian Bureau of Statistics (2021) 44300DO006_2018 Disability, Ageing and Carers, Australia: Tasmania, 2018. Released at 11:30am Wednesday 5 February 2020.

¹¹ <https://www.treasury.tas.gov.au/Documents/Labour-Force.pdf>

were employed.¹² The most current ABS Census 2021 release states that it will provide data on employment statistics in the October 2022 release.

The Tasmanian State Service (TSS) reported that as of March 2019, there were 31,022 employees and officers in the TSS, and in the year leading up to this, 9.34% of staff accessed paid carers leave entitlements. However, this figure does not completely represent the total number of carers in the TSS as some employees with caring responsibilities possibly worked without taking leave or identifying that they were a carer and others may have utilised sick leave or forms of flexible working arrangements.¹³

Being a carer often results in a need to alter employment conditions. The 2020 National Carer Survey¹⁴ found that across Australia, ceasing employment and reducing employment hours were common occurrences for carers. Furthermore, out of 1024 respondents from the same survey who identified as Tasmanian carers, only 189 (22.4%) reported that they were employed. Of those employed carers, 148 identified as female and 30 as male.

The survey also found that in Tasmania, carers spend on average 12.6 years in a caring role and 80 hours per week caring.¹⁵ Another key finding from the survey¹⁶ was that in Tasmania, the most common group of people being cared for by respondents were people with physical disability, followed by people with a chronic condition and people who were frail and aged.

The National Carer survey¹⁷ found that over 60% of Tasmanian respondents had access to flexible start and finish times or the ability to work from home. Many carers (32.8%) took paid personal leave to enable them to undertake their caring role. Carers were asked about the impact of their work on their caring role, and 46% of carers reported that they were often so emotionally drained when they finished work that it impacted their ability to provide care. 46.6% of respondents reported missing work activities due to the amount of time required to fulfill their caring responsibilities and 32.5% indicated that their caring responsibilities impacted their capacity to concentrate on their tasks at work.

With regards to the impact that their caring role had on their employment, some carers reported that they quit work or reduced their hours of work to maintain their caring role. 177 carers reported that they quit work or looking for work to care and 160 carers indicated that they reduced their work hours because of the caring role. 137 carers reported that their skills and qualifications had become out of date, 125 carers said they retired earlier than anticipated to care and 84 carers indicated that they felt less prepared to meet the demands of their job.¹⁸

People of all ages and from varying circumstances may become a carer at any time, even if they did not plan on it. A variety of scenarios may occur resulting in the need for carers to take leave from employment. There are many different situations that may require additional

¹² <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>

¹³

https://www.dpac.tas.gov.au/divisions/ssmo/leave_and_other_entitlements/personal_leave_incorporating_sick_leave_and_special_leave

¹⁴ https://www.carersnsw.org.au/uploads/main/Files/5.About-us/Our-research/Summary_Report_HighRes.pdf

¹⁵ https://www.carerstas.org/wp-content/uploads/2017/06/FINAL-CTAS-National-Carer-Survey-Report-3_compressed.pdf

¹⁶ Ibid.

¹⁷ Ibid.

¹⁸ Ibid.

care and the length and types of leave required to provide this support vary greatly depending on the health of the person, the support they require, how they are functioning, and the consequences of them not being supported. Common reasons often requiring increased levels of care include:

- The first health incident or hospital admission, which is often unexpected. This can sometimes eventuate into needing interim services whilst waiting for a home care package or admission into residential respite
- A fall or a series of falls
- Transition into residential respite or permanent placement
- A UTI and associated behaviours
- A decline in health and waiting to be assessed for residential respite or a bed to become available
- A rapid decline in cognition
- Diagnosis of a life-limiting condition requiring ongoing therapy
- Entering the palliative stage of an illness
- For carers of someone with mental ill health or alcohol or other drug dependence, it may be more sporadic and/or episodic
- A planned, but significant surgery
- Issues with the school (when caring for school-aged children)
- Periods of serious chronic illness
- Lack of services or running out of funding (this is common in NDIS)
- During a pandemic or other such events
- The person being cared for becomes homeless
- A psychological crisis or suicidal distress
- An alcohol or other drug overdose
- The person being cared for in trouble with the authorities

Current entitlements are not adequately meeting the needs of all working carers. Flexible working arrangements such as amendments to start and finish times may support carers only needing minimal time off during the day for tasks during normal business hours, but these arrangements are not always suitable.

Working from home may sometimes be a suitable option. The pandemic forced many workplaces to adapt to working from home, however, face-to-face roles, (eg retail shops, hospitality and healthcare) cannot be completed effectively, or at all from home. If an employee with caring responsibilities has the equipment and ability to work from home successfully, this option must be considered. However, this option is not always agreed upon by employers.

Taking paid personal/carers leave may result in carers exhausting their leave entitlements in order to support the person they care for and leaving themselves with no personal leave to

enable rest and recovery when they become unwell. Similarly, if carers use all of their annual leave to support the person they care for, they will not have annual leave to enable them to take a proper break from work.

Some carers are hesitant to take periods of leave for fear of consequences. Having legislated additional entitlements could reinforce that taking leave is ok when necessary to provide care.

The care and support needs of each person will always differ between individuals, with some people requiring basic support and others requiring complex care. Carers often provide supports that may also be provided through government subsidised or privately paid services, with common support types including:

- Personal care tasks such as dressing, toileting, showering, other hygiene needs, eating and drinking
- Mobility support, such as getting in and out of bed and moving around the house
- Assistance with medications and accompanying the person being cared for to medical appointments
- Household tasks such as cleaning, gardening, or maintenance
- Meal preparation
- Shopping for groceries, medications, and other supplies
- Transport
- Support with communication and booking appointments

3.2 Impact of combining work and care

Taking on a caring role can have significant impacts on wellbeing. The National Carer survey,¹⁹ explored this by measuring psychological distress using the Kessler 5-Item Scale of Psychological Distress (K5) to indicate low to moderate, or high to very high levels of psychological distress. 47.7% of the survey respondents reported high or very high levels of psychological distress.

The survey also aimed to measure carer wellbeing using the Personal Wellbeing Index²⁰ and life satisfaction across seven domains. The survey respondents reported the lowest satisfaction on the measures of what they are achieving in life, their future security, and their health. The greatest difference compared to the general population was found in the domain of satisfaction with personal relationships. Overall, carers' satisfaction with life was 18.2% lower than it was for the general Australian population.

It is important to note that poor wellbeing and psychological distress may have been partially attributed to the covid-19 pandemic. In addition, the survey,²¹ indicated that nearly half of the Tasmanian carers who responded were experiencing moderate to high levels of distress, and 81% were feeling some level of isolation.

¹⁹ https://www.carersnsw.org.au/uploads/main/Files/5.About-us/Our-research/Summary_Report_HighRes.pdf

²⁰ (PWI, Cummins et al. 2003, IWB 2013)

²¹ https://www.carerstas.org/wp-content/uploads/2017/06/FINAL-CTAS-National-Carer-Survey-Report-3_compressed.pdf

The 2021 Carer Wellbeing Survey²² found that nationally, carers are two and a half times more likely to have low wellbeing than the average Australian adult, with 55% of carers reporting low wellbeing compared to only 20% of the broader population. Furthermore, the highest prevalence of low wellbeing was found amongst carers supporting a person with autism, other developmental disorders, mental ill health/psychosocial disability, alcohol or other drug dependence, intellectual disability, if they identified as Aboriginal or Torres Strait Islander or were caring for a child or grandchild.

The National Carer Survey²³ found that carers in the workforce had higher rates of wellbeing (58.5%) compared to carers who were unemployed (49.8%), and that carers in the workforce had lower levels of psychological distress (46.7%) compared to carers not in the workforce (58.4%). In addition, carers in the workforce were less socially isolated (53.3%) compared to carers who were not in the workforce (69.2%), indicating that employment not only provides financial benefits, but also facilitates social connection, may increase wellbeing, and reduce psychological stress.

3.3 Adequacy of workplace laws

The Productivity Commission is currently conducting an inquiry into the effects of potential amendments to the national employment standards (NES) with possible additions to the current carer leave entitlements. We strongly advocate for the following:

- Any additional carer leave entitlements must be inclusive and available to all employees who are carers within the meaning of state-based carer recognition legislation (as definitions vary state-to-state)
- The entitlements must consist of both paid and unpaid leave options which can be used flexibly as required
- The entitlements must be accompanied by comprehensive and best practice guidance on flexible work arrangements for staff with carer responsibilities, with a focus on carer identification, recognition, and support
- The Australian Government must investigate and implement the proposals suggested in the Caring Costs Us Report
- The Australian Government must support suitable and sustainable national options to support carers or former carers into training pathways for re-entering the workforce
- There must be improved levels of access to support across all areas such as disability, aged care, mental health, palliative care services and access to GPs, specialists and allied health support. This will require a coordinated, whole of government approach

Implementing these recommendations will not only support Australians who need additional support, but it will also align with national and state-based carer recognition legislation and strategies, by improving the economic security, employment, social and wellbeing outcomes for carers.

²² https://www.carersaustralia.com.au/wp-content/uploads/2021/10/211011_Carer-Wellbeing-Survey-Executive-Summary_FINAL.pdf

²³ https://www.carersnsw.org.au/uploads/main/Files/5.About-us/Our-research/Summary_Report_HighRes.pdf
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3.4 Adequacy of current work/care supports, systems, legislation and relevant policies

Despite the NES already including some provisions to support working carers, not all workplaces are educated or supportive of these standards.

The following case study is an account of a recent experience faced by a Tasmanian carer who tried to access flexibility under the current NES standards but faced barriers. By the time she had sought support, it was too late. More education, flexibility, and supports are required to enable working carers to successfully and safely manage both priorities.

Case study: *Charlotte *name has been changed to protect privacy*

29/08/22: *Charlotte works for a government organisation and has done for the last 6.5 years. She is aged 62 and cares for her husband Bill who is aged 64. Bill has Dementia, is insulin-dependent, has diabetes, is non-verbal, and has low mobility and vision. He is supported by the NDIS with 2:1 worker ratio, but Charlotte coordinates the support workers to ensure they are providing the right care and monitoring of his health.*

Charlotte was forced to work from home during the pandemic period and recently requested flexible working arrangements with a mixture of some in-office and some working from home hours to assist her in being close to her husband and monitoring his support workers. Charlotte's role is not face-to-face and can be completed effectively via phone, email, and online platforms. She worked like this successfully during the pandemic.

Her request for flexible working arrangements was refused. Charlotte said her employer is not open to any negotiation and she was told she is either in the office or not working at all. Her Father passed away last month, and she took some leave for that. Her husband recently was admitted to hospital due to pneumonia and sepsis. She accompanied him in the ambulance and whilst he was in the hospital, she completed personal care tasks and fed him to keep his blood sugar levels stable. She also advocated for support from medical staff as they were run off their feet.

Upon returning home, Charlotte was told that she needed to come into the office or would be forced to take leave. Charlotte took forced annual leave whilst waiting for advice from her union representative and Fair Work. She didn't want to use this leave as she wanted to keep it for when it is needed as Bill's condition is unpredictable. Charlotte's employer/manager did not provide her anything in writing requesting her to take annual leave until she complies to return to the office.

Charlotte also had a meeting via teams with a supervisor who told her that perhaps she should consider resigning and 'just be a carer'. Charlotte said she feels like she is being discriminated against for trying to manage care and employment and that possibly they are trying to force her to retire.

Charlotte said this is very upsetting and feels conflicted and unsupported. She also reported feeling degraded by being called 'just a carer'. She has also received comments from another colleague in the past that her husband should just go into a nursing home.

Charlotte's husband has severe and complex needs, and their goal is to keep him at home for as long as possible. Charlotte was upset and exhausted but said she will fight this with support from her union and Fair Work.

09/09/22: *Charlotte sought advice from the Community and Public Sector Union (CPSU). They have agreed that this is a discrimination case, and the lawyer has requested a meeting with the employer and Charlotte. The first meeting did not go ahead due to technical difficulties on the employer's end but a new meeting was scheduled for the 14th of September.*

Charlotte said she is permitted to work from home until then. However, her husband is now in the hospital again and she is too upset to inform her employer.

15/09/22: *Charlotte requested a phone call to check how the meeting with the lawyer and her employer went. Carers Tasmania phoned Charlotte as discussed and was informed that her husband had just died.*

She was too scared to tell her employer about what had happened and was seeking support from her union to do this. Charlotte said these last few months could have been different if she was adequately supported to work at home whilst being close to her husband in the final stages of life. It has been a nightmare and emotional roller coaster for her. She does not want anyone else to experience this sort of situation.

Some may argue that carers shouldn't need to take much leave from employment because there are other formal supports available such as NDIS, Carer Gateway, My Aged Care, and mental health supports, etc. However, these supports are often inflexible and do not adequately meet the large variety and complexity of care needs.

There are often tasks that can be difficult to obtain through a service, such as:

- Support with cognitive tasks
- Companionship and emotional support (sometimes multiple times a day or during odd hours)
- Regular monitoring of psychological and physical health
- Support or management of administrative tasks including reading, writing, and legal matters
- Assistance to access services and navigate service systems (researching, calling on behalf of, interpreting information)
- Coordinating formal care services (initially and ongoing)
- Informal advocacy and when required, sourcing and working with formal advocacy
- Prompting and reminding of personal care tasks/ or any other task
- Social or recreational support
- Booking and taking to appointments, such as hairdresser, clothing, shopping, dentist, GP
- Liaising with health professionals
- Financial support and assistance with budgeting and/or bill paying

Data from the 2018 SDAC²⁴, shows that over half of all primary carers said they assisted or supervised the main person they cared for with the following core activities:

- Mobility tasks (74.0%)
- Self-care (56.5%)

²⁴ <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#carers>

- Communication (54.1%)

In addition, the findings indicated that for people aged over 65 and requiring support, 1.8% received only formal care, 36.6% only informal care and 62.5% received both formal and informal care.

It is significant to highlight that a person moving into residential aged care does not always define the end of a caring role. In fact, carers often continue to provide a range of assistance to their family members or friends living in residential care, and usually the tasks are the same as the informal supports often provided in the home.

For older Australians to access in home support or be deemed eligible for residential respite, they first require assessment either by the Regional Assessment team (RAS) for low levels of support or the Aged Care Assessment team (ACAT) for home care packages and/or residential respite. Quite notably, a report from the Australian Institute of Health and Welfare²⁵ found that in 2019-2020, hospitalisation was the trigger for 46,459 home support (RAS) assessments and 65,096 (ACAT) comprehensive assessments. This reinforces the point that caring roles often commence unexpectedly.

It is significant to highlight that the major difference between informal and formal supports is that workers providing formal supports are legally provided with entitlements such as pay, breaks, days off, mandatory levels of training, support from staff and sometimes employee assistance programs. Informal carers, on the other hand, do not receive any of this, rather they struggle through to their own detriment and take portions of support where they are available. Working carers often juggle their employment with the responsibilities of caring and therefore put their own wellbeing at risk.

Often, carers are informal advocates or case managers who play a huge role in connecting their loved ones with formal supports. Carers are often involved in providing informal support in the first instance, many people experience difficulties or go without formal support due to barriers such as:

- Digital exclusion due to lack of skills or technology
- Low literacy levels
- Lack of awareness or information about what is available and how to access support
- Cultural barriers
- Planning is not person-centred
- Time-based pressures to accept offers of support
- Lack of transport support
- Lack of financial support
- Lack of practical supports, eg assisting to get dressed to travel to the GP to discuss health and support needs

Despite supports that are available through initiatives such as the NDIS, Commonwealth Home Support Program, Home Care Packages, Residential Respite, Home and Community

²⁵ <https://www.aihw.gov.au/getmedia/ef5c05ee-1e4a-4b72-a2cd-184c2ea5516e/aihw-aus-236.pdf.aspx>
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Care, Mental Health Services and Alcohol and Other Drug Services, there are often barriers to accessing support or the right types of support.

Some of the common barriers include:

- Shortage of adequately trained staff
- Shortage of culturally appropriate care, or reluctance to use formal support due to cultural reasons
- Denial of the need for support (from carer or care recipient)
- Lack of diversity awareness (on both sides)
- Limited supports available in the required location (especially in rural or remote areas)
- Costs of support depending on assets and financial situation
- High turnover or frequently changing staff
- The widespread issue of homelessness, particularly in Tasmania – eg the person needing care might not have a house or fixed address
- Shortage of funding for palliative care services/ or limited services available
- Not enough supports available when required
- High care needs and might not want residential respite or permanent placement
- The person requiring support may be a heavy smoker and unwilling to stop around support workers
- Time available for support might not align with needs
- Limitations around the types of practical tasks that are able to be completed
- Safety limitations for workers in houses where hoarding and/or squalor is present
- Some people do not meet eligibility for service

Some older Australians choose to live at home with support instead of entering residential aged care, even when they are approved for this service. Residential aged care is sometimes only considered as a last resort, or not at all.²⁶ When this is the case, these choices should be respected and supported.

After first being assessed by My Aged Care, there is often confusion about what all the support levels mean and what steps are required next. Furthermore, there are often long wait times before actually receiving the levels of care that a person has been deemed eligible for.

The Home Care Packages Program Data Report for the period of 1 October to 31 December 2021²⁷ reports that in Tasmania 757 home care packages were approved in this quarter, compared with the national number of 32,853. For the same period, in Tasmania, there were 4,595 people who had a home care package and the total national number of people with a

²⁶ Orthia L., Hosking D. and McCallum J. (2022) [“As close to home as possible”: Older Australians’ hopes and fears for aged care](#). Canberra: National Seniors Australia.

²⁷ https://gen-agedcaredata.gov.au/www_ahwgen/media/Home_care_report/Home-Care-Data-Report-2nd-Qtr-2021-22.pdf

home care package was 198,109. The following table represents both the Tasmanian and national numbers of home care package recipients for the quarter 1 October 2021 – 31 December 2021.

	Tasmania	Australia total
Level 1	318	16,648
Level 2	1,805	79,909
Level 3	1,502	56,713
Level 4	971	44,839

Table 1: Number of home care package recipients

The results also revealed that in the same quarter, there were only 911 approved home care providers nationally, and this number had decreased by 1.8% since the same quarter in the previous year.

At 31 December 2021, there were 68,429 people nationally seeking a home care package at their approved level, with 44,650 of these people not being offered an interim level home care package. This speaks volumes about the number of carers who would have needed to provide support in these instances. In Tasmania, the number of people waiting for adequate support in this situation was 1,267.²⁸

Since the COVID pandemic, carers in Tasmania have faced significant difficulty with aged care facility lockdowns, restrictions around availability for respite, shortages in accessing support workers, and inappropriate hospital discharge due to bed shortages and poor discharge planning.

In addition to people who may be eligible for aged care supports, the 2018 SDAC found that 26.8% (140,100) of people in Tasmania have disability²⁹ and as of 30 June 2022, there were only 12,104 people utilising the NDIS. Whilst the aim of the NDIS is to provide support to people with significant and lifelong disability, there are many people who for various reasons are not eligible for this service. For example, it can be difficult to obtain the correct diagnostic reports, or some people who do require support from their family member or friend deny that they would fit a particular diagnosis and believe they don't need support. This is particularly common when supporting someone with mental ill health, meaning that it is likely that the carer is their only constant support.

²⁸ Ibid.

²⁹ [Disability, Ageing and Carers, Australia: Summary of Findings, 2018 | Australian Bureau of Statistics \(abs.gov.au\)](https://abs.gov.au)

There are high rates of chronic illness present in Tasmania in comparison to the rest of Australia. The prevalence of certain conditions both on a Tasmanian and national level are represented in the table below based off data from the 2021 ABS Census data.^{30, 31}

	Tasmania	Australia total
Arthritis	12%	9%
Asthma	9%	8%
Cancer	4%	3%
Dementia	1%	1%
Diabetes	5%	5%
Heart Disease	5%	5%
Kidney Disease	1%	1%
Lung Condition	3%	2%
Mental ill Health	12%	10%
Stroke	1%	1%

Table 2: Long-term health conditions

The Census data also illustrated high rates of mental ill health, nationally and even more so in Tasmania. Whilst some people with a diagnosed psychosocial disability may be able to access services under the NDIS, or through state-wide mental health services, many people do not and fall through the cracks leaving carers left to pick up the pieces.

On a national level, the Carer Wellbeing Survey³² asked carers to describe the challenges they experienced in accessing services for the person they cared for. Frequently reported issues included:

- Challenges in finding out about available support services
- Long wait times to access services
- Lack of availability of services in their local area
- Services being reduced or changed when the person they cared for shifted to NDIS
- Lack of skilled and experienced staff providing services
- Difficulties in accessing funding to enable them access to services.
- Complex and confusing processes for accessing support

Carers Tasmania recommends that the Australian Government continues to invest and improve the supports available through these services, in addition to carer friendly workplace initiatives.

³⁰ <https://www.abs.gov.au/statistics/detailed-methodology-information/information-papers/comparing-abs-long-term-health-conditions-data-sources>

³¹ <https://www.abs.gov.au/census/find-census-data/quickstats/2021/6>

³² https://www.carersaustralia.com.au/wp-content/uploads/2021/10/211011_Carer-Wellbeing-Survey-Executive-Summary_FINAL.pdf

3.5 Hours and conditions, job security, flexibility and workplace arrangements

Employment outcomes for carers are poor, with the SDAC 2018 reporting that carers were less likely to be employed (66.6%) compared with people who are not carers.³³

For the carers who are employed, they face other difficulties such as insecurity of stable employment, income and superannuation, additional physical and mental wellbeing stressors, lack of time for self, lack of sleep, work-related pressures that result from taking time off, stigma and judgement or the feelings of stigma and judgement from taking time off, and less opportunity for promotion.

Carers often take up part-time, casual or temporary employment in order to try and balance working and caring. In our recent caring and employment survey (not yet published), we asked the question *“What entitlements/flexibilities does/or did your employer provide to help you balance working and caring?”*, and the following are some of the responses that were provided:

- *“3 days carers leave”*
- *“10 days carers leave/yr”*
- *“Used my own personal leave for times when not able to work due to person’s health issues”*
- *“Allowed to work from home for a few months then initially withdrew it with no notice, despite no-one notifying of any issues”*
- *“I didn’t get flexible time”*
- *“As a Temp worker at an employment agency I am able to pretty much pick my times”*
- *“Being casual I can choose”*
- *“Currently on carers leave coming out of my sick leave bank”*
- *“None at the time”*
- *“Work part-time. Work from home. Flexible hours”*
- *“None, I am in debt due to my incomings not matching my outgoings!”*
- *“Currently working from home, but needed to temporarily accept a lower paid role to do this”*

3.6 Impact and lessons arising from the COVID-19 crisis

Carers Tasmania conducted an online survey³⁴ in early 2022 to explore the effects of COVID-19 on Tasmanian carers. This survey was conducted soon after the Tasmanian borders opened to visitors following almost two years of restrictions. Caution must be taken when interpreting these results as this survey is not representative of the full population of Tasmanian carers. Of the 323 respondents, 75.8% indicated that they had not had the option

³³ [Disability, Ageing and Carers, Australia: Summary of Findings, 2018 | Australian Bureau of Statistics \(abs.gov.au\)](https://www.abs.gov.au/Disability%2C%20Ageing%20and%20Carers%20Australia%3A%20Summary%20of%20Findings%2C%202018%20%7C%20Australian%20Bureau%20of%20Statistics)

³⁴ <https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-COVID-Impact-Survey-2022-Report-.pdf>

or ability to work from home throughout the pandemic. 12.2% of carers indicated that they had reduced their employment hours to provide extra support in the caring role and 10% said they would like to reduce their work hours to provide more care but couldn't afford to.

Furthermore, the survey³⁵ found that 25.5% of respondents indicated that they didn't think anyone else could provide the level of care that they do and 13% reported that the level of care required is complex and they didn't feel confident in allowing someone else to step in. Alarming, 50% of respondents reported that there is nobody else who can step in for them.

4. Any related matters

4.1 The replacement cost of caring and financial impacts on carers

In a report by Deloitte Access Economics: 'The Value of Informal Care in 2020', it was found that informal care in Australia was valued at \$77.9 billion in 2020.³⁶ To further expand on these findings, The Carers Australia Network commissioned an additional study by the company Evaluate, the 'Caring Costs Us' report³⁷ which explored the cost of all informal care in Australia. Findings showed that on average, carers in Australia will lose \$392,500 in lifetime earnings up to the age of 67 and \$175,000 in superannuation at the age of 67. Some carers will also lose substantially more depending on the duration of time they spend in a caring role and the age that they first become a carer. The study also found the Carer Payment to be significantly lower than most weekly earnings for singles and couples in Australia and that the value of the Carer Allowance has significantly decreased since it was first introduced.

This study provides a framework that can be used to explore different caring scenarios, including age, duration of the caring role, and gender. Caring has traditionally been a female-dominated role, with higher rates of females providing informal care as opposed to males. As a result, it is a common occurrence for females to take up part-time employment or forms of employment that may be below their skill level to combine unpaid care and paid work.³⁸ There are a disproportionate number of female carers with negative flow-on effects to the superannuation of female carers. Recently, Women in Super launched a policy framework calling for the implementation of carer credits on superannuation, to assist with addressing inequalities in Australian superannuation.³⁹

Females are already financially disadvantaged compared to men with the gender pay gap and superannuation loss due to childbearing duties. Taking up the role of an unpaid carer adds additional layers of disadvantage. Research has found that the time spent in unpaid care work can negatively affect a person's ability to participate fully in paid employment and that gender inequalities in unpaid care work translate to inequalities in female and male labour force participation.⁴⁰

³⁵ Ibid.

³⁶ <https://www2.deloitte.com/au/en/pages/economics/articles/value-of-informal-care-2020.html>

³⁷ <https://www.carersaustralia.com.au/wp-content/uploads/2022/04/Final-Economic-impact-income-and-retirement-Evaluate-Report-March-2022.pdf>

³⁸ Hegewisch, A. & J. C. Gornick (2011). The impact of work-family policies on women's employment: a review of research from OECD countries. *Community, Work & Family*, 14(2), 119-138.

³⁹ <https://www.wgea.gov.au/sites/default/files/documents/australian-unpaid-care-work-and-the-labour-market.pdf>

⁴⁰ Ferrant, G., Pesando, L.M. & K. Nowacka (2014). Unpaid Care Work: The missing link in the analysis of gender gaps in labour outcomes. OECD Development Centre, viewed 09 August 2016, https://www.oecd.org/dev/development-gender/Unpaid_care_work.pdf

The following is a quote from a Tasmanian carer who participated in the National Carer Survey.⁴¹

- *“Once my daughter moved into her home for over 63 days a year, I lost all carers payments/allowances. I care for her directly most weekends, also get called on in emergencies regularly by carers. Carers payment/allowance has been my only contribution to family finances for many years and when it stopped I was very depressed as I felt I was nothing. It felt like the government did not recognise the many hours of care I still put in and I felt like the high intensity care I still provide isn't important, and still feel the government regards me as useless.”*

4.2 Examples of best practice programs

The Tasmania State Service (TSS) prides itself on promoting carer friendly workplaces and has developed a 'Carer Toolkit'⁴² aiming to support carers who are employees of the service. Many other Tasmanian and national workplaces have Employee Assistance Programs available, but often people don't know or understand what this is for, that it's available or how to access this support.

The New South Wales Carers and Employers program⁴³ is the first initiative in Australia to provide formal accreditation of carer friendly workplaces and this is an example of an initiative that could be supported to be implemented nationally.

Employed carers must be supported to remain in the workforce. To understand what supports will make the biggest difference to working carers, we recommend direct consultation with carers. The following is just a snapshot of comments from Tasmanian carers on what they believe is required to support carers to remain in employment:

- *“Empathy for the experience people have outside of the workplace, with clarity for how the employer can/will support their staff. I think when this is explicit and upfront, and referred to often it creates a culture that taking carers leave is as acceptable as taking annual leave so people feel less burdensome taking last minute, unplanned carers leave”*
- *“More flexibility, more carers leave – paid”*
- *“For myself, I need to be able to work from home so that I am there to monitor the person I care for and help if needed. I need the opportunity to accrue flextime (TOIL) to cover 'bad' mornings or doctor's appointments. I need understanding and the flexibility to be put into a role where I can be 'late' to work and allowed to make up the time at the end of the day. I need to feel as if I'm trusted, not as if I'm being monitored.”*
- *“Better income support for leave periods.”*
- *“Good quality and affordable home support and aged care facilities”*

⁴¹ https://www.carerstas.org/wp-content/uploads/2017/06/FINAL-CTAS-National-Carer-Survey-Report-3_compressed.pdf

⁴²

https://www.dpac.tas.gov.au/divisions/ssmo/workforce_diversity_and_inclusion/supporting_carers_in_the_state_service/supporting_carers_in_the_state_service

⁴³ <https://www.carersnsw.org.au/services-and-support/programs-services/carers-employers>

- *“More readily available in home support, easily accessible and free therapy(s) for carers as needed, MORE RESPITE HOURS PER ANNUM, employer training in the role requirements of a carer and clear understanding of the toll it can take on that person. more flexibility with shift times, latitude with needing to leave work at short notice and also with working from home at short notice.”*
- *“I would love to know that I could access more sick leave instead of having to use holidays or make up time. Being worried about having to take time off for COVID-19 has been a big stressor.”*
- *“Understanding and support and not having to disclose the condition of the person you are caring for as with mental illness the judgement is ridiculous.”*
- *“Additional leave entitlements. Should never have to choose between paying the bills or caring for your child.”*

** Quotes from the Tasmanian Employment and Caring Survey 2022 – not yet published*

6.4 Additional ways to support carers

We encourage the Government to implement the recommendations of the Caring Costs Us Report which proposes increases to the carer allowance rate and the introduction of a superannuation guarantee on top of the carer payment.

In addition to increased financial support for carers, training for carers or past carers to re-enter the workforce must be provided. Many people who leave the workforce due to their caring role find that their job skills and knowledge become outdated, and therefore require training or additional qualifications to re-enter the workforce. There are various initiatives between Australian states, but a national commitment is essential to ensure equal access to all carers or past carers trying to re-enter the workplace.

Carers Tasmania would be supportive of amendments to the NES entitlements if they include the legislated right of carers to return to work after taking a period of unpaid leave (determined by their contact duration), which would be similar to the right to return to work after taking parental leave. This would provide carers with assurance that their job would be safe upon return.

National and local Governments have an opportunity to lead the way in following and adhering to carer recognition legislations, reinforcing that carers must be respected, valued, and supported to provide care no matter what their circumstances. A carer should not be disadvantaged if they leave the workforce to provide care, rather they should be supported to do so financially and supported to return to work (if they wish) when ready.

This would set the standard for all employers, managers, and staff to better understand and abide by the legislation and to model and encourage carer friendly workplaces. Key rights protected under international human rights law are “The right to just and favourable conditions of work, including equal pay and conditions for equal work, safe and healthy work conditions, and equal opportunities for promotion in the workplace.”⁴⁴ Further support and awareness raising of the aforementioned Carers and Employers Program⁴⁵ would be a great investment to support more carer friendly workplaces.

⁴⁴ <https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-civil-and-political-rights>

⁴⁵ <https://www.carersnsw.org.au/services-and-support/programs-services/carers-employers>

Initiatives that aim to support carers or former carers back into the workforce should be supported to continue as these programs can provide invaluable support such as planning, goal setting, confidence building and access to training and employment pathways.

In addition, access and availability of other supports must be improved so that more people can access the practical, emotional, and health supports they need, when they need it. This will require a whole of government approach across all areas of health and aged care, disability, education, and community services.