



**Submission on the
Australian Government Productivity Commission
Carer Leave Issues Paper**

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 Productivity Commission's Inquiry into Carer leave, specifically the Carer leave Issues paper¹. We acknowledge that the issues paper seeks to explore a variety of questions to inform the Productivity Commission's understanding of the potential effects of amending the National Employment Standards (NES). Our submission addresses some of the questions identified in the issues paper, both nationally and through the lens of the Tasmanian carer experience. We confirm our support and collectively advocate for the main points proposed in the Carers Australia Network submission on the same paper.

To inform our response, we have drawn on evidence collected from various national and Tasmanian carer surveys, as well as from relevant and well-established data sources.

Whilst being cognisant of the fact that this inquiry is a direct result of the Aged Care Royal Commission,² specifically recommendation 43, and we applaud progress on this important topic, we strongly propose that any additional leave entitlements are to be introduced for all carers, regardless of the age and care needs of the person for whom they care. A broader entitlement must be in alignment with the carer definitions in state and territory carer recognition legislation. Accordingly, our responses are not specific to only carers of older Australians, rather they include information relevant to carers supporting people of all ages and support needs.

Implementing entitlements for carers supporting someone of a certain age and excluding others could be seen as discriminatory, as age does not necessarily define care needs. In the *Tasmanian Anti-Discrimination Act 1998*, discrimination is defined as "when a person is treated less favourably than other people due to a particular characteristic, such as age, race, sex, or disability."³

We are supportive of the introduction of additional entitlements which may improve the capacity of carers to obtain and/or remain in employment and therefore provide an opportunity for increased financial stability, social connection, and a sense of satisfaction with employment. Supporting carers to remain employed will have a positive effect on the broader economy, particularly within the context of the current and foreseeable labour market.

We firmly believe that carer leave entitlements should incorporate a mixture of both shorter-term paid leave and longer unpaid leave options to meet the variety of caring circumstances. We also urge the Federal Government to consider other additional changes such as the introduction of a superannuation guarantee for carers in receipt of the carer payment and an increase to the carer payment and allowance. In addition, a whole of government approach is also required to address the widespread issues of service gaps and long wait lists to access health services and practical supports.

¹ <https://www.pc.gov.au/inquiries/current/carer-leave/issues/carer-leave-issues.pdf>

² <https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-recommendations.pdf>

³ <https://www.legislation.tas.gov.au/view/whole/html/inforce/current/act-1998-046>

3. Tasmanian statistics

The 2021 Census⁴ 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%).⁵ As of June 2022, there were an estimated 263,700 people employed in Tasmania.⁶ The most current ABS census 2021 release does not provide employment statistics; however, the ABS states that this data will be available in the October 2022 release.

The ABS 2015 Survey of Disability, Ageing and Carers (SDAC)⁷ remains informative with respect to carers and work, as noted in the Tasmanian Carer Policy.⁸ The SDAC data⁹ noted that 70% of female carers changed their working arrangements or jobs to fulfill caring responsibilities and women are more likely to give up employment compared with men who will change from full-time to part-time jobs. The labour force participation rate is 6% lower than workers without caring roles and Tasmanian carers earn less per week than non-carers. It was also the case that carers are less likely to be employed than those without caring responsibilities. Starkly, the survey identified that 56% of primary carers are in the lowest two quintiles of household income versus 34% for non-carers. As 74% of carers are women, the issue of carers and employment and associated conditions is prominently genderised.

Whilst it has not been possible to provide statistical insights into the total number of employed people living in Tasmania who are carers, data from 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 prior, 9.34% of staff accessed paid carers leave. However, this figure does not clearly represent the total number of carers in the TSS, as some employees who were carers possibly worked without taking leave and others may have utilised sick leave or flexible working arrangements.¹⁰ In other words, many carers have remained hidden.

Being a carer often necessitates changes to employment conditions. The 2020 National Carer Survey¹¹ found that across Australia, ceasing employment and reducing working hours were common occurrences for carers. Furthermore, out of 1,024 respondents from the 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. In addition,

⁴ <https://www.abs.gov.au/articles/snapshot-tas-2021#:~:text=In%20the%202021%20Census%2C%20the,the%20Census%20counted%20372%2C000%20people>.

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

⁶ <https://www.treasury.tas.gov.au/Documents/Labour-Force.pdf>

⁷ <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-first-results/latest-release>

⁸ https://www.communities.tas.gov.au/__data/assets/pdf_file/0023/173480/Supporting-our-Carers-Action-Plan-2021-24_-JULY-2021.pdf

⁹ Ibid.

¹⁰

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

¹¹ https://www.carersnsw.org.au/uploads/main/Files/5.About-us/Our-research/Summary_Report_HighRes.pdf
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of the employed carers, regardless of gender, 64 reported that they were caring for someone aged 65 or older.

The survey also found that in Tasmania, the average number of years spent in a caring role was 12.6 years, with an average of 80 hours spent caring per week.¹² Another key finding¹³ was that the most common group of people being cared for were people with physical disability, followed by people with a chronic condition and people who were frail or aged.

Tasmanian data from the National Carer survey¹⁴ also found that over 60% of carers 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 then asked about the impact of their work on their caring role, with 46% of carers reporting 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 that they were required to spend caring and 32.5% indicated that their caring responsibilities impacted their capacity to concentrate in their jobs.

With regards to the impact that their caring role had on their employment, some carers reported having to quit work or reduce 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.¹⁵

Carers Tasmania conducted an online survey¹⁶ 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 after 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 did not have the option 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.

The Carers Tasmania Covid Impact Survey¹⁷ 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.

¹² https://www.carerstas.org/wp-content/uploads/2017/06/FINAL-CTAS-National-Carer-Survey-Report-3_compressed.pdf

¹³ Ibid.

¹⁴ Ibid.

¹⁵ Ibid.

¹⁶ <https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-COVID-Impact-Survey-2022-Report-.pdf>

¹⁷ Ibid.

4. National statistics

The 2018 Survey of Disability, Ageing and Carers (SDAC)¹⁸ found that for carers aged between 15 and 64 years:

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

Of primary carers of working age (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 more than 40 hours of care a week to their main recipient were employed
- In comparison, over half (52.8%) of those caring for the main recipient for less than 20 hours a week were employed

Data from the Workplace Gender Equality Agency (WGEA) shows that females regularly choose part-time employment or other employment options which may be below their skill level to enable them to manage their caring role whilst employed.¹⁹ Furthermore, WGEA data found that the gender pay gap is greater in part-time roles as opposed to full-time roles and that consequentially superannuation payments are lower for those in part-time employment.²⁰

The 2018 SDAC²¹ found that the most common reason primary carers provided for taking on a caring role was a sense of family responsibility (70.1% of all primary carers) and that almost half of employed parent primary carers (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 Survey²² had 7,735 respondents who identified as carers living in Australia. The most common group of people being cared for were people with physical disability, followed by people with a chronic condition and people living with a 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 typical carer worked 27 hours per week in a permanent position
- 50% had used flexible start and finish times
- 44% had used carers leave in the form of paid personal/carers leave
- 15% had taken unpaid leave and
- 16% had taken paid carers leave

The most common impact of caring on employment, as reported by 27.5% of the national respondents, was resignation from employment due to requirements of the caring role. Combined with retiring early to continue caring, 44.5% of carers reported leaving the

¹⁸ <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>

¹⁹ <https://www.wgea.gov.au/sites/default/files/documents/australian-unpaid-care-work-and-the-labour-market.pdf>

²⁰ Ibid.

²¹ Ibid.

²² https://www.carersnsw.org.au/uploads/main/Files/5.About-us/Our-research/Summary_Report_HighRes.pdf
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workforce due to their caring responsibilities. The second most common impact for 27.4% of respondents was reducing working hours, followed by not being able to keep skills/qualifications up to date, which was reported by 17.4% of working carers.

The demands that caring responsibilities place on carers' time was also found to be a significant barrier to finding work. Roughly half of 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 Caring for Others and Yourself - Carer Wellbeing survey 2021²³ reports findings from 5,800 carers across Australia during April and May 2021 and found that:

- Carers are 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 participate in paid employment if they were younger and had fewer caring obligations
- They were less likely to be employed if they were older or had high caring obligations
- The longer a person remains in a caring role, the less likely they are to be employed
- Only 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 as of 31 December 2020,²⁴ found that education was the most reported employment industry for working families/carers of NDIS participants (across all age groups) and was followed by the health industry. Care work, aged care, and retail were other prevalent industries of employment.

In terms of the labour market funnel, young carers experience barriers to employment and/or to well-paid employment, as a result of their caring roles. Research indicates that school age carers are being left behind at alarming rates compared with students without caring responsibilities. Findings show that by year nine, boys who spent two or more hours per day caring were the equivalent of 1.9 years behind their peers in NAPLAN reading and girls caring for two hours or more per day were 1.6 years behind in NAPLAN reading. Both boys and girls in Year 9 providing care for two or more hours per day were approximately fifteen months behind their peers in NAPLAN numeracy.²⁵ Young carers are less likely to complete Year 12 and have lower labour force participation. In Tasmania, VET in Schools is significantly under-developed and options open to young carers in other states and territories

²³ https://www.carersaustralia.com.au/wp-content/uploads/2021/10/211011_Carer-Wellbeing-Survey-Executive-Summary_FINAL.pdf

²⁴ file:///C:/Users/JulieRyan/Care2Serve%E2%80%9393/Downloads/PB%20Family-Carers%20Employment%20Outcomes%20Report%20PDF.pdf

²⁵ 4 Australian Institute of Family Studies (2017) Longitudinal Study of Australian Children 2016 Annual Statistical Report Young Carers

to pursue non-academic qualifications remain largely closed to them, despite many in-demand apprenticeship areas experiencing uptake shortages.

5. Response to Carer Leave Issues Paper questions

5.1 To what extent do informal carers perform similar or different roles to formal support workers and care provided in residential aged 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 can sometimes be offered 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

There are often additional tasks that are sometimes 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 SDAC²⁶, 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%)
- Communication (54.1%)

In addition, the findings showed that of those who were aged over 65 and required support, 1.8% received only formal care, 36.6% only informal care and 62.5% received both formal and informal care.

In terms of the specific mobility activities for which primary carers provided help:

- Two-thirds (65.6%) helped the person they care for to move around when they were away from home
- 28.7% of carers supported the person they care for to get in or out of a bed or chair

Amongst primary carers who assisted with self-care activities:

- 41.5% assisted with dressing
- 35.8% assisted with bathing and showering
- Approximately one in five (18.7%) supported with toileting activities

It is significant to highlight that just because a person moves into residential aged care, the caring role does not cease. In fact, carers often continue to provide a range of supports to their family members or friends living in residential care and often the tasks are the same as the informal supports provided in home. In part, this reflects the poor state of residential care highlighted by the Royal Commission that informal care seeks to address and bridge the gap.

For older Australians to access in-home support or be 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 Welfare²⁷ found that in 2019-2020, hospitalisation was the trigger for 46,459 home support (RAS) assessments and 65,096 (ACAT) comprehensive assessments. This underscores the point that caring often begins 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.

²⁶ <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#carers>

²⁷ <https://www.aihw.gov.au/getmedia/ef5c05ee-1e4a-4b72-a2cd-184c2ea5516e/aihw-aus-236.pdf.aspx>
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5.2 What formal services might be difficult to access without informal support?

Often, carers are informal advocates or case managers who play a huge role in connecting their loved ones with formal supports. Without carers providing informal support in the first instance, many people would 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
- Lack of practical supports, eg assisting to get dressed to travel to the GP to discuss health and support needs
- Planning is not person-centred
- Lack of transport support
- Time-based pressures to accept offers of support
- Lack of financial support

5.3 Reasons why services may not be adequate

Despite valuable supports which are available through such initiatives as Carer Gateway, the NDIS, Commonwealth Home Support Program, Home Care Packages, Residential Respite, Home and Community 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 carers or care recipients)
- Lack of diversity awareness
- 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, but not wanting 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 the service. Residential aged care is

sometimes only considered as a last resort, or not at all.²⁸ If this is the case, these choices must be respected.

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. Often by the time they do, the level of care is higher and the approved supports no longer match the need.

The Home Care Packages Program Data Report for the period of 1 October to 31 December 2021²⁹ shows that in Tasmania there were 757 home care package approvals 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 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, in which the number had decreased by 1.8% since the same quarter in the previous year.

Nationally, as at 31 December 2021, there were 68,429 people seeking a home care package at their approved level, with 44,650 of these people not being offered an interim level home care package. In Tasmania, the number of people waiting for adequate support was 1,267.³⁰ This starkly demonstrates the number of carers who would have provided support and the ongoing levels of hidden informal care.

Since the COVID pandemic, carers in Tasmania have encountered significant difficulty with aged care facility lockdowns, restrictions around availability for respite, and at times, shortages in accessing support workers.

In addition to the challenges sometimes experienced in caring for older people, there are also difficulties faced in accessing support for people with other health needs. The 2018 SDAC found that 26.8% (140,100) of people in Tasmania have disability³¹ and as of 30 June 2022, there were only 12,104 people utilising the NDIS. Whilst the aim of the NDIS is to provide supports to people with significant and lifelong disability, there are many people who are not eligible for the Scheme or are unable to meet the burden of evidence required for entry. For example, it can be difficult to obtain the correct reports outlining eligible diagnosis, or some people who do require support from their family member or friend deny that they

²⁸ 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.

²⁹ https://gen-agedcaredata.gov.au/www_aihngen/media/Home_care_report/Home-Care-Data-Report-2nd-Qtr-2021-22.pdf

³⁰ Ibid.

³¹ [Disability, Ageing and Carers, Australia: Summary of Findings, 2018 | Australian Bureau of Statistics \(abs.gov.au\)](#)

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.

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.^{32, 33}

	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 supports under the NDIS, or others 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 Survey³⁴ 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

5.4 The impact of caring on wellbeing

Caring has significant impacts on wellbeing. This was explored in the National Carer survey,³⁵ with psychological distress measured using the Kessler 5-Item Scale of Psychological Distress (K5). This scale indicates low to moderate, or high to very high levels of psychological distress. Nearly half of the survey respondents (47.7%) reported high or very high psychological distress.

³² <https://www.abs.gov.au/statistics/detailed-methodology-information/information-papers/comparing-abs-long-term-health-conditions-data-sources>

³³ <https://www.abs.gov.au/census/find-census-data/quickstats/2021/6>

³⁴ https://www.carersaustralia.com.au/wp-content/uploads/2021/10/211011_Carer-Wellbeing-Survey-Executive-Summary_FINAL.pdf

³⁵ https://www.carersnsw.org.au/uploads/main/Files/5.About-us/Our-research/Summary_Report_HighRes.pdf
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The survey also aimed to measure carer wellbeing using the Personal Wellbeing Index³⁶ and measured satisfaction with life 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, with the greatest difference to the general population found in the domain of satisfaction with personal relationships. Overall, respondents' satisfaction with life was 18.2 percentage points lower than 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. From the Tasmanian response to the National Carer Survey,³⁷ nearly half of the carers who responded were experiencing moderate to high levels of distress, and 81% were feeling some degree of isolation.

The 2021 Carer Wellbeing Survey³⁸ 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, low wellbeing was more common amongst carers supporting person with autism spectrum disorder, other development disorders, mental ill health/psychosocial disability, alcohol or other drug dependence, intellectual disability, if they were Aboriginal or Torres Strait Islander or were caring for a child or grandchild.

The National Carer Survey³⁹ found that carers in the workforce had higher rates of wellbeing (58.5%) compared to carers not in the workforce (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 found to be less socially isolated (53.3%) compared to carers who were not in the workforce (69.2%), which indicates that employment not only provides financial benefits, but also improves social connectedness and may increase wellbeing and reduce psychological stress.

5.6 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 2020.⁴⁰ To build on these findings, The Carers Australia Network commissioned an additional study by the company Evaluate, the 'Caring Costs Us' report⁴¹ which explored the cost of all informal care in Australia.

Key findings of the report include:

- 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 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 Carer Payment is significantly lower than most weekly earnings for singles and couples in Australia and the value of the Carer Allowance has significantly decreased since it was first introduced

³⁶ (PWI, Cummins et al. 2003, IWB 2013)

³⁷ https://www.carerstats.org/wp-content/uploads/2017/06/FINAL-CTAS-National-Carer-Survey-Report-3_compressed.pdf

³⁸ https://www.carersaustralia.com.au/wp-content/uploads/2021/10/211011_Carer-Wellbeing-Survey-Executive-Summary_FINAL.pdf

³⁹ https://www.carersnsw.org.au/uploads/main/Files/5.About-us/Our-research/Summary_Report_HighRes.pdf

⁴⁰ <https://www2.deloitte.com/au/en/pages/economics/articles/value-of-informal-care-2020.html>

⁴¹ <https://www.carersaustralia.com.au/wp-content/uploads/2022/04/Final-Economic-impact-income-and-retirement-Evaluate-Report-March-2022.pdf>

This study provides a framework that can be used to explore different caring scenarios, including age, duration of the caring role, and gender. Caring remains a genderised role, with higher rates of women providing informal care compared with men. As a result, women are significantly more likely to seek part-time or casual employment that may be below their skill level to combine unpaid care and paid work.⁴² There are a disproportionate number of female carers who experience negative flow-on effects for their superannuation. Recently, *Women in Super* launched a policy framework calling for the implementation of carer credits on superannuation, to assist with addressing the inequalities experienced with Australian superannuation.⁴³

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.⁴⁴

The following is a quote from a Tasmanian carer who participated in the National Carer Survey.⁴⁵

- *“There are many carers who dread what will happen to them after the person they care for dies. They are looking at JobSeeker (Newstart) and the financial commitment taken on in consideration of their career - e.g., rent or mortgage - they could lose their home. For many they have lost contact with career/work and are emotionally and physically long-term exhausted.”*

5.7 When is leave likely to be taken or flexible working arrangements used and under what circumstances are the provisions inadequate?

People of all ages and from all different situations may become a carer at any time, even if they did not plan to. A variety of scenarios may occur resulting in the need for carers to take leave from employment. Situations requiring care as individual as people themselves, and the length and types of leave required vary greatly depending on the health of the person, the support they require, how they are functioning, the modes of care required, the frequency of care (ongoing/planned versus episodic) and the consequences of not being supported. Common reasons often requiring increased levels of care include:

- The first health incident or hospital admission, which is usually unexpected. This can sometimes eventuate to needing interim services whilst waiting for a home care package or admission into residential respite
- A fall or several falls
- First transition into residential respite or permanent placement
- A UTI and associated behaviours

⁴² 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.

⁴³ <https://www.wgea.gov.au/sites/default/files/documents/australian-unpaid-care-work-and-the-labour-market.pdf>

⁴⁴ 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

⁴⁵ https://www.carerstas.org/wp-content/uploads/2017/06/FINAL-CTAS-National-Carer-Survey-Report-3_compressed.pdf

- 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 stage of requiring palliative care
- For carers of someone with mental ill health or someone with 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 and symptoms
- Where there is a lack in service or running out of funding (this is common in NDIS)
- During a pandemic or other such events. Tasmania data⁴⁶ showed that 59.5% of carers chose to self-isolate in late 2021 and early 2022 due to the pandemic
- 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

The current entitlements are not adequately meeting the needs of all carers. Flexible work arrangements, such as changed start and finish times, may support carers only needing minimal time off during the day for caring tasks, for example accompanying the person they care for to appointments during normal business hours, but these arrangements are not always suitable.

Working from home may also be an option, and the pandemic saw many workplaces flexibly adapt to successfully working remotely. However, some roles are directly face-to-face with customers, for example retail or hospitality and other essential roles such as healthcare and are not able to be completed effectively or at all from home. If an employee has the equipment and ability to work at home successfully, this option should be considered. However, this option is not always agreed upon by employers.

Taking paid personal/carers leave may result in carers exhausting all of their leave in order to support the person they care for and may go beyond to leave without pay, but when they become unwell themselves, they have no entitlements left to enable rest and recovery. 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 may need to take unpaid leave but be scared to lose their job if they do. Having legislated additional entitlements could reinforce that this is an appropriate option.

⁴⁶ <https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-COVID-Impact-Survey-2022-Report-.pdf>

5.8 Do employers have other policies to support employees who are informal carers? Are there examples of best practice?

The Tasmanian State Service (TSS) promotes itself on being a carer-friendly workplace and has developed a 'Carer Toolkit'⁴⁷ to help support employed carers. In addition, many workplaces have Employee Assistance Programs available, but often people don't know about it or understand the full extent of supports available.

The New South Wales Carers and Employers program⁴⁸ is the first initiative in Australia to provide formal accreditation of carer friendly workplaces and this is a good example of an initiative that could be supported to be implemented nationally. Employed carers must be supported to remain in the workforce and 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"*
- *"Flexible working arrangements"*
- *"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"*
- *"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

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

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

6.1 Entitlements for all carers

Whilst we support this inquiry, Carers Tasmania believe that carers leave should be accessible for all carers no matter what the age or condition is of the person they care for. It would be discriminatory to introduce an entitlement for carers supporting someone of a certain age only.

6.2 Paid and unpaid leave

We recommend for any additional entitlements to include a blend of paid and unpaid care.

We acknowledge that the introduction of additional employment entitlements must be appropriate for both employers and employees. Carers Tasmania believes that any carer who has completed their probation and is a confirmed employee should be eligible for entitlement access, as this entitlement needs to be able to support carers in all circumstances.

We also highlight that many carers are employed casually. Carers Tasmania recommends that casual employees who need to take periods of unpaid carers leave can if they meet the following conditions:

- Have been working for their employer on a regular and basis for at least six months
- Have a reasonable expectation of continuing work with their current employer

We recommend that additional leave entitlements include both paid and unpaid leave. Specifically, we recommend, in line with Carers Australia and as per Recommendation 15a of the Australian Human Rights Commission in 2007, that the personal leave standard in the NES be increased from 10 days to 20 days per annum with the 10 days to be non-cumulative and accessible for paid carers leave.⁴⁹ The Human Rights Commission also suggested Recommendation 15b:

“That the Australian Government consider introducing a new 12-month unpaid Carer’s Leave Standard to be made available to employees who need to attend to the care of a seriously or terminally ill dependent.”⁵⁰

We also suggest that these additional days are paid by the government comparable to the paid parental leave scheme or pandemic payments, and for this to be a non-accruing entitlement. This was envisioned to be similar to the paid parental leave scheme, which has built in flexibility to enable the entitlements to be extended in a range of circumstances that would not be considered the ‘normal’ trajectory and because it can often be unexpected, their employer must be advised as soon as possible, in line with organisational policies.

We feel that these entitlements would take a reasonable and inclusive approach to support carers who require leave in different circumstances.

⁴⁹ Human Rights and Equal Opportunity Commission [It’s About Time: Women, men, work and family Final Paper 2007](#)

⁵⁰ Ibid.

6.3 Proof of caring requirements for accessing leave

We suggest that for carers to be deemed eligible to access additional leave entitlements or flexible arrangements, there must be nationally agreed and accepted forms of proof of caring.

We suggest that the following items should be accepted as appropriate forms of evidence:

- Medical certificate with minimum detail stating that the person is a carer and therefore requires leave or flexibility, but not providing detail of the person who is being cared for or their health conditions to protect their privacy
- Document from Centrelink showing proof of carer payment or allowance
- In states where it is implemented, such as Victoria, the Carer Card
- A statutory declaration

The Fair Work Ombudsman outlines the types of evidence required to access paid personal/carer's leave, and states that "medical certificates or statutory declarations are examples of acceptable forms of evidence. While there are no strict rules on what type of evidence needs to be given, the evidence must convince a reasonable person that the employee was genuinely entitled to the sick or carer's leave".⁵¹

Carers may face barriers to obtaining medical certificates, due to cost, the person they care for not wanting to access a GP, or not being able to access a GP in a timely manner. Carers Tasmania recommends that the other options are also considered as suitable evidence.

It is also important to highlight that each state in Australia has slightly different carer recognition legislation, and in Tasmania in particular, the draft Carer Recognition Bill⁵² acknowledges carers of people with alcohol or other drug dependence, whereas other states and the *National Carer Recognition Act 2010*⁵³ do not. Therefore, we suggest that when determining if a person is a carer, that this is aligned against the relevant legislation in each state.

6.4 Other additional ways to support carers

We encourage the Government to implement the recommendations of the *Caring Costs Us* report, which convincingly argues for an increase to the carer allowance rate and the adoption of a superannuation guarantee and contribution on top of the carer payment.

In addition to financial support, training for carers or past carers to re-enter the workforce must be provided. Many carers who leave the workforce 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.

Any amendments to the NES entitlements must 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 assure carers that their job would be safe upon return.

⁵¹ Fair Work Ombudsman [Sick & carer's leave, Notice & medical certificates](#)

⁵² https://www.parliament.tas.gov.au/Bills/current/33_of_2022.html

⁵³ <https://www.legislation.gov.au/Details/C2010A00123>

Recommending to the Australian Government to review the *Carer Recognition Act 2010*,⁵⁴ with a view to establishing it as a rights-based Act would be prudent to support carers access to supports necessary to contribute both informal care and equitably access the labour market.

If entitlements are to change within the NES, it would be a key time to remind governments of the relevant carer recognition legislations guiding their state and to set the standard of 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 require flexibility in their employment or 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 stipulate “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.”⁵⁵ Further support and awareness raising of the aforementioned Carers and Employers Program⁵⁶ would be a great investment to support more carer friendly workplaces.

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 are needed. This will require a whole of government approach across all areas of health and aged care, disability, education, and community services.

⁵⁴ <https://www.legislation.gov.au/Details/C2010A00123>

⁵⁵ <https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-civil-and-political-rights>

⁵⁶ <https://www.carersnsw.org.au/services-and-support/programs-services/carers-employers>

7. Summary

In summary, Carers Tasmania commend the inquiry into much needed additional employment entitlements for carers but believe that additional supports are required in conjunction.

We recommend:

- Any additional carer leave entitlements must be inclusive and be available to all employees who are carers
- 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 supports 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

The implementation of these recommendations will not only support Australians who need care and 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.

It is also important to highlight that we are currently in the process of collecting Tasmanian data on caring and employment. Whilst we have included some carer statements throughout this submission, we would be delighted to share the final results with the Productivity Commission.