

Carers Australia submission to Productivity Commission Carer Leave Inquiry

Introduction

Carers Australia and the Network of State and Territory Carers Associations are pleased that the recommendation of the Royal Commission into Aged Care Quality and Safety “to examine the potential impact of amending the National Employment Standards under Part 2-2 of the Fair Work Act 2009 (Cth) to provide for an additional entitlement to unpaid carer’s leave” has been referred to a Productivity Commission inquiry.¹

The Aged Care Royal Commission noted in its Summary of the Final Report that, while the introduction of such leave would have wider economic effects, “this change will likely be necessary as the population ages and people remain in the workforce longer, reducing the pool of available informal carers”.²

We are less pleased that this Inquiry has been largely confined to examining leave provisions for carers of older people rather than carers of people of all ages who fall within the definition of the *Carer Recognition Act* 2010.³ While we acknowledge that the Royal Commission focussed on the provision of long-term leave “on the same basis that employees are currently entitled to leave to care for a newborn or newly adopted child”⁴, we are disappointed that short-term Carers Leave is not also under consideration.

We have long been concerned that the personal leave standard conflates sick leave entitlements and carers leave entitlement for paid leave. As will be discussed in this submission, carers have poorer health and wellbeing and a higher rate of disability when compared to the non-carer population. There are a number of reasons for this, but one which is generally acknowledged is the propensity to put their own health needs below those for whom they are caring. We would argue that working carers trade off their leave entitlements to care for another person against their own health needs (in many cases not taking sick leave when they need to in order to accumulate leave to deal with carer emergencies, resulting in poorer health and wellbeing.

In preparing for this Inquiry Carers Australia undertook a comparative analysis of carers leave among OECD countries with similar economies, similar carer population profiles and similar incentives for providing carers leave. Of the 14 countries⁵ which met these criteria, none combined sick leave and carers leave into a single entitlement.

¹ [Final Report - List of Recommendations | Royal Commission into Aged Care Quality and Safety](#), Recommendation 43

² [Final Report - Executive summary | Royal Commission into Aged Care Quality and Safety](#), p.104

³ [Carer Recognition Act 2010 \(legislation.gov.au\)](#)

⁴ [Final Report - Executive summary | Royal Commission into Aged Care Quality and Safety](#), p.104

⁵ These countries were: the United Kingdom, Ireland, Canada, France, Germany, Austria, Switzerland, the Netherlands, Italy, Spain, Sweden, Denmark, Norway and Japan.

In summary, Carers Australia's position regarding extended unpaid carer leave is that:

- The entitlement must be available to all employees who are carers within the meaning of the Carer Recognition Act 2010
- Like the parental leave standard, this new standard should be job protected and available to employees who have 12 months continuous service
- The entitlement must be accompanied by an enhanced entitlement to paid personal leave as recommended by the Australian Human Rights Commission in 2007
- The introduction of the new entitlement must be accompanied by comprehensive guidance on flexible work arrangements for workers with carer responsibilities, setting out rights and responsibilities for both employers and employees.
- The entitlement should be available to carers of people of all ages.

We have endeavoured to respond to all questions except where they are explicitly directed to the experience of employers. We have numbered the questions for purposes of cross-reference.

Role of informal carers of older people

1. How often does the decision to become a carer necessitate changed work arrangements or leaving the workforce?

Choice about the caring role

A recent national survey commissioned by Carers Australia partnership with the Department of Social Services (not yet published) explored the 'decision' to become a carer. Over half (57.8%) of current carers said they had no choice about whether to be a carer or not, 19.0% said they had little choice, and only 14.8% actively decided to take on a carer role and could have chosen not to be a carer. The remaining 8.4% felt it was hard to say which of those options best described how they came to be a carer.

Having choice in life is something known to affect long-term wellbeing. Feeling little or no sense of control over important choices in your life is associated with significantly lower levels of wellbeing. Among people who actively chose to take on their caring role, wellbeing was significantly higher compared to those who reported having no or little choice: 61.0% of those who actively chose to be carers had typical or high levels of wellbeing, compared to only 35.9% of those who had no choice in becoming a carer, and 42.2% of those who had little choice.

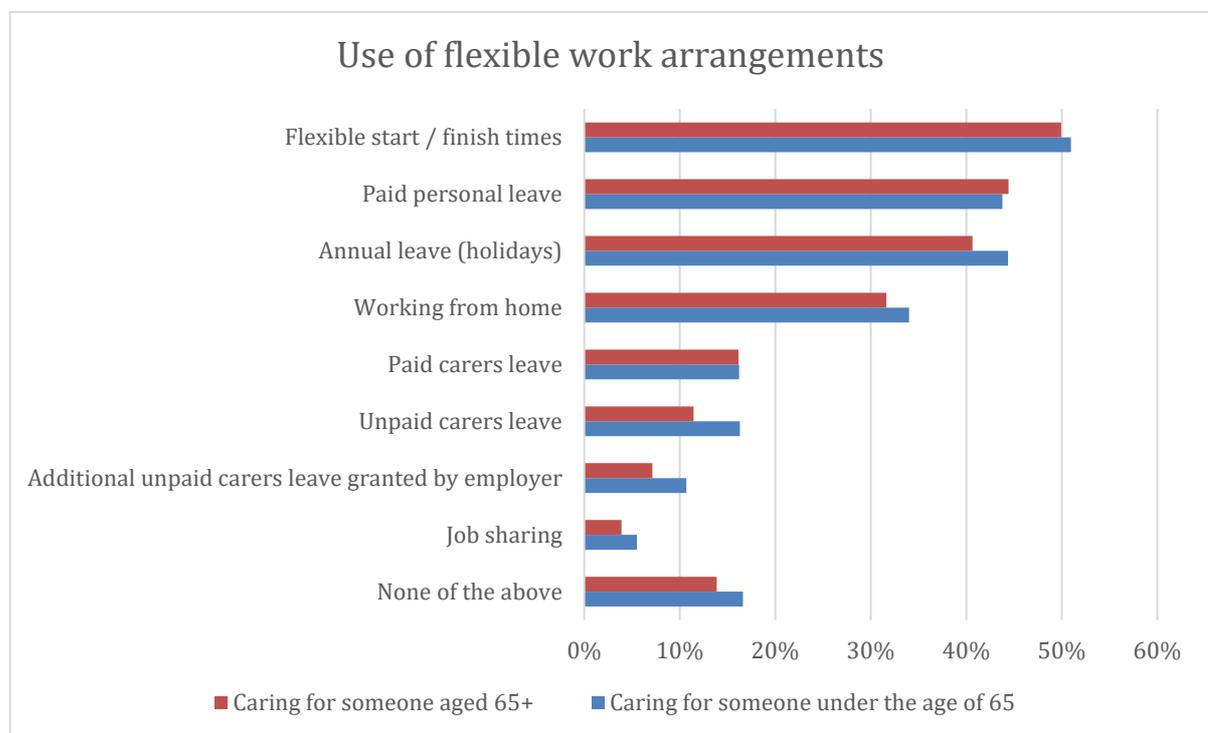
Several studies in the USA have found that carers without a choice in caring were more than three times as likely to report stress compared with carers with a choice in caring. Carers with no choice in caring were most likely to be employed.⁶

⁶ National Alliance for Caregiving (NAC) and AARP, *Caregiving in the U.S. 2020* (Washington, DC: NAC and Washington, DC: AARP, May 2020).

Changed work arrangements and work withdrawal

The 2020 National Carers Survey ⁷ found that the most common career impacts of caring on respondents' paid work were exiting employment and reduced working hours, with a typical carer working 27 hours per week. Half of all working carers had used flexible start/finish times in their current jobs and 44% had used carers leave.

A third of employed carers were working from home, which may have been impacted by COVID-19 restrictions in place at the time of data collection. The majority (84.4%) had used one or more flexible work arrangements. Carers use of flexible work arrangements is shown in the screenshot below:



Less than a third (29%) reported that caring had not impacted their career. The most common impact reported (27.5% of respondents) was having to quit paid work to care. Combined with having to retire early to continue caring, nearly half (44.5%) of carers reported having left the workforce due to their caring responsibilities. The second most common impact (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. Career impacts are shown in the screenshot below:

⁷ Carers NSW (2020). 2020 National Carer Survey: Summary report. Available online at: <http://www.carersnsw.org.au/research/survey>

Career impacts	Caring for someone under the age of 65 (N=3318)	Caring for someone aged 65+ (N=2407)
I quit working or looking for work to be able to care	31.5%	22.0%
I retired earlier than anticipated to be able to care	13.7%	21.6%
I have reduced my working hours	32.7%	20.0%
My skills and qualifications have become out of date due to time out of the workforce	28.1%	15.2%
q40_14 Other experiences	13.5%	13.4%
I feel less prepared to meet the demands of my job	21.5%	11.8%
I have worked in a job that is lower than my skill set	18.6%	9.1%
I have turned down a new job or promotion	16.6%	8.3%
I have changed industry or occupation	15.8%	7.6%
I could not find any jobs in my field that would allow me to continue caring	15.7%	7.5%
I have lacked the knowledge and confidence to apply for jobs	15.5%	7.4%
I have been denied an opportunity by an employer	7.1%	4.3%
An employer has changed my working conditions	6.1%	3.1%
None of the above	23.6%	37.1%

Involuntary and premature retirement by carers is common

The 2015 Productivity Commission inquiry into superannuation policy for post-retirement found that involuntary retirement because of caring responsibilities or poor health is common, with data suggesting that around 28% of men and 25% of women aged 60-64 who retire do so for these reasons.⁸

The individual financial and wellbeing impacts of early and involuntary retirement due to care responsibilities are significant, as are the national implications of reduced tax revenue and increased social security payments.

Insights from the pandemic

Carers Victoria surveyed 1,113 carers in December 2021 to understand the impact of the pandemic on their caring role. Some people reported they commenced their caring role due to the pandemic. There were differential impacts on employment for people who were new to caring and people who had been caring for longer.

People caring for the shortest amount of time (less than 1 year), were more likely to:

⁸ Productivity Commission 2015, [Superannuation Policy for Post-Retirement](#), Commission Research Paper, Canberra.

- Take paid leave (21%)
- Resign from their jobs (13%)

Those whose caring role began due to the pandemic were more likely to have had changes in employment due to the COVID-19 pandemic. They were more likely to:

- Have resigned (17% versus 5%)
- Take unpaid leave (10% vs 4%)

Older carers were more likely to retire early or resign to cope with their care role during the pandemic. Younger carers (aged 30-39) were more likely to accept a role that would allow more flexibility with their care role (13%) or resign (12%). This age group were also more likely to report the COVID-19 pandemic as having no impact on pre-COVID-19 working hours (9%).

Almost a third of people caring for between 1-2 years (29%) reported needing flexible work arrangements, while people caring the longest were more likely to report the need for respite care.⁹

2. How often is this a planned decision versus an impromptu decision triggered by an emergency?

Care strain impacts on work withdrawal

Researchers at the Australian Research Council (ARC) Centre of Excellence in Population Ageing Research (CEPAR) examined the effects of care strain on work withdrawal among Australian workers. The research found carers experience both 'time-based conflict' and 'strain-based conflict' and examined the extent to which the care responsibilities interfere with work and how stressful the care responsibilities are. Care intensity was defined as both care hours and care strain, and withdrawal from work was defined in terms of reduced time spent in paid work and withdrawal from career development and progression. Their analysis found that care strain is more strongly related to work withdrawal than care hours. It also found that care strain and work withdrawal can be reduced by a carer friendly work environment.¹⁰

Care strain may be more acute for carers who are thrust into the role of carer by a sudden illness or injury of a person who did not previously require care. When it is not yet clear whether the person will live or die, or will have long-term care needs or recover, carers may be more likely to leave employment once they have exhausted their paid leave entitlements. People in this heightened emotional state may not consider or even be aware of barriers to re-entering employment after a lengthy absence due to care responsibilities. Many carers

⁹ Carers Victoria, March 2022 [Overview of findings from the Victorian COVID-19 carer survey](#)

¹⁰ Constantin, A., Hamilton, M., Zettna, N., Baird, M., Dinale, D., Gulesserian, L., & Williams, A. (2022). Looking beyond hours of care: the effects of care strain on work withdrawal among Australian workers. *International Journal of Care and Caring*, 1-17.

report that they underestimated both the intensity and length of time they would be required to provide care.

Alternatively, carers of people whose care needs gradually increase over time may initially experience a lower level of care strain, but without access to carer support and regular planned respite care may reach a point of overwhelming care strain and exhaustion. There is a growing body of research showing that carer-friendly employment policies and practices (such as leave and flexibility) and workplace culture (such as supportive managers and co-workers) play an important role in enabling workforce participation by carers.

Case study 1:

Michalis was working in middle management at a utility company and his care responsibilities for his ageing parents, Maria and George, were increasing. He was required to support his application for workplace flexibility and carer leave with a business case on how his duties would be reallocated within his work unit. Michalis felt unsupported by HR or executive management and that it was unfair to require him to nominate his co-workers for additional tasks. He felt this contributed to being seen as getting 'special treatment' due to his care responsibilities.

Case study 2:

Pieter's mother Johanna had late-stage dementia and was living in an aged care facility. Pieter worked long shifts in emergency services and visited his mother regularly to assist at mealtimes whenever he could. As Johanna was approaching end-of-life, Pieter made his supportive manager aware of his circumstances. Pieter was able to combine his accumulated personal leave, long service leave and bereavement leave to be with his mother until her death, to remove her belongings from the facility and finalise her estate after her death. His manager and colleagues attended Johanna's funeral to show their support for Pieter.

3. How many older Australians receive informal care and formal in-home care?

A national survey conducted by Carers NSW in conjunction with the Network of State and Territory Carers Associations found that 39.1% were caring for someone with a Home Care Package and 26.7% were accessing entry level services through the Commonwealth Home Support Program. A further 8% were accessing private aged care services, 6.9% were in residential care and 21.7% weren't accessing any services.¹¹ While not all respondents were employed or seeking to be employed, a large proportion (40.8%) indicated that the aged care services provided to the person they care for had enabled them to keep their job or go back to work. However, just over one in three (34.4%) disagreed.

¹¹Summary report. Available online at: <http://www.carersnsw.org.au/research/survey>

4. To what extent do informal carers perform similar or different roles to formal in-home carers?

Depending on the needs of the person they care for, carers may provide many of the same kinds of assistance as care workers. These can include:

- Assistance with mobility
- Self-care, e.g. dressing, toileting, eating and drinking, a range of hygiene needs
- Health care, including assisting with medications and accompanying the person being cared for to medical appointments
- Household chores
- Property maintenance
- Meal preparation
- Assistance with transport
- Assistance with communication

In addition to these basic caring tasks, they also provide care that is less readily substituted by a paid care worker:

- Assistance with cognitive tasks
- Meeting the emotional needs of the people they care for
- Monitoring the person's psychological and physical health 24/7
- Assistance with administrative tasks including financial and legal matters
- Assistance with access to services and navigating service systems
- Coordinating formal care services
- Advocacy

With respect to assisting with access to services and service system navigation, many carers bridge the boundary between informal and formal care, performing roles that enable their older relatives and friends to access needed formal care services. They may seek relevant aged care information, assist with completion of paperwork, make arrangements with the older person for formal services and liaise with other family members and friends about formal and informal support.

Analysis of a large Canadian CARNET 'Work and Family Survey' sub-sample of 1,847 full-time employed carers of older relatives found that most provide both 'managerial' and direct care. Care management includes both the planning and coordination of care and financial and bureaucratic management. Researchers found such care generates stress amongst women and interferes with work amongst men, and the aspect that generates the greatest personal and job costs amongst both men and women is planning and coordination of care.

¹²

¹² Rosenthal, C. J., Martin-Matthews, A., & Keefe, J. M. (2007). [Care management and care provision for older relatives amongst employed informal care-givers](#). *Ageing & Society*, 27(5), 755-778.

The 2020 National Carer Survey found that, among carers of people over the age of 65, 87.2% provided administrative support and 74.2% coordinated support services or care workers.¹³

5. What formal services would be difficult for some older Australians to access without informal support?

The complexity of the aged care system means that many people find it difficult to navigate and access the services they need. In the years since the introduction of My Aged Care as the single-entry point to the aged care system, there has been increasing acknowledgement of the need to reinstate localised and face-to-face support to help people to navigate and access aged care.

The Legislated Review of Aged Care 2017 (Legislated Review) recommended providing a face-to-face community service for people who require extra support to access My Aged Care and the aged care system.¹⁴ In response to the Legislated Review, the aged care system navigator trials were announced in the 2018-19 Budget. The COTA Australia Aged Care Navigators Trial helps people who:

- are vulnerable, isolated, homeless, disadvantaged or impaired
- have dementia or mental health problems
- are unlikely to seek aged care support without assistance from others
- have limited access to the internet or other technologies
- live in rural or remote areas

The Navigator trials are operating in limited regions around Australia until December 2022 to help the target groups of people with:

- the types of subsidised age services available
- how to access age services
- consumer rights and responsibilities
- registering with My Aged Care and understanding how the system works
- supports available in the local area
- how to compare services, facilities and prices
- other options while on a waiting list for services

The Aged Care Royal Commission heard throughout its inquiry that aged care needs to have a much greater face-to-face presence. It recommended a workforce of care finders be funded to provide face-to-face support to help people navigate and access aged care.

The care finder program was announced in the 2021-22 Budget as part of the Connecting Senior Australians to Aged Care Services measure and will be delivered through Primary Health Networks (PHNs).

¹³ Carers NSW (2020). 2020 National Carer Survey: Summary report. Available online at: <http://www.carersnsw.org.au/research/survey>

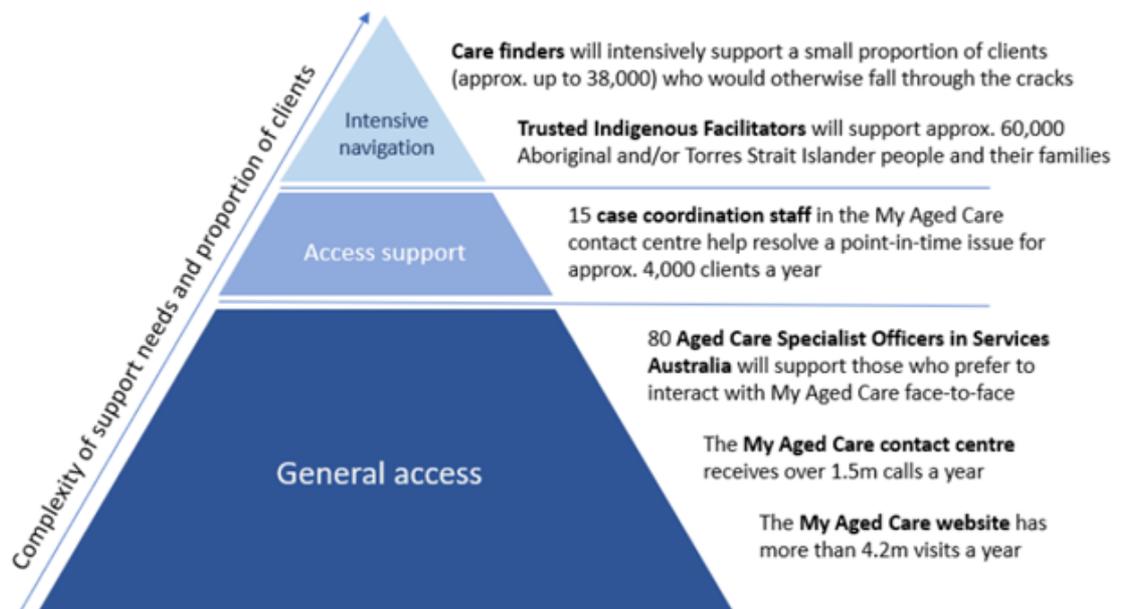
¹⁴ Australian Government Department of Health [Legislated Review of Aged Care 2017 Report](#)

Care finders will:

- provide specialist and intensive assistance to help people to understand and access aged care and connect with other relevant supports in the community
- specifically target people who have one or more reasons for requiring intensive support to interact with My Aged Care (either through the website, contact centre or face-to-face in Services Australia service centres), access aged care services and/or access other relevant supports in the community.

However, the Care Finders service will be targeted to only a small proportion of clients (see figure below). Many of the hundreds of thousands of other older Australians interacting with the aged care system every year rely on their families and carers to access and navigate this complex system.

Proportion of clients supported through access channels and navigation from January 2023



6. How many older Australians rely solely on informal care? In what circumstances, or for what reasons does this occur?

The 2018 Australian Bureau of Statistics' Survey of Disability, Ageing and Carers (henceforth referred to as SDAC) found that, of those over the age of 65 requiring assistance, 1.8% received only formal care, 36.6% only informal care, 62.5% received both formal and informal care.¹⁵

The 2020 National Carer Survey indicated that 21.7% of the cohort caring for someone over the age 65 reported that the person they cared for did not access any aged care services.¹⁶

¹⁵ [Disability, Ageing and Carers, Australia: Summary of Findings, 2018 | Australian Bureau of Statistics \(abs.gov.au\)](https://www.abs.gov.au/australian-bureau-of-statistics/publications/summary-of-findings-2018).

¹⁶ Carers NSW (2020). 2020 National Carer Survey: Summary report. Available online at: <http://www.carersnsw.org.au/research/survey>

There are many reasons why this occurs. For example:

- Many older people in need of care would simply prefer to be cared for by family members or friends. This is particularly the case for many culturally and linguistically diverse people and for Aboriginal and Torres Strait Islander communities where family care is culturally sanctioned. Older people feel they can rely on family for culturally appropriate care, and they may need someone to care for them who they can communicate with in language (bearing in mind that many people revert to their first language as they age).
- Many people living with dementia lack insight into their difficulties and can refuse formal services (although this perspective is not only confined to older people with dementia).
- They may have difficulty with getting access to home care services (or suitable services) in their area.
- They may avoid assessment for home and community care services, fearing the same assessors could recommend they enter residential aged care instead.
- They may find home care services unaffordable, especially people living in private rentals.
- They may be unaware of the supports available to them.
- They may be waiting for access to services.

There are strong cultural expectations for some people from culturally and linguistically diverse backgrounds as "in many communities, formal aged care services, particularly nursing homes, are considered taboo and a strong source of community shame".¹⁷ This can create additional barriers to employment and retention for carers of CALD backgrounds.

Carers themselves will have their own reasons for preferring to be the sole or primary provider of care. In response to a question in the Australian Bureau of Statistics 2018 SDAC on the reasons for taking on the caring role:

- 46.2% said because they could provide better care
- 70% cited family responsibility
- 16.5% said alternative care was too costly
- 16.5% said no other care arrangements available.¹⁸

Direct feedback from carers in the National Seniors 2020 *Who Cares? Older Australians do* survey included the following explanations:

- *My friend has had an assessment for home services, however is reluctant to access these, as he feels that this restricts his independence and that it is an admission that he isn't coping.*

¹⁷ Federation of Ethnic Communities' Councils of Australia, Submission 248 to the Australian Human Rights Commission, Willing to Work: National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability

¹⁸ [Disability, Ageing and Carers, Australia: Summary of Findings, 2018 | Australian Bureau of Statistics \(abs.gov.au\)](https://www.abs.gov.au/australian-bureau-of-statistics/publications/feature-articles/2018/07/disability-ageing-and-carers-australia-summary-of-findings-2018), Carers tables, 39.1

- *Unless the person being cared for considers they need to be in the care system there is no point forcing them while I can fill the gap...*
- *you can lead a horse to water but difficult to make it drink*
- *So far no services have been supplied for many reasons. i.e. care recipient not agreeing to accepting services. Person I care for doesn't like outside assistance*
- *I think it would be helpful but would first require acceptance of the need for external help.*
- *She was assessed twice by my aged care. But has refused all assistance except assisted shopping*
- *Would a care plan be of use to me, no I do not think so as there are so many restrictions on age, lifestyle, and financial..¹⁹*

7. How many older Australians would need to enter residential care, if less informal care was provided?

The decision to enter residential aged care is influenced by multiple factors. An estimated 82% of all older people receiving Government funded or subsidised home care services between 2002 and 2011 had a carer²⁰, but more recent data on carers of aged care recipients is not available from the Australian Institute of Health and Welfare (AIHW). For example, the latest available data report on the Home Care packages program reports the number of older Australians assessed for and using Home Care, but not on the number of recipients with carers or their use of respite care within their package (a potential proxy measure).

It must be noted that entry to Government subsidised residential aged care is only possible with an Aged Care Assessment Team (ACAT) approval. Overall, only 31% of the cohort approved for residential aged care entered permanent care in the 12 months following an Aged Care Assessment.²¹

Older Australians typically want to stay living at home with support in preference to entering residential aged care. Even when approved for entry to permanent care, they may consider this a last resort.²² A change of circumstances often precipitates this unwanted change. For example, continuing problems managing care at home may lead to a change, or their health or the health of their carer may change significantly. Common events include declining health, injuries and hospitalisation. People assessed in hospital are more likely than others to move into permanent care (49%). People with a co-resident carer were less likely to enter permanent care (29%).

Carers play an important role in supporting people with lower support needs who are not eligible for residential aged care admission, as well as supporting people with higher needs to remain living at home even if approved for residential aged care.

¹⁹ National Seniors, 2020, [Microsoft Word - NSA ResearchReport Whocares \(nationalseniors.com.au\)](#), p.29

²⁰ Australian Institute of Health and Welfare 2014. [Patterns in use of aged care 2002–03 to 2010–11](#). Data linkage series no.18. CSI 20. Canberra: AIHW.

²¹ Ibid

²² 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.

A potential counterfactual to the question posed is contained in recent data provided on request from Department of Health and Aged Care on emergency pandemic leave. It gives some indication of the number of older people in residential aged care who may be able to be cared for at home with additional support.

As at 30 April 2022, a total of 16,271 people had utilised emergency leave from residential aged care since the onset of the pandemic and the provision became active on 1 April 2020. A breakdown of this by state/territory is below:

Emergency leave	NSW	VIC	QLD	WA	SA	TAS	ACT	NT
1 April 2020 to 30 April 2022	4,598	4,327	4,010	1,648	1,071	369	218	55

While the ability to work from home during the pandemic is not without challenges, one of the probable benefits is that it can make it easier for carers to juggle work and care.

8. To what extent do informal carers support older Australians who are in residential aged care?

Many carers continue their caring role when their family member is admitted to residential care. The nature of this caring role can depend on:

- The level of care their family member needs
- The role the carer wishes to have
- The time they have available
- The extent to which the facility supports family involvement

Carers perform a range of roles with people living in residential care:

- Historian - knowledge keeper and sharer of information
- Personal care helper - e.g. helping with eating or walking
- Health care aide – taking the person to medical specialist appointments
- Recreational assistant - e.g. through outings or 1:1 activities
- Financial/legal supporter - e.g. Power of Attorney or bill payer
- Shopper - e.g. help with purchasing personal items
- Emotional supporter - comforting and providing companionship
- Assisting with language barriers when required
- Providing culturally appropriate food for residents
- Volunteer - helping out at the facility
- Advocate/care guardian - speaking up for their family member.²³

Older people in residential aged care have a right to see their family, friends, supporters and carers just like anyone else in Australia. During the pandemic, some homes had to restrict

²³ Carers Victoria, 2003, Outside looking in: resource kit on carer friendly practices in aged care facilities

visits in order to protect residents from COVID-19. Balancing these competing priorities meant some residents were unnecessarily barred from contact with their families. Carers Australia worked with COTA Australia, the Australian Government and providers to develop the Industry Code for Visiting Aged Care Homes.

The Code includes an 'Essential Visitor' policy which requires that residents are always permitted to have at least one visitor, regardless of the COVID outbreak status. Essential Visitors include:

- Partners-in-Care – Access by Partners-in-Care should be prioritised, recognising their role in the daily care and support of a resident such as helping with hydration, meals, hygiene and emotional support. These visitors are particularly important for residents with dementia and residents with a diagnosed mental health issue. The kinds of care and support which can be provided by a partner-in-care in a residential care setting are outlined in resources produced by the Aged Care Quality and Safety Commission.²⁴ Residents with a diagnosed mental health issue or at risk of mental health or psychological impacts associated with visitor restrictions (for example loneliness, anxiety, boredom, fear, and depression) must be provided support, including receiving regular visits from their Partner-in-Care.
- Named Visitor – If a resident does not have a Partner-in-Care, they may nominate one person to be a Named Visitor

9. What other evidence should the Commission consider relating to what causes informal carers to have lower labour force participation, or incomes, or poorer health and wellbeing compared to those without caring responsibilities?

There are a range of answers to these questions. Some of them are relatively self-evident and they tend to be interconnected.

Take lower labour force participation, for example. If someone finds it hard to combine work and care, they are likely to struggle to find suitable work which would allow them to do this and may be forced into part-time or casual employment or no employment at all. This will have an impact on their income. Their capacity to combine work and care is not only likely to be a by-product of the care they need to provide, but also a result of the amount emotional and psychological strain they are under in trying to perform in what is essentially two jobs – one paid and one unpaid.

Another trend which impacts on the profile of carers is that when a family member or friend is in need of significant care, it is often the person who is not currently in employment or is perceived to have the least to lose who takes on the caring role.

For example:

- The person who earns less.
- The person who has a lower status job.

²⁴ Aged Care Quality and Safety Commission, www.agedcarequality.gov.au/resources/partnerships-in-care

- The person whose employment prospects are curtailed by disability, poor health or level of educational achievement.
- The person who doesn't have children to care for as well.
- The person who doesn't have a partner (who might not want to be drawn into the care arrangement).

10. Are different groups of informal carers (for example, women, young people, older carers, etc.) more or less likely to be affected? Why?

Responses to a 2021 Carer Wellbeing Survey, commissioned by Carers Australia in partnership with the Department of Social Services and undertaken by the University of Canberra, sheds light on this question.

- Female carers are more likely than male carers to be lonely, have little time to themselves, and have poorer health and wellbeing
- While typically they had had better health and were less likely to experience social isolation or lack time for themselves, carers under the age of 35 had higher levels of psychological distress, higher financial stress, more negative emotions and lower confidence in their ability to be a good carer.
- Carers aged 35-44 had higher psychological distress, high loneliness, less time, lower confidence, and more negative emotions associated with their caring role.
- Carers aged 45-54 were at particularly high risk of low wellbeing, poor health, social isolation, financial stress, lack of time, and poor access to support from family and friends.
- Carers aged 55 and older in general had fewer wellbeing risks compared to other carers, although their wellbeing was still significantly poorer than other Australians of similar age.
- As caring hours increase, risk of poor outcomes also typically increased.
- Aboriginal and Torres Strait Islander carers were at high risk of psychological distress, financial stress, negative emotions associated with their carer role, and low confidence in being able to deliver on their caring role. However, they have better access to family and friend support than some other groups of carers.
- As the number of people cared for increase, risk of negative outcomes increase.

Some of the answers as to why these groups of carers experience negative impacts of caring are intuitive. For example, carers with multiple care recipients and those who put in very long of hours caring for even a single person will be more likely to be subject to higher levels of carer strain, which may impact on their health and psychological wellbeing and lower employment prospects, which in turn will affect their income.

For carers under the age of 35 the psychological and psychosocial impacts, confidence level and financial impacts are likely to be high because they are at a time in their lives where their peers who don't have caring roles are likely to be laying the foundations of their careers and their social networks, finding partners and starting families, all of which they

have the time and energy to do. Carers in age groups where they are raising families and face higher financial challenges as result are likely to be under significant pressure.

Older carers will be facing some of the health challenges which come with ageing and, to the extent that caring has impacted on their employment and financial prospects, are likely to be worried about their futures, including in retirement.

Social isolation is a factor which tends to impact on nearly all carers, however it can be much reduced if carers can retain an attachment to a workplace where they socially interact.

11. When do employees use paid or unpaid leave or request flexible working arrangements to care for an older person? In what circumstances are the provisions inadequate?

Short de-identified case studies in this submission which are based on real carer experiences of juggling works and care give some insights into this question. What they have in common is that these carers need to make use of a range of flexible working arrangements in combination with paid and unpaid leave at different stages of their caring trajectory. Understanding of the caring role and consistently followed workplace policies, with managers who are educated and empowered to exercise discretion and flexibility are just as important.

Carers report that their access to paid leave may be adequate if they have worked continuously for one employer for some years and have accumulated sufficient personal leave to attend to both their own health care and the care needs of others. However, NES paid leave provisions are frequently inadequate for carers living with chronic health conditions and/or working on fixed term contracts. Carers employed casually do not have access to any paid leave.

Unpaid leave can be inadequate as employers are not obligated to grant requests for unpaid leave and, in the case of sick leave, can dismiss an employee who has exhausted their sick leave if they do not return to work within 3 months.

Flexible working arrangements are most needed and frequently requested by carers, but inflexible employers and lack of understanding of the caring role hampers access to these.

Carers Australia supports the recommendation 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 10 days to be noncumulative
- the Australian Government consider introducing a 12-month unpaid carer leave Standard

- like the parental leave Standard, this new Standard should be job protected and available to employees who have 12 months continuous service.²⁵

Carers Australia also supports expansion of the number of days of short-term unpaid carer leave available to casual employees and exploration of options for paid carer leave such as the Victorian Government's Sick Pay Guarantee trial.²⁶

12. Do the eligibility requirements for the paid and unpaid leave entitlements allow them to be used by informal carers of older Australians? If not, why?

Carer leave is currently available from an employee's personal leave balance to take time off to care for an immediate family or household member who is sick or injured or help during a family emergency.

An immediate family member is a:

- spouse or former spouse
- de facto partner or former de facto partner
- child
- parent
- grandparent
- grandchild
- sibling, or child, parent, grandparent, grandchild or sibling of the employee's spouse or de facto partner (or former spouse or de facto partner).

This definition includes step-relations and adoptive relations.

While most carers are caring for their parents, partner or children, the restriction to immediate family/household member excludes carers of other relatives or friends. For example, carers of aunts, uncles and cousins and in some instances neighbours. It can also exclude carers in a 'chosen family' relationship with an older person who identifies as LGBTI and is estranged from their immediate family.

Case study 3:

Sharon works full time at a large disability support organisation. Her mother died when she was still at school and her mother's sister Noeline played a major role in her upbringing. Sharon describes Noeline as her second mother. Noeline is 70, does not have any children of her own and lives alone. When Sharon got a call at work that Noeline had been taken to hospital after a sudden heart attack, Sharon informed her manager who encouraged her to go to be with her aunt. Sharon travelled to the regional area her aunt lived in and stayed in Noeline's home, looking after the cat and supporting Noeline in hospital. After Noeline was discharged, Sharon stayed another few days to care for her and stocking the freezer with meals to reheat during her recovery. On her return to work,

²⁵ Human Rights and Equal Opportunity Commission [It's About Time: Women, men, work and family Final Paper 2007](#)

²⁶ Government of Victoria, Victorian Sick Pay Guarantee [Sick and carer's pay for casual and contract workers](#)

Sharon's application for carer leave with a certificate from Noeline's cardiologist was rejected by HR as Noeline was not her 'immediate family'. Her manager was sympathetic but said there was nothing she could do, saying "those are the rules".

Guidance from the Fair Work Ombudsman on types of evidence needed for paid sick / carers leave states:

"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 has to convince a reasonable person that the employee was genuinely entitled to the sick or carer's leave".²⁷

Carers Australia recommends that guidance for extended periods of leave should follow this same guidance, to accommodate the needs of people commencing their carer role, whose carer role is intermittent or who are supporting an older person living in residential aged care. Further guidance would suggest that examples of other acceptable forms of evidence would be a Carer Card issued by a State or Territory government or a letter from Services Australia stating receipt of Carer Payment/Allowance. These forms of evidence would reduce the need for longer term primary carers to continually acquire medical certificates or statutory declarations for every occasion of care.

Carers Australia is mindful that carers can experience barriers and additional costs due to medical consultations in order to provide evidence required by employers of the need for carer leave. Some demands from employers do not appear to be 'reasonable' under the circumstances. We consider this another important reason for increased education about and awareness of the needs of carers by employers, as this may help to enhance communication and trust and reduce demands for medical documentation.

13. Are there barriers that limit informal carers of older people from using the entitlements?

The barriers reported by most carers relate to lack of understanding of the carer role by employers.

Case study 4:

Rani works part time in a bank and cares for her mother-in-law Meera who lives with Rani, her husband and 2 adult student children. Rani accesses a few hours a week of flexible in-home respite care for Meera when no other family member can stay home with her. Rani called her carer support worker in distress when her application for one day of carer leave was rejected by her employer because the doctor's certificate stated she had accompanied Meera to a medical appointment but did not state that Meera 'required care'. The carer

²⁷ Fair Work Ombudsman [Sick & carer's leave, Notice & medical certificates](#)

support worker offered to call Rani's employer to explain her situation, but Rani declined, saying she would ask the doctor to write what her employer wanted next time.

Case study 5:

Amanda works full time in the office of a food manufacturing company. Her widowed father Les lives nearby. Every morning on her way to work, she calls in to make sure Les is up and about, has had breakfast and taken his medications. Every evening on her way home she does the same, often having dinner with her dad who complains of loneliness now that most of his mates are dead. Amanda feels exhausted doing this 'double shift' and has arranged for Les to take 2 weeks holiday staying with her sister in Queensland to give her some respite. While he is away, Amanda becomes ill herself. However, she has no personal leave left, as it is all used caring for her dad when he is feeling unwell, hospitalised or taking him to multiple doctor's appointments. When Amanda applies for additional unpaid leave, she feels devastated when her exasperated manager asks, "Can't you just put him in a home?"

14. Are there specific Awards that provide entitlements to informal carers that are beyond those provided in the NES?

Awards

One example is the former Social and Community Services (Victoria) award 2000 (now superseded by the Social, Community, Home Care and Disability Services (SCHADS) Industry Award 2010) provided for personal leave entitlements above the NES of 10 days per year:

During the first year of service, one working day for each month of service;

- During the second, third and fourth years of service, fourteen working days in each year; and
- Thereafter 21 working days in each year.²⁸

As part of the Modern Award process, personal leave entitlements in the SCHADS award were standardised to those in the NES.

Enterprise agreements

The Carers Victoria Enterprise Bargaining Agreement provides for up to 5 days (non-cumulative) additional carer leave for eligible employees:²⁹

43.1 Carers Victoria seeks to be a leader in employment practices that assist employees to balance their working and caring responsibilities. A carer is a relative or friend who provides unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail aged.

43.2 Employees are entitled to five days (or ten half days) paid and ten unpaid days of leave per year to meet their carer obligations towards an individual care recipient. Employees can access the Carers Victoria Leave for a maximum of two (2) care

²⁸ Fair Work Ombudsman [AP796561CRV - Social and Community Services - Victoria - Award 2000](#)

²⁹ Fair Work Commission [Carers Victoria Agreement 2018](#)

recipients per year. This leave is non-cumulative, and a pro rata entitlement applies to part time employees.

43.3 Applications for Carers Victoria leave taken under this clause must be by request to the line Manager. Any application/requests in excess of this provision will be referred to the line Manager for decision.

43.4 Employees who are carers are also entitled to access Personal Leave in Clause 4

Effects of an entitlement to extended unpaid carer leave

15. How many employees would take extended unpaid carer leave if they were entitled to do so, and how much more care they might provide?

Much will depend on the economic circumstances of individual carers as to whether they can afford to take extended unpaid leave and what alternative sources of financial support they can call on such as Government income support, an employed spouse or partner or financial assistance from the older person themselves.

There would need to be a national survey which would capture the responses of carers who might not have made a decision to curtail their employment if this leave had been available to them to provide more data in answer to these questions.

It would also be useful if research was undertaken to evaluate continuing carer participation in the workforce following the introduction of long-term leave entitlements in other countries.

16. How many of these employees would have continued working while providing some informal care?

Carers are more likely to be able to continue to work while still providing care if this is complemented by access to formal care services. This is even more likely if the community care is 'consumer-directed'. Studies from overseas have found that carers in this situation help just as often as carers of people using provider-directed care, but they provide fewer total hours of care, i.e., these carers remained available to the respond to the needs of the person receiving care but had more time to undertake activities other than care, such as employment. They were less likely to report caring infringed on their paid employment or personal lives and enjoyed better well-being.^{30 31}

Many of these consumer-directed-care schemes provide direct payments allowing consumers to select family, friends and neighbours to become paid care providers. Most

³⁰ Foster, L., Brown, R., Phillips, B., & Carlson, B. L. (2005). Easing the burden of caregiving: the impact of consumer direction on primary informal caregivers in Arkansas. *The Gerontologist*(4), 474.

³¹ San Antonio, P., Simon-Rusinowitz, L., Loughlin, D., Eckert, J. K., Mahoney, K. J., & Ruben, K. A. D. (2010). Lessons From the Arkansas Cash and Counselling Program: How the Experiences of Diverse Older Consumers and Their Caregivers Address Family Policy Concerns. *Journal of Aging & Social Policy*, 22(1), 1-17. doi: 10.1080/08959420903385544

families were found to have provided unpaid help prior to becoming paid and continued to provide unpaid care in addition to the care they were paid for. Older people preferred family over nonrelated care staff for their provision of warm care, sharing a close relationship of trust, and being reliable and flexible in the care provided. Married daughters of older people with higher needs were more likely to become paid to care.

17. We seek your views on whether there are costs and benefits of leaving formal employment to provide informal care that carers don't take into consideration. To what extent and how do carers consider the following factors when deciding whether to provide informal care:

- **their ability to return to work**
- **their future income, including retirement income**
- **the health and wellbeing of the care recipient**
- **their own health and wellbeing**
- **the cost of alternative care arrangements**
- **any other important matters?**

As discussed earlier in this submission, decisions about resolving conflicts between work and care may be made quickly, during a time of heightened stress and based on incomplete information. Decision-making about caring for older people within families shares some similarities with how such decisions are made by parents of young children. Family members seen to have the most availability e.g. geographically or emotionally closer and those with the least income earning capacity are more likely to become the primary carer. This disproportionately affects women.

One study of family decision-making found older mothers were three and a half times more likely to prefer care by daughters than sons and were less likely to seek care from adult children who lived at a greater distance. In this particular study the preferred carer's employment status only made them somewhat less likely to be preferred. However, there is often a discrepancy with adult children's preferences and actual provision of care, contributing to family disagreements and conflict. For example, if one child in the family is expected to provide care, other siblings tend to reduce their caring commitments. Although mothers may expect care from children who have provided it in the past, those carers may expect other siblings who have benefited from past help from their parent to step up. Relations with siblings are a major source of stress for carers and may result from a mismatch between parent's expectations, the expectations of the identified carer, and those of siblings.³²

Regarding financial decision-making, **Carers Australia recommends** the Productivity Commission models the impact of extended unpaid carer leave on carer's lifetime incomes and retirement incomes. We further recommend modelling of options for the practical

³² Pillemer, K., & Suito, J. J. (2006). Making choices: A within-family study of caregiver selection. *The Gerontologist*, 46(4), 439-448.

application of superannuation carer credits during extended leave from work in the Australian context.

18. We seek your feedback on how many employees who would take extended unpaid carer leave would subsequently return to work once they had ceased caring.

Clearly this will depend on a range of circumstances. Part of the purpose of extended unpaid leave is to help carers to adjust to a new caring situation or an escalation in an existing carer situation.

Carers Australia has plenty of anecdotal evidence that many people become so overwhelmed by these challenges that they will quit their job fairly quickly.

However, if carers are given enough time and opportunity to resolve these issues, it is highly likely that they will return to work even if they continue caring.

We note in passing that a number of OECD countries we have looked at which have introduced new, more generous carer leave arrangements have in part been motivated by workforce considerations. For example, in 2016 the Japanese Government extended the criteria for publicly funded employee leave to care for an infirmed loved one in an effort to stop family related job losses against a background where some 100,00 people a year quit their jobs to provide such care.³³

As remarked elsewhere, there are so many benefits of being able to combine work and care. Work can reduce the social isolation so many carers experience and it can also provide respite from caring. A current work history and continuing attachment to the workforce is very important to carers if they wish to be employed and improve their standard of living once their caring role diminishes or ceases. For people who have had to rely on the Carer Payment for income it is worth noting that, according to the *2017 Valuation Report* for the Australian Priority Investment Approach to Welfare, around two thirds of those on Carer Payment who were projected to exit over the following 10 years would move on to another income support payment, and a substantial proportion of these were projected to move onto a working age payment.³⁴

19. How do women and men experience different pressures to provide informal care?

Women and men can experience very different pressures to provide care, but also some similarities dependent on their individual circumstances. For example, men without sisters

³³ [Japan to loosen rules on nursing care leave - Nikkei Asia](#)

³⁴ Department of Social Services, *Australian Priority Investment Approach to Welfare - 2017 Valuation Report*, pages 102-3, <https://www.dss.gov.au/review-of-australias-welfare-system/2017-valuation-report>

are more likely to be called upon to care for ageing parents. However, women are more likely to provide care to their parents-in-law than men. Women are also more likely to experience both consecutive and concurrent caring pressures. For example, women may have to interrupt their employment consecutively to care for their children, parents, partners and grandchildren. Others will be caring for multiple people at the same time. This is so common that the term ‘sandwich’ carer has been coined. These are middle-aged people (mostly women) caring for their older parents while also providing care to children or grandchildren.³⁵

Case study 6:

Mai is a single woman working shift work at a distribution centre for a large freight forwarding company and shares care of her mother Cam with her sister Binh since their father died. Cam lives with Binh and her husband who run a small business together. When Binh was diagnosed with breast cancer and could no longer care for their mother, Mai feared she would have to leave her job to become the primary carer. However, her employer has implemented a range of family-friendly practices to improve workforce retention and reduce staff turnover costs. She talked with her manager and HR and said she thought she would need to take 6 months leave to care for her mother while her sister underwent cancer treatment. Her employer agreed and said they would be willing to extend the leave by another 6 months if her circumstances changed. Mai is relieved she will have a job to go back to as she fears she may experience discrimination from other employers as an older woman whose first language is not English.

Case study 7:

Alastair is an only child, and his mother Alice who has multiple health conditions and is now legally blind. Alastair and his mother had a difficult relationship in the past due his mother’s religious beliefs and disapproval of Alastair being gay. However, Alice was willing to accept care from him as she was very anxious about strangers coming into her home when her vision was so poor. Alastair works in the Commonwealth public service and has access to a range of flexible work arrangements to balance work and care including working from home. After Alice had a bad fall at home and fractured her hip, she was hospitalised, and the doctors recommended Alice be admitted to residential aged care. Alastair applied for 3 months carer leave to find a suitable facility for Alice and to get her settled in. He feels satisfied that he has been able to care for and support Alice as she approaches the end of her life and that his relationship with his mother is now better than it has been since he was a teenager.

20. How should we think about, and measure, the value of an entitlement to unpaid carer leave? Does it vary across employees?

The business case for reducing the costs of high staff turnover levels by implementing workplace flexibility and leave policies has been made in multiple studies in multiple countries.³⁶ Introducing an entitlement to unpaid carer leave, accompanied by a suite of flexible workplace practices, also offers less tangible benefits such as increased job

³⁵ The Canberra Times, April 24 2018 [The sandwich generation: Australians caring for both their kids and their parents](#)

³⁶ Employers for carers – [Business case.](#)

satisfaction, a powerful sense of loyalty to the employer, and a more trusting workplace culture.

While most people have a high degree of choice over whether to become parents and, to some extent, the timing of the arrival of their children, becoming a carer is different. Anyone at any time could become a carer. Employees would be more likely to consider unpaid carer leave as an equitable entitlement if it was available to carers in a range of circumstances, not just restricted to carers of older people. This would help employees to feel they would be treated equally if they found themselves thrust into the caring role, increasing a sense of cohesion and reducing any sense of 'special treatment'.

An example of building a 'caring culture' and cohesion in the workplace is via sick leave pooling or donation registries. For example, the National Australia Bank allows bank workers who have accrued at least 30 days of sick leave, to donate two days off a year to a collective sick bank. Workers who have contracted a serious disease or disability and who have exhausted their own sick leave can draw on the bank for extra relief. The same applies to bank employees who must take extended leave to care for an immediate family member who falls seriously ill or experiences a serious disability.

21. How has the 'better off overall' test been applied when evaluating an entitlement that might not benefit all employees?

Carers Australia is not aware of any application of the "better off overall" test (BOOT) to carer leave, although we are aware that restrictions on cashing out of annual leave in modern awards may prompt questions about cashing out other forms of leave, such as paid personal/carer leave and long service leave.

Carers Australia queries the relevance of the BOOT, which applies to enterprise agreements rather than to National Employment Standards.

22. Have employers or employees sought to introduce an entitlement to extended unpaid carer leave into an enterprise agreement but found barriers to them doing so? If so, what were these barriers?

Carers Australia is not aware of any unsuccessful attempts to introduce an entitlement to extended unpaid carer leave into an enterprise agreement, but is aware of agreements that provide for greater flexibility in taking unpaid leave for a variety of purposes.

Design Implications

Carers Australia's recommendations with respect to the design of extended carer leave are below.

- 23. Who should be eligible and why? What criteria should an employee need to meet and why? For example, tenure, relationship to the care recipient, and/or the nature of care required.**

Relationship of the carer to the care recipient

In our analysis of comparable OECD countries who provide carer leave, most specify immediate relatives which include grandparents, parents, children, siblings, partners. With respect to short-term paid leave, the Netherlands includes neighbours, friends and acquaintances. Canada includes immediate family as well as other relatives and individuals considered to be like family, whether or not related by marriage, common-law partnership, or any legal parent-child relationship (these provisions apply to both long-term leave and paid, short-term leave). In the UK, for unpaid leave of up to five days per year, the carer must be caring for:

- a spouse, partner or civil partner, a child, a parent,
- a person who lives in the same household who is not their employee,
- a tenant, lodger or boarder,
- a person who reasonably relies on the employee for care.

In Ireland, for unpaid long-term leave, the person being cared for can be a family member, spouse, friend or colleague.

Given that, according to the 2018 Australian Bureau of Statistics SDAC, 89,000 or 10.4% of carers cared for someone other than a partner, child or parent, we would prefer a wider relationship compass than under the current short-term personal leave provision. The definition of carers under the Carers Recognition Act 2010 would be our preference.

"A carer is an individual who provides personal care, support and assistance to another individual who needs it because that other individual:

- (a) has a disability; or
- (b) has a medical condition (including a terminal or chronic illness); or
- (c) has a mental illness; or
- (d) is frail and aged."³⁷

We note that under the *Fair Work Act*, carer leave is not restricted caring for a family member located in Australia.³⁸

³⁷ [Carer Recognition Act 2010 \(legislation.gov.au\)](http://legislation.gov.au)

³⁸ [Carer's leave and an ill family member overseas | AiGroup](#)

Tenure in employment

Carers Australia recognises that the introduction of any new employment entitlement to extended unpaid leave must balance the needs of employees with care responsibilities with the needs of employers.

Carers Australia considers that 12 months continuous service is a reasonable requirement for eligibility for an extended period of leave. However, in recognition that carers who have recently started with a new employer will have less paid (personal and annual) leave available to them, we recommend that the Commission considers the merits of extending to employees who have less than 12 months of continuous services to be eligible for periods of unpaid leave as follows:

- Employees with 12 months or more continuous service are eligible for up to 12 months of unpaid carer leave (extended leave).
- Employees with more than 6 months, but less than 12 months continuous service are eligible for up to 3 months of unpaid carer leave.
- Employees with less than 6 months continuous service are eligible for up to 1 month of unpaid carer leave.

Nature of the carer required

Currently an employee can take paid, short-term carer leave for support of a member of the immediate family or household who is sick, injured or has an unexpected emergency.

As remarked elsewhere, long-term carer leave can serve the purpose of allowing carers to adjust many aspects of their own lives and lives of those they care for when they are suddenly confronted with the need to provide significant amounts of care. These can include:

- confronting and complex financial decisions
- researching what formal supports are available to the person they care for and to themselves as carers and accessing those supports
- significant life-style adjustments
- the need to find alternative accommodation if the person being cared for has been living in a separate location
- training and acquiring skills to provide different levels and kinds of care needed by the care recipients
- intensive engagement with the health system
- just adjusting to the caring role and getting a sense of whether they can sustain it.

Extended carer leave should not be confined to just providing hands on care.

Employee coverage

Unlike current carer leave, which is not available to casual employees, parental leave is available to casual employees who:

- have been working for their employer on a regular and systematic basis for at least 12 months
- have a reasonable expectation of continuing work with the employer on a regular and systematic basis, had it not been for the birth or adoption of a child.

We recommend that long-term carer leave should be made available on the same basis.

24. Should access to the proposed entitlement be once-off or occur more often?

Carers Australia recommends the proposed entitlement should be accessible by carers more than once for each person receiving care; for example, on commencement of caring, escalation of caring, and for transitions in care such as residential care placement or end-of-life care.

Carers Australia also recommends that, consistent with parental leave, the proposed entitlement should be available for care of more than person.

Case study 8:

Geraldine has lived in Australia for 25 years and works as an office manager for a small not-for-profit. Her ageing parents still live in her home country and Geraldine had been becoming more concerned about how they were managing at home. After she had to take unexpected leave to fly home after her mother Róisín had a stroke, Geraldine contacted her employer to request extended leave so she could stay and arrange home care services after her mother came home from hospital. Eighteen months after she returned to Australia, her mother died of a subsequent stroke. When Geraldine flew home again, she discovered her father Pádraig's dementia had progressed significantly and contacted her employer to request another period of extended leave to get her father admitted and settled into a long-term care facility. Geraldine's own retirement plans have experienced a financial set-back due to two periods of extended unpaid leave, but she is very grateful for her employer's understanding and that she is able to return to her job rather than having to find another job when she returns to Australia.

25. How long should an entitlement to unpaid leave to care for an older person be? Why?

If long-term unpaid carer leave is to be modelled on parental leave, it should be for up to 12 months in the first instance with the possibility of extension by up to another 12 months with the agreement of the employer.

26. What should the process be for revising the return date, if any?

There may be a number of reasons why the carer may wish to revise the return date to work. For example, if the person they care for is admitted to residential care, if they find community care support services which they were not aware of or had no access to when they commenced their leave, or if another family member or friend steps into the caring role.

In terms of extending their leave, we turn again to the conditions for unpaid parental leave. The parent must give the employer at least 4 weeks' notice. Employers can only refuse if:

- they have given the employee a reasonable opportunity to discuss their request
- there are reasonable business grounds to do so.

We note, however, that the employer does not have to detail their reasons in writing and we can see no reason why this should not be a requirement.

27. How should the entitlement be provided (for example in single block or in multiple) and why? What would likely be the consequences

In the case of long-term leave in a number of OECD countries, the leave entitlement can be broken up into separate tranches. For example:

- In Japan (where the leave is paid) employees are entitled to take leave in up to three instalments totalling 93 days per family member in need of care.
- In Denmark up to 6 months leave with a possible extension for another 3 months.
- In Switzerland up to 14 weeks over an 18 month period.
- In Ireland, which has a minimum of 13 weeks and up to a maximum of 104 weeks, leave can either be continuous or shorter periods.

Breaking up the leave may benefit some employers and cause disruption for some others. But the same is true for parental leave. See also comments against Question 32 below.

28. Should all employers be required to provide the entitlement? Why or why not?

The focus of this Inquiry is the provision of extended care leave under the National Employment Standards. All employers are covered by the National Employment Standards, although there are some caveats applying to small businesses. However, this does not apply to parental leave entitlements.

29. What costs, perverse incentives or unintended consequences should the design of the entitlement aim to minimise or avoid? How might this be achieved?

Three examples come to mind.

- If leave is only available on a continuous basis, as opposed to the option of taking it in tranches (perhaps across a 12 month period), this is likely to disadvantage carers who may only require a shorter term period, or who cannot afford to take leave for an unbroken year, or who might have access to replacement care for a period of time. As a consequence, they may not apply for leave that would assist them to make many adjustments to their situation and would also assist those they care for.
- The absence of an entitlement to return to their employment would also constitute a disincentive for applying for long-term leave.

- Looking at new long-term leave entitlements from the perspective of employers, it may be argued that employers would be averse to employing people, or keeping people, who they know to be carers. Similar arguments were raised with the introduction of maternity leave - the fear or threat that employers would be less likely to employ women of child bearing age in relationships. There is no evidence to suggest that this was a wide-spread phenomenon, although there may be some employers who still operate in this way. Employers seem to have adjusted well to the introduction, first of maternity leave and then to broader parental leave, without any evidence that the proportion of women employed of child bearing age has declined.

30. What would be required practically to insert the proposed entitlement in the NES?

We have no expertise in employment law but would imagine that the same processes would apply as introducing any other changes to the *Fair Work Act*.

31. To what extent does eligibility for the existing payments affect carers' employment decisions?

Economic modelling prepared for Carers Australia ³⁹ on the impact on lifetime income and retirement savings of carers provides a comprehensive overview of the circumstances, rules and history of carer subsidies in Australia. It notes the historical rationale for carer payments was that they would substitute for formal care provided in a nursing home, at lower cost to Government.

Over time, this has been decoupled. When the first carer benefit was introduced in 1972 it was equivalent to 33% of the Government benefit payable to an approved nursing home for a person needing extensive care. It is now only 6%. Similarly, whereas it was originally around 25% of the income of a couple on the basic age pension, it has now fallen to 10%. Where the rewards for caring are reduced, the opportunity costs of care increases and fewer prospective carers will be willing to meet demand from an ageing population.

Carers Australia strongly suggests that eligibility for the Carer Payment provides little incentive for most carers to forego employment where the minimum wage is currently \$813.50 per week compared to \$493.80 for the Carer Payment (plus \$64.80 for those also in receipt of Carer Allowance to cover the additional costs of care). In addition, partnered carers have less access to the Carer Payment as it is means tested against a spouse or partner's income.

People are not always aware of the complex eligibility criteria for income support payments until after they have made the decision to cease employment. They are however frequently aware of the impact on their retirement savings of extended periods out of the workforce.

³⁹ Caring Costs Us: [The economic impact on lifetime income and retirement savings of informal carers](#). A report for Carers Australia. March 2022

Carers Australia supports calls from multiple sources for superannuation carer credits⁴⁰ to boost the retirement savings of carers during extended unpaid leave.

32. What challenges do informal carers of older people face in accessing the supports they need?

Carers face multiple challenges in accessing the supports they need for both the people they care for and for themselves.

Lack of carer recognition is an important barrier to carers accessing support services for themselves. Many carers are what we refer to as “hidden carers”. They don’t identify with the term and, as a result, are unlikely to be aware of the support services available to them. Nor to our knowledge do people who they interact with in their capacity as carers, such as medical professionals, have a high awareness of the existence of carer support services.

With respect to workplace support, many employers lack awareness of the role of carers, their need for some flexibility in the workplace and who they are among their employees. Having said that, a number of employers are cognisant of and supportive of carers. In the 2020 Carer Wellbeing Survey employed carers were asked if their employer or supervisor was understanding of their caring obligations. Of these, 17.2% reported they were not very understanding, 41.6% that they were somewhat understanding, and 41.3% that they were very understanding. Younger carers were more likely than other employed carers to report their employers were not very understanding (23.5% of those aged 15-24 and employed, and 25.7% of those aged 25 to 34).⁴¹ Older carers, those most likely to be caring for an older person, had more positive results with only 16.3% in the 45-54 age range and 14.1% in the 55-64 group reporting a lack of understanding.

With respect to supports for the people they care for, the challenges to accessing paid replacement care for those they care for are explored further in the answers to questions 5, 6 and 13 above. They include the person they provide care for being unwilling to access paid care in the home, difficulty in accessing culturally safe support for some groups of older people and their carers, long wait times for access to Home Care Packages and the lack of services provision in their communities even when the person being cared for has been assessed for a package.

While many improvements to aged care are in train or projected on the back of the Royal Commission into Aged Care Quality and Safety, there is still some way to go to address these problems

⁴⁰ Australian Human Rights Commission (2013) Investing in care: [Recognising and valuing those who care, Volume 1 Research Report](#), Australian Human Rights Commission, Sydney.

⁴¹ [211011_Carer-Wellbeing-Survey_Final.pdf \(carersaustralia.com.au\)](#), pp.45-47

33. What are the main types of supports that informal carers rely on?

The main types of support available to by carers are:

- Formal care and support services for the person receiving care, including the NDIS for carers of people under 65 and other disability support services and the Commonwealth Home Support Program and the Home Care Packages Program for carers of people over 65.
- Planned respite care services – in-home, community-based, overnight and in residential aged care homes
- Carer Support Services available through the Carer Gateway – counselling, coaching, peer support, education, carer-directed support packages and emergency respite care.
- Specialist advice and advocacy services available to culturally and linguistically diverse carers or to condition-specific carers such as those caring for someone with dementia or end of life care.

Whether they can rely on timely access to these services is another thing when it comes to support in home and respite (especially community-based respite).

Carers also rely on affordable, easy access to quality health services, both for the people they care for themselves. However currently the health system is under considerable strain and access to specialists in particular can take many months.

Alternative supports for informal carers

34. What types of alternative support measures are most needed by informal carers? Why?

Carers Australia considers the support measures needed most by both employed carers and carers not in the workforce is affordable, substitute care of sufficient quality and quantity to enable carers to choose how they spend their time away from caring.

For employed carers, support for the person receiving care that is timely and flexible e.g. day care centres, enables workforce participation by carers. For carers not in the workforce, timely flexible respite care services enable carers to focus on their own health and wellbeing, reduces social isolation, and may also supports their participation in volunteer work or unpaid caring for others e.g. grandchildren.

Access to day care centres by people with dementia has been shown to increase carers positive feelings and decrease negative feelings about providing care. These outcomes are

dependent however on the quality of day care and how well the service meets carer's needs for flexibility, support, information, and responsibility sharing.⁴²

Greater conflict between work and care is associated with higher role overload, worry and strain making employment difficult to reconcile with the carer role. As a reliable respite and support service, quality day care centres enable employed carers (mostly adult offspring) to spend more time at work, which influences their employability as they experienced fewer job-caregiving conflicts and reduced role strain.⁴³

Carers Australia recommends that existing Carer Gateway supports for employed carers are significantly enhanced by Department of Social Services and that the Department of Health and Aged Care boosts funding for day care centres in the new Support at Home Program.

35. Are there particular supports that would be needed to complement the introduction of an entitlement to extended unpaid leave?

The Australian Human Rights Commission National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability in 2016, found that employment discrimination and barriers were also experienced by carers of older people and people with a disability.⁴⁴

“The Commission heard from Carers NSW that overcoming the barriers to work for older Australians and Australians with disability requires an understanding of care and must address the issues that face those who have a care role in their personal lives. Many older Australians, although ‘retired’ have in fact exited the workforce in order to provide care to ageing parents, or to spouses with illness or disability. Many older Australians who would like to work, have spent years excluded from the labour market because of their caring role.”

The Inquiry heard of many experiences where people felt they had been discriminated against or had received unfair treatment from an employer due to their responsibility as a carer. A common theme was the denial of flexible working arrangements to accommodate caring responsibilities.

In their submission to the Inquiry, the NSW Public Service Association reported:

- Around 11% of respondents had experienced discrimination in employment because they were a carer (for an older person or a person with a disability).

⁴² Tretteteig, S., Vatne, S., & Rokstad, A. M. M. (2016). The influence of day care centres for people with dementia on family caregivers: an integrative review of the literature. *Ageing & mental health*, 20(5), 450-462.

⁴³ Ibid

⁴⁴ Australian Human Rights Commission 2016 [National Inquiry into Employment Discrimination Against Older Australians and Australians with Disability](#)

- Over 88% stated that they believed older Australians, Australians with disability and their carers experience barriers in employment.
- Many lamented the lack of authorisation to work from home in order to make juggling work and carer commitments easier.
- Some pointed out that taking breaks from the workforce to meet carer commitments may negatively affect people in the ‘prime’ of their career.
- A number use personal leave and long service leave, to meet carer obligations and remain in the workforce because they had been led to believe that workplace adjustment (including flexible working agreements) was not available.
- Others believed their application for workplace adjustment would not be approved, or they feared making such a request.
- Some indicated that accessing leave to care for family members was also often difficult. They reported being ‘cross-examined’ by their managers about why they needed the leave.
- Some expressed concerns over requests by managers and employers, considering this to be a breach of privacy.

Victoria is the only Australian jurisdiction where carer status is a protected attribute in terms of workplace discrimination. At the peak of the pandemic, the Victorian Equal Opportunity and Human Rights Commission surveyed and interviewed Victorian workers aged 18+ years, who are parents, carers and/or have a disability, to better understand how COVID-19 transformed approaches to flexible work.

The pandemic highlighted the struggle many carers and parents face in juggling their work and caring responsibilities, and the benefits of working flexibly in order to balance these responsibilities. Workplaces now have an opportunity to embed flexibility and enable caring and parenting to be shared equally within households, advancing gender equality and enabling all working parents and carers to make valuable contributions in the workforce and in public life more broadly

The Commission’s research demonstrates a need to:

- embed flexible work as part of a business-as-usual approach, enabling parents and carers to better balance and share caring responsibilities
- invest in strategies to transform societal attitudes towards unpaid caring and parenting, to adequately ascribe value to the ‘second shift’ many workers perform outside of their formal working hours
- strengthen enforcement of the Equal Opportunity Act to better protect parents and carers from discrimination.

Employers have a vital role to play in facilitating a range of flexible employment practices, including leave for caring responsibilities and carer entry back into paid work.

36. Are there alternative employment measures that ought to be considered in place of, or in addition to an entitlement to extended unpaid leave? What kind? Why?

Available research and lived experience evidence indicates that carers will need and benefit from different workplace measures at different stages in their time as a carer and according to their individual and family circumstances.

There are many ways businesses and employers can better support carers in their workforce in addition to an entitlement to extended unpaid leave. These do not have to be costly or require a major change in operations. Simple adjustments can make significant differences to recruitment, retention, and re-entry to employment for carers.

The Carers NSW Carers + Employers program promotes carer-friendly workplaces, including a workplace accreditation scheme. They have developed 10 tips for workplaces:⁴⁵

- Raise awareness of what it means to be a ‘carer’ and enable staff with caring responsibilities to self-identify.
- Recognise carers as a distinct group within HR policies and procedures.
- Develop a supportive culture in which carers feel comfortable disclosing their caring role and discussing their needs for flexibility. Managers play a key role.
- Consult with staff to understand the ‘carer population’ in your workplace.
- Provide practical support based on what carers have said would be helpful. Expand carer leave provisions where possible above the minimum legislated requirements and explore options such as purchased leave.
- Promote flexible working arrangements by making flexibility the norm, rather than the exception, for all job roles. Train line managers to understand the challenges faced by carers and workplace policies to ensure that support is offered consistently.
- Unlike most diversity groups, staff can become or cease being a carer throughout their career. Monitor changes in the carer population and their uptake of workplace supports.
- Explore supports such as paying superannuation during unpaid carer leave, offering career breaks, or promoting carer-specific return to work programs.

One in three carers have a reported disability of their own, and around one in five are aged 65 years and over.⁴⁶ In addition to their caring role, carers therefore also experience similar issues to older people and people with disability in relation to work.

Carers Australia recommends further change to the NES provisions for paid personal leave to increase access to carers leave. As discussed earlier in this submission, carers have poorer health and wellbeing than non-carers and are at risk of leaving employment both due to their own ill health and their caring responsibilities. This double jeopardy contributes to the

⁴⁵ Carers NSW Carers + Employers [10 tips for a carer friendly workplace](#)

⁴⁶ [Disability, Ageing and Carers, Australia: Summary of Findings, 2018 | Australian Bureau of Statistics \(abs.gov.au\)](#),

very low rates of workforce participation by carers, which extended unpaid leave may improve. However, a more substantial improvement in workforce participation rates could be achieved by complementing this with additional paid leave to reduce the financial burden on carers.

In line with Recommendation 15a of the Australian Human Rights Commission in 2007, **Carers Australia recommends** that the personal leave standard in the NES be increased from 10 days to 20 days per annum with 10 days to be noncumulative.⁴⁷ The Human Rights Commission considered this a complementary entitlement to 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. Like the Parental Leave Standard, this new Standard should be job protected and available to employees who have 12 months continuous service.”⁴⁸

The pandemic has also highlighted shortcomings and public health hazards in the current NES personal leave provisions for the working population without access to paid personal leave. Carers Australia commends the Victorian Government Sick and Carer’s Pay Guarantee. This is a two-year pilot program of five days paid leave for casual and contract workers in hospitality, supermarkets, aged care and disability support, cleaners and other essential occupations. Eligible workers without any sick and carer’s leave entitlements will no longer be forced to choose between being paid or looking after their own health or that of someone they care for.⁴⁹

Extensions to carers other than carers of older people

37. In which ways does informal care of older people differ from the care that other people might require?

See answer to question 38 below.

38. Are there reasons to have different policies for informal carers of older people than for informal carers of other types of people?

Carers Australia is of the view it makes no sense at all in terms of logic or social justice to confine an entitlement to extended unpaid carer leave to carers of older people, unless the intent is to artificially minimise the number of employees who have access to these provisions, which would be inequitable and overtly discriminatory.

⁴⁷ Human Rights and Equal Opportunity Commission [It’s About Time: Women, men, work and family Final Paper 2007](#)

⁴⁸ Ibid

⁴⁹ Government of Victoria, Victorian Sick Pay Guarantee [Sick and carer’s pay for casual and contract workers](#)

The same rationale which applies to carers of older people applies to carers of people under the age of 65 with disability, chronic illness, who are providing end of life care and who are caring for people with psychosocial disability.

According to the 2016 Survey of Disability, Ageing and Carers, 64.7% of people receiving informal care are under the age of 65 compared to 35.3% over the age of 65. The number of carers caring for people under 65 are considerably more likely to be of working age, and therefore to benefit from carer leave, given that carers over the age of 65 (that is, about a quarter of carers) are primarily the spouses and partners of the older person they are caring for.⁵⁰

The nature of the care they provide to someone under 65 is very similar to that of a carer of an older person. There are variations, of course, depending on the condition of the person being cared for. However, the nature of the care needed for different conditions across the age range are mostly very similar. For example, the 2018 SDAC compared the care provided to someone with severe core activity limitations and with profound core activity limitations across the age groups of carers (15-44, 45-64 and 65+) and the hours of care provided. There were few variations of significance between the hours of care per week provided by carers in different age cohorts except for the 40+ hours of care category⁵¹.

And as the table on page 4 of this submission illustrates, carers of people under the age 65 have had more profound effects on their employment, with the exception of early retirement, than carers of people over 65.

Nor is there a case for restricting support for carers based on the age of the person being cared for on the grounds of their contribution to the economy through containing the costs of government subsidised support services. Just as carers of older people are universally considered to be the bedrock of a financially and practically viable aged care system, carers of people under the age of 65 are essential to containing the costs and filling in the gaps in the paid care workforce for government subsidised disability and health services.

Carers Australia recommends that the entitlement should be available to carers of people of all ages.

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⁵⁰ Extracted from [Disability, Ageing and Carers, Australia: Summary of Findings, 2018 | Australian Bureau of Statistics \(abs.gov.au\)](#).

⁵¹ [Disability, Ageing and Carers, Australia: Summary of Findings, 2018 | Australian Bureau of Statistics \(abs.gov.au\)](#), Table 37.3

About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail aged.

In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represent the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers should have the same rights, choices, and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment, and education.

This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including 'grandparent carers'
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI+)
- Who are living in rural and remote Australia, and
- Who are no longer in a caring role (former carers).

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples and communities as the traditional custodians of the land we work on and pay our respects to Elders past, present and emerging. As an inclusive organisation we celebrate people of all backgrounds, genders, sexualities, cultures, bodies, and abilities.