



Australian Government Productivity Commission Carer Leave Inquiry

**A Dementia Australia submission to the Productivity
Commission**

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“Not only would I do the work of a formal paid carer, but I was also the psychologist, secretary, transportation, guardian, chef, nutritionist, keeper of the wardrobe and social planner.” Carer for older person living with dementia

Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia. We support and empower the estimated half a million Australians living with dementia and 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia, yet it remains one of the most challenging and misunderstood conditions. Founded by carers more than 35 years ago, our organisation engages with people with dementia, their families and carers in our activities, planning, policy and decision-making, ensuring we capture the diversity of the lived experience of dementia across Australia. Our advocacy amplifies the voices of people living with dementia by sharing their stories and helping inform and inspire others. As the trusted source of information, education and support services, we advocate for positive change for people living with dementia, their families and carers, and support vital research across a range of dementia-related fields.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive disorders which cause a progressive decline in a person’s functioning. It is one of the largest health and social challenges facing Australia and the world. There are estimated to be almost a million Australians currently living with dementia and around 1.6 million people involved in their care. Without a significant medical breakthrough, it is estimated that there will be almost 1.1 million people living with dementia by 2058.ⁱ

Introduction

For most people living with dementia, informal carers are an integral part of their lives, and are fundamental to their care and capacity to remain safe and supported in their own home or in residential aged care. Carers of people with dementia are often a spouse or child and typically they provide wide-ranging supports including assisting with activities of daily living, personal care, responding to changed behaviours. They are often involved in making decisions about treatment and care options, service provision and financial arrangements. Carers of people living with dementia play a critical role but face their own challenges including difficulties in accessing and navigating the aged services and support system, financial constraints as a result of taking on the carer role, impacts on their own physical and mental health and a range of other issues raised in the Carers Leave Issues Paper. To enable people with dementia to live at home for as long as possible, it is critical that the needs of carers are understood and well supported. Providing essential psychosocial, financial and other forms of support for carers of people living with dementia will ensure that they are able to fulfill their role, and equally, will minimise unnecessary hospitalisations, delay premature entry into residential care and ensure that people with dementia live as well as possible.

We are grateful for the opportunity to make a submission to this inquiry in relation to the proposed extended unpaid carer leave entitlement. As noted in a recent Deloitte Access Economics report, estimates on the economic value of informal care need to consider both the replacement cost and opportunity cost of informal care provision.ⁱⁱThe former considers the cost of replacing each hour of informal care with a formal sector equivalent and estimated the value of informal care was valued at \$77.9 billion in 2020. The report also noted that ‘... many informal carers will have to partially or fully withdraw from the labour force to provide their care. The lost earnings - or opportunity cost - from this reduced or relinquished employment was further valued at \$15.2 billion.’ⁱⁱⁱWe believe the proposed leave entitlement, in addition to other forms of support, will contribute to assisting informal carers of people living with dementia to remain in the workforce in some capacity and to undertake their caring role.

As the peak body for dementia advocacy in this country, we regularly survey people living with dementia, their carers and family members on the issues that are important to them. Our submission to this inquiry is informed by feedback from former and current carers who participate in our Dementia Advocates program. We selected key questions from the Carer Leave Issues Paper and surveyed 360 advocates who identified as a former or current carer. The statistically significant 34 per cent response rate attests to the importance of the issues raised around the informal carer role. The response rate should be qualified by acknowledging that not all respondents completed the full survey, and that the data presented below represents percentages in terms of the number of respondents for each individual question. The survey responses, in addition to other forms of feedback from our carer advocates, provides the basis for our submission. Dementia Australia's position supports the proposed extended unpaid leave entitlement could be beneficial in encouraging and supporting employees, particularly women, to remain in the workforce while providing informal care.

Informal carer demographics

A brief outline of the core demographics of our informal carer community is important to contextualise their responses in this submission. In line with the Issues Paper data, our findings reflected the gendered nature of the informal carer role, with 78 per cent of carers identifying as female. 98 per cent of carers were family members with the majority of those identifying as a partner or spouse of the care recipient (64 per cent). 46 per cent of survey respondents were under the age of 65 and are defined as of working age. Of those under 65, 90 per cent were women. The overrepresentation of female carers under the age of 65 reinforces the Issues Paper findings that women are more likely to take on caring responsibilities and to experience impacts on their workforce participation.

The impact of the informal caring role on workforce participation

The Issues Paper sought information about the circumstances in which people became informal carers for older people, including the necessity to change work arrangements or leave the workforce entirely. 80 per cent of survey respondents reported having had to make a change in their paid work arrangements. Of the women under the age of 65 who responded, 90 per cent reported having to reduce paid employment in some capacity.

Key findings from all respondents include:

- 29 per cent switched to part-time work or reduced hours
- 29 per cent of respondents reported resigning, taking voluntary redundancy, or being terminated due to inability to manage work and the caring role
- 14 per cent retired prematurely
- 11 per cent took personal leave or put in place flexible working arrangements to manage caring responsibilities

In addition to the changes made to paid employment listed above, many respondents reported that a combination of changes were required to manage their caring responsibilities. This included reducing hours worked followed by resigning when caring became too difficult to manage or resigning from full-time employment and taking up part-time work as a result of financial constraints. Some respondents described having to take up multiple, part-time roles to fund paid care. Of the respondents that reported remaining in full-time employment, most reported significant challenges in doing so.

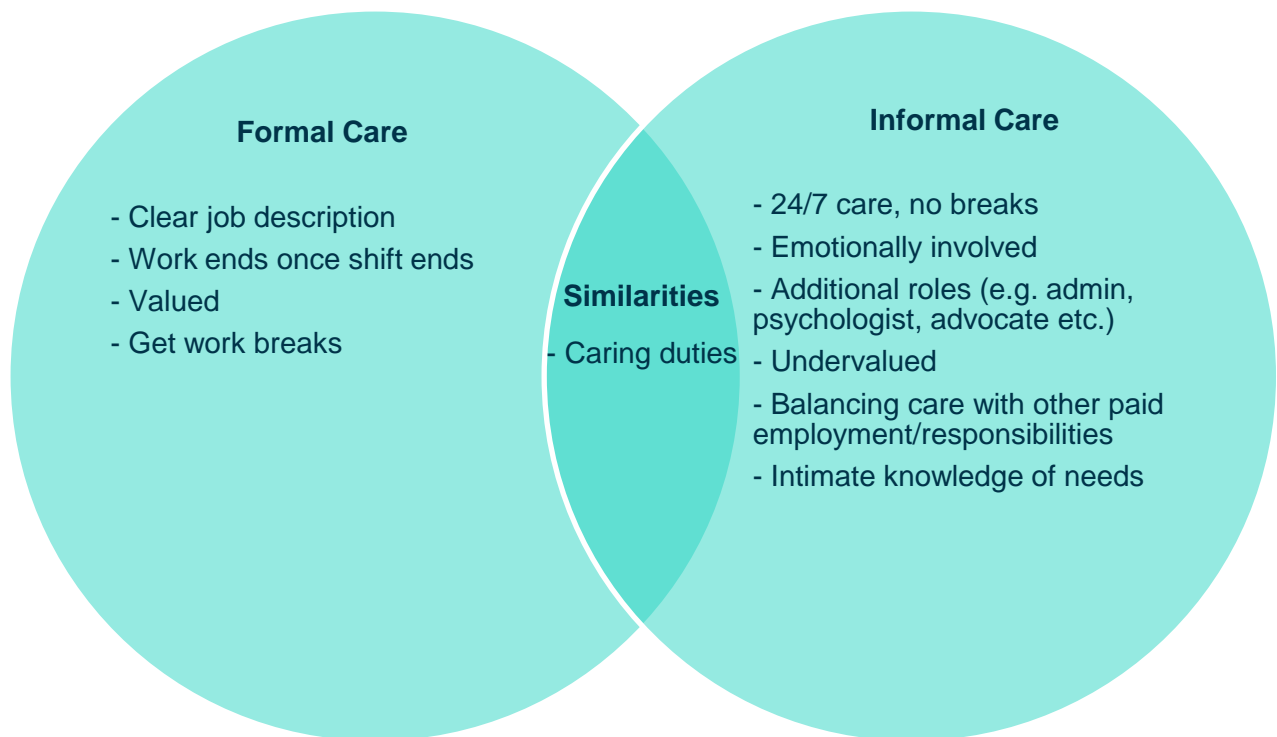
“Initially I worked less hours but eventually I had to stop work altogether. I was self-employed and could not sustain the business on reduced hours”

“I had to quit my teaching job completely. I then worked in customer service, starting full-time, and gradually decreasing. Then had to resign from that to become a full-time carer.”

“I had to take many days of carers leave to attend dr appointments with my husband. I retired 5yrs earlier than planned to take on a carer role”

Defining the differences between informal and formal care

Respondents were asked about the similarities and differences between their informal carer role and that of a formal (paid) in-home carer. Most respondents reported the primary differences related to the duration and obligation of care. Formal carers have defined working hours including scheduled breaks and can choose when to take time away from the caring role. Respondents noted that in contrast, the informal carer is responsible for the care recipient 24 hours a day and 7 days a week, while often also taking on additional tasks including financial, social and other responsibilities. The following diagram reflects the views of respondents:



'We do everything and more a paid carer does.'

"I think mainly of differences. My role is 24/7 since the person I am caring for lives with me. The paid carer sticks to a schedule and can always go home at the end of the day and switch off from their duties."

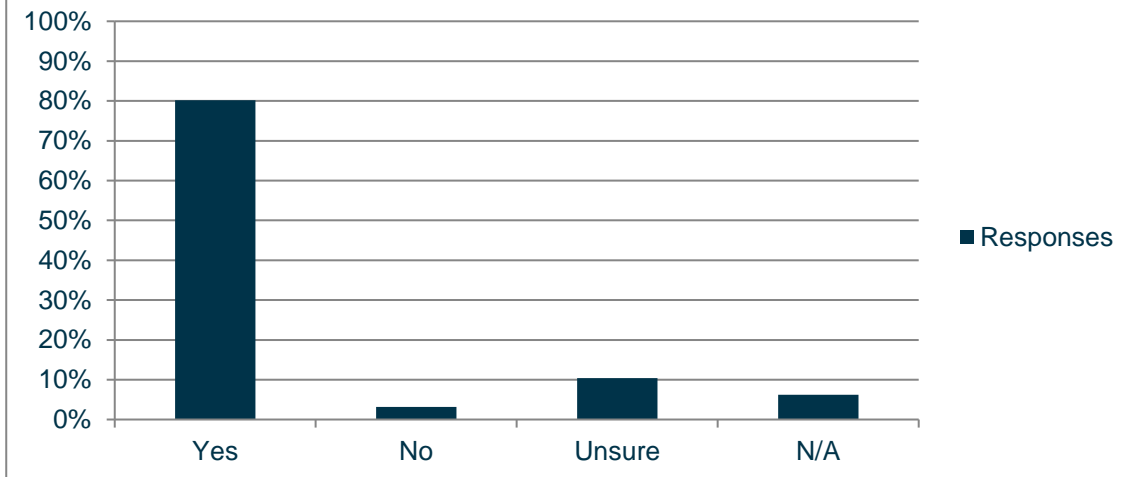
"Not only would I do the work of a formal paid carer, but I was also the psychologist, secretary, transportation, guardian, chef, nutritionist, keeper of the wardrobe and social planner."

The importance of informal care provision

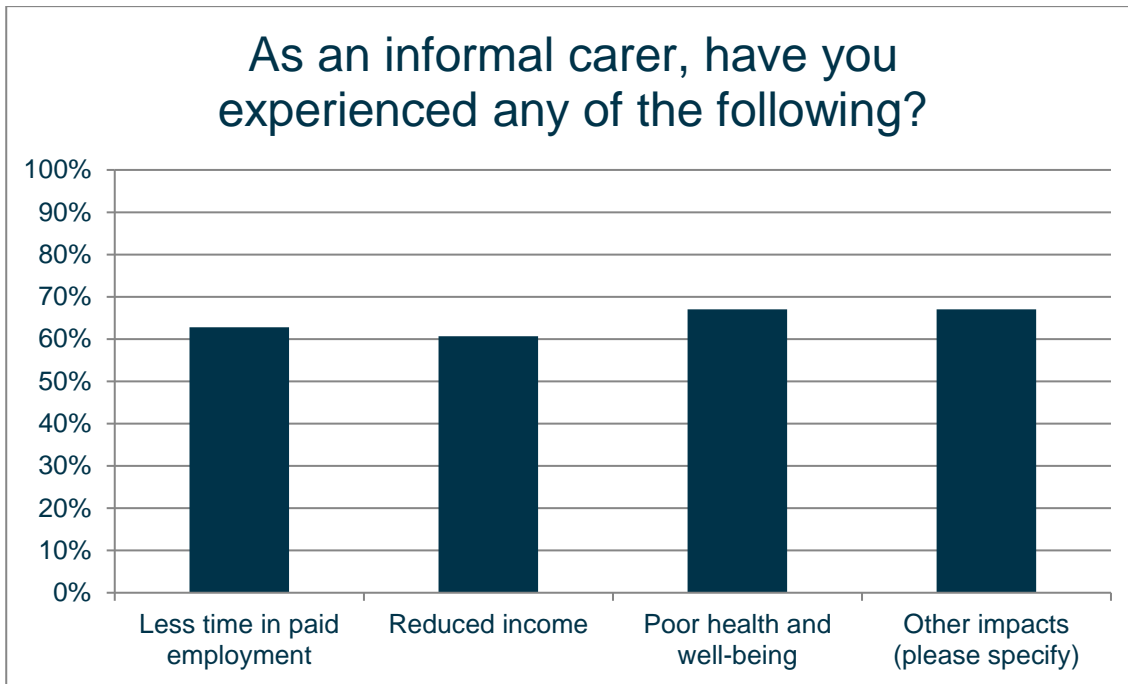
The Issues Paper sought information about how many older Australians rely solely on informal care, and the circumstances and reasons for this. Our survey asked participants if the informal care they provided was the only care that the person receives, and if this was the case, the circumstances underpinning this. Survey respondents who identified as the sole providers of informal care nominated a range of reasons including the lack of available support (including respite and home care), financial constraints (they were unable to afford private care), and a personal preference on the part of the carer or care recipient not to access other forms of assistance and care.

On the nexus between the provision of informal care and the potential need for residential aged care, we asked respondents if a reduction in informal care would necessitate their care recipient entering residential aged care. As indicated in the chart below, 80 per cent of survey respondents reported that the person they care for would need to enter residential care if they were unable to provide informal care. The strength of the response attests to the critical role that informal carers play in keeping people with dementia living in the community with the associated quality of life benefits, while also reducing the potential for premature entry into residential aged care. It equally draws attention to the significant contribution that informal carers make to the national economy in providing care in the home, as noted in the introduction to this submission.

Would the person need to enter residential care if you were not able to provide informal care?



Significantly, our survey found that once people living with dementia had entered residential aged care, informal carers continued to provide support in a variety of ways. These included finding allied and other health care providers, accompanying the older person to appointments outside the residential aged care facility, and providing other forms of assistance including supporting aged care staff in their roles as a result of staff shortages and perceived gaps in personal care.



The impacts of caring

Our survey findings supported data presented in the Issues Paper in relation to the ‘costs of caring.’ 80 per cent of survey respondents reported experiencing some impact as a result of their informal carer role. As presented above, 60 per cent or more of respondents reported experiencing reduced time in paid employment, reduced income and/or poor health and well-being. Two thirds of all respondents reported other impacts including ‘carer burnout,’ anxiety, social isolation, disruption to life plans, stress, and exhaustion. These findings support Australian and international research highlighting the physical, psychosocial, financial and other impacts that the caring role can entail.^{iv}

Carer employment entitlements

The Issues Paper requested information in relation to the use of paid or unpaid leave, or flexible working arrangements, and the circumstances in which these changes to employment conditions were accessed to facilitate the provision of informal care. There were a wide range of responses to this question and notably, many respondents indicated that rather than taking leave or requesting flexible work arrangements, they were forced to either

reduce their hours or in many cases resign altogether as illustrated in the representative comments below. It was not clear from these responses whether paid or unpaid leave, or the option of flexible work arrangements, was available to these employees.

‘While I was a manager I could organise all my work meetings around my father's caring and appointments. But then when I was no longer a manager my father's commitments caused me to miss work meetings and eventually I lost my job.’

‘Reduced hours, less wages, lost employment’

‘Had to give up paid work completely as the caring role was 24/7.’

Others indicated that they used a combination of different leave types and other work arrangements to accommodate their informal caring role.

‘At first I used up all my leave and then went onto part time work’

‘I used my leave entitlements for caring responsibilities. When in the primary care phase (as caring is a continuum) I went to minimal casual work.’

‘I had to ask for flexible work from home arrangements’

On the issue of barriers that limit informal carers of older people from using current leave entitlements or flexible working arrangements and the ways in which these barriers might be reduced or removed, there was again a range of responses. As noted above, many respondents were forced to leave work altogether to provide informal care.

Respondents who remained in some form of employment reported the following barriers to accessing leave entitlements or flexible working arrangements:

- Lack of employer education, awareness, and understanding of caring needs
- Shortage of staff/conflict with schedules
- Lack of flexibility in the role or workplace
- The challenges of living and working in remote locations
- Entitlements not available or applicable for those that are employed
- Current entitlements not always sufficient to prevent leaving employment eventually

Respondents suggested the following measures to mitigate or remove these barriers:

- More awareness training and education for employers and the community
- Greater leave availability
- Encouraging work from home arrangements when possible
- More home care options
- Increased flexibility of employers
- Subsidised respite

The benefits of the proposed extended unpaid carer leave entitlement

The Issue Paper sought feedback on the impact of the proposed extended carer leave entitlement and whether this would increase the ability to provide care and safeguard employment for informal carers. As outlined in the introduction, Dementia Australia supports the proposed leave entitlement as one of a range of measures, including access to respite and other care options, that could assist informal carers to remain in the workforce while

undertaking caring responsibilities. Our support for this measure is underpinned by our survey findings.

As noted above, many respondents reported having to leave their job due to the demands of the informal caring role. 80 per cent of survey respondents had to make some form of change to their employment as a result of their caring responsibilities. For many respondents, these changes to paid employment had significant consequences in terms of their financial stability and associated impacts on their mental and physical health and wellbeing. The survey findings indicated however, that in decision-making around care arrangements, these considerations were always secondary to their focus on the needs of their care recipient.

“They are not appropriately (formally/officially) recognised for their caring role. They are expected to juggle their caring responsibilities alongside their job - and caring for someone with dementia isn't something you do as a side hustle, it's an immense responsibility that you need be available 24/7 to take on.”

Existing supports for informal carers

65 per cent of survey respondents reported significant challenges in accessing income supports to assist in providing informal care. Most of these challenges involved the administrative workload, bureaucratic obstacles, and strict eligibility criteria involved in accessing carer payments. Navigating Centrelink was a consistent theme; for many respondents, the processes involved were experienced as overly complicated, time consuming, and difficult to understand. For these reasons, many respondents reported withdrawing from seeking income support entirely. In addition to the administrative complexities of applying for carer payments, if they were able to access income supports, most respondents reported that the carer payment was did not meet the needs of the costs involved in providing care.

“Centrelink is so complex to deal with. My dad was a country farmer and didn't want to claim the carers payment as it was too hard. Especially when you have to travel, deal with technology, need appointments whilst having a dementia person with you. Even for the period I cared for mum, it was too hard to claim the carers payment for the short period. just not worth it. Especially if you've never dealt with them before. You

need forms of ID that older people don't have like a full birth certificate - most don't have that. You have to register on mygov, have phones and GOOD INTERNET. So if you live rurally you are at such a disadvantage.”

“I haven't even tried Centrelink. I found it too overwhelming and so hard to understand if I was eligible for anything. Caring leaves you very drained so even the simplest admin task is very stressful and finding time to sit in waiting rooms or on the phone is impossible. Some sort of dedicated hot line or webpage would be good. I found Allied Health workers didn't understand Centrelink either.”

“The documentation is extremely confusing. Difficult to get help to fill it in and there is difficulty trying to contact the age care system to get help.”

A number of carers reported leaving paid employment to provide informal care, relying on personal savings to support themselves and the person they care for, and experiencing significant financial hardship as a result. Some respondents were unaware of what kinds of income support or assistance might be available to them. The low income threshold for eligibility for income support was also reported as a significant barrier to accessing income supports and remaining financially secure.

“My experience has been that Centrelink has an approach that makes applicants feel like criminals so this is unhelpful PLUS the paperwork is worse than doing a research grant! Using your own superannuation to fund your life is really unfair in the absence of economic support.”

“Carers Payment thresholds are discriminatory. My theoretical income doesn't match the reality when I have to take unpaid leave constantly.”

The Issues Paper requested information on other types of care and support the care recipient receives and our survey responses indicate that most carers have intermittent support. The majority of respondents reported receiving a combination of care, funded among other

sources, by the National Disability Insurance Scheme (NDIS) or a Home Care Package (HCP) and including:

- A mix of respite/day programs/home assistance/support work for a couple of hours per week
- Assistance from other family members
- Cleaners
- Allied health care providers

Alternative policies or additional supports to complement the introduction of an extended unpaid leave entitlement for informal carers of older people

Respondents suggested the following additional policies or supports are most needed to provide meaningful assistance for informal carers:

- Increase in current support packages to realistically meet costs of providing care
- Increased availability of respite care and payments to support respite care
- More accessible information on available forms of support and
- Assistance with navigating Centrelink
- Additional paid care leave provisions
- More counselling supports
- Flexible work arrangements
- Greater recognition and acknowledgment of carers

“Acknowledge the extensive work informal carers undertake and remunerate accordingly. It's a road to poverty for so many of us and we lose our health along the way.”

“The Carers benefit (not just the Carers Allowance) should be made available to all FULL-TIME carers. These people have sacrificed employment, socialisation, and freedom to support the care recipient . These people have lost their independent income and it is so difficult to make ends meet.”

Considerations for carers of people under the age of 65

The Issues Paper requested information on how informal care for older people might differ from the care provided to other people (under 65). A number of our Dementia Advocate carers support people living with younger onset dementia (people under the age of 65 years living with any form of dementia) and many people with younger onset dementia qualify for NDIS support. This issue was therefore significant for some of our survey respondents. Our survey findings reported differences and similarities between caring for people living with dementia aged 65 and over in contrast to those under the age of 65 as outlined below.

65 and over

- Higher probability of comorbid health issues and may require more care
- Higher probability the spouse is doing the caring and has health issues of their own
- Likely to more frail
- Likely to be retired and have financial arrangements in place

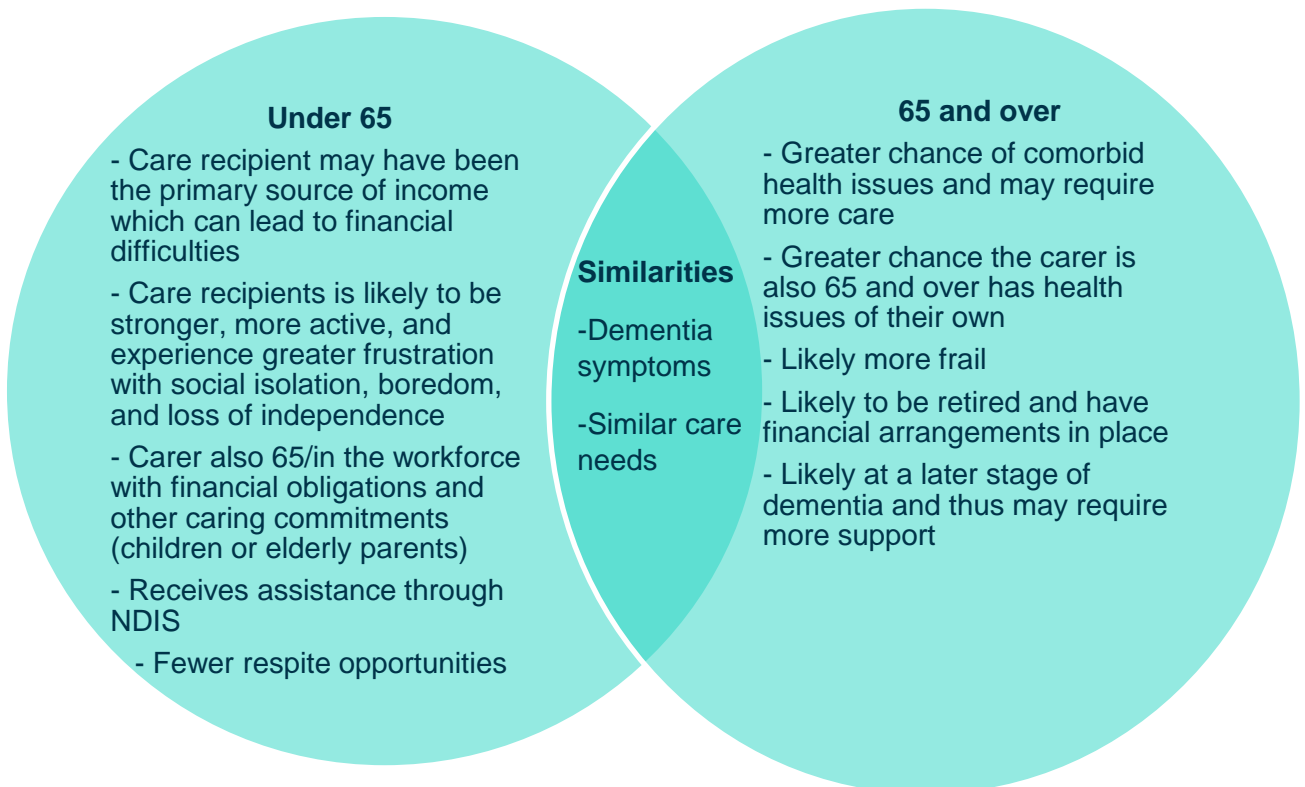
Under 65

- Care recipients may have been the primary source of income which can lead to financial difficulties
- Care recipient is likely to be stronger, more active, and experience greater frustration with social isolation, boredom, and loss of independence

- Higher probability that the carer is also under 65 and still in the workforce with financial obligations and other caring commitments (children or elderly parents)
- Care recipient under 65 receives assistance through the NDIS
- Fewer appropriate respite opportunities

Similarities

- Day-to-day caring needs may be the same
- Symptoms of dementia



“differences are more to do with the nature of disability and the degree of incapacity”

“Both groups manifest vulnerabilities and should be assessed on an individual case by case basis.”

“usually under 65 care recipients would still be working and ergo the carer is likely to also be under 65 years and possibly would otherwise be still working. It is dooming the carer to potential poverty because they stepped out of employment too early to ensure adequate superannuation, mortgage completion, and because they may not have met Centrelink requirements (or because an error occurred) they won't have a concession card to off-set the losses against the ongoing costs (say, seeing a DR, prescriptions etc).”

In response to this issue, there was consensus that services and support should be needs-based rather than age-based, given that the degree of support required depends on the stage of the condition the care recipient is living with, rather than their chronological age. When asked whether there should be different leave entitlements and income supports for people under 65, many respondents noted that the onset of dementia can be diagnosed within a variable age range so ensuring that support is available for carers, regardless of the age of the care recipient, is essential.

“For all carers of those under and over 65, my husband is now over 65. He is 67. Nothing has suddenly become easier it's all still very hard and perhaps becoming harder because I am not getting younger. I will have to continue working and caring until I am at least 70!”

“all carers need their leave entitlements and these should be negotiated to match the individual person and their needs. Age is not a good determinant. Sometimes a younger person is frailer than an older person and will need more care and attention.”

Conclusion

Our submission has been fundamentally informed by the lived experience of informal carers of people living with dementia. Our survey findings reflect a range of experiences, but there were consistent themes and issues. Most informal carers of working age are women, many of whom have had to modify their employment conditions to accommodate their caring responsibilities.

This includes taking paid and unpaid leave, reducing hours, transitioning to a casual position, or leaving the workforce entirely in order to provide care. The financial impacts of providing informal care, including changes in workforce participation, can be significant and often contribute to a range of other impacts experienced by carers, including a decline in physical and mental health.

On the basis of our survey findings, Dementia Australia supports the proposed measure of an extended unpaid leave entitlement. We believe the entitlement could be beneficial in encouraging and supporting employees, particularly women, to remain in the workforce while providing informal care. An extended unpaid leave entitlement may well make the difference between an informal carer remaining in the workforce or having to relinquish work to fulfil their caring responsibilities. There was consensus in our survey responses that the needs of the care recipient, rather than their age, should constitute the key criteria when determining eligibility for the entitlement. The kinds of barriers to seeking leave entitlements identified in our survey, including inflexible work conditions and inaccessible or unsuitable leave entitlements, would need to be addressed prior to the implementation of any new leave entitlement. Improving employer education and understanding of the demands of the informal carer role would be an essential part of this process to ensure that employees felt confident that there would be no ramifications for their current role or future prospects in taking up the extended leave entitlement. Finally, as indicated in our survey findings, many carers experience financial challenges, including difficulty accessing other forms of income support. It is important to emphasise that other sources of income assistance and care support can make an important contribution to carer financial stability, in conjunction with the assistance provided by the proposed extended unpaid care leave entitlement.

We thank the Productivity Commissioners for considering this submission and would welcome any further opportunities for consultation on this important proposal.

ⁱ *Dementia Australia (2018). Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra*

ⁱⁱ Deloitte Access Economics (2020). The value of informal care in 2020: Caring comes at a cost <https://www2.deloitte.com/au/en/pages/economics/articles/value-of-informal-care-2020.html>

ⁱⁱⁱ Deloitte Access Economics (2020). The value of informal care in 2020: Caring comes at a cost <https://www2.deloitte.com/au/en/pages/economics/articles/value-of-informal-care-2020.html>

^{iv} Carers Australia 2021, Caring for others and yourself – The 2021 Carer Wellbeing Survey. Vlachantoni, A., Evandrou, M. Falkingham, J & Robards, J., *Informal care, health and mortality, Maturitas*, Volume 74, Issue 2, 2013, pp.114-118.