Dementia Australia®

Senate Select Committee on Work and Care Inquiry

A Dementia Australia submission to the Senate Select Committee on Work and Care Inquiry

September 8, 2022

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Contents

> “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.”

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 half 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

Dementia Australia welcomes the opportunity to make a submission to the Senate Select Committee on Work and Care Inquiry.

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 and 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 which include balancing work and care, 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.

Balancing work and care can create significant challenges given that caring does not always fit around a person's work schedule. Caring is often a full-time role and one that substantially contributes to the quality of life of those living with dementia. However, due to the demands of caring, carers often withdraw from employment entirely. 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.[ii] The 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.' [iii]

Our submission to this inquiry is informed by feedback from former and current carers who participate in our Dementia Advocates program.[1] We recently surveyed 360 advocates who identified as a former or current carer on key questions relating to work and care. The statistically significant 34 per cent response rate attests to the importance of the issues

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[1] Dementia advocates program: https://www.dementia.org.au/about-us/dementia-advocates-program

raised around the informal carer role and the challenge of balancing work and care responsibilities. 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.

Dementia Australia advocates for efforts which support employees, particularly women, to remain in the workforce while providing informal care. 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 and that employment measures are in place to support carers. Further, providing essential psychosocial, financial and other forms of support for carers, including respite and home care packages 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.

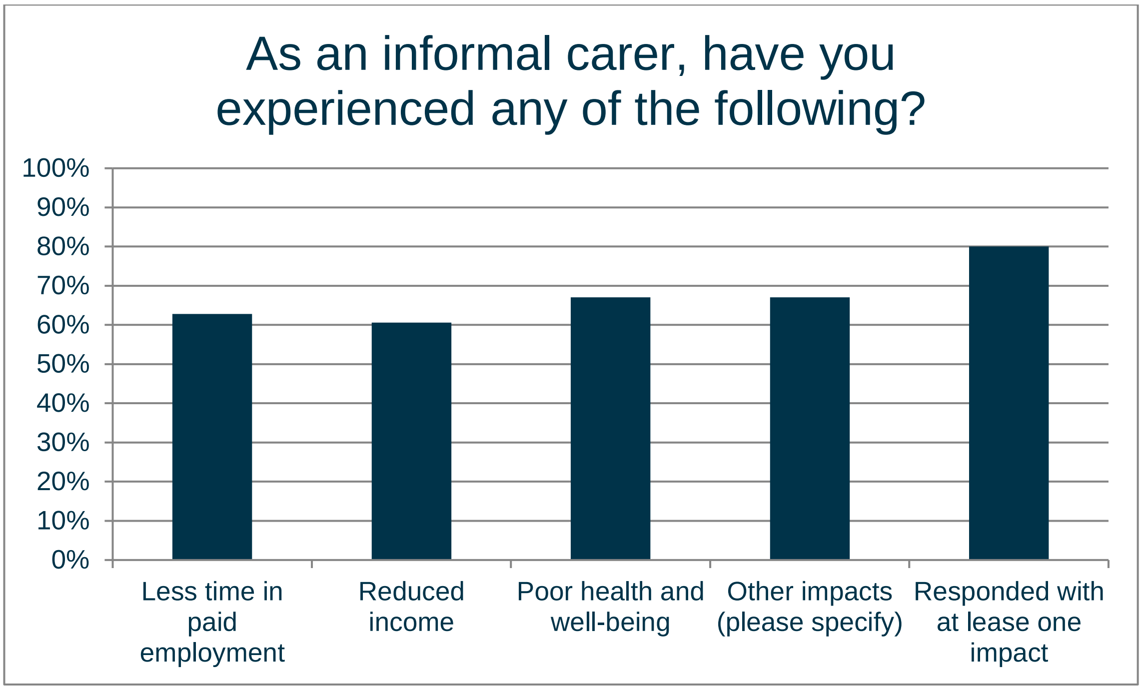
a. The extent and nature of the combination of work and care across Australia and the impact of changes in demographic and labour force patterns on work-care arrangements in recent decades;

Our survey findings reflect the gendered nature of the informal carer role, with 78 per cent of carers identifying as female. Ninety-eight 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). Forty-six 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 highlights that women of working age are more likely to take on caring roles when compared to men, which can disproportionately impact their workforce participation.

The increasing prevalence of dementia will require an increasing number of informal carers to support the number of people requiring care and support at home and in other settings. It is likely that women will continue to be overrepresented in the ranks of informal carers supporting people living with dementia, with concomitant impacts on workforce participation as outlined above. The ageing population will have other potential impacts including more individuals remaining in the workforce for longer to support rising costs of living and increased longevity. Balancing workforce and informal caring commitments in a sustainable way, particularly for Australian women, will play an integral role in providing the future support and care necessary for an ageing Australian population.

b. The impact of combining various types of work and care

The impact of work and care on the wellbeing of carers



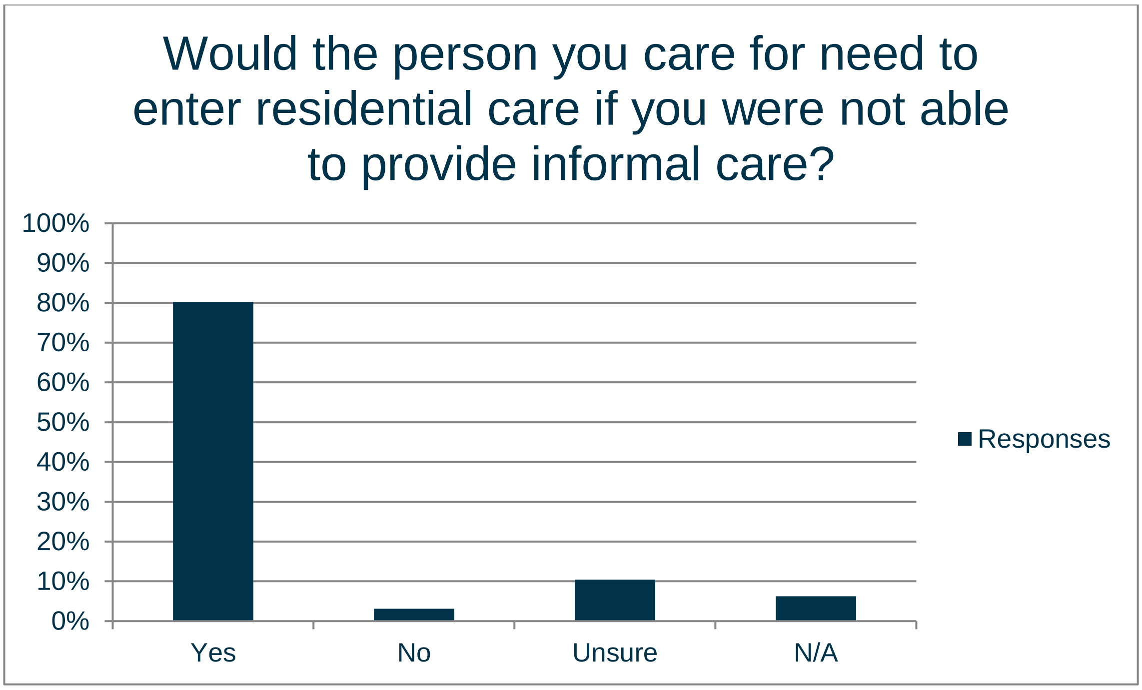
Our survey findings highlight the consequences caring can have, with 80 per cent of survey respondents reporting some impact due to their informal carer role. Balancing work and care appeared to be a challenge; as presented above, 60 per cent or more of respondents reported experiencing less time in paid employment and reduced income due to their caring role. Additionally, more than 60 per cent of respondents reported experiencing 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]

“Difficult to juggle the carer role responsibilities with any other work - professional/trade/other”

“I was already working part-time. But it was a challenge to juggle the carer role & my work”

The impact of caring on the wellbeing of care recipients

As outlined in the introduction, our submission to this inquiry is primarily informed by feedback from our advocates who are current or former carers. Sole providers of informal care nominated a personal preference on the part of the carer and/or care recipient *not* to access other forms of assistance and care as the rationale for their role. This offers insight into the care recipient's preference, where possible, to remain at home supported by informal care. We would also note that international research shows that people living with dementia, even those in the moderate to advanced stages, enjoy an improved quality of life when living in the community with various forms of formal and informal care, compared with a formal care setting. The study also indicated that living at home for as long as possible is beneficial for economic and health reasons and is associated with higher quality of life for persons with moderate dementia.'[v]



c. Adequacy of workplace laws in relation to work and care and proposals for reform

Our survey inquired about the level of satisfaction with workplace arrangements that currently support employees to care for an older person. With regard to their satisfaction with paid and unpaid leave arrangements, the majority (52 per cent) of respondents reported feeling dissatisfied or very dissatisfied. Thirty-seven per cent reported being neither satisfied nor dissatisfied, reflecting that they were either unaware of leave entitlements, did not avail of them, or the question did not apply to them as they may already be retired, self-employed, or were never in the workforce. Only 11 per cent of respondents reported being satisfied or very satisfied with paid or unpaid leave arrangements to support caring. When asked about their satisfaction with flexible working arrangements, there was a similar response pattern with the highest proportion of respondents (45 per cent) reporting feeling dissatisfied or very dissatisfied and only 13 per cent reporting feeling satisfied and very satisfied.

When asked about barriers to accessing leave or flexible working arrangements and how they might be reduced, 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’

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 responsibilities
- Shortage of staff/conflict with schedules
- Lack of flexibility in the role or workplace
- The challenges of living and working in remote locations
- Current entitlements not always sufficient to prevent leaving employment eventually

Carers 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

d. Adequacy of work and care supports, systems, and policies

Carers of people living with dementia are entitled to a range of supports that can assist with balancing work and care. However, our survey responses indicate that most carers have intermittent access to supports. Most respondents reported receiving a combination of support, funded among other sources, by the National Disability Insurance Scheme (NDIS) for carers of people living with younger onset dementia (under the age of 65) or a Home Care Package (HCP) for people with dementia over the age of 65 and including:

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

Income supports are another option for carers that have had to leave employment due to their caring role. Nevertheless, 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. Challenges 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 did not meet the needs of the costs involved in providing care.

> “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.”

e. Consideration of the impact on work and care of different hours and conditions of work, job security, work flexibility and related workplace arrangements.

Our survey sought information about the impact of combining work and care on carers’ employment and workforce participation. Our findings found that 80 per cent of survey respondents reported having had to make a change in their paid work arrangements due to their caring role. 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 main changes to work arrangements 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”

f. The impact and lessons arising from the COVID-19 crisis for Australia’s system of work and care

Throughout the pandemic there were extended lock downs where some services such as day programs and sessional respite were considered non-essential and closed under public health orders. Travel restrictions also impacted services that rely on staff travelling from the major cities. Further, during the spread of Omicron, there were significant staff shortages due to exposure to COVID-19. This meant services that many carers rely on to help balance work and care were no longer consistently available and subsequently lead to challenges in sustaining this balance.

Staff leaving the sector is also a concern and according to the 2022 CompliSpace Aged Care Workforce Report, 94 per cent of aged care staff reported an increase in their workload due to COVID-19 regulations and 50 per cent intend to quit their jobs within the next three years.[vi]

Inadequate respite has multiple flow-on effects including increases in carer stress and burn out, impacts on carers’ employment, and increases in loneliness and boredom for people with dementia. The impact of COVID-19 highlights existing weaknesses in the aged care sector, which requires a systemic approach to regulation and governance, quality dementia care, workforce training and education, and robust pandemic management strategies.

“Carer (son) is ‘unable to work as Mum cannot attend day respite which is currently closed due to COVID-19 staff shortages’.”

g. Consideration of gendered, regional and socio-economic differences in experience and in potential responses including for First Nations working carers, and potential workers;

The findings from our survey support the literature that women are more likely to take on caring roles. Of the women under the age of 65 who responded, 90 per cent reported having to reduce paid employment in some capacity, highlighting the gendered nature of caring arrangements and the overrepresentation of women exiting the workforce to provide care.

People living in remote regions are less likely to have the same care options available to them as someone living in an urban area. This can further the challenges of balancing work and care as carers may be required to travel longer distances to access specialist services and respite.

> “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.”

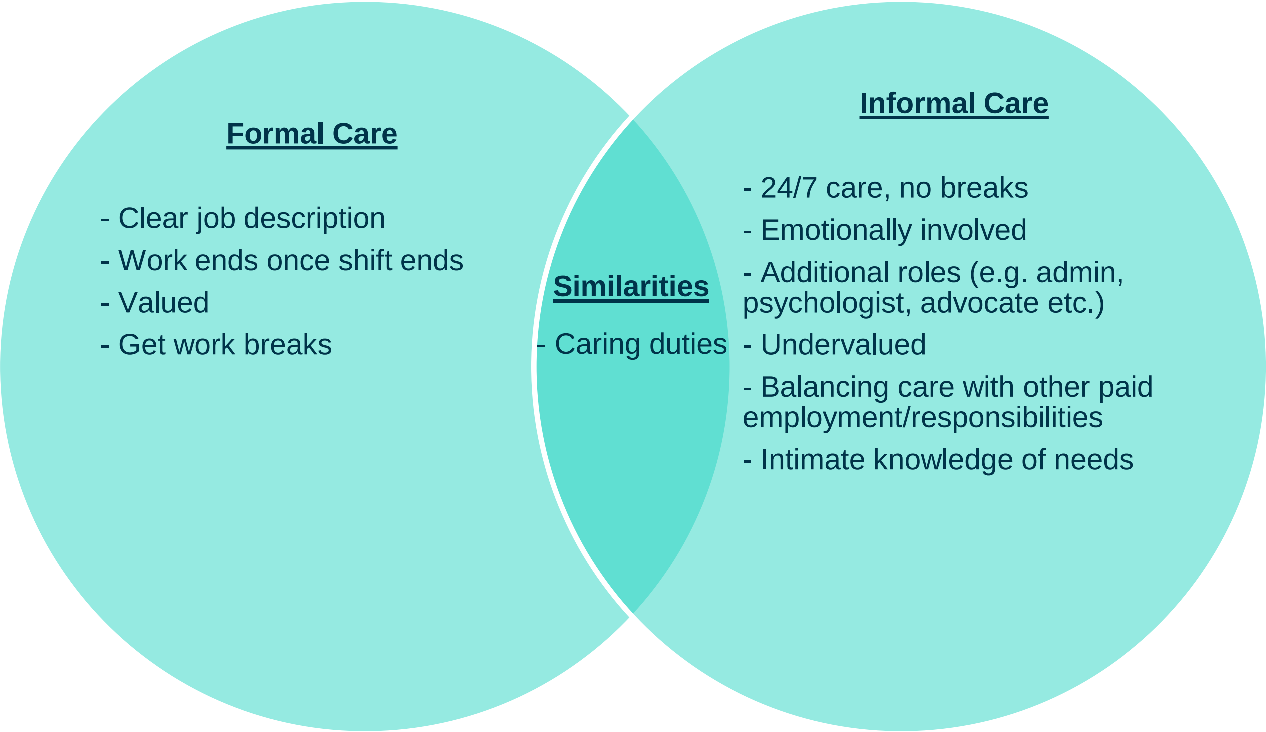
> “*the costs involved. I have to pick up dad (who now has vascular dementia) and drive him around. when I was looking after mum it was the same. When you live rurally it’s not just time, loss of work, but fuel as well. *Also, I lose out on work and my brother doesn’t and it costs my family in other ways, not just work, but my super too. *Time away from my kids.”

There is clear evidence that Indigenous Australians prefer Indigenous-specific services, including supports and services that allow people with dementia to remain in their homes and communities, and which are locally designed in partnership with those communities.[vii] A recent study noted that informal care for Indigenous Australians is gendered and generational, with one study noting that carers of older Aboriginal people living in remote Western Australia tended to be young and female.[viii] Evidence also points to limited options for culturally appropriate respite care, which places a greater burden on informal carers.[ix] Further, in some regional, rural and remote areas, there may be no respite services available.[ix] These comments are necessarily brief, and we would note that more research is needed to understand the experiences of Indigenous Australians living with dementia and the people who care for them.

h. Consideration of differences in experience of disabled people, workers who support them, and those who undertake informal caring roles;

Defining the differences between informal and formal care

The findings reflect the role of informal carers and their perspective. Respondents were asked about the similarities and differences between their informal carer role and that of a formal (paid) 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.”

i. Consideration of the policies, practices and support services that have been most effective in supporting the combination of work and care in Australia, and overseas;

Based on the high levels of dissatisfaction of current employer policies regarding leave and flexible working arrangements, there is a need for improved policies and supports for informal carers. Our survey inquired about support measures that would benefit informal carers, and 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
- 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.”

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 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 well-being. Dementia Australia supports a range of measures, including access to leave, flexible working arrangements, income supports, respite and other care options, which could assist informal carers, particularly women, to remain in the workforce while undertaking caring responsibilities. 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 seeking leave and/or flexible working arrangements. 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 other supports and policies.

We thank the Senate Committee on Work and Care for considering this submission and would welcome any further opportunities for consultation.

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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

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v Olsen, C., Pedersen, I., Bergland, A. et al. Differences in quality of life in home-dwelling persons and nursing home residents with dementia – a cross-sectional study. BMC Geriatr 16, 137 (2016). https://doi.org/10.1186/s12877-016-0312-4

vi CompliSpace Aged Care Workforce Report (2022). Retrieved September 8, 2022, from https://www.complispace.com.au/workforce-report-2022.

vii Lindeman MA, Smith K, LoGiudice D & Elliott M 2017. Community care for Indigenous older people: an update. Australasian Journal on Ageing 36(2):124–127.

viii LoGiudice D, Josif CM, Malay R, Hyde Z, Haswell M, Lindeman MA et al. 2020. The well-being of carers of older Aboriginal people living in the Kimberley Region of remote Western Australia: empowerment, depression, and carer burden. Journal of Applied Gerontology 2020 Jan 10:733464819898667. doi:10.1177/0733464819898667. Epub ahead of print. PMID: 31920136.

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