



Employment White Paper

**A Dementia Australia submission to the Employment
White Paper Consultation**

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“Organisations have got to learn more about dementia and understand it, and they've also got to have a commitment to ensuring that there's a safe environment for somebody to work”. 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 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 2058.¹

Introduction

Dementia Australia welcomes the opportunity to make a submission to the Employment White Paper. This submission addresses the needs of people living with dementia and carers in relation to the terms of reference themes on job security, fair pay and conditions, and reducing barriers and disincentives to work.

Dementia is commonly mistaken to be an age-related condition, yet it is not a normal part of ageing. Although Alzheimer's disease in older people continues to be dementia's most prevalent form, there are an estimated 28,800 Australians living with younger onset dementia (under the age of 65) in 2022.ⁱⁱ This misunderstanding leaves many employers unprepared for an employee presenting with dementia in their 40s or 50s, or even 30s. The lack of employer awareness of dementia as a disability presents as a significant barrier for people living with dementia who wish to remain in employment. Further, with improvements in dementia detection and diagnosis, there is likely to be an increase of people being diagnosed with dementia at working age, whom would benefit from support and inclusion in the workplace.

Additionally, the employment of carers of people living with dementia can be precarious, as balancing work and care can create significant challenges. Carers are an integral part of the lives of people living with dementia 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 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, particularly as it pertains to employment. Caring does not always fit around a person's work schedule and is often a full-time role leading many carers to 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.ⁱⁱⁱ 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.'^{iv} With our ageing population and average retirement age advancing, supporting people with dementia of working age and their carers is likely to emerge as a significant employment concern in coming years.

Our submission to this inquiry is informed by feedback from former and current carers and people living with dementia who participate in our Dementia Advocates program¹ and members of our Dementia Australia Advisory Committee.²

Dementia Australia advocates for efforts which support people living with dementia and their carers, to remain in the workforce as long as possible.

Summary of recommendations

Dementia Australia recommends:

- Improving dementia education for employers, the National Disability Insurance Agency (NDIA) and Centrelink
- Supporting carers and people living with dementia to remain in the workforce by incorporating inclusive policies for accessing leave and flexible working arrangements

Job security, fair pay and conditions, including the role of workplace relations: How do we ensure emerging employment practices benefit workers' economic security?

Eliminate employment stigma for people living with dementia

Too often, a diagnosis of dementia brings about the end of employment. Frequently, people are instructed by their medical practitioners to retire and begin planning for end of life.

Dementia advocate and 2017 South Australian of the Year, Kate Swaffer described this as 'prescribed disengagement':

“One has to ask the question: Why is it that one day I was studying a tertiary degree, working full time, volunteering, raising a family and running a household with my husband, and the next day, told to give it all up, to give up life as I knew it, and start 'living' for the time I had left? This prescribed disengagement sets up a chain reaction of defeat and fear, which negatively impacts a person's ability to be positive, resilient and proactive. Dementia is the only disease or condition and the only terminal illness

¹ Dementia advocates program: <https://www.dementia.org.au/about-us/dementia-advocates-program>

² Dementia Australia Advisory Committee: <https://www.dementia.org.au/about-us/dementia-australia/dementia-australia-advisory-committee>

that I know of where patients are told to go home and give up their pre-diagnosis lives, rather than to ‘fight for their lives’^v.”

There are many factors that contribute to medical practitioners declaring a person with dementia unfit for work. As there is no ‘gold standard’ assessment for legal capacity in Australia, people living with dementia can be vulnerable to their practitioner’s unconscious bias or assumptions about competency. The terminal prognosis of dementia and the limited treatments available can instil a pessimistic view of what it means to live with dementia. Well-intentioned advice to get ‘their affairs in order’ and prepare for the end of life disempowers people with dementia and reinforces a culture that focuses on a person’s deficits rather than what they can still achieve.

“Medical advice was – literally, at the point of diagnosis – gracefully retire while you still can. Then, from my long-time GP, a few days later: unfit to work from now till the time of my death.” Person with dementia

This deficit-driven attitude can then spill over into all aspects of a person with dementia’s life. Unlike many other disabilities, people with dementia are rarely offered rehabilitation or recovery-based services. People with dementia report that workplaces are unable or unwilling to offer alternate duties or reasonable adjustments that would support their continued employment, in breach of the Disability Discrimination Act 1992. When some people reveal their dementia status to their employer, their employment is rapidly terminated.

“I requested tasks be emailed to me as I found it easier to remember and could refer back to them. The employer would not do this for me. He claimed he was too busy, and I would have to cope.” Person with dementia

“With a dementia diagnosis and the nature of the job, there was no alternative to retirement that was ever offered or considered.” Person with dementia

“My dementia diagnosis, once identified by my employer (a government department), resulted in my employment being terminated overnight with absolutely no support offered whatsoever.” Person with dementia

The stigma associated with dementia leads many people with dementia who experience discrimination to avoid confrontation and withdraw from employment from that point on.

“When I informed the ‘powers that be’ that I might have a disability it was five months before I received a response of any kind. By which time I had formed the opinion that any chance of receiving any support to continue working was unrealistic and unlikely to happen in my lifetime. Hence, I took the opportunity to ‘leave’ rather than battle on.”

Person with dementia

“People with a disability often are unable or unwilling to speak out about mistreatment in the workplace, so nobody is made aware of the issues.” Person with dementia

Dementia is an umbrella term used to describe over 100 neurological conditions which cause significant cognitive and functional disability. Dementia is more than memory loss. Dementia can impair perception, executive function, facial recognition, motor function and more. As such, a ‘one size fits all’ workplace adjustment strategy is unlikely to be adequate. A bespoke response, developed in partnership with the individual living with dementia and their employer, is more likely to lead to longer workforce participation. Employers could be supported through this process with information on how to create an accessible and inclusive workplace for people living with dementia.

Some recommendations for improving work conditions from people living with dementia include:

- Focussing on abilities rather than disabilities in the workplace
- Recognising that with earlier diagnosis people can remain in employment longer
- Educating employers on dementia as a disability
- Ensuring that there is a safe environment for people with dementia to work
- Supporting people living with dementia to remain in work and promoting continued employment, with the NDIS being the primary source of this support
- Respectfully handling the termination of employees in the event they must medically retire

Improve policies and supports for carers to balance work and care

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 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. 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

“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.” Carer

“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.” Carer

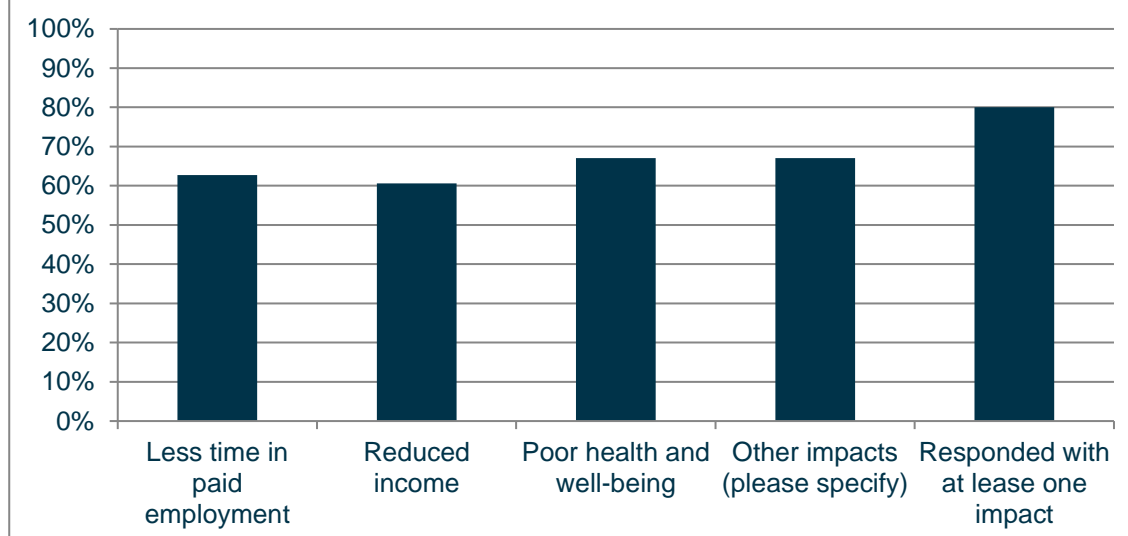
“I had to take many days of carers leave to attend dr appointments with my husband. I retired 5yrs earlier than planned to take on a carer role.” Carer

“Reduced hours, less wages, lost employment.” Carer

“Had to give up paid work completely as the caring role was 24/7.” Carer

Our survey findings also highlight the consequences caring can have, with 80 per cent of survey respondents reporting some impact due to their informal carer role.

As an informal carer, have you experienced any of the following?



Balancing work and care is 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.^{vi}

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

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

There is a need for improved policies and supports for informal carers of people living with dementia. 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 to remain in employment:

- 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.” Carer

“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.” Carer

How can we ensure workplaces are safe and fair, particularly for those people at higher risk of harassment, discrimination and other breaches of workplace minimum standards?

Educate employers on dementia

In recent times we have seen public awareness of dementia increase, however damaging misconceptions remain. A 2018 report on Australian attitudes and beliefs found that while there was increased awareness and empathy over the past decade, two-thirds of survey respondents were not confident about their knowledge of dementia.^{vii} Poor dementia literacy contributes to people with dementia, their family members and carers experiencing stigma and discrimination in a wide range of settings, from healthcare services to community and employment. Greater public understanding of the nature of dementia would lead to better employment outcomes for people living with dementia. With increased knowledge, employers would be better equipped to offer material and psychological support to employees diagnosed with, or displaying symptoms of, dementia. This would increase the person's opportunity to continue employment; where they continue employment, it would help to create a better working life.

“Foremost, an understanding and awareness around dementia, and acceptance of the diseases [is needed]. Then realistic and appropriate support strategies could be formulated and put in place.” Person living with dementia

“Education of employers so that they would be more understanding and more likely to modify tasks to enable the person with a disability.” Person living with dementia

“There is a lack of support to continue to work brought on by people’s general ignorance, from the shop floor, so to speak, to the powers of government to legislate appropriately.” Person living with dementia

Creating a supportive and inclusive workplace through flexible work policies, employer education and recognising dementia as a disability would enable people with dementia to feel safe and supported to remain in employment for as long as possible. Modifying work tasks to focus on the person’s strengths and abilities and understanding that peoples’ abilities and energy levels can change regularly can help facilitate a safe and fair work environment.

Flexible work arrangements to balance work and care

Our survey inquired about the level of satisfaction with workplace arrangements that currently support employees to care for someone living with dementia and remain in employment. The general dissatisfaction with workplace policies, leave arrangements, and general work environment as reported by survey respondents highlight the gaps in workplace policies and employer education that led to feelings of unfair employment. Regarding their satisfaction with paid and unpaid leave arrangements, the majority (52 per cent) of respondents reported feeling dissatisfied or very dissatisfied. 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.

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 among employers
- Subsidised respite

Reducing barriers and disincentives to work, including the role of childcare, social security settings and employment services

Improve services and supports for people living with dementia

Overall, the experience for people with younger onset dementia is different from those diagnosed with dementia at a later stage of life. People with younger onset dementia often receive a diagnosis when they are in full-time employment and actively raising and financially supporting a family, paying off a mortgage or have other significant financial commitments. Loss of income, self-esteem and perceived future purpose can pose multiple physical and psychological challenges for people with younger onset dementia, their families and carers.

People living with younger onset dementia, their families and carers can experience considerable financial stress due to the diagnosis and subsequent impact on employment. While some individuals can obtain early access to superannuation, others are not able to or do not have substantial superannuation funds. They may also experience difficulties accessing appropriate services and supports, such as the Disability Support Pension (DSP) and disability employment services.

“My mum was still working when she got dementia; it was a real drop plus no super provision. You are forced into poverty, especially if you are still paying a mortgage.”

Former carer

The DSP is a financial lifeline for many people living with younger onset dementia. However, without sufficient dementia education among assessors, people living with younger onset dementia may be denied the DSP and must undergo an unnecessary job capacity

assessment. The functional capacity of a person living with dementia can fluctuate from day to day and within a day and an assessment conducted over short period of time may not adequately capture the extent of disability and functional impairment. Additionally, some believe that the amount provided is not adequate to support an adequate standard of living and should be increased.

“As we are on DSP and I’m on Carers Pension I feel we do OK. I’m not sure if someone was only on DSP whether it would be sufficient.” Carer

“It is right for me but I also get a part pension from Commonwealth Super. I know of others where it is not enough particularly if you still are paying a mortgage and your partner has to work to support the family.” Person living with dementia

“Hopelessly inadequate just to get by!” Carer

Dementia Australia recommends that the DSP amount be increased to enable people to maintain an acceptable standard of living and that Centrelink staff are educated in dementia to avoid unnecessary employment abilities testing. Additionally, we recommend exploring the appropriateness of disability employment services for people living with dementia when they wish to be employed.

Better access to carer payments, services and supports

For carers, the responsibility of caring can act as a disincentive to work due to insufficient supports available to enable them to balance work and care.

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 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

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.”

A more streamlined approach to accessing carer supports and payments would reduce the administrative workload, financial stress, carer burnout and subsequently enable carers to better manage work and care.

Conclusion

Our submission has been fundamentally informed by the lived experience of people living with dementia and their carers.

Dementia Australia believes that a diagnosis of dementia should not result in discrimination, nor should it deprive an individual of their identity or dignity. The opportunity for meaningful and fulfilling vocational employment and volunteering should be available to all Australians, whether or not they live with a disability. It is incumbent on us as a society to dismantle workplace discrimination against people living with dementia wherever and whenever it occurs, and to promote the positive contribution of people living with dementia, their families and carers.

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 on dementia as a disability is essential to ensure that employees feel safe and supported in the workplace. Finally, it is important to emphasise that other sources of income assistance and care support can make an important contribution to the financial stability of people living with dementia and their carers, in conjunction with other supports and policies.

We thank you for considering this submission and would welcome any further opportunities for consultation.

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

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

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 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>

v Swaffer, K, Dementia and Prescribed Disengagement, *Dementia*, 2015, Vol. 14(1) 3–6, DOI: 10.1177/1471301214548136

vi 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.

vii *Dementia Australia (2018). Inclusion And Isolation: The Contrasting Community Attitudes To Dementia*