



National Carer Strategy

A Dementia Australia Submission

13 September 2024

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Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia.

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 living 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.

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Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of complex neurocognitive conditions which cause progressive decline in a person's functioning.

Dementia is not just memory loss - symptoms can also include changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease.

In 2024, it is estimated there are more than 421,000 people living with all forms of dementia. This figure is projected to increase to more than 812,500 by 2054.¹ More than 1.6 million people in Australia are involved in the care of someone living with dementia.²

Dementia is the leading cause of disease burden among Australians aged 65 and over.³ Dementia is the second leading cause of death for Australians and the leading cause of death of women.⁴

According to the Survey of Disability, Ageing and Carers (SDAC) in 2018, 126,700 people were providing informal care to individuals with dementia, with over half (55 per cent, or 70,200 people) identified as primary carers.⁵ While caring for someone can be a satisfying experience, it can also bring challenges, as highlighted by the 2022 National Carer Survey

¹ Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare instead of Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government.

² Based on Dementia Australia's analysis of the following publications - Department of Health and Aged Care (2020) Aged Care Workforce Census Report, 2020, p. 6; Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government.

³ Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government

⁴ National Health and Medical Research Centre, Cognitive Decline Partnership Centre (CDPC) (2019) Supported Decision-Making in Dementia Care: Final Project Report. Sydney: NHMRC Cognitive Decline Partnership Centre, <https://cdpc.sydney.edu.au>

⁵ ABS (Australian Bureau of Statistics) (2019) Disability, Ageing and Carers, Australia: Summary of Findings

from Carers NSW.⁶ The survey found that 80 per cent of carers for people with dementia are women, with a mean age of 66 years. Many of these carers are also the sole carers (60 percent) and dedicate a median of 168 hours per week to caring. The financial impact is substantial, with 32 per cent of dementia carers retiring or leaving work to provide care, and 54 per cent considering quitting their jobs in the past six months. The demands of caring also take a toll on mental health, with many carers reporting feelings of social isolation. These findings emphasise the critical need for better support and services for dementia carers as we develop the National Carer Strategy.

Introduction

Dementia Australia welcomes the opportunity to make a submission to the National Carer Strategy (the Strategy). Our submission to this inquiry is informed by feedback from former and current carers who participate in our [Dementia Advocates program](#) as well as Dementia Australia staff.

Dementia Australia has consulted on multiple carer related issues over the years and has previously made submissions to [the Draft National Strategy for the Care and Support Economy](#), [the Senate Select Committee on Work and Care](#), and [the Productivity Commission Carer Leave inquiry](#), and [Inquiry into the recognition of unpaid care](#).

For most people living with dementia, 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 due to taking on the carer role, impacts on their own physical and mental health and a range of other issues.

“They [carers] 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.” Former carer

Recommendations

To address these challenges, the National Carers Strategy should prioritise:

- Improved access to dementia-appropriate respite care that is flexible and responsive.
- A review of Carer Payment eligibility criteria to ensure more carers can qualify.

⁶ Carers NSW (2022): 2022 National Carer Survey. Unpublished dataset. Carers NSW: North Sydney.

- Support implementation of stronger protections for carers in the workplace, such as enhanced access to paid leave, flexible work arrangements, and income support.
- Enhanced formal recognition of carers' contributions through frameworks that value unpaid care and acknowledge the economic and social impact of carers.
- Increased availability and accessibility of culturally appropriate and dementia-friendly aged care and disability services for diverse groups.
- Improve well-being initiatives which increase access to mental health support services, check-ins for carers, stress management resources, and respite care options.
- Support the development of specialised peer support groups, such as those for carers of individuals with younger onset dementia, diverse groups and those residing in rural, regional and remote areas.

Satisfaction of caring

Many carers find emotional fulfillment in their roles, with many expressing that caring for a loved one brings a sense of purpose and allows them to give back to those who have supported them throughout life. They take pride in knowing they are making a difference, providing love, comfort, and safety to those in need, whether by keeping their loved ones at home or helping them navigate complex care systems. The journey of caring, though challenging, is also seen as an opportunity for personal growth and learning, particularly in advocacy and understanding dementia. Despite the exhaustion and difficulties, carers often feel a strong sense of duty and honour, finding satisfaction in the knowledge that they have done their best to ensure their loved ones' well-being, dignity, and happiness.

While many carers have found joy in their roles, it is essential to acknowledge that caring also brings significant challenges that transcend into all aspects of their lives. These difficulties highlight the urgent need for comprehensive support systems that recognise and value the vital role carers play in our society.

“The fact that I believe being at home is the best place for my husband at present. I believe he feels safe, secure, and cared for. And I value the fact that we are still able to enjoy times together/and have fun, in and around the constancy/and sometimes difficult aspects, of being a care partner.” Current carer

“I was caring for my mother for 5 years full time. For me it was an honour, an act of love, of given back all the love she gave me as a young child. Through caring I learnt that the giving and receiving are one.” Former carer

Impact on employment and volunteering

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.⁷ 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.'⁸ Carers of people with dementia often face significant disruptions to their employment, volunteering, and educational opportunities. Many are forced to reduce their working hours or leave the workforce entirely, which can have long-term financial and professional consequences.

Throughout our consultations with Dementia Australia staff and carers, consistent themes have emerged. Many carers report taking paid and unpaid leave, reducing hours, shifting to casual employment, or leaving the workforce entirely to provide care. These changes often lead to significant financial impacts, which, in turn, contribute to declines in both physical and mental well-being.

"I would take part-time and flexible work to support mum and dad... that was probably a lot lower paying roles than I'd had before." Carer

"I resigned from my position of employment to assist my mother... I suffered quite a lot financially by making the decision to assist my mum." Carer

Dementia Australia advocates for a variety of measures to support carers, including access to leave, flexible working arrangements, income supports, respite, and other care options. Additionally, employers should be educated about the unique challenges dementia carers face to ensure supportive workplace environments.

Financial implications of caring

Many carers expressed that the costs associated with caring, coupled with reduced income from employment, place a substantial financial strain on their households. Out-of-pocket expenses for care-related needs, combined with inadequate financial support from government programs, exacerbate these difficulties. Our survey findings highlight the financial challenges many carers face, emphasising the importance of accessible income assistance and care support. The Strategy must include provisions to support flexible work

⁷ Deloitte Access Economics (2020). The value of informal care in 2020: Caring comes at a cost

⁸ Deloitte Access Economics (2020). The value of informal care in 2020: Caring comes at a cost

arrangements, re-entry into the workforce, and opportunities for carers to continue their education and professional development.

For carers of people with younger onset dementia, the financial impacts can be particularly severe. Many families are amidst the peak of their earning years and when a person with dementia was the primary income earner, households can quickly move from a single income to no income. This sudden loss of income and financial stability is compounded by other expenses such as mortgages, children's education and other financial commitments, which can add immense stress to the primary carer especially in cases where they were not responsible for managing the finances. Additionally, they have less opportunity to accumulate savings or secure their long-term financial future. The complexity of navigating the NDIS and accessing appropriate financial support further exacerbates the burden, leaving many carers in precarious financial positions.

"When my husband went into care, we went from a two-person income at home to one, so I stayed at home on one income. His pension went to the facility." Former carer

"I was still doing 120 hours a week. Who does that without ever taking a break? It's insane and I'm very angry that we are not supported by government and that we're considered a source of unpaid labour." Current carer

"Living on carer payment plus allowance leaves you living below the poverty line for a role that is seven days a week 24 hours a day. No super, no holidays, no social life, no time for yourself. Draining savings from your former work, so you are now living in absolute poverty." Carer

"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)." Current carer

"It has had a huge impact over time. When my husband went into aged care his pension went too. It costs me more to clothe him due to clothing being lost or damaged by the laundry. I provide him extra food. He is on many more medications, some of which aren't on PBS i.e.: Voltaren and bowel laxatives and stimulants. Mostly, I had to relocate 800km to be near him and now I am paying double the rent we were previously paying." Former carer

Financial support

One of the main concerns for carers of people living with dementia is the inadequacy of carer payments. Carers expressed that the payments they receive do not sufficiently compensate for the financial impact of their caring roles. Many mentioned that the payments are insufficient to cover the costs associated with providing care, including lost income and the

additional expenses incurred. Some carers highlighted the difficulty in qualifying for carer payments due to strict eligibility criteria. This can leave many carers without financial assistance, despite their significant caring responsibilities. Additionally, some carers have experienced delays in receiving payments or inconsistencies in the payment schedule, which can create financial strain and uncertainty for carers who rely on this income. Many carers expressed the need for increased financial support, particularly given the intensity and demands of their caring roles. Most suggested that payments should be more reflective of the true costs and sacrifices involved in caring.

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

“The criteria for carer allowances and payments are SO strict and really do not take into consideration all the elements of informal care, like admin-based work”. Carer

Recommendations from staff and carers include increasing financial assistance for carers, such as raising the Carers Allowance, reviewing the eligibility criteria for Carer Payments and creating additional funding options to cover unexpected costs, ensuring that financial support is proportionate with the economic impact of caring.

Effects on health and relationships

Health and wellbeing

Caring for someone with dementia can have significant impacts on the health and well-being of carers. Many carers report neglecting their own health, often for extended periods, as they prioritise the needs of the person they care for. This neglect can lead to serious health issues as well as emotional and psychological well-being. The constant demands of caring can lead to exhaustion and burnout, with carers frequently placing their own medical needs on hold. For some, the lack of external support exacerbates these challenges, leaving them to navigate the complexities of caring and their own health in isolation. This highlights the need for accessible health services, respite care, and support for carers to ensure their health and well-being is managed.

“You spent so long not looking at yourself and probably not looking after yourself that you forget how”. Former carer

“Not having time to see doctors for their own health issues. Not wanting to burden family members/children with ‘their’ issues.” Dementia Australia staff

“I’ve now got osteoporosis, and my endocrinologist tells me that it’s probably been brought on earlier than expected because I was, you know, helping him out and chairs helping that in and out of bed. And I’m doing all the showering and everything. I’m putting extra strain on my body.” Current carer

“I’ve never felt so vulnerable and incapable. And coincidentally, having looked at him so sick in the hospital and thinking all these years of all of this, the care, and I still can’t stop the end result.” Current carer

“It’s like, how do you, how do you navigate? How do you manage your health? It’s really. You just come, you just come second. I can’t see it any other way.” Current carer

Relationships

Caring for someone with dementia can deeply affect relationships with friends, family, and the person receiving care. Relationships with family and friends can suffer due to the time and energy required to manage caring responsibilities. Many carers experience isolation as their social circles diminish, with friends and even close family members often unable to fully comprehend or support the demands of the caring role. This isolation can be exacerbated by the emotional toll of watching a loved one progress, leading to grief and feelings of loneliness. The constant demands of caring can strain family relationships. Additionally, the emotional connection with the person being cared for may change, as their dementia progresses, creating a complex mix of love, loss, and responsibility.

The National Carer Strategy could focus on increasing access to mental health support services and check-ins for carers, stress management resources, and improving respite care options to promote the health and wellbeing of carers.

“It has had an impact on my relationship with my mum, but also with my husband, because of the time that I was spending with mum and Dad. So, there was that tension between”. Current carer

“My relationships, my social connections all fell away. Nobody wants to talk about dementia. Nobody understands”. Current carer

“My experience was perhaps different from many others here in the. My partner and I were lesbians. We didn’t have any family support whatsoever. And where we had expected that our community would support us, that didn’t happen and that was a shock to me.” Former carer

Accessibility of support and services

When surveying both staff and carers, there was a unanimous consensus on the top two challenges faced by carers of people with dementia being a lack of awareness and limited availability of support services. This response aligns consistently with feedback from previous surveys and focus groups. Both staff and carers have highlighted a critical gap in accessible and adequate services, underscoring the urgent need for improvements in the support system.

Carers report difficulties in accessing timely and appropriate services, such as respite care, assessment processes, and information resources. The bureaucratic hurdles and lengthy wait times for services often exacerbate the challenges faced by carers.

The inadequacy of services for Culturally and Linguistically Diverse (CALD) communities in accessing support and services remains a significant issue, as highlighted by feedback from Dementia Australia's staff and carers. In a survey to staff, the majority of respondents indicated that services poorly or very poorly meet the needs of CALD communities. Carers from CALD communities expressed that there aren't culturally appropriate options to suit them. Many highlighted that existing services often fail to consider language barriers, cultural sensitivities, and diverse care preferences, making it difficult for families to access the support they require.

"Improvement in culture-appropriate respite, so the family carer is not the only person who can help the person with dementia who has reverted to mother tongue." Current carer

"For carers from culturally diverse backgrounds, the availability of culturally sensitive navigation support can help them access appropriate services and resources more effectively." Current carer

Carers of individuals with younger onset dementia face significant challenges in accessing appropriate services and support, particularly when managing changed behaviours associated with dementia. Many respite and care services are not tailored to the unique needs of younger individuals with dementia, leaving carers struggling to find suitable options. Additionally, a widespread lack of training among care providers in managing changed behaviours further exacerbates these difficulties, increasing the strain on carers.

Respite

A predominant theme is the lack of available respite options and the difficulty in accessing those that do exist. Carers of people with younger-onset dementia face additional challenges, as there is a shortage of tailored services that meet their specific needs. A widespread lack of understanding about the different types of respite care, their benefits, and how to access them further complicates the process, particularly for overnight respite. Additionally, some providers impose a minimum two-week stay, limiting flexibility for carers who need short-term relief. Cultural and linguistic inclusivity in respite services is also insufficient, and the current number of residential respite beds is inadequate to meet demand. Staffing shortages, particularly in home-based respite care, exacerbate the issue, especially in remote areas, and many care providers lack specialised training in dementia care. Carers express concerns about the safety, quality, and emotional toll of entrusting their loved ones to respite care, especially when dealing with the behavioural changes associated with dementia. Additionally, many carers face resistance from the person with dementia when trying to access respite services. This highlights the urgent need for more dementia-friendly respite options, a well-trained workforce, and streamlined processes to make respite care more accessible and supportive for carers.

“Hard to get spots for respite, even when you can plan ahead, often not told respite available, so cannot plan anything. Also, would be good to be able to know could get respite regularly, make it easier to cope with caring for someone with dementia”.
Former carer

“I have only had Respite care twice in 8 years. I would like to be able to forward plan and book a decent break once a year, but this is impossible. On one occasion I booked Respite care which was then cancelled. I had already paid a deposit for a trip away. My deposit was returned as a gesture of kindness”. Former carer

“Not many facilities offer respite unless you are intending on using them eventually on a permanent basis”. Former carer

Specialised peer support

Carers expressed that peer support groups help in providing connection and understanding from others who are going through similar experiences. The emotional benefits of peer support reported by carers include feeling less alone and having a space to share their experiences and challenges. Peer support groups are seen as a valuable resource for emotional well-being, helping carers cope with the stress and isolation that often accompany their roles.

However, despite the benefits of peer support, many carers mentioned that peer support networks are not always easy to find, especially for more specialised groups such as those caring for individuals with younger onset dementia and/or from diverse groups. This lack of access can leave carers feeling isolated and without the necessary emotional and practical support. Additionally, carers in more remote or regional areas expressed difficulty in accessing peer support groups. The lack of local groups can make it difficult to connect with others who understand their situation. Recommendations include the need for more specialised peer support groups, such as those for carers of individuals with younger onset dementia as well as those residing in rural, regional and remote areas.

Recognition of caring role

Overall, the feedback received from our carer surveys and focus groups indicate that there are several gaps and challenges in the recognition of unpaid care, leaving many carers feeling unsupported and undervalued in their role.

Dementia Australia has made a submission to the [**Inquiry into the recognition of unpaid care**](#) which emphasises the need for stronger legislative frameworks to improve the recognition of carers.

“Unpaid carers, are predominately not recognised and very undervalued within their community despite the economic savings they make to different governments.”
Current carer

Carers still feel undervalued by governments, employers and the community. Improving community messaging and dementia education can help organisations, employers, and community members have a better understanding of dementia to better support carers.

“Recognition in the workplace and community in general that carers are essential to a civilised community. Any financial assistance offered to carers is not a cost to the budget it is an investment in our community just like building roads is. Carers to be seen as community providers of care and support”. Former carer

“One of the things that I feel is that as a carer that it’s not recognised as a job. It’s the hardest job any person will ever do. It’s the longest hours... but even government departments don’t recognise it as a job.” Current carer

Feelings of recognition were nearly non-existent, with carers expressing that their role is often overlooked. Many carers face significant challenges balancing work, finances and health yet feel invisible to within the systems meant to support them, which highlights the need for stronger acknowledgment within the Strategy.

“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.” Current carer

Conclusion

The National Carers Strategy presents an opportunity to influence the way Australia supports its carers, particularly those caring for people living with dementia. By addressing the challenges outlined in this submission the Strategy can lay the foundation for a more effective carer support system.

We welcome the opportunity for further consultation.