



Draft National Strategy for the Care and Support Economy

Dementia Australia Submission

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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.

Dementia is one of the largest health and social challenges facing Australia and the world. In 2023, it is estimated there are more than 400,000 people living with all forms of dementia in Australia. This number will continue to grow to more than 800,000 by 2058.¹

In February, the Australian Institute of Health and Welfare released data showing dementia is now the leading cause of disease burden among Australians aged 65 and over. Dementia is the second leading cause of death for Australians and the leading cause of death of women.²

¹ AIHW (2023) *Dementia in Australia*. <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>

² AIHW (2023) *Dementia in Australia, Summary, Impact* <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>

Introduction

Dementia Australia welcomes the opportunity to provide feedback on the Draft National Strategy for the Care and Support Economy. In our submission we will focus on two key themes:

- A system which prioritises quality care outcomes
- Recognising the contribution and support needs of informal carers.

We put forward important considerations in building a sustainable care economy in context of increasing demand for both aged and disability care. We argue that strongly regulated workforce development and education is a key enabler for quality, person-centred care. We also outline the significant contribution of informal carers to the sustainability of the care sector and make recommendations to strengthen ongoing support to informal carers.

In preparing this submission, we have consulted with our national network of Dementia Advocates, who are people living with dementia and informal carers. We have outlined their perspectives, priorities and recommendations for a sustainable, high-quality care and support system.

People living with dementia and the care and support system

People living with dementia receive care across the aged, disability, veterans, and early childhood care sectors. Many are supported by informal family carers, with up to 337,000 informal primary carers for people living with dementia in Australia in 2021.³

In the aged care sector, people living with dementia access both residential and home-based care services. There is a high prevalence of dementia among residential aged care residents, with more than two-thirds having moderate to severe cognitive impairment. There are also many people living with dementia who receive home care supports, with an estimated 67% of people with dementia living in the community.⁴

Veterans living with dementia also access mainstream aged care services or may receive support through veterans' home care programs. It is thought that veterans may have increased risk factors for dementia including traumatic brain injury, post-traumatic stress disorder and major depressive disorder. The experience of dementia may also be different, with veterans living with dementia and post-traumatic stress disorder at risk of more severe behavioural and psychological symptoms.⁵

Dementia does not just affect people in older age. In 2023, it is estimated that there are more than 28,650 people living with younger onset dementia, who are those who are diagnosed when under the age of 65.

People living with younger onset dementia experience many challenges, having to navigate their way through multiple care systems as their dementia progresses. While they are

³ AIHW (2023) [Dementia in Australia. Carers.](#)

⁴ AIHW (2023) [Dementia in Australia. Prevalence of Dementia.](#)

⁵ AIHW (2023) [Dementia Among Veterans.](#)

generally eligible to access the National Disability Insurance Scheme, the disability sector is poorly equipped to respond to the needs of people living with younger onset dementia.

At the same time, because of the progressive nature of dementia, many people with younger onset dementia will require support from the aged care sector, which is also not well designed to meet their needs.

There are also a range of childhood dementias, resulting from progressive brain damage that can be caused by over 70 rare genetic disorders. An estimated 2,300 Australian children are living with dementia⁶ and some will access early childhood care.

People living with dementia also receive care and support from general practice, nursing and allied health care. Dementia Australia notes that the strong intersections between health, mental health, aged and disability care sectors are particularly relevant.

This submission will primarily focus on aged care, although issues of relevance to the disability and veterans' care sector will be noted.

Future developments

Around 1 million Australians currently receive in home aged care services.⁷ Most Australians prefer to remain living at home as they age, and the demand for home support services is predicted to increase as more people choose to receive care at home.⁸ As well as the increasing need for supply of qualified paid care workers to support people at home, in the future there will be more unpaid family carers providing support to their loved ones at home. Work to shape the future of care and support economy must take account of all these trends, as well as the volume of reform taking place in the aged and disability care sectors.

We note that many aspects of this draft Strategy will be influenced by other significant national reform pieces, including the development of the new Aged Care Act and new aged care regulatory system, future development of an aged care worker national registration scheme, the transition to the new Support at Home Program, the NDIS Review, the Royal Commission into Defence and Veteran Suicide, and significantly, the Australian Parliamentary Inquiry into the Recognition of Unpaid Carers.

We support the development of regulatory frameworks with as much synchronicity as possible across different care sectors, in cases where core workforce, governance and quality standards can be naturally aligned. Human rights should be the foundation of all regulatory systems, embedded in requirements and standards across care sectors.

⁶ Childhood Dementia Initiative (2023) [What is childhood dementia?](#)

⁷ Australian Government Department of Health January 2022 [Support at Home Program Overview](#).

⁸ Ratcliffe J. et al (2020) [Australia's aged care system: assessing the views and preferences of the general public for quality of care and future funding](#). Caring Futures Institute, Flinders University, South Australia.

Quality care

Dementia Australia agrees that Australia needs a sustainable care sector that delivers high quality care with a trained and supported workforce. The priority for reforms to the care sector should be on enabling high quality, person-centred care to be delivered across different service environments, with investment in workforce development and education backed by strong regulatory and compliance frameworks.

In preparing this submission, we asked people living with dementia and their carers what quality care means to them. Their responses emphasised that:

- Quality care means a good quality of life based on a high standard of emotional, physical, and environmental supports to enable people to live their best life.
- Care should be provided with honesty, understanding, reliability and friendliness.
- Quality care means dignity and interest in the client as a person.
- Care should be person-centred, providing appropriate, customised and necessary supports to address individual needs, while also supporting independence and choice.
- Care should be based on living well, support autonomy and the rights of the person, and offer the person what they want rather than what is thought best for them by others.
- Staff should be professional, in secure, paid employment, appropriately skilled and with adequate training.
- There should be wrap around care, with a team providing support. There needs to be better information sharing and communication among teams about people's needs, with systems to support this.
- Staff should spend more time interacting, observing, and responding to people's needs.
- Care in residential facilities should deliver services to the standard that is advertised.
- Tasty, healthy food should be provided in residential aged care.

A person living with dementia observed that quality care means:

Someone who listens to me. Someone who understands me. Someone who can provide me with what I need or tell me what options I have. If they provide the care required, I expect them to be competent and knowledgeable about my condition and caring and respectful in providing what I need.

Importantly, people living with dementia and carers said that:

- The aged care system should be more person-centred, responsive and better resourced.
- There need to be less complicated options to access and navigate the care and support system.
- The aged care system needs professional workers who are treated with respect. Workers should be properly remunerated in secure, safe employment and trained to a high standard with options for career progression.
- Aged care workers should be educated in understanding the different types of dementia, communicating with people with dementia, responding appropriately to changed behaviours, and providing culturally safe care.

- The government should have continued oversight of the market to manage provider spread and to ensure that providers prioritise the delivery of high-quality person-centred care.

All reforms to the care and support economy should prioritise making quality, person-centred care accessible across the population. As a carer for a person with dementia commented in relation to quality care:

It means everything. If care is not top quality, my partner suffers.

Dementia education

A care and support economy that prioritises quality needs an educated workforce with clear career pathways. Pathways for rewarding long-term careers in the care sector can attract and retain qualified, experienced and satisfied staff. In the aged care sector, a care workforce with the capability to provide quality dementia care is a necessary and core element of quality care.

Dementia is one of the largest challenges for the aged care sector. Dementia Australia's position is that:

- All care workers in the aged care sector should be required to undertake compulsory dementia education, tailored to their role.
- All care workers in the veteran's, disability and early childhood care sectors should have access to information and training about dementia, its impact, and the delivery of person-centred supports.

Core elements of dementia education for aged care workers should include:

- Person-centred care
- The nature and impact of different types of dementia
- Effective communication
- Activities for engagement
- Identifying elder abuse and restrictive practices
- Understanding changed behaviour and developing effective responses
- Creating supportive environments.

People living with dementia and carers further emphasised that the most important aspects of dementia education for the care workforce are:

- Understanding the individuality of people living with dementia, with each person having unique experiences of the condition.
- Respecting the rights of people living with dementia, treating them with dignity and understanding.
- Knowing that people with dementia may be scared or confused and responding with compassion to them as an individual.
- Understanding how to communicate with people living with dementia, to listen and to be patient, calm and caring. To understand the person's experience day by day.

- Having more comprehensive education about dementia, including changes in the brain and their impact.
- Having regular opportunities to engage with new research and adapt practice.
- Understanding how to identify signs of dementia early in the development of the condition.

There are existing pathways which can support and be built upon, to improve the dementia capability of the aged care workforce.

Generally speaking, Dementia Australia supports specialisation for care workers rather than a generic qualification across multiple sectors. However, we recognise that in some areas of low supply such as regional and remote areas, a common qualification for care workers can increase the availability of support in the community. The Certificate III in Individual Support is appropriate in this context, provided there continues to be a compulsory unit of dementia competency in the ageing specialisation.

The Certificate IV in Dementia Practice is now also available to support the development of leadership capacity in aged care providers. This type of development could be supported with peer mentorship, practice supervision, creation of communities of practice, and the implementation of national education standards for dementia care.

As a priority, we advocate for the creation of dementia education and career pathways, with ongoing training and mentoring. This can enable paid care workers to remain in the sector in rewarding jobs over the long term and increase the quality of care provided.

The requirement for aged care workers to be educated in dementia should apply regardless of how services are funded or paid for, meeting minimum community expectations for quality care.

A critical enabler to improve the quality of the care sector is the development of a national aged care worker registration scheme. Dementia Australia strongly supports registration for all workers providing direct support and care to older people, including those living with dementia.

While the Australian Health Practitioner Regulation Agency currently administers the registration of Registered and Enrolled Nurses working aged care, there is no equivalent registration process for direct care workers (personal care workers/ attendants and Assistants in Nursing). We believe this is a necessary reform to ensure minimum qualifications are in place to enter the sector and that ongoing levels of knowledge and skill are maintained.

Informal carers

The sustainability of the care sector depends in large part on the enormous contribution of informal family carers to the economy. It has been estimated that there around 2.8 million Australians providing nearly 2.2 billion hours of care per year, including 906,000 primary carers. The financial value of this care was estimated to be \$77.9 billion in 2020,⁹ representing a substantial saving to government and the community.

The care provided by informal carers reduces the demand for publicly funded services across the ageing, disability and veteran's care sectors, including for acute and residential care. Informal carers also understand their loved one's needs well. They advocate for and assist their loved ones to get the best outcomes from care and support services, improving the quality of care.

It is imperative to the sustainability of the future care economy that informal carers are well supported in their caring role.

Who are the carers for people living with dementia?

Around two thirds of people living with dementia live at home¹⁰ and a 2017 study found that around half of all people living with dementia in the community received informal care only.¹¹ Informal carers are an integral part of the care economy, providing care and support for their loved ones to remain safe and supported at home.

Informal carers of people living with dementia are typically a spouse or child. They provide a wide range of supports including emotional support, personal care and activities of daily living for their loved one, as well as responding to changed behaviours. Informal carers are involved in making decisions about treatment and care, services and finances. They must navigate complex administrative and bureaucratic systems which are not user friendly.

Carers also continue to provide support when a loved one moves into residential care. They advocate and coordinate services to meet their loved one's needs as well as other support like managing finances, legal matters and providing practical and emotional care.

Dementia Australia has previously surveyed carers of people living with dementia and found that 78 per cent are women. Ninety-eight per cent of carers are family members with the majority of those identifying as a partner or spouse (64 per cent). Forty-six per cent are under the age of 65 and defined as of working age. Ninety per cent of those under 65 are women, reinforcing that women are more likely to take on caring responsibilities and to experience impacts on their workforce participation.¹²

A national study by Carers NSW has further shown that carers of people living with dementia are likely to be older than other carers, and the vast majority are caring for someone aged 65

⁹ Deloitte Access Economics (2020) [The value of informal care in 2020](#).

¹⁰ AIHW (2023) [Dementia in Australia, Prevalence of Dementia](#).

¹¹ The Institute for Governance and Policy Governance, University of Canberra (2017) [Economic Cost of Dementia in Australia 2016-2056](#).

¹² Dementia Australia (2022) Dementia Australia Submission to the Senate Select Committee on Work and Care Inquiry.

or above. Twenty per cent of carers of people with dementia identify as Culturally and Linguistically Diverse and 1.5 per cent identity as Aboriginal or Torres Strait Islander.¹³

There are different demands on carers depending on their age, and the age of the person that they are caring for. Carers supporting someone with younger onset dementia (diagnosed before the age of 65) are in a different stage of life, still in the workforce with financial obligations and other active care commitments such as children or elderly parents.

The care recipient may have been the primary source of income, causing financial difficulties. The experience of dementia is also likely to be different, with the person living with younger onset dementia more likely to be active and experience greater frustration with loneliness, boredom and loss of income, independence, and self-esteem. There are likely to be less respite options available to families.

On the other hand, carers for older people with dementia are more likely to have their own health issues, and their loved one is more likely to be frail or have comorbid health issues.

Across the board, carers are likely to experience a financial impact from their caring role. Caring is a full-time role, and paid employment is often significantly affected to the point that many carers must withdraw from paid employment entirely. Their own physical and mental health is often affected as carers strive to meet the needs of their loved one.

What support do informal carers for people with dementia need?

A range of measures could be implemented to support informal carers in their critical role in the care and support economy. Carers that Dementia Australia consulted with for this submission noted that:

- There needs to be more respite available for carers and families, and this needs to be accessible and regularly available. Caring can be exhausting, and carers need time out.
- Services need to be easier to access and navigate, with significantly reduced administrative complexity. A central access point for carers would be beneficial.
- Carers need access to training or education and support groups are also helpful.
- Carers need better financial and income support.
- A system which supports carers well helps to enable people with dementia to remain living at home when they choose to.
- Carers need access to flexible working arrangements including extra leave.

The Carers NSW national survey further showed that the services needed most by carers for people with dementia were planned respite and emergency respite. The need for these services was higher for carers of people with dementia than for other carers. The survey also highlighted that a large proportion of carers are not asked about their needs as a carer by GPs and other health services¹⁴.

¹³ Carers NSW (2022): 2022 National Carer Survey. Unpublished dataset. Carers NSW: North Sydney.

¹⁴ Carers NSW (2022): 2022 National Carer Survey. Unpublished dataset. Carers NSW: North Sydney.

Recommendations

There is a need to think beyond economics and to address and envision the kind of society we want to become.

~Carer of a person living with dementia

The Draft National Care and Support Economy Strategy is an opportunity to shape the future care system to deliver better quality care which enshrines the human rights of vulnerable people. Informal carers are integral to the care and support economy and need to be actively supported in their caring roles.

Dementia Australia recommends that:

1. The priority of the strategy be to develop a care and support system which can deliver quality outcomes universally for all care recipients in the community.
2. The vision and goals of the strategy be reframed to be person-centred and include consumer engagement and co-design.
3. The Priority Workforce Initiatives Plan:
 - a. Maintain the compulsory dementia unit of competency in the Certificate III Individual Support (Aged Care Specialisation) as a minimum requirement for work in the aged care sector.
 - b. Ensure that the requirement for aged care workers to be educated in dementia applies regardless of how services are funded or paid for, meeting minimum community expectations for quality care.
 - c. Progress a national registration scheme for aged care workers including regular dementia education to an appropriate standard, as outlined in the national dementia education standards currently under development.
4. A Priority **Carer** Initiatives Plan be developed, which:
 - a. Recognises the integral role of informal carers in the national care and support economy and their enormous contribution to its sustainability.
 - b. Addresses findings of the current Australian Parliamentary Inquiry into the Recognition of Unpaid Carers.
 - c. Considers a range of measures to support carers including appropriate income support, employment flexibility, access to respite and easier navigation of services.