

# **Aged Care Task Force Funding Principles**

Dementia Australia Submission

August 2023

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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.<sup>1</sup>

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<sup>2</sup>.

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

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

## Universal access to quality care

Dementia Australia welcomes the opportunity to provide a submission to the Aged Care Taskforce on the draft aged care funding principles. Dementia Australia is the leading voice for people living with dementia in Australia and is an active participant in the aged care reform process. Our advocacy has highlighted some key themes across all current aged care reforms:

- A system which prioritises quality care outcomes
- Embedding human rights, autonomy and choice
- Recognising and supporting the needs of carers
- The need for investment in workforce capability.

An estimated 67% of people with dementia live in the community.<sup>3</sup> This will likely increase as more Australians choose to live at home in their older age.<sup>4</sup> The new aged care funding model needs to reflect this evolving community expectation and ensure that regardless of the care setting, people living with dementia receive safe and appropriate care delivered by a skilled workforce.

People living with dementia account for at least two thirds of aged care residents in Australia.<sup>5</sup> The prevalence of dementia in aged care underpins Dementia Australia's position that the new funding model must enable the delivery of quality, individualised care to older people with dementia, empowering them in their choices and upholding their human rights.

Central to any reform decisions should be the voice of aged care consumers and the community in determining minimum expectations for aged care and the assessing the best funding mechanisms to deliver a future-proofed system.

The Australian Government has an ongoing and central role to play in directly funding a safe and quality aged care system which delivers individualised dementia care to a high standard. No one should be denied high-quality care because of an inability to pay.

## Choice and control

**Principle 1 – The aged care system should enable and encourage participants to remain in their home for as long as they wish and can do so.**

Principle 1 should focus on embedding choice, dignity and autonomy into the aged care system. These are a fundamental aspect of quality care and a human right.

The funding system should deliver models of care that enable older people to make their own choices about their lives, with appropriate supports, promoting healthy ageing and wellbeing in the population. For people living with dementia or other cognitive impairment, supported decision-making must be embedded in the model, to enable true choice and autonomy.

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<sup>3</sup> AIHW (2023) [Dementia in Australia, Prevalence of Dementia.](#)

<sup>4</sup> AIHW (2023) [Dementia in Australia, Community Based Aged Care.](#)

<sup>5</sup> National Institute of Labour Studies (2017) The Aged Care Workforce, March 2016.

Care should be offered to older people based on their assessed need and their personal choices. Models of care should be flexible enough to respond to changing needs over time or with the progression of disease, such as dementia.

Individuals should be able to choose to receive care at home or in a residential care environment and carers need access to respite. This means that health and aged care services need to be integrated and accessible across the community to meet older people's needs.

People living with dementia and their carers report that the care system is often difficult to navigate and access, and that choices are limited by services not being available.

**a dementia caring world which is notoriously difficult to negotiate, with a plethora of hard to distinguish clinical, therapeutic and support organisations that often overlap and have their own agendas and funding orientated parameters and objectives.**

**~ Carer of a person living with dementia**

## Accessible and sustainable care

**Principle 2 – Aged care funding arrangements and their outcomes should be fair, simple, transparent and sustainable.**

The key outcome sought from aged care funding reforms should be quality, person-centred care which supports older people to remain connected to their families and communities, respects their choices and decisions, and supports good health and mental health.

**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**

People living with dementia and their carers have told us that quality dementia care encompasses:

- Understanding diversity and maintaining identity through relationships.
- Involving carers and advocates as vital partners in care.
- Flexibility in provision of care, how and when services are received.
- Including people in the community, in meaningful activities and in decision-making.
- Providing a community and home-like design, look and feel in residential settings.
- Feedback and complaints being taken seriously.
- Having staff trained in dementia with ongoing mentoring.
- Leadership and culture that understands the impact of dementia.<sup>6</sup>

Dementia Australia supports a principle of fairness, ensuring that care is accessible to all those who need it and that no one is disadvantaged because they have lesser financial

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<sup>6</sup> Dementia Australia, 2019. [Our Solution: Quality Care for people living with dementia.](#)

means. The system should be equitable, affordable and easy to understand and navigate, including for people living with dementia and their carers.

To deliver such a system, Government should remain the primary funder of care. Government should continue to provide strong oversight of the aged care system including through implementation of a robust regulatory framework.

Redesign of the funding system must be focussed on broad sustainability, rather than just on financial mechanisms. There are multiple aspects of sustainability to consider, including accessibility of services, workforce development and support for informal carers.

Informal carers make an invaluable contribution to the aged care system, and their contribution should be properly recognised and valued.

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<sup>7</sup>, representing a substantial saving to government and the community.

**[Carers] are without doubt the unsung heroes of the dementia world... their impact on the care economy is immeasurable. They keep patients out of expensive full-time care for as long as they possibly can. They significantly reduce the demands on short term respite care and home-care provision until matters have moved beyond the ability of anyone to care singlehandedly anymore and still retain some semblance of their own health and wellbeing.**

#### **~ Carer of a person living with dementia**

Recognition involves acknowledging and valuing the significant contribution of carers, respecting their work, understanding their challenges, and providing them with practical, financial, and emotional support.

Empowering informal carers with access to respite, counselling, care navigation and employment support will greatly contribute to the ongoing sustainability of the aged care system, especially as more people choose to remain living in their own homes in older age.

**Unpaid carers are predominately not recognised and very undervalued within their community despite the economic savings they make to different governments.**

#### **~ Carer of a person living with dementia**

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<sup>7</sup> Deloitte Access Economics (2020) [The value of informal care in 2020.](#)

## Universal coverage

**Principle 3 – Government is and will continue to be the major funder of aged care. Government funding should be focused on care costs. Personal contributions should be focused on accommodation and everyday living costs with a sufficient safety net.**

Dementia Australia supports a principle of universal coverage, so that all older people have access to the care they need and choose. The baseline should be high-quality care and accommodation, that meets community expectations. Personal contribution payments should be means tested and based on ability to pay, and no one should be deprived of quality care because of their personal financial position.

We recognise the increasing cost to Government as the population ages and support a community discussion as to how best to deliver a system of universal coverage focussed on the key outcome of quality, person-centred care.

The funding model should give primacy to meeting the core health and wellbeing needs of older people, providing choice, respecting autonomy and identity and retaining family and social connections. This will require continuity of care across aged care, health and hospital systems and investment in support for informal carers.

The definition of care costs and every day living costs will be critical in the new funding model and have a significant impact on the accessibility of support. To support universal access, government should guarantee funding for key components of care regardless of an individual's ability to pay:

- Nursing, clinical and allied health
- Reablement and rehabilitation
- Personal care including assistance with showering, toileting and mealtimes
- Dementia support services
- Respite services
- Mental health care
- Equipment and aids for health and disability support
- Domestic services including cleaning, laundry and yard work
- Meals in residential aged care and respite services
- Social support
- Transport.

Dementia Australia notes that regardless of the funding source, all older people should have access to nutritious meals that meet their personal choices. Provision of nutritious, appealing food that meets individual and cultural preferences is a core element of quality care leading to better health and wellbeing outcomes and should be provided to all age care recipients regardless of their financial means or contribution.

Similarly, regardless of the care environment, all older people should have access to support to remain connected to their family, community and social life, and this should not be affected by an individual's financial position.

## Skilled and supported workforce

**Principle 4 – Government and participant contributions should be sufficient to provide quality and appropriate care delivered by a skilled workforce, allowing and encouraging innovation by the health, hospital and aged care systems.**

Long term investment in workforce development is critical to deliver a sustainable aged care system with the capability to provide quality care into the future. The funding model should enable a skilled, qualified and appropriately remunerated workforce to deliver quality care all parts of the aged care system.

This includes strategies for long-term retention and career pathways for a skilled workforce, to enable paid care workers to remain in the sector in rewarding jobs over the long term and increase the quality of care provided.

This must include models of care that take account of dementia or other cognitive impairment, disability, complex mental health and health needs, and the workforce capacity required to deliver safe and person-centred care to these older people.

A skilled workforce at the interface of health, hospital and aged care services is critical for people living with dementia. Workforce in the health and hospital systems must have capacity to coordinate transitions with appropriate services and engage with carers. The funding model should support workforce development in the health sector where this interface is critical to the delivery of quality care outcomes.

## True accountability for all participants

**Principle 5 – There should be accountability for funding received from government and participants, how it is spent, and the quality of the services provided.**

Accountability and complaints mechanisms must be appropriate for people with dementia and other cognitive impairment. At both an individual and system level, transparency and accountability need to be dementia friendly, including accessible complaints mechanisms and methods of engagement.

There should be ongoing investment in a strong regulatory model encompassing both compliance and continuous improvement approaches. The government should have continued oversight of the market to manage provider spread and to ensure that providers are accountable for prioritising the delivery of quality person-centred care outcomes.

## Dementia friendly environments

**Principle 6 – The residential sector should have access to sufficient, and new, capital to encourage the development of new accommodation and upgrades to existing accommodation.**

Principle 6 should include a requirement for any development or upgrade to be dementia friendly, regardless of funding source.



Aged care providers have a responsibility to ensure that assets they own and operate are safe and appropriate. This includes the provision of dementia friendly environments in residential care.

Dementia friendly environments enable the delivery of best practice care for all older people, not just those living with dementia. These environments are accessible, home-like and connected to the community, support personalisation and can meet different people's need for physical and psychosocial support.