

# **Productivity Commission Inquiry into Delivering Quality Care More Efficiently**

Dementia Australia is grateful for the opportunity to respond to the Productivity Commission's Inquiry into delivering quality care more efficiently.

Dementia is the leading cause of death for women and the second leading cause of death overall in Australia. Despite this, dementia has not yet been fully recognised or embedded as a public health and prevention priority across national and state health frameworks. There is an urgent need for long-term, coordinated investment in dementia risk reduction to reduce the future burden on aged care, health, and disability systems.

This significant public health issue requires strategic planning and investment in prevention initiatives with broad, long-term benefits for the Australian community.

Dementia Australia recommends that the Productivity Commission consider how national prevention frameworks, regulatory reform, and system-wide investment can support improved outcomes across the care economy. Specifically, we recommend:

- Reform quality and safety regulation to better support integration across aged care, disability, health, and mental health sectors
- Support consistent training in dementia to ensure safe care across all systems
- Recognise dementia as a public health and prevention priority across all national and jurisdictional strategies.
- Embed brain health and dementia risk reduction throughout the life course, with targeted programs and campaigns that begin in early adulthood and extend into later life.
- Invest in long-term, evidence-based prevention initiatives, including programs that address modifiable risk factors for dementia.

#### Dementia in Australia

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Dementia is one of Australia's most significant public health, social and economic challenges. It has been estimated that in 2020-21, almost \$3.7 billion of health and aged care spending was directly attributable to the diagnosis, treatment and care of people with dementia.

There are 433,300 Australians living with dementia, a figure projected to almost double in the next 30 years. Dementia is the leading cause of death for Australian women and the second leading cause of death overall.<sup>1</sup>

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<sup>&</sup>lt;sup>1</sup> Australian Institute of Health and Welfare. Dementia in Australia. Australian Government 2024.

Dementia causes significant cognitive and physical disability through progressive impairment of brain function, impacting memory, speech, thought, personality, behaviour and mobility.<sup>2</sup>

Despite medical advances, there is currently no cure for dementia. As dementia progresses, so do care needs, with care provision relying on both the paid workforce and unpaid family carers.

# Reform of quality and safety regulation to support a more cohesive care economy

To what extent do differences in quality and safety regulation make it costly or complex to provide or access care services?

### System navigation burden

Carers are often required to navigate multiple assessment pathways for the same individual: ACAT for aged care, NDIA assessments for disability services, and Carer Gateway assessments for respite or support. These assessments collect overlapping information but are not connected.

Individuals may have to retell their story repeatedly, which can be distressing — especially for people with cognitive impairment. This also leads to delays in service access.

### Dual regulatory burden

Feedback from people with lived experience of dementia and service providers suggests that some aged care providers refuse entry to people with younger onset dementia who are already NDIS participants. This is reportedly due to the administrative burden and cost of having to be registered under both the NDIS and Aged Care Quality and Safety Commission systems as well as the lack of integration between the two systems. While we recognise that residential aged care may not be the preferred or most appropriate setting for people with younger onset dementia, in situations where residential aged care is the only viable option, it is essential that access remains available and appropriate.

Feedback has also suggested that people with younger onset dementia entering aged care with NDIS funding are often pressured to relinquish their NDIS plan due to duplication or complexity, despite the fact that NDIS may provide more comprehensive allied health and behaviour support services than aged care. This

<sup>&</sup>lt;sup>2</sup> Australian Institute of Health and Welfare. Dementia in Australia. <u>Australian</u> Government 2024.

creates gaps in care and limits choice, especially where aged care does not have equivalent services or expertise.

## Inconsistent regulation of restrictive practices and medication use

The regulation of restrictive practices differs between sectors (hospital, aged care, disability), leading to inappropriate or unregulated use.

Medication management is inconsistent across sectors, posing a risk to safety and human rights.

### Gaps in clinical governance and dementia-specific guidance

While dementia is explicitly addressed in the strengthened Aged Care Quality Standards, its inclusion across other sector quality standards, such as the NDIS Practice Standards and clinical governance frameworks, remains inconsistent. This lack of consistency can make it challenging to ensure consistent quality and safety for individuals with dementia moving across different care settings.

Regulatory standards differ in their expectations around clinical governance, leading to variability in care quality and accountability.

### Workforce screening and training

While there is increasing support for universal worker registration, without consistent dementia-specific education requirements across sectors, registration alone will not improve quality or safety for people living with dementia.

As highlighted in numerous Dementia Australia's submissions, mandatory, consistent training in dementia is essential to ensure safe care across all systems.

### To what extent should quality and safety regulations be more aligned across the different care service sectors and jurisdictions?

- Regulatory consistency such as shared standards and terminology would allow for integrated care across sectors and would improve workforce mobility, reduce administrative burden for both providers and consumers, and ensure continuity of care.
- This would also reduce barriers to services for people with younger onset dementia, who can be caught between systems due to age- or system-based exclusions.
- As outlined in various Dementia Australia's submissions, quality care requires regulatory alignment, practice standards and training requirements that address the needs of people with dementia and cognitive impairment.
- Improved communication between regulators would prevent poor-quality providers from switching sectors without oversight.

- Alignment should also include embedding consistent oversight of restrictive practices across sectors.
- Opportunities exist to align assessment processes across My Aged Care,
  NDIA and Carer Gateway to reduce duplication.
- Streamline and harmonise worker screening processes for care and support workers across My Aged Care and NDIS.

# A national framework to support government investment in prevention

What are the main barriers to governments investing in evidence-based prevention programs across the care economy?

- Short-term political and budget cycles make investment in initiatives where benefits show over time less likely/appealing.
  - Governments plan around election cycles, which makes it difficult to prioritise programs that take 10, 20, or more years to show impact.
  - Dementia prevention requires continued action across the life course such as improving access to education in early life, addressing cardiovascular health in midlife, or reducing social isolation in older age.
  - These initiatives are unlikely to show immediate results, so they often struggle to compete for funding against programs with faster, more obvious outcomes.
  - This short-term prioritisation can lead to less investment in prevention, even though the long-term savings in health, aged care, and disability support would be significant.

### What are some examples of successful prevention programs (this could include discontinued programs)?

National anti-smoking campaigns and Slip, Slop, Slap, Seek, Slide have successfully improved public awareness, changed behaviour, reduced healthcare costs, and lowered disease incidence. These programs show that sustained, government-led efforts can deliver long-term health benefits.

A similar approach is urgently needed for dementia. Despite dementia now being the leading cause of death for women and the second overall cause of death in Australia, there has been no national prevention campaign or sustained investment in dementia risk reduction.

Evidence shows that this is a missed opportunity:

 The Maintain Your Brain (MYB) trial showed that a three-year online coaching program in physical activity, diet, cognition and mental health improved

- cognitive outcomes and reduced dementia risk scores. With an average cost of \$1,572 per participant, it was found to be cost-effective and potentially cost-neutral from a healthcare system perspective.<sup>3</sup>
- McRae et al. (2021) modelled cost-effective price thresholds for dementia prevention and found that even a modest 5% reduction in population-level risk factors could be cost-effective at \$460 per person. More targeted programs (e.g. combining online training with allied health input) costed at \$825 per person were still considered cost-effective when focused on higher-risk groups.<sup>4</sup>

#### These findings highlight that:

- Prevention works, even with modest changes in risk factors.
- Dementia prevention can be cost-effective, especially when targeted.
- Interventions that support brain health can also reduce risk for other chronic diseases (e.g. heart disease, diabetes), further strengthening their value for government investment.

### Address social determinants of health and health equity

Evidence from See et al. (2023) and the Australian Burden of Disease Study highlights that dementia risk is not evenly distributed. Social determinants such as poverty, low education, and poor access to healthcare disproportionately affect First Nations people, people from culturally and linguistically diverse communities, and those living in rural or socioeconomically disadvantaged areas. Prevention efforts should remove barriers and provide supports that make lifestyle change possible.

### Invest in brain health promotion initiatives

Governments should fund public education campaigns that promote brain health, similar to successful efforts in cancer and cardiovascular disease prevention.

Although many of the risk factors for dementia are the same as for other chronic diseases, there is still limited community understanding that people can reduce their risk or delay the onset of dementia through 'brain healthy' choices across the life span. A recent Ipsos survey highlighted that 83% of people surveyed indicated that they would like to know more about how to reduce their risk of developing dementia, and we also know that modifying risk factors might prevent or delay up to 45 per cent

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<sup>&</sup>lt;sup>3</sup> Welberry, H., Ku, L.-J. E., Shih, S. T. F., Jorm, L., Fiatarone Singh, M. A., Valenzuela, M., Ginige, J. A., Heffernan, M., Chau, T., & Brodaty, H. (2025). Cost-effectiveness of an online randomised controlled trial for dementia prevention, Maintain Your Brain, to improve cognition and lower dementia risk after 3 years. Alzheimer's & Dementia, Published online 09 January 2025. https://doi.org/10.1002/alz.088790

<sup>&</sup>lt;sup>4</sup> McRae, I., Zheng, L., Bourke, S., Cherbuin, N., & Anstey, K. J. (2021). Cost-effectiveness of dementia prevention interventions. The Journal of Prevention of Alzheimer's Disease, 8(2), 210–217. https://doi.org/10.14283/jpad.2020.71

of dementias.<sup>5</sup> The number of Australians living with dementia is expected to double in the next 25 years without significant levels of intervention. There is currently no cure for dementia, and very few treatment options. A focus on preventing or delaying dementia is crucial.

As such, Dementia Australia recommends a national brain health initiative to improve community understanding of dementia risk factors and support Australians to reduce their own individual risk and/or delay the onset of dementia. We propose a comprehensive behaviour change promotional campaign that is: underpinned by formative research; includes facilitated community education and other awareness raising activities; and takes a targeted focus on specific demographics and/or communities, such as working with First Nations communities to tackle the disproportionate risk factors experienced by Indigenous Australians.

The key benefits of a brain health initiative will be:

- Increasing public awareness of dementia and risk reduction measures;
- Increasing the number of Australians taking steps to reduce their risk of developing dementia;
- Increasing knowledge among communities at higher risk of developing dementia about risk factors for dementia; and
- Tacking the stigma and discrimination experienced by people living with dementia, their families and carers by improving people's understanding of dementia

### Improve access to early intervention supports and services

Dementia risk reduction requires government support across sectors. This includes access to allied health, dementia-skilled primary care and referrals to effective programs, hearing services, social prescribing, and mental health support, especially in regional and rural areas.

### Support carers

Carers of people with dementia experience high levels of stress and burnout. Government-funded programs, such as increasing availability and accessibility of respite for carers, could delay entering residential aged care and improve outcomes for both carers and people living with dementia.

Thank you for considering our submission. The Dementia Australia Policy team can be contacted at **policyteam@dementia.org.au**.

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<sup>&</sup>lt;sup>5</sup> Livingston G, Huntley J, Liu KY, Costafreda SG, Selbæk G, Alladi S, et al. Dementia prevention, intervention, and care: 2024 report of the Lancet Standing Commission. The Lancet. 2024;404 (10452):572-628.