

Draft National Consumer Engagement Strategy for Health and Wellbeing

Dementia Australia Submission 4 September 2023

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.

The Dementia Australia Policy team can be contacted on [**policyteam@dementia.org.au**](mailto:policyteam@dementia.org.au).

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 2058¹.

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 women².

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>

Include people with a cognitive disability

Dementia Australia appreciates the opportunity to provide feedback on the Draft National Consumer Engagement Strategy for Health and Wellbeing. As the peak advocacy organisation for people with dementia in Australia, we advocate for a strong consumer voice in health, aged care and disability support systems. People living with dementia and their carers play a key role in our organisation, providing expert advice to inform policy, strategy and services.

Cognitive disability is an umbrella term that can broadly be conceptualised as difficulties with memory and thinking that arise from intellectual disability, dementia, brain injury, autism, neurological disorders, fetal alcohol spectrum disorder, learning disorders or mild cognitive impairment. People with cognitive disability may have challenges with remembering, learning, concentrating, decision-making, attention, communication and problem-solving, among other difficulties³.

Dementia is a cognitive disability which affects people of all ages, causing difficulties with thinking, memory and behaviour. Community awareness of dementia as a disability is limited. The cognitive and other changes that are associated with the condition are under-recognised. People living with dementia regularly experience stigma and discrimination and may be denied their human rights.

We note that while the Draft National Consumer Engagement Strategy for Health and Wellbeing has made efforts to identify and include some diverse communities for consultation, there is very little focus on the inclusion of people with cognitive disabilities.

As well as more than 400,000 people living with dementia, there are around 450,000 people with an intellectual disability⁴, and over 700,000 people with a brain injury in Australia⁵. These health consumers are a significant group in the Australian population, and inclusion approaches should include a range of accessibility, communication, and engagement strategies that are meaningful to people with a cognitive disability.

Understand the full story

Dementia Australia has developed a comprehensive guide to meaningful engagement with people living with dementia, families and carers called **Half the Story**. Meaningful engagement means seeking out, affirming and ratifying the voices of people living with dementia, families and carers. It is necessary to understand the full story.

Meaningful engagement requires us to remove or reduce the barriers that prevent people from participating. It requires us to work differently. Meaningful engagement respects people's dignity and human rights, recognises their knowledge and skills, amplifies their voices, and involves people in decisions that will affect their lives.

It is essential that the voices of people with a cognitive impairment, including people living with dementia, are heard in any health consumer consultation. People living with a cognitive impairment and their carers:

- are experts in the lived experience
- can identify shortfalls, gaps or unmet needs
- bring new ideas and perspectives
- can help you reach your target market, and
- come from a broad range of professional backgrounds.

³ **Cognitive Impairment, Identifying and managing cognitive impairment, Indefinite detention of people with cognitive and psychiatric impairment in Australia, Issues Paper: Health Care for People with Cognitive Disability, Cognitive Impairment and the NDIS.**

⁴ **National Roadmap for Improving the Health of People with Intellectual Disability.**

⁵ **Brain Injury Australia – About Brain Injury.**

Meaningful engagement of people with cognitive disability can include involvement in:

- scoping, feasibility or needs analyses
- developing new services or programs
- reviewing existing services or programs
- setting strategic goals, aims or plans
- applying for funding or grants
- end user or accessibility testing
- creating resources
- wanting to understand the lived experience
- community development
- involvement in research studies
- training for policy makers.

It is also important to engage the expertise of advocacy and consumer organisations when designing consultation, to ensure that the consultation plan is thorough and barriers to participation are removed.

Aim for inclusion

We recommend that the Department of Health and Aged Care review **Half the Story – A Guide to Meaningful Consultation with People Living with Dementia, Families and Carers**. There are also numerous resources available online to support engagement of people with other types of cognitive disability, and range of consumer and advocacy organisations that can provide expertise.

The National Consumer Engagement Strategy for Health and Wellbeing will be strengthened by the authentic engagement of people with a cognitive disability, including people living with dementia.

Provided that consultation strategies are inclusive, people with living experience can offer advice and insight into how prevention and health promotion strategies can be more effective in the community. Inclusion will also empower people with cognitive disability in the advancement of their own health and wellbeing and the prevention of disease.

“It takes different experiences and expertise to understand an issue, together our voices are stronger, and together we can achieve so much more than we ever can on our own.”

~ Living experience expert.