

# **Review of the SA Mental Health Act 2009 – Supplementary Consultation**

# Dementia Australia Submission February 2025

Thank you for the opportunity to provide feedback on the review of SA Mental Health Act 2009.

Dementia Australia is the peak dementia advocacy and service delivery organisation in Australia. As the trusted source of information, education and support services, we elevate the living experience of people impacted by dementia to advocate for positive change.

We support a network of people living with dementia and carers to advocate for systemic change, known as the Dementia Advocates Network. We have encouraged the Dementia Advocates Network in South Australia to respond directly to your Office's consultation survey. Some Advocates also contacted us directly to share their insights for this submission.

In this submission, we make some general commentary about the accessibility of this consultation process, notes on contemporary approaches to dementia care, and recommendations for future work related to involuntary detention in the health system of people living with dementia.

#### Recommendations

- 1. Ensure that the human rights of people living with dementia are paramount in any changes to the Mental Health Act 2009, including clear processes for oversight, review and minimisation of restrictive practices or involuntary detention for treatment.
- 2. Mandate training of mental health professionals in dementia care, including understanding of responsive behaviours. This should include First Responders.
- 3. Ensure that any legislative reform aligns with the <u>National Dementia Action Plan 2023-</u> 2024 and the forthcoming <u>National Plan to End the Abuse and Mistreatment of Older</u> <u>People</u>.
- 4. Investigate the experiences of people living with dementia in the mental health system in South Australia with a view to program and service improvement, including number and age of those admitted, reasons for admission, use of restrictive practices and/or involuntary treatment orders, length of stay, treatment outcomes and discharge destination.

- 5. Include Dementia Australia in future project work to investigate powers for care for people living with dementia in the health system and meaningfully consult with people living with dementia and carers.
- 6. Consult with the **National Centre of Excellence in Intellectual Disability Health** in relation to the proposed neurodevelopmental disorders and mental health co-morbidity principle.

## Dementia prevalence in Australia

Dementia is the term used to describe the symptoms of a large group of 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 ultimately a terminal condition.

In 2025, it is estimated there are more than 433,000 people living with all forms of dementia nationally. This figure is projected to increase to more than 812,500 by 2054.<sup>1</sup>

Dementia is major public health concern and a leading cause of disease burden among Australians aged 65 and over.<sup>2</sup> It is the second leading cause of death for Australians and the leading cause of death for women.<sup>3</sup> In 2023, there were an equivalent of 15 people with dementia per 1,000 Australians.<sup>4</sup>

## Dementia and mental health in South Australia

There are an estimated 35,00 people living with all forms of dementia in South Australia. This figure is projected to increase to more than 55,600 by 2054. In South Australia, there around 2,100 people living with younger onset dementia, which is dementia diagnosed under the age of 65.

People living with dementia commonly experience depression and can also experience anxiety, sleep disturbance and confusion, hallucinations and other forms of mental distress.<sup>5</sup>

Generally speaking, it is critical that the emotional and psychological needs of each individual living with dementia are understood and attended to. This can promote wellbeing and quality of life for the person, reduce the risk of behavioural responses such as agitation, restlessness or aggression and reduce over-reliance on pharmacological treatment.

Psychological and psychosocial care should be person-centred and developed in partnership with the individual and their family, delivering evidence-based treatment and support.<sup>6</sup>

However, there is little known about the experience of people living with dementia, including those with comorbid mental illness, in the mental health system in South Australia. We do not

<sup>&</sup>lt;sup>1</sup> Dementia Australia (2025) **Dementia Facts and Figures.** 

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

<sup>&</sup>lt;sup>3</sup> Australian Institute of Health and Welfare (2024) **Dementia in Australia.** 

<sup>&</sup>lt;sup>4</sup> Australian Institute of Health and Welfare (2024) **Dementia in Australia.** 

<sup>&</sup>lt;sup>5</sup> Dementia Australia (2024) <u>Mood and behaviour changes.</u>

<sup>&</sup>lt;sup>6</sup> Australian Psychological Society (2023) Supporting the mental health of Australia's aged-care residents, InPsych 2023 Vol 45, Spring 2023.

have a clear picture of how many people living with dementia are admitted for mental health care or detained for involuntary treatment in the mental health system, or their treatment and discharge outcomes.

#### Human rights are central

Dementia is a misunderstood, stigmatised condition. Many people living with dementia continue to have adverse experiences in the community and in aged care, disability and health sectors.

Dementia Australia supports a human rights approach to dementia care. A rights-based approach has been embedded in the new Federal aged care legislation and remains relevant to implement in the mental health sector.

Some relevant critical components of a human rights approach to dementia care include:

- Respect for the person, their inherent dignity and their right to make decisions about their own life.
- Use of supported decision-making and a clear understanding of how decision-making capacity can be maximised.
- Individualised care based on the will and preferences of the person.
- Understanding and appropriate responses to causes of responsive and changed behaviour in dementia.
- Minimisation, safeguards, oversight and review of restrictive practices.
- Dignity of risk.
- Centred human rights of the patient in the clinical model.
- Prevention of violence and abuse.
- Involvement of family and carers in treatment planning, including those with legal appointment as substitute decision-makers, noting that there must be safeguards in place with awareness of elder abuse dynamics.

#### Powers for care

Dementia Australia notes the Office of the Chief Psychiatrist's intention to undertake future work related to finding an alternative to current use of the Mental Health Act for people living with dementia or experiencing delirium or substance withdrawal.

This is likely to be a highly complex piece of work, and we strongly recommend that the work includes a thorough analysis of the human rights implications of any legislative change aimed at allowing involuntary treatment in the health system of people living with dementia.

In the first instance, there needs to be better information, including data analysis and investigation of the experiences of people living with dementia in the mental health system in South Australia.

We seek inclusion in any future project related to powers for involuntary treatment in the health system of people living with dementia.

We also recommend that future work have an authentic consultation process with people living with dementia and carers. Members of our Dementia Advocates Network reported to us that the consultation process used in this Supplementary Consultation was inaccessible and difficult to engage with. The documents were difficult to comprehend for someone living with dementia, and the survey questions did not track easily against the Discussion Paper.

In future, we would be happy to facilitate consultation with people living with dementia and carers to ensure there is meaningful engagement about policy and legislative reform. We also recommend that your Office consult with our guide <u>Half the Story: A Guide to Meaningful</u> <u>Consultation with People Living with Dementia, Families and Carers.</u>

Thank you for this opportunity to raise these important issues related to dementia care. We look forward to working with you further to comment on the Exposure Draft of the revised Mental Health Act, and being involved in any future work related to powers of care for people living with dementia.

The Dementia Australia Policy and Advocacy team has dedicated policy staff in South Australia and can be contacted via **policyteam@dementia.org.au**.