

## **Parliament of New South Wales Committee on Ageing and Disability**

### **Inquiry into supported decision-making in NSW**

#### **Dementia Australia Submission March 2026**

##### **Dementia in New South Wales**

Dementia Australia is grateful for the opportunity to provide feedback to the Inquiry into supported decision-making in NSW. We are the peak body representing the estimated 446,500 people living with dementia, and their carers, across Australia (1).

A growing number of Australians are affected by dementia. Dementia prevalence is set to increase to more than a million people across the country by 2065 (1). Dementia is the leading cause of death for all Australians, as well as the leading contributor to disease burden for those aged over 65 (2).

In NSW, there are an estimated 145,700 people living with all forms of dementia in 2026, including 9,200 people under the age of 65 living with young onset dementia. Dementia prevalence in NSW is predicted to increase to an estimated 252,800 by 2054 (1). This means that legislation that upholds the rights of people living with dementia in NSW and supports them to live well is more important than ever.

##### **Recommendations**

Dementia Australia recommends that:

- 1) A statutory definition of legal capacity and universal model of supported decision-making be adopted in relevant NSW legislation and adhere to principles of:
  - a. Non-discrimination and equal enjoyment of rights
  - b. Assumption of capacity
  - c. Responsive and individualised support
  - d. All relevant provisions of the United Nations Convention on the Right of People with Disabilities (UNCRPD).

- 2) Where substitute decision-making is necessary, decisions should align with the rights and ascertainable will and preferences of the person, be proportionate to the decision and the capacity of the person, and contain safeguards against abuse or coercion. Clear guidance for NSW government employees should be developed and implemented consistently to guide assessment of decision-making capacity and factors which would indicate referral for guardianship, financial management or other substitute powers.
- 3) The NSW Ageing and Disability Commission be empowered and sufficiently resourced to lead and promote best practice in supported decision-making across NSW Government agencies, including development of resources, guidance and training.
- 4) NSW Government agencies be required to implement supported decision-making in policy and practice, with departmental performance monitoring and public reporting.
- 5) People living with dementia and families have access to well-resourced independent advocacy from the non-government sector.
- 6) People living with dementia and families have access to support, training and guidance on supported and substitute decision-making matters, including case advice, potentially through expansion of the Ageing and Disability Commission's scope and resourcing.

## **Supported decision-making and dementia**

Dementia is a cognitive disability which affects people of all ages, causing difficulties with thinking, memory, perception, mood and behaviour. Dementia describes a collection of symptoms caused by disorders affecting the brain. It is not one specific disease.

People living with dementia generally experience a decline in their cognitive ability as disease symptoms progressively become more severe. However, decision-making capacity fluctuates and is strongly influenced by a range of internal and external factors. Each person's experience is different. A diagnosis of dementia does not mean that someone suddenly does not have capacity to make their own decisions.

It is often incorrectly assumed that a diagnosis of dementia means people lack decision-making capacity. Capacity can be influenced by fatigue, noise, sensory disruptions, medication, delirium, illness, and time of day. These can all impact on a person's ability to make an informed decision about a specific issue at a specific time but that does not mean they are unable to make any decisions at any time.

Decision-making capacity describes a person's ability to understand information that may be relevant to a decision, including the consequences, to retain this information for decision-making purposes even if only briefly, and to communicate those decisions in any way. However, there are varying legal definitions and tests of capacity that apply in different scenarios across NSW and the rest of the country.

Acknowledging differences in understanding and beliefs about dementia and decision-making in the culturally and socially diverse communities that characterise contemporary Australia is also critical. Presenting information in an appropriate language and accessible format can support engagement in the process. (3) People living with dementia are routinely discriminated against and assumed to be unable to make decisions for themselves (4). Such action denies people living with dementia their fundamental right to autonomy and freedom to make choices, conferred under the UNCRPD to which Australia is a signatory.

*The doctor would not address mum directly and only spoke to me.*

*~ Carer of a person with dementia*

Supported decision-making is an essential approach to ensure that people living with dementia and other cognitive disabilities can make decisions about their own lives, with appropriate assistance from people they know and trust.

To align with Australia's commitments under the UNCRPD, a statutory definition and uniform model of supported decision-making should be articulated in relevant NSW guardianship, power of attorney and advance care planning legislation. Consistency with relevant Federal legislation including the Aged Care Act and the NDIS Act should be pursued, to minimise risk of inconsistent requirements for supporters or substitute decision-makers.

*Stop making assumptions about me.*

*~ Person living with dementia*

Dementia Australia advocates for a model of supported decision-making which:

- Assumes that people have capacity to make their own decisions unless it is disproven.
- Requires that people with dementia be supported to make decisions.
- Acknowledges that decision-making ability fluctuates, can be influenced by a variety of physical, psychological and environmental factors, and that these must be considered when providing assistance for specific decisions.
- Is responsive to the specific needs of the individual as their dementia progresses.
- Recognises that people living with dementia will require different levels and types of support to maximise involvement in decision-making for as long as possible.
- Holds that if substitute decision-making is required, the person's rights and ascertainable will and preferences should be given effect. Substitute decision-making should be a last resort and be proportionate. This is consistent with the Australian Law Reform Commission's *National Decision-Making Principles* for reform of Commonwealth state and territory laws and frameworks (5).

We recommend that the model of supported decision-making adopted in NSW Government align with these principles and apply consistently across relevant legislative frameworks, rather than continuing to rely on varying interpretations in law and policy. This would ensure that there are consistent requirements across agencies and a legislative basis for expectation by individuals of supported decision-making practices in health, legal, financial and service contexts.

## Substitute decision-making

While Dementia Australia strongly advocates for the use of supported decision-making for people living with dementia, we also recognise that because dementia is a progressive condition, there will be contexts in which substitute decision-making is an appropriate approach. Most people with advanced dementia will require a substitute decision-maker. Before substitute decision-making is used, it must be demonstrated that all avenues for supported decision-making have been exhausted.

Even in cases where a substitute decision-maker has been legally appointed, such as through an Enduring Power of Attorney or a Public Guardianship order, we recommend that decision-makers use supported decision-making where possible for specific decisions. Given that capacity can be assessed in relation to specific decisions and dependent on a range of conditions, this should be explored wherever possible to support the person living with dementia to exercise choice over different matters. Substitute decision-making powers should also be proportionate to the needs of the person and least restrictive of their autonomy, and contain safeguards to prevent abuse or coercion (6).

Contemporary models of rights-based and supported decision-making in disability, ageing and other fields are continuing to move away from a paternalistic “best interests” approach where decisions made for a person are primarily based on what others consider to be in the person’s best interest.

Instead, attention is given to ensuring that decisions are made in a way that is consistent with the will and preferences of the person, despite whether stakeholders believe the outcome will be in the person’s best interests. This allows decision-making models to actualise dignity of risk and focuses choices on what the person actually wants for their own life.

Dementia Australia recognises that each individual will have different views on how they would wish decisions to be made for them if they no longer have capacity. Ideally, substitute decision-makers would have strong knowledge of the individual’s views and values, and a sense of how they would wish to live their life.

In cases where a substitute decision-maker has been appointed who is not closely familiar with the person, every effort should be made to learn about their identity, personality, family, culture, background, values and preferences and to make decisions which would accord with their choices. This should be done as early as possible to maximise the opportunity for the person living with dementia to share this information first-hand.

We recommend that where substitute decision-making is necessary, decisions should align with the will and preferences of the person, to maximise their autonomy and protect their right to make their own decisions. This includes in relation to palliative and end of life care for people with advanced dementia, for example, decisions about life-sustaining treatment.

There is no Australian best practice standard for assessment of legal capacity or decision-making ability, and this has consequences for people living with dementia who are vulnerable to unconscious bias or presumptions about competency and capacity.

Dementia Australia supports further investigation into the factors and assessments which lead to a person being considered to not have decision-making capacity in interaction with different NSW government agencies, and subsequently to the appointment of guardians and financial managers, particularly through the NSW Trustee and Guardian. Consistent guidance on this matter is essential, including a publicly available standard for assessment and statutory definition of decision-making capacity.

Workforce training will be needed if supported decision-making is to be successfully expanded across NSW health, legal, financial and service environments. Training should be mandatory and prepare employees to apply supported decision-making in complex clinical and legal situations. We recommend that government agencies be required to implement supported decision-making in policy and practice, including consultation with the Ageing and Disability Commission in a leadership capacity.

It is especially important to ensure that there is expertise within NSW government agencies in capacity assessment and supported decision-making practice, including how capacity can fluctuate for people living with dementia and how environmental factors can influence capacity. There should also be a positive duty on government entities to provide conditions which maximise the opportunities for supported decision-making.

To achieve consistency with obligations under the UNCRPD and to expand supported decision-making consistently across legal and policy settings in NSW, we support ongoing review of the NSW Guardianship Act and other relevant legislation to establish a statutory definition of legal capacity and universal model of supported decision-making which is consistent with the UNCRPD.

## **Role and function of the Ageing and Disability Commission**

The Ageing and Disability Commission plays a critical role in promoting and protecting the rights of people living with dementia in NSW. With sufficient resourcing and mandate, the Ageing and Disability Commission would be well placed to provide leadership and expertise to embed supported decision-making in NSW law, policy and practice.

We recommend that the NSW Ageing and Disability Commission be empowered to lead and promote best practice in supported decision-making across NSW government agencies, including development of resources, guidance and training. However, it is important that NSW government agencies are considered responsible for implementation of supported decision-making, including workforce development, with implementation linked to departmental performance reporting.

It is important that individuals also have access to support, training and guidance on supported and substitute decision-making matters so that supporters and substitute decision-makers can provide skillful support, including where there are complex situations (6). A centre of expertise at the Ageing and Disability Commission could potentially be appropriate if the scope and resourcing of the Commission was expanded.

We also recommend that that people living with dementia and families have access to well-resourced independent advocacy from the non-government sector, to ensure practice and outcomes are consistent with rights and principles.

## Conclusion

Dementia Australia urges the Inquiry Committee to recommend reforms that:

- uphold the rights, dignity and autonomy of people living with dementia;
- embed a consistent definition of capacity; and
- deliver a uniform model of supported decision-making; in relevant guardianship and related legislation.

It must be clear that where substitute decision-making is necessary, it is a last resort, proportionate, and guided by the person's will and preferences. Making such reforms would give effect in NSW to related commitments under the UNCRPD.

Legal reform should be accompanied by resourcing of leadership for good practice in embedding supported decision-making across government agencies, and support for individuals, families and carers.

With dementia prevalence increasing significantly, a clear, consistent and rights-based decision-making framework is essential for quality of life for people living with dementia in NSW. These reforms present an important opportunity for NSW to demonstrate leadership in protecting the rights of people living with dementia and supporting them to live with dignity.

Dementia Australia would be pleased to provide any further information you may require and can be contacted on [policyteam@dementia.org.au](mailto:policyteam@dementia.org.au)

## References

1. Dementia Australia. Facts and Figures 2026 [Available from: <https://www.dementia.org.au/about-dementia/dementia-facts-and-figures>].
2. Australian Institute of Health and Welfare. Dementia in Australia. Australian Government; 2025.
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5. Australian Law Reform Commission. National Decision-Making Principles. Sydney: Australian Law Reform Commission; 2014. Report No.: ALRC Report 124.
6. Stewart C. Supported decision-making for people living with dementia in NSW. Sydney, NSW: NSW Parliamentary Research Service; 2025.