

National Safety and Quality Health Service (NSQHS) Standards (third edition)

Dementia Australia submission

25 September 2026

Introduction

Dementia Australia welcomes this opportunity to provide feedback on the third edition of the National Safety and Quality Health Service Standards ('the Standards').

This response builds on the submission provided by Dementia Australia during the initial consultation phase in September 2025, which was informed by significant feedback from people living with dementia and their carers. We welcome the substantial inroads made in the third edition to address many of the issues outlined in that **submission**.

In considering the consultation questions, we have revisited some of our original recommendations, in combination with new analysis.

Recommendations

1. Ensure dementia education and training for all health services staff, appropriate to role and setting.
2. Embed supported decision-making as a core principle across all standards.
3. Assess and document baseline cognition and function at admission and identify dementia and cognitive impairment, where present, to ensure proactive and coordinated care.
4. Strengthen actions to require dementia-friendly design features in new builds and facility upgrades.
5. Embed consent-based safeguards for restrictive practices and non-beneficial interventions as a foundation of high quality and integrated practice in clinical governance.
6. Support timely care transitions for people with cognitive impairment and dementia.
7. Embed dementia-informed palliative and end-of-life care across the continuum of care.

Dementia Australia is the peak body representing the estimated 446,500 people living with dementia and their carers across Australia [1], estimated to exceed one million by 2065. [1]

This includes 29,000 people living with young onset dementia (a diagnosis of any kind of dementia when you're aged 18-65). Dementia is the leading cause of death for all Australians, as well as a leading second leading cause of disease burden for people of all ages [2].

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.

Evidence shows that people living with dementia and cognitive impairment:

- are hospitalised at twice the rate of their peers without dementia
- are 2-3 times more likely to experience adverse events during hospitalisation than people of the same age who do not have dementia.
- routinely spend up to 4.5 times longer in hospital than general population [3].
- more than 1.4 times more emergency admissions (68% versus 48%);
- nine times more intensive care unit admissions (18% versus 2%);
- more than twice the rate of in-hospital mortality (90 versus 39 per 10,000) [4].

These outcomes demonstrate the critical need for the Standards to be underpinned by understanding of cognitive impairment and dementia and its potential impact on the health care journey of both patients and carers.

Ensure dementia education and training for all health services staff, appropriate to role and setting

The Standards must reflect that people living with dementia are a population at risk of poorer health outcomes, and that improving outcomes for this population requires dementia training and education for all staff, including de-escalation training for changed behaviours.

Adverse patient outcomes due to a gap in dementia knowledge and skills was a common experience amongst those surveyed for the original 2025 consultation.

Lack of training in dementia management in hospital ER resulting in mania and delirium due to excessive medications. ~ carer

Care often felt unsafe and uncoordinated — dementia carers excluded from decisions, discharge rushed, and no recognition of cognitive disability or trauma. ~ carer

Dementia Australia strongly recommends a commitment within the NSQHS Standards to strengthening workforce capability with dementia knowledge and skills relevant to their role.

There is often a lack of understanding of dementia and how to work with a patient who has dementia. ~ carer

Felt very unsafe with wrong medication...staff not educated in dementia care. ~ carer

A clear commitment to implementing dementia education and training, aligned with the National Dementia Education and Training Standards Framework (NDETSF), should be explicitly articulated within the Standards to support the delivery of safe, person-centred care.

Embed supported decision-making as a core principle across all standards

Dementia Australia welcomes the increased focus of the Standards on participatory decision-making; however the current edition does not explicitly require supported decision-making, which is essential to recognising the equal right of people with cognitive disability to exercise legal capacity, in accordance with the UN Convention on the Rights of Persons with Disabilities.

We advocate for decision-making capacity to be assessed in relation to the specific decision at hand, with appropriate support provided to maximise the person's ability to participate. A diagnosis of dementia - or the presence of cognitive impairment - should not be interpreted as an absence of capacity.

We recommend that supported decision-making be explicitly embedded across the continuum of care, including as part of proactive advance care planning (ACP).

For someone living with dementia, ACP is not simply an end-of-life document, it is a process that enables the person to articulate their values, preferences and goals while they can participate in decisions, and provides guidance as decision-making capacity changes. Dementia Australia's current **ACP position** specifically recommends that conversations commence early and be revisited as dementia progresses.

Feedback from people with a lived experience of dementia consistently highlights decisions being made in healthcare settings that do not reflect the will or preferences of the person living with dementia.

They need to count and to have a voice-even if that voice takes extra effort to hear.
~ carer

Assess and document baseline cognition and function at admission and identify dementia and cognitive impairment, where present, to ensure proactive and coordinated care.

Dementia is frequently identified in hospital during treatment for another acute condition or event, rather than via cognitive assessment at admission. Which means it is likely under-diagnosed and under-recorded. [7]

Proactive screening at admission will benefit healthcare providers and patients by enabling earlier therapeutic and clinical interventions and strengthening care planning and coordination. It may also reduce instances of unwanted clinical variations and improve the patient experience overall. [7]

I do not think our health care addresses dementia adequately and the current treatment and management of dementia patients is not safe or of high quality. In fact, I think it is mostly inhumane and undignified. ~ carer

ED experiences have been frightful several times not just the above. I don't ever want to go back. ~ person living with dementia

The third edition of the NSQHS Standards must adequately respond to the care needs of people with dementia and their families. With dementia prevalence projected to more than double over the next three decades, failure to address these risks in the Standards now will mean even greater strain on hospitals and worsening outcomes for people with dementia in the future.

Strengthen actions to require dementia-friendly design features in new builds and facility upgrades

Acute care environments that are dementia-friendly use dementia-enabling design and inclusive language to reduce stigma and assumptions that can lead to adverse care outcomes.

People living with dementia and their carers describe hospital settings as overwhelming, distressing and disorienting. Dementia Australia requests that Requirement 3.01 be strengthened to clarify that safe, culturally welcoming and therapeutic care environments include cognitive accessibility and **dementia-enabling design**.

Dementia Australia also recommends that the term 'behaviours of concern' within the Standards be replaced with 'changed behaviours' or 'expressions of unmet need'. Beyond any change in terminology, the Standards should also require clinicians to investigate why patient behaviours have changed since admission. For instance, behaviours interpreted as aggressive may be in response to an adverse reaction to medication, which cannot be articulated by the person living with dementia.

Embed consent-based safeguards for restrictive practices and non-beneficial interventions

Dementia Australia welcomes the explicit requirements for health services staff to work with patients, carers and families to 'prevent, recognise and manage' behaviours that may indicate unmet need or patient distress.

It is important to understand that behavioural changes are caused by changes to the brain and can also be affected by an individual's environment (social and physical), health and medication. [6] The Standards should require health services to ensure that people living with dementia receive systematic assessment and management of pain and other symptoms, including when they cannot reliably self-report. This is particularly important in advanced dementia, where symptoms may present through:

- facial expression;
- vocalisation;
- withdrawal;
- agitation;
- changes in movement;
- sleep disturbance;
- appetite changes; or
- other changes from the person's baseline.

We recommend that people living with dementia are cared for by staff with education and training to enable them to deploy evidence-based de-escalation strategies that do not include

the use of restraints, except as a last resort. We also recommend that consent-based safeguards for restrictive practices be included in the Standards and that any use is strictly as a last resort, time limited and regularly reviewed.

The dementia patient may be so distressed they are medicated unnecessarily, which causes more problems. ~ carer

Support timely care transitions for people with cognitive impairment and dementia

Extended hospital stays can result in significant physical, cognitive, functional, and behavioural decline especially for people living with dementia. Unfamiliar environments, disruption to routines and communication difficulties can increase confusion and distress and reduce a person's ability to regain function [3, 8].

Timely discharge to home or residential aged care – and/or transitions between care providers - can be greatly improved by sharing of patient data which accurately captures a person's regular/baseline functional status and behaviour, as well care preferences, communication needs and care goals. Such an approach to documentation and information sharing will enhance care transitions and longer-term support,

Embed dementia-informed palliative and end-of-life care across the continuum of care

Dementia Australia and Palliative Care Australia recognise palliative care as a core component of care from diagnosis through to end of life and bereavement, rather than something that commences only when a person is imminently dying.

The Standards should require health services to provide a dementia-informed palliative approach that supports quality of life, comfort, dignity, and personhood throughout the course of dementia, including at the end of life. This should include timely **advance care planning**, regular review of goals of care, recognition and management of pain and other symptoms, appropriate referral to specialist palliative care, and avoidance of burdensome or non-beneficial interventions.

Conclusion

We thank the Commission for the opportunity to contribute to this consultation.

Dementia Australia urges the Commission to further strengthen the latest edition with explicit requirements for dementia education and training, supported decision-making, cognition assessments at admission, dementia-enabling environments, consent-based safeguards against restrictive practices and dementia informed palliative and end-of-life care. With these enhancements, the Standards will go much further towards ensuring safe, person-centred, and respectful care for all Australians including people living with dementia.

We would be pleased to discuss any of the issues raised in this submission in more detail. For more information, please contact the Dementia Australia Policy and Advocacy team at policy@dementia.org.au.

References

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