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

September 2025

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.

Dementia 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 433,300 people living with all forms of dementia in Australia. Without a significant medical breakthrough, this figure is projected to increase to an estimated 812,500 by 2054.[1] Dementia is a major public health concern and a leading cause of disease burden among Australians aged 65 and over.[2] Dementia is also the leading cause of death for all Australians.[2]

Introduction

Dementia Australia welcomes the opportunity to respond to the consultation on the third edition of the National Safety and Quality Health Service (NSQHS) Standards and commends the Commission for its commitment to improving safety and quality in Australian health services.

This submission is informed by the lived experiences of participants in our Dementia Advocates Program, a national initiative where people living with dementia and their carers influence policy, practice, and service design.

The feedback presented here reflects the voices of people with dementia and their carers who have engaged with health services across Australia in the last five years. Their insights highlight persistent gaps in dementia care, including:

- Unsafe and unsuitable hospital environments
- Inadequate dementia-specific training across the health workforce
- Workforce shortages and inconsistent care
- Exclusion of carers from decision-making
- Lack of supported decision-making
- Inappropriate use of restrictive practices
- Lack of person-centred care and care planning

This submission calls for the third edition of the NSQHS Standards to strengthen protections for people living with dementia including, dementia-friendly environments, dementia training for staff, carer inclusion, supported decision-making, safeguards on restrictive practices, and cultural safety, and effective earlier management of health conditions.

Summary of recommendations

- Detect cognitive impairment and dementia at admission and initiate relevant care pathway.
- Strengthen actions to require dementia-friendly design features
- Ensure dementia education for all staff appropriate to role and setting
- Recognise carers as partners in care
- Embed supported decision-making as a core principle across all standards
- Embed consent-based safeguards for restrictive practices
- Embed cultural safety across all standards

Existing and emerging safety and quality risks

Dementia care pathways

In Australia, 6.5% of all hospitalisations are potentially avoidable, and older people account for between 14 and 27% of all potentially avoidable hospitalisations.[3] People living with dementia are 2–3 times more likely to experience adverse events during hospitalisation than people of the same age who do not have dementia.[3] Common reasons for people living with dementia to present to Emergency Departments are pain and falls.[3] Evidence shows that people living with dementia are hospitalised at twice the rate of their peers without dementia and routinely spend up to 4.5 times longer in hospital than the general population.[4]

Delayed discharge is a national systemic issue with a significant impact on the quality of life and wellbeing of people with dementia and their carers. With our population ageing rapidly, and increasing dementia prevalence and multimorbidity, the health and aged care systems are not keeping pace with demand for services.

Hospitals are not a suitable environment for long-term care of people living with dementia, who face higher risks of delirium, falls, malnutrition, infection, and functional decline in acute settings.

Some people with dementia remain in hospital longer due to a lack of aged care places, challenges in sharing patient records between hospital and aged care providers, or inadequate discharge planning. These prolonged stays increase the risk of hospital-acquired complications, distress, impacts to carer wellbeing and highlights the need for health services to identify patients with dementia or cognitive impairment early and ensure they are supported by an appropriate model of care.

The feedback from people living with dementia and carers highlights systemic issues within health care settings for people living with dementia that undermine safety, dignity, and quality of care. This includes poor communication and information sharing, exclusion of carers from decision-making, inappropriate use of medications and restrictive practices, and hospital environments that are overstimulating, confusing, and distressing. These challenges are compounded by workforce shortages, lack of dementia-specific education of hospital staff, and inconsistent care practices. Together, they contribute to preventable harm, distress and a loss of trust in the health system.

> *"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 address these issues with strengthened standards that respond to the care needs of people with dementia and their families. This is essential because hospitals are not designed for long-term dementia care, and people with dementia face disproportionately poor outcomes during admission. 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.

Recommendation: Health services identify cognitive impairment and dementia on admission and ensure this triggers an appropriate cognitive care pathway.

Unsuitable and unsafe environments

People living with dementia and their carers have described hospital settings as overwhelming, disorienting, and distressing and generally unsuitable and unsafe for people living with dementia.

> "*Hospital and facilities for X-rays etc are not very dementia friendly, often poor signage, loud, difficult to access toilet facilities and equipment not designed or staff not experienced working with patients with cognitive decline." Carer*

The combination of harsh lighting, excessive noise, and poor signage creates a sensory overload that can exacerbate confusion and behavioural changes in people with cognitive impairment. As one advocate noted:

> *"ER in particular is quite overwhelming for a dementia patient; lots of lights, noise, people, it adds to the confusion and disorientation." -Carer*

The layout of wards is often difficult to navigate, and the lack of dementia-friendly design features contributes to anxiety, distress and increased risk of harm.

Health services must ensure care environments are safe, accessible and dementia-friendly, including appropriate lighting, signage, noise reduction, wayfinding, and accessible toilet facilities and that the needs of people with cognitive impairment are considered in this design.

Recommendation: Action 5.6 should be strengthened to require health service organisations to ensure the care environment is safe, accessible and dementia-friendly.

To assist in the design of dementia-enabling environments, Professor Richard Fleming and Kirsty Bennett developed **Ten dementia-enabling environment principles**. These principles are evidence-based and have been designed to maximise enablement and wellbeing for people living with dementia.

Workforce shortages and lack of dementia education

The previously stated environmental stressors are compounded by a workforce that is not consistently trained in dementia care and stretched thin due to staffing shortages.

This lack of education and continuity in staffing leads to inappropriate responses to dementia-related behaviour changes, including shouting, rudeness, hurried interactions, and failure to communicate clearly or compassionately

> *"Felt very unsafe with wrong medication. staff not educated in Dementia Care". Carer*

> *"There is often a lack of understanding of dementia and how to work with a patient who has dementia." Carer*

> *"Care staff leaving medication unattended, little to no understanding of dementia and the care needs required". Carer*

These examples reflect a lack of dementia knowledge which leads to an absence of person-centred care, where the needs of the person with dementia are not recognised or respected.

Recommendation: Health services should ensure all staff who provide care to people living with dementia receive dementia education and training that is appropriate to their role and setting, aligned with the National Dementia Education & Training Standards Framework (NDETSF). Additionally, workforce planning must ensure sufficient staffing levels and continuity to deliver safe, person-centred care.

Carer exclusion

The second edition of the NSQHS Standards recognises the importance of partnering with consumers (Actions 2.06 and 5.13), including the involvement of carers and substitute decision-makers where appropriate. However, feedback from people living with dementia and their families demonstrates that in practice these provisions are inconsistently applied and overlooked.

Carers report being excluded from decision-making, even when the person they support has significant cognitive impairment or has lost decision-making capacity. Many carers reported being excluded despite being essential to communicating and advocating for the person they care for. Carers also reported breakdowns in communication between staff, services, and families. This included rushed explanations, lack of updates, and failure to include carers in decision-making.

> *"It's such a mess, that being person centred is least of the problems. there is no inclusion of carers. hospital tried to discharge my dad who is paralysed and cognitive issues without me even being there." Carer*

> *"Inability to ensure patient understands questions and instructions. Lack of understanding of the role of an advocate. Lack of involvement of family in supporting patient with dementia, despite several conversations." Carer*

> *"It is difficult when someone is losing capacity and the doctors are making decisions without discussing things with your loved one." Person living with dementia*

These experiences highlight a gap between the current Standards and good practice. While the Standards reference substitute decision-makers, they do not embed supported decision-making as a default approach, nor do they require involvement of carers and advocates in the care plan.

Health services should involve carers in care planning, decision-making, and discharge processes, unless the person explicitly declines their involvement.

Recommendation: The implementation of the third edition of the standards must ensure carers are recognised as partners in care and supported in this role.

Lack of supported decision-making

The second edition of the NSQHS Standards references shared decision-making and the involvement of substitute decision-makers (e.g. Actions 2.06 and 5.13) but does not explicitly address the needs of people living with dementia with respect to supported decision-making.

Feedback from advocates highlights a persistent lack of supported decision-making among health care staff. Carers report being excluded from critical decisions, and people with dementia often describe their voices being overlooked. This results in decisions being made on behalf of people living with dementia which may not reflect their will and preferences.

> *"Such decisions generally did not take into account the needs of persons living with dementia." Carer*

The UN Convention on the Rights of Persons with Disabilities (CRPD) recognises the equal right of people with cognitive disability to exercise legal capacity and requires governments to provide access to the supports necessary to enable people to make their own decisions.

Dementia Australia strongly supports the principles of supported decision-making for people living with dementia as this approach is critical to safe, respectful, and person-centred health care for people living with dementia and ensures that individuals are involved in decisions about their care to the greatest extent possible.

> *“Always include the person AND the carer / family member (where there is one) in decisions and care planning.”* Carer

> *“They need to count and to have a voice - even if that voice takes extra effort to hear”* Carer

Recommendation: The third edition should embed supported decision-making as a core principle across all standards and align hospital practice with Australia’s obligations under the CRPD and include staff training in supported decision-making.

Restrictive practices and medication mismanagement

Feedback from people living with dementia and their families highlights inappropriate use of restrictive practices in hospital and acute care settings, including the inappropriate use of chemical restraint (inappropriate medication use). These practices may be applied without informed consent from the person or their carer and cause harm and breach human rights.

> *“The care given was drugs to dope the person living with dementia.”* Carer

> *“I was a carer for my mum who had dementia. After a bad fall we took her to hospital. No-one seemed to know what to do with her. She was drugged to try and control her behaviour and put into a mixed ward in the middle of the night. I stayed in the hope she would go to sleep, but of course the strange new environment prevented that. They soon decided she was a falls risk due to the amount of sedative they had given her, and asked me to take her home.”* Carer

> *“This particular hospital chose to isolate client in room most of the day and during meal times knowing that they live with dementia. Knowing that I was carer/guardian they also chose to apply drugs to restrain client without my knowledge.”* Carer

In the second edition, Action 5.35 (Restraint) and Action 5.36 (Seclusion) require health services to minimise restrictive practices and align with state/territory legislation. However, consent is not embedded as a standardised national requirement which results in inconsistent practices across states and territories. Additionally, chemical restraint is recognised but not subject to mandated national reporting or explicit consent safeguards and accountability mechanisms are weak.

As a result, people living with dementia in health care settings are not afforded the same human rights protections that will apply in aged care from November 2025 under the new Aged Care Act.

> *“My mother was given ground up slow-release high strength pain killers which nearly killed her.”* Carer

> *“To administer dangerous and unproven medications to the scared and elderly because 'that is all we have' is questionable.”* Carer

The third edition must go beyond general medication safety and limit the use of restrictive practices unless clinically necessary, consented to, and regularly reviewed.

To close the gap and ensure consistent protections across health and aged care settings, Dementia Australia recommends that the Third Edition of the NSQHS Standards embed a consent-based safeguard for restrictive practices, and clarify expectations for governance and workforce training, including de-escalation strategies, supported decision-making, and person-centred care.

> *“Treat the patient with respect and understanding of their condition. The dementia patient may be so distressed they are medicated unnecessarily which causes more problems. Reassurance, kindness and a calm environment where they feel safer will help.” Carer*

Recommendation: The third edition should embed consent-based, enforceable principles modelled on the new Aged Care Act into NSQHS and include staff training on inappropriate use of anti-psychotics.

Experiences of diverse groups

The second edition of the NSQHS Standards references the need for services to consider cultural and linguistic diversity. However, feedback from people living with dementia and carers shows that these provisions are not sufficiently embedded or consistently applied in practice. Dementia Advocates from Aboriginal and Torres Strait Islander and culturally and linguistically diverse (CALD) communities report experiencing barriers to assessment, communication, and culturally appropriate care.

> *“We could not get assessments done that were badly needed for cognitive function because we are Aboriginal, that is what we were told.” Carer*

Health services must ensure care is culturally safe, inclusive, and responsive to diverse needs, including Aboriginal and Torres Strait Islander peoples and people from culturally and linguistically diverse backgrounds.

> *“When in emergency wing it was important that I stayed with the patient (living with dementia) in order to relay history… communication would combine English and birth language in the same sentence.”-Carer*
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> *“Cultural safety should also be explicitly included in the standards, recognising the role of food, language, and community connection in creating familiar, safe environments for Aboriginal and Torres Strait Islander families.” Carer*
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> *“Importantly, cultural safety is key for supporting people with dementia. A culturally safe environment helps create familiarity and comfort, which is especially important as dementia can heighten confusion and distress. For Aboriginal and Torres Strait Islander families, this may include food, language, symbols, and community connections that reflect culture and feel familiar. Without this, care can feel clinical and alienating, which increases distress for the person and their family. Building cultural safety into the standards is not just about respect — it is essential for quality dementia care.” Carer*

Embedding cultural safety across the Standards aligns with the UN Declaration on the Rights of Indigenous Peoples and the CRPD and is essential for ensuring that people with dementia from diverse backgrounds receive appropriate care.

Recommendation: The third edition must embed cultural safety across all standards and ensure co-design with Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse communities.

Conclusion

We thank the Commission for the opportunity to contribute to this consultation. The third edition of the NSQHS Standards is an opportunity to address safety and quality concerns for people living with dementia. Unless the Standards explicitly address supported decision-making, carer inclusion, dementia-specific training, and consent-based safeguards on restrictive practices, we are concerned that people with dementia will continue to experience preventable harm in health care settings.

We urge the Commission to align the NSQHS with human rights principles to ensure safe, person-centred, and dignified care for all Australians.

References

1. Dementia Australia. *Facts and Figures* 2025; Available from: **https://www.dementia.org.au/about-dementia/dementia-facts-and-figures**.
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3. Panayiotou, A., *Preventing Avoidable Hospital Admissions for People with Dementia – Final Report*. 2018, Melbourne Ageing Research Collaboration (MARC).
4. Dementia Australia, *Hospital Care for People Living with Dementia*. 2019, Dementia Australia.