

Tuesday 30 June 2020

Alice Bhasale

Director, Clinical Care Standards

Australian Commission on Safety and Quality in Health Care

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Dear Ms Bhasale

Thank you for the opportunity to comment on the review of the Delirium Clinical Care Standard (2016) (the Standard). Dementia Australia continues to support the Standard, which provides guidance to consumers, clinicians and health services on delivering appropriate care to people at risk of, or with, delirium. This is particularly important for a person living with an existing cognitive impairment, including dementia, as they are more likely to develop delirium during their hospital stay.

The Standard specificity addresses this key challenge people living with dementia can experience, and sets out clear indicators to maintain quality care and support improvements in treating people experiencing delirium. As such, the Standard remains a sound document with relevant and appropriate information regarding delirium. Dementia Australia supports the use of this Standard, with the additional suggestion of including reference to supported decision making.

While Dementia Australia praises the Standard for the inclusion of substitute decision making, and acknowledgement of the important role family members and carers play in the prevention, early recognition, assessment and recovery relating to a patient's health conditions, we would like to see reference made to supported decision-making. Supported decision-making is particularly important for people living with dementia to help them make their own decisions so they can have control over things that are important to them.

A person's decision-making ability is to be assumed, and the presence of cognitive impairment is not a reason to exclude someone from decision-making. It is important that the Standard adopts a rights-based approach, guiding clinicians and services in the approach and processes that will enable them to involve, listen to, and respect the views of the person, and seek to accommodate them.

When assessment of a person's decision-making ability is needed, clinicians will need to determine a functional approach, focused on assessing the person's understanding of the context, choices and consequences of the specific decision to be made, and understanding what supports might be needed to make the decision. It should not involve a judgement on the perceived wisdom or outcome of the person's decision.

There are four principles specific to supported decision-making:

PRINCIPLE 1: All adults have an equal right to make decisions that affect their lives and to have those decisions respected;

PRINCIPLE 2: Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives;

PRINCIPLE 3: The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives;

PRINCIPLE 4: Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

If and when a person does not have decision-making ability, another person can be appointed in advance by the person or by a tribunal, or assigned under State and Territory laws as a substitute decision-maker.¹

More information about supported decision-making can be found through contacting Dr Craig Sinclair at Neuroscience Research Australia (NeuRA).

Additionally, Dementia Australia would like to recommend that any changes made to the Standard maintain the same style of language. The current Standard has been praised by people living with dementia, their families and carers as being clearly written and easy to understand.

“The Clinical Delirium Care Programme is very clearly written and I would have no alterations to recommend.” – Person living with dementia

In any modifications to the Standard, Dementia Australia recommends keeping the language simple and consistent, with clear sections outlined for the different intended audiences. Particularly regarding the ‘For patients’ sections, it would be useful to test the copy among consumers, particularly people living with dementia, their families and carers to ensure it is clearly understood and articulates their key information needs.

We would also like to take this opportunity to flag, that while outside the scope of the review of the Standard, there is a need for consistent implementation, monitoring and evaluation of the Standard across different health settings and locations to improve consistency in quality of care.

Healthcare environments are required to provide high quality health care for people with cognitive impairment and keep them safe.

At present, the Standard is able to be adapted according to different health settings and providers. This creates a risk of inconsistent quality of care. While flexibility is important at a local level to address local need, without consistency across Australia, people could experience different levels of care and not have their needs appropriately met.

Additionally, it can be confusing to the workforce, should they change care settings and have different expectations when handling the same health issue. A national approach where care settings are monitored and evaluated consistently could improve the quality of care to people at risk of, or with, delirium.

Labelling a person is often done in a rush and can have dire consequences for their independent future. – Former carer

I have been horrified to find some nursing staff feel an ‘assessment for either/or delirium and dementia’ can be done on the spot. – Former carer

It is recommended that Federal, State and Territory governments work with health, aged and disability services to promote more consistency in the quality of care to meet the needs of people living with dementia experiencing delirium. Particularly, a rights based approach for people living with dementia, their families and carers is recommended. This is to enable them to feel safe and supported to speak with clinicians and health service staff about their needs, preferences and consent to any course of treatment.

“Unless both federal, state and territory health departments work together to make all hospitals conform to going about policy in one way, there is always going to be much overlap, that confuses everyone, and nothing changes. We should be able to tick the box on this document and say yes, it is

¹ Sinclair, C. (2018) Cognitive Decline Partnership Centre, Supported decision making in aged care: A policy development guideline for aged care providers in Australia, Second edition. Available at <https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/SDM-Policy-Guidelines.pdf>

working really well, and may just need a little touch up, but who is actually using it in the first place, if all the hospitals are doing something different, or close, but different, can anyone really say it's all good?" – Carer

Dementia Australia is satisfied that the Delirium Clinical Care Standard continues to provide relevant and well-communicated guidance to consumers, clinicians and health services on delivering appropriate care to people at risk of, or with, delirium.

Should you or your team at the Australian Commission on Safety and Quality in Health Care wish to discuss this submission further, Dementia Australia would welcome the opportunity.

Yours sincerely



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