



Response to Counsel Assisting's final submission

A submission to the Royal Commission into Aged Care
Quality and Safety

12 November 2020

About Dementia Australia

No matter how you are impacted by dementia or who you are, Dementia Australia is here for you.

We exist to support and empower the estimated half a million Australians living with dementia and almost 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia yet remains one of the most challenging and misunderstood conditions.

Founded by carers more than 35 years ago, today we are the national peak body for people impacted by dementia in Australia.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences across Australia. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

Dementia Australia is the source of trusted information, education and support services. We advocate for positive change for people living with dementia, their families and carers, and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible.

Dementia Australia welcomes the opportunity to provide a response to the submissions and recommendations made by Counsel Assisting the Royal Commission into Aged Care Quality and Safety.

Overall, Dementia Australia is supportive of the bulk of Counsel Assisting's recommendations (or the intent of the recommendations). We are especially pleased to see the inclusion of dementia-specific recommendations and believe many of the recommendations will, if accepted and implemented, benefit people living with dementia, their families and carers. We also welcome the focus on a human rights approach informing the redesign of the aged care system.

As outlined in our submissions to the Royal Commission on program design, the current aged care system does not adequately support people living with dementia as part of core business. We applaud Counsel Assisting for recognising that dementia must be core business for aged care.

In order for dementia to become core business, a series of foundational shifts in leadership, culture and workforce capacity across all elements of the system is required. If this transitional and capacity building work does not occur, the same barriers, challenges, and at worst, breach of human rights, will continue to impact people with dementia, their families and carers in any new system.

A key priority for Dementia Australia is quality dementia care and what it looks like. In 2019, we consulted with people with a lived experience of dementia to find out what quality dementia care meant to them, particularly in the context of the Aged Care Quality Standards. We asked people:

- What does quality dementia look/feel like?
- What are the key points of difference between quality dementia care and aged care more generally?

The culmination of this consultation was a Consumer Summit to discuss findings and ratify a communique – *Our Solution: Quality Care for people living with dementia*.¹ The result was an unequivocal vision of holistic and person-centred care that is underpinned by an appropriately educated and skilled workforce, which has strong leadership that promotes positive organisational cultures within and across the sector.

Although the principles in the Communique are framed within the context of the Aged Care Quality Standards, they speak to the need for sector-wide transformation – the seeds for which have in part been planted by other capacity-building work, including the strategic vision outlined in the Matter of Care report compiled by the Aged Care Workforce Taskforce in 2018², key work by the Aged Care Quality and Safety Commission and, of course, by individual providers.

¹ Dementia Australia (2019) *Our Solution: Communique Care for people living with dementia* <https://www.dementia.org.au/files/documents/DA-Consumer-Summit-Communique.pdf>

² Aged Care Workforce Strategy Taskforce (2018) *A Matter of Care. Australia's Aged Care Workforce Strategy*, June 2018 https://agedcare.health.gov.au/sites/default/files/documents/09_2018/aged_care_workforce_strategy_report.pdf

A copy of the Communique is attached to our response.

“If you can get it right for dementia, you can get it right for everyone else” – Person living with dementia

Based on Counsel Assisting’s vision of a new aged care system, Dementia Australia’s Quality Dementia Care Initiative is well positioned to oversee the path through aged care reform towards more consistent, foundational quality dementia care. The Initiative has the ability to map and track key initiatives that address the facets of quality identified by people living with dementia, families and carers, develop meaningful indicators in conjunction with people with a lived experience of dementia and collaborate with key stakeholders across the sector to ensure effective implementation and evaluation. We would be willing to share key Initiative documents with the Commissioners when they are finalised.