Dementia Australia™

Response to the Consultation Paper: Care and support sector code of conduct

A submission to the Australian Government
Department of Health

December 2021

This page is left blank intentionally

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.

Introduction

Dementia Australia welcomes the opportunity to provide a submission in response to the Consultation Paper: Care and support sector code of conduct.

Largely, Dementia Australia supports regulatory alignment across the care and support sector, incorporating the aged care, veterans' care and disability support sectors, to reduce red tape for employers, increase mobility of staff to work across the three sectors and strengthen safeguards for people who are provided with care, supports and services.

It is important that a code of conduct for the care and support sector ensures that all people who are provided with care, supports and services can have confidence in the workforce and feel equally safeguarded by the regulatory arrangements.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive diseases which cause a progressive decline in a person's functioning. Symptoms can include memory loss as well as 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 one of the largest health and social challenges facing Australia and the world. There are an estimated 472,000 Australians living with dementia in 2021[1] and around 1.6 million people[2] involved in their care. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.[3]

Dementia is a terminal condition and there is currently no cure. It is the leading cause of death of women in Australia, and the second leading cause of death overall. It is predicted to become the leading cause of death within the next five years.[4]

It is generally not well understood that dementia is a progressive cognitive disability. Although dementia is commonly perceived to be an age-related illness, it is not a normal part of ageing. Dementia is more common in older people, but it can affect people in their 40s, 50s and even their 30s.[5]

---

[1] Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

[2] Based on Dementia Australia's analysis of the following publications – M.Kostas et al. (2017) *National Aged Care Workforce Census and Survey – The Aged Care Workforce*, 2016, Department of Health; Dementia Australia (2018) *Dementia Prevalence Data 2018–2058*, commissioned research undertaken by NATSEM, University of Canberra; Alzheimer's Disease International and Karolinska Institute (2018), *Global estimates of informal care*, Alzheimer's Disease International; Access Economics (2010) *Caring Places: planning for aged care and dementia 2010–2050*

[3] Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by The National Centre for Social and Economic Modelling [NATSEM], University of Canberra

[4] Australian Bureau of Statistics (2018*) Causes of Death, Australia, 2017* (cat. no. 3303.0)

[5] There are also some rare forms of childhood dementia, including Sanfilippo Syndrome, Niemann Pick Type C Disease and others.

Younger onset dementia describes any form of dementia diagnosed in people under the age of 65. In 2021, there are an estimated 28,300 people living with younger onset dementia in Australia. This number is expected to rise to 29,353 people by 2028 and 41,249 people by 2058.[6]

The misconception that dementia is a condition of old age contributes to, and exacerbates, multiple challenges experienced by younger people with a diagnosis of dementia. Overall, the experience for people with younger onset dementia – who often receive a diagnosis when they are in full-time employment and actively raising and financially supporting a family – is different from those diagnosed with dementia at a later stage of life. Loss of income, self-esteem and perceived future purpose can pose multiple physical and psychological challenges for people with younger onset dementia, their families, and carers.

People with younger onset dementia are required to navigate their way through multiple care systems as their dementia progresses. While people living with younger onset dementia are generally eligible to access the NDIS, due to the progressive nature of their condition and need for increasing supports – which may not be available in the disability system – many people with younger onset dementia also require support from aged care services. As such, people with younger onset dementia are typically required to straddle both the aged care and disability systems – neither of which is currently fully equipped to respond to the complex needs of people living with younger onset dementia. Not only is it confusing to juggle two support systems, but the lack of a clear diagnosis and care pathway often results in people with younger onset dementia, their families and carers falling through the cracks.

Elements of the Code

Dementia Australia largely supports the seven elements of the Code, with the following recommendations for inclusion:

- A specific reference to dignity of risk and promotion of independence, and that providers understand and actively promote this;
- Workplace training and continuous improvement (this could be integrated into sections c and/or f). In addition to this, including a section within the guidance material of how this works in practice to promote consistent understanding;
- Explicit mention of accessibility of information and supported decision making. This is particularly important for people living with dementia so they can be actively involved in the decision-making process concerning their own care. This could include exploring the decision with the person being supported, using the person's support network to support them making a decision, documenting the support used in making a decision and documenting the decision;
- Include the role of carers; and

---

[6] Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

- Ensure that the language is inclusive across all sectors and to prohibit certain conduct from occurring – tweaking the language will strengthen protections to consumers.

Additionally, Dementia Australia suggests keeping the language simple and having anything that requires a definition (for example, self-determination, dignity of risk, and supported decision-making) clearly explained in the guidance material.

If the language is kept simple for workers it will be implemented more effectively, they will be able to understand it and not have any ambiguity, therefore improving compliance with the code.

Dementia Australia supports the inclusion of case studies to demonstrate how the Code could apply in practice in different contexts.

Another key consideration is that the Code be driven to protect vulnerable consumers, while concurrently building the capacity of staff. A balance between the two drivers is imperative to ensure that people receiving care are safe and that the care being received is of high quality, but also that staff are supported in their roles to build skills, knowledge and expertise to deliver that care. The model used by the NDIS which has not gone to registration, but rather to screening to mitigate risk is a benefit and should be maintained in further implementation of the Code.

Dementia Australia strongly supports the Code being developed in the context of the Human Rights Approach to Ageing and Health, which focuses on a person-centred framework being meaningfully connected to practice. Consumers are the central point around which the workforce should be supported to build their capacity to deliver consistent high-quality care. Building workforce capacity is key, which we have documented in our communique Our Solution: Quality care for people with dementia.

Enforcement of the Code

Dementia Australia supports the Code being enforced through the Aged Care Quality and Safety Commission.

Managing breaches of the Code will be key to the success of its implementation. Dementia Australia recommends that the Code be complimented by the worker screening process, and in alignment with the current Serious Incident Reporting Scheme.

The primary measure of its effectiveness in promoting quality and ensuring the safety of the people who use care and supports. The approach needs to be person centred and involve care partners from the get-go and throughout the care journey.

Additionally, the Code needs to support workers and consumers to raise issues and make complaints through a single point of contact. Feedback and complaints need to be taken seriously (especially from people living with dementia, their families and carers). This could involve the workforce actively involving carers, advocates or family members in feedback and complaints processes to get a fuller and more accurate picture when the person living with dementia is unable to communicate their own concerns effectively. It could also involve improved workforce training, particularly in pain management and non-verbal communication so workers can recognise when there is a potential issue to address for a person living with dementia.

It is also important that the Code supports the rights of workers in its development. Further consideration should be given to the issue of supporting existing workers to benefit from this alignment of the Code. Their current employment and existing education status should not be a barrier for care workers already delivering quality care within the sectors, noting that many will not have all the necessary qualifications or meet the requirements of the new regulations. Recognition of prior learning, minimum qualifications and ongoing professional development ought to be considered for current as well as new workers. The existing workforce may also need additional support to transition to any new processes/policies implemented. Consistency around approach will be important in the context of an aligned regulatory framework, as allowing for local variation could mean inconsistent levels of quality, rather than achieving greater consistency in the quality of care nationally.

As such, consideration of the personal qualities displayed by care workers could also be explored; for example, does the person demonstrate patience, compassion and empathy? These are skills that cannot easily be taught through a qualification, but they are key attributes to being a competent worker in the care and support sector. Of course, the challenge of monitoring ‘soft skills’ is regulating and monitoring the consistent application of these attributes.

Conclusion

It is imperative that the new Code of Conduct for the care and support sector is designed to support the needs of people living with dementia. Dementia Australia supports the new Code being based on the existing NDIS code, with consideration and inclusion of the points raised in this submission. We would welcome the opportunity for further discussion with the Department on this critical issue.