



**dementia
australia™**

The new voice of Alzheimer's Australia

Review of the NSW Guardianship Act 1987 Draft Proposals

A response from Dementia Australia to the NSW
Law Reform Commission

February 2018

About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 425,000 Australians living with dementia and the estimated 1.2 million Australians involved in their care.

Dementia Australia works with consumers, all levels of government, and other key stakeholders to ensure that people with dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with consumers means that we are an important advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International (ADI), the umbrella organisation of dementia associations around the world.



Introduction

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning including loss of memory, intellect, rationality, social skills and physical functioning. There are many types of dementia including Alzheimer's disease, vascular dementia, and frontotemporal dementia. Dementia is a progressive neurological disability and is the leading cause of disability burden for people over the age of 65 years in Australia.¹

Dementia is one of the largest health and social challenges facing Australia and the world. It is the leading cause of death of women in Australia, the second leading cause of death in this country, and is predicted to become the leading cause of death within the next five years.²

Dementia is not a natural part of ageing. It is a terminal condition and there is currently no cure. Dementia affects people's abilities and memories and has a profound impact on the individual and their loved ones.³ It is cloaked in stigma and misunderstanding,⁴ isolates people with dementia and their carers from social networks,⁵ and carries significant social and economic consequences.⁶ People living with dementia constitute one of the most vulnerable groups in our society.

There are more than 425,000 Australians living with dementia in 2018 (including 25,000 people under the age of 65 years with younger onset dementia) and, without a significant medical breakthrough, there will be over one million people living with dementia in Australia by 2056. There is currently an estimated 138,700 people living with dementia in NSW. This is expected to increase to 175,000 by 2025 and 326,000 by 2056.⁷

Dementia Australia welcomes the opportunity to respond to the NSW Law Reform Commission's Review of the Guardianship Act 1987 Draft Proposals. We were involved in the review process throughout 2016 and 2017 (as Alzheimer's Australia NSW) and are pleased to see the resulting draft proposals for change. We have read the detailed proposals and structured our comments in response to the summary of key draft proposals outlined on pages 2-3 of the Draft Proposal document.

¹ Australian Institute of Health and Welfare (2012) *Dementia in Australia*

² Australian Bureau of Statistics (2016) *Dementia: Australia's leading cause of death?* Accessed online

³ Mitchell, S. et al. (2009) The clinical course of advanced dementia, *The New England Journal of Medicine*, 361: 1529-38

⁴ George, D. (2010) Overcoming the 'Social Death' of dementia through language, *The Lancet*, 376: 586-87

⁵ Blay, S. & Peluso, E. (2010) Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2): 163-7

⁶ Access Economics (2003) *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*. Report for Alzheimer's Australia, Available at: www.fightdementia.org.au/research-publications/access-economics-reports.aspx

⁷ The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2016) *Economic Cost of Dementia in Australia 2016-2056*

A new Framework and a new Act

Dementia Australia is supportive of the Commission's view that a new framework for assisted decision-making laws in NSW should reflect the UN Convention on the Rights of Persons with Disabilities. We also support the proposal that there be a new Act called the *Assisted Decision-Making Act* to replace the existing *Guardianship Act 1987 (NSW)* and the enduring power of attorney provisions in the *Powers of Attorney Act 2003 (NSW)*.

We are pleased the Commission is recommending that this new Act be simple and accessible in language and structure, and that it should include principles to guide the assessment of decision-making ability as well as to guide decision-making. People appointed to positions of supported and substitute decision-makers must be made aware of their responsibilities and obligations, and be supported in these roles. Furthermore, people with dementia who appoint a decision-maker or have one appointed for them, need to understand their rights where practicable or appropriate. Clear communication and language is very important for people with dementia. Dementia Australia has worked with people with dementia and their carers to ensure our communication is accessible and respectful. A copy of the Dementia Australia language guidelines is available on the Dementia Australia website⁸ and we encourage the Commission to view this in preparing its final report and recommendations.

Decision-making ability

Dementia Australia supports the proposal that the term 'decision-making ability' be adopted instead of 'capacity'. Based on feedback we have received from people impacted by dementia, it is clear that the term 'capacity' is often misunderstood or interpreted in different ways; 'decision-making ability' is much clearer and to the point.

In the case of people living with dementia, their decision-making ability can fluctuate from day to day and throughout the day. An individual may be able to make decisions about some things, but other decision-making processes will be too complex. Dementia Australia advocates that, where possible, people with dementia should be supported to keep making decisions about what they can, yet recognise that there will come a point at which they will no longer have the decision-making ability to make their own decisions and a substitute decision-maker will be necessary. Dementia Australia therefore recommends that the guidance provided in the Act (and associated documents) acknowledges this and provides information about where people can learn more about decision-making and dementia.

We are also supportive of the Commission's proposal that the term 'disability' be removed as a precondition for a Tribunal Order. In our previous submissions, Dementia Australia (as Alzheimer's Australia NSW) outlined that 'decision-making capacity' is the more appropriate conceptual language for the guardianship and financial management regime. A person may have a disability yet have the cognitive ability to make decisions about all aspects of their lives.

⁸ www.dementia.org.au/files/NATIONAL/documents/language-guidelines-full.pdf

Supported and substitute decision-makers

Dementia Australia supports the notion of supported decision-making for people with disabilities, including dementia; however consumers we have consulted with acknowledge that there are limits to supported decision-making for people living with dementia.

A diagnosis of dementia does not necessarily mean that a person can no longer make decisions for themselves, although they may require a process of supported decision-making. As dementia progresses, however, the ability to make even supported decisions may be impacted and substitute decision-makers will probably be required. Certainly, for people living with advanced or end stage dementia, who have lost the ability to communicate their wishes, Dementia Australia recommends the appointment of a substitute decision-maker who is familiar with the wishes and preferences of the individual. This highlights the importance of planning ahead which we actively promote to ensure that Enduring Powers of Attorney and Guardianship are completed as early as possible.

From best interests to will and preferences

Dementia Australia welcomes the Commission's proposal that, in line with the UN Convention on the Rights of Persons with Disabilities, new decision-making principles should require representatives to give effect to a person's will and preferences wherever possible rather than to act in their 'best interests'.

Substitute decision-makers who are very familiar with a person living with dementia may be able to draw on their familiarity with the decisions that individual has made over their lifetime, and use this understanding to inform the decision-making process. However this knowledge of an individual's preferences and wishes may not always be present. Substitute decision-makers who are appointed on behalf of a person with dementia for example (including health professionals, formal advocates etc.) do not necessarily have that history to draw upon. It is therefore important that people with dementia are supported to be clear about their preferences while they are able to do so. As stated earlier, Dementia Australia encourages everyone to plan ahead, have discussions about their wishes for their future, and to document these wishes if necessary.

Implementing this new approach will not be without challenges; it requires a significant shift in cultural attitudes and traditional ways of thinking about supported and substitute decision-making after years of best interest principles underpinning guardianship frameworks. Dementia Australia recommends that guidelines be developed and advice is provided to supported and substitute decision-makers about how they determine and enact the will and preferences of the individuals they are supporting or making decisions on behalf of.

A Public Advocate for NSW

Based on consumer views expressed to us, Dementia Australia is very supportive of the Commission's proposed introduction of public advocate model. As Alzheimer's Australia NSW we advocated for a public advocate role in NSW for several years.

Public advocate positions exist in Victoria, South Australia, Queensland, Western Australia and the Australian Capital Territory (ACT). In these jurisdictions their role is to promote and

protect the rights of adults with decision-making disabilities to reduce their risk of neglect, exploitation and abuse. In some jurisdictions the public advocate has the power to investigate abuse and we are particularly pleased to note that the Commission is recommending that the NSW public advocate have an investigative function as well. Dementia Australia believes that this investigative function is important especially in cases of alleged abuse or neglect of a person with dementia by a substitute decision-maker.

Conclusion

Dementia Australia thanks the NSW Law Reform Commission for the opportunity to review and provide comment on the Review of the Guardianship Act 1987 Draft Proposals. We look forward to reading the full report of the Review when it is released. We are hopeful that the NSW Government will implement the recommendations and proposals outlined by the Commission and look forward to seeing a new framework and Act in NSW. Dementia Australia is committed to working with the NSW Government as it considers and implements the Commission's recommendations. In particular, we can assist the Government in consulting with people impacted by dementia to ensure that a new framework is inclusive of and accessible to people living with dementia in NSW.