



**dementia
australia™**

The new voice of Alzheimer's Australia

Review of the NSW Civil and Administrative Tribunal Guardianship Division

A response from Dementia Australia

July 2019

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 447,115 Australians living with dementia and the estimated 1.5 million Australians involved in their care.

Dementia Australia works with people impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of 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 individuals and communities 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, the umbrella organisation of dementia associations around the world.



Background

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.

Dementia is one of the largest health and social challenges facing Australia and the world. Dementia is not a natural part of ageing. It is a terminal condition and there is currently no cure. 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.

In New South Wales, there are 149,250 living with dementia. Without a medical breakthrough, we can expect that number to rise to 326,411 by 2053.¹

Introduction

Dementia Australia welcomes this opportunity to contribute to the Department of Justice's review of the Civil and Administrative Tribunal Act 2013, which established the NSW Civil and Administrative Tribunal (NCAT). Our response to this review focuses on the Guardianship Division of NCAT, which determines applications for individuals who require a substitute decision maker.

A diagnosis of dementia does not automatically mean that a person can no longer make decisions for themselves. Yet, as dementia progresses, it impacts significantly on the decision making abilities and capacity of individuals. This results in the vast majority of people with dementia eventually requiring a substitute decision maker.

Dementia Australia encourages people who receive a diagnosis of dementia to plan ahead for their future. This includes appointing an attorney under an Enduring Power of Attorney to manage their financial and legal affairs, as well as an Enduring Guardian to make lifestyle, care and accommodation decisions on their behalf, updating their Will and making an Advance Care Directive to ensure their end of life wishes are carried out. Giving a trusted individual decision making responsibilities empowers people with dementia by extending their decision making autonomy and allowing individuals to plan for when they no longer have capacity to articulate their wishes.

However, in some cases, people living with dementia do not have an Enduring Power of Attorney or Guardian in place before their decision making abilities become impaired. In this scenario, a Guardianship application or Financial Management application will need to be made on their behalf. Typically, these applications will be made by a family member or carer, who knows the individual well and is able to represent the individual's wishes and

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

preferences. However, we are also aware that in some cases service providers will raise applications on behalf of an individual with dementia.

People living with dementia make up the majority of cases presented to the Guardianship Division on NCAT. According to the most recent NCAT annual report, in 2017-18, 42% of cases were regarding a person living with dementia and just under 80% of these cases were to put in place a Guardianship or Financial Management order.²

With such a high prevalence of dementia-related cases, it is essential that NCAT processes and procedures are inclusive of people with dementia. To ensure high quality decision making of the panel, it is essential that NCAT staff and hearing panel members have a good understanding of dementia and are attuned to the challenges impacting people living with dementia.

Overall, Dementia Australia is supportive of current NCAT processes, which largely support the inclusion and participation of people living with dementia, their families and carers. Our submission highlights the specific areas which we see as key assets to NCAT, in addition to recommendations for further improvements.

1. Inclusivity and access for people living with dementia

Overall, the Guardianship Division supports the inclusion of people living with dementia. For example, the use of face-to-face hearings is a valuable feature that enables people with cognitive impairments to engage in their case, should they wish to. People living with dementia are progressively impacted by cognitive impairment, which can make it increasingly difficult to engage with legal documentation and paper work. By introducing face-to-face hearings, people living with dementia have the opportunity to engage in a meaningful way, should they wish to.

Dementia Australia supports the efforts to increase accessibility for individuals living in rural areas of NSW. In the past, people living in rural and remote areas have been restricted from engaging directly in hearings because of geography. According to the NCAT Annual Report, 77% of Guardianship Division hearings included the person whom the inquiry was about, and almost a quarter of hearings were conducted in regional NSW. This clearly demonstrates a commitment to engagement from the Guardianship Division.

Improving awareness and access:

Dementia Australia encourages people with dementia to appoint their own Enduring Power or Attorney and/or Guardian, early on following their diagnosis. Appointing an Enduring Guardian and/or Power of Attorney enables people with dementia to exert more control in decision making through the help of their trusted advocate. However, it is important to note that there are circumstances where the person with dementia did not, or could not plan ahead. The Guardianship division is there in instances where the individual has not been able to make their own appointments, or where there are concerns about how an appointed person is behaving, for example by misusing money or taking advantage.

² https://www.ncat.nsw.gov.au/Documents/ncat_annual_report_2017_2018.pdf

In these instances it is important that family members, carers or other prospective guardians are aware of the role of the Guardianship division and know how to make or amend applications. It is especially important that, in situations where there are concerns over the appointed person's behaviour, people are educated and aware of how to engage with the Guardianship division in order to prevent potential abuse.

However, according to some of our advocates – which includes people living with dementia, their carers and families – NCAT services are not widely recognised/understood by family members or carers. This is because individuals are not routinely informed about how to apply to the Guardianship Division or what role the Division can play. Therefore, individuals who do not have an existing Enduring Power of Attorney or Guardian in place could be disadvantaged by a lack of information and awareness of the Division.

Given the high proportion of Guardianship Division applications which involve people living with dementia, we strongly recommend that the NCAT Guardianship Division raise awareness of their services amongst people who have received a diagnosis of dementia, and their families and carers. To do this, some of our Advocates suggested that information regarding NCAT services could be provided when an individual receives their initial Aged Care assessment (ACAT), or from the point of diagnosis. This would encourage people to plan ahead for the future and think about perspective substitute decision makers.

2. Multi-member panel model

The NCAT three-member panel, which consists of a professional expert, community member and legal representative, is a notable feature of the Guardianship Division hearings. The inclusion of a professional expert and a community member means that decisions are not purely led by legal guidance, but are considered from a clinical, health and social view point, therefore making decisions more person-centred and holistic.

3. Professional development and education

Tribunal staff:

Dementia Australia supports the efforts put into staff training and development, including specific training to support staff communicate with individuals who may have a cognitive impairment. Given the prevalence of applications involving people with dementia, we recommend this training includes specific education and awareness of dementia.

We are also pleased that, where appropriate, Guardianship Division staff assist people to identify informal solutions where problems arise with a person's decision-making capacity. As noted in the 2017-18 NCAT Annual Report, there are often cases where applications are not made to the Tribunal and, instead, the person will be supported to make their own decisions by their family and friends. Whilst we appreciate that people living with dementia will eventually require assistance with their decision making, we also strongly advocate for these supported decision making techniques.

Panel Members:

Having a professional and community representatives on the panel, including someone who is familiar with dementia, is essential to ensure the circumstance and needs of a person

living with dementia are understood and reflected in the decision being made. In many cases, applications for Guardianship orders are made at a point where the individual's capacity is significantly impaired. Therefore the individual with dementia may not be able to directly engage in the case themselves.

Research demonstrates that dementia knowledge amongst health professionals is relatively low;^{3, 4} therefore, despite the inclusion of doctors, psychologists and other relevant health professionals, Dementia Australia sees it as essential for panel members to receive specific dementia education. Currently it is unclear if dementia education is included in the professional development of panel members. However, the professional development courses presents a good opportunity to embed specific dementia education and knowledge into ongoing training for members.

4. Protection against abuse

Financial abuse is a significant concern for people living with dementia. Dementia Australia advocates that the best way to safeguard oneself against financial abuse is to plan head and appoint a trusted individual to act as your attorney through an Enduring Power of Attorney (EPOA). However, whilst EPOAs do provide protection, they can also enable abuse to occur.

Unfortunately, people with dementia can be vulnerable to attorneys misusing their power and not acting in the best interests of those they were appointed to represent. This type of financial abuse is able to occur without legal ramifications because there are no criminal offences for breaches of Power of Attorney obligations in NSW. NSW laws are currently quite limited in safeguarding older people, especially from financial abuse.

It is therefore important that proactive action is taken to prevent financial abuse. For example, as part of the pre-hearing information gathering, and the hearing itself there should be careful consideration to the individual's ability to manage finances effectively, and to act with integrity with regards to another's finances. We also recommend that additional guidance be offered to prospective financial managers, to support them in understanding their responsibilities and undertaking their role effectively. Support could include financial planning courses and links to online resources and materials that are easily available to newly appointed finance managers. Equipping individuals with information may also help reduce unintentional financial abuse, which typically stems from lack of awareness of understanding of the role and responsibilities.

Similarly, prospective Guardians should also have access to supports and resources which outline the typical responsibilities of a Guardian. They should be provided with easy to access information or links to information that will assist them in their decision-making responsibilities. For example, resources might include information on, how to use supported

³ Smyth, W., Fielding, E., Beattie, E., Gardner, A., Moyle, W., Franklin, S. & MacAndrew, M. (2013). A survey-based study of knowledge of Alzheimer's disease among health care staff. *BMC geriatrics*, 13(1), 2.

⁴ Wang, Y., Xiao, L. D., Luo, Y., Xiao, S. Y., Whitehead, C., & Davies, O. (2018). Community health professionals' dementia knowledge, attitudes and care approach: a cross-sectional survey in Changsha, China. *BMC geriatrics*, 18(1), 122. doi:10.1186/s12877-018-0821-4

decision making, care planning advice, options for palliative care and end of life care and general information on the progression of dementia. Providing Guardians with this information will support them to understand what sorts of decisions they may be responsible for making, and help them to make more informed-decisions on behalf of an individual. We would also suggest providing links to support and advocacy organisations such as Dementia Australia – who are positioned to provide further guidance and support.

Conclusion

Overall, Dementia Australia is supportive of the Guardianship Divisions efforts to include and support people living with dementia, their families and carers throughout the application and hearing process. However, there remain some areas for improvement, in particular around access to services and information regarding NCAT. We hope that you consider our recommendations made in this submission and welcome any opportunity to contribute to the Review further. Please do not hesitate to contact us, should you require further information.