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# **Northern Territory Health Care Decision Makers Discussion Paper**

**A response from Dementia Australia**

**January 2020**

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## 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 459,000 Australians living with dementia and the estimated 1.6 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.



# Introduction

Dementia Australia welcomes this opportunity to contribute to the Northern Territory Government's consultation on health care decision makers.

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.<sup>1</sup>

In the Northern Territory alone there are almost 2,000 people living with dementia. Without a medical breakthrough, that number is expected to rise to almost 6,500 by 2058.<sup>2</sup>

Although a diagnosis of dementia does not automatically mean that a person can no longer make decisions for themselves, as dementia progresses, it impacts significantly on individuals' decision making abilities, and may result in people with dementia requiring a substitute decision maker. According to the latest Northern Territory Civil Administrative Tribunal (NTCAT) annual report, in 2017/18, 232 new cases were made to the Guardianship jurisdiction.<sup>3</sup> Based on the average percentage of dementia related cases seen in other states and territories, it is reasonable to assume that around 40-50% of guardianship cases in the Northern Territory will be in respect to a person living with dementia.<sup>4</sup>

Dementia Australia encourages people who receive a diagnosis of dementia to plan ahead for their future. This includes preparing an Advanced Care Directive to record their end of life wishes, appointing an attorney under an Enduring Power of Attorney to manage their financial and legal affairs, as well as an Enduring Guardian and/or healthcare decision maker to make health, lifestyle, care and accommodation decisions on their behalf. Generally, 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. By using supported decision making techniques, substitute decision makers can assist people with dementia to weigh up

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<sup>1</sup> Australian Bureau of Statistics (2018) Causes of Death, Australia, 2017 (cat. No. 3303.0)

<sup>2</sup> Dementia Australia. Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra. 2018

<sup>3</sup> Northern Territory Civil and Administrative Tribunal. Annual Report 2017-2018. Found on [https://ntcat.nt.gov.au/sites/default/files/ntcat\\_a\\_report\\_2017-2018.pdf](https://ntcat.nt.gov.au/sites/default/files/ntcat_a_report_2017-2018.pdf)

<sup>4</sup> Assumption based on data from: NSW Civil and Administrative Tribunal. NCAT Annual report 2017-2018. Accessed on [https://www.ncat.nsw.gov.au/Documents/ncat\\_annual\\_report\\_2017\\_2018.pdf](https://www.ncat.nsw.gov.au/Documents/ncat_annual_report_2017_2018.pdf); ACT Civil and Administrative Tribunal. Annual Review 2017-2018. Accessed at: [https://www.acat.act.gov.au/\\_data/assets/pdf\\_file/0005/1362947/ACAT-Annual-Review-2017-18.pdf](https://www.acat.act.gov.au/_data/assets/pdf_file/0005/1362947/ACAT-Annual-Review-2017-18.pdf)

decisions and make informed choices about their own care.

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. This may be due to a quick progression of dementia, but in other cases this is due to a lack of awareness of advanced care planning processes and legislation.

In the absence of an advanced care plan or legal guardian, people with dementia in the Northern Territory must await a Guardianship application, to be processed by NTCAT – which can delay access to treatments or care. Alternatively, decisions will be referred to the NTCAT – who may not be attuned to the individual's wishes or preferences. A key concern with these two pathways is the lack of recognition for families and carers, who are often able to represent the wishes of the individual, but may not have the legal authority to make health care decisions. In these instances, there is a risk that people with a cognitive impairment will not have their personal preferences upheld – which can be particularly distressing for the individual with dementia, and their family and carers, who are unable to represent their loved ones wishes.

Overall, Dementia Australia supports the recommendation to amend the *Advanced Personal Planning Act 2013* to enable statutory health care decision makers in the Northern Territory. As such, in the absence of an advanced care directive or an already appointed Enduring Power of Attorney, trusted individuals who have been appointed as statutory health care decision makers should be called upon by health care practitioners to make health care related decisions.

The remainder of this submission addresses three critical issues: the need for safeguards that protect individuals with a cognitive impairment from potential abuse by individuals with decision making powers; the importance of protecting the wishes and preferences of individuals with a cognitive impairment; and the continued need for raising awareness of advanced care planning processes to ensure people with a cognitive impairment have the opportunity to set out their wishes for their future care.

## Recommendations

Dementia Australia recommends the following:

***Recommendation 1:*** *The Northern Territory government make a concerted effort to raise awareness of advanced care planning and substitute decision making processes and procedures. Integrating educational resources into the health care pathway for people with dementia would help to ensure individuals with a recent diagnosis have timely access to relevant information.*

***Recommendation 2:*** *Health care practitioners should, where practicable, consult with statutory health care decision makers before performing health interventions to ensure decisions are made in the interests of the individual. The NTCAT should provide clear guidance on performing medical interventions in emergency situations, where health professionals may need to act without obtaining consent.*

**Recommendation 3:** *Face to face supports and written guidance on 'health care decision making' should be easily accessible to all statutory health care decision makers. Guidance should provide advice on reaching informed decisions on behalf of other people, the roles and responsibilities of a substitute decision maker, and information on cognitive impairments, such as dementia.*

**Recommendation 4:** *The NTCAT should develop clear provisions that will ensure all prospective health care decision makers are appropriate and able to represent the individual without decision making capacity. All health care decision makers should be regarded as trusted individuals, who can demonstrate they understand and can represent the individual's wishes and preferences for their care.*

## Education and awareness

Dementia Australia encourages people with dementia to develop an advanced care directive and to appoint their own substitute decision maker early on following their diagnosis, to ensure their preferences for their future are recorded whilst they are still able to communicate them. Advanced care directives are one of the few ways to ensure that any health care decisions truly reflect the preferences and wishes of the person living with dementia.

Education and awareness of advanced care planning, and the process of appointing substitute decision makers, is integral to ensuring people with a dementia have the opportunity to plan for their future. However, Dementia Australia is often told by people living with dementia, their carers and families, that they are either unaware of their local advanced care legislation, or they do not know how to start the process of advanced care planning and appointing a decision maker. In some cases, people with dementia, their families and carers may not even know that such legislation exists, until the individual has lost their decision making capacity and are therefore unable to prepare an advanced care plan.

Even if Territorians have access to a hierarchy of health care decision makers, Dementia Australia believes that planning for the future – through advanced care planning and appointing a substitute decision maker – should be encouraged for people with dementia.

**Recommendation 1:** *The Northern Territory government make a concerted effort to raise awareness of advanced care planning and substitute decision making processes and procedures. Integrating educational resources into the health care pathway for people with dementia would help to ensure individuals with a recent diagnosis have timely access to relevant information.*

## Protecting the rights and wishes of people living with dementia

Over time, dementia will inevitably lead to progressive cognitive and functional decline. Most people in the later stages of dementia require significant care and support across almost every aspect of their life.

When reaching the end of life stage, many people with dementia may choose to refuse particular medical interventions, through an advanced care directive – particularly if interventions are considered intrusive. Ultimately, an individual’s medical preferences should be upheld and substitute decision makers are critical to protecting the wishes and preferences of people with a cognitive impairment who cannot represent themselves.

Dementia Australia supports that all health care practitioners should attempt to discuss medical interventions with a health care decision maker before carrying out a procedure to ensure that medical decisions are aligned to the individuals wishes. In the scenario where emergency care is required, the NTCAT must distribute clear guidelines around consent and when health care practitioners are able to act without consent. The NTCAT may also consider consulting with the health care decision makers on their preferred approach if emergency medicine is required.

***Recommendation 2:*** *Health care practitioners should, where practicable, consult with statutory health care decision makers before performing health interventions to ensure decisions are made in the interests of the individual. The NTCAT should provide clear guidance on performing medical interventions in emergency situations, where health professionals may need to act without obtaining consent.*

Making health care decisions on behalf of a loved one can be emotionally challenging, particularly if a decision maker holds different views or values to the individual they are acting on behalf of. There may also be instances where a decision maker does not know how best to act on behalf of the individual, either because they are not sure what their views are regarding a particular issue, or because the decision is about a particularly sensitive or confronting topic, such as palliative care. In these instances, health care decision makers would benefit from supports to guide them through the decision making process.

Given the complexity of some health care decisions, we recommend that two options of support be available to all health care decision makers. First, written guidance should be distributed to all statutory health care decision makers. This guide should define the role of a decision maker, and make clear where people can access further supports. A guidance document could also provide advice on how to determine what the other person would want for their care, potential challenges relating to health care decision making and how to translate an individual’s personal preferences into medical decision making. A good example is the ‘A medical treatment decision maker’s guide’, for medical treatment decision makers in Victoria.<sup>5</sup> Written guidance should also provide key information on the progression of complex cognitive conditions, such as dementia, so decision makers can understand what to

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<sup>5</sup> Office of the Public Advocate, Victoria. Information for medical treatment decision makers: for when the person lacks capacity to undertake advanced care planning. February 2019

expect as the condition progresses, and prepare for potential health care decisions they may have to make in the future. Second, face-to-face, or telephone support services should be made available to all health care decision makers, to allow people to talk through complex decisions. Staff operating in these services should be equipped with knowledge on complex health conditions, such as dementia, and be able to provide support on key topics, such as palliative care and end-of-life care decision making.

**Recommendation 3:** *Face to face supports and written guidance on 'health care decision making' should be easily accessible to all statutory health care decision makers. Guidance should provide advice on reaching informed decisions on behalf of other people, the roles and responsibilities of a substitute decision maker, and information on cognitive impairments, such as dementia.*

## Safeguarding people living with dementia

As dementia progresses, individuals can become increasingly at risk of all forms of abuse including financial, psychological, physical abuse and neglect. Dementia Australia recommends that the best safeguard against abuse is to plan ahead with an advanced care directive and by appointing a trusted attorney or substitute decision maker who can act honestly on your behalf. Unfortunately, however, there are cases where people with dementia are subject to attorneys misusing their power and not acting in the best interests of those they were appointed to represent.

Similarly, there may be instances where a health care decision maker could misuse their powers. It is therefore important that proactive action is taken to prevent all forms of abuse to people with a cognitive impairment by potential statutory health care decision makers.

To safeguard against abuse, the NTCAT should ensure that all individuals who are eligible in the hierarchy of decision makers can demonstrate that they are a trusted individual, who is able to act with integrity when representing the views and wishes of the person they are making decisions on behalf of.

**Recommendation 4:** *The NTCAT should develop clear provisions that will ensure all prospective health care decision makers are appropriate and able to represent the individual without decision making capacity. All health care decision makers should be regarded as trusted individuals, who can demonstrate they understand and can represent the individuals wishes and preferences for their care.*

The provision of education about the expectations, obligations and responsibilities of a health care decision maker is also a key imperative. As set out in recommendation 3, we recommend that the Northern Territory Government produce guidance on the role of health care decision makers, which makes clear their responsibilities and how to act respectfully on behalf of another person.

## Conclusion

Thank you for the opportunity to participate in this important consultation. Dementia Australia welcomes further discussions with the Northern Territory Government as work progresses to ensure that the needs of people with dementia living in the Northern Territory are appropriately considered in the development of any health care decision maker legislation and process.