

Question Paper 1: Preconditions for alternative decision-making arrangements.

Alzheimer's Australia NSW welcomes the opportunity to provide the NSW Law Reform Commission with a submission regarding the Review of the Guardianship Act 1987, Question Paper 1: Preconditions for alternative decision-making arrangements. In preparing this submission we have considered the relevant developments in law, policy, and practice by the Commonwealth, in other States and Territories of Australia and overseas. Our comments are particularly focused on the potential implications for people with dementia.

Alzheimer's Australia NSW is the peak body for people with dementia and their families and carers in NSW. We provide advocacy, support services, education and information. Our organisational mission is to minimise the incidence and impact of dementia through leadership, innovation, and partnerships – in advocacy, policy, education, services and research.

Dementia is the term used to describe 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. It is a progressive neurological disability and also the leading cause of disability burden for people over the age of 65 years in Australia.¹ Dementia is the second leading cause of death in Australia and currently has no cure.²

Question 3.1: Elaboration of decision-making capacity

1) Should the *Guardianship Act* provide further detail to explain what is involved in having, or not having, decision-making capacity?

Yes. A diagnosis of dementia does not necessarily mean that a person can no longer make decisions for themselves. Legislation throughout Australia is informed by the United Nations (UN) Conventions on the Rights of People with a Disability (CORPD) and the Common Law presumption of capacity where it is assumed a person has capacity unless it can be proven that they do not. As dementia progresses it impacts significantly on the decision making abilities and capacity of individuals. This results in people with dementia being particularly vulnerable and possibly in need of a substitute or supporting decision maker. It is usually the responsibility of the treating health professional to determine whether or not someone has capacity to manage their financial affairs and other matters.

2) If the *Guardianship Act* were to provide further detail to explain what is involved in having, or not having, decision-making capacity, how should it be done?

Alzheimer's Australia NSW (AANSW) believes that the *Guardianship Act* should provide further detail to explain what is involved in having or not having decision-making capacity. This definition should be similar to that set out in the NSW Government Capacity Toolkit which states that a person can be deemed as having capacity when:

- They understand the facts involved
- Understand the main choices

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

² Australian Bureau of Statistics (2015) *Causes of Death, Australia 2013*: CAT no. 3303.0

- Weigh up the consequences of their choices
- Understand how the consequences affect them
- Communicate their decision.

Question 3.2: Disability and decision-making capacity

How, if at all, should a person's disability be linked to the question of his or her decision-making capacity?

The United Nations Convention on the Rights of Persons with Disabilities states that "*Considering that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them*". The principles of the UN Convention on the Rights of Persons with Disabilities include the right of people with disability to dignity, autonomy, full and active participation in society and equal recognition before the law. Therefore, a person's decision-making capacity should not be linked to their disability, but rather assessed and their decisions supported.

In terms of dementia, the ability of a person to make certain types of decisions can vary from case to case, but can also fluctuate. A person with dementia may not have capacity to make a decision at one time, but they may find themselves able to do so on another occasion. It is for this reason that AANSW supports the concept of supported decision making for some people with dementia. That being said, decision-making capacity is severely impacted as dementia progresses and the reality is that supported decision making, although the preferred decision making model, will not work for everyone.

Question 3.4: Acknowledging variations in capacity

1) Should the law acknowledge that decision-making capacity can vary over time and depend on the subject matter of the decision?

Yes. Due to the rapidly progressing and ever-changing nature of dementia, decision-making capacity can vary over time, even from day to day. Each case of dementia varies from the next and may affect the capacity to make some types of decisions more than others. Capacity cannot be extrapolated from one decision to another. For example, a person's capacity to consent to medical treatment cannot be inferred from their capacity to make a decision to execute a power of attorney or appoint an enduring guardian.

2) How should such acknowledgements be made?

Alzheimer's Australia NSW believes that it is important for the *Guardianship Act* to accommodate the progressive and variable nature of many neurological disabilities including dementia. Different capacity standards apply in relation to different activities. We agree with the recommendation of the Victorian Law Reform Commission that capacity assessment principles should note that:

- A person's capacity is specific to the decision being made
- Impaired decision making capacity can be temporary or permanent and can fluctuate over time
- When assessing a person's capacity, every attempt should be made to ensure that the assessment occurs at a time and in an environment in which their capacity can be most accurately assessed.

- 3) If the definition of decision-making capacity were to include such an acknowledgement, how should it be expressed?**

No comment on this.

- 4) If capacity assessment principles were to include such an acknowledgement, how should it be expressed?**

No comment on this.

Question 3.5: Should the definitions of decision-making capacity be consistent?

- 1) Should the definitions of decision-making capacity within NSW law be aligned for the different alternative decision-making arrangements?**

Alignment for consistency, but there is a need to acknowledge that there are practical issues that may make the different levels of decision-making capacity difficult to execute in practice.

- 2) If the definitions of decision making capacity were to be aligned, how could this be achieved?**

No comment on this.

Question 3.6: Statutory presumption of capacity

Should there be a statutory presumption of capacity?

Yes. Capacity should be assumed until it is proven otherwise through a decision-making capacity assessment. In the case of people with dementia, a diagnosis of a neurological impairment does not automatically mean that an individual is unable to make decisions for themselves. The progression of the impairment and the consideration of a person's abilities as well as their wants, need to be considered prior to considering whether they possess capacity.

Question 3.7: What should not lead to a finding that a person lacks capacity?

- 1) Should capacity assessment principles state what should not lead to a conclusion that a person lacks capacity?**

Yes. From the perspective of advocating for people with neurological impairments, Alzheimer's Australia would not like to see that a person is deemed to lack capacity purely because of this disability type.

A person should not be deemed to lack decision-making capacity based on the fact that they make an unwise or imprudent decision or if it is possible for them to make that decision with appropriate supports.

- 2) If capacity assessment principles were to include such statements, how should they be expressed?**

No comment on this.

Question 3.8: The relevance of support and assistance to assessing capacity

- 1) Should the availability of appropriate support and assistance be relevant to assessing capacity?**

Yes. In cases where a supporting decision-maker is available, it should be taken into account when assessing capacity. For example, a husband and wife couple in which one of the is affected by dementia, the other is an appropriate and available supporting decision maker. He/she is able to make decisions on behalf of the couple as the other party experiences diminishing decision-making capacity. However, in instances where there is a single party involved, the availability of appropriate support and assistance can be made more difficult, particularly in the absence of a Public Advocate.

- 2) If the availability of such support and assistance were to be relevant, how should this be reflected by the law?**

No comment on this.

Question 3.9: Professional assistance in assessing capacity

- 1) Should special provision be made in NSW law for professional assistance to be available for those who must assess a person's decision-making capacity?**

Yes.

- 2) How should such a provision be framed?**

No Comment on this.

4. Other preconditions that must be satisfied

Question 4.1: The need for an order

- 1) Should there be a precondition before an order is made that the Tribunal be satisfied that the person is 'in need' of an order?**

A person should have a capacity assessment conducted and be found not able to make some or all decisions. The preconditions should reflect what the person is not able to make decisions about and what they are.

- 2) If such a precondition were required, how should it be expressed?**

No comment on this.

Question 4.2: A best interests precondition

- 1) Should there be a precondition before an order is made that the Tribunal be satisfied that the order is in the person's 'best interests'?**

Yes. However, Alzheimer's Australia NSW encourages orders to be made to act in the wishes of the person, encouraging a supported decision-making model rather than a substitute decision-making model for some people with dementia. The principles of the UN Convention on the Rights of Persons

with Disabilities include the right of people with disability to dignity, autonomy, full and active participation in society and equal recognition before the law. Therefore, a person's decision-making capacity should not be linked to their disability, but rather assessed and their decisions and wishes supported.

2) If such a precondition were required, how should it be expressed?

No comment on this.

3) What other precondition could be adopted in place of the 'best interests' standard?

No comment on this.

Question 4.3: Should the preconditions be more closely aligned?

1) Should the preconditions for different alternative decision-making orders or appointments in NSW be more closely aligned?

No, because the preconditions for different alternative decision making orders or appointments will be different as the capacity tests for these will also be different. The principles of the UN Convention on the Rights of Persons with Disabilities include the right of people with disability to dignity, autonomy, full and active participation in society and equal recognition before the law. Therefore, a person's decision-making capacity should not be linked to their disability, but rather assessed and their decisions and wishes supported.

2) If so, in relation to what orders or appointments and in what way?

No comment.

Question 4.4: Any other issues?

Are there any other issues you want to raise about the preconditions for alternative decision-making arrangements?

Alzheimer's Australia NSW encourages everyone, but especially those who have received a diagnosis of dementia, to plan ahead for their future. This includes appointing an attorney under an Enduring Power of Attorney to manage their 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. This empowers people, extends their decision-making autonomy and allows them to plan for when they no longer have capacity to articulate their wishes.

Alzheimer's Australia NSW supports the notion of supported decision making for people with disabilities, including dementia; however we recognise that there are limits to supported decision making for people living with dementia. During the early stages of dementia, we believe that supported decision making is appropriate but as dementia progresses and people lose their capacity to articulate their wishes and make decisions, there remains a need for a substitute decision maker to be in place. Certainly, for people living with advanced or end stage dementia, who have lost the ability to communicate their wishes, a substitute decision maker is needed.

5. Other factors that should be taken into account

Question 5.1: What factors should be taken into account?

- 1) What considerations should the Tribunal take into account when making a decision in relation to:**
 - a. A guardianship Order**
 - b. A financial management order**
- 2) Should they be the same for all orders?**

No. A holistic approach that seeks to understand the person and the context in which they live, their aspirations, their life history, their wishes, goals etc. should be reflected in the Tribunal's considerations. In many cases, a physiological inability to communicate, does not mean that a person lacks capacity, this should be considered by the tribunal. However, where this is the case, the person should be supported in communicating their decisions through whichever means are possible to them.

- 3) Are there any other issues you want to raise about the factors to be taken into account when making an order?**

Since conducting research into financial abuse of people with dementia in 2013, Alzheimer's Australia NSW has been recommending that a public advocate be established in NSW. In relation to financial abuse, a NSW public advocate could be developed with the statutory authority to receive reports and investigate instances of financial abuse of people with dementia and other vulnerable adults. The role could also extend to facilitating resolution of the abuse and providing understanding and clarification of the responsibilities and obligations of attorneys. Establishing a Public Advocate requires changes to the Guardianship Act and possibly the extension of the role of the Public Guardian.