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**SUBMISSION TO THE NSW LAW
REFORM COMMISSION**

REVIEW OF THE GUARDIANSHIP ACT 1987

Alzheimer's Australia NSW

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To discuss this submission, please contact:

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Pursuant to section 10 of the Law Reform Commission Act 1967, the NSW Law Reform Commission is asked to review and report on the desirability of changes to the Guardianship Act 1987 (NSW) having regard to:

1. The relationship between the Guardianship Act 1987 (NSW) and

- **The NSW Trustee and Guardian Act 2009 (NSW)**
- **The Powers of Attorney Act 2003 (NSW)**
- **The Mental Health Act 2007 (NSW)**
- **other relevant legislation.**

2. Recent relevant developments in law, policy and practice by the Commonwealth, in other States and Territories of Australia and overseas.

3. The report of the 2014 ALRC Equality, Capacity and Disability in Commonwealth Laws.

4. The UN Convention on the Rights of Persons with Disabilities.

5. The demographics of NSW and in particular the increase in the ageing population.

Alzheimer's Australia NSW welcomes the opportunity to provide a submission to the Review of the Guardianship Act 1987. 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 of the 2014 Australian Law Reform Commission (ALRC) report on *Equality, Capacity and Disability in Commonwealth Laws*, as well as the *United Nations Convention on the Rights of Persons with Disabilities* (UNCRPD).

Alzheimer's Australia NSW is the peak body for people with dementia and their 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 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 fronto temporal dementia. Dementia is a progressive neurological disability and is the leading cause of disability burden for people over the age of 65 years in Australia¹. Dementia is the second leading cause of death in Australia² and there is no cure.

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*

Australia has an ageing population and the biggest risk factor for dementia is age. Three in ten people over the age of 85 and almost one in ten people over 65 have dementia. There are currently more than 353,800 Australians living with dementia. Without a major medical breakthrough this figure is expected to increase to almost 900,000 by 2050³. In NSW, it is estimated that there are 115,000 people living with dementia, with projections indicating that this number will increase to 272,000 by 2050⁴.

In particular, the Commission is to consider:

1. The model or models of decision making that should be employed for persons who cannot make decisions for themselves.

A diagnosis of dementia does not automatically mean that a person can no longer make decisions for themselves. Legislation throughout Australia is informed by the UNCRPD and the Common Law presumption of capacity where it is assumed a person has capacity unless it can be proven that they do not. Yet as dementia progresses it impacts significantly on the decision making abilities and capacity of individuals. This results in many people with dementia eventually requiring a substitute decision maker. It is usually the responsibility of the treating health professional to determine whether or not someone has capacity to determine at what point substitute decision making is enacted.

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 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. 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. Currently, substitute decision makers are required to make informed decisions based on what is in the best interests of the person with dementia. If the recommendations

³ Australian Institute of Health and Welfare (2012) *Dementia in Australia*

⁴ Alzheimer's Australia NSW and Deloitte Access Economics, August 2014

of the ALRC report were to be implemented, substitute decision makers would be required to make decisions based on the wills and preferences of the individual.

The ALRC report would suggest that a rethinking of the underlying drivers of decision making processes is needed, in particular, the move away from acting in a person's best interests to their will and preferences. For people with dementia, substitute decision makers have a life time of the individual with dementia making their own decisions to inform what their will and preference might be in particular circumstances (compared to people with severe intellectual disability, for example, who may never have had the opportunity to enact their own will and preference). This is an important area of reform that AANSW looks forward to the opportunity to participate further in the discussions on this matter.

2. The basis and parameters for decisions made pursuant to a substitute decision making model, if such a model is retained.

AND

3. The basis and parameters for decisions made under a supported decision making model, if adopted, and the relationship and boundaries between this and a substituted decision making model including the costs of implementation.

Capacity is severely impacted as dementia progresses and the reality is that supported decision making cannot work for everyone. Some level of substitute decision making power needs to be retained and what is required therefore is reform to substitute decision making models and how they are implemented.

The issue of capacity is complex and a proposed supported decision making model raises the concern of who decides when someone can truly be supported to make decisions and when a substitute decision maker is required. People with progressive dementia are vulnerable and need to be protected. If Australia moves to supported decision making, what would replace the formal mechanisms for supported decision making? For example, a person with early stage dementia may appoint a supported decision maker but when capacity is lost, this person in effect turns into a substitute decision maker and there would be no formal recognition or acknowledgement of this, leaving an individual potentially open to abuse. AANSW queries the important details as to how this would be implemented and what would the practical implications be? These complex issues need to be thoroughly worked through.

Alzheimer's Australia NSW is unable to comment of the costs of implementation of a supported decision making model. Until we see the details of such a model, we could only speculate on the costs and other implications of it.

4. The appropriate relationship between guardianship law in NSW and legal and policy developments at the federal level, especially the National Disability Insurance Scheme Act 2013, the Aged Care Act 1997 and related legislation.

Alzheimer's Australia NSW recognises that Australian Government policy developments and legislative changes with regard to aged care and disability service provision and support is making the implementation of guardianship law in NSW more complex, without appropriate compensation to NSW agencies including the Guardianship Division of NCAT, the NSW Trustee and Guardian and the Office of the Public Guardian for their increased workload.

In particular, the increasing number of people living with dementia, combined with increased sizes of personal estates and changes to the financial arrangements for entry into residential aged care is creating challenges for the above listed NSW agencies.

The Commonwealth changes also have significant ramifications for state legislation and instruments of Enduring Powers of Attorney, Enduring Guardian and Advance Care Directives. There are inconsistencies in state-based guardianship law which creates confusion and unnecessary complexity for people with dementia, their carers and service providers throughout the country. Individuals face challenges particularly if they move interstate and are not aware that they are required to update their documents. Service providers who operate on a national basis require different policies and practices based on state laws. Alzheimer's Australia NSW therefore believes that a nationalised system for these legal instruments would be advantageous.

5. Whether the language of 'disability' is the appropriate conceptual language for the guardianship and financial management regime and to what extent 'decision making capacity' is more appropriate.

Alzheimer's Australia NSW is of the view that decision making capacity is the more appropriate conceptual language for the guardianship and financial management regime. A person may have a disability yet be cognitively intact and be able to make decisions about all aspects of their lives.

In the case of dementia, decision making capacity fluctuates and changes over time. A person living with dementia may be able to make decisions about some things, but other decision making processes are too complex. Alzheimer's Australia NSW 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 where a person with dementia no longer has the cognitive capacity to make their own decisions and a substitute decision maker is necessary.

6. Whether guardianship law in NSW should explicitly address the circumstances in which the use of restrictive practices will be lawful in relation to people with a decision making incapacity.

The use of restrictive practices for people with dementia in residential aged care facilities, hospitals and community settings should always be viewed as a last resort and as a temporary, time-limited solution. Consultations should take place with the person or legal representatives, family and medical professionals. The Australian Government's *Decision-making tool: Supporting a restraint free environment in residential aged care*⁵ refers to inconsistencies in State laws with regard to the use of restrictive practices and restraint, noting that:

“a guardianship order or an enduring power of attorney may cover a limited range of matters not including decisions about restraint. In such cases, it might not be appropriate to involve the guardian or the holder of an enduring power of attorney in making decisions about restraint. Legal requirements for consent to the use of restraint where the resident is not mentally competent may vary in different states and territories. A family member who does not have a relevant guardianship order or enduring power of attorney may not have the legal capacity to consent on behalf of the resident to the use of restraint, or may only be able to consent to its short term use in response to a crisis. In some circumstances consent might need to be obtained from the Guardianship Board or its equivalent in the particular state or territory.”

Alzheimer's Australia NSW understands that there is no NSW legislation defining what a restrictive practice is in the *Guardianship Act 1997*. The Guardianship Division of NCAT has jurisdiction to appoint a substitute decision maker to authorise or consent to its use. Consequently, Alzheimer's Australia NSW believes that legislation should explicitly address use of restrictive practices. We believe that the use of restrictive practices should be based on the principles outlined in the Australian Government's decision-making tool referred to above. Specifically, the use of restrictive practices should be specific, time-limited, the least restrictive form possible, reviewed and only enacted with consent from a 'person responsible'.

The President of the Guardianship Board of Tasmania has suggested that apart from a Court, Tribunal or a duly appointed guardian, no person has the legal ability to agree to detention on behalf of another adult⁶. This interpretation suggests that

⁵ Commonwealth of Australia (2012) *Decision-making tool: Supporting a restraint free environment in residential aged care*

⁶ Smith, A. (no date) *Detention of People with Dementia in Secure Facilities in State Care in Tasmania*, President of the Guardianship and Administration Board Tasmania
http://www.guardianship.tas.gov.au/_data/assets/pdf_file/0009/203967/Detention_of_people_with_dementia_in_secure_facilities.doc_31.7.12.pdf

family members of a person with dementia do not have the authority to consent to a person with dementia being placed in a secure unit. According to human rights conventions, any person with dementia who is to be placed in a secure unit should have an appointed guardian or be the subject of a mental health order. This highlights the complexity of the issue for guardianship law in relation to restrictive practice in aged care. Formal appointment of a guardian (not just person responsible) in all cases would be desirable from a human rights perspective. However, Alzheimer's Australia NSW believes that this would have significant practical ramifications if this were to play out in all admissions of people with dementia to a secure dementia specific unit. Our understanding is that currently most admissions are accepted through the Aged Care Assessment Team assessment of need and then entry based on this without recourse to a guardian for consent to the move. Carers and families invariably decide that this level of care and support is needed and seek assessment and admission. Alzheimer's Australia NSW believes that clarity in legislation in this challenging area is desirable for both people with dementia and their families, and aged care providers.

7. In the light of the requirement of the UNCRPD that there be regular reviews of any instrument that has the effect of removing or restricting autonomy, should the Guardianship Act 1987 provide for the regular review of financial management orders.

Alzheimer's Australia NSW understands that every other State and Territory except NSW reviews financial management orders. While we accept that some organisations and individuals would be critical of the NSW situation and acknowledge that, in effect, it is in breach of the UNCRPD, it is unlikely that financial management orders for people with dementia need to be regularly reviewed because if an order is required it is due to the fact that the individual has lost capacity and that situation is not going to change.

It is assumed that regular reviews would assess the appropriateness of financial management orders from both an autonomy and risk of abuse perspective of people with disabilities. However as financial literacy and capacity is one of the first functional abilities a person with dementia loses, it is likely that financial management orders for people with dementia would only need to be reviewed if there were discrepancies in the annual accounting process or if another party requested a review.

If the Guardianship Act 1987 were to be updated to provide for the regular review of financial management orders, the workload of the Guardianship Division would increase significantly, and Alzheimer's Australia NSW would support the division

being appropriately funded and resourced to carry out this extension of their responsibilities.

8. The provisions of Division 4A of Part 5 of the Guardianship Act 1987 relating to clinical trials.

Alzheimer's Australia NSW supports clinical trials involving people with dementia. They are necessary in the search for a cause, treatment and ultimately a cure for dementia. There have been no concerns expressed to us about the provisions of Division 4A of Part 5 of the Guardianship Act 1987 relating to clinical trials.

We support the conditions that are currently in place and believe that the ethics approval processes that studies undergo and the informed consent procedures in place for clinical trials involving people with dementia are sufficient.

9. Any other matters the NSW Law Reform Commission considers relevant to the Terms of Reference.

The following matters are based on our research paper examining financial abuse of people with dementia completed in 2014 and available at:

<https://nsw.fightdementia.org.au/sites/default/files/20140618-NSW-Pub-DiscussionPaperFinancialAbuse.pdf>

Alzheimer's Australia NSW recommends 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 elder 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.

Currently, the best way to safeguard oneself against financial abuse in NSW is to plan ahead and appoint a trusted individual to act as your attorney through an Enduring Power of Attorney (EPOA). Although 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 and recourse 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. One clear example of this is the lack of criminal offences for breaches of power in the Power of Attorney Act 2003. If a person perpetrates financial abuse by misusing an EPOA

they cannot be charged with a criminal offence because technically their behaviour, although immoral, is not illegal under NSW law. Although victims (or their representative) can pursue a civil case against the perpetrator, this is a time consuming, stressful, expensive process, and is unlikely to result in the recovery of stolen assets. This loophole acts as a significant enabler and masks the actual prevalence of abuse because people believe it is not worth the effort of reporting and pursuing civil action. Therefore, Alzheimer's Australia NSW recommends that the Law Reform Commission also investigate the adequacy of the Powers of Attorney Act 2003.

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