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# **Inquiry into Dementia: Early Diagnosis and Intervention**

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## **House Standing Committee on Health and Ageing**

**2 May 2012**

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## Introduction

1. The Law Council of Australia (**the Law Council**) is the national peak body representing the Australian legal profession through the Law Societies and associations of the States and Territories and the Large Law Firm Group (collectively referred to as the “constituent bodies” of the legal profession). The Law Council advocates on behalf of the legal profession on national issues including for the improvement of federal and inter-jurisdictional legal frameworks, such as elder and succession laws and matters affecting the rights of the disabled and infirm. For further information on the Law Council, please see **Attachment A**.
2. The Law Council welcomes the opportunity to provide comments to the House Standing Committee on Health and Ageing’s “Inquiry into Dementia: Diagnosis and Intervention”.
3. Dementia represents the leading cause of disability in Australia and currently affects approximately 280,000 Australians. This figure is expected to increase in the near future. As such, it is timely to consider the manner in which early diagnosis and intervention may help to improve the quality of life of Australians with dementia and their family and carers.
4. The Law Council is concerned that there is insufficient awareness regarding the significant implications that dementia may have on an individual’s ability to plan for their future. Early dementia diagnosis and intervention will help to provide individuals with a greater opportunity to engage with important legal issues and to ensure that any legal instruments that are required to give effect to their wishes for the future, are appropriately arranged whilst they possess the capacity to do so.
5. Substitute decision maker regimes and advanced care directives provide a mechanism through which individuals can plan for the future. However, there are significant differences between jurisdictions in the laws governing substitute decision makers and advance care directives.
6. Such differences are highly undesirable as they make it difficult for individuals to understand the options that are available and to thereby take appropriate action to plan for their future. Differences between jurisdictions also create uncertainty regarding the inter-jurisdictional validity and scope of substitute decision maker appointments and advance care directives.
7. The Law Council submits that sustained efforts are needed to achieve greater consistency and harmonisation in relation to capacity, substitute decision makers and advance care directives, to promote greater clarity for dementia sufferers and their families; and facilitate a more accessible system through which individuals can give legal effect to their decisions.
8. The Law Council supports the adoption and implementation of the guidelines and principles outlined in the National Framework for Advance Care Directives, as endorsed by the Australian Health Ministers’ Advisory Council (**AHMAC**).
9. The Law Council also encourages the Australian Government to provide greater support for individuals with dementia and their families and carers, in order to promote awareness and enable individuals to actively engage in planning for the future, prior to the stage where their incapacity may render them unable to legally do so.

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## Dementia

10. As is recognised at all levels of government, Australia has an ageing population which each year is significantly increasing the burden on the aged care and public health systems.
11. Dementia currently represents the leading cause of disability in Australians aged 65 and over, with recent statistics highlighting that there are approximately 280 000 Australians currently suffering from dementia. The number of dementia sufferers is expected to increase to approximately 1 million by 2050.<sup>1</sup>
12. Dementia has also been flagged internationally as a public health issue, with the World Health Organisation, in collaboration with Alzheimer's Disease International recently releasing a report entitled "*Dementia: A Public Health Priority*". Current estimates indicate that as at 2010, 35.6 million people worldwide are living with dementia and that this number is set to double by 2030 and triple by 2050. This will have significant economic, social and health implications.<sup>2</sup>
13. Alzheimer's Australia's recent report "*Consumer Engagement in the Aged Care Reform Process*" highlighted that the quality of life experienced by people with dementia and their families and carers, is significantly influenced by a timely diagnosis and appropriate support services which enable them to manage changes as a result of the disease. Furthermore, the report highlighted agreement that there was a need for greater information and awareness regarding the importance of putting into place advance care plans and powers of attorney.<sup>3</sup>

## Capacity

14. The onset of dementia has significant implications for capacity, broadly understood as referring to the prerequisite cognitive ability required to make a legally valid decision.
15. Although previously viewed as a level of cognition that either exists or is absent, there is increasing acceptance that capacity may be fluid and vary from time to time. Dementia's effects on capacity will manifest differently in each individual circumstance. Some individuals may experience a gradual decline, whilst others may experience episodic incapacity.
16. The Law Council is aware that there are varying approaches to the assessment of capacity, with some jurisdictions relying upon common law principles and other jurisdictions outlining the relevant tests and standards through legislation.
17. Different capacity tests, thresholds and standards may also be applicable depending on the relevant context or activity under consideration, as is demonstrated at

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<sup>1</sup> Alzheimer's Australia, *Dementia Statistics*, Available at: <http://campaign.fightdementia.org.au/the-campaign/dementia-statistics/>

<sup>2</sup> World Health Organisation and Alzheimer's Disease International, 2012, *Dementia: A Public Health Priority*, p2

<sup>3</sup> Alzheimer's Australia, 2012, *Consumer Engagement in the Aged Care Reform Process*, Available at: [http://www.health.gov.au/internet/main/publishing.nsf/Content/D8BFDAF025E639F2CA2579510017ACE7/\\$File/FINAL%20AA%20-%20Consumer%20Engagement%20in%20the%20Aged%20Care%20Reform%20Process.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/D8BFDAF025E639F2CA2579510017ACE7/$File/FINAL%20AA%20-%20Consumer%20Engagement%20in%20the%20Aged%20Care%20Reform%20Process.pdf)

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Appendix A of the Law Society of New South Wales' practitioner's guide "When a client's capacity is in doubt".

18. These various differences between and within jurisdictions have resulted in unnecessary complexity and uncertainty.
19. The issue of capacity is particularly important in the context of the execution of wills and the appointment of substitute decision makers; as such decisions can only be validly made where an individual has legal capacity. Capacity therefore has significant implications for an individual's autonomy and ability to make important decisions about their life.
20. Early diagnosis and intervention provides individuals with a greater opportunity to consider the implications of a loss of capacity, to seek information and to engage in discussions with their families, carers and friends regarding their wishes. It is important that dementia sufferers are encouraged to make decisions in relation to lifestyle, medical and financial matters and take the necessary steps to execute any necessary legal instruments, before a loss of capacity precludes them from being able to validly do so.
21. The Law Council considers that a nationally consistent approach to the assessment of capacity in the context of substitute decision making, is highly desirable in order to promote greater clarity and ultimately, to more effectively provide protection and foster individual autonomy as circumstances require.

## **Substitute Decision Makers**

### **Clarity and harmonisation**

22. Substitute decision making regimes allow another individual to 'stand in the shoes' of a person who lacks capacity to make decisions about their lives. They may be personally appointed, or appointed by a tribunal in cases where no personal appointment has been made and the relevant issues are unable to be informally resolved.
23. The legislative framework for substitute decision makers varies across jurisdictions, and in some cases may be distributed across a number of legislative instruments. This is problematic as it makes it difficult for individuals to understand their options in relation to substitute decision makers and the actions that they need to take to appoint a substitute decision maker. Differences between jurisdictions and across instruments within jurisdictions may also lead to uncertainty and confusion regarding the validity of a substitute decision maker appointment and the scope of their roles and responsibilities.
24. The Law Council notes that the Victorian Law Reform Commission (VLRC) has recently released a report regarding guardianship laws, which proposes to integrate the different types of substitute decision makers that are provided for under Victorian provisions.
25. The Law Council further notes that simpler and more streamlined regimes for substitute decision makers may improve the accessibility of the regime and more easily enable individuals to personally appoint substitute decision makers, whilst they have the capacity to do so.

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26. The Law Council considers that a nationally uniform approach to substitute decision makers is highly desirable and should be the ultimate objective of Federal, State and Territory governments.
  27. However, as an interim measure, the Law Council recommends greater co-ordination between different jurisdictions in relation to substitute decision making, to promote greater consistency between jurisdictions.

## **Appointing substitute decision makers**

28. A power of attorney authorises a person to act on behalf of another person (the donor) for a specific purpose or over a certain period of time. An enduring power of attorney on the other hand provides another person with the authority to act on behalf of the donor, with continuing effect even after the donor loses capacity.<sup>4</sup>
29. In the context of dementia, the latter arrangement provides a more appropriate mechanism for the personal appointment of a substitute decision maker. However, it can only be made whilst the person has capacity and thus requires planning.
30. Personal appointments are preferable to tribunal or automatic appointments because they:
  - a) enable the individual to appoint a trusted person who is well placed to know and implement their wishes;
  - b) promote quality of life and the autonomy and dignity of the person concerned; and
  - c) reduce the burden on public tribunals and other relevant bodies responsible for the appointment of substitute decision makers, which should be avoided wherever possible.
31. Australia's ageing population means that there will be a continuing need for state based guardianship regimes to be effective and functional. However, Tribunal made orders should be a measure of last resort, in circumstances where other less restrictive options have been exhausted.
32. Unfortunately, many individuals with dementia may only consider the issue of substitute decision makers at a later stage, at which point it is too late for them to make a personal appointment. They will then be forced to rely on the state based guardianship system.
33. In certain circumstances, the Tribunal may appoint a family member to act as a trustee / guardian / financial manager to manage the financial and / or lifestyle affairs of the relevant individual (the Law Council notes that there may be differences in terminology between jurisdictions). However, where public trustees and administrators are appointed, they are faced with the responsibility of making significant decisions; in what may be complicated circumstances and may not be as well placed as family, friends or carers, to accurately ascertain and reflect the wishes of the individual with dementia.
34. It is essential that individuals take control of their own affairs where possible. Early diagnosis and intervention provide individuals with a greater capacity to seek

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<sup>4</sup> It should be noted that powers of attorney are appointed to make decisions in relation to financial matters. Enduring guardians are the relevant substitute decision makers in relation to lifestyle matters, including decisions such as where someone should live and what medical treatment and services should be received.

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relevant information, to engage in planning for the future and to ensure that they have appropriately arranged their affairs prior to a loss of capacity, including the personal appointment of a substitute decision maker(s).

## Advanced care directives

35. Advance care directives enable an individual to outline their wishes for medical treatment to be provided in the future, after they have lost the capacity to make decisions for themselves.
36. Advance care directives are used in all States and Territories; however they are often referred to using different terminology and are approached differently across jurisdictions. An advanced care directive can only be validly made by an individual whilst they possess capacity.
37. The National Framework for Advance Care Directives (**National Framework**) was endorsed by the AHMAC in 2011, to promote greater national consistency in legal frameworks governing decisions regarding health and end-of-life. Greater consistency was seen to better enable individuals to engage in decision making about the future and to enhance mutual recognition of advance care directives across all states and territories. However, further efforts need to be made to encourage jurisdictions to adopt and implement the principles and standards as outlined in the National Framework.
38. The Law Council understands that these issues have been referred to the Council of Australian Governments (**COAG**) and encourages COAG to continue working towards an approach that will facilitate greater clarity and consistency in relation to advanced care directives.

## Increased community awareness

39. As part of a strategy of early dementia diagnosis and intervention, the Law Council believes that greater information and support for individuals with dementia, as well as their families and carers, is vital. In particular, awareness of the substitute decision making options and advanced care directives need to be further promoted within the general community.
40. Access to advice and support will help individuals to make informed choices and enable them to clearly articulate their wishes, so that family, carers and medical practitioners are aware of the appropriate care and treatment that the individual desires.
41. Programs and initiatives such as the Respecting Patient Choices<sup>5</sup> program should be promoted and further developed to help facilitate dialogue between individuals and their families, carers and medical professionals, regarding the individual's wishes for the future. Due to the challenging and highly emotional circumstances that may surround these discussions, a structured approach to guide parties through the difficult process will help to ensure that appropriate arrangements are put in place and are properly understood by all parties.

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<sup>5</sup> The Respecting Patient Choices Program is an initiative supported by the Department of Health and Ageing, which 'aims to promote the use of advance care planning to care professionals and the wider community in a range of care settings.' For further information, please refer to: <http://www.respectingpatientchoices.org.au/>

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42. Discussion of these important issues at an early stage is important to avoid confusion and/or potential conflict that may arise as a result of differing opinions on the appropriate measures to be taken for the treatment and care of a loved one suffering from dementia. Where they do not already exist, the development of alternative dispute resolution mechanisms may be beneficial in this context, to prevent conflict within families and preclude the escalation of issues, which if unresolved, may lead to litigation. The Law Council notes that the Law Institute of Victoria has made detailed submissions in relation to these points in response to the VLRC's recent Review of Guardianship.
  43. Early diagnosis and support may also operate to address issues of elder abuse, the risks of which are arguably heightened by the increasing number of Australians with dementia. In the absence of appropriate planning, the declining mental capacity of an individual with dementia may increase their vulnerability to actions taken by others, which may lead to physical, psychological, financial, sexual and/or social harm. Where an individual has clearly set out their wishes and preferred course for the future and appointed a trusted attorney, this might reduce the risk of disingenuous decisions and actions being undertaken on their behalf.
  44. Increased support is also necessary for those appointed as substitute decision makers, in order to sufficiently inform them of their roles and responsibilities and reduce the risk of an unintended abuse of power. In jurisdictions where such information and assistance is not already available, it would be beneficial to provide substitute decision makers with a better understanding of the standards/principles that should be taken into consideration and applied when exercising their decision making responsibilities, to improve accountability of decision-making.

## Conclusion

45. The Law Council considers that early diagnosis and intervention is important, due to the opportunity it provides for individuals with dementia and their families, carers and friends to adequately prepare for the future.
46. The Law Council is concerned that currently, there is insufficient awareness and understanding of the legal issues that need to be considered. Many individuals with dementia will only look to these issues at a later stage, at which time they no longer possess the requisite capacity to make important decisions in relation to their lifestyle and financial and medical matters.
47. The personal appointment of substitute decision makers and the execution of advance care directives enable an individual to clarify their wishes for the future. However, differences between jurisdictions in relation to the substitute decision maker and advance care directive regimes create uncertainty and make it more difficult for individuals to understand the actions that they need to take to put these arrangements in place.
48. The Law Council recommends simplification and harmonisation of the assessment of capacity and the substitute decision maker and advance care directive regimes, in order to promote greater clarity and enable individuals to understand their options and to take control of their future.
49. Increased community awareness is also vital in order to support individuals with dementia to adequately assess their options, make decisions for their future and to

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effectively communicate these to their families, friends and carers. Greater community awareness and assistance for families, friends and carers is also important to help them understand their role in supporting a loved one, as they deal with the onset of dementia.

50. The Law Council would be pleased to assist in developing appropriate models to promote uniformity regarding capacity, substitute decision making and advanced care directives, which will assist individuals and communities to address relevant legal issues following a diagnosis of dementia.

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## Attachment A: Profile of the Law Council of Australia

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The Law Council of Australia exists to represent the legal profession at the national level, to speak on behalf of its constituent bodies on national issues, and to promote the administration of justice, access to justice and general improvement of the law.

The Law Council advises governments, courts and federal agencies on ways in which the law and the justice system can be improved for the benefit of the community. The Law Council also represents the Australian legal profession overseas, and maintains close relationships with legal professional bodies throughout the world.

The Law Council was established in 1933, and represents 16 Australian State and Territory law societies and bar associations and the Large Law Firm Group, which are known collectively as the Council's constituent bodies. The Law Council's constituent bodies are:

- Australian Capital Bar Association
- Australian Capital Territory Law Society
- Bar Association of Queensland Inc
- Law Institute of Victoria
- Law Society of New South Wales
- Law Society of South Australia
- Law Society of Tasmania
- Law Society Northern Territory
- Law Society of Western Australia
- New South Wales Bar Association
- Northern Territory Bar Association
- Queensland Law Society
- South Australian Bar Association
- Tasmanian Independent Bar
- The Large Law Firm Group (LLFG)
- The Victorian Bar Inc
- Western Australian Bar Association

Through this representation, the Law Council effectively acts on behalf of approximately 56,000 lawyers across Australia.

The Law Council is governed by a board of 17 Directors – one from each of the constituent bodies and six elected Executives. The Directors meet quarterly to set objectives, policy and priorities for the Law Council. Between the meetings of Directors, policies and governance responsibility for the Law Council is exercised by the elected Executive, led by the President who serves a 12 month term. The Council's six Executive are nominated and elected by the board of Directors. Members of the 2012 Executive are:

- Ms Catherine Gale, President
- Mr Joe Catanzariti, President-Elect
- Mr Michael Colbran QC, Treasurer
- Mr Duncan McConnel, Executive Member
- Ms Leanne Topfer, Executive Member
- Mr Stuart Westgarth, Executive Member

The Secretariat serves the Law Council nationally and is based in Canberra.