

*By continuing to insist that what was happening inside my brain was definitely not usual I was diagnosed while still at a relatively early stage and therefore I have been able to have my say about our lifestyle decisions. But had the diagnosis been in 2006 when I first became aware of changes I would have had much greater capacity to make decisions and therefore more choices from which to make them...  
... I would have retained my identity and continued to be financially independent.<sup>1</sup>*

## Diagnosis

- 4.1 'Early' or 'timely' diagnosis of dementia can have significant benefits for a person with dementia, their families and carers.
- 4.2 These benefits are far-reaching and can include:
  - The ability to plan early and prepare for the future; and
  - The ability to obtain a diagnosis and appropriate treatment early.<sup>2</sup>
- 4.3 In addition, having timely access to appropriate medical treatment for dementia may improve cognitive function, prolong independent living, reduce carer burden and improve quality of life.<sup>3</sup>
- 4.4 Despite the obvious benefits to early or timely diagnosis, the Committee heard that as many as two-thirds of people with dementia live and die with the condition without ever being diagnosed. Those people who do receive a diagnosis wait an average of approximately three years from first symptoms to diagnosis.<sup>4</sup>

---

1 Robert, *Submission 19*, pp. 1-2.

2 Alzheimer's Australia, *Early diagnosis of dementia*, paper 10, March 2007, p. 2.

3 Australian Government Department of Health and Ageing (DoHA), *Submission 89*, p. 9.

4 Alzheimer's Australia (National Office), *Submission 44*, p. 3. See also: Alzheimer's Australia (National Office), *Submission 44.1*, p. 1.

- 4.5 The Committee was told that primary care practitioners, such as General Practitioners, have a major role in improving early diagnosis. Consequently, there is a need to improve early or timely diagnosis by General Practitioners and other primary care practitioners.
- 4.6 Cognitive Dementia and Memory Services (CDAMS) told the Committee that ensuring timely diagnosis requires a multi-faceted approach:
- Ensuring availability of timely diagnosis and advice will require a multi-pronged approach including education and up-skilling of GP's, practice nurses, and service providers, provision of specialist services to provide assistance and advice particularly in more complex presentations, along with increased community awareness of dementia and the benefits of early diagnosis.<sup>5</sup>
- 4.7 The concepts of early and timely diagnosis, the benefits to achieving a timely diagnosis, and how a timely diagnosis might be obtained, are discussed below. The barriers to achieving early and timely diagnosis are discussed in Chapter 5.
- 4.8 The need to increase community awareness about the benefits of early diagnosis is discussed in detail in Chapter 3.

## **What is 'early' or 'timely' diagnosis?**

- 4.9 The optimal time for a person to receive a diagnosis of dementia was the subject of some discussion during the inquiry. The Committee has considered the difference between the concepts of 'early' and 'timely' diagnosis in the context of this discussion.
- 4.10 Minister Butler's Dementia Advisory Group (MDAG) distinguished 'timely' diagnosis from 'early' diagnosis:
- For example a person with undiagnosed moderately advanced dementia first coming to medical attention on admission to hospital should receive a diagnosis; this would be timely though not early. Early diagnosis refers to reducing the gap from first symptoms to receiving a diagnosis.<sup>6</sup>
- 4.11 Alzheimer's Australia National Office defined 'early diagnosis' as 'a diagnosis as soon as possible after symptoms are brought to the attention

---

5 Cognitive Dementia and Memory Services (CDAMS), *Submission 39*, p. 5.

6 Minister Butler's Dementia Advisory Group (MDAG), *Submission 48*, p. 1.

- of the health care system.' Defined in this way, Alzheimer's Australia considered that 'early' diagnosis was in fact similar to 'timely' diagnosis.<sup>7</sup>
- 4.12 Alzheimer's Australia Victoria believed that a 'timely' diagnosis coincided with action being taken at the point that concern was expressed, and the timely provision of advice, treatment and support services.<sup>8</sup>
- 4.13 In this regard, it was submitted that a 'timely' diagnosis was preferable to an 'early' diagnosis:
- Health professionals involved in diagnosing dementia must be careful to balance, and be sensitive to, the perceived and potential positive and negative effects of a dementia diagnosis. The RACP (Royal Australasian College of Physicians) and the ANZSGM (Australian and New Zealand Society for Geriatric Medicine) support a person-centred approach to diagnosis that responds to the person with dementia and their carers' needs and preferences. Often timely diagnosis will be more appropriate than early diagnosis.<sup>9</sup>
- 4.14 While acknowledging the potential benefits of an 'early' diagnosis, the Royal District Nursing Services Ltd (RDNS) considered that for interventions to be successful, the person with dementia, along with their family and friends, had to be ready to seek information, diagnosis, and treatment. RDNS stated, 'This readiness will come at different times for different people but when it does expeditious and timely assessment is then critical.'<sup>10</sup>
- 4.15 MDAG explained the factors a practitioner was required to balance in making a diagnosis:
- The advantages of a diagnosis are that it can be a relief (paradoxically) and trigger support, medications and planning ahead. On the other hand it is important to respect peoples' preferences not to know and acknowledge possible distress. The clinician's skill is to navigate these issues sensitively.<sup>11</sup>
- 4.16 Dr Owen Davies, of the South Australia Division of the Australian and New Zealand Society for Geriatric Medicine (ANZSGM), considered the ideal point at which to make a diagnosis of dementia:
- 

7 Alzheimer's Australia (National Office), *Submission 44*, p. 3.

8 Alzheimer's Australia Vic, *Submission 35*, p. 2. See also, Tasmanian Government Department of Health and Human Services, *Submission 41*, p. 7.

9 The Royal Australasian College of Physicians (RACP) and the Australian and New Zealand Society for Geriatric Medicine (ANZSGM), *Submission 22*, p. 8.

10 Royal District Nursing Services Ltd, *Submission 78*, p. 2.

11 MDAG, *Submission 48*, p. 2. See also: Dr Lyndon Bauer, Health Promotion Central Coast, *Official Committee Hansard*, Terrigal, 12 October 2012, p. 30.

My view is that we should be making a diagnosis at the point where someone is struggling to manage to live a day-to-day life at home or they are just beginning to develop those problems.<sup>12</sup>

### Committee comment

- 4.17 This inquiry focusses on how an 'early' diagnosis of dementia might improve a person's quality of life, as well as the lives of their family and carers. In hearing evidence about the benefits of receiving a 'timely' diagnosis, the Committee considers that 'early' diagnosis in the context of this report has the same meaning as 'timely' diagnosis.
- 4.18 'Early diagnosis' sometimes includes reference to a diagnosis of pre-symptomatic Alzheimer's disease or other causes of dementia using biomarkers (biological rather than symptomatic indications of disease presence). The Committee was told that preclinical diagnosis is currently confined to research settings.<sup>13</sup>
- 4.19 The Committee heard that the time of readiness to receive a diagnosis varies from person to person. A General Practitioner or other medical professional must consider their patient's readiness with a number of other factors, such as the risk of damaging the patient-doctor relationship, and the need to commence beneficial treatment or interventions.
- 4.20 The Committee accepts that in the majority of cases, the appropriate and timely point for a person to receive a diagnosis of dementia is when they are experiencing symptoms which begin to impact upon their everyday lives.
- 4.21 It is clear that there is currently an unacceptable delay between when a person first displays symptoms of dementia, and when they receive a diagnosis (if they receive a diagnosis at all). These delays, along with the barriers which contribute to a delay or failure to receive a diagnosis, are discussed in Chapter 5.
- 4.22 How a diagnosis is obtained, as well as the benefits to achieving a 'timely' diagnosis, are discussed further below.

---

12 Dr Owen Davies, ANZSGM, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 14. See also: Dr Lyndon Bauer, Health Promotion Central Coast, *Official Committee Hansard*, Terrigal, 12 October 2012, p. 33.

13 Alzheimer's Australia National Office, *Submission 44*, pp. 3 and 27. See also: MDAG, *Submission 48*, p. 1; NSW Department of Health, *Submission 95*, p. 1.

## Benefits of timely diagnosis

- 4.23 The Committee was told that the benefits to receiving an early diagnosis were three-fold:
- It gives a person the power to control their life and plan for their future, including organising enduring powers-of-attorney and discussing advance care directives;
  - It empowers the person with dementia, their carer and their family to accept the diagnosis and reach a better understanding about the person's condition; and
  - Treatment, services and support are usually built around a diagnosis, so achieving an early diagnosis provides a person with access to dementia care services.<sup>14</sup>
- 4.24 The Committee acknowledges the significant challenges faced by families of people who receive a diagnosis of dementia. It follows that the benefits of timely diagnosis will extend to families, so that they can also access the range of available support services for carers.
- 4.25 Mrs Judy Ratajec, of Uniting Church Frontier Services, told the Committee that appropriate and timely diagnosis should be promoted:
- The benefits of that timely and appropriate diagnosis would obviously be around being able to rule out any other cause for the symptoms that are presenting, to look at treating other risk factors, to look at linking the family and/or the carers into support systems so that they actually have that support system to go with them through the journey...
- ... The earlier a person is diagnosed the more able they are to actually look at self-determining for the journey, so empowering them through the decision-making.<sup>15</sup>
- 4.26 The Australian General Practice Network (AGPN) submitted there were a number of potential clinical benefits associated with timely diagnosis of dementia, including the opportunity to:
- treat the reversible causes of dementia
  - help slow the progression of dementia through pharmaceutical and lifestyle interventions

---

14 Associate Professor Mark Yates, MDAG, *Official Committee Hansard*, Canberra, 8 February 2013, p. 17. See also: Associate Professor Yates, MDAG, *Official Committee Hansard*, Canberra, 21 August 2012, p. 21.

15 Mrs Judy Ratajec, Uniting Church Frontier Services, *Official Committee Hansard*, Broome, 13 November 2012, p. 25.

- support symptom management through pharmaceutical and lifestyle interventions (many of which are likely to be more effective earlier in the course of disease progression) and minimise the impact of symptoms, for example through the establishment of routines that can help patients and families manage declining cognitive function.<sup>16</sup>

4.27 It was argued there was also a range of non-clinical benefits of timely diagnosis and management of dementia, for both a person with dementia and their family. These benefits included offering insight into the symptoms a person was experiencing and a greater understanding of disease progression and what the future may hold. The AGPN considered:

In this sense, timely diagnosis can provide an important opportunity for the patient to experience a sense of self determination at a time when it can feel that their self-agency is being eroded.<sup>17</sup>

4.28 Jill, who appeared in a private capacity, believed that an earlier diagnosis for her husband may have assisted in easing his symptoms and allowing her to take control of business decisions sooner:

There are medications that help slow it and the earlier they get on them the more effective they are. He could have perhaps been on medication. As I said in my opening speech, for a month or two he would not be able to do anything and then he seemed to come all right and I would let him take over again. Perhaps if I had realised that it was a real problem with his brain, I would not have been allowing him to step in and out of the business.<sup>18</sup>

4.29 The benefits of early diagnosis could also be seen in the health and aged care systems, as early diagnosis, effective treatment and support could lead to a reduction in unnecessary hospitalisations and crisis interventions, and delay a person's entry into residential or hospital-based care.<sup>19</sup>

4.30 In addressing the inquiry's terms of reference, MDAG noted the following benefits to achieving a timely diagnosis:

  - In improving the quality of life and assisting people with dementia to remain independent for as long as possible:
    - ⇒ By reversing dementia if a reversible cause could be discovered;
    - ⇒ By enhancing safety in workplace for those still working;

---

16 Australian General Practice Network (AGPN), *Submission 87*, p. 7.

17 AGPN, *Submission 87*, p. 8.

18 Jill, private capacity, *Official Committee Hansard*, Moree, 27 August 2012, p. 9.

19 AGPN, *Submission 87*, pp. 8-9.

- ⇒ By monitoring and if necessary assessing driving so as to enhance safety with driving;
- ⇒ By optimising management of other medical conditions;
- ⇒ By alerting the person, and his or her family, friends and doctor to the need to assist the person psychologically;
- ⇒ By helping families and friends to understand changes in people with dementia leading to better relationships and development of strategies to compensate for cognitive deficits;
- ⇒ By receiving advice from health professionals such as occupational therapists and from Alzheimer's Australia (Living with Memory Loss course) on strategies to compensate for memory loss; and
- ⇒ By enabling medications to be commenced earlier, which could help someone stay independent for longer.<sup>20</sup>
- In increasing opportunities for continued social engagement and community participation for people with dementia and their carers:
  - ⇒ By alerting others to make them more tolerant and supportive;
  - ⇒ By structuring social engagements so as not to be overwhelming;
  - ⇒ Through support groups for people with early dementia; and
  - ⇒ By building on retained strengths of person with early dementia.<sup>21</sup>
- In helping people with dementia and their carers plan for their futures:
  - ⇒ Enabling planning for future life decisions, living arrangements, proximity to services and family;
  - ⇒ Alerting the person and the family to the need for financial planning; and
  - ⇒ Enabling affairs to be arranged in timely manner while person with dementia still has legal mental capacity.<sup>22</sup>

## How is a diagnosis of dementia obtained?

4.31 In considering what barriers exist in achieving a diagnosis of dementia, it is important to examine how a diagnosis of dementia is obtained in Australia.

4.32 International guidelines recommend that an initial assessment of a patient for dementia include obtaining a comprehensive medical history,

---

20 MDAG, *Submission 48*, p. 7.

21 MDAG, *Submission 48*, p. 8.

22 MDAG, *Submission 48*, p. 8.

undertaking a physical examination and conducting necessary laboratory and imaging tests.<sup>23</sup>

4.33 The Australian Institute of Health and Welfare (AIHW) stated in its report, *Dementia in Australia*, that there was no single definitive diagnostic test:

There is no single or simple test that will definitively diagnose dementia. The assessment process may vary according to who is conducting it and the symptoms the person presents with. In general, the aim of the assessment is to gather sufficient information about changed behaviours, functional capacity, psychosocial issues and relevant medical conditions to allow for a diagnosis to be made. Often, the information gathering process includes input from third parties (for example, carers, family members and service providers) and the use of screening tools.<sup>24</sup>

4.34 If the results from a screening test suggest cognitive impairment, it is recommended that a person be referred to a medical specialist (such as a geriatrician, psychiatrist or neurologist) for further assessment. On the advice of the specialist, other tests, such as radiological and laboratory investigations, may be undertaken.<sup>25</sup>

4.35 The strengths and weaknesses of screening tests for dementia are outlined below.

## Screening tests

4.36 There are a number of screening tools available to medical practitioners who are tasked with making a diagnosis of dementia. These tools include:

- The Mini-Mental State Examination (MMSE);
- Modified Mini Mental Exam (3MS);
- The General Practitioner assessment of Cognition (GPCOG);
- The 7-Minute Screen;
- The Addenbrooke's Cognitive Examination – Revised (ACE-R);
- The Rowland Universal Dementia Assessment Scale (RUDAS);
- The Montreal Cognitive Assessment (MoCA);
- The CogState; and

---

23 Royal Australian College of General Practitioners (RACGP), *Submission 83*, pp. 5-6.

24 Australian Institute of Health and Welfare (AIHW) 2012, *Dementia in Australia*, catalogue no. 70, p. 4. See also: Alzheimer's Australia, *Timely diagnosis of dementia: can we do better*, paper 24, September 2011, p. 14; Mr Mark Howland, Hunter New England Local Health District (Tablelands, Mehi and McIntyre Clusters), *Official Committee Hansard*, Moree, 27 August 2012, p. 18.

25 AIHW, *Dementia in Australia*, 2012, p. 4.



- The Kimberly Indigenous Cognitive Assessment Screen (KICA).<sup>26</sup>
- 4.37 A positive screen does not mean that a person has dementia. Rather, a score below a threshold on a cognitive test merely indicates poor performance, and a more detailed assessment is required before a diagnosis can be made.<sup>27</sup>
- 4.38 Professor Dimity Pond, a professor of General Practice, explained how conducting screening tests was not an exact science:
- Doing a mini mental state exam or even our GP cog exam on everyone does not work because it is not an exact science. Those screening tests can overdiagnose or underdiagnose people. You can do really well. I have had people score 30 out of 30 and they cannot find their way out of my surgery. They have dementia to the degree that they get lost every time they walk out of my door and yet they score perfect scores. Then other people might score a 22 or 23 but they have been like that all the[ir] lives. They did not have a good education. People in their 80s often did not get much beyond primary school. Their literacy might not be that good. They do not spend a lot of time listening to the news. They might be a bit stressed by the questions and they just do not score well. It does not mean they have dementia. There is not an easy way for GPs to make this diagnosis.<sup>28</sup>
- 4.39 The Australian Psychological Society (APS) submitted that competent use of diagnostic instruments and valid interpretations of the results was crucial in developing treatment plans that responded to a person's needs. For example:
- It is recognised that people not trained in the administration of the MMSE can inadvertently or unwittingly affect the results and scoring of the test; thus increasing the chance of under- or over-estimating the level of cognitive impairment, and in turn affecting treatment decisions...
- ... The implications of inaccurate or possibly erroneous diagnosis of a person with dementia are vast and varied including

---

26 See: AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 4; RACP and ANZSGM, *Submission 22*, p. 8; Queensland Health, *Submission 23*, p. 4; and Dementia Collaborative Research Centres, *Cognitive Assessment Measures*, <<http://www.dementia-assessment.com.au/cognitive/index.html>>, viewed 7 June 2013. For further discussion on dementia assessment and screening, see Dr Ross Colquhoun, *Submission 66*.

27 MDAG, *Submission 48*, p. 1.

28 Professor Dimity Pond, *Official Committee Hansard*, Newcastle, 8 November 2012, p. 39.

prescription of the wrong medication or, put simplistically, failure to treat.<sup>29</sup>

## Screening challenges

4.40 While the proportion of patients who are incorrectly diagnosed using the most common diagnostic instruments is low, the Committee was told that the risk is amplified for patients who are highly educated, speak English as a second language and/or have a sensory impairment.<sup>30</sup>

4.41 Associate Professor Mark Yates, of MDAG, explained that the gaps in some of the language-based screening tools were well recognised and therefore could be addressed:

When you use these tools a lot, it is like anything else: if you know the holes or if you know when the tool is not going to work, it is often as useful as having a tool that works perfectly in every scenario because you can use its gaps and you know its blind spots. So that is quite useful. There are other tools we can use. There are validated equivalents to the Mini Mental State Examination, such as the RUDAS, which has been validated in Australia and has multiple language capability. That is what I would use in my clinic if I had someone who was of a non-English-speaking background.<sup>31</sup>

4.42 Queensland Health stated the importance of recognising a variety of validated tools such as the MMSE, the RUDAS and the KICA tool, to assist in the diagnosis of people from a range of backgrounds.<sup>32</sup>

4.43 The Committee was told that the KICA screening tool had been introduced in Alice Springs and surrounding desert communities, to assist in the diagnosis of dementia in Indigenous Australians. However, it was recognised that the application of KICA in Central Australia was in its preliminary stages and training was necessary to achieve the full benefit of the testing.<sup>33</sup>

---

29 Australian Psychological Society, *Submission 50*, p. 4.

30 Queensland Health, *Submission 23*, pp. 3-4. See also Leo, *Official Committee Hansard*, Launceston, 27 July 2012, pp. 1-2; DutchCare Ltd, *Submission 17*, p. 2; and Multicultural Communities Council of SA, *Submission 24*, p. 2.

31 Associate Professor Yates, *Official Committee Hansard*, Canberra, 21 August 2012, p. 21.

32 Queensland Health, *Submission 23*, pp. 3-4. See also, Mr Mark Howland, Hunter New England Local Health District (Tablelands, Mehi and McIntyre Clusters), *Official Committee Hansard*, Moree, 27 August 2012, p. 18; Fronditha Care, *Submission 72*, p. 5; Doutta Galla Community Health, *Submission 75*, p. 4.

33 Ms Wilma Gibson, Central Desert Shire Council, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 39.

- 4.44 Ms Nina Bullock, of MacDonnell Shire Council (servicing remote Indigenous communities outside of Alice Springs) told the Committee that the context of the tool needed to be taken into account:

The KICA is a good example of an assessment tool that works in its context. Its context is tropical north territory. In many ways it is a good step forward but it is not the tool for us right now from the shire's perspective.<sup>34</sup>

- 4.45 Mr Graham Kraak, of Queensland Health, said KICA had been trialled for Indigenous communities in Queensland, but further evaluation of its effectiveness was required:

Often the challenge with these is that it might work for one particular community but it is not necessarily generalisable to all Indigenous communities or to Torres Strait Islanders. Often they are grouped together, but the cultural needs and the cultural nuances are very, very different across the country – even within Queensland.<sup>35</sup>

- 4.46 Ms Cate Young, of Tangentyere Council, told the Committee that inaccurate assumptions were often made during the assessment process for Indigenous Australians, due to language barriers:

I have seen a Ngaanyatjarra woman having a dementia assessment with the help of a Pitjantjatjara interpreter who thought she was a bit mixed up because the Pitjantjatjara interpreter did not understand Ngaanyatjarra. It was only because a Ngaanyatjarra person walked past and said, 'Oh, she is speaking Ngaanyatjarra,' that we actually realised that this lady was not mixed up at all and the interpreter was mixed up. It is not just those kinds of things but even some of the assessments. There are huge cultural divides and language divides that are not well addressed.<sup>36</sup>

- 4.47 Ms Young also illustrated the cultural issues associated with obtaining a diagnosis of dementia:

I have assessed a lady who, when you asked her that question about how many animals can you name when going hunting, only named one. But then her family told me later that she only named one because she is only officially allowed to speak about one, not

---

34 Ms Nina Bullock, Macdonnell Shire Council, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 38.

35 Mr Graham Kraak, Queensland Health, *Official Committee Hansard*, Brisbane, 1 August 2012, p. 31.

36 Ms Cate Young, Tangentyere Council, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 25. See also: Mr Brian Gleeson, Office of the Coordinator General for Remote Indigenous Services, *Official Committee Hansard*, 8 February 2013, p. 4.

but because she could not name them. There are lots of discrepancies and mixed up assessments that are being not done well and not followed up well because of quite big cultural and language divides. They leave hospital and then there is not that follow up. So there is an opportunity missed.<sup>37</sup>

- 4.48 Mrs Stephanie Waters, of Kimberley Aged and Community Services, told the Committee that language and distance barriers exacerbated difficulties in achieving an accurate diagnosis. Mrs Waters outlined the methods used to assist in diagnostic testing for dementia in Indigenous communities, such as the use of interpreters:

Sometimes people will come in with a daughter or an escort, a family member, so sometimes that will be one of the strategies used. We try to use the Kimberley Interpreting Service. I guess getting awareness across all the hospitals that that even exists is difficult with the high turnover of doctor staff and nursing staff. A lot of them are not aware initially that that service exists. And then there is the timeliness of having someone able to come and interpret, especially in an acute setting, if someone is really unwell. But it is a common occurrence. With all the many languages – and do not ask me how many there are, but there are lots – an interpreter who can actually speak in that language is not always available.<sup>38</sup>

- 4.49 Due to the cultural bias embedded in some of the screening tools, CDAMS recommended that a best practice model for the assessment and diagnosis of dementia for people from culturally and linguistically diverse (CALD) and Aboriginal and Torres Strait Islander backgrounds be identified to assist in achieving a more timely diagnosis.<sup>39</sup>

- 4.50 Dr Jennifer Torr submitted that diagnosis of dementia in people with intellectual disabilities was a complex clinical challenge for a number of reasons, including that standard assessment instruments were not valid for use in this population.<sup>40</sup>

- 4.51 National Disability Services agreed that there were particular challenges when assessing people with an intellectual disability for dementia:

While the diagnosis of dementia in someone with an intellectual disability should follow the same process as for other people,

---

37 Ms Cate Young, Tangentyere Council, *Official Committee Hansard*, Alice Springs, 30 January 2013, p. 25.

38 Ms Stephanie Walters, Kimberley Aged and Community Services, *Official Committee Hansard*, Broome, 13 November 2012, p. 9. See also: p. 8.

39 CDAMS, *Submission 39*, p. 8.

40 Dr Jennifer Torr, *Submission 73*, pp. 1 and 3.

special challenges arise from the fact that people with intellectual disability have pre-existing difficulties with tasks that involve thinking, remembering and daily living skills. They, therefore, do not perform well on the standard tests used for the general population.<sup>41</sup>

- 4.52 Dr Torr and CDAMS called for the identification of best practice guidelines for assessing people with intellectual disabilities for dementia.<sup>42</sup>
- 4.53 MDAG recommended the promotion of the use of standardised cognitive screening instruments, as have been evaluated by the Commonwealth funded Dementia Outcomes Measurement Suite (DOMS).<sup>43</sup>

### Committee comment

- 4.54 The Committee notes there are a range of screening tools available to medical practitioners to assist in making a diagnosis of dementia. It is clear that the application of these tests is not an exact science, and at times this testing can produce either a false diagnosis, or fail to diagnose someone who is later found to have dementia. All screening tests and assessment processes have their strengths, weaknesses, and limitations.
- 4.55 It is not the Committee's intention to offer an exhaustive list of available screening tools for dementia in this report, or to offer a judgement on the effectiveness of each tool.
- 4.56 The Committee understands that best practice dictates that screening tools be used as only one step of the assessment process. Ideally, a diagnosis of dementia should be obtained through the results of a suitable screening test, a GP's clinical judgment, information gathered from the patient and/or their families, and a referral to geriatricians or other specialists, if required.
- 4.57 The Committee heard there are challenges associated with achieving an accurate diagnosis in some population groups, such as people with an intellectual disability, people from CALD backgrounds and Aboriginal and Torres Strait Islander people, where English is a second language. Further, the Committee heard standard cognitive testing is invalid for people with intellectual disabilities.
- 4.58 Alternate tools have been developed which may be more useful for people of CALD or Indigenous backgrounds. However, the Committee was told

---

41 National Disability Services, *Submission 43*, p. 2.

42 Dr Torr, *Submission 73*, pp. 1 and 3; CDAMS, *Submission 39*, p. 8.

43 MDAG, *Submission 48*, p. 9. See also: Dementia Collaborate Research Centres, *Dementia Outcomes Measurement Suite*, <<http://www.dementia-assessment.com.au/>> viewed 7 June 2013.

- there is no 'one size fits all' screening test, and tests need to be adapted to suit a particular community's needs.
- 4.59 Cultural sensitivity and understanding, as well as flexibility in assessment processes, is necessary when undertaking assessments for dementia for people from CALD backgrounds, and Indigenous people for whom English is a second language.
- 4.60 Where necessary, interpreters should be utilised to assist with the screening process. Unfortunately, the Committee heard that finding an appropriate interpreter to assist Indigenous communities is difficult, given the range of languages spoken across different communities. Further, hospital or medical staff members may not be alert to some of the language barriers and the availability of interpreters to assist in the screening processes.
- 4.61 In its submission to the Committee, MDAG referred to the development of the Dementia Outcomes Measurement Suite (DOMS), a project commissioned under the Australian Government's National Dementia Initiative (administered through the Department of Health and Ageing). The DOMS aims to develop a standard suite of instruments to be circulated throughout Australia to encourage clinicians to 'talk the same language', by using the same instruments as much as possible.<sup>44</sup>
- 4.62 The Committee supports this project and encourages the dissemination of standardised best practice guidelines for the assessment and diagnosis of dementia, including separate guidelines for assessment of people from CALD backgrounds.
- 4.63 The Committee also notes the work of the National Aboriginal and Torres Strait Islander Dementia Advisory Group (NATSIDAG) in consulting with Alzheimer's Australia to develop principles to underpin best practice, to improve services and support for Aboriginal and Torres Strait Islander communities. Presumably this includes best practice principles for diagnosis.
- 4.64 It appears from the evidence that the diagnostic needs of people with disabilities, particularly those with intellectual disabilities, have not yet been considered in the development of best practice principles, as a population group with special needs.
- 4.65 The Committee is of the view that the development of best practice guidelines for diagnosis of dementia for people with an intellectual disability should be prioritised.

---

44 Dementia Collaborate Research Centres, *Dementia Outcomes Measurement Suite*, <<http://www.dementia-assessment.com.au/>> viewed 7 June 2013.

### Recommendation 3

- 4.66 **The Australian Government, through the Dementia Outcomes Measurement Suite, develop best practice guidelines for diagnosis of people with intellectual disability.**

### Targeted screening for dementia?

- 4.67 Over the course of the inquiry, there were wide-ranging discussions regarding whether targeted screening for dementia should be undertaken at an age when individuals are most at risk of developing dementia.
- 4.68 Specifically, discussion canvassed whether cognitive screening should form part of health assessments undertaken for people over 75 years of age, which are free to patients through the Medicare Benefits Schedule (MBS).
- 4.69 A health assessment for people aged 75 and over (a '75-plus health assessment') provided under the MBS involves an 'assessment of a patient's health and physical, psychological and social function for the purpose of initiating preventive health care and/or medical interventions as appropriate'.<sup>45</sup> The assessment may be undertaken once every 12 months, with a consultation time of up to one hour, and must include:
- measurement of the patient's blood pressure, pulse rate and rhythm;
  - an assessment of the patient's medication;
  - an assessment of the patient's continence;
  - an assessment of the patient's immunisation status for influenza, tetanus and pneumococcus;
  - an assessment of the patient's physical function, including the patient's activities of daily living, and whether or not the patient has had a fall in the last 3 months;
  - an assessment of the patient's psychological function, including the patient's cognition and mood; and
  - an assessment of the patient's social function, including the availability and adequacy of paid and unpaid help, and

---

45 DoHA, *Medicare Benefits Schedule*, 'Note A29', <<http://www9.health.gov.au/mbs/fullDisplay.cfm?type=note&q=A29&qt=NoteID>> viewed 7 June 2013.

whether the patient is responsible for caring for another person.<sup>46</sup>

4.70 Alzheimer's Australia argued that the MBS be strengthened to emphasise the assessment of cognitive issues, as well as for physical issues.<sup>47</sup>

4.71 The wider use of the MBS items by GPs is discussed further in Chapter 5, in the context of considering the barriers for primary practitioners in making a timely diagnosis.

4.72 Dr Robert Prowse, of ANZSGM, considered that 75 years of age was a sensible point in time to screen people for dementia:

One of the problems with screening ... is that we probably do not want to screen people at 60 or 65, when the incidence is about one per cent in the population. It goes up quite rapidly from there.

Perhaps 75-plus, we thought, would not be a bad time to do a screen, because by then it is sufficiently common that you might be picking up things. Of course, with a screening test you will still pick up all sorts of things that we have already talked about – depression, sleep apnoea – but they in themselves still need treatment. So, if someone has a cognitive problem that is not just due to normal ageing, then that is the time at which making a diagnosis might be helpful.<sup>48</sup>

4.73 Dr Lyndon Bauer, of Health Promotion Central Coast, was of the view that targeted screening of people over 75 would likely lead to an increase in false positive results:

... you will find that a surprisingly high number of patients, if you randomly select them from your practice without them having any sort of underlying problem, will come up positive. There are number of different reasons why this might be: the stress around taking the test, their literacy levels et cetera, and because the tests are not so good. Many of the tests have weaknesses. If we then take that percentage of people – it is a large number; let's say it is 35 per cent but I am only guessing – and put that pressure on

---

46 DoHA, *Medicare Benefits Schedule*, 'Note A29', <<http://www9.health.gov.au/mbs/fullDisplay.cfm?type=note&q=A29&qt=NoteID>> viewed 7 June 2013.

47 Alzheimer's Australia (National Office), *Submission 44*, p. 15. See also: Mr Glenn Rees, Alzheimer's Australia Inc., *Official Committee Hansard*, Canberra, 11 September 2012, p. 1; Ms Kathryn Cunningham, Alzheimer's Australia South Australia, *Official Committee Hansard*, Adelaide, 4 March 2013, p. 18; Alzheimer's Australia (National Office), *Submission 44.1*, p. 2.

48 Dr Robert Prowse, ANZSGM, *Official Committee Hansard*, Sydney, 22 June 2012, p. 22.



them, 'Gee, you've come up positive for dementia,' that can be very damaging.<sup>49</sup>

4.74 Some individuals and organisations advocated for a 'case-finding' approach to diagnosis, triggered when a person presents to a doctor with relevant symptoms, rather than a targeted approach where all individuals were screened once they reached a certain age.

4.75 MDAG explained that while the 'case-finding' approach to diagnosis was widely accepted, targeted screening was also recommended by many:

Targeted screening followed by more detailed assessment for individuals at high risk of dementia is recommended by many, e.g. people over 75 in general practice, older people admitted to hospital. Case-finding is recommended by all, i.e. once concerns or symptoms are voiced, comprehensive assessment is mandatory.<sup>50</sup>

4.76 NSW Health favoured the case-finding approach and did not support targeted screening:

NSW Health does not support population-level universal dementia screening of older individuals as the sensitivity and specificity the screening tools available would lead to many false positives, causing undue distress and unnecessary follow-up assessment costs. Instead, a 'case-finding approach' is recommended where the General Practitioner acts on concerns raised or on symptom presentation.<sup>51</sup>

4.77 An alternative model of targeted screening was to screen people over a certain age when they were admitted to hospital. Associate Professor Yates explained:

Simple screening of the over 65 population in all hospitals (where our estimates put the prevalence at 30%) using validated tools usable by medical, nursing and allied health staff with simple education such as the MMSE, AMTS or miniCOG would rapidly improve awareness of patients at risk.<sup>52</sup>

4.78 Ms Marianne Cummins, from the Australian Association of Gerontology (AAG), told the Committee that in Alice Springs, for example, it would not be appropriate to undertake mandatory screening of people admitted to hospital, as this would likely lead to false diagnosis:

---

49 Dr Bauer, Health Promotion Central Coast, *Official Committee Hansard*, Terrigal, 12 October 2012, p. 31.

50 MDAG, *Submission 48*, p. 1.

51 NSW Health, *Submission 95*, p. 2.

52 Associate Professor Yates, *Submission 13*, p. 1. See also: Dr Leslie Bolitho, RACP, *Official Committee Hansard*, Sydney, 22 June 2012, p. 22.

As a nurse working in the hospital we already have people, as Cate said, that are identified as having dementia and are labelled with dementia because of a whole range of things. They may be delirious and acutely unwell. That is really the common cause. It is the most common cause of people's confusion, and it is on top of their chronic illnesses. It is well-known that if you have a chronic illness and you become acutely unwell then you can become delirious. There are a lot of risk factors. Sometimes it is actually about the hospital not then going down the track of making sure that that acute illness is treated. That would be the most disastrous thing I think because they have a lot of people that that is an issue for.<sup>53</sup>

### Committee comment

- 4.79 Currently, there are unacceptable delays in the average time taken for an individual to receive a diagnosis of dementia. The Committee has considered how the screening of dementia might contribute to these unacceptable delays, and how this might be addressed.
- 4.80 The Committee heard conflicting evidence regarding whether targeted or population-based screening of dementia was an appropriate means of improving capacity to detect dementia early.
- 4.81 Some evidence suggested that cognitive screening should form a more significant part of the annual health assessment that a person over the age of 75 can access through Medicare ('the 75-plus health assessment'). It was argued that targeted screening of people over the age of 75 would help increase the rates of early diagnosis.
- 4.82 The Committee accepts that targeted screening for people at most risk of developing dementia would likely result in higher levels of diagnosis, and in many cases, in earlier diagnosis. This goal is to be commended.
- 4.83 On the other hand, the Committee heard that targeted screening could lead to more false positives, and the costs of administering this screening for patients who were not experiencing symptoms of cognitive decline may outweigh the ultimate benefits of the screening.
- 4.84 The Committee is of the view that cognitive screening should not be included in a 75-plus health assessment as a specific item of assessment. The 75-plus health assessment aims to assess a person's 'physical, psychological and social function for the purpose of initiating preventive

---

53 Ms Marianne Cummins, Australian Association of Gerontology, *Official Committee Hansard*, Alice Springs, 30 January 2013, pp. 29-30.

- health care and/or medical interventions as appropriate'.<sup>54</sup> Emphasising cognitive screening over other important basic health assessments would likely defeat the intended purpose of the assessment.
- 4.85 The Committee notes that the 75-plus health assessment can include an assessment of the patient's psychological function, and appears to allow a General Practitioner to provide a person with a referral for a cognitive screen or specialist assessment, if appropriate.
- 4.86 Rather than extend the 75-plus health assessment to allow for cognitive screening, it may be more appropriate to promote the use of other existing MBS items which allow for cognitive screening, or review the need to create additional MBS items. The use of MBS items is discussed further in Chapter 5.
- 4.87 The Committee supports the promotion of a 'case-finding' approach to diagnosis. This approach supports the timely assessment of an individual who has reported symptoms relevant to dementia to their doctor or other medical practitioner.
- 4.88 This view is in keeping with evidence provided in this inquiry, suggesting that there is no 'one size fits all' approach to screening for dementia. Targeted screening may encourage inaccurate screening which does not recognise a person's background or individual needs.
- 4.89 As discussed earlier in this chapter, a diagnosis of dementia should not result from one screening test alone. A diagnosis should be formed by undertaking a comprehensive assessment based on a GP's clinical judgment, screening test results, information gathered from the patient and/or their families, and an assessment by an appropriately trained specialist, if required.

## Future planning

- 4.90 One of the benefits of early or timely diagnosis of dementia is the ability for a person to plan for their own future, including:
- Planning their financial future;
  - Planning their future care, including advance care directives; and
  - Organising their legal affairs.

---

54 DOHA, *Medicare Benefits Schedule*, 'Note A29', <<http://www9.health.gov.au/mbs/fullDisplay.cfm?type=note&q=A29&qt=NoteID>> viewed 7 June 2013.

- 4.91 Early diagnosis provides a greater opportunity for a person with dementia to engage with important legal issues and arrange legal instruments necessary to give effect to their wishes for the future, while they have the capacity to do so.<sup>55</sup>
- 4.92 Early diagnosis of dementia assists a person to make decisions about their preferences for their care when their condition progresses. As Professor Kichu Nair submitted:
- Advance care planning is important in dementia; often without this patients are subjected to invasive and futile medical interventions. There should be clear-cut instructions regarding this in patients who are admitted to nursing homes.<sup>56</sup>
- 4.93 Planning for the future has been identified as one means of assisting people with dementia to retain their independence. The NSW Department of Health recommended that 'Planning for the future and putting mechanisms in place should be encouraged as a normal practice as we grow older.'<sup>57</sup>
- 4.94 Kate Swaffer stated that diagnosing dementia early allows people to consider their future care needs and resolve financial and legal issues:
- Early diagnosis for people with the symptoms of dementia is essential as they may still have the ability to think logically, even though their powers of reasoning may have started to be impaired. They will still be able to discuss the implications of the illness and how it will affect them and their families now and in the future, and it is the time when decisions regarding future care needs and financial and legal issues must be considered, while the person with dementia is still legally competent.<sup>58</sup>
- 4.95 The Committee heard that a lack of awareness across the community about future planning options prevented people with a diagnosis of dementia from seeking advice early. This lack of awareness extends to some health and legal professionals, meaning that many people do not receive accurate future planning information and advice, if they receive advice at all. Those who have made advance care directives at times do not have their wishes implemented. Further, the legislative steps required to secure financial and legal matters are complex and differ between the states, adding to the difficulty of future planning.

---

55 Law Council of Australia, *Submission 56*, p. 3. See also: DoHA, *Submission 89*, p. 10.

56 Professor Kichu Nair, *Submission 108*.

57 NSW Department of Health, *Submission 95*, p. 11. See also, Financial Services Council Ltd, *Submission 71*, p. 2.

58 Ms Kate Swaffer, *Submission 77*, p. 7.

- 4.96 The barriers which prevent or delay a person planning for their future with dementia, including legal barriers and lack of awareness, are discussed further below.

## Legal barriers

- 4.97 There are a number of legal barriers which prevent people with dementia from organising their legal affairs early in the dementia journey. Primarily, these barriers relate to the complex legislative framework covering issues such as capacity, guardianship, advance care planning and directives, wills and powers of attorney.

- 4.98 Woy Woy Community Aged Care told the Committee that there are a number of processes and documents a person must understand to successfully plan for their future:

It is very complicated and time consuming for the person with dementia and their family/carer to know the difference between Power of Attorney, Enduring Guardianship, ACAT assessment, bonds/accommodation fees as well as Advance Care Plans.<sup>59</sup>

- 4.99 All adults, regardless of disability, are entitled to make their own decisions, unless it is found that they do not have, or have lost, the capacity to make certain decisions.<sup>60</sup>

- 4.100 The Law Council of Australia (the Law Council) considered how early diagnosis provided greater opportunities to consider the implications of a future loss of capacity:

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.<sup>61</sup>

- 4.101 To retain control over their future medical care, living arrangements, finances and guardianship, a person must engage with a number of processes while they have capacity, including:

---

59 Woy Woy Community Aged Care, *Submission 102*, p. 4.

60 Office of the Public Advocate, Victoria, *Guardianship*, <[http://www.publicadvocate.vic.gov.au/file/Guardianship%20290909\[1\].pdf](http://www.publicadvocate.vic.gov.au/file/Guardianship%20290909[1].pdf)> viewed 7 June 2013.

61 Law Council of Australia, *Submission 56*, p. 5.

- The making of valid powers of attorney;
- The making of a valid will; and
- The making of valid advance care directives.

4.102 Where a person is deemed not to have capacity to make certain decisions, and they have not made valid legal documents advising of their decisions, guardianship<sup>62</sup> laws may come into play.

## Capacity

4.103 Capacity generally refers to the cognitive ability required to make a legally valid decision.<sup>63</sup> The onset of dementia can have significant implications on the future capacity of a person to make legally valid decisions relating to important matters such as medical care, financial and legal matters.

4.104 A person's capacity to make decisions about their future care, as well as organise their own legal and financial affairs, is influenced by the timeliness of diagnosis. As the Law Council explained:

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.<sup>64</sup>

4.105 Ms Colleen Pearce, Public Advocate in Victoria, told the Committee that capacity was a vexed issue:

There are different tests of capacity in law for things such as marriage, wills or guardianship, so capacity is really very vexed. For people with dementia, as John said, capacity fluctuates. Can a person remain at home and manage their own purse – the day-to-day? Perhaps they can. Can they enter into a contract to sell their house? Perhaps they cannot. Capacity is not an all-or-nothing; it is very situational. We say it really depends on the decision that needs to be made and people should be able to make as many

---

62 Guardianship is 'the appointment of a person (a 'guardian') to make decisions for an adult with a disability (the 'represented person') when they are unable to do so.' See Office of the Public Advocate, Victoria, *Guardianship*, <[http://www.publicadvocate.vic.gov.au/file/Guardianship%20290909\[1\].pdf](http://www.publicadvocate.vic.gov.au/file/Guardianship%20290909[1].pdf)>, viewed 7 June 2013.

63 Law Council of Australia, *Submission 56*, p. 4. See also: Victorian Law Reform Commission, *Guardianship: Final report 24*, 2012, <[http://www.lawreform.vic.gov.au/sites/default/files/Guardianship\\_FinalReport\\_Full%20t%20ext.pdf](http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20t%20ext.pdf)>, pp. 98-116 viewed 7 June 2013.

64 Law Council of Australia, *Submission 56*, p. 5.

decisions for themselves for as long as possible—but the law is a blunt instrument.<sup>65</sup>

- 4.106 HammondCare considered that a major barrier to people planning their future was in the confusion surrounding the definition of ‘legal capacity’ or competence. HammondCare submitted:

A major impediment to effective planning at the moment is the confusion around legal capacity or competence, which varies from state to state. With the exception of Queensland, there are no legal definitions of capacity in Australia so a number of tests are used to assess capacity. If the definition of capacity was expressed more clearly and consistently, it would assist people with dementia and their families to make critical plans about future legal, financial and care decisions.<sup>66</sup>

- 4.107 The Victorian Law Reform Commission (VLRC) investigated issues of capacity and incapacity in detail, in its 2012 report for the review of the *Guardianship and Administration Act 1986* (Vic). The report noted that different capacity standards apply for different activities, such as entering into contracts, getting married, or making a will. These legal rules have developed over time and without coordination.<sup>67</sup>

- 4.108 The report noted that the Victorian guardianship laws drew a sharp distinction between those people who had capacity, and those people who did not. It did not cater for different levels of cognitive functioning. Accordingly, the VLRC recommended that the way in which guardianship law described and assessed incapacity be clarified, and that the guardianship laws become sufficiently flexible to accommodate different levels of cognitive ability and decision-making needs.<sup>68</sup>

- 4.109 The Committee received evidence advocating for recognition of ‘contextual capacity’, to avoid a person being shut out of all decision-making after being diagnosed with dementia:

Legally recognise ‘contextual capacity’ for decision-making (similar to Europe) to ensure individuals living with a dementia

---

65 Ms Colleen Pearce, Office of the Public Advocate, Victoria, *Official Committee Hansard*, 14 June 2013, p. 37.

66 HammondCare, *Submission 86*, p. 4.

67 Victorian Law Reform Commission, *Guardianship: Final report 24*, 2012, <[http://www.lawreform.vic.gov.au/sites/default/files/Guardianship\\_FinalReport\\_Full%20t%20ext.pdf](http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20t%20ext.pdf)>, pp. 98-116 viewed 7 June 2013.

68 Law Council of Australia, *Submission 56*, p. 4. See also: Victorian Law Reform Commission, *Guardianship: Final report 24*, 2012, <[http://www.lawreform.vic.gov.au/sites/default/files/Guardianship\\_FinalReport\\_Full%20t%20ext.pdf](http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_FinalReport_Full%20t%20ext.pdf)>, pp. 98-116 viewed 7 June 2013.

[diagnosis are] not deemed 'incompetent' for all decisions and choices with each decision being assessed for its appropriateness for an individual living with a dementia to make.<sup>69</sup>

### Committee comment

- 4.110 The Committee strongly supports any means of assisting people with dementia to retain their independence for as long as possible.
- 4.111 One way in which people can maintain their independence is to make decisions regarding their future care, living, legal and financial arrangements while they still have capacity to do so, and record these decisions through valid legal documents such as an enduring power of attorney, a will and advance care directives.
- 4.112 The Committee notes that the law regarding a person's capacity to make certain decisions about their life, including care, financial or legal matters, has developed over time, and in a range of different contexts. While this report considers capacity in the context of people who have dementia, the Committee notes the wider application of capacity in various other areas of the law. This law also varies across each state and territory.
- 4.113 The assumption of capacity is the axis around which future planning must revolve. The Committee therefore supports all efforts to ensure that the recognition of capacity is assumed until proven otherwise, whether by clinical or legal means.
- 4.114 The Committee supports the development of a national standard definition of capacity, as it relates to a person's ability to make decisions about their care, or financial or legal matters. As advocated by the Victorian Law Reform Commission, this definition should acknowledge 'contextual capacity' and support the concept that a person may have capacity for some aspects of decision-making, while perhaps not having capacity for others.

### Recommendation 4

- 4.115 **The Australian Government collaborate with the state and territory governments, through the Standing Council on Law and Justice, to develop uniform definitions and guidelines relating to capacity.**

---

<sup>69</sup> Traynor, Devries, Fares and Pilkington, *Submission 70*, p. 4.



## Complexity of legal processes

- 4.116 The Committee was told that there was unnecessary complexity in some of the legal instruments and processes that would allow a person to successfully plan for their future, including advance care directives and powers of attorney. This complexity also extended to guardianship laws.
- 4.117 State and territory governments are responsible for making the laws governing issues such as guardianship, advance care directives, wills and powers of attorney. The Office of the Public Advocate, Victoria, explained that these laws varied across the different states and territories:
- Unfortunately, laws vary significantly in each State and Territory as to the requirements for creation, execution and registration of enduring instruments and operation of advance care directives. Although there have been discussions in the Standing Committee of Attorneys-General (now the Standing Council on Law and Justice) about uniformity or harmonization of these instruments, such discussions have not resulted in actual reform.<sup>70</sup>
- 4.118 Dr John Chesterman, of the Office of the Public Advocate, Victoria, advised that the guardianship systems in place across the states and territories were comparable, although slightly different. Dr Chesterman considered the benefits of uniformity in guardianship laws and practices:
- It makes sense for guardianship systems to be organised at the state and territory level because service provision and accommodation options for people with cognitive impairments and/or mental ill health are normally provided at the state and territory level. Having said that, there would be many benefits if we had greater interjurisdictional consistency in our guardianship laws and practices.<sup>71</sup>
- 4.119 An advance care directive is based on 'respect for personal autonomy and is intended to ensure that a person's preferences can be honoured during any period of temporary or permanent impaired decision-making capacity, not only at the end of life.'<sup>72</sup>

---

70 Australian Guardianship and Administration Council, *Submission 76*, p. 30.

71 Dr John Chesterman, Office of the Public Advocate, Victoria, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 30.

72 An Advance Care Directive (ACD) is a written advance care plan which is recognised by either common law or through legislation, which has been completed and signed by a competent adult. See The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives*, September 2011, <[http://www.ahmac.gov.au/cms\\_documents/AdvanceCareDirectives2011.pdf](http://www.ahmac.gov.au/cms_documents/AdvanceCareDirectives2011.pdf)>, p. 5 viewed 29 May 2013.

- 4.120 The types of advance care directives available in Australia varied between the states and territories and include the ability to:
- allow directions to be recorded, but not appoint a substitute decision maker;
  - appoint or allow the appointment of a substitute decision maker, but not record directions for treatment; and
  - allow directions to be recorded and the appointment of a substitute decision maker.<sup>73</sup>
- 4.121 Dr Chesterman advised that the laws around enduring powers of attorney were even more complicated:
- Each of Australia's states and territories has its own laws around enduring powers of attorney. They are all slightly different. Some of them require registration; some do not. Some cover the three fields that ours cover in Victoria; some do not.<sup>74</sup>
- 4.122 The Law Council of Australia advised the Committee that there were a number of problems with substitute-decision making laws:
- 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.<sup>75</sup>

### Moves towards uniformity

- 4.123 In 2011 the Productivity Commission published a report titled *Caring for Older Australians*.<sup>76</sup> The Commission found that there were difficulties arising from jurisdictional differences in legislation relating to advance

---

73 The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives*, September 2011, p. 10.

74 Dr John Chesterman, Office of the Public Advocate, Victoria, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 31.

75 Law Council of Australia, *Submission 56*, p. 5.

76 Productivity Commission, *Caring For Older Australians*, Productivity Commission Inquiry Report, Vol. 2. No.53, June 2011.

care directives, powers of attorney and enduring guardianship legislation.<sup>77</sup>

- 4.124 Recognising the need for a standardised national format for advance care directives, the *National Framework for Advance Care Directives* was published by the Australian Health Ministers' Advisory Council (AHMAC) in September 2011. The Framework consists of a national terminology, a code for ethical practice and best practice standards for advance care directives.<sup>78</sup>
- 4.125 Some of the objectives that underpinned the creation of the National Framework are:
- To have mutual recognition of advance care directives across all states and territories;
  - That a person's preferences can be known and respected after the loss of decision-making capacity;
  - That decisions by substitute decision-makers chosen and appointed under advance care directives will be respected and will reflect the preferences of the person;
  - That they be recognised and acted upon by health and aged care professionals, and will be part of routine practice;
  - That clinical care and treatment plans written by health care professionals will be consistent with the person's expressed values and preferred outcomes of care as recorded in their advance care directive.<sup>79</sup>
- 4.126 The Law Council told the Committee that it supports the adoption and implementation of the guidelines and principles outlined in the *National Framework for Advance Care Directives*, as endorsed by AHMAC.<sup>80</sup>
- 4.127 In its report, the Productivity Commission recommended that other 'onerous duplicate or inconsistent regulations' such as powers of attorney or guardianship rules, be identified and removed.<sup>81</sup>
- 4.128 In its report titled *Older people and the law*, the House of Representatives Standing Committee on Legal and Constitutional Affairs recommended:
- Recommendation 26 (paragraph 3.183)

---

77 Productivity Commission, *Caring For Older Australians*, Productivity Commission Inquiry Report, Vol. 2. No.53, June 2011. p. 460.

78 DoHA, *Submission 89*, p. 11.

79 The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives*, September 2011, p.1.

80 Law Council of Australia, *Submission 56*, p. 3.

81 Productivity Commission, *Caring For Older Australians*, Productivity Commission Inquiry Report, Vol. 2. No.53, June 2011. p. 463.

- The Committee notes that the third Key Priority of the National Framework for Action on Dementia 2006-2010 proposes that the jurisdictions refer the issue of legislative barriers regarding Guardianship, advance care planning, advance care directives, wills, and powers of attorney to the Australian Government and to the State and Territory Attorneys-General Departments.
- The Committee recommends that the Australian Government place the third Key Priority of the National Framework for Action on Dementia 2006-2010 on the agenda of the Standing Committee of Attorneys-General.

Recommendation 28 (paragraph 3.200)

- The Committee recommends that the Australian Government encourage the Standing Committee of Attorneys-General to work towards the implementation of nationally consistent legislation on guardianship and administration in all states and territories.<sup>82</sup>

- 4.129 In April 2006, the Australian Health Ministers' Conference endorsed the *National Framework for Action on Dementia 2006-2010* (the Framework).<sup>83</sup> One of the priorities for action identified in the Framework was to refer the legislative barriers regarding guardianship, advance care planning and advance care directives, wills and powers of attorney to the Australian Government, State and Territory Attorneys-General Departments.<sup>84</sup>
- 4.130 The Committee questioned why, given the consensus regarding creating uniform laws, there was not yet uniformity in the laws. The Public Advocate for Victoria outlined some possible reasons:

It is two things. Firstly, political will. Secondly, it is very difficult to get national uniform legislation. The Australian Council on Guardianship and Administration put forward a proposal at one stage to try and harmonise the laws: if we cannot get national laws, can we get harmony in the laws at a state level? But you have got to have the political will to do that and have it high on the agenda. I think the enduring power of attorney laws have been on the attorney-generals committee but that has fallen off the agenda. So it has to be on the agenda and be a priority.<sup>85</sup>

---

82 Dr John Chesterman, Office of the Public Advocate, Victoria, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 31. See also: House of Representatives Standing Committee on Legal and Constitutional Affairs, *Older people and the law*, September 2007, <[http://www.aph.gov.au/Parliamentary\\_Business/Committees/House\\_of\\_Representatives\\_Committees?url=laca/olderpeople/report.htm](http://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=laca/olderpeople/report.htm)> viewed 7 June 2013.

83 The Framework is discussed in more detail in Chapter 2.

84 DoHA, *Submission 89*, pp. 10-11.

85 Ms Colleen Pearce, Office of the Public Advocate, Victoria, *Official Committee Hansard*, 14 June 2013, p. 34.

4.131 Dr Chesterman expanded:

One of the politically contentious aspects of this concerns not the most frequently used enduring power of attorney – which is the financial one – but others regarding medical treatment and the ability of people to appoint others to, for instance, refuse medical treatment. That creates some political consternation among the various jurisdictions, so it is hard to get uniformity on that issue. That is a significant impediment.<sup>86</sup>

### Committee comment

- 4.132 From the evidence before the Committee in this inquiry, the Committee is of the view that there is merit in simplifying the laws relating to guardianship, advance care planning, wills and powers of attorney, so that there is uniformity across the states and territories.
- 4.133 The Committee has heard that creating uniformity and simplicity could make it easier to raise general awareness and educate people about the laws, and what it means for them, or their patients. The issue of awareness regarding future planning is discussed further below.
- 4.134 The Committee supports the steps taken by government thus far, towards creating uniformity in these laws. The Committee notes, for example, the *National Framework for Advance Care Directives* endorsed by AHMAC.
- 4.135 The Committee is of the view that if the creation of uniform legal instruments and legislation will assist people with dementia plan for their future and retain some control over the major decisions in their lives, then this goal should be supported.

## Recommendation 5

- 4.136 **The Australian Government collaborate with the state and territory governments, through the Standing Council on Law and Justice, to develop uniform definitions and guidelines relating to powers of attorney.**

---

86 Dr John Chesterman, Office of the Public Advocate, Victoria, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 34.

## Awareness about future planning

4.137 There is concern within the legal and medical community about what is perceived to be a lack of awareness regarding the significant implications that dementia may have on an individual's ability to plan for their future.<sup>87</sup>

4.138 The Office of the Public Advocate in Victoria outlined a number of statistics which showed the lack of awareness about future planning:

When we add our guardianship clients with dementia to our clients with acquired brain injuries and mental ill health, we find that more than half of our guardianship clients are people who once had capacity to make their own decisions. This has important implications for the promotion of alternatives to guardianship, in particular enduring powers of attorney...

... Most of our clients could have avoided the need for a guardianship order if they themselves had appointed someone to make their key decisions for them.<sup>88</sup>

4.139 Dr Chesterman continued:

... One of the key challenges I imagine for this inquiry will be to ascertain how we might improve the general public's knowledge of and uptake of enduring powers of attorney.<sup>89</sup>

4.140 The Australian Guardianship and Administration Council (AGAC) considered that the appointment of a responsible enduring attorney or enduring guardian following an early diagnosis of dementia could avoid the need for an application to a guardianship tribunal to be made, whereby a statutory authority of 'last resort' such as the Public Advocates/Guardians or the Public Trustees was appointed:

Sadly, many people put off consideration of appointment of an attorney or guardian until well after a diagnosis has been made, because it can be emotionally difficult, may involve the expense of consulting a trustee company or a legal practitioner or is administratively demanding. Often people do not consider it necessary until the stage at which the person with dementia is admitted to a nursing home. At that stage, the person's dementia

---

87 Law Council of Australia, *Submission 56*, p. 3.

88 Dr John Chesterman, Office of the Public Advocate, Victoria, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 30.

89 Dr John Chesterman, Office of the Public Advocate, Victoria, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 31.

may be so advanced that they are incapable of executing a valid instrument.<sup>90</sup>

- 4.141 While discussion about planning for the future may often focus on legal matters or accommodation, the medical profession and allied services and industries also play a critical role in assisting those with an early diagnosis of dementia. As the RACGP stated:

The GP is well placed to inform the patient and family not only about the condition, diagnosis and prognosis but also about the consideration of legal and financial matters, available support, and care options. Early intervention allows for future planning of more complex areas such as financial planning and future care, to simpler issues such as driving capacity and daily activity.<sup>91</sup>

- 4.142 The Australian Government Department of Health and Ageing explained that GPs reported feeling reluctant about providing advice regarding future planning:

General Practitioners report uncertainty as well as reluctance about their role in relation to legal matters arising in dementia care, e.g. enduring power of attorney, advance care plans. This uncertainty is also a cause of frustration and confusion for the person with dementia and their carer.<sup>92</sup>

- 4.143 The NSW Department of Health has advised the Committee that:

...eliciting preferences about future care in the event they can no longer make decisions should be normalised as part of routine health checks. Consumers expect their health professionals to raise Advance Care Planning with them.<sup>93</sup>

- 4.144 The Consumers Health Forum of Australia was advised that awareness within the health sector about advance care directives was at times variable:

Consumers have told CHF that awareness of the option of an advance care plan is dependent on their care location and care provider. In other words, it is dependent on 'luck'...<sup>94</sup>

- 4.145 Mr Tim Tierney, of Tierney Law in Tasmania, submitted that more practical training was needed for lawyers and health professionals on dealing with capacity issues.<sup>95</sup>

---

90 Australian Guardianship and Administration Council (AGAC), *Submission 76*, p. 2.

91 RACGP, *Submission 83*, pp. 6-7.

92 DoHA, *Submission 89*, p. 7.

93 NSW Department of Health, *Submission 95*, p. 13.

94 Consumers Health Forum of Australia, *Submission 31*, p. 3.

- 4.146 Dr Chesterman submitted that creating uniformity in the laws regarding powers of attorney would assist in attempts to educate the public about future planning:

If we had national laws around enduring powers of attorney, we could then engage in a national education program which would encourage people to have the conversation with family and friends, and say, 'In the event that I am not able to make my own decisions, I want such and such to make those decisions for me.'  
By doing that you obviate the need for public guardianship.<sup>96</sup>

- 4.147 The Committee heard that one resource which was effective in helping people understand the definition and implications of capacity was the NSW Capacity Toolkit, developed by the NSW Attorney-General's Department. This toolkit has since been adapted for use in Tasmania.<sup>97</sup>

- 4.148 CDAMS submitted:

Clearer guidelines and education regarding the assessment of capacity are required for the legal profession, health workers and for those that are able to act as witnesses. The NSW Capacity toolkit is a good example of this.<sup>98</sup>

### Committee comment

- 4.149 A major barrier to a person retaining their independence following a diagnosis of dementia is the lack of awareness about available future planning options.
- 4.150 Achieving greater rates of early diagnosis of dementia would be futile if a person is not made aware of the options available to them to achieve greater independence, or provided with the tools necessary to plan for their future care and support.
- 4.151 Accordingly, the Committee takes the view that along with the move towards uniform laws regarding future planning, there is also a need to educate and inform the public, as well as the medical and legal community, about the importance of future planning, and the options available to a person.
- 4.152 As part of this education, the Committee supports the development of a national 'toolkit', such as the one developed by the NSW Attorney-General's Department, which provides guidance on the issue of capacity

---

95 Mr Tim Tierney, *Submission 16*, p. 1.

96 Dr John Chesterman, Office of the Public Advocate, Victoria, *Official Committee Hansard*, Melbourne, 14 June 2012, p. 31.

97 Alzheimer's Australia Tasmania, *Submission 37*, p. 6.

98 CDAMS, *Submission 39*, p. 10.



and its implications. This toolkit could be expanded to include broader information relevant to a person who has received a diagnosis of dementia and their family or carers, including general information on advance care directives, powers of attorney, wills and other processes relevant to their future care or financial and legal arrangements.

- 4.153 The Committee discusses the need for contextualised practice guidelines for GPs to provide people with advice on local pathways, including future planning options, in Chapter 6.

### **Recommendation 6**

- 4.154 **The Australian Government collaborate with the state and territory governments to develop a toolkit or guidelines to assist medical/legal professionals, or a person diagnosed with dementia and their carer understand future planning options.**



