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**Preparing for the impact of  
dementia**

by

**Talina Drabsch**

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# **Preparing for the impact of dementia**

by

**Talina Drabsch**

## **NSW PARLIAMENTARY LIBRARY RESEARCH SERVICE**

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## **EXECUTIVE SUMMARY**

Dementia is increasingly a reality for many Australians. Almost 200,000 Australians are believed to have dementia and many more are involved in caring for a family or friend with dementia. Its social and economic impacts are significant. It is estimated that dementia costs the community \$6.6 billion a year. The prevalence of dementia is growing, largely as a result of people living longer than ever before and as the effects of the ageing of Australia's population start to be felt.

There are many forms of dementia and many illnesses/diseases with which it is associated. Alzheimer's disease is the most common form of dementia and perhaps also the best known. The major forms of dementia are identified in section one (pp 1-6). The symptoms of dementia and the various risk and protective factors are noted.

An overview of the prevalence of dementia in Australia as a whole, and in the states and territories is provided in section two (pp 7-9). This section also examines the projected increase in the number of people with dementia over the next 50 years, and compares its prevalence per age group.

Section three (pp 10-14) discusses the economic and social costs of dementia, including direct and indirect financial costs, as well as non-financial ones. The particular impact on the health and aged care systems is highlighted. Dementia is generally of a disabling rather than a fatal nature, and is a major cause of disability burden in Australia, second only to depression.

As dementia progresses, an individual's capacity to make decisions may be affected. Section four (pp 15-33) details the various ways an individual may prepare for this reality. In relation to health and lifestyle decisions, individuals may utilise guardianship mechanisms, particularly by appointing an enduring guardian. Advance care directives may also be formulated to indicate the individual's preferences regarding future medical treatment. This section also considers enduring powers of attorney, which may be used for financial decision-making once the principal has lost capacity.

The complexities of housing and care needs are discussed in section five (pp 34-54). More than half of those with dementia live in the community and are key users of such services as Home and Community Care, Community Aged Care and Extended Aged Care at Home. A significant proportion of users of residential care have dementia. The possible impact of building and landscape design on the experience of a person in residential care is highlighted. This section also explores the role of carers and the factors that are likely to influence the pool of available carers in the future. A sample of the various programs that exist to support the needs of people with dementia and their carers are discussed.

Section six (pp 55-57) considers the particular issues that may arise in relation to driving. It notes the applicable standards that apply to licensing and discusses the results of a study funded by the Australian Transport Safety Bureau on the impact of early dementia or mild cognitive impairment on the driving competence of older people.

Finally, the problems of elder abuse are examined in section seven (pp 58-67). People with

dementia and their carers have been found to be particularly vulnerable to such abuse. Various preventive strategies are identified, with special consideration given to the issue of mandatory reporting.



## 1 INTRODUCTION

The issues associated with dementia have been receiving greater publicity in recent years, largely as a consequence of growing concern regarding the ageing population of Australia and recognition of the need to prepare for its impact. Dementia refers to a large group of illnesses (including Alzheimer's disease and vascular dementia) and directly affects approximately 200,000 Australians. Many other Australians are involved in the care for, and support of, family and friends with dementia and thus feel its impact, as do those health professionals who come across patients with dementia. The economic and social costs of dementia are more extensive than many realise, with estimates that the cost of dementia is in the vicinity of \$6.6 billion.

This paper considers various issues associated with dementia. It discusses the concept of capacity and the difficulties that may arise in terms of financial, health and lifestyle decisions once capacity is lost. However, it also highlights the available options that allow one's wishes to be respected in the event of a loss of capacity. These options include the use of advance care directives, enduring powers of attorney and enduring guardianships. This paper also considers the various housing options, both in the community and residential care, and highlights the potential impact of building and landscape design on the quality of life experienced by a person with dementia. The issues associated with caring for a person with dementia are significant, and a sample of the numerous programs that have been established to assist in the care of people with dementia and provide support to their carers are identified. The realities of elder abuse are also noted as well as strategies that may be implemented to prevent such situations arising.

As the number of people affected by dementia has grown, so has the profile of agencies established to raise awareness of, and provide support for, those living with dementia and their families and friends. Alzheimer's Australia is the national peak body for the provision of support and advocacy for Australians living with dementia. Alzheimer's Australia NSW was established in 1982 and represents the interests of people affected by dementia in NSW.

### 1.1 How has dementia been defined?

Key stakeholders have variously defined dementia. A sample of these definitions follows.

- World Health Organisation

Dementia is:

a syndrome due to disease in the brain, usually of a chronic or progressive nature, in which there is impairment of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. The cognitive impairments are commonly accompanied, and occasionally preceded by, deterioration in emotional control, social behaviour or

motivation.<sup>1</sup>

- Organisation for Economic Co-operation and Development (OECD)

The OECD adopted the following definition of dementia in its Health Working Paper:

Dementia is an acquired syndrome of decline in memory and other cognitive functions sufficient to affect daily life in an alert patient.<sup>2</sup>

- Commonwealth Department of Health and Ageing

Dementia is:

a syndrome characterised by confusion and behavioural and functional changes in individuals. 'Dementia' is a broad term to describe loss of memory, intellect, social skills and normal emotive reactions.<sup>3</sup>

- Australian Institute of Health and Welfare (AIHW)

Dementia describes a syndrome associated with a range of diseases which are characterised by the progressive impairment of brain functions, including language, memory, perception, personality and cognitive skills.<sup>4</sup>

- Alzheimer's Australia

Dementia is the term used to describe the symptoms of a large group of illnesses, which cause a progressive decline in a person's mental functioning. It is a broad term, which describes a loss of memory, intellect, rationality, social skills and normal emotional reactions.<sup>5</sup>

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<sup>1</sup> NSW Department of Ageing, Disability and Home Care and NSW Health, *Future Directions for Dementia Care and Support in NSW 2001-2006*, 2002, p 6.

<sup>2</sup> Moise P et al, *Dementia Care in 9 OECD Countries: A Comparative Analysis*, OECD Health Working Papers No 13, Organisation for Economic Co-operation and Development, July 2004, p 13.

<sup>3</sup> Commonwealth, Department of Health and Ageing, *The Carer Experience*, 2002, p 2.

<sup>4</sup> Australian Institute of Health and Welfare, *The impact of dementia on the health and aged care systems*, June 2004, p 2.

<sup>5</sup> Alzheimer's Australia, *Dementia Facts at a Glance*, March 2005. This definition was also used by Pfizer Australia in 'Dementia', *Pfizer Australia Health Report*, Issue 6, 2004, p 2: [www.alzheimers.org.au](http://www.alzheimers.org.au) Accessed 24/1/06.

- Access Economics

Dementia is a disabling organic brain syndrome characterised by progression from mild, through moderate, to severe illness, with death after an average of eight years.<sup>6</sup>

## 1.2 What are the various forms of dementia?

There are various forms of dementia. Some of the most common forms or diseases associated with dementia are:<sup>7</sup>

- Alzheimer's disease (50% to 70% of all cases)

A disease that affects the brain resulting in impaired memory, thinking and behaviour.<sup>8</sup>

- Vascular dementia

Damage develops as a result of a narrowing of the arteries supplying the brain, usually following a stroke.

- Frontal lobe dementia and Pick's disease

Damage starts in the front part of the brain. Personality and behavioural symptoms are the first to appear.

- Dementia with Lewy bodies

Abnormal brain cells form in all parts of the brain.

- Parkinson's disease

The disease involves the loss of dopamine (a neurotransmitter) in the brain. Whilst dementia is more common in people with Parkinson's, not all develop it.

- Alcohol and drug-related dementia

Brain function deterioration is caused by excessive alcohol consumption.

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<sup>6</sup> Access Economics, *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*, Alzheimer's Australia, March 2003, p 39.

<sup>7</sup> Pfizer Australia, above n 5, p 2; AIHW, above n 4, pp 2-3. The description of the various types of dementia is based on information in the AIHW paper.

<sup>8</sup> Alzheimer's Australia, 'FAQ' [www.alzheimers.org.au](http://www.alzheimers.org.au) Accessed 13/3/06.

- Huntington's disease

An inherited disorder of the central nervous system in which cell death occurs, and is usually accompanied by dementia.

- Creutzfeldt-Jakob disease

Nerve cells swell, increase in size and number, and are lost, producing a spongy change throughout the brain.

Alzheimer's disease and vascular dementia are the most common causes of dementia, followed by dementia with Lewy bodies and frontal lobe dementia.

### 1.3 What are some of the symptoms?

There are various symptoms of dementia including:<sup>9</sup>

- cognitive impairment (memory – particularly in relation to recent events, speech, understanding, carrying out physical tasks);<sup>10</sup>
- psychiatric and behavioural features (depression, delusions, hallucinations, apathy, wandering, confusion, getting lost, agitation, repetition); and
- dysfunction in activities of daily living (shopping, driving, handling money, dressing, eating).

Dementia can be difficult to diagnose. In 1998, about 50% of GPs were found to have the ability to recognise dementia in its mild form, and about 70% could recognise moderate dementia.<sup>11</sup> Some GPs find it difficult to distinguish between depression and mild dementia in older people. One of the difficulties associated with the detection of dementia is that it cannot be definitively diagnosed until after death and the completion of a post-mortem analysis.<sup>12</sup>

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<sup>9</sup> Parnell D, 'Dementia: a major health problem for Australia', *Journal of the Home Economics Institute of Australia*, 12(2) 2005, p 16; AIHW, above n 4, p 2; Access Economics, above n 6, p 7.

<sup>10</sup> Studies have found that people who speak more than one language generally lose the most recently acquired language first: Access Economics, above n 6, p 22. This has implications for the care of older Australians with dementia for whom English is their second language.

<sup>11</sup> Access Economics, above n 6, p 19.

<sup>12</sup> AIHW, above n 4, p 3.

## 1.4 Risk factors and protective factors

There are currently no known cures or preventions for dementia. According to Access Economics, the attempts to prevent dementia currently focus on: postponing the onset of symptoms; increasing health span; and preventing the annual number of institutionalisations.<sup>13</sup> There are a number of existing medications that can reduce some of the symptoms of dementia. However, many people are unaware of their availability.<sup>14</sup>

Some factors thought to increase the risk, and alternatively, to protect against the risk of developing dementia have been identified. Some of the risk factors include:<sup>15</sup>

- age;
- family history;
- cardiovascular risk factors; and
- stroke-related causes.

There are also various factors thought to protect against the risk of developing dementia. These include:<sup>16</sup>

- leisure/social activities;
- physical activity;
- ongoing intellectual stimulation;<sup>17</sup>
- higher education;

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<sup>13</sup> Access Economics, above n 6, p 39.

<sup>14</sup> Pfizer Australia, above n 5, p 5.

<sup>15</sup> Parnell, above n 9, p 16.

<sup>16</sup> Woodward M, *Dementia: Can it be prevented?*, Alzheimer's Australia, Position Paper 6, August 2005, p 2; Pfizer Australia, above n 5, p 7.

<sup>17</sup> One of the latest crazes in Japan is 'Brain Training for Adults' a package of computer games developed by Nintendo and marketed towards the over 45s. It is claimed that the games improve mental agility and slow the onset of dementia and Alzheimer's disease: 'Video games for the elderly: an answer to dementia or a marketing tool?', *The Guardian*, 7/3/06 [www.guardian.co.uk](http://www.guardian.co.uk). There is also an argument that people with more intellectually stimulating lives, of greater intelligence and education, and with high-status occupations may be partly protected from the mental decline that comes from age: Melton L, 'Use it don't lose it', *New Scientist*, 188(250) December 2005, pp 32-35. This is thought to be due to 'cognitive reserve': higher reserve allows greater damage to be sustained without a person exhibiting signs of mental decline. However, this argument remains controversial.

- moderate alcohol intake;
- anti-inflammatory drugs;
- cholesterol lowering drugs;
- controlling high blood pressure;
- a balanced diet; and
- smoking cessation.

A poll conducted by Pfizer Australia found that more than one-quarter of those surveyed believed that no action could be taken to reduce the risk of developing dementia.<sup>18</sup> This would indicate scope for further education.

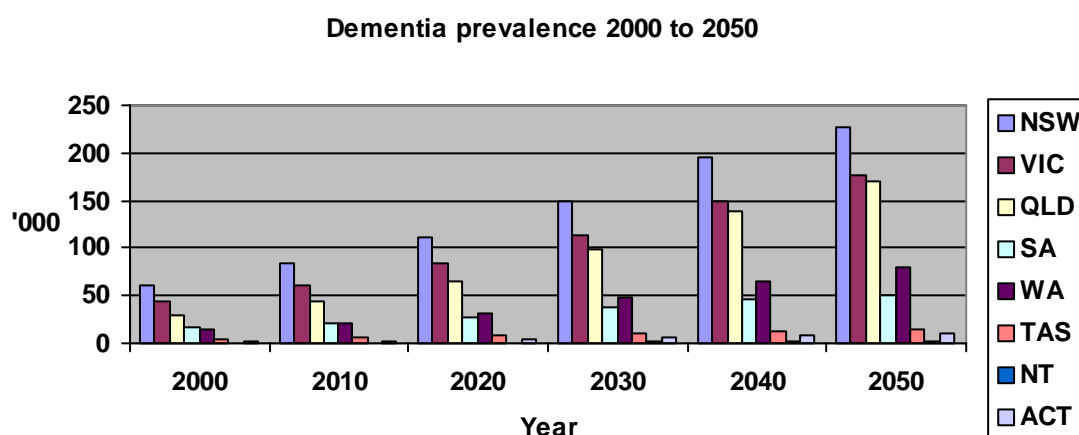
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<sup>18</sup> Pfizer Australia, above n 5, p 5.

## 2 STATISTICAL OVERVIEW

In 2005, there were approximately 200,000 Australians with dementia.<sup>19</sup> Concerns have been raised about the increasing prevalence of dementia in Australian society, sometimes referred to as the ‘dementia epidemic’. Whilst the Australian population will increase by 40% in the next 40 years, the prevalence of dementia will increase by more than 300%.<sup>20</sup> It has been estimated that about 730,000 people will have dementia by 2050 unless there is a medical breakthrough.<sup>21</sup> This is partly due to the ageing population, as the risk of developing dementia increases with age. The prevalence of dementia doubles about every five years from the age of 65 and approximately half of those with dementia are aged 85 or older.<sup>22</sup> However, it should be stressed that dementia is not a natural part of ageing.<sup>23</sup>

The following chart indicates the significance of the predicted increase in the number of people in Australia with dementia over the next 50 years. It reveals the disparity in the experience of the states and territories and highlights that most people with dementia live in NSW, Victoria and Queensland, with the dementia population in each of these states increasing substantially over the next 50 years.



Source: Access Economics, *Dementia Estimates and Projections, Australian States and Territories*, February 2005, p 9.

There were a little over 18,000 new cases of dementia in NSW in 2005, and about 52,000 nationwide.<sup>24</sup> The following graph pictures the increase in the number of people with

<sup>19</sup> Alzheimer’s Australia, above n 5.

<sup>20</sup> Parnell, above n 9, p 16.

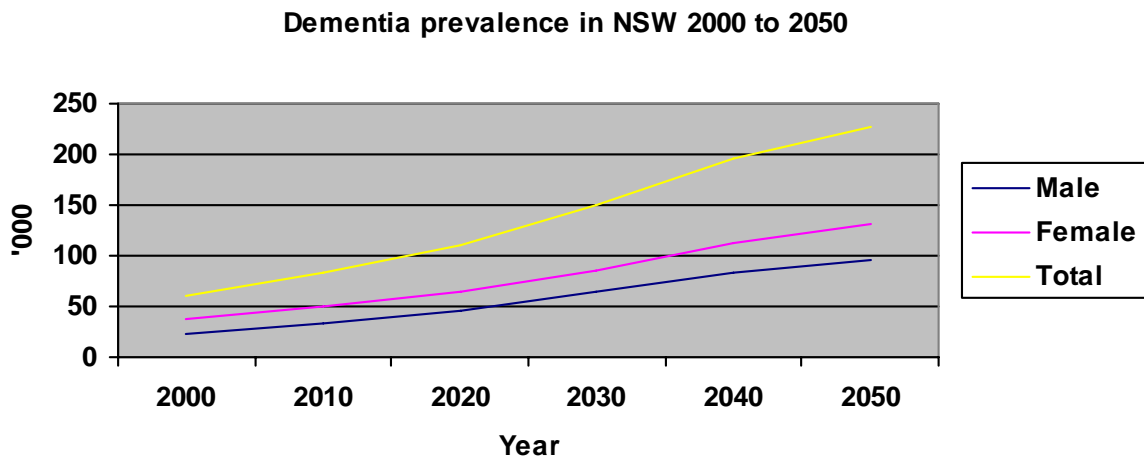
<sup>21</sup> Alzheimer’s Australia, above n 5.

<sup>22</sup> Parnell, above n 9, p 17; Australian Institute of Health and Welfare, above n 4, p 1.

<sup>23</sup> Alzheimer’s Australia, above n 5.

<sup>24</sup> Access Economics, *Dementia Estimates and Projections, NSW and its regions*, June 2005, p 28; Access Economics, *Dementia Estimates and Projections: Australian States and*

dementia in NSW between 2000 and 2050. Whilst there were approximately 60,000 people with dementia in NSW in 2000, the number will rise to almost four times that amount, reaching about 225,000 in 2050.



Source: Access Economics, *Dementia Estimates and Projections, NSW and its regions*, June 2005, p 7.

The prevalence of dementia in a particular age group throughout the world doubles every five years from 1% at 60, 2% at 65, 4% at 70, 8% at 75, 16% at 80, to 32% at 85.<sup>25</sup> The prevalence of dementia in Australia is about 1.5% of people between the ages of 65 and 74, 6.3% of those between 75 and 84, and 30.2% of those aged 85 and over.<sup>26</sup> The following table compares the number of people with dementia by age group and sex. It reveals that the largest proportion of people with dementia is over the age of 85. It also indicates that whilst there are more men with dementia in the younger age groups, the situation reverses from the age of 75 when there are more women than men with dementia. It should be noted that the estimates in the table are lower than others calculated by a different method, as the survey on which it is based relied on the self-reporting of people or their carers, a factor which is thought to lead to the under-reporting of dementia.

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*Territories*, February 2005, p 18.

<sup>25</sup> Access Economics, above n 6, p 31.

<sup>26</sup> *Ibid*, p 31.



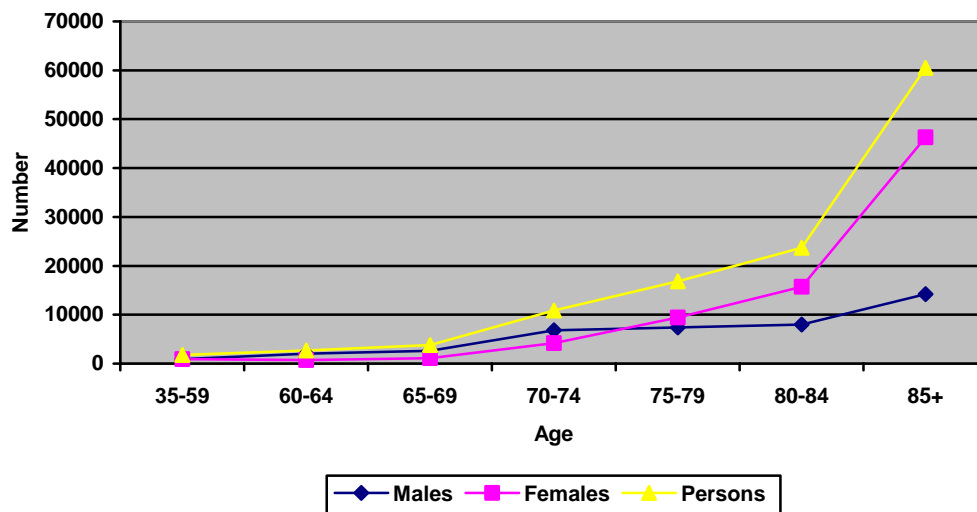
**Prevalence of dementia in Australia estimated using survey-based age-sex specific rates, by age and sex, 30 June 2002**

Age	Males	Females	Persons
35-59	900	900	1 800
60-64	2 000	700	2 700
65-69	2 600	1 100	3 800
70-74	6 800	4 200	10 900
75-79	7 400	9 400	16 800
80-84	8 000	15 700	23 700
85+	14 200	46 300	60 500
<b>Total</b>	<b>41 900</b>	<b>78 300</b>	<b>120 200</b>

Source: Australian Institute of Health and Welfare, *The impact of dementia on the health and aged care system*, June 2004, p 11.

This same information is presented in the following graph. It dramatically illustrates the significant increase in the prevalence of dementia from the age of 85 onwards, especially for women.

**Prevalence of dementia by age and sex in 2002**



A particular issue is the experience of people with younger onset dementia, that is, those under the age of 65. There were 6,600 people under the age of 65 with dementia in 2002.<sup>27</sup> Access Economics has highlighted that people with younger onset dementia: are more likely to be working; have children at home; have financial commitments; have a form of dementia that may be inherited; and experience difficulty in terms of diagnosis and care.<sup>28</sup> Accordingly, the situation for those with younger onset dementia and their families, friends and work colleagues is particularly complex.

<sup>27</sup> Ibid, p 41.

<sup>28</sup> Ibid, p 7.

### 3 ECONOMIC AND SOCIAL COSTS OF DEMENTIA

The economic and social costs of dementia are significant. Access Economics believes that the costs associated with dementia fall into three categories:<sup>29</sup>

- i. Direct financial costs to the Australian health system.
- ii. Indirect financial costs primarily borne by those with dementia and their carers.
- iii. Non-financial costs in the form of pain, suffering and premature death.

According to Access Economics, dementia costs \$6.6 billion (\$5.6 billion in real economic costs and \$1 billion in transfer costs).<sup>30</sup> This equates to more than \$40,000 per annum per person with dementia.<sup>31</sup> These costs include real indirect costs of \$1.7 billion in carer costs; \$364 million in terms of the lost earnings and mortality burden of patients; and \$120 million in the cost of aids and home modifications. People with dementia generally have a lower than average income, with 70% in the lowest two income quintiles.<sup>32</sup> Only 2.3% of people with dementia aged 65 and over are employed (compared to 8.5% of all Australians aged 65 and over).<sup>33</sup>

In relation to transfer costs, \$592 million is attributed to tax foregone by people with dementia, their families and carers; \$324 million is paid to carers; and additional welfare payments constitute \$52 million. Almost one million Australians are currently involved in caring for a family member or friend with dementia.<sup>34</sup> In 2002, the value of informal care provided to people with dementia was more than \$1.7 billion, of which 80% was provided by family members without compensation.<sup>35</sup> It is projected that the cost of dementia will equate to more than 3% of GDP by the mid-twenty first century (compared to the current almost 1%).<sup>36</sup>

Over 5,000 Australians died from dementia in 2002.<sup>37</sup> Dementia is increasingly a cause of death in Australia. In 2000, dementia and related disorders was the fourth leading cause of death for females, ahead of such causes as breast cancer and lung cancer. The rate of deaths

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<sup>29</sup> Ibid, p 42.

<sup>30</sup> Ibid, p iv.

<sup>31</sup> Ibid, p 49.

<sup>32</sup> Ibid, p 33.

<sup>33</sup> Ibid, p 34.

<sup>34</sup> Alzheimer's Australia, above n 5.

<sup>35</sup> Access Economics, above n 6, p 47.

<sup>36</sup> Ibid, p 49.

<sup>37</sup> Ibid, p 50.

due to Alzheimer's disease has risen significantly, from 0.8 deaths per 100,000 males in 1980 to 6.6 in 2000. The increase for women was even greater from 0.4 deaths per 100,000 females in 1980 to 9.2 in 2000.<sup>38</sup>

The Australian Bureau of Statistics has been coding multiple causes of death since 1997.<sup>39</sup> In terms of dementia as an *underlying* cause of death (a disease or injury which initiated the train of morbid events leading directly to death, or the circumstances of the accident or violence which produced the fatal injury), the total number of deaths attributed to dementia has increased from 3,294 in 1997 to 3,740 in 2001.<sup>40</sup> Twice as many women as men died in circumstances in which dementia was the main cause of death, and death rates due to dementia were highest amongst those aged 95 and over. In terms of dementia as a *contributing* cause of death (all causes and conditions reported on a death certificate, one of which is the underlying cause of death), the number of deaths to which dementia contributed varied from 9,007 in 2000 to a peak of 11,072 in 1999.<sup>41</sup>

Whilst certain types of dementia can shorten life expectancy, death is more likely to be the result of co-morbidity.<sup>42</sup> Dementia has a much greater impact on the number of healthy years of life lost than on years lost to premature mortality.<sup>43</sup> This is because dementia is generally of a disabling as opposed to fatal nature. In 1996, dementia was responsible for 10% of the years of healthy life lost by men and 17% of those lost by women.<sup>44</sup>

Dementia is a major cause of disability burden in Australia, second only to depression.<sup>45</sup> It is thought that it will become the largest cause by 2016. However, when the burden of disease due to disability is limited to people of an older age, dementia is the greatest contributor.<sup>46</sup> Almost 99% of people with dementia are disabled (the proportion of the general community is less than 20%).<sup>47</sup> The burden of disease resulting from disability represents the greatest cost of dementia.<sup>48</sup>

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<sup>38</sup> Australian Institute of Health and Welfare, *Mortality over the twentieth century in Australia: Trends and patterns in major causes of death*, Australian Institute of Health and Welfare, Canberra, 2006, pp 40 and 44.

<sup>39</sup> AIHW, above n 4, p 59.

<sup>40</sup> Ibid, p 60.

<sup>41</sup> Ibid, p 63.

<sup>42</sup> Ibid, p 1.

<sup>43</sup> Ibid, p 66.

<sup>44</sup> Ibid, p 66.

<sup>45</sup> Alzheimer's Australia, above n 5.

<sup>46</sup> AIHW, above n 4, p 1.

<sup>47</sup> Access Economics, above n 6, p 33.

<sup>48</sup> Ibid, p 54.

More than \$2.6 billion is currently spent by the Australian Government on providing care for people with dementia in Australia (\$2.1 billion is spent on funding residential care).<sup>49</sup> In addition, the various state and territory governments also spend money on care for people with dementia. The following table sets out the cost of dementia in the health and aged care systems in 2000-01:

**Direct health and aged care system expenditure for dementia by government and individuals, by sector, 2000-01**

Sector	\$ million	Per cent
<b>Residential aged care (high and low care needs)</b>		
Government	1756	69.5
Individuals	360	14.2
Total	2116	83.7
<b>Community care programs</b>		
Aged Care Assessment Program	8	0.3
Home and Community Care	50	2.0
Community Aged Care Package	43	1.7
Extended Aged Care at Home	3	0.1
Total	104	4.1
<b>Health, other than high care in residential aged care*</b>		
Hospital	160	6.3
Pharmaceuticals	27	1.1
Other	120	4.7
Total	307	12.1
Total	2527	100.0

\* Includes expenditure by government and individuals.

Source: Australian Institute of Health and Welfare, *The impact of dementia on the health and aged care systems*, June 2004, p 75.

### 3.1 Health system

People with dementia are likely to use medical services more often, have longer hospital stays, and greater pharmaceutical costs.<sup>50</sup> In 2000-01, 86% of the cost of dementia to the health system could be attributed to nursing homes (\$1,902 million out of a total of \$2,209 million).<sup>51</sup> Hospitals were another major cost at 7%. The following table compares the amounts spent on different aspects of the health system as a result of dementia.

<sup>49</sup> Commonwealth Department of Health and Ageing, *National Framework for Action on Dementia: 2005 Consultation Paper*, p 7. A copy of the paper is available from [www.health.gov.au](http://www.health.gov.au)

<sup>50</sup> Access Economics, above n 6, p 35.

<sup>51</sup> AIHW, above n 4, p 69.

**Direct health system expenditure for dementia by government and individuals, by health sector, 1993-94 and 2000-01 (\$ million) (2000-01 prices)**

	Hospital	Pharmaceuticals	Aged care homes	Other total	All sectors
<b>1993-94</b>					
\$ million	132	2	647	32	814
Per cent	16.3	0.3	79.5	3.9	100.0
<b>2000-01</b>					
\$ million	160	27	1902	120	2209
Per cent	7.3	1.2	86.1	5.4	100.0
7 year increase (%)	21	995	194	275	171

Source: Australian Institute of Health and Welfare, *The impact of dementia on the health and aged care systems*, June 2004, p 70.

The impact of dementia on the health system is not a phenomenon limited to Australia. According to Access Economics:

The dementia epidemic is worldwide. As demographic ageing progresses, we witness another epidemiological transition. The management of neurodegenerative disease is the major challenge of health care systems all around the globe.<sup>52</sup>

### **3.2 Aged care system**

#### **3.2.1 Community care**

The primary diagnosis of about 20% of clients of Aged Care Assessment Teams (ACATs) is dementia.<sup>53</sup> ACATs are funded by the Commonwealth, state and territory governments and provide older people and their carers with information on suitable care options for when they are no longer able to manage at home without help.<sup>54</sup> ACATs may arrange access or referral to relevant residential or community care services. In some cases, an ACAT assessment may be required before a person is able to access particular care options such as Extended Aged Care at Home packages or residential aged care.

The Australian Institute of Health and Welfare has estimated that 7% of people aged 65 plus and living in the community with a severe/profound core activity restriction have dementia.<sup>55</sup> It accordingly calculated the cost of dementia to the Home and Community Care program in 2000-01 as \$50 million in government funding. It also estimated that 18% of recipients of Community Aged Care Packages had dementia and received 22% of the

<sup>52</sup> Access Economics, above n 6, p 41.

<sup>53</sup> AIHW, above n 4, p 71.

<sup>54</sup> Information on ACATs is available from Commonwealth Department of Health and Ageing, 'Aged Care Assessment Teams', [www.health.gov.au](http://www.health.gov.au)

<sup>55</sup> AIHW, above n 4, p 71.

total hours of service provided.<sup>56</sup> This cost the government \$43 million. 32% of recipients of Extended Aged Care at Home had dementia and they also received 32% of the total hours of service provided.<sup>57</sup> The cost to the government of the provision of this service to people with dementia was \$3 million.

### 3.2.2 Residential aged care

Half of those with moderate to severe dementia live in the community and half live in residential facilities.<sup>58</sup> Dementia is frequently one of the main reasons for entry into residential care.<sup>59</sup> The main long-term health condition of about 30% of residents of aged care homes in 1998 was dementia.<sup>60</sup>

Dementia is the greatest contributor to the cost of care in nursing homes.<sup>61</sup> The Australian Institute of Health and Welfare (AIHW) has estimated that residential care subsidies from the Australian Government for permanent residents with dementia as the main disabling condition totalled almost \$1.6 billion in 2000-01.<sup>62</sup> Funding also comes from other sources including state and territory governments, and payments by residents. The AIHW estimated that the cost of dementia to users of residential aged care in 2000-01 was approximately \$360 million.<sup>63</sup> The cost of dementia has significantly increased from 19% of nursing home costs in 1993-94 to 41% of the cost of residential aged care in 2000-01.<sup>64</sup> Whilst the actual magnitude of the change is uncertain, the AIHW has concluded that the increase was certainly substantial.

The Government essentially saves almost \$31,000 per entry for every year that residential care is delayed.<sup>65</sup> However, there are numerous costs associated with dementia irrespective of where one lives. When entry into residential care is delayed, the location of the economic burden may shift, particularly onto families and friends.

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<sup>56</sup> Ibid, p 72.

<sup>57</sup> Ibid, p 72.

<sup>58</sup> Alzheimer's Australia, above n 5.

<sup>59</sup> Ibid.

<sup>60</sup> AIHW, above n 4, p 72.

<sup>61</sup> Ibid, p 1.

<sup>62</sup> Ibid, p 73.

<sup>63</sup> Ibid, p 74.

<sup>64</sup> Ibid, p 75.

<sup>65</sup> Access Economics, above n 6, p vii.

## 4 DECISION-MAKING

This section examines the potential complications facing a person with dementia and those around them in relation to decisions regarding finance, health or lifestyle. It considers the concept of capacity and how it may be affected by dementia. Some of the options available to ensure one's wishes are complied with should capacity be lost are addressed including enduring powers of attorney, enduring guardianships and advance care directives.

### 4.1 Concept of capacity

The concept of capacity is often discussed in relation to the testamentary capacity of a person. The NSW Law Reform Commission published its report *Wills for persons lacking will-making capacity* in 1992. It noted that a testator must be of sound mind, memory and understanding when making a will. The report referred to the words of Cockburn CJ in *Banks v Goodfellow* in relation to the degree of capability required for making a will:

It is essential to the exercise of [testamentary] power that a testator shall understand the nature of the act and its effects; shall understand the extent of the property of which he is disposing; shall be able to comprehend and appreciate the claims to which he ought to give effect; and, with a view to the latter object, that no disorder of the mind shall poison his affection, pervert his sense of right, or prevent the exercise of his natural faculties – that no insane delusion shall influence his will in disposing of his property and bring about a disposal of it which, if the mind had been sound, would not have been made.<sup>66</sup>

It is important that a person has an up-to-date will prior to a loss of capacity. This will help ensure that his or her property is distributed as desired following death.

The concept of capacity is also relevant to other decisions such as those made in relation to finances and health. For example, a person must be able to understand the nature and effect of a document prior to signing it to be said to have the legal capacity to appoint an enduring guardian.<sup>67</sup> Alzheimer's Australia describes legal capacity as the ability of a person to make decisions that the legal system will uphold.<sup>68</sup> This means that the person can:

- i. understand the information being given;
- ii. make a decision on the basis of the information given after having weighed and fully appreciated the consequences of that decision; and
- iii. communicate that decision to another person.

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<sup>66</sup> NSW Law Reform Commission, *Wills for Persons Lacking Will-making Capacity*, Report 68, February 1992, p 3.

<sup>67</sup> Office of the Public Guardian, *Enduring Guardianship in New South Wales: your way to plan ahead*, Revised June 2005, p 4.

<sup>68</sup> Alzheimer's Australia, *Legal Planning and Dementia*, Position Paper 5, April 2005, p 6.

According to the guidelines issued by NSW Health in relation to end-of-life care and decision-making, a person has the capacity to make decisions if they have the ability to comprehend, retain and consider relevant information and make a choice.<sup>69</sup> A person is presumed to be of sound mind and to be capable of making decisions, unless the contrary is indicated.<sup>70</sup>

The concept of capacity is not absolute. A person may be able to make decisions about his or her care yet may not retain the capacity to make financial decisions.<sup>71</sup> A person, provided they still have capacity, may accept or refuse treatment that would sustain his or her life.<sup>72</sup> It does not matter that the consequences of that decision may be serious. Health professionals, in terms of treatment options, play an advisory role – the decision-making authority of a capable patient is not shared with health professionals.<sup>73</sup>

However, the situation is more complex when a person does not have capacity, whether temporarily or permanently. Experts in the area say there is much value in a person planning for the future to ensure their wishes are respected in the event that capacity is lost. An anticipatory statement can be made whilst capable, or another person who has the ability to act as a substitute decision-maker can be informed of his or her wishes.<sup>74</sup>

An enduring power of attorney can be used to make financial decisions and an enduring guardian can be appointed to make medical or lifestyle decisions on behalf of another. Other options include making a will and the use of an advance care directive (also known as a 'living will'). Despite the availability of these options, many people do not consider the implications of a loss of capacity until it is too late, that is, many only confront this reality in the event that a diagnosis is made and capacity may already be affected.<sup>75</sup> Therefore, the earlier dementia is diagnosed the greater the chance an individual has to plan for the loss of capacity.<sup>76</sup>

The Office of the Public Guardian subscribes to the principle that the freedoms of decision

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<sup>69</sup> NSW Health, *Guidelines for end-of-life care and decision-making*, NSW Department of Health, 2005, p 4.

<sup>70</sup> Alzheimer's Australia, above n 68, p 6.

<sup>71</sup> Benevolent Society of NSW and the Centre for Education and Research on Ageing, *Taking Charge: Making Decisions for Later Life*, NSW Committee on Ageing, December 1999, p 37.

<sup>72</sup> NSW Health, above n 69, p 4.

<sup>73</sup> *Ibid*, p 4.

<sup>74</sup> Squires B and Barr F, 'The development of advance care directives in New South Wales', *Australasian Journal on Ageing*, vol 24 Supplement, June 2005, S30-S35, p S31.

<sup>75</sup> *Ibid*.

<sup>76</sup> NSW DADHC and NSW Health, above n 1, p 31.



and action exercised by a person with a disability should be restricted as little as possible.<sup>77</sup> It therefore encourages the use of enduring guardianship and advance care directives as opposed to a guardianship order, and ‘continues to promote them as the most effective way for people to decide for themselves who should assist them and what decisions should be made on their behalf should they lose capacity’.<sup>78</sup>

## 4.2 Decisions about health and lifestyle

NSW Health has identified four means by which a person in NSW can plan his or her end-of-life care:<sup>79</sup>

1. Developing an advance care plan in conjunction with their healthcare professionals while being treated in a care setting.
2. Discussing their preferences for life-sustaining treatment with their family before they are acutely ill.
3. Formally appointing and informing an enduring guardian.
4. Writing an advance care directive.

This section considers the options of guardianship, including the appointment of an enduring guardian, and preparation of an advance care directive.

### 4.2.1 *Gardner: Re BWV*

Some of the difficulties that may arise in the event that a person loses capacity are illustrated in the decision of the Supreme Court of Victoria in *Gardner: Re BWV* [2003] VSC 173. Ms BWV was a 68 year old woman believed to suffer from a form of dementia known as Pick’s disease. She was not conscious and had not experienced any cortical activity in the three years prior to the decision. A PEG (percutaneous endoscopic gastrostomy) enabled her to receive fluid and nutrition as well as medication. She required full nursing care, was doubly incontinent, received regular pressure care, and was moved into the shower by a hoist. There was no prospect of either recovery or improvement of her condition.

The Public Advocate was appointed as her guardian in February 2003 with the power to make decisions regarding medical treatment. Three medical witnesses considered the provision of nutrition and hydration futile. The Public Advocate sought a declaration that the provision of nutrition and hydration via the PEG constituted medical treatment as defined in the *Medical Treatment Act 1988* (Vic) and that refusal of further nutrition and hydration constituted refusal of medical treatment as opposed to palliative care. This

<sup>77</sup> Office of the Public Guardian, *Summary of Activities 2004/05*, p 3.

<sup>78</sup> Ibid.

<sup>79</sup> NSW Health, above n 69, p 3.

distinction was significant as a guardian could refuse medical treatment but not palliative care. The Public Advocate could refuse *medical* treatment if it would cause unreasonable distress to BWV or if there were reasonable grounds for believing that should BWV be competent and able to seriously consider her health and wellbeing she would consider the medical treatment to be unwarranted. Following consultation with the husband and family of BWV, the Public Advocate believed it was contrary to the wishes of BWV to continue to receive nutrition and hydration through the PEG.

The Court considered the key issues of the case to be:

- what is the meaning of the words used in the definitions of medical treatment and palliative care in the Act?
- whether, having regard to the meaning of the defined terms and the facts, it is appropriate to make the declaration sought by the Public Advocate or decline to make such declarations, either absolutely or because it would be better for the Court to exercise its powers within the *parens patriae* jurisdiction of the Court.

Morris J concluded that artificial nutrition and hydration is medical treatment within the meaning of the *Medical Treatment Act* and not palliative care. The declarations sought by the Public Advocate were subsequently made.

According to Julian Gardner (the Public Advocate in *BWV*):

The decision is important for people who, while competent, make known their views and wishes about medical treatment including treatment that may be proposed after they have become disabled. It does not affect those who have never been able to express their wishes or who, although once able, did not do so. It should also give greater certainty to medical practitioners and eliminate inconsistencies in practice.<sup>80</sup>

#### **4.2.2 Guardianship**

Some decisions can be made without a guardian. This is known as informal decision-making and may be sufficient when the subject does not object to the decisions being made, and it is believed that the decisions are in the best interests of the subject.<sup>81</sup> There is a hierarchy of persons who could be considered the person responsible for one who is incapable of consenting to treatment.<sup>82</sup> The hierarchy is as follows:

1. A person who has been appointed as a guardian or enduring guardian with a medical and dental consent function.

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<sup>80</sup> Gardner J, 'Withdrawing medical treatment in Victoria', *Elder Law Review*, 3, 2004.

<sup>81</sup> Office of the Public Guardian, above n 67, p 29.

<sup>82</sup> *Ibid*, p 22.

2. A spouse or de facto spouse who has a close and continuing relationship with the person. This includes same-sex partners.
3. The carer or person who arranges care on a regular basis and is unpaid (payment does not include receipt of the Carers Allowance) or the carer of the person before they went into residential care.
4. If there is no one in this category, the person responsible is a close friend or relative of the person.

It may be necessary to have a guardian appointed when a significant decision needs to be made and there is no enduring guardian. In such a case, an application should be made to the Guardianship Tribunal. A guardian is 'a legally appointed substitute decision-maker' who may make 'a lifestyle decision or provide medical and dental consent on behalf of a person under guardianship during the time of a guardianship order'.<sup>83</sup> According to Carney:

research demonstrates that guardianship is principally utilised by people who are in, or are on the cusp of consideration for entry to, some type of supported or institutional care setting. A constituency heavily skewed towards vulnerable older groups.<sup>84</sup>

Section 9 of the *Guardianship Act 1987* (NSW) allows an application for a guardianship order to be made to the Guardianship Tribunal in respect of a person aged 16 or over by: the person concerned; the Public Guardian; or any other person deemed to have a genuine concern for the welfare of the person. The Tribunal, after a conducting a hearing and having been satisfied that the person is in need of a guardian, may make a guardianship order.<sup>85</sup>

Section 4 of the *Guardianship Act 1987* requires those exercising functions under the Act to observe the following principles:

- The welfare and interests of such persons should be given paramount consideration.
- The freedom of decision and freedom of action of such persons should be restricted as little as possible.
- Such persons should be encouraged, as far as possible, to live a normal life in the community.
- The views of such persons in relation to the exercise of those functions should be taken into consideration.

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<sup>83</sup> Office of the Public Guardian, 'Guardianship', [www.lawlink.nsw.gov.au](http://www.lawlink.nsw.gov.au) Accessed 15/2/06.

<sup>84</sup> Carney T, 'Challenges to the Australian Guardianship and Administration Model?', *Elder Law Review*, 2, 2003.

<sup>85</sup> Section 14 *Guardianship Act 1987*

- The importance of preserving the family relationships and the cultural and linguistic environments of such persons should be recognised.
- Such persons should be encouraged, as far as possible, to be self-reliant in matters relating to their personal, domestic and financial affairs.
- Such persons should be protected from neglect, abuse and exploitation.
- The community should be encouraged to apply and promote these principles.

Section 36 allows the person responsible for the patient to consent to the carrying out of minor or major medical or dental treatment, or the Tribunal may consent in any case. The guardian may consent to the carrying out of continuing or further special treatment if the Tribunal has previously given consent to the carrying out of the treatment and has authorised the guardian to give consent to the continuation of that treatment or to further treatment of a similar nature. The consent is to have effect as if the patient had been capable of giving consent to the carrying out of the treatment and as if the treatment had been carried out with the patient's consent.<sup>86</sup>

The Public Guardian is the guardian for people who have a disability such as dementia and are unable to make decisions about lifestyle and medical matters.<sup>87</sup> The Public Guardian is appointed for a limited period and with restricted authority through a guardianship order. Decisions are to reflect the person's best interests after the person's views, experiences and circumstances, and the opinions of those around them have been considered. The Public Guardian is only appointed as a last resort as it is preferable that a family member or friend be appointed as a private guardian.

In NSW, the Office of the Public Guardian provided services to 1,672 people as at 30 June 2005 (an increase of 100 people within 12 months). The majority of people under guardianship are single and of an average age of 55. The Offices of Public Guardian and Protective Commissioner share the role of default guardians.<sup>88</sup> According to section 77 of the *Guardianship Act 1987*, the Protective Commissioner is to also be the Public Guardian. The staff members of the Office of the Protective Commissioner are also the staff members of the Office of the Public Guardian.

Guardians do not make financial decisions.<sup>89</sup> The loss of capacity without execution of an enduring power of attorney may necessitate an application to the Guardianship Tribunal or

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<sup>86</sup> Section 46 *Guardianship Act 1987*

<sup>87</sup> The source for information in this and the following paragraph, unless otherwise stated, is: Office of the Public Guardian, above n 76.

<sup>88</sup> Carney, above n 84.

<sup>89</sup> Office of the Public Guardian, 'Guardianship', [www.lawlink.nsw.gov.au](http://www.lawlink.nsw.gov.au) Accessed 15/2/06.

Supreme Court for the appointment of a financial manager.<sup>90</sup> The application may be made by the Protective Commissioner or a person deemed to have a genuine concern for the welfare of the person who is the subject of the application.<sup>91</sup> Section 25G of the *Guardianship Act 1987* empowers the Tribunal to make a financial management order in respect of a person if the Tribunal has considered the person's capability to manage his or her own affairs and is satisfied that:

- (a) the person is not capable of managing those affairs, and
- (b) there is a need for another person to manage those affairs on the person's behalf, and
- (c) it is in the person's best interests that the order be made.

The Tribunal may subsequently order a suitable person or the Protective Commissioner to be manager of the estate.<sup>92</sup>

One of the potential areas of concern with guardianship is the possibility of the guardian abusing his or her position. Indeed, Carney believes that:

The Achilles heel of the Australian model of guardianship is undoubtedly the extent to which it ultimately rests on the quality of the private and the public guardians to whom the daily job of work must inevitably be delegated.<sup>93</sup>

However, should someone be concerned about the actions of the guardian, an application for a review of the appointment can be made to the Guardianship Tribunal. The Tribunal can review its orders and the appointment of an enduring guardian.

A party to a proceeding before the Tribunal may appeal to the Supreme Court from any decision as of right on a question of law, or by leave of the Supreme Court on any other question.<sup>94</sup> However, a person who has appealed to the Administrative Decisions Tribunal under section 67A against a decision of the Guardianship Tribunal generally may not appeal to the Supreme Court in relation to the same decision.

### *Enduring guardians*

A particular type of guardianship is the role played by an enduring guardian. An enduring

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<sup>90</sup> The Benevolent Society, *Your Future Starts Now: A Guide for the Over 50s*, March 2005, p 8.

<sup>91</sup> Section 25I *Guardianship Act 1987*

<sup>92</sup> Section 25M *Guardianship Act 1987*

<sup>93</sup> Carney, above n 84.

<sup>94</sup> Section 67 *Guardianship Act 1987*

guardian is ‘a formally appointed substitute decision-maker of an individual’s choice to make lifestyle and/or health care decisions should the individual lose the capacity to make their own decisions at some time in the future’.<sup>95</sup> An enduring guardianship only takes effect once the subject loses the capacity to make decisions and only applies whilst the person remains in need of a guardian.<sup>96</sup> A person aged 18 or over may appoint another person aged 18 or over as his or her guardian.<sup>97</sup> However, an enduring guardian cannot be involved in a professional or administrative way in providing certain services for fee nor may he or she be a relative of such a person.<sup>98</sup> Schedule 1 of the Guardianship Regulation 2005 sets out the prescribed form for the appointment of a person as an enduring guardian. The guardian must accept the appointment in writing.<sup>99</sup>

The enduring guardian is given particular functions, but he or she must also act in the best interests of the subject and within the parameters of the *Guardianship Act*. Two or more guardians may be appointed to act jointly (must agree on all decisions), severally (can make decisions separately from the others), or jointly and severally (can act together or separately).<sup>100</sup> Different functions may be conferred on each person appointed as a guardian, in which case the guardians are considered to have been appointed severally.

A guardian may, unless limited by the terms of his or her appointment, exercise the following functions:<sup>101</sup>

- Decide the place (such as a specific nursing home, or the subject’s own home) in which the subject is to live.
- Decide the health care that the subject is to receive.
- Decide the other kinds of personal services that the subject is to receive.
- Give consent under Part 5 to the carrying out of medical or dental treatment on the subject.
- Any other function relating to the subject’s person that is specified in the instrument.

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<sup>95</sup> NSW Health, *Using Advance Care Directives: New South Wales*, June 2004, p 11.

<sup>96</sup> Information on enduring guardians is sourced from: NSW Department of Ageing, Disability and Home Care, *Planning Ahead Kit: Resources for Managing Financial, Health and Lifestyle Decisions into the Future*, August 2005.

<sup>97</sup> Sections 6 to 6B *Guardianship Act 1987* (NSW)

<sup>98</sup> Office of the Public Guardian, above n 66, p 5.

<sup>99</sup> Section 6C *Guardianship Act 1987* (NSW)

<sup>100</sup> Section 6D *Guardianship Act 1987* (NSW)

<sup>101</sup> Section 6E *Guardianship Act 1987* (NSW)

However, an enduring guardian cannot do any of the following on behalf of the subject:

- make a will;
- vote;
- consent to marriage;
- manage finances;
- override objections to medical treatment; or
- consent to ‘special’ medical treatment.<sup>102</sup>

The Guardianship Tribunal has the power to review the appointment of an enduring guardian. Consequently, it may: confirm or revoke the appointment; vary the functions of an enduring guardian; or make a guardianship order and/or a financial management order.<sup>103</sup>

An enduring guardianship may end by one of the following:<sup>104</sup>

- The subject, the Guardianship Tribunal or the Supreme Court revokes the appointment.
- The subject marries after appointing an enduring guardian.<sup>105</sup>
- The subject dies.
- In the case of a joint guardianship, one of the joint guardians dies, resigns or becomes incapacitated (unless the terms state that guardianship is to continue regardless of any of these events).
- An enduring guardian resigns.<sup>106</sup>

Section 6O of the *Guardianship Act 1987* allows for the recognition of enduring guardians appointed in other States and Territories to the extent that the functions conferred could

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<sup>102</sup> ‘Special’ medical treatment includes new or experimental treatments. This requires the consent of the Guardianship Tribunal: NSW DADHC, above n 96, p 12.

<sup>103</sup> Office of the Public Guardian, above n 67, p 26.

<sup>104</sup> Guardianship Tribunal, ‘Planning Ahead... Enduring Guardianship’, [www.gt.nsw.gov.au](http://www.gt.nsw.gov.au) Accessed 2/12/05.

<sup>105</sup> Section 6HA *Guardianship Act 1987* (NSW)

<sup>106</sup> Section 6HB *Guardianship Act 1987* (NSW)

have been validly conferred under NSW law. It is also subject to any limitations on the functions that apply in the State or Territory in which the guardianship order was made.

Enduring guardianship is only a relatively recent possibility in NSW, having been introduced as an option in 1998. According to Squires and Barr:

The creation of enduring guardianship was a very significant development as the grantor can attach ‘directions’ to the instrument, setting out specific requirements or limitations that the enduring guardian is bound to observe. Writing an ACD [advance care directive] and attaching it as directions in the appointment of an enduring guardian gives clear legal authority to the ACD.<sup>107</sup>

Advance care directives are discussed in the following section.

#### **4.2.3 Guidelines for end-of-life care and decision-making**

At common law, which currently regulates the NSW position, life-sustaining treatment may be withdrawn or withheld from an incompetent patient if it is in his or her best interests.<sup>108</sup> However, determining what is in a person’s best interests may be fraught with difficulties. NSW Health published *Guidelines for end-of-life care and decision-making* (‘the Guidelines’) in 2005. The purpose of the Guidelines is to establish a process for reaching end-of-life decisions that involves communication, compassionate and appropriate treatment decisions, fairness, as well as the provision of safeguards for patients and health professionals. The Guidelines are designed to be particularly relevant in situations where patients have lost the capacity to make decisions and their wishes regarding use of life sustaining treatment have not been determined. The development of the Guidelines is thought to have been influenced by the following decisions: *Northridge v Central Sydney Area Health Service* (2000) 50 NSWLR 549<sup>109</sup>, *Messiha v South East Health* [2004]

<sup>107</sup> Squires and Barr, above n 74, p S33.

<sup>108</sup> Bowen T and Saxton A, ‘New developments in the law – withholding and withdrawal of medical treatment’, *Australian Health Law Bulletin*, 14(5) February 2006, p 57.

<sup>109</sup> *Northridge* concerned an application by family members to the court for orders to be made that the treatment and feeding of Mr Thompson be recommenced. Mr Thompson was 37 years old and had been admitted to Royal Prince Alfred Hospital in an unconscious state, having suffered cardiac arrest as a result of a heroin overdose. Doctors had determined there to be no hope for him within a few days of his admission, and despite the objections of the family, withdrew antibiotics and feeding and ordered that Mr Thompson not be resuscitated if his bodily functions ceased. O’Keefe J noted that as a result of its *parens patriae* prerogative, the Crown has a right and duty to take care of those who cannot do so for themselves as a result of disability. The Court may act to protect the right of an unconscious person to receive ordinary, reasonable and appropriate medical treatment, sustenance and support. O’Keefe J noted (at 566):

The evidence reveals a lack of communication, a premature diagnosis, an inadequate adherence to the hospital’s own policies in relation to consultation with relatives and an absence of recognised criteria for the making of the diagnosis of ‘vegetative state’.

The court accordingly ordered that Mr Thompson be provided with necessary and



NSWSC 1061<sup>110</sup>, and *Gardner; Re BWV* [2003] VSC 173.<sup>111</sup>

The Guidelines follow *BWV* (discussed in section 4.2.1) in terms of its view that the provision of artificial hydration and nutrition is medical treatment as opposed to palliative care.<sup>112</sup> However:

It may be that a patient's family would find an attempt to remove artificial hydration and nutrition to be unacceptable, which would lead to a court application. In those circumstances, it is not clear whether the NSW Supreme Court would follow *BWV* and judicial decisions that, unshackled by legislative interpretation, provide a similar result. The decision in *BWV* was influenced by legislative intent to allow death with dignity and the avoidance of the forced provision of nutrients. It seems far from certain that the same emphasis would be placed upon these considerations and not upon other interpretations that would allow for a broader approach towards what constitutes 'palliative care'.<sup>113</sup>

According to Bowen and Saxton, the most difficult circumstances arise when a patient is likely to survive but with significant impairment as it will be difficult to resolve which family member best represents the wishes of the patient.<sup>114</sup> They note that generally treatment will not be withdrawn if its continuance is not futile. They conclude:

Thanks to the Guidelines, NSW hospitals, both public and private, have comprehensive guidance for managing decisions on the appropriateness of withdrawing and withholding of treatment from incompetent patients. These Guidelines clearly take into account lessons learned in earlier cases, both legal and practical....

However, we are still likely to see occasional court applications for continuance of

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appropriate medical treatment for the preservation of his life and promotion of his good health and welfare. It also ordered that a not for resuscitation order could not be made without leave of the Court.

<sup>110</sup> *Messiha* concerned an application made to the Supreme Court by members of Mr Messiha's family for an order restraining St George Hospital from terminating current treatment of Mr Messiha. Mr Messiha, a 75 year old man, was in a deep coma after suffering an asystolic cardiac arrest following which his brain was without oxygen for at least 25 minutes. He had suffered severe brain damage, had severe lung disease, and had been admitted three months previously in relation to a cardiac arrest. The evidence showed the current treatment to be futile as there was no real prospect of significant recovery. Howie J concluded that the court was in no better position to make a determination of future treatment than those principally under the duty to make such a decision. He was not satisfied that the withdrawal of treatment was not in Mr Messiha's best interest and welfare.

<sup>111</sup> Bowen and Saxton, above n 108, p 57.

<sup>112</sup> *Ibid*, p 60.

<sup>113</sup> *Ibid*, p 60.

<sup>114</sup> *Ibid*, p 59.

life-sustaining treatment. In many situations, families quite understandably will not accept what could be considered to be reasoned medical opinion. In these circumstances, with the emphasis on communication and shared decision-making, families may be less tempted to make an application and even if one is made, the emphasis on documentation and considered medical decision-making places the treating team in arguably the best position possible to defend the appropriateness of their decision-making.<sup>115</sup>

### *Advance care directives*

Advance care directives are dealt with in the Guidelines. According to NSW Health, an advance care directive (sometimes known as a ‘living will’) ‘contains instructions that consent to, or refuse use of specified medical treatments. It becomes effective in situations where the patient no longer has the capacity to make treatment decisions’.<sup>116</sup> An alternative definition for an advance directive is:

a document which gives directions about medical treatment in advance. It can be described as an instrument for making decisions while one is still competent and before a serious illness occurs. An advance directive is either in the form of a written document, which expresses one’s wishes in writing (also called a “living will” or “instructional directive”), or it involves appointing another person to make the decisions (proxy or medical power of attorney) if an individual is no longer able to do so. It may also be a combination of the two.<sup>117</sup>

Advance directives differ from enduring guardianship in that:

enduring guardianship is about the legal appointment of a substitute decision-maker in the personal and lifestyle area. An advance directive is a document that sets out your wishes about future medical treatment if you lose the capacity to make these decisions for yourself.<sup>118</sup>

Advance care directives emerged in the context of a medical profession that was concerned with the implications of technological developments that allowed life to be sustained/prolonged in an environment where there was greater questioning of medical decisions and demand for patient control.<sup>119</sup> The NSW Department of Health subsequently, after a period of consultation, released *Dying with Dignity: Interim guidelines on management* in March 1993. These guidelines remained in force for a decade before being

<sup>115</sup> Ibid, p 61.

<sup>116</sup> NSW Health, above n 69, p 16.

<sup>117</sup> Brown M, ‘The law and practice associated with advance directives in Canada and Australia: similarities, differences and debates’, *Journal of Law and Medicine*, 11(1) August 2003, p 60.

<sup>118</sup> Office of the Public Guardian, above n 67, p 20.

<sup>119</sup> Squires and Barr, above n 74, p S32.

replaced by *Guidelines for end-of-life care and decision-making*, which was published in 2005.

There is no mandated form for an advance care directive in NSW. However, the *Guardianship Act* allows a person to appoint an enduring guardian to act as a substitute decision maker. An advance directive on medical treatment can be incorporated into an enduring guardianship appointment document.<sup>120</sup>

Some of the issues that may be dealt with in an advance care directive include:<sup>121</sup>

- Medical treatment preferences.
- Particular conditions or states a person would find unacceptable should they be the likely result of the application of life-sustaining treatment.
- The extent of treatment when the condition of the patient is terminal.
- The nomination of a substitute decision-maker with whom treatment decisions may be discussed.
- Non-medical aspects of care important to the person during the dying phase.

According to the Guidelines, the following conditions should be met before the treatment decisions in an advance care directive are followed:

- i. the directive is intended to apply to the clinical circumstances that have arisen;
- ii. the directive must be sufficiently clear and specific to guide clinical care;
- iii. there must not be any evidence to suggest that the directive does not reflect the current intentions of the patient, or was made as a result of undue influence; and
- iv. the directive should be made by the patient him or herself and should reflect his or her wishes, rather than the wishes of another person.

To ensure the utility of an advance care directive, NSW Health encourages the following actions:

- The patient should periodically review the directive, for example, once a year, after an illness, or following a change in health status.
- The directive should be available at the time decisions need to be made, for example, by ensuring the likely person responsible and primary healthcare provider

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<sup>120</sup> NSW Health, above n 95, p 5.

<sup>121</sup> Ibid.

have a copy of the directive and any of its revisions.

- The directive should be signed and witnessed.
- A medical practitioner should be involved in discussions with the patient to assist with the development of the directive.

A doctor must comply with an advance care directive if it is: specific; current; made by a mentally competent person; and witnessed.<sup>122</sup> Such a directive functions as an extension of the common law right to determine one's own medical treatment, as all competent adult patients have the right to consent to or refuse medical treatment.<sup>123</sup> A health professional who fails to comply with an acceptable advance care directive and treats a person in circumstances in which treatment was refused may be guilty of assault and battery under the common law and may also be liable in a civil claim.<sup>124</sup> However, it should be noted that an advance care directive cannot demand treatment that doctors consider futile, nor can it request a person to actively and deliberately end the life of the person giving the directive.<sup>125</sup>

An advance care directive may only be challenged if:<sup>126</sup>

- the patient was incompetent at the time of executing the advance directive;
- the patient was affected by undue influence or coercion at the time of executing the advance directive; or
- the patient changed his or her mind about the terms of the advance directive after its execution.

There is some debate as to whether advance care directives should be governed by statute. Arguments against the use of legislation include:<sup>127</sup>

- The current situation works well and legislation will create inflexibility.
- Circumstances may change with time and it is difficult for a person to accurately

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<sup>122</sup> NSW DADHC, above n 96, p 17.

<sup>123</sup> NSW Health, above n 95, p 5.

<sup>124</sup> Ibid, p 9; Biegler P et al, 'Determining the validity of advance directives', *Medical Journal of Australia*, 172(11), June 2000, p 545.

<sup>125</sup> The Benevolent Society, above n 90, p 19.

<sup>126</sup> Porter D, 'Advance directives and the persistent vegetative state in Victoria: A human rights perspective', *Journal of Law and Medicine*, 13(2) November 2005, p 258.

<sup>127</sup> Ellison S et al, *Access to Justice and Legal Needs: The Legal Needs of Older People in NSW*, Law and Justice Foundation of New South Wales, Sydney, 2004, p 156.

predict the exact circumstances that may occur, when writing the directive.

- Doctors would have to comply with the directive and could be sued for a failure to act in accordance with the directive.

Squires and Barr, after referring to the circumstances which led to the emergence of advance care directives in NSW, noted:

The working group recommended that NSW not enact specific legislation for ACDs on the basis that the best practice advice could operate within the existing law. The group favoured continuing to operate within a common law approach to ACDs, rather than the approach of specific legislation taken by other states. There was no evidence that the latter approach had increased either the number of people completing ACDs or their recognition by the medical profession. Specific legislation has the effect of focusing attention on the use of the correct form, rather than on the process of discussion around advance care planning, which the group believed was most important and to be encouraged.<sup>128</sup>

However, others disagree and argue that advance care directives need to be covered by statute. Some of the arguments regarding the benefits of advance care directives being enshrined in legislation are:<sup>129</sup>

- It would clarify the legal ramifications and liabilities for stakeholders, for example, government departments and doctors.
- It would increase the confidence of people that doctors will comply with the advance care directive.
- More Australians than before live alone and do not have a family member or friend they could ask to carry out their wishes when they are no longer capable.
- It would make it easier for people to regularly update their advance care directive.

There may be a need for further public education regarding the role of advance care directives in planning ahead. Nonetheless, even if there was greater awareness amongst the public of the availability and benefits of advance care directives, a number of factors may continue to hinder their use. For example, people may be wary of burdening those they would appoint as their agent; others may not be able to sufficiently clarify their thoughts to express their wishes in writing.<sup>130</sup> Squires and Barr have warned that any public awareness campaign promoting the use of advance care directives must be carefully managed to

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<sup>128</sup> Squires and Barr, above n 74, p S33.

<sup>129</sup> Benevolent Society of NSW and the Centre for Education and Research on Ageing, above n 71, p 36.

<sup>130</sup> Brown, above n 117, p 60.

prevent the public becoming suspicious of the motives for their greater use.<sup>131</sup>

### 4.3 Financial decisions

#### 4.3.1 *Enduring powers of attorney*

Many people are familiar with powers of attorney, which allow the appointment of an attorney to make decisions and conduct certain transactions, especially financial ones, on behalf of the principal. However, a power of attorney ceases to be effective once the principal has lost the capacity to make financial decisions.

An enduring power of attorney is also a legal document through which the principal can appoint a person to make decisions about property or financial matters.<sup>132</sup> However, an enduring power of attorney is still effective once the principal has lost capacity. The principal can indicate when the enduring power of attorney is to commence – whether immediately or at some point in the future, such as when assistance with financial decisions becomes necessary. The principal must be of sound mind when granting the power.

Enduring powers of attorney are governed by the *Powers of Attorney Act 2003* (NSW), particularly division 2 of part 4. Section 19 provides that an enduring power of attorney is created if:

- (a) the instrument is expressed to be given with the intention that it will continue to be effective even if the principal lacks capacity through loss of mental capacity after execution of the instrument, and
- (b) execution of the instrument by the principal is witnessed by a person who is a prescribed witness (not being an attorney under the power), and
- (c) there is endorsed on, or annexed to, the instrument a certificate by that person stating that:
  - (i) the person explained the effect of the instrument to the principal before it was signed, and
  - (ii) the principal appeared to understand the effect of the power of attorney, and
  - (iii) the person is a prescribed witness, and
  - (iv) the person is not an attorney under the power of attorney, and

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<sup>131</sup> Squires and Barr, above n 74, p S34.

<sup>132</sup> Guardianship Tribunal, 'Planning Ahead... Enduring Power of Attorney', [www.gt.nsw.gov.au](http://www.gt.nsw.gov.au) Accessed 2/12/05.

- (v) the person witnessed the signing of the power of attorney by the principal.

Authority is not conferred on an attorney until he or she has accepted the appointment in writing.<sup>133</sup> The effect of an enduring power of attorney is such that:

an act done by an attorney that is within the scope of the power conferred by an enduring power of attorney and that is of such a nature that it is beyond the understanding of the principal through mental incapacity at the time of the act is as effective as it would have been had the principal understood the nature of the act at that time.<sup>134</sup>

Multiple attorneys may be appointed to act jointly (attorneys must agree), severally (attorneys can act separately), or jointly and severally (attorneys can act together or separately).

Attorneys must act in the principal's best interests and:<sup>135</sup>

- avoid any conflicts of interest;
- obey the principal's instructions while he or she is mentally capable – any directions made in the enduring power of attorney must also be obeyed;
- act within any limits or conditions placed on their authority;
- not give gifts or give themselves or others a benefit using the finances of the principal unless specifically authorised;
- keep their finances and money separate; and
- keep accurate and proper records of their dealings with the finances and property of the principal.

The enduring power of attorney must be registered for the attorney to be able to deal with real estate. There are additional advantages to registering a power of attorney including: it is on record as a public document; it is kept safe from loss or destruction; and it is more easily accepted as evidence of the attorney's authority.<sup>136</sup>

An enduring power of attorney will end:<sup>137</sup>

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<sup>133</sup> Section 20 *Powers of Attorney Act 2003* (NSW).

<sup>134</sup> Section 21 *Powers of Attorney Act 2003*

<sup>135</sup> Guardianship Tribunal, above n 132.

<sup>136</sup> The Benevolent Society, above n 90, p 12.

<sup>137</sup> Guardianship Tribunal, above n 132.

- if revoked by the principal, provided he or she has the mental capacity to do so;
- on the death of the principal;
- when the attorney dies or can no longer act as attorney; or
- in the case of multiple attorneys appointed jointly, one of them dies or can no longer act as attorney.

Both the Guardianship Tribunal and the Supreme Court have jurisdiction to deal with an application in relation to an enduring power of attorney.<sup>138</sup> Each may refer such an application to the other after considering such factors as:<sup>139</sup>

- whether the application relates to the effect of the enduring power of attorney on third parties;
- whether the application is likely to raise for consideration complex or novel legal issues that the Supreme Court is better suited to determine; and
- any other matter it considers relevant.

The *Powers of Attorney Act 2003* commenced on 16 February 2004. It introduced a number of key changes:<sup>140</sup>

- Benefits may be given to the attorney (for example, reasonable living and medical expenses).
- Benefits may be provided to third parties (for example, reasonable living and medical expenses of third parties).
- Attorney may give gifts (seasonal or occasional gifts and donations).
- Beneficiaries in a will retain the same interest in surplus money or other property should the attorney dispose of property specifically given in a will.
- The donor can elect when the power of attorney is to commence.
- No authority is conferred until the attorney indicates his or her acceptance in writing.
- The Tribunal is to deal with enduring powers of attorney.

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<sup>138</sup> Section 33 *Powers of Attorney Act 2003*

<sup>139</sup> Section 34 *Powers of Attorney Act 2003*

<sup>140</sup> Whitehead P, 'Powers of Attorney Reform in NSW', *Elder Law Review*, vol 3, 2004.



- Enduring powers of attorney made in other states and territories are recognised, subject to certain limitations.

There is the potential for powers of attorney to be abused. However, since February 2004, the Guardianship Tribunal has had power to review enduring powers of attorney and may, if necessary, vary or revoke them.

#### **4.3.2 Protective Commissioner**

The *Protected Estates Act 1983* (NSW) establishes the powers of the Protective Commissioner and provides for the financial management of those incapable of managing their own affairs. The Office of the Protective Commissioner was established in its present form in 1985 under the *Protected Estates Act 1983* (NSW). The Protective Commissioner is an independent statutory official who can be appointed to protect and administer the financial affairs of those incapable.<sup>141</sup> An application for a financial management order can be made to either the Guardianship Tribunal or the Equity Division of the Supreme Court of NSW.<sup>142</sup> The applicant is often a family member, friend, social worker or health professional with a concern for the welfare of the person on whose behalf the application is being made. The Protective Commissioner or a suitable private individual (supervised by the Protective Commissioner) may be appointed to manage the person's financial affairs. Around 16% of clients of the Office of the Protective Commissioner have dementia.<sup>143</sup>

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<sup>141</sup> Benevolent Society of NSW and the Centre for Education and Research on Ageing, above n 71, p 7.

<sup>142</sup> Much of the information on the Protective Commissioner is sourced from the website for the Office of the Protective Commissioner, [www.lawlink.nsw.gov.au](http://www.lawlink.nsw.gov.au)

<sup>143</sup> Office of the Protective Commissioner, *Annual Report 2004/05*, p 17.

## 5 HOUSING AND CARE

The care needs of people with dementia are varied and can range from requiring assistance with more complex tasks, such as financial decisions, to the basic necessities of everyday living, such as eating and bathing. More than 80% of people with dementia who need assistance, require it in relation to mobility. Many also require assistance with property maintenance, health care, transport, paperwork, meal preparation, and housework.<sup>144</sup> The level of care required and services available can influence decisions as to the appropriate home for a person with dementia, whether that is his or her own home, the home of a family member, or a residential facility.

The Organisation for Economic Co-operation and Development (OECD) found the following principles to be common features of dementia policy in the nine OECD countries it surveyed:<sup>145</sup>

- Remain at home as long as possible – delay institutionalisation.
- Support carers in order to achieve this.
- Patients need as much control over their care as possible, but recognise limitations due to cognitive impairment (eg in relation to having the capacity to make informed choices).
- Co-ordination of services at local level where possible.
- Institutional care, when required, should be as home-like as possible.
- Equate service provision with need.
- Early diagnosis should be encouraged.

The OECD review concluded:

Allowing dementia patients to live in the community for as long as possible is a universally desirable policy principle espoused by policymakers. Knowing the circumstances under which dementia patients require admittance to a long-term care institution is important for informing policy. Demented persons and their families will not face this decision of entering a long-term care facility until the latter stages of the disease, at which point two main factors play a decisive role. The first of these is the severity of the disease: there will come a point where the patient will need constant surveillance due to problems such as wandering and behavioural problems that are extremely taxing for carers, such that care can no longer be provided at home. The second of these is the availability of a family

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<sup>144</sup> Access Economics, above n 6, p 27.

<sup>145</sup> Moise, above n 2, p 20.

caregiver. Many people with moderate to severe dementia can remain at home for an extended period of time if there is someone there to care for them.<sup>146</sup>

This section considers the various issues raised in relation to care for people with dementia, whether residential or in the community. It highlights the various options available, as well as ways in which the experience may be enhanced. It also considers the role played by carers, and the particular issues and difficulties they face.

## 5.1 Community care

More than half of the number of people with dementia live in the community.<sup>147</sup> They are key users of the following services:<sup>148</sup>

- Home and Community Care

The Home and Community Care program (jointly funded by the Commonwealth, state and territory governments) is the main provider of home-based care services in Australia, providing such services as: nursing care; allied health care; meals and other food services; domestic assistance; personal care; home modification and maintenance; transport; respite care; counselling, support, information and advocacy; and assessment.<sup>149</sup> People with dementia and their carers are deemed a special needs group. Services specific to dementia include: centre-based and in-home respite; training, support and counselling for carers; and advocacy services.<sup>150</sup>

- Community Aged Care Packages

This program is an alternative to low-level residential aged care providing home-based care (personal care, domestic assistance, meals, transport) to frail or disabled older people who live in the community.<sup>151</sup> About 20% of those receiving Community Aged Care Packages have dementia.<sup>152</sup> 85% of those with dementia and receiving such care were aged 75 and over.<sup>153</sup>

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<sup>146</sup> Ibid, p 62.

<sup>147</sup> Access Economics, above n 6, p 26.

<sup>148</sup> Ibid, p 26.

<sup>149</sup> Commonwealth Department of Health and Ageing, 'Home and Community Care Program Overview', [www.health.gov.au](http://www.health.gov.au) Accessed 22/2/06.

<sup>150</sup> Commonwealth Department of Health and Ageing, above n 3, p 84.

<sup>151</sup> AIHW, above n 4, p 27.

<sup>152</sup> Ibid.

<sup>153</sup> Ibid, p 30.

- Extended Aged Care at Home

This program provides nursing and personal care equivalent to high-level residential care but to people living in the community. About one-third of those receiving Extended Aged Care at Home have dementia.<sup>154</sup> On 15 December 2005, then Minister for Ageing, the Hon Julie Bishop MP, announced 667 new Extended Aged Care at Home Dementia packages, of which 225 were for NSW.<sup>155</sup> These packages are to contribute to the high care needs of people with dementia who live in their own homes.

## 5.2 Residential care

There are two types of residential care: low care (hostel) and high care (nursing homes). People with dementia constitute a large proportion of residents of these types of facilities. 60% of nursing home residents and 30% of hostel residents have dementia.<sup>156</sup> Two-thirds of people with dementia who live in residential care are in nursing homes, one-quarter live in hostels and 8% reside in psycho-geriatric facilities or other supported residential services.<sup>157</sup> People with dementia in residential care stay an average of three years.<sup>158</sup> According to the Australian Institute of Health and Welfare, 72% of those who reported having dementia in 1998 had either been or expected to be living in care accommodation (eg residential aged care services or hospitals) for at least three months.<sup>159</sup> The overwhelming majority of people with dementia in residential care live in mainstream facilities (79%).<sup>160</sup> Only 6% of beds are deemed dementia-specific, with the remainder being dementia areas located within mainstream facilities.<sup>161</sup>

Physical dependence, irritability, nocturnal wandering, and incontinence often precipitate entry into residential care.<sup>162</sup> Fall injuries also play a role and people with dementia are at an increased risk of falling.<sup>163</sup> Dementia doubles the likelihood of a person being recommended to enter a lower care facility and triples the likelihood of people being

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<sup>154</sup> Ibid, p 27.

<sup>155</sup> Bishop J, 'New aged care places for Australia', *Media Release*, 15/12/05; Bishop J, '3780 new aged care places for NSW residents', *Media Release*, 15/12/05.

<sup>156</sup> Access Economics, above n 6, p 40.

<sup>157</sup> Ibid, p 41.

<sup>158</sup> Ibid.

<sup>159</sup> AIHW, above n 4, p 10.

<sup>160</sup> Access Economics, above n 6, p 41.

<sup>161</sup> Ibid, p 41.

<sup>162</sup> NSW DADHC and NSW Health, above n 1, p 29.

<sup>163</sup> Ibid, p 7.

admitted to a high care facility when compared to older people with other diagnoses.<sup>164</sup>

The reliance on residential care has particular implications for those with younger onset dementia as approximately half of those who live in residential facilities are aged 85 plus. However, it is often the only accommodation option for those with younger onset dementia. The need to explore more appropriate options for those with younger onset dementia as well as those who have both an intellectual disability and dementia is recognised in the NSW Department of Ageing, Disability and Home Care and NSW Health document *Future Directions for Dementia Care and Support in NSW 2001-2006*.<sup>165</sup>

Delaying entry into residential care has the potential to save the Government millions of dollars. It has been estimated that delaying entry into residential care by one year will save \$600 million.<sup>166</sup> However, much of this saving is at the expense of family carers who will be \$320 million worse off, unless the progression of illness is delayed as well.

### 5.2.1 *Impact of design*

Gilling has highlighted some of the ways that landscape features can be adapted to positively influence the experience of a person with dementia.<sup>167</sup> As recent memories are usually the first lost, building features and landscape designs from the pre-war era (Californian bungalow, Federation, Victorian) can be used to cue old memories. Gilling also suggests the provision of a safe, secure and interesting outdoors environment so as to minimise staff supervision. Exits should be camouflaged to avoid problems. The use of a central feature (eg tree) with a path around it can accommodate those who often walk in a continuously circular route. She also suggests that potential activities be provided in the form of: raised planters; vegetable and herb gardens; Hills Hoist washing lines; potting benches; garden sheds; compost heaps; pets; old cars; old telephone boxes; birdbaths; dovecotes, wheelbarrows and bus stops. Gilling stresses the benefits of incorporating such ideas:

The nursing home industry is realising that an environment specifically designed to meet the needs of people with dementia means economy of staffing, since less staff time and energy is spent resolving conflict and dealing with problem behaviours.<sup>168</sup>

Wilkes et al conducted a study that considered the impact of environmental design on people with dementia in nursing homes.<sup>169</sup> They compared the differences made when

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<sup>164</sup> Ibid, p 29.

<sup>165</sup> Ibid, p 30.

<sup>166</sup> Access Economics, above n 6, p 71.

<sup>167</sup> Gilling T, 'Designing for dementia', *Landscape Australia*, 26(1) February 2004, pp 42-44.

<sup>168</sup> Ibid, p 44.

<sup>169</sup> Wilkes L et al, 'Environmental approach to reducing agitation in older persons with dementia in a nursing home', *Australasian Journal on Ageing*, 24(3) September 2005, pp 141-145.

dementia residents were moved from an old unit into a special care unit. The study was concerned with the effect of the environment on such challenging behaviours as aggression, noisiness and wandering, as approximately half of people with dementia display agitated behaviours at some stage. The study noted that research had found the following factors to be important:

- a natural environment;
- bright lights;
- sensory stimulation through music;
- outdoor walks and outdoor wandering areas;
- contact with animals;
- enhanced light during meals; and
- a decrease in night-time interruptions.

The following table compares the environment of the old unit with that of the special care unit used in the study.

**Comparison of care environments in a nursing home**

Old unit	Special care unit
Limited to the garden, due to uneven paving and limited observation.	Unrestricted resident use of garden areas via two glass doors, where wandering paths accommodate organised walks or mimic daily routine (the path featuring a bus stop).
Limited domestic chores	Greater access for residents to be involved in domestic activities (eg sweeping, wiping down and setting tables).
Unit had reasonable light with standard size windows in each room and these provided a limited view to the outside.	All 21 rooms have large bay windows with low windowsill to enable residents to look out the windows when sitting in a chair. The lounge/dining area was an open plan with windows to the floor on the external wall areas. Skylights in the corridors increase natural light into the unit.
Clocks and pictures were present on the walls in the corridors and in residents' rooms and calendars were displayed in the lounge areas.	Picture rails have been built into all resident rooms as well as in the common areas. Residents and their families are able to bring family pictures and other art works to each individual room. Paintings have been placed along the corridors as well as in the lounge areas; clocks and calendars are displayed in common areas.
Communal bathrooms and commodes at the side of	Every resident has their own bathroom including

<p>every bed.</p> <p>Residents had limited space for personal items, however, most had family pictures in their rooms taking into account the shared accommodation.</p>	<p>toilet, shower and vanity. The unit also has a spa bath.</p> <p>Residents are able to decorate their rooms with photos and other personal items. Some residents have their own lounge chairs, cupboards etc, most have personalised their room with familiar memorabilia.</p> <p>Snoezelan room: A multisensory room that can accommodate up to 10 residents at once.</p>
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Source: Wilkes L et al, 'Environmental approach to reducing agitation in older persons with dementia in a nursing home', *Australasian Journal on Ageing*, 24(3) September 2005, p 143.

The study found that there were initial changes in behaviour as a result of environmental conditions. However, the only changes to be sustained were in relation to verbal agitated behaviour – there were less complaints, negativism, screaming and requests for attention. Nonetheless, it was concluded that special care units are an imperative adjunct to caring for persons with dementia, as environmental design does have a positive impact on the care of people with dementia.

An example of the use of innovative design in the nursing home environment is that of ADARDS (Alzheimer’s Disease and Related Disorders) Nursing Home in Tasmania.<sup>170</sup> ADARDS is funded by the Australian Government and provides residential care for ambulant people with dementia whose behaviour disorders mean that no other residential facility can take care of them. The design of the home is particularly unique. It can be arranged to allow four self-contained houses or as four wings around a nursing station. It also has camouflaged doors (doors leading out of the house resemble the wall and have no handle, an unlocked door with a handle is located next to it – as a result, residents do not rattle on locked door handles); a system to alert the night nurse if a resident gets out of bed; disguised closets (one closet door is camouflaged so that clothes can remain folded whilst the other door is normal and contains clothes through which the resident can sort); fecal drains in the suites; and gardens with animals and birds as well as paths on which the residents can wander, barbecues, clothes hoists, and a disabled car. During the day, the central corridors, verandahs and passages form a loop around which residents can wander, which prevents the residents feeling like they are locked in. Lifestyle habits of the residents are maintained as much as possible, for example, there is no fixed time for residents to get up in the morning or go to sleep at night.

### 5.3 Carers

Informal carers play a large role in the provision of care for those with dementia. Almost one million Australians are involved in caring for a family member or friend with dementia.<sup>171</sup> A national poll conducted for the Pfizer Australia Health Report found that 10% of Australians aged over 51 years are involved in caring for a family member or friend

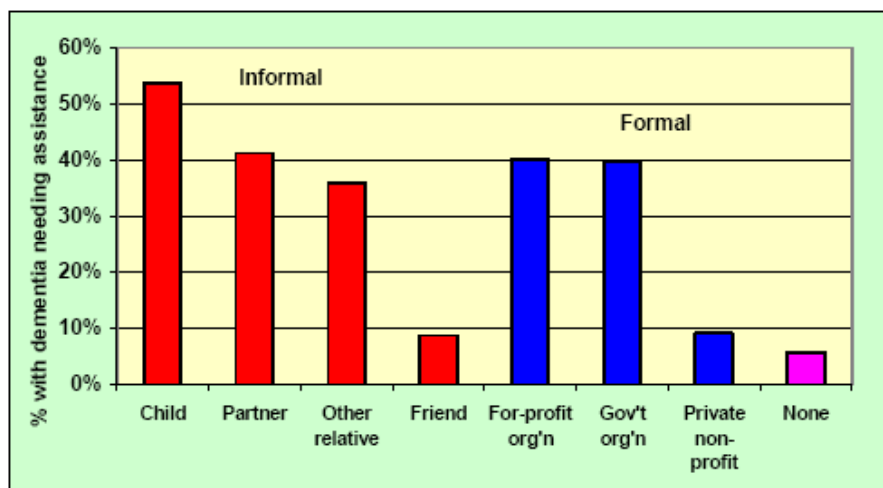
<sup>170</sup> See ADARDS Nursing Home [www.adardsnursinghome.com.au](http://www.adardsnursinghome.com.au).

<sup>171</sup> Pfizer Australia, above n 5, p 3.

with dementia.<sup>172</sup>

The following chart details the provision of informal and formal care for people with dementia who live in households.

**Informal and formal types of care for people with dementia in households**



Source: Access Economics, *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*, Alzheimer's Australia, March 2003, p 27.

A particular issue regarding carers is their ability to continue to work in paid employment, if desired. Almost 80% of primary carers are between the age of 18 and 64, that is, of workforce age.<sup>173</sup> Anti-discrimination laws protect carers from discrimination on the basis of their caring responsibilities.<sup>174</sup> Nonetheless, 59% of carers do not participate in the paid workforce as it is often not possible in the circumstances.<sup>175</sup> More than half of primary carers provided care because alternative care was either not available or too expensive, or because they felt they had no choice.<sup>176</sup>

The impact of providing care on the carers can be significant with many suffering from generally worse physical health, tiredness, stress, back and muscle problems, depression, anxiety and a lack of respite.<sup>177</sup> Research by the OECD concluded that group-living was the only effective intervention regarding improvement of the health of the carer in terms of energy, social isolation, emotional reactions and sleep.<sup>178</sup> It was found to be the most

<sup>172</sup> Ibid.

<sup>173</sup> Access Economics, above n 6, p 24.

<sup>174</sup> See Part 4B of the *Anti-Discrimination Act 1977* (NSW).

<sup>175</sup> Access Economics, above n 6, p 24.

<sup>176</sup> Ibid.

<sup>177</sup> Ibid.



effective means of reducing the care burden.

However, there is more to the experience of caring than the negative impacts on the individual:

Understandably, the situation of caregivers for persons suffering from dementia is portrayed in a negative tone. This characterisation, however, belies what many caregivers may feel; that caring for an afflicted loved one, while an unexpected task, is seen more as an accepted responsibility that they wish to be an integral part of, rather than an unwelcome burden.<sup>179</sup>

The following extract is reproduced from *The Carer Experience*, a guide published by the Department of Health and Ageing. The guide recounts the various experiences of carers, both positive and negative, collected from discussion groups and through the completion of questionnaires. This particular extract relates the personal experience of a carer in the ACT and illustrates some of the positive aspects of the caring role.<sup>180</sup>

*I think carers of people with Alzheimer's would do well to try to look at the caring role in an objective way, but importantly still keep their love for the person, young or elderly, they are caring for. I know that is difficult but I think it saved me a lot of stress and frustration.*

*One of my many memorable experiences happened one night when I was putting my wife to bed. I was about to put out the light when my wife said in a soft voice, 'Thank you, Noel, for looking after me'. I went over and kissed her again and she gave me one of her lovely smiles. This was the first time in two years that she had spoken my name.*

*Some wonderful things can happen to you during your life. The privilege of being able to protect and care for someone who was totally dependent on me has been the most rewarding experience in my life. My wife died peacefully last year.*

A particular concern is the likely reduction in the future pool of potential carers. This is partly a result of the ageing of Australia's population, as older Australians constitute an increasing proportion. Other contributing factors include: decreasing fertility rates resulting in fewer children available as carers; the increased rate of female participation in the workforce; less secure employment; movement away from standard working hours; a trend for families to live further away from parents than before; and changing norms about caring for parents.<sup>181</sup> The current push for people to work to an older age is also likely to have an impact. The OECD has noted:

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<sup>178</sup> Moise, above n 2, p 52.

<sup>179</sup> Ibid, p 50.

<sup>180</sup> Commonwealth Department of Health and Ageing, above n 3, p 42.

<sup>181</sup> Carney, above n 84; Moise, above n 2, pp 22 and 39.

Most signs point to a diminishing pool of informal caregivers to choose from which could put strains on other caring modes for dementia patients. For example, this could lead to long-term care facilities in earlier stages of the disease or a greater use of formal home-based care. However, current lower remuneration and difficult working conditions may have the same effects on the supply of formal carers, exacerbating the problem further.<sup>182</sup>

#### 5.4 Rural areas

People with dementia in rural areas may experience difficulties as a result of their location outside major urban centres. A study by Hansen et al considered the various barriers that hinder the effective care of people with dementia in a rural community.<sup>183</sup> The study examined a rural remote Tasmanian community with the aim of developing a transferable model for the effective care of people with dementia in small rural communities. They considered the impact of such barriers as distance and isolation as access to dementia-related services and expertise was generally restricted. There was only limited access to members of the Aged Care Assessment Team, geriatricians and psycho-geriatricians, with travel of at least 90 minutes often required. Consequently, assessments were generally made on the basis of fewer visits.

Residential care options were also limited in rural areas. The study found that many people with dementia lived in the aged wing of the local hospital which was not secure. Carers were limited in their ability to visit those living in a residential facility as a result of distance. The authors found that this discouraged families moving a person with dementia into a residential care facility. It was also found that stigma played a role in the reluctance with which services were accessed. There was a belief amongst many families that they should take care of their own as well as a concern that the respite carer would be someone they knew.

#### 5.5 Dementia programs

This section considers a sample of the various programs that have been developed to support people with dementia and their carers, both at the federal level and in NSW. It also looks at some of the ways in which the behavioural and psychological symptoms of dementia may be managed.

##### 5.5.1 Federal

There are various programs that currently support people with dementia and their carers including:<sup>184</sup>

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<sup>182</sup> Moise, above n 2, p 46.

<sup>183</sup> Hansen E et al, 'Barriers to the provision of care for people with dementia and their carers in a rural community', *Australian Journal of Primary Health*, 11(1) 2005, pp 72-79.

<sup>184</sup> Murnane M, *Australian Government initiatives in research and dementia*, presentation to the National Dementia Research Workshop, 29 August 2005, Melbourne. A copy of this and

- residential aged care homes;
- Home and Community Care packages;
- Community Aged Care packages;
- a range of targeted dementia specific services;
- dementia medication through the Schedule of Pharmaceutical Benefits; and
- Extended Aged Care at Home packages.

Dementia has gained a larger national profile in recent years. It was an election commitment of the Government in 2004 to make dementia an Australian Government National Health Priority with \$200 million to be provided over four years in support of people with dementia.<sup>185</sup>

The Australian Health Ministers jointly agreed to the development of a National Framework for Action on Dementia in January 2005. The Health Ministers identified five key priority areas considered fundamental to the quality of life of people with dementia, their families and carers:<sup>186</sup>

1. Research
2. Information and Education: promotion of healthy lifestyles; information and education for people with dementia, families and carers; protection of rights and interests.
3. Access and Equity: culturally and linguistically diverse communities; Aboriginal and Torres Strait Islander Communities; rural and remote areas; younger people with dementia; people who are homeless.
4. Quality, integration and continuum of care: primary health; community care; respite care; acute care; residential care; palliative care; and behavioural issues that impact on care and support.
5. Workforce and training

The 2005/06 Budget made dementia a National Health Priority. It provided \$320 million over five years to target better prevention, treatment and care.<sup>187</sup> This funding is to:<sup>188</sup>

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other presentations made to the workshop are available from [www.health.gov.au](http://www.health.gov.au)

<sup>185</sup> Ibid

<sup>186</sup> Commonwealth Department of Health and Ageing, above n 49, pp 10-11.

<sup>187</sup> Alzheimer's Australia, '2005/06 Budget: A Vision for People Living with Dementia', *Media*

- support more dementia research;
- increase the skill and provide support to health care professionals and aged care workers;
- help people with dementia and their carers directly;
- improve dementia awareness for people in the community such as police, transport and emergency workers; and
- provide aged and community care worker training.

In the 2005-06 Federal Budget, the Government announced that \$225.1 million would be provided over four years for an additional 2,000 Extended Aged Care at Home places specifically targeting people with dementia.<sup>189</sup> It would also increase the number of hours of support available to recipients at these places. It was announced that \$25 million would be provided over four years to provide dementia-specific training for up to 9,000 community and residential care workers, and up to 7,000 carers and community workers such as police and transport workers. This was to build on the Carer Education and Workforce Training Project to which the Government provided \$1.3 million in 2004-05. The 2005-06 Budget also provided \$11.9 million over four years to continue funding for the Dementia Education and Support Programme (assists people with dementia and their carers to reduce stress, increase effectiveness of the caring role and delay entry to residential care) and to provide additional funding for Aged Care Assessment Teams (ensure that Aged Care Assessment Teams in rural areas have access to dementia expertise and training to enhance their capacity to assess people with dementia and support them and their families in making appropriate care choices).

\$25 million has been made available over four years for dementia research and innovation. This involves: a National Dementia Research Workshop; Dementia Research Grants Rounds; Dementia Research Mapping Exercise; development of a Dementia Research Website; and the establishment of Dementia Prevention Collaborative Research Centres (to bring together key ageing and dementia research with strong links with international and national research).<sup>190</sup>

In his 2005 Budget Speech, the Treasurer, the Hon Peter Costello MP stated:

This budget makes dementia a National Health Priority. The \$321 million package will enhance the quality of life of dementia sufferers and their carers. It includes

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*Release, 11/5/05.*

<sup>188</sup> Murnane, above n 184.

<sup>189</sup> Australian Government, *2005-2006 Budget Paper No 2*, p 185.

<sup>190</sup> Murnane, above n 184.

2000 new Extended Aged Care at Home places dedicated to people with dementia, which will provide them with individually planned and coordinated nursing care and support services to help them remain living at home for longer, in familiar surroundings.

As life expectancy increases, dementia will become more common. Accordingly the package will offer more opportunities for dementia-specific training for carers, community and residential care workers, and people working in services such as the police, transport and emergency services.<sup>191</sup>

These commitments form part of the *Helping Australians with dementia, and their carers – making dementia a National Health Priority* initiative.<sup>192</sup> Whilst guided by similar principles, this is a separate process to the National Framework for Action on Dementia.<sup>193</sup> The National Framework provides a mechanism for governments to share ideas and develop a national vision. *Helping Australians with dementia* is an Australian government initiative based on many of the priorities of the Framework.

There are various opinions regarding the best policy approach to dementia. Access Economics has argued that aside from the prioritisation of dementia, the five pillars of a national strategy should be:<sup>194</sup>

1. A significant investment in research for cause, prevention and care.
2. Early intervention through improvement in diagnosis and the provision of cost-effective pharmacotherapies.
3. Comprehensive provision of support, education and respite services – in place in the community as far as is optimal.
4. Quality residential care, appropriately financed, that are centred on the person with dementia and their family/carer.
5. Provision for special needs, including people with younger onset dementia, people with behavioural and psychological symptoms of dementia, people from culturally and linguistically diverse backgrounds, Indigenous Australians and people in rural and remote areas.

According to Access Economics:

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<sup>191</sup> Costello P, *Budget Speech 2005-06*, 10/5/05.

<sup>192</sup> Commonwealth Department of Health and Ageing, 'National Dementia Research Workshop', [www.health.gov.au](http://www.health.gov.au) Accessed 1/3/06.

<sup>193</sup> Commonwealth Department of Health and Ageing, above n 49, p 14.

<sup>194</sup> Access Economics, above n 6, p vi.

Intergenerational planning needs to acknowledge the *need* for health and aged care spending to grow in real and relative terms, with strategies for successfully managing the change. These strategies will include minimising inter-generational transfers (fewer younger people financing the growing number of elderly), maximising intra-personal transfers (savings schemes), coming to consensus on the private-public mix of care provision, improving models of care to promote both cost-efficiency and quality and providing safety nets for disadvantaged groups. Access for such groups, including people with younger onset dementia and people from culturally and linguistically diverse backgrounds, should also begin to be addressed now. More needs to be done to destigmatise dementia. Better use should be made of Alzheimer's Australia and of new information technologies in delivering services. We should not assume that future generations would provide the levels of voluntary care that previous generations have provided.<sup>195</sup>

In his 2006-07 Budget Submission, Glenn Rees, National Executive Director of Alzheimer's Australia, argued that the following seven point action plan provides a framework to guide the implementation of dementia as a National Health Priority:<sup>196</sup>

1. Improve the assessment and diagnosis of dementia.
2. Improve the responsiveness of acute care so it better meets the needs of people with dementia.
3. Ensure easy access to quality community care services.
4. Provide more flexible responses to supported accommodation in the home and in residential settings.
5. Increase the recognition and understanding of the financial cost and legal implications of dementia.
6. Promote and ensure greater public awareness and understanding about dementia and risk reduction.
7. Increased investment in dementia research.

### 5.5.2 *New South Wales*

NSW is currently in the midst of its second action plan on dementia – *Future Directions for Dementia Care and Support in NSW 2001-2006*. The first action plan on dementia was implemented between 1996 and 2001. The *NSW Action Plan on Dementia 1996-2001* was a joint initiative of the Department of Ageing, Disability and Home Care and NSW Health, to

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<sup>195</sup> Ibid, p 67.

<sup>196</sup> Rees G, *Budget Submission 2006/2007*, 8/11/05. Available from [www.alzheimers.org.au](http://www.alzheimers.org.au) Accessed 10/2/05.

which \$3.5 million was provided in funding.<sup>197</sup> Strategies were implemented under seven focus areas with the purpose of informing and supporting people with dementia as well as assisting professionals and service providers to better meet their needs. It also sought to increase co-operation between government and non-government agencies. The seven focus areas, as well as examples of projects, were as follows:

#### NSW Action Plan on Dementia 1996-2001

Focus Area	Examples of projects
Information, assessment and diagnosis	Dementia advisory services established on the Far North Coast, Central Coast and in the Far West; dementia materials produced in 23 community languages; a dementia awareness training project for health care interpreters; development and trial of a multicultural screening instrument; integrated care pilot projects between GPs and Aged Care Assessment Teams; a shared care pilot project involving GPs, a local mental health team and an aged care facility; a dementia skills enhancement course for GPs; and the development and testing of Guidelines for the Care of Patients with Early Dementia in General Practice.
Community support services	Completion of research project – Dementia Carers and the Non-Use of Services; a ‘Cultures in the Workplace’ program at the Alzheimer’s Association of NSW; ten telephone support groups together with a group facilitators’ manual; a resource manual and workshops assisting respite service providers and planners to increase respite options; and research and consultation on the needs of younger people with dementia.
Health care	A Ballina Hospital project on ‘Better practice resources for the Hospital Care of People with Dementia Behaviour’.
Accommodation options	Publication of the resource manual – <i>Better Building, Better Care: A Planning Guide to Improving an Aged Care Facility for People with Dementia</i> ; a resource manual to assist small rural hospitals to provide safer and more appropriate options for people with dementia; development of preliminary policy options to improve accommodation for younger people with dementia; eight help sheets on dementia and residential care added to the series by the National Alzheimer’s Association; and publication of <i>At Home with Dementia</i> to provide carers and service providers with information on modification of the home environment.
Protection of rights and interests	Dementia Awareness Day held in Law Week in Sydney in 2000 and a Dementia Awareness for Lawyers seminar held in Sydney in November 2001; development of dementia-specific resources and a website through the Continuing Legal Education Centre at the University of NSW; and the publication of a Planning Ahead Kit.
Community awareness, education and training	Conduct of a community awareness campaign in 1999; conduct of a project to increase dementia awareness in 10 specific language groups; translation of poster series ‘Life doesn’t stop when dementia starts’ into Italian and Greek; a magazine for teenagers to increase awareness amongst children of early onset dementia; and an Aboriginal dementia awareness training project to increase knowledge of dementia amongst key Aboriginal workers and service providers; a number of agencies planned training components to assist staff to respond appropriately to a person with dementia; and conduct of a dementia training day

<sup>197</sup>

NSW DADHC, *Achievements under the NSW Action Plan on Dementia 1996-2001*, 2002, p 1.

	for Aged Care Assessment Team members.
Policy and planning	Publication of <i>NSW Action Plan on Dementia 1996-2001</i> ; establishment of the NSW Dementia Reference Group; and the development of Area Health Service dementia plans.

*Future Directions for Dementia Care and Support in NSW 2001-2006*, jointly published by the NSW Department of Ageing, Disability and Home Care and NSW Health, has five major goals:<sup>198</sup>

1. Increase awareness of the needs of people with dementia.
2. Influence policy and funding environments to respond to dementia needs.
3. Improve access to and quality of community, acute care and residential services and the ability of these services to respond to individual needs.
4. Enhance the capacity of the health system to respond appropriately to the health needs of people with dementia and their carers.
5. Develop a comprehensive and coordinated service system for dementia care.

Its focus areas include: policy and planning; supportive and inclusive communities; diagnosis, assessment and management; education and training; community support services; acute care; and accommodation options. Details of the aims within each of these areas are noted in the table below.

#### **Future Directions for Dementia Care and Support in NSW 2001-2006**

<b>Focus Area</b>	<b>Future aims</b>
Policy and planning	Develop a public health approach to dementia that encompasses the concepts of prevention, early intervention, healthy ageing, and evidence-based practice in order to maintain function and improve quality of life.
	Strengthen local planning and service development.
	Recognise and support the central role of carers in maintaining function and quality of life for people with dementia and provide appropriate supports for carers.
	Influence state and national policy and planning processes to address the needs of people with dementia.
	Develop an equitable and coordinated system of dementia care in NSW.
Supportive and inclusive communities	Increase awareness of dementia and available services.
	Address the specific needs of Aboriginal communities.
	Improve awareness of dementia amongst diverse cultures in NSW.
	Promote more supportive and inclusive community environments.
Diagnosis, Assessment and Management	Provide equitable access to early diagnosis, appropriate assessment, timely information and short term counselling on diagnosis and at key stages, and referral to support services.
	Improve the detection, diagnosis, assessment and management of people with an intellectual disability and dementia.

<sup>198</sup>

NSW DADHC and NSW Health, above n 1, p 16.



	Continue to support GP skills development in early diagnosis, assessment, management and referral to support services.
	Continue to support ACATs in their assessment role with people with dementia.
	Improve GP links to ACATs, community services and residential care.
	Promote the involvement of carers in care decisions.
	Provide equitable access to behavioural advice for carers, community support services and residential care facilities to manage challenging behaviour.
	Reduce the current complexity of the service system for people with dementia.
	Enhance workforce skills in diagnosis, assessment and management in targeted, critical areas.
Education and Training	Improve access to dementia training for critical sections of the NSW workforce, including community, residential and acute care staff.
	Ensure that training promotes understanding of the person living with dementia, and the crucial role of family carers, and encourages the trainee to maintain their dignity and enhance their quality of life.
	Support GPs' access to dementia education to improve diagnosis, management and referral.
	Increase carer access to education.
Community Support Services	Improve access to information, education, employment assistance, counselling and peer support for people in early stages of dementia and those with early onset.
	Continue to expand the availability of a range of community support services for people with dementia.
	Recognise and support carers of people with dementia.
	Improve access to consultative expertise on the management of challenging behaviour for community support services and family carers.
Acute Care	Improve dementia diagnosis and management in public hospitals, including management of challenging behaviour.
	Make hospital settings more appropriate for people with dementia.
	Develop alternatives to hospital admission, when appropriate.
	Ensure that the needs of people with dementia and their carers are incorporated into discharge planning.
Accommodation Options	Promote strategies to maintain independence and safety of people with dementia living at home including strategies to maintain healthy lifestyles.
	Develop appropriate accommodation options for people with dementia, including care of people with challenging behaviour, younger people and people with an intellectual disability and dementia.
	Increase the capacity of mainstream residential facilities to respond to the needs of people with dementia including people with challenging behaviour, and their carers.
	Improve access to appropriate residential care for people in rural areas.
	Improve access to appropriate care for people from culturally and linguistically diverse backgrounds.
Protection of Rights and Interests	Increase access for people in early stage dementia to information and opportunities for planning ahead options and substitute decision making for their future financial, health and lifestyle needs.
	Introduce mechanisms to further protect the rights and interests of people with dementia.
	Support families involved in decisions regarding clinical management in final stages.
	Increase access to palliative care for people with dementia in final stages.

Source: NSW Department of Ageing, Disability and Home Care and NSW Health, *Future Directions for Dementia Care and Support in NSW 2001-2006*, Department of Ageing, Disability and Home Care, 2002.

The Department of Ageing, Disability and Home Care funds Dementia Advisory Services. These services promote local awareness of dementia, provide information, education and support, and link people to assessment and support services. A NSW Dementia Awareness

Week was held in September 2005. During this week: Alzheimer's Australia NSW received \$100,000 to organise education forums, training sessions and grants to carer support groups to hold events; 23 Dementia Advisory Services throughout NSW and a dementia counselling service received \$5000 each to conduct events, provide information and awareness activities about dementia for local communities; and Dementia Advisory Services in west and south-west Sydney and Queanbeyan received funding to pilot projects with local culturally and linguistically diverse communities.<sup>199</sup>

The NSW Department of Ageing, Disability and Home Care and NSW Health have concluded:

NSW is well placed to develop and deliver effective and quality services and systems for people with dementia, their families, carers and service providers. The NSW Government will achieve positive outcomes by implementing a range of strategies such as strengthening partnerships and linkages between services, providing targeted training to service providers, promoting good primary health care, recognising and supporting the valuable work of carers, and working towards early intervention.<sup>200</sup>

However, the *Mental Health Act Guide Book* has highlighted how dementia can cause difficulties regarding application of the *Mental Health Act 1990* (NSW). Whilst the illnesses that cause dementia do not fall within the Act's definition of 'mental illness', a person with dementia may experience symptoms, such as auditory hallucinations, delusions or a serious disorder of mood, that are recognised by the Act.<sup>201</sup> The inquiry of the Select Committee on Mental Health into mental health services in NSW noted some of the difficulties that may result from a case where a person has dementia and mental health problems. Professor Brodaty, in his submission to the inquiry, noted:

Dementia is by and large a Commonwealth issue – residential care Medicare-subsidised medical consultations; while Government mental health services are funded by the State.

People who have dementia complicated by mental health problems somehow fall between the two schools.<sup>202</sup>

In December 2002, the Select Committee concluded that NSW Health had yet to sufficiently address 'the need for adequate facilities for older people with dementia and

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<sup>199</sup> Della Bosca J, 'NSW Dementia Awareness Week', *Media Release*, 18/9/05.

<sup>200</sup> NSW DADHC and NSW Health, above n 1, p 32.

<sup>201</sup> Centre for Mental Health, *Mental Health Act Guide Book (amended May 2003)*, NSW Department of Health, 2003, p 70.

<sup>202</sup> Quoted in NSW Parliament, Legislative Council, Select Committee on Mental Health, *Inquiry into mental health services in New South Wales: Final report* (B Pezzutti MLC Chair), 2002, p 204.

behavioural or mental health problems such as aggression'.<sup>203</sup>

### 5.5.3 Programs targeting carers

There are many programs that have been developed to provide support to carers. The options listed in this section are just a sample of the different forms of support available.

#### *Financial support*

The Australian Government provides financial support for carers in the form of the Carer Allowance (a non-income tested fortnightly allowance provided to a person caring for a relative or friend requiring fairly high level care) and Carer Payment (income-tested income support for carers of someone requiring constant personal care or supervision at home for at least six months).<sup>204</sup>

#### *Respite*

The Australian Government also funds the National Respite for Carers Program.<sup>205</sup> This program provides carers with information, respite care and support. More than 450 community-based respite services are funded. These services include day care centres (half or full day respite) and in-home respite services (overnight care and personal care). Another option is residential respite care which involves short-term care in aged care homes subsidised by the Federal Government. This is for people who intend to return to the community but require temporary care as a result of an emergency, carer stress, illness, holidays, or if the carer is unavailable. Generally, other than in cases of emergency, an Aged Care Assessment Team must have assessed the person as requiring residential respite care. Up to 63 days of respite care may be provided in a financial year.

Provision of respite for the carer of a person with dementia is thought to have many benefits. As well as providing support for carers, it can delay the entry of the person with dementia into residential care, and it can offer the person with dementia a chance to interact with others and participate in recreational activities.<sup>206</sup>

The Brotherhood of St Laurence through the Banksia Centre in Victoria piloted a different form of respite care – host-home respite.<sup>207</sup> Small groups of people with dementia met once

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<sup>203</sup> Ibid, p 210.

<sup>204</sup> Commonwealth Department of Health and Ageing, 'National Respite for Carers Program (NRCP) and other Australian Government support for carers'. [www.health.gov.au](http://www.health.gov.au) Accessed 22/2/06.

<sup>205</sup> Information in this paragraph is sourced from: Commonwealth Department of Health and Ageing, above n 204.

<sup>206</sup> Holm S and Ziguras S, *It's the simple things that matter: an evaluation of the Banksia host-home respite program*, Brotherhood of St Laurence, November 2001, p 4. Available from [www.bsl.org.au](http://www.bsl.org.au) Accessed 21/2/06.

<sup>207</sup> The source for information on the Banksia host-home respite program is: Holm and Ziguras,

a week in a care-worker's home, akin to friends catching up for the day. This program is based on the Family Day Care model with respite provided in the home of a care-worker, as opposed to a centre or in the carer's/care-recipient's home. It also differs from more usual forms of respite in that the hours of respite are six, and transport is provided to and from the home of the host care-worker. An evaluation of the program found it to be a success in a number of ways: the person with dementia enjoyed the program and was happy to attend; the smaller size of the group meant that the care-worker could better match activities to the individual's interests and skills; the carers were more at ease with this form of respite; and it was almost 40% cheaper than in-home care (although it was more expensive than respite provided in a centre). It was also found to be particularly beneficial for those who would have had difficulty using a service located in a centre due to: the advanced stage of their dementia; hearing problems; preferences for a smaller group; or location near a host-home but not a centre. The evaluation also concluded that host-home respite was likely to be particularly advantageous for people from non-English speaking background and for Indigenous Australians as it could allow for more culturally sensitive options – workers from the same background, choice of activities, and the provision of food specific to that culture. The evaluation stressed the need for guidelines and standards to be established to avoid problems of inadequate supervision and exploitation of staff.

#### *National Dementia Behaviour Advisory Service*

The National Dementia Behaviour Advisory Service (ph 1300 366 448) provides telephone based assistance to respite care staff, health professionals and carers 24 hours a day seven days a week. The service assists callers to: gain an understanding of the behaviours observed; identify factors that trigger concerning behaviours; develop strategies to reduce the frequency and impact of concerning behaviours; and contact services and support.<sup>208</sup>

#### *Working Carers Support Gateway*

The 'Working Carers Support Gateway' [www.workingcarers.org.au](http://www.workingcarers.org.au) is a service developed by the Disability and Aged Information Service Inc to provide information and support to low income and isolated carers in NSW who try to balance caring with workplace responsibilities. Various resources are provided on its website. NSW Health is a partner in the project.

#### *Making Memories*

A study by Brodaty and Low evaluated the effects of the Alzheimer's Association's (NSW) Making Memories pilot program on people living at home with dementia and their carers.<sup>209</sup> As part of the program, people with dementia would participate in a memory loss

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above n 206.

<sup>208</sup> Information on the service may be found at Commonwealth Department of Health and Ageing [www.health.gov.au](http://www.health.gov.au)

<sup>209</sup> Brodaty H and Low L, 'Making Memories: pilot evaluation of a new program for people with dementia and their caregivers', *Australasian Journal on Ageing*, 23(3) September 2004, pp 144-146.

group whilst their carers attended an education and support group. It also involved weekly leisure activity groups. The authors noted that successful carer interventions could: reduce carer distress, depression and psychological morbidity; delay nursing home admission of patients; and improve patients' psychological wellbeing. It found that whilst the program reduced the psychological distress of people with dementia, carer depression and psychological wellbeing did not improve. Nonetheless, they did find a trend towards improved carer quality of life. The key findings of the study were: decreased psychological morbidity in persons with dementia; a short term decrease in carer reactions to behavioural disturbance that was not maintained at follow-up; and a trend towards increased carer quality of life after participating in the *Making Memories* program.

#### 5.5.4 *Managing the behavioural and psychological symptoms of dementia*

The behavioural and psychological symptoms of dementia (BPSD) include psychosis, depression, agitation, aggression and disinhibition and are associated with 'lowered functional abilities and poorer prognosis, an increased burden on caregivers and nursing-home staff, higher costs of care and earlier institutionalisation'.<sup>210</sup> Brodaty, Draper and Low have highlighted what they perceive as a lack of comprehensive planning for managing and preventing these symptoms in Australia:

Currently, in Australia, services for people with BPSD are ad hoc and fragmented. It is unclear who should bear responsibility for this population. Should it be State or federal governments, geriatric or psychogeriatric services, generic mental health services or specialist mental health services for older people, primary or secondary health services?<sup>211</sup>

Whilst they acknowledge the establishment of specialised facilities in some states such as the Confused and Disturbed Elderly units in NSW<sup>212</sup>, they argue that the distribution of such facilities is not equitable and may not have the special resources required for people with dementia. They also note the management of dementia patients with these symptoms is particularly difficult in rural and remote areas.

Consequently, Brodaty et al have developed a seven-tiered model of service delivery for the management of the behavioural and psychological symptoms of dementia.<sup>213</sup> The interventions are designed to prevent patients from moving to higher tiers as well as assist in the movement to lower tiers as a result of treatment or management of the symptoms. The level of disturbance increases, and the use of interventions cumulates, as one moves up the table.

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<sup>210</sup> Brodaty H, Draper B and Low L, 'Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery', *Medical Journal of Australia*, 178(5) March 2003, p 231.

<sup>211</sup> Ibid.

<sup>212</sup> Note the recent debate in NSW Parliament regarding the closure of the Confused and Disabled Elderly Unit in Queanbeyan: *NSWPD*, 14/3/06.

<sup>213</sup> Brodaty et al, above n 210, pp 231-234.

**Seven-tiered model of management of behavioural and psychological symptoms of dementia (BPSD)**

<b>Tier</b>	<b>Description</b>	<b>Prevalence and Management</b>
7	Dementia with extreme BPSD (eg physical violence)	Prevalence: Rare Management: In intensive specialist care unit
6	Dementia with very severe BPSD (eg physical aggression, severe depression, suicidal tendencies)	Prevalence: <1% Management: In psychogeriatric or neurobehavioural units.
5	Dementia with severe BPSD (eg severe depression, psychosis, screaming, severe agitation)	Prevalence: 10% Management: In dementia-specific nursing homes, or by case management under a specialist team.
4	Dementia with moderate BPSD (eg major depression, verbal aggression, psychosis, sexual disinhibition, wandering)	Prevalence: 20% Management: By specialist consultation in primary care.
3	Dementia with mild BPSD (eg night-time disturbance, wandering, mild depression, apathy, repetitive questioning, shadowing)	Prevalence: 30% Management: By primary care workers.
2	Dementia with no BPSD	Prevalence: 40% Management: By selected prevention, through preventive or delaying interventions (not widely researched).
1	No dementia	Management: Universal prevention, although specific strategies to prevent dementia remain unproven.

Source: Brodaty H, Draper B and Low L, 'Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery', *Medical Journal of Australia*, 178(5) March 2003, p 233.

Brodaty et al identify the Commonwealth government as being primarily responsible for funding tiers one to three, with State governments responsible for tiers four to seven. They argue:

There needs to be collaboration between State and federal governments to fund dementia and BPSD prevention education programs that will in the long term reduce the need for higher-level services, delay institutionalisation and improve quality of life for people with dementia and their caregivers.<sup>214</sup>

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ibid, p 234.

## 6 DRIVING

The odds that an older driver involved in a fatal crash will be responsible for that crash have been calculated as 5.7 to 1 (compared to 0.75 for middle aged drivers and 2.2 for young adolescent drivers).<sup>215</sup> It has been estimated that there may be approximately 162,500 older drivers with cognitive impairment associated with dementia on Australian roads. According to Snellgrove, potentially 107,250 accidents may be attributable to these drivers every year.<sup>216</sup>

In NSW, individuals are required to undertake a medical examination every year from the age of 80 should they wish to retain their licence.<sup>217</sup> Driving tests are required every year from the age of 85. In the case of motorcyclists, medical and driving tests are required every year from the age of 80. The Roads and Traffic Authority (RTA) has produced *A Guide for Older Drivers*, available from [www.rta.nsw.gov.au](http://www.rta.nsw.gov.au) to provide older drivers with information about how to determine whether they are driving safely, how to continue to drive safely and when to hand in their licences to the RTA.

The holder of a drivers licence is required to notify the RTA of any long term injury or illness that may affect his or her ability to drive safely.<sup>218</sup> Doctors, the RTA or police may require some older drivers to undertake driving tests. In relation to people with dementia, the RTA suggests licence holders seek advice from their doctor and reconsider their driving ability, should they experience difficulty with any of the following:<sup>219</sup>

- Seeing things coming straight at you or from either side.
- Hearing the sound of approaching cars, car horns or sirens.
- Stopping, turning or speeding up quickly.
- Feeling confused or upset when more than one thing happens at a time.
- Becoming confused on familiar routes.
- Your mood changing when you are driving.

The medical standards for licensing and clinical management guidelines published by Austroads require a patient with a neurological disorder to be assessed to determine

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<sup>215</sup> Snellgrove C, *Cognitive screening for the safe driving competence of older people with mild cognitive impairment or early dementia*, January 2005, p 1. A copy of the study is available from the Australian Transport Safety Bureau [www.atsb.gov.au](http://www.atsb.gov.au) Accessed 24 January 2006.

<sup>216</sup> Ibid, p 4.

<sup>217</sup> NSW Roads and Traffic Authority, 'Older Drivers', [www.rta.nsw.gov.au](http://www.rta.nsw.gov.au) Accessed 16/2/06.

<sup>218</sup> NSW Roads and Traffic Authority, *A guide for older drivers*, p 53. [www.rta.nsw.gov.au](http://www.rta.nsw.gov.au)

<sup>219</sup> Ibid, p 64.

whether the sum of symptoms (physical, mental and behavioural) is compatible with driving.<sup>220</sup> The general management guidelines specific to dementia and other cognitive impairments state:

The person should not drive if there is significant impairment of memory, visuospatial skills, insight or judgement or if there are problematic hallucinations or delusions. Baseline and periodic review are required as most forms of cognitive impairment and dementia are progressive. Relatives may provide valuable information about driving ability; however, this information needs careful assessment. If unsure refer to a driver assessor. Where a driver assessment is refused by the patient, then consideration should be given to reporting the matter to the Driving Licensing Authority. Referral to a neuropsychologist may be helpful in cases of cognitive impairment.<sup>221</sup>

Carol Snellgrove recently completed a study funded by the Australian Transport Safety Bureau on the impact of early dementia or mild cognitive impairment on the driving competence of older people.<sup>222</sup> The study had two aims:

1. Describe the on-road driving performance of a group of older people with mild cognitive impairment or early dementia.
2. Validate a new cognitive screening instrument (the Maze Task) developed to indicate the likely competence of older people with mild cognitive impairment or early dementia.

115 older drivers with mild cognitive impairment or early dementia who lived in the community participated in the study. They were required to complete the Maze Task followed immediately by an on-road driving test. 70% of study participants failed the on-road test, most broke an important road law, and physical intervention was required in nearly half of the cases in order to prevent an accident. When the failure rate was further broken down, it was revealed that approximately half of those with mild cognitive impairment failed the driving test, as did three-quarters of those with early dementia.

The study determined that the difficulties in completing the on-road driving test were related to poor planning; poor observation skills regarding other vehicles, signs and signals; an inability to monitor and control the speed of the car; poor positioning of the car; confusion regarding the pedals and gears; and a lack of anticipatory or defensive driving. Most participants were not aware of their driving faults.

According to Snellgrove, the results highlight the need for cognitive screening of driving ability, as there are a number of concerns about the ability of older drivers with either mild

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<sup>220</sup> Austroads, *Assessing Fitness to Drive: Commercial and Private Vehicle Drivers*, 3<sup>rd</sup> edition, September 2003, p 71.

<sup>221</sup> Ibid.

<sup>222</sup> Snellgrove, above n 215.



cognitive development or early dementia to drive safely. She believes that:

Current Australian drivers licence renewal practices of physical and visual screening do not tap into those cognitive skills deemed necessary for safe driving; cognitive skills that are likely to be impaired in the expanding population of older people.<sup>223</sup>

She promotes the use of the Maze Task, as it correctly identified those drivers who would pass and fail the on-road test in 79% of cases. Therefore, the most dangerous drivers, as well as the most competent, could be determined without the need for an on road test.

Snellgrove accepts that it is difficult to determine the point at which driving becomes unsafe. She also notes that the use of a car links many older people to goods and services, and activities, including social ones. However, she describes the results of the study as 'hazardous or potentially catastrophic' and argues:

For reasons of individual and public road safety, a recommendation to preclude all older individuals with dementia, even in its early stage, from driving motor vehicles may well be appropriate.

Not all agree with the concept of a blanket prohibition. The position adopted by Alzheimer's Australia, as indicated by its Driving Policy Statement, is that whilst all people with dementia will reach a stage where it is not safe for them to drive, a person diagnosed with dementia should not be automatically precluded from driving.<sup>224</sup> It notes that the automatic cancellation of a licence could discourage people from presenting for early diagnosis and treatment. Clearly, a number of factors need to be considered when determining the appropriate policy for older drivers with dementia.

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<sup>223</sup> Ibid, p 32.

<sup>224</sup> Alzheimer's Australia, *Driving Policy Statement*, March 2004.

## 7 ELDER ABUSE

According to the Law and Justice Foundation, elder abuse includes the following:<sup>225</sup>

- financial abuse;
- psychological abuse;
- physical abuse;
- sexual abuse;
- neglect; and
- multiple abuses.

Studies have found that people with dementia are more likely to suffer financial abuse and neglect by a carer, whereas carers are more likely to suffer physical and psychological abuse.<sup>226</sup> The circumstances in which people with dementia are abused can differ dramatically. As Koch and Nay have highlighted: it may have commenced after diagnosis; it may be long-term domestic violence that has continued after the onset of dementia; or it may be retribution where the carer (the previous victim) becomes the abuser of the person with dementia (the previous perpetrator).<sup>227</sup>

### 7.1 Preventive strategies

People with dementia and their carers have been found to be particularly vulnerable to elder abuse.<sup>228</sup> Factors that contribute to the greater risk include: stresses placed on the carer in relation to caring for a person with dementia; carer stress due to other life factors; psychopathology or substance abuse by the carer; and a history of domestic violence.<sup>229</sup> A study by Koch and Nay identified the following as factors that had contributed to abuse involving a person with dementia:<sup>230</sup>

- insufficient staff numbers;

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<sup>225</sup> Ellison et al, above n 127.

<sup>226</sup> Weeks E and Sadler P, *Elder Abuse and Dementia*, Discussion Paper 1, NSW Advisory Committee on Abuse of Older People, Sydney, April 1997, p 8.

<sup>227</sup> Koch S and Nay R, 'Reducing abuse of older people with dementia and their carers', *Australasian Journal on Ageing*, 22(4) December 2003, p 191.

<sup>228</sup> *Ibid*, p 192.

<sup>229</sup> *Ibid*.

<sup>230</sup> *Ibid*, p 193.

- increased carer stress;
- lack of education on dementia;
- lack of education on the antecedents of abuse;
- lack of professional supports;
- lack of engaging activities suitable for the person with dementia;
- inadequate practices;
- inflexible systems and poor environments;
- vulnerability of people with dementia and their carers;
- disempowerment of carers and people with dementia; and
- lack of respite.

Participants in the study included: an individual with dementia; carers; carer supports; co-ordinators; counsellors; managers; registered nurses; a Director of Nursing; an Assistant Director of Nursing; Clinical Nurse Consultants; Enrolled nurses; occupational therapists; a physiotherapist; and social workers, amongst others.

Koch and Nay therefore suggested the following preventive strategies be adopted:<sup>231</sup>

1. Recognise the stressors related to dementia and caring for a person with dementia.
2. Recognise the role of carers and reflect this in the organisation and delivery of services.
3. Provide for more flexibility in service provision.
4. Provide easier access to information about services.
5. Lobby government for improved services.
6. Raise public awareness of the issues related to dementia and abuse.
7. Provide education regarding the benefits/problems of enduring power of guardian and powers of attorney.
8. Provide information identifying a first point of contact and ensure the contact point can provide useful, non-judgmental and supportive information.

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<sup>231</sup>

ibid, p 194.

9. Provide carers with access to education about how to care for the person with dementia, how to care for themselves and information on the process of dementia.
10. Provide information about dementia, choice of care provision, and information on services already available.

### **7.1.1 Abuse of Older People: Inter-Agency Protocol**

The NSW Advisory Committee on Abuse of Older People published the *Abuse of Older People: Inter-Agency Protocol* in October 1995.<sup>232</sup> The development of the protocol fulfilled one of the major recommendations of the NSW Task Force on Abuse of Older People in 1993. The Protocol provides that:

All service providers, training officers, policy officers from government and non-government bodies can use this protocol to become acquainted with the issues of abuse of older people, to become aware of the referral networks, to train staff, and to develop processes to handle cases of abuse of older people. It is not necessary to have firm ‘proof’ of abuse in order to use the protocol.<sup>233</sup>

The Protocol protects professionals, agencies and workers who follow it in terms of assisting them in demonstrating that they have taken all possible steps in carrying out their duty of care.<sup>234</sup> It does not deal with abuse in residential aged care facilities, as that is primarily a Commonwealth responsibility. See section 7.1.2 for discussion of this aspect of elder abuse.

The Protocol notes that the following principles were established by the NSW Task Force on Abuse of Older People and subsequently accepted and endorsed by the NSW Government in 1992:<sup>235</sup>

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<sup>232</sup> A copy of the protocol may be accessed from the NSW Department Ageing, Disability and Home Care website: [www.dadhc.nsw.gov.au](http://www.dadhc.nsw.gov.au)

<sup>233</sup> NSW Advisory Committee on Abuse of Older People, *Abuse of Older People: Inter-Agency Protocol*, October 1995, p 2.

<sup>234</sup> *Ibid*, p 3.

<sup>235</sup> *Ibid*, pp 4-5; see also New South Wales Task Force on Abuse of Older People, *Abuse of Older People in their Homes: Final Report and Recommendations*, January 1993, pp 10-11.

<b>General principles</b>	Older people have a right to live safely in their own homes, free of violence, abuse, neglect and exploitation.
	Older people are entitled to make their own decisions on matters affecting their lives.
	Older people are entitled to participate in the development and implementation of services, policies and programs affecting them.
	Older people are entitled to autonomy and dignity.
	The welfare, rights and interests of older people should be of paramount consideration in decisions affecting them.
	Older people are entitled to comprehensive, accurate and accessible information and advice about their rights and options, to enable them to make informed decisions.
	Older people should be provided with assistance which is culturally and linguistically appropriate.
	Communities of Aboriginal people and people of non-English speaking background should be encouraged and supported to establish infrastructures and services to meet the needs of older people within their community which cannot be met by mainstream services.
<b>Principles for Intervention</b>	Self determination is to be encouraged. Individuals are to be encouraged and assisted to make their own decisions, provided with information about all relevant options and given the option to refuse services if able to do so. Even where people cannot make all of their own decisions, their views should be taken into account.
	The interests of the victim take precedence over those of the victim’s family or of other members of the community.
	Intervention must be victim focussed with a view to ensuring safety and ongoing protection from violence and abuse.
	Victims of violence, abuse, threats, intimidation and harassment should be offered protection through legal remedies.
	Assault and some other forms of abuse (eg theft and fraud) are criminal offences.
	Confidentiality of information is to be respected in accordance with professional ethics, agency policy and legal obligations.
	The desire of an older person for an independent advocate of their own choice should be respected.

The Protocol recommends that the following factors be considered when making decisions about the possible abuse of older people:

1. Worker’s judgments: workers need knowledge and skills, and access to the relevant resources and networks.
2. Older person’s capacity: an assessment of the capacity of the older person is the

primary consideration.

3. Effects: the frequency, duration and severity of the abuse.
4. Intention: focus on the effects on the older person rather than the intention of the abuser.
5. Documentation: document observations and information received about suspected abuse or neglect.

People with dementia and their carers are deemed by the Protocol to be a group with special needs. According to the Protocol, a full multi-disciplinary assessment by a geriatric health service or Aged Care Assessment Team is essential in cases of abuse that involve a person with dementia. Useful interventions include respite care, carer support services and dementia care counsellors.

The Aged and Community Services Association (ACS) has called for a review of the Inter-Agency Protocol on Abuse of Older People.<sup>236</sup> The NSW Department of Ageing, Disability and Home Care has recently established a working group to review the effectiveness of the Inter-Agency Protocol by June 2006.<sup>237</sup> The NSW Government has indicated its desire to: strengthen the ongoing training requirements of agency staff; re-examine the reporting requirements; co-ordinate a quick and appropriate response when abuse is reported; and ensure that the training, policies and support initiatives of agencies are co-ordinated and consistent.

### 7.1.2 *Mandatory reporting*

Many incidents of elder abuse are not reported. The Law and Justice Foundation of NSW has identified some of the barriers that hinder the reporting of elder abuse. These barriers include:<sup>238</sup>

- A lack of community and professional awareness about the problem.
- A lack of identification of certain situations as constituting elder abuse, for example, where no physical violence is being experienced.
- People may not know who will be able to help them – who do they report it to and what will they do?
- Victims of elder abuse tend to be quite isolated, which means that they may not be able to access assistance and that the abuse continues in the absence of the scrutiny

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<sup>236</sup> Aged and Community Services Association of NSW and ACT, 'Mandatory reporting for elder abuse no answer', *Media Release*, 21/2/06.

<sup>237</sup> The Hon John Della Bosca MLC, 'Elder Abuse', *NSWPD*, 28/3/06.

<sup>238</sup> Ellison et al, above n 127, p 283.

of others.

- Older people and professionals may be afraid that the consequences of reporting the abuse will place the victim in a worse position than they are currently in, such as being institutionalised.
- Older people may be ashamed that they are being abused by people they should be able to trust, such as close family members, they may not want to jeopardise important relationships with family or friends, or may fear retaliation from their abuser.
- Health professionals may lack protocols and procedures for addressing abuse.

Other barriers include<sup>239</sup>

- lack of awareness of legal rights;
- lack of confidence in enforcing their rights;
- the affordability of legal services;
- lack of awareness on where to obtain legal information;
- lack of interest and/or expertise by some legal practitioners in older clients and their specialist legal needs; and
- potential conflict of interests when legal practitioners for older people are arranged by family members.

Whether the reporting of elder abuse should be mandatory remains a controversial issue. One of the factors that distinguish it from the reporting of child abuse is that adults, as opposed to minors, are involved. Some have raised concerns that mandatory reporting will result in a loss of autonomy for older people, as they will be treated in a similar way to children. This section notes some of the outcomes of recent discussions by various committees on the issue of mandatory reporting.

#### *Aged Care Advisory Committee*

The Aged Care Complaints Resolution Scheme provides a forum for a person who wishes to make a complaint about a Commonwealth funded aged care service.<sup>240</sup> The issue of elder abuse, including the abuse of older people with dementia, was recently in the spotlight following allegations on *Lateline* on ABC television that a number of elderly residents with

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<sup>239</sup> Elder Abuse Prevention Project, *Strengthening Victoria's Response to Elder Abuse*, Report of the Elder Abuse Prevention Project, Office of Senior Victorians, Melbourne, 2005, p 27.

<sup>240</sup> *Ibid*, p 21.

dementia in a nursing home in Victoria had been sexually abused in 2005.<sup>241</sup> The program raised the issue of mandatory reporting. It noted that no Australian state has mandatory reporting for elder abuse, as automatic intervention risks the destruction of families and well-meaning carers.

Following the allegations of abuse, the Federal Minister for Ageing, Senator Santo Santoro, announced that he would consider any proposal that would prevent elder abuse. A special meeting of the Aged Care Advisory Committee was held on 14 March 2006. The Committee was to consider possible solutions to allegations of abuse in aged care facilities.<sup>242</sup> Some possibilities included: police checks on staff; mandatory reporting of suspected or actual abuse; consideration of the state of the complaints scheme and whether improvements should be made; and protection of whistleblowers.

Dr Mukesh Haikerwal, President of the Australian Medical Association, argued that mandatory reporting of elder abuse in aged care must be seriously considered at the summit.<sup>243</sup> However, Paul Sadler, the Chief Executive Officer of Aged and Community Services Association of NSW and ACT argued that mandatory reporting is not the answer, stating 'claims that Australia needs an American-style system of mandatory reporting are misguided... There are effective laws already against physical assault and fraud and guardianship legislation in situations where people cannot make their own decisions'.<sup>244</sup> Nonetheless, Mr Sadler agreed that the Complaints Resolution Scheme needed to be reviewed, as it does not have the authority to make a final determination following an investigation of a complaint.

Reports of the Summit indicated that the Committee was split on the issue of mandatory reporting.<sup>245</sup> It is thought that Senator Santoro will propose to Cabinet that police checks of aged-care staff be introduced, as well as more surprise inspections of aged care facilities and improved complaints mechanisms.<sup>246</sup>

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<sup>241</sup> 'Claims of sexual abuse at Victorian nursing homes', *Lateline*, ABC television, 20/2/06.

<sup>242</sup> Santoro S, 'Aged care advisory committee meeting on abuse claims', *Media Release*, 26/2/06.

<sup>243</sup> Australian Medical Association, 'Older Australians must be protected', *Media Release*, 22/2/06.

<sup>244</sup> Aged and Community Services Association of NSW and ACT, 'Mandatory reporting for elder abuse no answer', *Media Release*, 21/2/06. The Law and Justice Foundation of NSW has identified various statutes in NSW that may be used to deal with aspects of elder abuse: *Crimes Act 1900* (NSW) – assault and theft; *Contracts Review Act 1980* (NSW) – improper contracts; and the *Family Provision Act 1982* (NSW) – disputed wills, unconscionability, undue influence: Ellison et al, above n 127, p 287.

<sup>245</sup> 'Aged care staff face police screening', *Sydney Morning Herald*, 15/3/06, p 3.

<sup>246</sup> 'Reporting sex abuse not part of my job: aged-care manager', *Sydney Morning Herald*, 16/3/06, p 3.



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*Elder Abuse Prevention Project*

The Elder Abuse Prevention Project was established in Victoria in March 2005 to consult and report on current prevention and response arrangements to elder abuse in Victoria. A report was published in December 2005.<sup>247</sup>

The Advisory Committee adopted the following definition of elder abuse:

Any act occurring within a relationship where there is an implication of trust, which results in harm to an older person. Abuse may be physical, sexual, financial, psychological, social and/or neglect.<sup>248</sup>

According to the Committee, financial abuse is reported most often.<sup>249</sup> Whilst the Committee recognised that elder abuse does occur in institutional care, it stressed that it is more likely to occur in the community.<sup>250</sup> The Committee considered various studies of elder abuse that have been conducted in Australia and noted that its prevalence is generally estimated as between 1 and 5% of the ageing population and is most likely to occur between the ages of 75 and 85.<sup>251</sup>

One of the factors identified by the Committee as likely to stimulate an increase in the number of incidents of elder abuse is the growing number of people with dementia, as mental impairment is a risk factor for abuse. The Committee considered possible strategies that could be adopted to prevent elder abuse and to assist older people in dealing with abuse. As part of the consultation process, the Committee considered the introduction of mandatory reporting and statutory audit protection services. However, the Committee did not support their introduction, as it found minimal support in the available evidence for such strategies as well as no proof of their effectiveness in relation to older people. The criminal law was not found to be inadequate nor had any state introduced mandatory reporting after considering the issue. They also believed there was the potential for mandatory reporting to become a crisis response service, and thus shift emphasis from prevention. The Committee stressed:

the absence of mandatory reporting, be it in the United States or Australia, does not mean the absence of reporting altogether. In Victoria there is no prohibition on members of the public or professionals voluntarily expressing their concern to a response service be it the OPA [Office of the Public Advocate], the police or a community-based service.<sup>252</sup>

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<sup>247</sup> Elder Abuse Prevention Project, above n 239.

<sup>248</sup> Ibid, p 12.

<sup>249</sup> Ibid, p 26.

<sup>250</sup> Ibid, p 12.

<sup>251</sup> Ibid, p 13.

<sup>252</sup> Ibid, p 29.

The Committee suggested that a response to elder abuse should involve.<sup>253</sup>

- provision of community education to raise awareness;
- support for communities to feel safe and confident and address social isolation;
- building professional knowledge and capability;
- improving the effectiveness of service responses; and
- providing support to older people in need of assistance.

It has been suggested that to require the mandatory reporting of elder abuse is to liken it to child abuse and ‘compel the infantilisation of older people’.<sup>254</sup> The Committee emphasised the need to understand the rights and decision-making capacities of older people in the community. It accordingly recommended:

That the Victorian Government strengthens its response to elder abuse based on current legislative and service arrangements. This approach recognises the right of older people to determine their own course of action, and where required, access practical assistance to support their needs to deal with situations of abuse and regain independence and control over their lives.<sup>255</sup>

However, the situation for those with dementia is arguably more complex, as their capacity for making decisions is often reduced.

#### *NSW Advisory Committee on Abuse of Older People in their Homes*

The NSW Advisory Committee on Abuse of Older People in their Homes published its final report in October 1997.<sup>256</sup> It estimated that there were up to 25,000 older victims of abuse in NSW.<sup>257</sup> The NSW Advisory Committee on Abuse of Older People highlighted in its 1997 discussion paper, *Elder Abuse and Dementia*, that the difficulties surrounding the appropriate response to elder abuse involve questions about freedom of choice compared to the need for safety. The Committee noted that older people have the right to: choice; privacy; independence; a decent quality of life; and protection and safety.<sup>258</sup> Where the

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<sup>253</sup> Elder Abuse Prevention Project, above n 239, p 31.

<sup>254</sup> Ellison et al, above n 127, p 283.

<sup>255</sup> Recommendation 1.

<sup>256</sup> NSW Advisory Committee on Abuse of Older People in their Homes, *Abuse of Older People: The Way Forward*, Ageing and Disability Department, Sydney, 1997.

<sup>257</sup> Ibid, p 11.

<sup>258</sup> Weeks and Sadler, above n 226, p 13.

rights of an older person with dementia and an older person who is the carer are in conflict, the rights of the victim of abuse are to prevail.<sup>259</sup>

Amongst other things, the Committee considered the possibility of introducing mandatory reporting in NSW and concluded that it should not be adopted as a policy as yet. An earlier discussion paper produced by the Committee noted that the following arguments had been advanced in support of mandatory reporting:<sup>260</sup>

- Mandatory reporting protects older people by ensuring that all cases of abuse are brought to public attention.
- Mandatory reporting puts the issue on the social agenda.
- Mandatory reporting provides clear procedures.
- A large number of reports may lead to allocation of additional funding to address the problem.

However, the Committee questioned the extent to which each of these supposed benefits have been realised in those places where mandatory reporting is required. The final report and recommendations of the NSW Task Force on Abuse of Older People published in January 1993 reaffirmed that mandatory reporting should not be introduced as the arguments against it were deemed to be stronger than those in favour of it.<sup>261</sup> It also stressed that the absence of mandatory reporting does not prevent abuse from being reported.

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<sup>259</sup> Ibid.

<sup>260</sup> NSW Advisory Committee on Abuse of Older People, *Mandatory Reporting of Abuse of Older People*, Discussion Paper 4, Ageing and Disability Department, Sydney, 1997, p 16.

<sup>261</sup> New South Wales Task Force on Abuse of Older People, above n 235, p 43.

## 8 CONCLUSION

Dementia is an increasingly important issue, as the number and proportion of people with dementia continues to grow. People are living longer than ever before and an ageing of our population is occurring. Recognition of the importance of this phenomenon resulted in dementia being deemed a national health priority in 2005.

Almost 1% of the population has dementia. Many more are involved in the care for and support of a family member or friend with dementia. Whilst the prevalence of dementia increases with age, it must be stressed that the majority of older Australians do not have dementia.

The economic impact of dementia is significant. Its current cost has been estimated to be \$6.6 billion (about 1% of GDP). It is predicted that the cost of dementia will rise to 3% of GDP by 2050 when dementia will also be the largest cause of disability burden in Australia.

The experience of people with dementia is diverse. It depends on such things as the form of dementia and its severity, whether people have planned for the time when they may no longer have the capacity to make decisions, and the availability of support services and potential carers that prolong the time one may continue to reside in the community.

Whilst there is not yet a known cure or prevention for dementia, there is a need for more education about dementia to encourage people to engage in activities and make lifestyle choices thought to reduce the risk of it developing. Education can also lead to earlier diagnosis as well as a greater awareness of the options available once a diagnosis is made. This includes the availability of such things as medication to manage some of the symptoms of dementia, and the various support services that exist for those with dementia and their carers.

Unless there are medical breakthroughs, the presence of dementia will only become more marked. The report by Access Economics on *The Dementia Epidemic* referred to the following analogy to describe the growing importance of dementia:

A century ago, Australia's birth rate was much higher, but few people survived to old age. With better sanitation, the dangers of the past – infectious diseases and childbirth – became far less serious threats to our health. As the tide of infectious diseases receded, the rocks that were always there were exposed – systemic degenerative diseases such as cardiovascular disease and cancer. But, gradually, even these problems are receding as we see the benefits of prevention programs and the better treatments possible with new technologies, particular new surgeries and drugs. As the tide recedes further, the new rocks to be revealed are the neurodegenerative diseases that strike the brain most often in old age. It is predicted that the neurodegenerative disorders will over the next two decades replace the systemic disorders as the major causes of both death and disability. Managing the challenges presented by these diseases, most notably dementia, will be the overwhelming

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priority of health care in the 21<sup>st</sup> century.<sup>262</sup>

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Access Economics, above n 6, p iii. The report notes that the analogy of the receding tide is drawn from Jorm, paraphrased, in turn drawn from Gavin Andrews of St Vincent's Hospital, Sydney.