

The Senate

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Community Affairs

References Committee

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Care and management of younger and  
older Australians living with dementia and  
behavioural and psychiatric symptoms of  
dementia (BPSD)

March 2014

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## **Secretariat**

Mr Matthew Crawshaw (Committee Secretary)

Dr Ian Holland (Committee Secretary)

Mr Gerry McInally (Principal Research Officer)

Dr Richard Grant (Principal Research Officer)

Ms Erin East (Principal Research Officer)

Mr Jarrod Baker (Senior Research Officer)

Ms Annemieke Jongsma (Senior Research Officer)

Ms Monika Sheppard (Senior Research Officer)

Ms Elise Williamson (Research Officer)

Ms Eloise Menzies (Research Officer)

Ms Carol Stewart (Administrative Officer)

PO Box 6100  
Parliament House  
Canberra ACT 2600

Phone: 02 6277 3515

Fax: 02 6277 5829

E-mail: [community.affairs.sen@aph.gov.au](mailto:community.affairs.sen@aph.gov.au)

Internet: [www.aph.gov.au/senate\\_ca](http://www.aph.gov.au/senate_ca)

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# MEMBERSHIP OF THE COMMITTEE

## 43<sup>rd</sup> Parliament

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## 44<sup>th</sup> Parliament

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| Senator the Hon Lin Thorp (from 6 March) | Tasmania, ALP           |

### Substitute members

|   |               |
|---|---------------|
| Senator the Hon Lin Thorp<br>for Senator Carol Brown<br>(from 4 December 2013 to 26 March 2014) | Tasmania, ALP |
|---|---------------|

### Participating members for this inquiry

|                           |                 |
|---------------------------|-----------------|
| Senator Carol Brown       | Tasmania, ALP   |
| Senator Claire Moore      | Queensland, ALP |
| Senator the Hon Lin Thorp | Tasmania, ALP   |



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## ABBREVIATIONS

|             |   |
|-------------|---|
| ACAP        | Aged Care Assessment Program  |
| ACAT        | Aged Care Assessment Team   |
| ACFI        | Aged Care Funding Instrument  |
| ADARDS      | Alzheimer's Disease and Related Disorders Society   |
| AIHW        | Australian Institute of Health and Welfare  |
| AMA         | Australian Medical Association  |
| APS         | Australian Psychological Society  |
| BPSD        | Behavioural and Psychological Symptoms of Dementia<br>(formerly Behavioural and Psychiatric Symptoms of Dementia) |
| CHSP        | Commonwealth Home Support Program   |
| DBMAS       | Dementia Behaviour Management Advisory Service  |
| Department  | Department of Health and Ageing   |
| DSM-5       | <i>Diagnostic and Statistical Manual 5</i>  |
| DSP         | <i>Dementia Services Pathways – An essential guide to effective service planning</i>                              |
| DSS         | Department of Social Services   |
| ERA         | Elder Rights Advocacy   |
| GPs         | General Practitioners   |
| HACC        | Home and Community Care   |
| HCPP        | Home Care Packages Program  |
| Key workers | Younger Onset Dementia Key Workers  |
| KWP         | Key Worker Program  |
| NDIS        | National Disability Insurance Scheme  |
| NDS         | National Disability Services  |
| NHPA        | National Health Priority Area   |
| NRCP        | National Respite for Carers Program   |
| NSWNMA      | New South Wales Nurses and Midwives' Association  |
| PAG         | Planned Activity Groups   |
| PBS         | Pharmaceutical Benefits Scheme  |
| PCC         | Person-centred care   |

|        |   |
|--------|---|
| RACF   | Residential aged care facility                            |
| RACFs  | Residential aged care facilities                          |
| RACGP  | Royal Australian College of General Practitioners         |
| RANZCP | Royal Australian and New Zealand College of Psychiatrists |
| SARRAH | Services for Australian Rural and Remote Allied Health    |
| WHO    | World Health Organisation                                 |
| YOD    | Younger onset dementia                                    |
| YPINH  | Young People in Nursing Homes National Alliance           |



# **LIST OF RECOMMENDATIONS**

## **Recommendation 1**

**2.42** The committee recommends that the Commonwealth create a new Medicare item number that encourages General Practitioners, registered psychologists or other relevant accredited professionals, to undertake longer consultations with a patient and at least one family member or carer where the patient has presented with indications of dementia.

## **Recommendation 2**

**3.39** The committee recommends that the Commonwealth consider increasing funding for the Younger Onset Dementia Key Worker Program in order to provide support to all people living with dementia. The increased funding should also ensure that accurate data is collected for evaluation purposes.

## **Recommendation 3**

**3.40** The committee recommends that each State and Territory develop dementia training facilities similar to the Perc Walkley Dementia Learning Centre in Victoria.

## **Recommendation 4**

**3.53** The committee recommends that the Commonwealth encourage relevant professional organisations, such as the Royal Australian College of General Practitioners, to ensure that patients diagnosed with dementia and their carers are informed by health professionals of the dementia supports available and how to access them.

## **Recommendation 5**

**3.95** The committee recommends that the Commonwealth facilitate and potentially fund the establishment of dementia-specific respite facilities, including in regional and remote areas.

## **Recommendation 6**

**3.96** The committee recommends that the Commonwealth, in consultation with industry, develop guidelines regarding dementia-specific respite facilities that can effectively manage BPSD.

### **Recommendation 7**

**3.97** The committee recommends that the Commonwealth explore options for improving the provision of respite in rural and remote areas.

### **Recommendation 8**

**4.79** The committee recommends that the accreditation standards for Residential Aged Care Facilities include requirements for dementia-friendly design principles.

### **Recommendation 9**

**4.80** The committee recommends that the accreditation standards for Residential Aged Care Facilities reflect a better balance between clinical and quality-of-life outcomes.

### **Recommendation 10**

**5.44** The committee recommends that a phased program of accredited training in dementia and the management of Behavioural and Psychological Symptoms of Dementia (BPSD) be required for all employees of Residential Aged Care Facilities.

### **Recommendation 11**

**5.45** The committee recommends that the Commonwealth take a proactive stance in highlighting the importance of staff training in dementia care, and develop linkages between care and education providers.

### **Recommendation 12**

**6.19** The committee recommends that the use of antipsychotic medication should be reviewed by the prescribing doctor after the first three months to assess the ongoing need.

### **Recommendation 13**

**6.20** The committee recommends that residential aged care facilities, as part of their existing Aged Care Standards and Accreditation Agency annual audit process, report:

- circumstances where an individual has been prescribed antipsychotic medication for more than six months, together with the reasons for and any steps taken to minimise that use; and
- general usage patterns of antipsychotic medications in each facility.

#### **Recommendation 14**

**6.31** The committee recommends that the Commonwealth develop, in consultation with dementia advocates and service providers, guidelines for the recording and reporting on the use of all forms of restraints in residential facilities.

#### **Recommendation 15**

**6.32** The committee recommends that the Commonwealth collect and report:

- the number of residents in aged care and acute care facilities with a diagnosis of dementia;
- the number of these residents who are taking, or have taken, antipsychotic medication;
- the number of instances where a patient has been prescribed multiple anti-psychotic medications;
- the reason the medication was prescribed; and
- the average duration of a course of prescribed antipsychotics.

#### **Recommendation 16**

**6.48** The committee recommends that the Commonwealth undertake an information program for doctors and residential aged care facilities regarding the guidelines *Responding to Issues of Restraint in Aged Care in Residential Care*.

#### **Recommendation 17**

**7.29** The committee recommends that a review of the adequacy of respite facilities for Younger Onset Dementia patients be carried out urgently.

#### **Recommendation 18**

**7.30** The committee recommends that the Commonwealth fund the development of a pilot Younger Onset Dementia specific respite facility at either the Barwon or Hunter area National Disability Insurance Scheme trial sites.



# Chapter 1

## **The care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)**

### **Terms of Reference**

1.1 On 28 February 2013, the Senate referred the following matter to the Senate Community Affairs References Committee (committee) for inquiry and report:

(a) the scope and adequacy of the different models of community, residential and acute care for Australians living with dementia and BPSD, with particular reference to:

- (i) Commonwealth-provided support and services,
- (ii) state- and territory-provided services, and
- (iii) services provided by the non-government sector;

(b) resourcing of those models of care; and

(c) the scope for improving the provision of care and management of Australians living with dementia and BPSD, such as:

- (i) access to appropriate respite care, and
- (ii) reduction in the use of both physical and chemical restraints.

1.2 The reporting date for the inquiry was set by the Senate for 26 June 2013. On 18 June 2013, the Senate granted an extension of time to report until 12 August 2013. On 12 August 2013, the committee tabled an interim report expressing the committee's intention to seek re-referral from the Senate to continue work on this inquiry in the 44<sup>th</sup> Parliament.

1.3 The new Parliament re-referred the inquiry to the committee with the same terms of reference, for reporting on 28 February 2013.

### **Conduct of the inquiry**

1.4 The committee invited submissions from Commonwealth, State and Territory governments and interested organisations. The committee received public submissions from 62 organisations and individuals (listed at Appendix 1).

1.5 Five public hearings were held over the course of the inquiry:

- Hobart – 10 July 2013;
- Canberra – 17 July 2013;
- Melbourne – 16 December 2013;
- Warracknabeal, Victoria – 17 December 2013; and
- Canberra – 14 February 2014.

1.6 A list of witnesses who appeared before the committee is set out in Appendix 2.

1.7 Submissions, additional information, the *Hansard* transcript of evidence and responses to questions on notice can be accessed through the committee's website at: [http://www.aph.gov.au/Parliamentary\\_Business/Committees/Senate/Community\\_Affairs/Dementia](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Dementia).

1.8 References in this report are to individual submissions as received by the committee, not to a bound volume.

1.9 The committee would like to especially thank the staff and residents at the Yarriambiack Lodge in Warracknabeal in Victoria. The committee had the opportunity to visit the lodge, meeting with the residents, staff and families there. Seeing the options that are available for persons living with dementia in residential aged care facilities shaped much of the thinking in this report.

1.10 The committee also received the hospitality of the Alzheimer's Australia Vic.'s Perc Walkley Dementia Learning Centre in Melbourne and were provided with a glimpse of what it is like to live with dementia through the centre's virtual reality facilities.

1.11 Due to the prorogation of the 43<sup>rd</sup> Parliament, this inquiry was more protracted than most committee inquiries, and the committee thanks those who participated in the inquiry for their patience.

### ***House of Representatives Inquiry***

1.12 On 24 June 2013, the House of Representatives' Standing Committee on Health and Ageing presented a report, *Inquiry into Dementia: Early diagnosis and Intervention* (House report).<sup>1</sup> The House report focused on ways to improve early diagnosis and to improve the quality of life for people with dementia by remaining independent as long as possible. While there is some cross-over between the House report and this report, the committee has endeavoured to complement the House report rather than reproduce or counter it.

### **Structure of the committee's report**

1.13 The committee's report is comprised of six chapters:

- chapter 2 provides an overview of dementia in Australia;
- chapter 3 discusses community care;
- chapters 4 and 5 consider residential care;
- chapter 6 reviews the use of restraints in aged care;
- chapter 7 summarises issues particular to younger onset dementia; and
- chapter 8 presents the committee's concluding comments.

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1 House Standing Committee on Health and Ageing, *Inquiry into Dementia: Early diagnosis and Intervention*, June 2013.

# Chapter 2

## What is Dementia?

2.1 Many Australians have an intuitive understanding of what constitutes dementia, sometimes derived from personal experience. The Department of Health and Ageing<sup>1</sup> (Department) reported 'nearly 1.5 million Australians are affected by dementia including the families and carers of people living with dementia'.<sup>2</sup> The Australian Institute of Health and Welfare (AIHW) provides a useful introduction to dementia:

Dementia is not a single specific condition. Rather, it is an umbrella term that describes a syndrome associated with more than 100 different conditions which are characterised by the impairment of brain functions, including language, memory, perception, personality and cognitive skills. Although the type and severity of symptoms and their pattern of development varies with the type of dementia, it is usually of gradual onset, progressive in nature and irreversible.

...

In the early stages of the condition, close family and friends may notice symptoms such as memory loss and difficulties with finding familiar words, but the casual observer may not notice any symptoms. In the mid-stages, difficulties may be experienced with familiar tasks, such as shopping, driving or handling money. In the latter stages, difficulties extend to basic or core activities of daily living, such as self-care activities, including eating, bathing and dressing.<sup>3</sup>

2.2 The causes of dementia remain poorly understood:

Dementia is not a natural part of ageing, although the great majority of people with dementia are older people. Many diseases can cause dementia, the most common being *Alzheimer disease*. Other common forms include *Vascular dementia*, dementia with Lewy bodies, frontotemporal dementia (including *Pick disease*) and mixed forms of dementia.<sup>4</sup>

2.3 Although the epidemiology is poorly understood, issues such as alcohol, traumatic brain injury, the human immunodeficiency virus, multiple sclerosis and a range of metabolic, infectious, neoplastic and autoimmune disorders have been linked to younger onset dementia (YOD).<sup>5</sup> Indigenous Australians are also more likely to

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1 Following the 2013 federal election, the Department of Health and Ageing was renamed the Department of Health. This report uses the title Department of Health and Ageing in order to reflect the evidence at the time it was provided to the committee.

2 Department of Health and Ageing (Department), *Submission 56*, p. 6.

3 *Dementia*, <http://www.aihw.gov.au/dementia/> (accessed: 26 March 2014).

4 For a comprehensive list of specific types of dementia, see: Australian Institute of Health and Welfare, *Dementia in Australia*, 2012, p. 2.

5 Royal Australian and New Zealand College of Psychiatrists, *Submission 49*, p. 7.

present with dementia, as are those with disabilities such as Down syndrome or Huntington's disease.<sup>6</sup>

2.4 The course of dementia is often characterised as occurring in three stages:

- mild or early-stage dementia;
- moderate or middle-stage dementia; and
- severe or late stage dementia.

2.5 The following table, reproduced from the AIHW's *Dementia in Australia*, provides an overview of these stages:

| Stage                     | Description   |
|---------------------------|---|
| <b>Mild or early</b>      | Deficits are evident in a number of areas (such as memory and personal care) but the person can still function with minimal assistance.<br>Symptoms include: moderate memory loss especially for recent events, some disorientation in time, moderate difficulties with problem solving, reduced interest in hobbies, and the need for prompting regarding personal care tasks.   |
| <b>Moderate or middle</b> | Deficits become more obvious and severe, and increasing levels of assistance are required to help the person maintain their functioning in the home and community.<br>Symptoms include: severe memory loss, considerable difficulty orienting to time and place, obvious difficulties in finding words, severe impairment of judgement and problem solving, need for assistance with personal care tasks, and emergence of behavioural difficulties (for example, wandering, aggression, sleep disturbance and disinhibited behaviour). |
| <b>Severe or late</b>     | Characterised by almost total dependence on the care and supervision by others.<br>Symptoms include: very severe memory loss, very limited language skills, unable to make judgements or solve problems, regularly not recognising familiar people, frequent incontinence, requires substantial assistance with personal care, and increased behavioural difficulties.<br>By this stage the majority of people with dementia are in residential care.   |

Sources: Draper 2011; Morris 1993.<sup>7</sup>

2.6 It is important to remember that there are crossovers between the stages and progress through each stage is not always easy to define. The stages merely provide a useful framework for discussions.

2.7 The American Psychiatric Association's *Diagnostic and Statistical Manual 5* (DSM-5) reclassified dementia as major Neurocognitive Disorder.<sup>8</sup> Some forms of dementia may also fall under a new category called mild Neurocognitive Disorder. The DSM-5 does not preclude the use of the term dementia from use in the etiological sub-types where that form is standard. Due to the terminology used in the evidence, this report will use the term dementia.

### ***Behavioural and Psychological Symptoms of Dementia***

2.8 Behavioural and Psychological Symptoms of Dementia (BPSD) is defined as:

6 Mr Cunningham, Director – The Dementia Centre, HammondCare, *Committee Hansard*, 17 July 2013, p. 19; Dr Baker, Chief Executive, National Disability Services, *Committee Hansard*, 14 February 2014, p. 9.

7 Australian Institute of Health and Welfare, *Dementia in Australia*, 2012, p. 3.

8 *Highlights of changes from DSM-IV-TR to DSM-5*, American Psychiatric Publishing, p.16.



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Symptoms of disturbed perception, thought content, mood or behaviour that frequently occurs in patients with dementia. These include aggression, apathy, anxiety, agitation, psychotic symptoms, depression, disinhibited behaviours, wandering, nocturnal disruption and vocally disruptive behaviours.<sup>9</sup>

2.9 BPSD is common in people with dementia and may occur for many reasons other than direct changes in the brain from dementia: these include having important unmet needs; physical or mental distress or illness; or reactions to medications and factors in their environment.<sup>10</sup>

2.10 The effects of dementia on a person not only impede memory, but also have significant effects on perception. Ensuring that care environments are appropriate for people with dementia is an important step toward improving the care of people with dementia in residential and community care. These concerns are covered more fully in chapters 3 and 4 of this report.

2.11 The committee heard that symptoms widely described as BPSD are attempts by a person with dementia to communicate that their needs are not being met. These behaviours can be perceived as disruptive when they are not understood.<sup>11</sup> Although dementia does physically alter the brain, BPSD is reportedly rarely 'caused' by these changes. As BlueCare informed the committee:

While BlueCare acknowledges that changes in the brain forms part of the disease, it understands that many behaviours occur because individual needs are not being met and sometimes that the only way that a person can communicate these needs is by behaving in a way perceived by others as concerning or challenging.<sup>12</sup>

2.12 Dementia Care Australia similarly noted that BPSD is often an expression of unmet need that may include physical needs (eg. pain or discomfort), social needs (eg. loneliness), and environmental needs (eg. the need for quiet).<sup>13</sup> As an expression of an unmet need, the behaviours will only escalate if the reason they started is not addressed:

In many cases the behavioural symptoms are exacerbated if the support provided to them does not adequately respond to someone's needs or to the issues that lead to the person using the behaviour in the first instance.<sup>14</sup>

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9 Department, *Submission 56*, p. 6.

10 Royal Australian and New Zealand College of Psychiatrists, *Submission 49*, p. 2.

11 Brotherhood of St Laurence, *Submission 40*, p. 7.

12 Mrs Edwards, Service Development and Improvement Advisor, BlueCare, *Committee Hansard*, 17 July 2013, p. 11.

13 Mrs Verity, Founder and Chief Executive Officer, *Dementia Care Australia and Spark of Life*, *Committee Hansard*, 16 December 2013, p. 39.

14 Ms Cook, Public Advocate, Office of the Public Advocate Queensland, *Committee Hansard*, 17 July 2013, p. 3.

2.13 Evidence from the Minister's Dementia Advisory Council provides a useful glimpse into what can cause BPSD, and some suggestions for its management:

The example I find that always works is to imagine yourself at home on your sofa, in your living room, near your backdoor and the garden. You have been dozing or daydreaming or whatever and then you come to. There is a noise at the door. You turn around and, because the light is not very good, you can only see the silhouette of a person carrying something. You sort of look and then you see that your best friend, who has been away, has come to your door, with a bunch of flowers. Your behaviour is going to be correlated to how you interpret what you see. If you turn around and see a stranger carrying a big stick or a knife then your behaviour is going to be perfectly and reasonably correlated to what you think you see.

When there is damage to your brain processing, how you interpret what you see is also going to affect how you respond. If it is your best friend with flowers and you pick up something and throw it at them or push them away because you think they are a stranger with a knife, you are going to be seen as a bit mad. But if your cognitive processing has been damaged and that is literally what you have seen, your behaviour is in perfect correlation to what you have seen. A lot of what we see in the detailed training of people working with those with dementia is their learning how to read that person's body language, mood and emotion so that their approach is correlated to how that person is feeling. Are they feeling threatened or not? If that person's experience is one of being demeaned and bossed around then they are going to get a bit stroppy. If they are being demeaned and their autonomy is being limited, they might feel a bit stroppy and verbalise it, and so they are further demonised for being stroppy. Or is it really that people have not understood that, with a respectful approach which gives a person extra time to interpret what is happening around them physically, that person is going to be perfectly okay.

So it really is a correlation between the fact that there is real organic damage to a person's brain and how they interact with the environment and other stimulus which surrounds them. This is why I would assert it is our responsibility to get the environment and our behaviour towards people correct. It is not to say that this is not really difficult sometimes; I am not trying to minimise it. But what we have seen time and time again is that it can be done. Research is starting to give a lot of validation to the different ways of doing this. It extends from education and support for families and care givers so that they can understand the degree to which they can put themselves in a person's shoes and so keep a situation calm, through to all sorts of institutional approaches. It goes across the gamut of care situations, and it can make a difference—at least to a degree and sometimes totally.<sup>15</sup>

2.14 This interaction between a person with dementia's environment, their perceptions and resultant actions is a key consideration in determining how the disease

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15 Ms Pieters–Hawke, Co-Chair, Minister's Dementia Advisory Council, *Committee Hansard*, 17 July 2013, p. 31.

should best be managed. Chapters 3 and 4 highlight the importance of design in minimising BPSD by recognising how perception may be altered by dementia.

2.15 It is estimated that 56% to 90% of people with dementia will experience BPSD at some stage, with the most common symptoms being apathy, depression and anxiety. About 50% of people with dementia will have at least four symptoms simultaneously.<sup>16</sup> BPSD is not a rare condition: the Royal Australian and New Zealand College of Psychiatrists (RANZCP) estimated the prevalence of BPSD at:

- 61–88% among people with dementia in a community setting;
- 29–90% in residents in Australian nursing homes; and
- 95% among hospitalised patients in long-term acute care.<sup>17</sup>

2.16 The relationship between BPSD and the progression of dementia is non-linear. In other words, a person with dementia will not necessarily experience more BPSD as the disease progresses. BPSD can occur at any stage of dementia.<sup>18</sup> The prevalence rates of BPSD are greatest in the middle stages of the disease, when people are still mobile and may retain much of their physical strength.<sup>19</sup>

2.17 The incidence, treatment and manifestations of BPSD are often different between community and residential care for various reasons. The management of severe BPSD is predominantly a concern for residential care, as once people with dementia begin exhibiting severe BPSD it is difficult to provide care in the community and they are admitted into residential care. As noted by the RANZCP):

The occurrence of BPSD in people with dementia is the major clinical factor that causes stress in carers and often leads to the breakdown of community care and institutionalisation.<sup>20</sup>

2.18 BPSD and its management are discussed at greater length in Chapters 4 and 5 of this report.

## **Dementia in Australia**

[T]he number of people with dementia are rising in every single electorate, in every state and territory across Australia. As the population ages, we must all be prepared for a radical shift in health priorities.

– Ita Buttrose AO, OBE<sup>21</sup>

2.19 As the words of Alzheimer's Australia's National President Ita Buttrose indicate, the growing number of people with dementia in Australia is one of our most

16 Department, *Submission 56*, p. 6.

17 *Submission 49*, p. 3.

18 Ms Cook, Public Advocate, Office of the Public Advocate Queensland, *Committee Hansard*, 17 July 2013, p. 7.

19 Department, *Submission 56*, p. 6.

20 *Submission 49*, p. 3.

21 Deloitte Access Economics, *Dementia Across Australia: 2011–2050*, 9 September 2011, p. 7.

pressing public health issues. In August 2012, all Australian Health Ministers recognised dementia as the ninth National Health Priority Area (NHPA).<sup>22</sup> As explained by the AIHW:

The [NHPAs] are diseases and conditions that Australian governments have chosen for focused attention because they contribute significantly to the burden of illness and injury in the Australian community...By targeting specific areas that impose high social and financial costs on Australia society, collaborative action can achieve significant and cost-effective advances in improving the health status of Australians. The diseases and conditions targeted under the NHPA initiative were chosen because through appropriate and focused attention on them, significant gains in the health of Australia's population can be achieved.<sup>23</sup>

2.20 Recognising dementia as a NHPA accords it the status of a chronic disease and as equally important as other national health priorities, such as cancer, diabetes, obesity and heart disease. NHPA status also indicates that more can be done to deliver cost-effective improvements in the health of Australians generally and those living with dementia in particular. It is this aim to which this report seeks to contribute.

2.21 The inclusion of dementia as a NHPA comes as no surprise when some key statistics are considered. In Australia, the best estimates indicate almost 300,000 people are currently living with dementia, 70% of whom live in the community.<sup>24</sup> Estimates for 2011 suggest that dementia was the fourth leading cause of overall burden of disease, and the third leading cause of disability burden. For people aged 65 and over, dementia was the second leading cause of overall burden of disease and the leading cause of disability burden, accounting for one-sixth of the total disability burden in older Australians.<sup>25</sup>

2.22 The number of Australians living with dementia is projected to rise to about 900,000 in 2050 as the population ages.<sup>26</sup> Dementia prevalence rates are relatively low until the age of 70 years and over when the prevalence rates start to increase exponentially.<sup>27</sup> After the age of 65 the probability of receiving a diagnosis of dementia doubles every five to six years.<sup>28</sup> There is likely to be little change in this pattern, with the AIHW reporting:

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22 The eight other national health priority areas include: cancer control; cardiovascular health; injury prevention and control; mental health; diabetes mellitus; asthma; arthritis and musculoskeletal conditions; and obesity.

23 Australian Institute of Health and Welfare, *National Health Priority Areas*, <http://www.aihw.gov.au/national-health-priority-areas/>, (accessed 28 October 2013).

24 Australian Institute of Health and Welfare, *Dementia in Australia*, 2012, p. ix.

25 Australian Institute of Health and Welfare, *Dementia in Australia*, 2012, p. ix.

26 Department, *Submission 56*, p. 6.

27 Deloitte Access Economics, *Dementia Across Australia: 2011–2050*, 9 September 2011, p. 14.

28 Australian Institute of Health and Welfare, *Dementia in Australia*, 2012, p. 5.

There are no definitive protective factors for dementia although many factors thought to probably protect against developing dementia have been identified. These include better cardiovascular health, maintaining a physically, socially and cognitively active lifestyle throughout middle age, and higher levels of education. There are numerous other possible protective factors for which evidence is less conclusive, including intake of omega-3 fatty acids, the use of cholesterol-lowering medications, non-steroidal anti-inflammatory medications and aspirin.<sup>29</sup>

2.23 In 2011, one-in-ten Australians over 65 had dementia, a figure increasing to three-in-ten for those aged 85 or over.<sup>30</sup> The number of women with dementia outnumbers men, accounting for more of the projected disease burden (63% compared to 37%).<sup>31</sup> These figures should be used with caution however as Australia relies on international prevalence studies to estimate the size of the problem in Australia. There is also limited data on dementia within the indigenous and culturally and linguistically diverse communities.<sup>32</sup>

2.24 The economic costs of dementia are significant, as is the burden it places on healthcare infrastructure. Over 50% of permanent residents in Commonwealth-funded aged care facilities have a diagnosis of dementia, and these residents are more likely to require high care (87% compared to 63% of residents without dementia).<sup>33</sup> The average cost of hospital care for people with dementia was \$2,500 more per episode than those without dementia.<sup>34</sup> Research published by the AIHW found that the total direct health and aged care system expenditure on people with dementia was at least \$4.9 billion in 2009–10.<sup>35</sup>

2.25 Although dementia is often seen as a disease of the elderly, an estimated 23,900 Australians under the aged of 65 suffer from YOD.<sup>36</sup> YOD typically refers to the onset of dementia before the age of 65. The World Health Organisation (WHO) has estimated that YOD accounts for around 6% to 9% of dementia cases. The Australian figure, at around 8%, is in line with this estimate.<sup>37</sup>

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29 *Dementia in Australia*, 2012, p. 5.

30 Australian Institute of Health and Welfare, *Dementia*, <http://www.aihw.gov.au/dementia/>, (accessed: 28 October 2013).

31 Australian Institute of Health and Welfare, *Dementia in Australia*, 2012, p. 15.

32 Mr Cooper-Stanbury, Head – Ageing and Aged Care Unit, Australian Institute of Health and Welfare, *Committee Hansard*, 16 December 2013, pp 31–32.

33 Australian Institute of Health and Welfare, *Dementia*, <http://www.aihw.gov.au/dementia/>, (accessed: 26 March 2014).

34 Mr Cooper-Stanbury, Head – Ageing and Aged Care Unit, Australian Institute of Health and Welfare, *Committee Hansard*, 16 December 2013, p. 33.

35 Australian Institute of Health and Welfare, *Dementia in Australia*, 2012, p. 150.

36 Department, *Submission 56*, p. 6.

37 Australian Institute of Health and Welfare, *Dementia in Australia*, 2012, p. 15.

2.26 Over the course of the illness, people with dementia need access to a range of health care and social services including General Practitioners (GPs), community services, allied health services, hospital, day and respite care, in-home care and residential care.<sup>38</sup>

### ***Diagnosing dementia***

2.27 Dementia is a progressive illness that presents in different ways in different people. An accurate diagnosis of dementia is important for sufferers of the disease to enable them to access appropriate care and delay admission to residential care.<sup>39</sup> The Australian Psychological Society (APS) emphasised:

Early diagnosis and intervention has been demonstrated to reduce the need for residential care placement and to keep people with dementia living in the community for longer.<sup>40</sup>

2.28 GPs, in their role as frontline health providers, are often the first to diagnose dementia in their patients. As might be expected, accurately and correctly diagnosing a person with dementia is not simple due to a number of issues. The committee was given some insight into this problem:

Moving...onto the assessment of dementia, as you are no doubt well aware, it is complex. There is no simple blood test. You might have heard of common simple screening tests like the [General Practitioner assessment of Cognition] or the mini-mental state examination. They work reasonably well in secondary care, where there is a higher prevalence of dementia.<sup>41</sup>

2.29 Highlighting the difficulty of diagnosing dementia, the Australian Medical Association also noted that a diagnosis of dementia can only be confirmed post-mortem.<sup>42</sup>

2.30 The committee also heard that many people are reluctant to discuss dementia with their GP or other health professionals. This poses additional challenges in diagnosing dementia as GPs often rely on history provided by the family or carer about impaired cognition and functioning in everyday life.<sup>43</sup> In some communities, there is a particular reluctance to discuss dementia:

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38 Services for Australian Rural and Remote Allied Health, *Submission 19*, p. 3.

39 Catholic Health Australia, *Submission 14*, p. 4; BlueCare, *Submission 32*, p. 11.

40 *Submission 31*, p. 5.

41 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 34.

42 Dr Kidd, Chair, Australian Medical Association Committee for Health and Ageing, *Committee Hansard*, 14 February 2014, p. 1.

43 Dr Kidd, Chair, Australian Medical Association Committee for Health and Ageing, *Committee Hansard*, 14 February 2014, p. 1.

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In rural areas, I have heard it said that the issue 'will be dealt with on the farm' or 'in the family' and that people who have dementia have been withdrawn from community events...to save embarrassment and shame.<sup>44</sup>

2.31 The committee similarly heard of the importance of carer and family input to form a diagnosis, and the difficulties there can be in obtaining that information:

As you are no doubt aware, a full assessment requires input from carers...We are allowed to talk to a carer with the person there, but the carer may not want to tell us the full extent of that person's disability in front of them...Without that carer input it is very, very difficult for GPs to assess the full extent of a behaviour of concern. Most of the ways of assessing behaviours of concern like the antecedent behaviour consequence—the ABC—all really need an external person to say: 'This is what was happening. That is what upset mum and then she reacted in this way. And that was a consequence'.<sup>45</sup>

2.32 As indicated above, it is crucial that a diagnosis of dementia is accurate. The committee heard concerns from the Royal Australian College of General Practitioners (RACGP) that the current Medicare funding model does not lend itself to accurate diagnoses of illnesses such as dementia:

The system issue I would like to flag is that in general practice there is a tension, I believe, between the numbers of patients that GPs are expected to see and the time that the GP can spend with each patient. Time is of the essence when we are looking at behaviours of concern in people with dementia or in any assessment of cognitive impairment.<sup>46</sup>

2.33 In addition to time constraints, the committee heard that the omission of a Medicare item number for consulting with carers does not encourage GPs to properly explore pertinent information in forming a diagnosis:

GPs tend to take the fact that there is no Medicare item number for talking to a carer as an indication that this activity is not encouraged – it is perhaps a breach of confidentiality or an undesirable thing to talk to family members about the person you are caring for. So they feel very anxious about that.<sup>47</sup>

2.34 It was emphasised to the committee that the families and carers of older persons who may be suffering from dementia needed to be included in making

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44 Mr Hunt, Private Capacity, *Committee Hansard*, 10 July 2013, p. 33.

45 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 34.

46 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 34.

47 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 34.

assessments of whether a person does or does not have dementia, and that more needs to be done to encourage this process.<sup>48</sup>

2.35 The APS stressed the need for expert knowledge to evaluate dementia diagnoses.<sup>49</sup> Professor Dimity Pond emphasized that the limitations in GPs diagnosing dementia were not a result of a lack of ability, but the constraints of the system based around relatively short consultations.<sup>50</sup> The Australian Medical Association (AMA) noted that 'it is very difficult to achieve [accurate diagnosis] within the current constructs of Medicare items which do not support prolonged assessments or interaction with family and carers'.<sup>51</sup> The committee heard that there presently was no mechanism for a GP to refer a person to psychological experts for assessment under Medicare.<sup>52</sup>

2.36 The Services for Australian Rural and Remote Allied Health gave evidence that in remote communities there are very few people diagnosed with dementia, particularly among Indigenous populations, despite the fact that research has indicated that the prevalence of dementia in Aboriginal communities is more than five times that of the non-Aboriginal population.<sup>53</sup> This would indicate that there is a significant under-diagnosis and associated treatment in those communities.

2.37 The lack of accurate and timely diagnosis can result in years of delay in the person with dementia and their carers receiving adequate social and health supports.<sup>54</sup> The AMA similarly emphasised '[a] specific diagnosis of dementia is important, because it can have implications for families and support networks...Early access to services delivers better outcomes to patients and their families and carers'.<sup>55</sup>

2.38 The other face of the diagnosis coin is the potential to over diagnose dementia in older people. Professor Pond noted that other factors may present as dementia:

But in primary care [the mini-mental state and General Practitioner assessment of Cognition] are both insensitive to dementia and also run the risk of over diagnosing it when people for varied reasons to do with their background, education, literacy, ability to speak English or perhaps

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48 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 37.

49 Mr Stokes, Principal Advisory, Australian Psychological Society, *Committee Hansard*, 16 December 2013, p. 19.

50 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 36.

51 Dr Kidd, Chair, Australian Medical Association Committee for Health and Ageing, *Committee Hansard*, 14 February 2014, p. 1.

52 Mr Stokes, Principal Advisory, Australian Psychological Society, *Committee Hansard*, 16 December 2013, p. 20.

53 Services for Australian Rural and Remote Allied Health, *Submission 19*, p. 3.

54 Mercy Health, *Submission 29*, p. 3.

55 Dr Kidd, Chair, Australian Medical Association Committee for Health and Ageing, *Committee Hansard*, 14 February 2014, p. 1.



concomitant depression or because they are not well that day fail that test. It is very important that we do not rush into labelling them as having dementia, because it carries with it stigma and the potential loss of autonomy for that person, which is a very, very serious thing.<sup>56</sup>

2.39 The committee heard that the risk of misdiagnosis could be reduced through the acquisition of a strong patient history through family and carers, as well as improving the awareness of differential diagnosis techniques among medical professionals. Differential diagnosis considers alternative reasons that might explain dementia like symptoms, such as side effects from medication.<sup>57</sup>

2.40 The committee heard evidence that there remains a stigma associated with dementia that can create barriers to community engagement.<sup>58</sup> The Brotherhood of St Laurence reported:

There is a stigma around dementia...We get many carers coming to us very distraught because the family member they are caring for has been told they can no longer access a certain [activity]...It is very distressing for those people who have been excluded and for their carers. It is hard enough to be diagnosed with dementia, let alone to then be excluded from a club.<sup>59</sup>

2.41 Further, the use of certain terminology such as 'memory loss' and 'BPSD' was reported to the committee as creating a stigma that detracted from a focus on the person and centred attention on the disease.<sup>60</sup> Ms Pieters-Hawke from the Minister's Dementia Advisory Group lamented:

Essentially we are living with a view of [who] a person with dementia [is] that really has not crept out from the shadows of the mediaeval demonisation of people with mental and behavioural differences.<sup>61</sup>

## Recommendation 1

**2.42 The committee recommends that the Commonwealth create a new Medicare item number that encourages General Practitioners, registered psychologists or other relevant accredited professionals, to undertake longer consultations with a patient and at least one family member or carer where the patient has presented with indications of dementia.**

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56 *Committee Hansard*, 16 December 2013, p. 34.

57 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 37.

58 Mr Hunt, Private Capacity, *Committee Hansard*, 10 July 2013, p. 33.

59 Ms Astete, Senior Manager – Day and Respite Programs, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 11.

60 Mrs Edwards, Service Development and Improvement Advisor, BlueCare, *Committee Hansard*, 17 July 2013, p. 11.

61 *Committee Hansard*, 17 July 2013, p. 27.



# Chapter 3

## Community care

3.1 Community care aims to assist a person with dementia to live in their own home for as long as possible so that the person can remain with their family and in a familiar environment. In Australia, the majority of people with dementia are living in the community.<sup>1</sup> Appropriate community care can prevent early admission to residential care for people with dementia, as well as improve their quality of life before they reach residential care.<sup>2</sup> It is estimated that delaying the entry to residential aged-care saves the government significant amounts of money.<sup>3</sup> National Disability Services' (NDS) evidence highlighted the importance of the work of informal supports to the public purse:

[T]he public system funding could not afford it if families did not continue to perform the very important role of supporting a person [in the community].<sup>4</sup>

3.2 This chapter considers three key issues regarding supporting people to stay in the community for as long as possible: finding and accessing the supports that are available to keep people in the community; the adequacy and appropriateness of those supports; and respite care.

3.3 There was a general agreement among submitters that, for most persons living with dementia, it is better to remain in the community for as long as possible, rather than move into a residential aged care facility (RACF). It was put to the committee however, that for people living alone, residential care may be more appropriate depending on that person's level of care need.<sup>5</sup> Also, some Behavioural and Psychological Symptoms of Dementia (BPSD) are very difficult to manage in the community and can best be catered for in a residential setting.<sup>6</sup>

### Supports to keep people with dementia in the community

3.4 There are a number of services and supports provided by the Commonwealth to people with dementia living in the community. State and Territory governments, as

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1 Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 28.

2 Ms Astete, Senior Manager – Day and Respite Programs, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 10; Mrs Edwards, Service Development and Improvement Advisor, BlueCare, *Committee Hansard*, 17 July 2013, p. 12.

3 Australian Psychological Society, *Submission 31*, p. 5; Brotherhood of St Laurence, *Submission 40*, p. 11; Royal Australian and New Zealand College of Psychiatrists, *Submission 49*, pp 10–11.

4 Dr Baker, Chief Executive, National Disability Services, *Committee Hansard*, 14 February 2014, p. 11.

5 Dr Smith, Private Capacity, *Committee Hansard*, 17 December 2013, p. 18.

6 HammondCare, *Submission 25*, p. 4.

well as the non-government sector, also provide some services for people with dementia.

3.5 Since 1 August 2013, the primary support to assist people to remain in the community is the Commonwealth-funded Home Care Packages Program (HCPP).<sup>7</sup> The objectives of the HCPP are to assist people to remain in the community for as long as possible, and for consumers to have choice and flexibility in the care that is provided in their homes.<sup>8</sup> There are four levels of Home Care Packages:

- Level 1 – to support people with basic care needs;
- Level 2 – to support people with low level care needs;
- Level 3 – to support people with intermediate care needs; and
- Level 4 – to support people with high care needs.<sup>9</sup>

3.6 While these packages are targeted at 'frail older people', there is no minimum age limit to access HCPP.<sup>10</sup> Therefore, people with a diagnosis of younger onset dementia (YOD) can access the HCPP.

3.7 In recognition of the added costs of managing dementia in the community, the Dementia and Cognition Supplement in Home Care is available at all levels of home care to support people with dementia. The supplement provides a 10% subsidy level to eligible clients. This supplement replaced the former Extended Aged Care at Home Dementia packages.<sup>11</sup> The HCPP Guidelines make clear that providers of home care services 'should also have policies and practices that address the provision of care for people with dementia'.<sup>12</sup>

3.8 The HCPP provides an important tool in assisting people to stay in the community for as long as possible. Chapter 2 of this report highlights how dementia can alter a person's perceptions of the world. The challenges—such as trips and falls—created by these changing perceptions of the natural world can be minimised through sound design practices. It has been shown that use of sound design principles can also minimise BPSD; a key trigger for entering RACFs.

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7 These packages replaced the former community and flexible packaged care programs – Community Aged Care Packages, Extended Aged Care at Home, and Extended Aged Care at Home Dementia.

8 Department of Health and Ageing (Department), *Home Care Package Program Guidelines*, 2013, p. 6.

9 Department, *Overview of changes between the former CACP, EACH and EACHD packages and the Home Care Packages Program*, <http://www.livinglongerlivingbetter.gov.au/internet/living/publishing.nsf/Content/Overview-of-home-care-packages-program-changes>, (accessed: 13 February 2013).

10 Department, *Home Care Package Program Guidelines*, 2013, p. 6.

11 Ms Smith, First Assistant Secretary, Ageing and Aged Care Division, Department, *Committee Hansard*, 17 July 2013, p. 47.

12 Department, *Home Care Package Program Guidelines*, 2013, p. 7.

3.9 There are guides available that highlight simple changes that can be made to the environment in order to improve accessibility by someone with dementia. For example, HammondCare produces:

...a guide around the environment in people's own homes to help families make better decisions around fixing the environment so as to be able to support people who have dementia stay at home longer.<sup>13</sup>

3.10 Similarly, the Dementia Enabling Environments Program has created a number of free resources translating research on dementia-friendly environments into practice.<sup>14</sup>

3.11 As well as providing services (such as meal preparation and transport), HCPP can also be used for home modifications to enable people with dementia to remain at home and safe for longer.

3.12 Another important support measure is the Home and Community Care (HACC) services,<sup>15</sup> which can be accessed by all Australians over the age of 65; those who are at risk of premature or inappropriate admission to long-term residential care; and carers of people eligible to access HACC services.<sup>16</sup> HACC services provide access to a broad range of services from domestic assistance to transport, counselling, centre-based care, and respite care.<sup>17</sup> People with dementia, including YOD, can typically access HACC due to being at risk of entry into residential care.

3.13 Planned Activity Groups (PAG), which are typically funded through HACC and delivered by non-government organisations and health service providers, provide support for people living with dementia and their carers. The Victorian HACC program manual explains:

Planned activity groups support people's ability to remain living in the community by providing a range of enjoyable and meaningful activities. These activities support social inclusion, community participation, and build capacity in skills of daily living.

Planned activity groups are designed to enhance people's independence by promoting physical activity, cognitive stimulation, good nutrition, emotional wellbeing and social inclusion.<sup>18</sup>

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13 Mr Cunningham, Director – The Dementia Centre, HammondCare, *Committee Hansard*, 17 July 2013, p. 18.

14 Alzheimer's Australia, *Submission 42.2*, p. 2.

15 The Commonwealth administers HACC services in all states and territories except Victoria and Western Australia. HACC programs and services are available in all jurisdictions.

16 Department of Health, *Commonwealth (HACC) Program*, <http://health.gov.au/hacc>, (accessed: 4 February 2013).

17 Department of Health, *Commonwealth (HACC) Program*, <http://health.gov.au/hacc>, (accessed: 4 February 2013).

18 Department of Health – Victoria, Victorian Home and Community Care program manual, Victoria, November 2013, p. 153.

3.14 The foremost dementia specific service the committee heard about was the Dementia Behaviour Management Advisory Service (DBMAS), a program that provides clinical support for people caring for someone with dementia who is demonstrating BPSD which is impacting upon the care they receive. DBMAS' website explains the role and function of the scheme:

The role of the DBMAS program is to improve the quality of life of people with dementia and their carers where the behaviour of the person with dementia impacts on their care. This is achieved by improving the dementia care capacity of care workers, carers and service providers.

...

DBMAS is sensitive to each person's dementia journey being unique. As a result, our teams are equipped with a diverse range of clinicians who undertake thorough individual assessments and care planning that assists carers in supporting the person with dementia and establishing links to appropriate support networks.<sup>19</sup>

3.15 The DBMAS provides a highly valuable resource that can be used by carers and medical professionals alike to receive high quality advice regarding the treatment of dementia.<sup>20</sup> Since 2007, eight organisations have been delivering DBMAS activities in each State and Territory.<sup>21</sup>

3.16 The committee heard that, in an appropriate environment with an appropriately trained carer, a person with dementia and BPSD can be successfully accommodated in the community:

[It] is our responsibility to get the environment and our behaviour towards people correct. It is not to say that this is not really difficult sometimes; I am not trying to minimise it. But what we have seen time and time again is that it can be done. Research is starting to give a lot of validation to the different ways of doing this. It extends from education and support for families and care givers so that they can understand the degree to which they can put themselves in a person's shoes and so keep a situation calm, through to all sorts of institutional approaches. It goes across the gamut of care situations, and it can make a difference—at least to a degree and sometimes totally.<sup>22</sup>

3.17 The Commonwealth funds groups such as Alzheimer's Australia to provide services such as the National Dementia Hotline, as well as education and training courses for carers.<sup>23</sup> Illustrating the importance of equipping carers to undertake their

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19 Dementia Behaviour Management Advisory Services, *What we do*, [http://dbmas.org.au/What\\_we\\_do.aspx](http://dbmas.org.au/What_we_do.aspx), (accessed: 3 February 2014).

20 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 37.

21 Department, *Submission 56*, p. 7.

22 Ms Pieters–Hawke, Co-Chair, Minister's Dementia Advisory Council, *Committee Hansard*, 17 July 2013, p. 31.

23 Department, *Submission 56*, p. 19.

role, the committee was encouraged to consider one case of dementia having two clients that need support from the health care system: the person with dementia *and* their carer.<sup>24</sup>

3.18 Groups like Alzheimer's Australia provide support for carers in transitioning into their roles as the primary support for someone with dementia. The committee heard, for instance, that Alzheimer's Australia ACT provides education services for carers:

They have programs for carers, not only the course on living with memory loss but eight sessions, I think, for carers about communication and what to expect and how to deal with different aspects. They run that, and they also have a dementia network where they do training and have speakers come in, for everybody really but specifically for people working in the dementia community.<sup>25</sup>

3.19 Critical to keeping people in the community is adequate care and support for carers. Alzheimer's Australia NSW emphasised that 'strategies to increase the capacity, resilience and knowledge of carers...in the care and management of BPSD is critical'.<sup>26</sup> Carer training was reported to the committee as 'a huge area that we are going to need to address if we are going to successfully support people to remain in the community and support families to do that'.<sup>27</sup>

3.20 As was discussed in chapter 2, BPSD often occurs in response to unmet need. Providing carers with the tools that they need to understand behaviours and remedy them is important in keeping people in the community for longer. DBMAS provides some education services to families and carers to help them provide care in the community.<sup>28</sup> The committee heard that Massive Open Online Courses<sup>29</sup> for dementia training, which are facilitated by the University of Tasmania, had attracted over 9,000 enrollees.<sup>30</sup> Alzheimer's Australia Victoria's Perc Walkley Dementia Learning Centre has developed a virtual reality suite that allows stakeholders to experience what it is like to have dementia. Resources such as this represent remarkable advances in improving understanding of dementia among carers, health professionals and the community.

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24 Ms Hudson, Wellbeing and Dementia Support Coordinator, Brightwater Care Group, *Committee Hansard*, 14 February 2014, p. 30.

25 Ms Woolstencroft, Carer, Carers ACT, *Committee Hansard*, 17 July 2013, p. 24.

26 Alzheimer's Australia NSW, *Submission 23*, p. 5.

27 Ms Hudson, Wellbeing and Dementia Support Coordinator, Brightwater Care Group, *Committee Hansard*, 14 February 2014, p. 30.

28 Dr Cleary, Geriatrician, Dementia Behaviour and Management Advisory Service, *Committee Hansard*, 10 July 2013, p. 23.

29 Massive Open Online Courses—often referred to as MOOCs—are free online courses run by accredited education providers over the internet.

30 Professor McInerney, Professor of Aged Care, Mercy Health and the Australian Catholic University, *Committee Hansard*, 14 February 2014, p. 31.

3.21 As well as these cornerstone supports, the committee received evidence regarding numerous pilots and programs that are currently being run around Australia to assist people with dementia and their carers remain in the community. This report does not attempt in any way to provide a definitive discussion of the support options available to people. Instead, it discusses systemic issues that were raised in evidence.

### *Accessing and navigating dementia support services*

3.22 For most people, the first step to receiving treatment for dementia is a diagnosis from their General Practitioner (GP), who typically refers that person to an Aged Care Assessment Team (ACAT). ACAT's role is to:

...comprehensively assess the care needs of frail older people and assist them to gain access to the types of available services most appropriate to meet their care needs. This may involve referring clients to community care services, such as those available under the [HACC] program, which do not require approval under the Act. Alternatively, they may approve a person as eligible for Australian Government subsidised aged care services, including residential, community and flexible care services.<sup>31</sup>

3.23 Following a referral by a GP, ACAT visits the person in their home and assesses their eligibility for available services.<sup>32</sup>

3.24 In addition to the aforementioned government services, the committee heard of a number of providers that provide people with dementia and their carers with relevant information, counselling and training. Unfortunately, many of these services appear to be fragmented and poorly integrated resulting in people receiving less than optimal support at a time of great need. As illustrated by BlueCare:

Aged care providers and clients and families find having a range of services that can assist with behaviours confusing as to what services provide and which services should be contacted in specific needs. An example of this is DBMAS (providing assistance to residential and community services), The Dementia Outreach Service (providing assistance to residential staff in Metro South Health district) and Ozcare's [Dementia advisory and support services] (providing assistance to HACC funded services) who all provide a similar service but have slightly different referral systems. This often constitutes a duplication of services and may not be the best cost effective option.<sup>33</sup>

3.25 'Generally, you have to do the legwork yourself to find out what is available', reported one carer to the committee.<sup>34</sup> The committee similarly heard from other

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31 Assessments for subsidised care, *Report on the Operation of the Aged Care Act 1997*, <http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-roaca-12-toc~ageing-roaca-12-03-info~information-3-2>, (accessed 13 February 2013).

32 Department, *Aged Care Assessment Teams*, <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-acat-assess.htm-copy2>, (accessed: 3 February 2014).

33 BlueCare, *Submission 32*, p. 10.

34 Ms Woolstencroft, Carer, Carers ACT, *Committee Hansard*, 17 July 2013, p. 23.



carers that, at the same time as you are coming to terms with a life-changing medical diagnosis, you must also identify what help is available, what needs to be done, and how to manage and utilise the support that is available.<sup>35</sup> The committee heard that some people might be fortunate enough to encounter a provider or doctor who had a good understanding of the system but there is no centralised point of information and support.<sup>36</sup>

### ***Improving access to dementia supports***

3.26 For most people, it appears that it is necessary to undertake a substantial amount of independent research in order to find the services that are appropriate to them. It is hardly surprising that few people in the community have turned their mind to the issues of accessing care and support services prior to a diagnosis of dementia being received. There were a number of suggestions put to the committee regarding how access to dementia services could be improved.

3.27 One suggestion to improve the transition into care was to ensure that GPs are appropriately informed of the available services in their area, and advise patients at the time of diagnosis what support is available. As Carers Australia put it:

[When] somebody is first diagnosed, it is incredibly important for the GP to take some time right away to talk to the carer and explain what is going to happen and tell them what support services are available to them. Accompanying that there may be a need, too, for GPs to have more [of] such information systematically available to them.<sup>37</sup>

3.28 Alzheimer's Australia similarly emphasized the important role of medical professionals in ensuring people with dementia receive the help they need:

It is important that doctors refer to services more efficiently than they do. Some doctors do it automatically, and they refer to us, Carers Australia or the local ACAT team. I think doctors are very important, and we are working on a number of strategies that encourage doctors, as well as practice nurses and nurse practitioners, to do that.<sup>38</sup>

3.29 The Department of Health and Ageing (Department) nominated Medicare Locals as a prospective point of coordination, noting that their purpose is to work with stakeholders 'to ensure that patients receive the right care in the right place at the right time'.<sup>39</sup>

3.30 Another suggestion put to the committee to improve the accessibility of dementia care services was to expand the gateway and key worker initiatives from the *Living Longer, Living Better* aged-care reforms. At present, the Commonwealth is

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35 Dr Macpherson, *Submission 62*, p. 2.

36 Ms Pieters-Hawke, Co-Chair, Minister's Dementia Advisory Council, *Committee Hansard*, 17 July 2013, p. 33.

37 Ms Elderton, Policy Manager, Carers Australia, *Committee Hansard*, 17 July 2013, p. 23.

38 Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July, p. 33.

39 *Submission 56*, p. 24.

trials a Younger Onset Dementia Key Worker Program (KWP) which is being implemented by Alzheimer's Australia.<sup>40</sup> The Department explained the purpose of this program:

One component of [Living Longer, Living Better] is the roll out of a national network of key workers to act as a single point of contact for people with younger onset dementia. Key workers will help younger people with dementia to access the care and support services most appropriate for their needs, to navigate the care system, and to achieve their long and short term goals.<sup>41</sup>

3.31 Alzheimer's Australia argued that the KWP should be extended to older people with dementia as 'their need is almost identical to those of younger people in that key sense'.<sup>42</sup> Services for Australian Rural and Remote Allied Health (SARRAH) recommended the employment of key workers 'to ensure timely diagnosis, management, treatment and the provision of emotional and social support'.<sup>43</sup> The Department informed the committee:

The government's view is that it wants to understand how [the KWP] works with the younger onset group first before any further expansion of the program is considered.<sup>44</sup>

3.32 Trial funding of \$18.2 million runs from 2012–13 to 2015–16, after which time an 'independent evaluation of the service' will be commissioned to assess the effectiveness of the program.<sup>45</sup>

3.33 The Department's submission highlights the document *Dementia Services Pathways – An essential guide to effective service planning* (DSP) as a key tool to help in 'the planning of support services once dementia has been diagnosed'.<sup>46</sup> The Department's submission itself goes on to note that '[DSP] encourages the use of a key worker for the management of people with dementia to ensure appropriate treatment along the pathway'.<sup>47</sup>

3.34 Some community groups have voluntarily incorporated the principles of a key worker scheme into their own practice. The Brotherhood of St Laurence, for instance, reported:

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40 Ms Smith, First Assistant Secretary, Ageing and Aged Care Division, Department, *Committee Hansard*, 17 July 2013, p. 48.

41 Department, *Submission 56*, p. 16.

42 Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July, p. 29.

43 Services for Australian Rural and Remote Allied Health, *Submission 19*, p. 4.

44 Ms Smith, First Assistant Secretary, Ageing and Aged Care Division, Department, *Committee Hansard*, 17 July 2013, p. 48.

45 Department, answer to question on notice, 17 July 2013 (received 9 August 2013).

46 Department, *Submission 56*, p. 22.

47 Department, *Submission 56*, p. 22.

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We have developed a model of dementia care called 'The Dementia Care Pathway': this assists clients/carers and professionals to negotiate the journey through the dementia experience and involves a Dementia Care Consultant and Dementia Care Coordinator who provide expertise, consultancy, advice and support.<sup>48</sup>

3.35 Another suggestion to improve the ability of people with dementia and their carers to better access support services was the use of a Gateway—such as that proposed for the *National Disability Insurance Scheme* (NDIS)—or centralised portal of information and services.

3.36 Alzheimer's Australia's Chief Executive Officer expressed doubts—also articulated by other service providers<sup>49</sup>—about a gateway replacing the key role of medical and other professionals:

The gateway may eventually be important. It is a long way off in terms of resources and development, but that is another piece of the jigsaw. I think a lot of people with dementia and family carers want the human face rather than a checkpoint. That is resource-intensive and quite expensive, but that is what consumers would like.<sup>50</sup>

3.37 The critical role of a human face to support people during times of need is recognised in the National Disability Insurance Scheme with Local Area Coordinators complementing the gateway system. It also should be noted that DBMAS and groups such as Alzheimer's Australia already provide large amounts of information, contingent on consumers being made aware of these key portals.

#### ***Committee view***

3.38 The Australian Government, along with its State and Territory counterparts and the community sector, provide many supports for people with dementia and their carers. However, these supports do little good if people do not know about them or how to access them. At present, it appears the accessibility to information about many of these services could be improved. Based on the evidence received during this inquiry, the committee is of the view that dementia key workers are an important conduit linking clients and providers, providing community education, and working with local medical professionals.

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48 Brotherhood of St Laurence, *Submission 40*, p. 7.

49 Ms Morka, General Manager, Retirement, Ageing and Financial Inclusion, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 11.

50 Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July, p. 33.

## Recommendation 2

**3.39 The committee recommends that the Commonwealth consider increasing funding for the Younger Onset Dementia Key Worker Program in order to provide support to all people living with dementia. The increased funding should also ensure that accurate data is collected for evaluation purposes.**

## Recommendation 3

**3.40 The committee recommends that each State and Territory develop dementia training facilities similar to the Perc Walkley Dementia Learning Centre in Victoria.**

### Adequacy of community care

#### *Under resourcing of existing services*

3.41 The committee repeatedly heard—from carers, community organisations, and service providers alike—that the work of bodies such as DBMAS and ACAT was hamstrung through critical underfunding. Stakeholders suggested that it is not a matter of a lack of tools, but that there are not enough of them.

3.42 Despite DBMAS' key role in providing dementia care in Australia, DBMAS was reported as being critically underfunded.<sup>51</sup> Alzheimer's Australia argued:

I think we should double the resources available to the Dementia Behaviour Management Advisory Service, because they support not only families but now acute care, GPs and residential care and community care services. They really are very much underfunded.<sup>52</sup>

3.43 Representatives from the Tasmanian Government articulated just how thinly this resource is spread:

It is a tiny resource. It equates to about 3 ½ clinicians or so – give or take half a clinician – across Tasmania. When you are asking a service to deal with disturbed behaviour not just in nursing home settings but in acute care settings and community settings, I think you will get some idea of how thinly that resource is spread.<sup>53</sup>

3.44 There were several calls to expand the DBMAS program to help it meet, or at least better address, the demand for that service.<sup>54</sup> The Department reported that DBMAS is being expanded through additional funding of \$12.5 million (over five years) as part of the *Living Longer, Living Better* aged care reforms.<sup>55</sup>

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51 Ms Elderton, Policy Manager, Carers Australia, *Committee Hansard*, 17 July 2013, p. 24.

52 Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 28.

53 Dr Morrissey, Old Age Psychiatrist, Department of Health and Human Services – Tasmania, *Committee Hansard*, 10 July 2013, p. 22.

54 Services for Australian Rural and Remote Allied Health, *Submission 19*, p. 4; Mercy Health, *Submission 29*, p. 4; BlueCare, *Submission 32*, p. 3; Carers Australia, *Submission 46*, p. 4.

55 Department, *Submission 56*, p. 7.

3.45 The committee heard concerns regarding the provisioning of ACAT teams. The Australian Medical Association (AMA) reported that 'timely access [to services] is frustrated by long delays with ACAT assessments', despite 'early access to services delivering better outcomes to patients and their families and carers'.<sup>56</sup>

3.46 It was also put to the committee that, because of inadequate resources, ACAT were only able to perform basic assessments of eligibility and not provide the level of advice that the community might expect:

ACAT is now so busy that they tend to assess people as to their eligibility for packages. If that person is not impaired enough, if they are in the early stages, ACAT does not usually have the capacity to do any sort of case management. I know there are exceptions to that, and I have talked to some wonderful small teams in rural areas that do all that, but in big city areas they just do not have the capacity to plug people into, say, a program like Alzheimer's Australia's Living with Memory Loss program, some home care, whatever the council might be running, dementia advisory services.

...

They assess people as eligible for the packages, or for residential aged-care, and they then have to move on to the next case. And if the person [is] not actually eligible for a package – they are functioning okay, with maybe a little bit of cognitive impairment and perhaps not really able to manage their money so well, or the house is not looked after as well as it could be but is not too bad – they will just say, 'Oh, you are all right: we will come back next year' or something.<sup>57</sup>

3.47 The strain on the ACAT team was highlighted by the example of a former carer:

I am still hearing today, that people are being told, that unless they want a placement in a residential care facility, do not ring for an ACAT, as they are so under resourced they cannot do [assessments]. The assessment team are not even recommending people be assessed for respite, due to them not being able to cope with demand.<sup>58</sup>

3.48 The limited resources of ACAT affect access to respite care.<sup>59</sup> To access Commonwealth funded respite, it is necessary for ACAT to have conducted an initial assessment, a process that the committee heard can take up to three months.<sup>60</sup> In crisis

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56 Dr Kidd, Chair, Australian Medical Association Committee for Health and Ageing, *Committee Hansard*, 14 February 2014, p. 1.

57 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 38.

58 Mrs Potter, *Submission 20*, p. [3].

59 Dr Kidd, Chair, Australian Medical Association Committee for Health and Ageing, *Committee Hansard*, 14 February 2014, p. 4.

60 Australian Medical Association, *Submission 39*, p. 2.

situations, this requirement results in patients being admitted to hospital rather than a more appropriate respite setting, causing great distress to the patient and their carers.<sup>61</sup>

3.49 The committee was provided with data from the Department of Social Services (DSS) regarding the average waiting times between referral and first face-to-face contact under the Aged Care Assessment Program (ACAP). This data reveals that since 2008–09 the average wait time for a person with a diagnosis of dementia has decreased from 23.7 days to 17.2 days in 2012–13.<sup>62</sup> While this is a positive sign, the committee does note that during the same period there has been a greater than 20% reduction in the number of assessments completed on clients diagnosed with dementia.

3.50 It was suggested to the committee that many patients should be put into contact with HACC prior to ACAT, but that many GPs 'are not aware of the local HACC phone number, how it works, who they should send the person to and so on'.<sup>63</sup> The Brotherhood of St Laurence emphasised:

General Practitioners are most people's link with the primary health system. It is therefore essential that GPs be educated and made aware of the resources available within their communities to assist their patients.<sup>64</sup>

3.51 The committee heard that there is often a gap between people needing a home care package and being eligible for assistance. As the ACAT teams are so busy, they are often unable to conduct assessments for people who are in the early stages of dementia. Improved education for GPs regarding the dementia support services that are available was nominated as one tool that could be used to improve the interface between patients and services available.<sup>65</sup> The idea behind this appears to be that GPs would only refer a person to ACAT once they reach the level of eligibility for assistance. Although this might relieve some of the pressure on ACAT, the committee does not consider it to be a reasonable solution. The ACAP is supposed to be a support service, not only a gateway to funding. As explained by the Department of Human Services:

The core objective of ACAP is to comprehensively assess the care needs of frail older people and to assist them to gain access to the most appropriate

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61 Australian Medical Association, *Submission 39*, p. 2.

62 Answer to question on notice, 20 February 2013 (received 28 February 2014), p. [5]. The 2012–13 data remains subject to revision.

63 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 38.

64 *Submission 40*, p. 5.

65 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 34.

types of care, including approval for Commonwealth Government subsidised care services.<sup>66</sup>

3.52 In the opinion of the Royal Australian College of General Practitioners (RACGP), it appears that due to the current shortcomings of the system, many people are allowed to continue in the community with a minimum of supports until a crisis occurs and the person is adequately looked after.<sup>67</sup>

#### **Recommendation 4**

**3.53 The committee recommends that the Commonwealth encourage relevant professional organisations, such as the Royal Australian College of General Practitioners, to ensure that patients diagnosed with dementia and their carers are informed by health professionals of the dementia supports available and how to access them.**

#### *Gradation of care*

3.54 Evidence indicates that many dementia patients enter residential care prematurely. This may be partly explained by gaps in the spectrum of support services. Ideally, the care (and funding) available to a person would allow services between community and residential care to overlap.

3.55 The committee was informed that this was often not the case, and that carers were forced to prematurely put their loved ones into residential care as they had reached the end of their community care funding package.<sup>68</sup> As BlueCare submitted:

A care package may not be adequate or flexible enough to provide the supervision and support the person's needs, so a transfer to a residential care home is often the next step to ensure that [the] person is not at harm to themselves or others.<sup>69</sup>

3.56 Some evidence suggested that the person with dementia—and their families and carers—would benefit from funding to remain in the community longer:

**Senator BOYCE:** We are talking about people who, in your view, could remain at home with sufficient, extra support?

**Mrs Nicholl:** People would be able to stay at home—yes, I believe so. There are particular cultural issues for families as well, when it comes to caring for their loved ones at home. When they find themselves having to place their loved ones into residential care, the particular family member who has been the primary carer is still going into residential care on a daily

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66 Department of Human Services, Aged Care Assessment Program, <https://www.medicareaustralia.gov.au/provider/aged-care/assessment-program/index.jsp>, (accessed: 17 February 2013).

67 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 38.

68 Mrs Nicholls, Advocate, Elder Care, *Committee Hansard*, 16 December 2013, p. 27; Royal District Nursing Service, *Submission 24*, p. 3.

69 *Submission 32*, p. 12.

basis, from first thing in the morning until last thing at night. So really they would be much happier if they were at home with the supports. It would be much better for that care recipient as well because they would be in a good environment.<sup>70</sup>

3.57 The early entry to aged care of people with dementia can partly be accounted for by evidence received by the committee that community care is less effective at managing mental health than for physical ailments.<sup>71</sup> As Helping Hand explained:

[People] are often assessed in a system which relates to functional decline rather than psychological decline and therefore funding is inflexible to meet the behavioural needs of people living with dementia.<sup>72</sup>

3.58 The committee received evidence indicating that caring for people with dementia in the community presents a different set of requirements than the requirements traditionally associated with ageing:

Traditionally, community care services have focused on supporting people who are frail and elderly. There has been a standard range of interventions that are appropriate in supporting people with physical limitations, and this care often tends to be task focused.

Such a standard community care approach does not work well for people with a dementia. While people with dementia may have health issues that need to be managed, other issues such as memory loss, confusion, impaired judgement and impaired interpersonal skills are the major risk factors in their lives.<sup>73</sup>

3.59 The Brotherhood of St Laurence also noted that the current community care system falters once people with dementia begin displaying multiple BPSD and developing complex needs:

[Services] such as day care [are] vital to living in the community...there is also evidence that the current structure is unable to meet the needs of individuals who are showing more than one behavioural symptom of dementia. This exclusion not only has a detrimental impact on the person with dementia but also impacts on their carer and places both at risk of isolation.<sup>74</sup>

3.60 Evidence received from one carer highlighted the lack of gradation in service provision, especially during the later stages of community care:

The real fact of the matter is that the higher the needs are, the more the doors actually close. It is very ironic that the more you need help as needs increase, the less there is out there. When Chris was low care, we had

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70 Mrs Nicholls, Advocate, Elder Care, *Committee Hansard*, 16 December 2013, pp 28-29.

71 Dr Smith, Private Capacity, *Committee Hansard*, 17 December 2013, p. 24.

72 *Submission 11*, p. 1.

73 Catholic Health Australia, *Submission 14*, p. 6.

74 *Submission 40*, p. 9.



fabulous support. But as his needs changed there was less and less available out there.<sup>75</sup>

3.61 It should also be noted that encouraging people to remain in the community at all costs may not be in the person's best interests. Depending on a person's familial situation, the appropriateness of remaining in the community and the level of care received under existing programs may vary. People living in the community alone were reported to the committee as being those most at risk, with community care services most needed to provide appropriate nutrition, medication management and social, emotional and practical support.<sup>76</sup>

### ***Committee view***

3.62 The committee believes it is important that people who wish to do so are supported in the community for as long as possible. The introduction of the dementia supplement at all levels of home care goes some way toward addressing the high costs of caring for someone with dementia in the community. Due to the currency of the *Living Longer, Living Better* reforms, the impact on community care is not possible to assess at this point in time. It appears that the greater availability of the dementia supplement, as well as four discrete levels of care packages, may improve the care received by people with dementia in the community.

3.63 There does appear to remain a tension however, between a system that was designed to deal with age- and disability-related physical decline, and the needs of a person with dementia who may be physically able but has significantly impaired decision-making facilities.

### **Respite care for people with dementia**

3.64 Respite care provides an important component of Australia's community care infrastructure. Respite care facilities provide short-term accommodation for people with disabilities and illnesses in order to provide time for their carers to attend to their own mental and physical health needs.

3.65 The Commonwealth funds respite care through the National Respite for Carers Program (NRCP), which includes planned and emergency respite, Commonwealth Respite and Carelink Centres, Carer Counselling Services, Carers Australia, and Consumer Directed Respite Care.<sup>77</sup> It was pointed out to the committee that:

The NRCP program does fund some agencies to deliver respite care to people with high care needs; however there has been no growth in funds since 2007 to meet the increased demand or provide alternative models of respite for people with more extreme BPSD.<sup>78</sup>

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75 Ms Woolstencroft, Carer, Carers ACT, *Committee Hansard*, 17 July 2013, p. 21.

76 Catholic Health Australia, *Submission 14*, pp 6–7.

77 Ms Smith, First Assistant Secretary, Ageing and Aged Care Division, Department, *Committee Hansard*, 17 July 2013, p. 47.

78 Brotherhood of St Laurence, *Submission 40*, p. 9.

3.66 Respite care is also provided by HACC and residential care homes. The committee heard evidence that the not-for-profit sector was heavily subsidising the provision of respite care for people with dementia.<sup>79</sup>

3.67 From 1 July 2015, the Commonwealth Home Support Program (CHSP) will commence:

This new and streamlined approach will bring together under the one program all the services currently providing basic home support - the existing Home and Community Care program for older people, the National Respite for Carers Program, the Day Therapy Centres program and the Assistance with Care and Housing for the Aged program.<sup>80</sup>

3.68 In developing the CHSP, there will also be a large-scale review of the services offered through the program.<sup>81</sup>

### ***Importance of respite for carers***

3.69 Carers play a key role in supporting people with dementia in the community. There should be no doubt that caring for a person with dementia is a physically and emotionally demanding task. It was reported to the committee that four out of five carers provide more than 40 hours per week of care.<sup>82</sup> The committee heard that the stress of providing care can result in the carer themselves being hospitalised.<sup>83</sup> For people without an able spouse, the care of a person with dementia often falls on adult children who themselves are juggling careers and young families.<sup>84</sup>

3.70 The evidence received by the committee from Carers Australia indicates that respite services are of particular importance to carers of people with dementia:

Dementia brings with it a great emotional and physical strain for carers. So it is hardly surprising that carers of people with dementia are *four times as likely to use respite services as the average for primary carers* and that unmet need for respite is rated as the greatest area of unmet need.<sup>85</sup> (emphasis added)

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79 Ms Morka, General Manager, Retirement, Ageing and Financial Inclusion, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 14.

80 Department of Health, "Staying at Home", *Living Longer, Living Better*, <http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-aged-care-reform-measures-toc~ageing-aged-care-reform-measures-chapter3.htm>, (accessed: 17 February 2013).

81 Department of Health, "Staying at Home", *Living Longer, Living Better*, <http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-aged-care-reform-measures-toc~ageing-aged-care-reform-measures-chapter3.htm>, (accessed: 17 February 2013).

82 Ms Elderton, Policy Manager, Carers Australia, *Committee Hansard*, 17 July 2013, p. 20.

83 Royal District Nursing Service, *Submission 24*, p. 3.

84 Dr Macpherson, *Submission 62*, p. 2.

85 Ms Elderton, Policy Manager, Carers Australia, *Committee Hansard*, 17 July 2013, p. 20.

3.71 Respite services also provide an opportunity for the person with dementia to socialise with others and engage in activities that they enjoy outside of the home.<sup>86</sup>

3.72 The adequate provision of respite care for carers of people suffering from BPSD is particularly important, but also particularly challenging. As the Department advised:

The increased demands of care associated with BPSD impacts on the wellbeing of family carers and can lead to stress, burn-out and depression. Carer stress is a major reason why people exhibiting BPSD are admitted to residential aged care homes earlier than people without BPSD.<sup>87</sup>

3.73 Alzheimer's Australia NSW similarly noted, 'Carers identify BPSD as the most stressful aspect of the caring role, as well as being a trigger for admission to residential aged care'.<sup>88</sup> BlueCare noted that 'if more respite services [were] available this would assist family carers to keep the person living with dementia at home for longer'.<sup>89</sup> One carer reported having to place her husband into permanent residential care, but noted: 'I could have kept him at home longer if there was adequate high care respite'.<sup>90</sup> With a similar emphasis, the Office of the Public Advocate – Queensland explained the importance of respite care:

While the provision of respite may not be seen to be as critical as other supports, it is a key strategy to enabling people to remain living in their home and community for as long as possible. Caring for a person living with dementia and BPSD, particularly as the syndrome progresses, is an around-the-clock role that can lead to physical fatigue, emotional exhaustion and social isolation. Respite can help carers remain in their caring role for longer, [thereby] reducing the need for additional and more costly supports.<sup>91</sup>

3.74 The importance of appropriate respite facilities was highlighted in evidence provided by the Brotherhood of St Laurence:

It has been the [Brotherhood of St Laurence] experience that when the carer is notified that day care / respite can no longer be provided, many carers will then decide to place the person into residential care.<sup>92</sup>

3.75 Despite the obvious importance of this service, the committee heard a number of shortcomings and failings within the current respite care system as it relates to dementia, and especially BPSD. The committee heard that respite care is often not

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86 National Rural Health Alliance Inc, *Submission 45*, p. 5.

87 *Submission 56*, p. 17.

88 *Submission 23*, p. 7.

89 *Submission 32*, p. 14.

90 Alzheimer's Australia, *Submission 42*, p. 11.

91 *Submission 37*, p. 6.

92 *Submission 40*, p. 10.

flexible enough for dementia patients and their families, nor is it appropriately structured for dementia care.<sup>93</sup>

### ***BPSD and the provision of respite care services***

3.76 Caring for people with dementia in respite care poses a different set of challenges than dealing with a person whose care needs are principally physical in nature.

3.77 In particular, it was pointed out to the committee that the standard two-week stays of traditional respite care do not work for people with dementia, who require stable environments:

Research says that it is best for the person to keep the continuum of care going, if possible. If you are going to have a shorter stay than a two-week block, at this point in residential respite your option is a two-week block. That is a long time for a person with dementia, because it is a totally different environment, a totally different environment and so form. So when they get back home it takes a long time for the carer to settle that person back in.<sup>94</sup>

3.78 In light of this, it is little surprise that the most popular forms of respite for carers of people with dementia were reported as bringing a paid carer into the home; going to a home-like environment which specifically cater to dementia; or family holidays accompanied by a paid carer.<sup>95</sup> Knowing that significant changes in environment are disruptive to a person with dementia, these options may be the only ones that a carer views as viable.<sup>96</sup> Unfortunately, it was reported that these options are 'thin on the ground and very expensive'.<sup>97</sup> One of the reasons for the popularity of these approaches is that they keep the person in a familiar environment. BlueCare explained the importance of a familiar environment:

Respite in an unfamiliar surrounding can be particularly stressful for the person living with dementia and can be the catalyst to return early due to changes in the person's behaviour as a result of the disruption to their usual routine and familiarity of the people around them.<sup>98</sup>

3.79 Indicative of the way that many carers of people with dementia view the available respite care is that only 27% of individuals with dementia approved for

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93 Mrs Edwards, Service Development and Improvement Advisor, BlueCare, *Committee Hansard*, 17 July 2013, p. 12.

94 Ms Astete, Senior Manager – Day and Respite Programs, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 13.

95 Ms Elderton, Policy Manager, Carers Australia, *Committee Hansard*, 17 July 2013, p. 20.

96 BlueCare, *Submission 32*, p. 15.

97 Ms Elderton, Policy Manager, Carers Australia, *Committee Hansard*, 17 July 2013, p. 20.

98 *Submission 32*, p. 9.

residential respite care actually use these services.<sup>99</sup> Alzheimer's Australia notes the various reasons for this underuse:

Important contributory factors are that respite care is inflexible and is not available at the right time or provide insufficient hours of care. Consumers for their part may be reluctant to use a service because there is no perceived benefit for the person with dementia. Service providers may feel unable to provide and appropriately support individuals with BPSD. Family carers report that once the person with dementia develops BPSD services refuse to continue providing support.<sup>100</sup>

3.80 The committee heard that it is extremely difficult to access high-care respite, such as is required for someone with BPSD, as there are very limited facilities and long waiting lists. One carer reported that '[finding] pre-booked, high-care respite, in a memory support unit in residential care was virtually impossible'.<sup>101</sup> Existing dementia facilities are often either not appropriately equipped to deal with BPSD or they lack the human resources to effectively manage people with BPSD.<sup>102</sup> Helping Hand observed:

Respite care in residential facilities is difficult to access as it tends to be in communal, non-secure, areas so precludes people who wander or may have challenging behaviours, also many people have high needs, and receive reduced stimulation and activity, are at risk of decline and may struggle to return home.<sup>103</sup>

3.81 Facilities that are not equipped to deal with BPSD also present challenges to the person with dementia and their carers. As explained by Carers Australia:

[F]inding suitable respite options for people with dementia, particularly those with moderate to severe BPSD, is not an easy ask. People with dementia have a very marked level of discomfort and resistance when removed [from] their familiar environment and familiar routines. Carers often remarked that the long-term cost of taking a break is not worth the effort since it can take weeks for the person they care for to settle down again.<sup>104</sup>

3.82 Due to facilities recognising that they cannot provide sufficient care for some people with BPSD, they do not offer services for that group at all:

[It] is not unusual for our clients with dementia and BPSD to be denied placement at community respite centres purely because the level of services

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99 Brotherhood of St Laurence, *A preliminary evaluation of the Short Break Stay Program*, tabled 16 December 2013, p. 2.

100 *Submission 42*, p. 10.

101 Mrs Potter, *Submission 20*, p. [3].

102 Ms Astete, Senior Manager – Day and Respite Programs, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 12.

103 *Submission 11*, p. 2.

104 Ms Elderton, Policy Manager, Carers Australia, *Committee Hansard*, 17 July 2013, p. 20.

available do not meet the needs of clients. Issues such as inappropriate building environments, lack of staff expertise in assisting people with BPSD and unsuitable hours of operation are paramount in this lack of access.<sup>105</sup>

3.83 In addition to existing services being poorly suited to the needs of people with dementia, the structure of two-weeks respite care is a poor fit for service providers. The following example illustrates the difficulties of providing traditional respite care to a person with dementia and BPSD, their carer and the service provider:

When a person needs to go into residential respite and they have those behaviours of concern, the residential services are unable to support that person for those two weeks, because they need a lot more intensive support than you can be given in residential respite...I have had reports where a carer has been called, after the person with dementia has been in respite two or three days, saying that they are unable to be supported in that residential respite because of those behaviours. So there are people out there who are unable to be supported within residential respite.<sup>106</sup>

3.84 Evidence received from Alzheimer's Australia makes a similar point, noting that extra funding will be required to address the problem of appropriate respite for carers of people with BPSD:

The real difficulty is for people with moderate to severe BPSD in the community. We come across numerous cases of a carer saying: 'I had a booking. I took my person along, and two hours later I got a call saying to bring them home.' That is why we are saying that, if you do not reward respite care services and give them extra funding so that they can train their staff for that and maybe for social engagement activities that make the person relax so they go home in a reasonable state, you are not going to win.<sup>107</sup>

3.85 It was argued that some people with dementia—who may have trouble accessing traditional respite care—could be effectively managed in day care as 'often those behaviours tend to happen in the evening and overnight'.<sup>108</sup> Recognising the importance on maintaining the continuum of care, several stakeholders suggested that greater use of short-stay and day respite should be encouraged.<sup>109</sup> For instance, the Brotherhood of St Laurence contended:

It is really important to ensure that there are day programs that are especially designed for and provide that specialist care to people with

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105 Benetas, *Submission 21*, p. [3].

106 Ms Astete, Senior Manager – Day and Respite Programs, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 12.

107 Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 37.

108 Ms Astete, Senior Manager – Day and Respite Programs, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 12.

109 Brightwater Care Group, *Submission 50*, p. 11.

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dementia. We know that the demand for dementia care will increase as the prevalence of dementia increases.<sup>110</sup>

3.86 The Brotherhood of St Laurence reported success in providing three-day breaks for carers, which is long enough for carers to receive some tangible respite from their caring role but short enough to avoid unduly disrupting the care routines already established at home.<sup>111</sup> Carers reported little evidence of disorientation when people returned home from this short-stay service, and the high staff-client ratio enabled staff to emulate the routines that the person is used to receiving at home.

3.87 The committee heard of a small number of facilities across Australia that provide suitable respite care for people with dementia and BPSD.<sup>112</sup> The existence of these services—however few of them there currently may be—highlights that it is possible to provide suitable respite care for people with dementia and BPSD.<sup>113</sup>

3.88 Benetas argued that there is a need to review the way that respite care is accredited and funded to ensure that respite providers in receipt of government funding are able to do so for those who need it most:

In this regard it is no longer acceptable to tie respite funded services to centres which operate more or less as senior citizen's community centres. Given the rapidly increasing number of older people with dementia and BPSD all respite services for older people need to be able to accommodate those people with dementia. Consequently policies for the National Carers' Respite Program need to be reviewed and amended, where appropriate, to ensure funding from this program only goes to those services which can demonstrate they can provide quality respite services for older people with dementia and BPSD. These services need to demonstrate they have suitable buildings, appropriately trained staff and offer flexible hours of service to be eligible for specific respite funding.<sup>114</sup>

3.89 Alzheimer's Australia also argued for service providers to meet certain standards around training and staffing levels:

Service[s] which provide respite to clients who have dementia supplement would be required to show they were providing appropriate care including having staff with appropriate training and qualifications and appropriate staff to patient ratios required to support individuals with BPSD.<sup>115</sup>

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110 Ms Astete, Senior Manager – Day and Respite Programs, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 11.

111 Ms Astete, Senior Manager – Day and Respite Programs, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 13.

112 Mrs Potter, *Submission 20*, p. [3]; Catholic Health Australia, *Submission 14*, p. 7.

113 Benetas, *Submission 21*, p. [3].

114 *Submission 21*, p. [3].

115 *Submission 42*, p. 11.

### ***Respite care in regional and remote areas***

3.90 The challenges of providing health care to rural and remote areas are well known. These include a lack of suitably qualified healthcare professionals, fewer healthcare and community facilities, and greater travel distances.<sup>116</sup> The National Rural Health Alliance argued:

Respite care is especially important—but more difficult to achieve—for clients and their carers who live in rural and remote communities where isolation and distances increase the challenges they face day-to-day.<sup>117</sup>

3.91 Similarly, SARRAH argued:

There needs to be options for flexible respite and residential care in rural and regional areas to overcome access barriers created by distance and isolation. The provision of respite for 'time out' for carers enhances their ability to cope with in-home care over longer periods.<sup>118</sup>

3.92 SARRAH went on to suggest that respite could take many forms depending on local circumstances and needs, including in-home care, mobile services, or day centres or clubs based on a person's interests.<sup>119</sup>

### ***Committee view***

3.93 Based on the evidence received by the committee, there appears to be a clear shortage of BPSD appropriate respite facilities. These facilities and services are necessarily more expensive to provide, requiring higher staff-to-patient ratios, highly trained staff and appropriately designed facilities. Given the crucial role BPSD appears to play in deciding to place someone in residential care however, the committee considers providing appropriate respite to allow people to stay in the community is a sound investment of public money.

3.94 As discussed in this chapter, there are significant economic and social gains from enhancing community care supports for dementia sufferers and their carers. The aged-care sector could not cope if all of those with dementia currently receiving care in the community—many of whom would be in residential care were it not for the efforts of their carers—needed to be treated in the more expensive residential aged-care system. There is a strong incentive for the Commonwealth to ensure that the supports necessary for people with BPSD to remain in the community are available.

### **Recommendation 5**

**3.95 The committee recommends that the Commonwealth facilitate and potentially fund the establishment of dementia-specific respite facilities, including in regional and remote areas.**

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116 Services for Australian Rural and Remote Allied Health, *Submission 19*, p. 2.

117 *Submission 45*, p. 5.

118 *Submission 19*, p. 8.

119 *Submission 19*, p. 10.



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## **Recommendation 6**

**3.96 The committee recommends that the Commonwealth, in consultation with industry, develop guidelines regarding dementia-specific respite facilities that can effectively manage BPSD.**

## **Recommendation 7**

**3.97 The committee recommends that the Commonwealth explore options for improving the provision of respite in rural and remote areas.**

## **Conclusion**

3.98 Providing the necessary assistance to help people stay in the community as long as possible yields personal health benefits to the person with dementia, allows families and communities to remain together, and reduces the demands on the residential aged care system. To this end, there are a number of supports available to people with dementia and their carers.

3.99 Carers form a particularly important component of the care system, undertaking much of the work that is necessary to ensure the ongoing quality of life for people with dementia. Carers can be further supported in several key ways:

- The provision of training regarding support of people with dementia;
- Improved access to support services and assistance in utilising those services; and
- The availability of dementia-friendly respite care.

3.100 As noted earlier in this report, dementia is a progressive disease with no known cure. At some point, due to the progression of dementia, most people will need dedicated dementia care that cannot be provided in the community and must be transferred to residential care.<sup>120</sup> Residential care and its related issues is the topic for the next chapter of this report.

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120 Ms Astete, Senior Manager – Day and Respite Programs, Brotherhood of St Laurence, Committee Hansard, 16 December 2013, p. 10; BlueCare, *Submission 32*, p. 12.



## Chapter 4

### Meeting the needs of Behavioural and Psychological Symptoms of Dementia in residential care

4.1 Managing the behavioural and psychological symptoms of dementia (BPSD) in residential care is a significant aspect of providing care for people with dementia. As noted in chapter 2, most people with a diagnosis of dementia will experience BPSD at some point. Demonstrating the need for suitable BPSD care, Alzheimer's Australia estimated that between 10% and 15% of aged care beds are required to meet the needs of residents demonstrating moderate to severe BPSD.<sup>1</sup> While there are a small number of people with dementia for 'whom no amount of care and management will reduce the incidence or severity of their BPSD', for almost everyone with dementia, their BPSD can be minimised through appropriate care.<sup>2</sup>

4.2 The committee heard that in residential care, behaviours are often not seen as an expression of need, but rather as a symptom of dementia, just as a cough might be a symptom of a cold. The behaviour is seen as something that must be clinically managed rather than investigated for the underlying cause:

This is commonly overlooked in the aged care industry and behaviour is often seen purely as a symptom of dementia and so no action is taken to improve the situation and improve the quality of life for both the person and their carers.<sup>3</sup>

4.3 This chapter discusses the provision and quality of residential aged care for people with dementia in Australia. It considers issues including continuity of care, the provision of dementia friendly facilities and care, staffing and funding. The use of restraints in residential care was one of the key issues raised in this inquiry and is discussed in chapter 6.

#### Accreditation standards

4.4 The physical environment can have a significant impact on the likelihood of a person experiencing BPSD.<sup>4</sup> One of the challenges of providing care for people with dementia in the residential care system is that the current system was designed to manage physical deterioration associated with the ageing process. It was pointed out that Australia's residential care system is based on a model that was designed more

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1 Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 34.

2 Alzheimer's Australia NSW, *Submission 23*, p. 3.

3 Mrs Edwards, Service Development and Improvement Advisor, BlueCare, *Committee Hansard*, 17 July 2013, p. 11.

4 HammondCare, *Submission 25*, p. 3.

than half a century before 'when the decision was to put old people in an institution based on either a prison or a medical model'.<sup>5</sup>

4.5 To ensure that residential aged care facilities (RACFs) are of an acceptable quality, successive governments have developed accreditation standards. The current status of these standards was outlined by the Department of Health and Ageing (Department):

In terms of aged-care regulation, all facilities which receive a Commonwealth subsidy have to be accredited. They are accredited against four accreditation standards, which I think have 44 outcomes. Some of those outcomes are very relevant in this area. They include behaviour management, medication management and the staffing that the facility has to have. Facilities are required to have the appropriate number of appropriately qualified staff to meet the care needs of residents and the provider is required to assess, on an individual basis, the care needs of the resident and put in place strategies to manage those care needs.<sup>6</sup>

4.6 The New South Wales Nurses and Midwives' Association (NSWNMA) queried the efficacy of the current accreditation standards, noting that 'while there are many checks and balances in place under existing accreditation arrangements, many aspects seem to slip through the net or are sacrificed for the sake of budgets'.<sup>7</sup>

4.7 Rural Northwest Health argued that standards are insufficient for people with dementia:

There is no specific accreditation outcome included for people living with dementia and how their physical and mental health can be demonstrated to be at that optimum level. These outcomes do not send a clear message to providers that people living with dementia should have demonstrated systems and processes in place to meet and improve people's optimum health and personal care needs.<sup>8</sup>

4.8 Perhaps reflecting the concerns expressed above, a family member of a dementia patient in residential care argued that the area most in need of improvement is supporting 'the sufferer's emotional needs, and their right to quality of life'.<sup>9</sup>

4.9 It appears that in many ways, the Australian aged care system still struggles to support people whose needs are primarily psychological in nature. Some stakeholders criticised these standards as continuing to emphasise clinical outcomes, rather than quality of life measures. The care and facilities provided by the market are in many

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5 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 1.

6 Ms Smith, First Assistant Secretary, Ageing and Aged Care Division, Department of Health and Ageing (Department), *Committee Hansard*, 17 July 2013, p. 40.

7 *Submission 55*, p. 10.

8 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 2.

9 Dr Macpherson, *Submission 62*, p. 5.

ways a response to the standards set by regulators. One service provider candidly explained:

Accreditation standards across the board for every aged-care facility could certainly be changed to reflect outcomes that need to be achieved if you are going to try and change the industry. If you want people to change their behaviour, then maybe it requires a stick approach and you have to measure what they are delivering. But outcome standards for accreditation are very focused on clinical—17 out of 44. You are asking us to focus on the task and the clinical outcomes. If you look at lifestyle, there are three out of 44 that would perhaps address that area. So what are we telling the industry? What is important? If we want to change, we have to start measuring and informing the industry how we want it to go.<sup>10</sup>

4.10 There also appears to be a lag in the aged care sector accepting its role in the provision of dementia and mental health services. Although RACFs were developed long ago to care for the aged in their final years, they now must learn to cater for the mental decline that increasingly affects their residents. More than half of permanent residents in RACFs have a recorded diagnosis of dementia. A further quarter has a diagnosed mental illness other than dementia.<sup>11</sup> Although the evidence suggests mental illnesses are a key competency needed by RACFs, the committee was informed:

Despite this, few residential aged care facilities consider BPSD or mental illness as part of their 'core business'. This is reflected in staff training, care practices and environmental design of residential aged care facilities. Environments are often not designed to cater for people with cognitive impairment, as this is not a mandatory requirement under the relevant building regulations.<sup>12</sup>

## Funding

4.11 To meet these standards, service providers rely on a base level of government funding. For providers with dementia patients demonstrating BPSD, there is now also a supplement available. Most funding for aged care comes from the Commonwealth, although philanthropic organisations and not-for-profit organisations also play a significant role. The Department elaborated on the mechanisms of residential funding:

In residential care, what we have is the aged care funding instrument [(ACFI)]. That instrument allows needs to be assessed in three different domains: activities of daily living, complex health care and also behaviour. So there is already the capacity for a resident who has got high behaviour needs to get funding up to a certain level. It was always acknowledged that there was this relatively small number of people with very extreme behaviours who were not being adequately funded through the ACFI so

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10 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 8.

11 Royal Australian and New Zealand College of Psychiatrists, *Submission 49*, p. 8.

12 Royal Australian and New Zealand College of Psychiatrists, *Submission 49*, p. 8.

there is now this separate dementia and severe behaviour supplement, which will allow the provider to claim an extra \$16.15 a day for eligible clients who have been assessed against the [Neuropsychiatric Inventory] tool and who have an appropriate diagnosis of a condition that is listed.<sup>13</sup>

4.12 Over the years, aged care funding has undergone significant changes to improve the industry and the quality of care. However, it was reported that although buildings had improved, quality of life appeared to be a secondary consideration and aged care still operated on an institutional model.<sup>14</sup>

4.13 One recent change has been the introduction of the Dementia Supplement to help facilities meet the costs of providing care for people with dementia. It was proposed by Alzheimer's Australia that the receipt of the supplement should be linked to a facility meeting certain standards of dementia specific care:

We think the [D]epartment should show some interest in the profile of the residential care provider in terms of their capacity to deliver dementia care to those who have severe behavioural difficulties. We would want to see, for example, organisations with a commitment to no physical restraint. We would like to see organisations who have a coordinator who is there to advise on behavioural issues. We would like to see them have environmental audits to show that their facilities are in fact sensitive to the needs of people with dementia. I will not go through the list, but we think there are ways of defining capacity so that people are protected from residential providers who really do not have the capacity to care for people with severe BPSD.<sup>15</sup>

4.14 Although the new behaviour supplement introduced under the *Living Longer, Living Better* reforms is now available, it is unclear how much of an impact this will have on service provision:

Whilst BlueCare understands that dementia supplements are now being implemented within home care packages and residential placements...it is in its infancy and the impact of this new supplement has yet to be analysed as to the outcomes for the residential client.<sup>16</sup>

4.15 HammondCare argued that the supplement would only work if providers take on sufficient numbers of people with BPSD to garner sufficient supplements to improve care services:

Whilst the Commonwealth introduction of behaviour supplements for residential aged care is a step in the right direction, at \$16-a-day the impact

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13 Ms Smith, First Assistant Secretary, Ageing and Aged Care Division, Department, *Committee Hansard*, 17 July 2013, p. 48.

14 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 1.

15 Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 28.

16 Mrs Edwards, Service Development and Improvement Advisor, BlueCare, *Committee Hansard*, 17 July 2013, p. 12.

of that will not be seen unless there are providers that are prepared to start looking after more people who are displaying severe BPSD. That will mean there can be some economies with receiving a level of subsidy that does actually improve the care and services that are provided.<sup>17</sup>

4.16 The committee heard calls to review the ACFI tool 'to enable "behaviours" to be more easily claimed for and allow for more realistic staffing levels'.<sup>18</sup> It should be noted that the receipt of ACFI funds does not come with any staffing ratio requirements.<sup>19</sup> BlueCare provided an example highlighting the potential frustrations of dealing with the ACFI:

Another factor that is often overlooked when claiming for behaviours is that 'all behavioural symptoms must disrupt others to the extent of requiring staff assistance'. The current ACFI does not provide funding for the intervention required to manage or prevent the assessed behaviour. For example, a resident who yells, shouts, and swears at the television in their own room with the door closed is not a claimable behaviour unless it can be proven that other residents can hear and are disrupted by this behaviour. However staff need to intervene and settle the person which can take considerable time if they are using a person centred approach which is best practice.<sup>20</sup>

4.17 It was put to the committee that the ACFI is unduly focused on clinical outcomes and provides funding in anticipation of completing those tasks. There is no requirement for ACFI funding to be used to improve the quality of life of residents.<sup>21</sup>

4.18 The Brotherhood of St Laurence said that many of the innovative programs they undertake rely on non-government funding sources—such as bequests or donations—to operate.<sup>22</sup> Improvements often come through innovation, which carries some level of risk. The many non-government organisations that are exploring new ways of providing care and sharing what they learn do not accrue any fiscal benefit for their research. BlueCare submitted that governments need to do more to support the innovation work that the non-government sector has been spearheading.<sup>23</sup>

4.19 A natural concern for governments and citizens of any new—or even different—system is the cost of change. The committee heard that providing better

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17 Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 13.

18 BlueCare, *Submission 32*, p. 3. Also see: Brightwater Care Group, *Submission 50*, pp 5 and 10.

19 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 2.

20 *Submission 32*, p. 13.

21 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 2.

22 Ms Morka, General Manager, Retirement, Ageing and Financial Inclusion, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 10.

23 *Submission 32*, p. 3.

care for people with dementia through environs that better meet their needs and increased staff training will not necessarily be more significantly expensive, as currently there is a lot of money wasted doing things poorly.<sup>24</sup>

### **Leaders in dementia-appropriate facilities and care**

4.20 Evidence received by the committee indicated that there is a cultural change underway which will bring about better care for people with dementia,<sup>25</sup> but that this change needs to be encouraged and nurtured:

The culture of aged care is changing, but it will take a long time because it is a very entrenched culture. It has moved from the medical model to be a little bit more personal and a little bit custodial. It probably needs to continue to move, and I think that needs to happen through government support.<sup>26</sup>

4.21 The committee heard about a number of promising models being developed to improve dementia care in RACFs that combine the features of effective dementia support: appropriate facilities; well-trained staff; supportive leadership; and person-centred care (PCC).

4.22 One of the outstanding facilities that the committee had the privilege to visit was the Yarriambiack Lodge in Warracknabeal in rural Victoria. A family member of a former resident of that facility summarised what it was that made life in Yarriambiack Lodge good for people with dementia:

In summary, the important aspects that make Yarriambiack Lodge better for dementia patients are, one, making the residents feel useful, two, encouraging them to spend their days in a group, as they would in a family, three, enabling them to participate in domestic activities and hobbies, rather than passively watching, and, four, having caring, constant and loving staff.<sup>27</sup>

4.23 It was explained to the committee that Yarriambiack Lodge operates using the Montessori method for dementia:

The focus of the Montessori method for dementia is on the abilities, needs, interests and strengths of people living with dementia. These methods focus on creating worthwhile roles, routines and activities for the person, while also supporting the person's environment.

...

With Montessori, it is about the staff letting go of control. The staff job is to enable, not to do. Everything we do for the residents we take away from

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24 Ms Pieters–Hawke, Co-Chair, Minister's Dementia Advisory Council, *Committee Hansard*, 17 July 2013, p. 35.

25 Mr Hunt, Private Capacity, *Committee Hansard*, 10 July 2013, p. 33.

26 Ms Calvert, Manager, Dementia Tas, *Committee Hansard*, 10 July 2013, p. 10.

27 Dr Smith, Private Capacity, *Committee Hansard*, 17 December 2013, pp 15–16.



them. Our motto is: use it or lose it. Staff that do the least for the residents get a prize. Staff who do nothing get the grand prize.<sup>28</sup>

4.24 The committee also heard of the promising 'Greenhouse' model being introduced into residential care in Australia:

[Small] household environments are developed, allowing people living there to take part in the running of the home and live together as a community. The model embraces people living with dementia as an opportunity for continued growth and development. It creates an environment where individual needs are met because each person is known and valued. Everyday tasks are seen as an opportunity to support autonomy, decision making and meaningful engagement.<sup>29</sup>

4.25 This model is similar to that described by a former employee of the Alzheimer's Disease and Related Disorders Society (ADARDS) home in Tasmania:

This little home was AWESOME, quiet, slow paced and very respectful of the needs/wants of the residents...We were always able to enter the kitchen and get residents any requirement, fluid or nutrition wise and could sit with them at breakfast time enjoying a cup of tea/coffee and eating a piece of toast or bowl or cereal; this encouraged the demented residents to eat as they would mimic what you were doing. Those that were able read the newspaper and we would discuss the news. This was all after a calm morning routine of walking, showering and dressing at the resident's pace. We often engaged in walks around the garden, picking flowers, feeding the chooks or birds or just walking with each other in silence whatever the resident wanted to do to keep their happiness at a maximum level. This was THEIR home and we were to respect this fact above all else!<sup>30</sup>

4.26 ADARDS, opened in 1991, was a pioneering and internationally recognised dementia-friendly RACF, which demonstrated that difficult problems in dementia care can be handled in comfortable surroundings, provided special design features are observed, and well-chosen, skilled, and caring staff are employed.<sup>31</sup>

4.27 The facility was designed by Dr John Tooth OAM, the then Tasmanian State psychogeriatrician, and two experienced psychogeriatric nurses.<sup>32</sup> As explained by Dr Tooth:

We needed to have residents in small houses with furnishings and décor resembling homes of 50 years ago. There were four houses of nine single

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28 Ms Walters, Innovation and Continuous Improvement Manager, Rural Northwest Health, *Committee Hansard*, 17 December 2013, pp 4–5.

29 BlueCare, *Submission 32*, p. 9.

30 Ms Mathers, *Submission 3*, p. 2.

31 *Australian of the Year Awards: Honour Roll*; Dr John Tooth OAM, 2007 State Finalist Australian of the Year in recognition of contribution to dementia care, <http://www.australianoftheyear.org.au/honour-roll/#browse:view=fullView&recipientID=743> (accessed: 25 March 2014).

32 Dr Tooth, *Submission 8*, p. 3.

bedrooms, each with en-suite facilities...Each house had a kitchen, dining room, living room and tub bathroom. The design was simple but the furnishings of each of the four houses resembled those of a previous era.<sup>33</sup>

4.28 The former ADARDS home received international acclaim for both its design and the management of people with dementia while significantly reducing reliance on medication.<sup>34</sup> In 2007, Dr Tooth was an Australian of the Year State Finalist in recognition of his pioneering approach to dementia care.

4.29 Although there are models that appear to be best placed to deal with people with dementia, all aged care providers must be appropriately resourced and staffed to provide care to people with dementia. The existence of specialised facilities does not remove the responsibility from others to provide care for people with dementia.<sup>35</sup> Some of mechanisms to improve dementia care across all RACFs are discussed below.

### *Size and layout*

4.30 The size, layout and design of RACFs are important factors in the quality of life enjoyed by the residents of that facility. Just as a noisy and confusing setting can exacerbate BPSD, a calming, clear and appropriate environment can prevent and manage it. One of the key considerations in dementia facilities is their size.

4.31 Representatives from Rural Northwest Health highlighted the differences that now exist between disability and aged care in relation to the provision of residential care:

Today, if I went to a government department responsible for people with a disability I would be told that the maximum number of people that I should have living in a house with a disability is seven and that the members must be engaged within the community. If I went to the government department responsible for funding older people living with a physical or cognitive disability I would be told that the minimum number of people I should have living together would be 90.<sup>36</sup>

4.32 HammondCare highlighted the importance of smaller facilities that have lower levels of noise and are easier to navigate as a means of reducing the incidents of BPSD:

It is really hard to provide the right level of care to a person who has those needs in a 100-bed facility, which is confusing and large and noisy. Noise is

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33 *Submission 8*, p. 3.

34 *The Companion to Tasmanian History*: Edited by Alison Alexander, Centre for Tasmanian Historical Studies at the University of Tasmania, [http://www.utas.edu.au/library/companion\\_to\\_tasmanian\\_history/A/Adards%20Nursing%20Home.htm](http://www.utas.edu.au/library/companion_to_tasmanian_history/A/Adards%20Nursing%20Home.htm), accessed 25 March 2014.

35 Mr Lipmann, Chief Executive Officer, Wintringham Specialist Aged Care, Committee Hansard, 16 December 2013, p. 6.

36 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 1.

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to people with dementia what stairs are to someone in a wheelchair. That is what can exacerbate a person's behaviour within that environment.<sup>37</sup>

4.33 The above example also illustrates the degree to which many facilities are inappropriate for sufferers of dementia.

4.34 The committee received evidence that dementia is best managed in smaller home-like facilities. HammondCare contended that:

I think the ideal number [of residents] is between six and 10. Any more than 10 and I think it is not manageable. In order to make that economically viable within the current funding structure, one of the big challenges is providing care for that number of people.<sup>38</sup>

4.35 The committee heard that units with up to 16 beds are manageable, but beyond that it is necessary to have a separate unit to provide best-practice dementia care.<sup>39</sup>

4.36 According to the evidence, current funding arrangements make it very difficult to provide residential care homes that mimic the home-like environment considered ideal for dementia patients. BlueCare noted that '[s]taffing smaller environments has an impact on economies of scale and is often cost prohibitive within a business model of care'.<sup>40</sup> The committee heard that facilities need to have around 90 beds in size in order to be financially viable.<sup>41</sup>

4.37 Smaller self-contained units within a larger facility were one suggested means of providing high quality care while remaining economically viable.<sup>42</sup> Brightwater Care Group described two such facilities that it operates:

- The Village which comprises 65 private rooms in six connected houses that caters for people living with dementia who are independently mobile and need high care support; and
- Edgewater which comprises 33 private rooms in four co-located houses.<sup>43</sup>

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37 Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 13.

38 Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 13.

39 Ms Walters, Innovation and Continuous Improvement Manager, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 11.

40 Mrs Edwards, Service Development and Improvement Advisor, BlueCare, *Committee Hansard*, 17 July 2013, p. 12.

41 Mr Davidson, Principle Policy Consultant – Complex, Chronic and Community Service, Tasmania Health Organisation South, *Committee Hansard*, 10 July 2013, p. 16.

42 Ms Pieters-Hawke, Co-Chair, Minister's Dementia Advisory Council, *Committee Hansard*, 17 July 2013, p. 37.

43 *Submission 50*, p. 6.

4.38 The committee did hear of at least one facility with between 50 and 60 residents that was able to provide dementia friendly care by creating 'a wonderful sense of it being someone's home' while remaining viable.<sup>44</sup>

4.39 As well as the size of a facility, the look, layout and fittings of a facility can have a large impact on the people with dementia living there. The committee was informed that properly designed facilities can also reduce 'unnecessary' BPSD. Dementia-friendly designs in RACFs minimise risks to a resident's physical health and also improve their emotional health, by avoiding confusion for instance. HammondCare provided a comprehensive summary of the interaction between design and BPSD:

When talking about BPSD in residential aged care, it is important to recognise that physical environments and care models that are not suitable can actually exacerbate the symptoms of dementia, even to the point of creating 'unnecessary' BPSD.

The evidence demonstrates that while spaces designed for people who are 'cognitively able' can cause stress for people with dementia, the following environmental features are closely linked to improved behavioural outcomes: privacy and scope for personalisation in bedrooms; a small environment and residential character; an ambient environment that provides 'cues' and minimises confusion for people with cognitive impairment; a range of common areas that vary in ambience; a genuinely homely interior environment; and hidden exits and 'destination' areas at the end of corridors (no dead ends).

When these features are missing, it is much more likely that people with dementia will display excess BPSD, as a result of the confusion and frustration caused by their environment.<sup>45</sup>

4.40 The committee was informed that even in types of dementia where BPSD is more prevalent and cannot be entirely controlled, an appropriate care strategy and environment can significantly reduce BPSD:

There are people whose type of dementia means that they are more likely to present with BPSD such as people with frontotemporal dementia and people who have Korsakoff syndrome or alcohol-related brain damage. For those people, that BPSD may only be able to be managed to a certain point and you will continue to have that behaviour but it would be best managed and minimised in an environment that is designed to reduce agitation, reduce confusion and is small.<sup>46</sup>

4.41 The following example highlights how simple considerations in design can make a large difference to a person with dementia:

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44 Dr Morkham, National Director, Young People in Nursing Homes National Alliance, *Committee Hansard*, 17 July 2013, p. 36.

45 *Submission 25*, p. 3.

46 Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 13.

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Often you walk into areas that have lots of glitzy carpets and things like that. The classic would be if you think about some of our airports, where we use those big swirly carpets and things like that. For somebody with dementia, that is highly disabling because people cannot have 3D-depth. The problem is that people start to think that they have things to step over and step around, and that creates some of the fall risks that we have already talked about. But we see those consistently in some of the designs that are being drawn up and provided.<sup>47</sup>

4.42 As well as design contributing to confusion and the potential for falls, other design elements actively contribute to some of the 'difficult' behaviours some people with dementia display, as illustrated by the following example:

How do you even find the toilet if it is in an all-white bathroom and you cannot actually see the toilet? Contrast is needed to help people see where they are going and to use something like a toilet. Things that are often seen as challenges, like incontinence, could actually be caused by people not being able to find the toilet because they just see a white area.<sup>48</sup>

4.43 The above example illustrates the importance of utilising dementia friendly design principles in RACFs. Like handrails are used in bathrooms to support mobility, contrasting colours can be used in interior designs to assist with the perceptions of residents living with dementia.

4.44 Rural Northwest Health's Yarriambiack Lodge is designed around these dementia friendly design principles, including infrastructure changes:

A person with dementia is a normal person who has memory loss, and so the environment is changed to support their memory loss. We use external cues to help the residents—hence, the reason we changed the name to Memory Support Unit instead of Dementia Unit. Research shows that it is easy to read black writing on yellow paper, like road signs and cleaning signs. The environment continues to change as the residents change. Residents and staff wear name badges that are clear and easy to read, prompts are used, materials look familiar and are taken from the resident's everyday environment. We have interactive wall spaces which give prompts to staff and relatives. We removed the large TV from the big room and put a small TV in the old cabinet. The people who complained the most about the TV being removed were the staff. We closed the nurses station and changed it into a relaxation room. Spaces that were not utilised effectively are now being used to a maximum. We had the doors of a large cupboard removed and had that area transformed into a flower nook, a sewing nook and a nursery. It disguised the exit door.<sup>49</sup>

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47 Mr Cunningham, Director – The Dementia Centre, HammondCare, *Committee Hansard*, 17 July 2013, pp 16–17.

48 Mr Cunningham, Director – The Dementia Centre, HammondCare, *Committee Hansard*, 17 July 2013, p. 17.

49 Ms Walters, Innovation and Continuous Improvement Manager, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 4.

4.45 There are useful tools available such as those produced by the *Dementia Enabling Environments Program*, a national project focussing on translating research into practice in the area of dementia friendly environments.<sup>50</sup>

4.46 Many of the entertainment and lifestyle options available to residents of aged care facilities are not applicable to people with dementia and can contribute to their BPSD through confusion and boredom. Appropriate cognitively stimulating social and physical activities protect against the development of BPSD.<sup>51</sup> As one service provider noted:

I am sure that if we looked at every aged-care leisure calendar we would see bingo, movies and newspaper reading occurring daily and weekly, and if we asked the residents they would tell us that these activities do not provide appropriate options for people living with dementia.<sup>52</sup>

4.47 It was reported that providing people with dementia with appropriate activities can also significantly reduce BPSD:

We know from research conducted that wandering behaviours are often contributed to by boredom and lack of motivation which can be attributed to low staffing levels, due to inadequate government funding and unskilled staff.<sup>53</sup>

4.48 The committee similarly heard concerns from carers that RACFs 'often lack activity and social engagement on a level that is suitable for a person in the early or medium stages of dementia'.<sup>54</sup>

### ***Person-centred care***

4.49 One of the key themes to come out in the evidence to this inquiry is the need to provide PCC for people with dementia. PCC has been shown to be effective at reducing BPSD in RACFs.<sup>55</sup> It has also been identified by patients, carers, service providers and policy representatives as being a desirable characteristic of community care service for people with dementia.<sup>56</sup> At the heart of the matter, individualised care is built upon the recognition that although someone may have lost their memory, they

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50 Alzheimer's Australia, *Submission 42.2*, p. 2. Information regarding this program can be found at [www.enablingenvironments.com.au](http://www.enablingenvironments.com.au) along with a number of useful free resources.

51 Henry Brodaty, Brian M Draper, Lee-Fay Low, "Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery", *Medical Journal of Australia*, no. 178, 2003, p. 232.

52 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 2.

53 BlueCare, *Submission 32*, p. 13.

54 Carers Australia, *Submission 46*, p. 10.

55 Minister's Dementia Advisory Group, *Submission 28*, p. 3.

56 Lee-Fay Low, Fiona White, Yun-Hee Jeon, Meredith Gresham and Henry Brodaty, 'Desired characteristics and outcomes of community care service for persons with dementia: What is important according to clients, service providers and policy', *Australasian Journal on Ageing*, vol. 32, no. 2, June 2013, p. 95.

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are 'still real people behind a bit of fog'.<sup>57</sup> They still have personal preferences, habits, mannerisms and needs just like someone without dementia, and these needs must be recognised and met.

4.50 The Psychogeriatric Care Expert Reference Group's *Report to the Ministerial Conference on Ageing* provides a succinct explanation of PCC in RACFs:

Person-centred care is an alternative to conventional care practices. It considers a person's needs and preferences from a holistic perspective so that services and supports are organised in a personalised way rather than attempting to fit within pre-existing service systems. By treating the person as an individual, person-centred care encourages independence and autonomy rather than control by carers and/or staff. Use of person-centred care is becoming more common in residential care because it can reduce need-driven dementia-compromised behaviours, help maintain personhood and mitigate cognitive and functional deterioration.<sup>58</sup>

4.51 Brightwater Care Group emphasised the provision of PCC required 'a radical re-orientation' away from the biomedical model of care toward a partnership that involves the person with dementia, their family and carers, as well as RACF staff.<sup>59</sup>

4.52 The committee heard that as a result of the institutional model of care upon which Australia's aged care industry is based, many residents in RACFs lose many of their basic freedoms:

We have frequently witnessed situations where people with dementia are denied the right to decide what will happen in their life. They can no longer decide: what time they will wake up in the morning, what time they will get dressed, what they will eat, who they will have relationships with, whether they can remain at home or go out, how they spend their money, what they do with their assets, or who they will socialise with.<sup>60</sup>

4.53 The idea of PCC appeared throughout the evidence to this inquiry, but the committee was cautioned that different providers and individuals may have very different understandings of what this entails in practice:

One of the things we find in our work both in New South Wales and across Australia is that, in having generic services for people with dementia, when we ask people what they mean by the provision of person centred care to people with dementia it is sometimes defined as what time people have a shower in a facility. But what we are actually talking about in terms of this

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57 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 9.

58 Professor Draper, *Submission 17 – Attachment 1*, p. [3].

59 *Submission 50*, p. 2.

60 Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, p. 1.

specific group of people is a very specialised serviced where staff need a very high level of support.<sup>61</sup>

4.54 A PCC approach might ask the person when they wanted to shower, and accept that on different days the person may wish to shower at different times, for instance.

4.55 It was reported to the committee that through taking the time to understand a person's interests and preferences, fulfilling care is able to be provided to people with dementia. For example, the committee heard about the approach of Yarriambiack Lodge:

When a new resident arrives, the staff asks the relatives lots of questions about the person's skills and experiences, likes and dislikes and his or her hobbies prior to the onset of dementia. They then make use of the information to design tasks which the person would like to do, like gardening and cooking, making beds and untangling wool and so on. My mother loved arranging flowers so her job was to arrange the artificial flowers on the tables each day. The staff disarranged them overnight and get her to do them again the next day.<sup>62</sup>

4.56 It was suggested that one of the best ways to ensure personalised care was to get the family and other care partners actively involved in devising management strategies:

Really good care planning involves all the partners of care and in particular family members who know that person very well and they have quite often already the knowledge as to how best to handle their difficult behaviours, yet they are not really brought into the mix to the extent we would like them to be.<sup>63</sup>

4.57 Elder Rights Advocacy (ERA) detailed how families are sometimes excluded from assisting with the care of their loved ones as some professionals may feel their professionalism and skills are being questioned.<sup>64</sup>

4.58 The committee heard that to implement PCC it was necessary to understand each person's individual needs and work to meet those, rather than provide the same services for everyone, regardless of need or preference.<sup>65</sup> It was argued that the larger providers are not so good providing services at a truly individual level:

[I]n more mainstream facilities they have a way of doing things that they think would work for the majority and they are not good at adapting that for

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61 Mr Cunningham, Director – The Dementia Centre, HammondCare, *Committee Hansard*, 17 July 2013, p. 14.

62 Dr Smith, Private Capacity, *Committee Hansard*, 17 December 2013, p. 15.

63 Mrs Nicholl, Advocate, Elder Rights Advocacy, *Committee Hansard*, 16 December 2013, p. 27.

64 Mrs Nicholl, Advocate, Elder Rights Advocacy, *Committee Hansard*, 16 December 2013, p. 27.

65 Professor Draper, *Submission 17 – Attachment 1*, p. [4].



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the individual. That is what they need to learn to do. It is the underlying concept of where aged care is moving and where NDIS is going, that you focus on the individual.<sup>66</sup>

4.59 One the key commonalities that RACFs who provided high standards of dementia care shared was a leadership that had a strong understanding of dementia and commitment to PCC. Improving dementia care in Australia will also have to be led from an engaged management and boardroom. The committee heard of the importance of leadership in driving change and to ensure that all of the staff follows new procedures and practices.<sup>67</sup> Change needs to be nurtured from positions of authority as it is a slow and arduous process to change a culture:

Cultural change takes a minimum of five years, if not 15 years, to become sustainable. Implementing change is problematic and soul destroying for leaders and managers when they are already dealing with a complex business, minimal resources, unskilled staff and business owners expecting a significant return on investment.<sup>68</sup>

4.60 The NSWNMA provided evidence that there is an:

...ingrained management culture where the [nurse's] role is designed by task completion within an allocated (often impossible) timeframe, rather than quality of care. This is in stark contrast to the identified needs of residents with BPSD, for a calm, unrushed, consistent and orderly environment.

...

It is very difficult to imagine how true person-centred care or management of complex behaviours related to BPSD can be truly accommodated, let alone routine 'psychosocial care', leisure and companionship, when staffing is designed on minimum care, and task orientated care.<sup>69</sup>

4.61 The NSWNMA went on to emphasise the important role that must be played by senior management in changing the industry's culture to provide PCC:

We believe that responsibility starts with management to set policies and create a culture where person-centred care can be provided, and to properly resource nurses and care staff to deliver this care.<sup>70</sup>

4.62 The committee was informed that following a person centred approach could actually save staff time, as well as being more beneficial for the person with dementia:

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66 Mr Lipmann, Chief Executive Officer, Wintringham Specialist Aged Care, *Committee Hansard*, 16 December 2013, p. 5.

67 Ms Fischer, Nurse Unit Manager, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 9; Dr Morkham, National Director, Young People in Nursing Homes National Alliance, *Committee Hansard*, 17 July 2013, p. 35.

68 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 3.

69 *Submission 55*, pp 3, 6.

70 *Submission 55*, p. 9.

Coming back to staff being able to provide care that is individualised: if a person can themselves, it is actually less work for the staff member; if they can walk to the dining room, it is less work for the staff member; if they are not being aggressive and wandering, it is less work for the staff member. But the focus is always on: 'We'll do this, this and this, and it is quicker for me to walk you up in a wheelchair and shove the food down your throat than it is for you to feed yourself'.<sup>71</sup>

4.63 The committee did hear concerns, however, that it is difficult to appropriately staff small facilities so that staff have time to engage with residents—'looking at their hobbies, their biography, their history'—while staying within budget.<sup>72</sup>

### **Specialised dementia facilities?**

4.64 The importance of having appropriately designed and staffed facilities to care for people with dementia prompts the question of whether people with dementia need to be cared for in special dementia facilities, or whether they ought to be—and can be—cared for in mainstream residential facilities.

4.65 There appears to be a lack of agreement regarding what is a dementia unit, and how dementia care can best be provided:

There is no definition of what a dementia unit is; there is no definition of what a dementia-specific unit might be. And there is a bit of a [divided] view between providers about the extent to which you need special capacity – mainstream can manage quite well – depending on the staff.<sup>73</sup>

4.66 The committee heard that even many care units designated as 'dementia units' are not appropriately designed for people suffering from the effects of dementia:

[The] dementia unit has 30 beds and is huge; I have actually got lost in there myself. It is not an environment suitable for people with dementia or with behaviours of dementia but it is not uncommon for us to see, particularly in the new, flash facilities, large dementia units.<sup>74</sup>

4.67 It was noted that many RACFs that offered low-care dementia support often provided the same services to persons with dementia as well as other residents.<sup>75</sup> The committee heard that many RACFs cannot provide, or do not feel able to, care for people with BPSD resulting in those people being passed from one provider to another:

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71 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 8.

72 Mrs Edwards, Service Development and Improvement Advisor, BlueCare, *Committee Hansard*, 17 July 2013, pp 13–14.

73 Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 34.

74 Mrs Nicholl, Advocate, Elder Rights Advocacy, *Committee Hansard*, 16 December 2013, p. 24.

75 Dr Macpherson, *Submission 62*, p. 2.

[C]onventional aged care facilities are often unable to accommodate people with acute BPSD. In our experience, they end up 'bouncing around' the system, unable to find a suitable care setting. These people experience distress and upheaval as they are subjected to inconsistencies in approach and uncoordinated variations in medication. This can lead to significant negative side effects including increased stress and trauma to the people with BPSD and their families. As well as posing high risks and increasing distress...constant transfers are also costly and extremely inefficient.<sup>76</sup>

4.68 The committee heard that people displaying BPSD are scattered throughout the aged care system and do not receive the care they need in an appropriate environment:

[The] way people are cared for in mainstream aged care is generally as a small cluster of people, possibly smaller than five people per service. What that means is that the services are generally provided ad hoc and people with BPSD are within a larger group of people.<sup>77</sup>

4.69 It was pointed out that providing PCC is difficult in traditional aged care facilities, where the behaviours associated with dementia are seen as a problem to be managed:

It is about being able to intervene before a person's behaviour escalates...That is not generally achievable in mainstream aged care because it is perhaps one or two scattered people and they are perceived as people with a problem. In order to manage that person's needs within an environment that is not suited for them they will be bounced around the system and perhaps be inappropriately restrained chemically or physically.<sup>78</sup>

4.70 Having people with untreated BPSD in ill-equipped RACFs can also be distressing for other residents:

My mum is in another nursing home. They do not have a dementia unit but they do have dementia patients. At night time, Mum gets really upset because of their wandering and screaming sometimes.<sup>79</sup>

4.71 The committee received evidence that dementia-specific facilities such as the former ADARDS facility are able to effectively manage and reduce BPSD through person centred care.<sup>80</sup>

4.72 Mission Australia was clear that people demonstrating BPSD should be in specialised facilities for their benefit and the benefit of other clients in aged care:

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76 HammondCare, *Submission 25*, p. 4.

77 Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 13.

78 Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 14.

79 Mrs Dickins, Private Capacity, *Committee Hansard*, 10 July 2013, p. 5.

80 Dr Tooth, *Submission 8*, p. 6.

In our view and experience, the strategy of integrating BPSD clients with other clients in aged care facilities poses significant issues and impacts on the overall delivery of service delivery. As a result Mission Australia believes that younger and older Australians living with behavioural and psychiatric symptoms of dementia need to have specialised care.<sup>81</sup>

4.73 This view was not held universally:

I am one of the probably few people who do not believe that people with dementia should be in a separate facility. They are people. We do not put everyone with arthritis in one facility so that it is easier to care for them. I think people with dementia are often misunderstood.<sup>82</sup>

4.74 Elder Rights Advocacy emphasised that, given the numbers of people living with dementia in RACFs, it must be expected that the RACFs cultivate the ability and tools to care for those people in an appropriate manner.<sup>83</sup> Some providers reported to the committee success in reducing the incidence of BPSD through improved training and management in a non-dementia specific environment.<sup>84</sup>

### **Committee view: best practice care**

4.75 Aged care in Australia is not always well suited to the needs of people with dementia, especially those with BPSD. There are areas where there is broad agreement that care can be improved, such as facility design and staff training. Staff training is discussed more fully in the next chapter of this report.

4.76 There is no single correct model of care for dementia. This report has highlighted some of the best practices of organisations including Wintringham, Rural Northwest Health, HammondCare and the BrightWater Group. These models of care provide a higher quality of life for people with dementia than have previously been offered. A common thread joining these organisations' philosophies together appears to be a strong focus on PCC, high levels of staff training and investment from management. Innovation among these providers and the RACF sector as a whole is to be encouraged. The Commonwealth can play an important role to support and publicise these developments.

4.77 Given the high incidence of dementia among residents of RACFs, it cannot be left to dementia-specific facilities and providers to shoulder the entire burden. All RACFs need to have the staff and expertise to manage residents suffering with dementia. All RACFs must take important steps to improve the lives of those living with dementia.

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81 *Submission 16*, p. 2.

82 Ms Calvert, Manager, Dementia Tas, *Committee Hansard*, 10 July 2013, p. 10.

83 Ms Lyttle, Chief Executive Officer, Elder Rights Advocacy, *Committee Hansard*, 16 December 2013, p. 26.

84 Ms Delmonte, Allied Health Manager and Spark of Life Practitioner, Mercy Parklands, *Committee Hansard*, 16 December 2013, p. 44.

4.78 These steps include ensuring that facilities are designed and fitted out in a way that is appropriate to the needs of people with dementia and other mental illnesses. This chapter has highlighted the importance of a person's environment on the incidence of BPSD. These design principles can be included in new facilities built to meet the need of an ageing Australia, as well as being retrofitted to existing facilities as items, fittings and furnishings require replacement.

**Recommendation 8**

**4.79 The committee recommends that the accreditation standards for Residential Aged Care Facilities include requirements for dementia-friendly design principles.**

**Recommendation 9**

**4.80 The committee recommends that the accreditation standards for Residential Aged Care Facilities reflect a better balance between clinical and quality-of-life outcomes.**



## Chapter 5

### The dementia care workforce

5.1 The terms of reference for this inquiry directed the committee to consider the care and management of Australians living with dementia. Much of that care and management is provided by the staff in residential aged care facilities (RACFs). The impact of appropriate staff training on the care of people with dementia was regularly noted in evidence received by the committee as a key determinant in the quality of care received by people with dementia. People working in aged care were almost universally lauded for their work in a sector that is widely recognised to be personally very challenging, while not generally financially rewarding. Many working in aged care advised that they had chosen the field because they enjoyed working with older people.<sup>1</sup>

5.2 Although providing dementia appropriate environments is important, unless staff have the appropriate training, 'they have little ability to understand and manage behaviour disturbances' associated with dementia and Behavioural and Psychological Symptoms of Dementia (BPSD).<sup>2</sup> The commitment to staff training—from the executive through to the entry levels—is a notable commonality between the leading dementia service providers. This chapter highlights the importance of appropriately skilled staff and discusses issues around staff training.

5.3 The care of people with dementia and BPSD requires a number of professions including geriatricians, social workers, occupational therapists, nurses, aged care attendants, psychologists and physiotherapists, among others.<sup>3</sup> In addition to formal qualifications, the committee heard the importance of people working with people with dementia being empathetic to their needs: 'you really need people who have personal attributes such that they can engage with people with dementia. They need understanding and some empathy'.<sup>4</sup>

#### *Human resources in dementia care*

5.4 The committee heard that there were increasing pressures on a workforce that is concurrently dealing with more complex clients while at the same time managing with a less skilled workforce.<sup>5</sup> The Productivity Commission report

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1 NSW Nurses and Midwives' Association, *Submission 55*, p. 2.

2 Mercy Health, *Submission 29*, p. 3.

3 Professor McInerney, Professor of Aged Care, Mercy Health and the Australian Catholic University, *Committee Hansard*, 14 February 2014, p. 26; Mr Li, Senior Policy Adviser, Australian Psychological Society, *Committee Hansard*, 16 December 2013, p. 20.

4 Ms Morka, General Manager, Retirement, Ageing and Financial Inclusion, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 10.

5 NSW Nurses and Midwives' Association, *Submission 55*, p. 2.

*Caring for Older Australians* detailed a troubling trend of movement toward a lower skilled workforce, while expanding the responsibility of that workforce:

There is a trend towards employing less skilled (and lower cost) staff in residential settings in the delivery of direct care services. Despite an increase in the workforce overall, the number of full-time equivalent registered and enrolled nurses working in [residential aged care facilities] fell from 27,210 to 23,103 between 2003 and 2007. This represents a decrease from 35.8 per cent to 29.3 per cent of all full-time equivalent direct care employees in only four years, with most of the reduction occurring at the registered nurse level.

While the substitution towards less skilled workers may be partly driven by financial constraints and difficulties in attracting and retaining nurses, the scopes of practice for some personal carers have also been widened (for example, undertaking medication management).<sup>6</sup>

5.5 Evidence presented to the committee argued that this trend is also in evidence in community care where workers are often untrained in important skills such as hygiene and nutrition, as well as unprepared for the emotional aspects of care giving.<sup>7</sup> Highly trained workers are especially important in community care as care workers only have short periods of time with each patient.<sup>8</sup> Care workers entering peoples' homes also need to be adequately resourced to provide the sub-acute care needed by people with dementia.<sup>9</sup>

5.6 The committee heard that the difficulty of attracting skilled workers to the sector was seriously lowering the barriers to entry to dementia and aged care:

Staffing is an ongoing issue in the aged care industry. Staff work across a number of organisations. People apply and are appointed without qualifications and with minimal experience or expertise...We are short-staffed. If they have a police check and can speak English, they can be given a job and start that day.<sup>10</sup>

5.7 There are currently no legislated staffing ratios in residential aged care. The committee heard that the level of staffing is a reflection of the level of resourcing of aged care, and that providers would choose to have more staff on shift:

Choices often have to be made by administrators about staffing levels, and some family members are still shocked to discover that residential aged care is not like an intensive care unit. I think every administrator of

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6 *Caring for Older Australians*, Canberra, 2011, p. 351.

7 *In-camera evidence*.

8 Mr Oldham, Private Capacity, *Committee Hansard*, 10 July 2013, p. 7.

9 Mr Brooks, Chief Executive Officer, Presbyterian Care Tasmania, *Committee Hansard*, 10 July 2013, pp 26–27.

10 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 2.



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aged-care facilities would like to increase staffing levels, but organisations need to break even unless they have other sources of income.<sup>11</sup>

5.8 It was suggested to the committee that one worker for eight residents is a functional ratio when working with people with dementia.<sup>12</sup> It was also reported to the committee that at times when the needs of patients with BPSD are at their highest, during the nights, staffing levels in residential facilities are at their lowest.<sup>13</sup>

***Current staffing situation exacerbates BPSD***

5.9 It was reported to the committee that people caring for clients with dementia without the appropriate skills and training may exacerbate BPSD.<sup>14</sup> The committee also heard that low staff levels result in a greater use of restraints (see chapter 6 of this report).<sup>15</sup>

5.10 From the point of view of the residents in aged care facilities, the people that work in aged care are guests in their home. The committee heard concerns that workers do not have the time to work with residents as if they were assisting someone in their home, but instead endeavoured to move through their list of tasks as fast as possible. One care worker explained:

I do not believe that there is enough time spent with people with this cognitive problem. They have this illness through no fault of their own, and they are just treated like a herd of sheep...We as carers were expected to get nine or ten people up in just over an hour – wake them up, shower them, dress them and do a full bed change if need be, and have them sitting out at breakfast. That is just not right. It is those people's homes. They should not be rushed.<sup>16</sup>

5.11 Simple considerations are often overlooked due to a lack of understanding and the speed at which some staff members are either required to—or feel they are required to—work.<sup>17</sup> Examples include male carers showering female residents and residents being changed in rooms with open curtains.<sup>18</sup> One submitter who had a parent with dementia in residential care observed that:

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11 Mr Hunt, Private Capacity, *Committee Hansard*, 10 July 2013, p. 33.

12 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 11.

13 NSW Nurses and Midwives' Association, *Submission 55*, p. 2.

14 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 2.

15 BlueCare, *Submission 32*, p. 8.

16 Ms Mathers, Dementia Care Tasmania, *Committee Hansard*, 10 July 2013, p. 1.

17 Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, p. 4.

18 Mr Oldham, Private Capacity, *Committee Hansard*, 10 July 2013, p. 3; Dr Macpherson, *Submission 62*, p. 4.

In circumstances of chronic under-staffing, apparent lack of training in the emotional and social needs of dementia [patients], and lack of funds, care tasks centre overwhelmingly on the physical needs of patients: showering, toileting and feeding.<sup>19</sup>

5.12 The Australian Medical Association (AMA) was unequivocal in reporting that poorly trained staff exacerbate BPSD:

**Senator THORP:** Is it fair to say that, if you have a carer who does not have that level of education and understanding, their reaction to a patient can exacerbate and accelerate that patient's behaviours?

**Dr Kidd:** Yes, absolutely, and that is one of the bad outcomes I was starting to refer to. That is why I think it is quite critical that in this area there is adequate resourcing and funding so that staff can have appropriate and adequate training and also that the industry can afford staff that have sufficient literacy, sophistication, qualifications, I guess, to be able to provide what can be very challenging services at a level that requires quite a bit of knowledge and at times quite a bit of emotional sophistication or emotional intelligence.<sup>20</sup>

5.13 Due to staffing shortages many service providers use agency staff to fill short-term gaps in their workforces. It was reported that this practice can exacerbate residents' BPSD as the staff do not know the residents' personalities, likes, dislikes and behavioural triggers.<sup>21</sup>

5.14 A lack of experienced staff has also meant that new staff are quickly moved into leadership positions that they do not have the experience to adequately manage:

The problem is that a registered nurse comes out and we put them in charge of a ward in aged care. It is really hard to get into a graduate program at the moment, so they work in aged care because it is easy to work in. They have no experience and their training does not give them any real in-depth expertise in dementia. So the first thing they are going to do is either cause the resident to behave in an inappropriate manner, because of the way they have responded to the person with dementia, or ask the doctor to put them on drugs. So we have doped people who are more at risk of fall, who do not eat, who lose weight and who are unhappy, and it is because the nurse does not have the expertise to know that there are other ways.<sup>22</sup>

5.15 The Royal Australian and New Zealand College of Psychiatrists (RANZCP) recommended:

All residential aged care facilities have access to a clinician with expertise in BPSD and mental health who is employed by the facility and is

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19 Dr Macpherson, *Submission 62*, p. 4.

20 Dr Kidd, Chair, Australian Medical Association Committee for Health and Ageing, *Committee Hansard*, 14 February 2014, p. 3.

21 Ms Dickens, *Submission 2*, p. 1.

22 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 12.

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responsible for core tasks required if a facility is to meet the needs of people with BPSD.<sup>23</sup>

5.16 Wintringham similarly suggested that aged care facilities have ready access to BPSD management techniques.<sup>24</sup>

### *Staff training*

5.17 Despite the clear importance of those working with people with dementia having the appropriate skills to manage that condition, the committee heard that many workers do not have the necessary skills. Unfortunately, the committee heard that many people are not made aware of, or taught, appropriate management techniques. As the Co-Chair of the Minister's Dementia Advisory Council lamented:

We are dealing with a system that systematically fails to train, educate, monitor and incentivise people who have responsibility for supporting people with dementia to do so in a way that allows them dignity and a quality of life.<sup>25</sup>

5.18 Professor Draper similarly explained:

[Overall] I think there is a general lack of training there in the system and so many of the staff who work in residential facilities but also in community care settings are not that well trained. They are people who have had very limited general training and it is a challenge for the whole system to actually increase the level of training that people are receiving and have received.<sup>26</sup>

5.19 There were regular calls throughout this inquiry to improve the level of training for staff working with people with dementia.<sup>27</sup> Rural Northwest Health recommended that all staff interacting with people with dementia—from registered nurses through to administration staff—should be required to undertake 'an accredited module in dementia of at least two days in length'.<sup>28</sup>

5.20 Service providers are already required to provide their workers basic training in a number of areas such as manual handling, emergency situations and infection control. In this environment, dementia training falls down the list of priorities. There is a need to convince providers that dementia training is both important and

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23 *Submission 49*, p. 8.

24 Mr Lipmann, Chief Executive Officer, Wintringham Specialist Aged Care, *Committee Hansard*, 16 December 2013, p. 6.

25 Ms Pieters–Hawke, Co-Chair, Minister's Dementia Advisory Council, *Committee Hansard*, 17 July 2013, p. 27.

26 Professor Draper, private capacity, *Committee Hansard*, 17 July 2013, p. 51.

27 Mr Oldham, Private Capacity, *Committee Hansard*, 10 July 2013, p. 3; Mr Osbourne, private capacity, *Committee Hansard*, 17 December 2013, p. 23.

28 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, pp 2–3.

beneficial.<sup>29</sup> Providers also face the challenge of high staff turnover which results in a situation where 'you can train all of your people today but in six months' time you would have to go back and do it [again]'.<sup>30</sup>

5.21 The New South Wales Nurses and Midwives' Association (NSWNMA) noted that even registered nurses—who shoulder much of the responsibility for care decisions in residential facilities—rarely have sufficient training in mental health:

Many registered and enrolled nurses working in aged care do not have mental health as part of their general training, and care staff seldom have specific training or experience in mental health matters.<sup>31</sup>

5.22 Rural Northwest Health voiced similar concerns:

If you look at any allied health professional and nursing qualification—enrolled nurses and registered nurses, which are the majority of people who work in residential aged care—if you look at their training, the time they spend on learning about dementia is about three hours. There is not a significant module on dementia. They come out and they do not know how to care for people living with dementia. They have a registered nurse or an enrolled nurse qualification but it is not a priority.<sup>32</sup>

5.23 It appears that many healthcare professionals are graduating, and being employed, without the necessary skills to adequately manage dementia. However, the evidence provided to this committee indicates that the necessary skills can be developed in the dementia care workforce.

5.24 The skills and techniques to manage dementia and BPSD are learnable provided the training is made available.<sup>33</sup> As explained by the Minister's Dementia Advisory Council:

As the experts and people who work closely and with compassion in such a situation understand, the behaviour of a person with dementia will make perfect sense correlated to their experience of the world. We can support them based on that. This is not to say that some of the behaviours that happen are not challenging to the people around them, but it is our job if we are working in care to learn the ways that do exist to support that person without demeaning them or attributing a demeaning set of motives, intent or incapacity to them.<sup>34</sup>

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29 Ms Calvert, Manager, Dementia Tas, *Committee Hansard*, 10 July 2013, p. 13.

30 Mr Reed, Assistant Director of Nursing – Mental Health Services, Department of Health and Human Services, *Committee Hansard*, 10 July 2013, p. 22.

31 *Submission 55*, p. 9.

32 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 12.

33 Mr Lipmann, Chief Executive Officer, Wintringham Specialist Aged Care, *Committee Hansard*, 16 December 2013, p. 5.

34 Ms Pieters–Hawke, Co-Chair, Minister's Dementia Advisory Council, *Committee Hansard*, 17 July 2013, p. 27.

5.25 High level training in dementia and BPSD also allows for more services to be provided to people in the community, helping them remain there for longer.<sup>35</sup>

5.26 One of the factors that the facilities most successful in managing dementia had in common was the extensive training given to staff regarding dementia.<sup>36</sup> As noted by the Psychogeriatric Care Expert Reference Group:

Well trained and experienced staff have the capacity to recognise early signs of behavioural disturbances and prevent their escalation, while conversely, the actions of inexperienced staff can readily escalate behaviours.<sup>37</sup>

5.27 As well as providing appropriate training to those providing direct services to residents, it was argued that training should be provided at the decision-making level:

One of the things that has been a strong push from the Commonwealth over the last decade is providing training at the frontline care worker level. There have been a lot of systemic programs that aim to increase the knowledge, expertise and qualifications that people at that level are receiving. The gap is that we have not done the same thing for our registered nurse population and we have not done the same thing for our GP population. Those education programs have been more ad hoc. We need to address that if we are going to raise the bar. We want clinical care to be driven at the registered nurse and primary care level, yet we are feeding a lot of the care approaches to the direct frontline care staff, and we do not have the expertise in the people who are leading those services. If you do not address that, there are going to be leaky buckets down at the bottom.<sup>38</sup>

5.28 Targeting training at senior levels would also seem to address one of the problems reported to the committee whereby staff who had received training in dementia care were overruled by more senior but less qualified colleagues.<sup>39</sup> The Minister's Dementia Advisory Council similarly emphasised the importance of ensuring those in leadership positions support the work of those trained in appropriate dementia care.<sup>40</sup>

5.29 It was suggested that there is strong demand for dementia specific training within the aged care sector as staff and facilities recognise that they do not presently have the tools to manage dementia, but often people do not know where to go for

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35 Ms Small, General Manager of Operations, Wintringham Specialist Aged Care, *Committee Hansard*, 16 December 2013, p. 7.

36 Ms Dickins, *Submission 2*, p. [1]; Benetas, *Submission 21*, p. [3].

37 Professor Draper, *Submission 17 – Attachment 1*, p. [6].

38 Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 15.

39 Mr Cunningham, Director – The Dementia Centre, HammondCare, *Committee Hansard*, 17 July 2013, p. 15.

40 Ms Pieters-Hawke, Co-Chair, Minister's Dementia Advisory Council, *Committee Hansard*, 17 July 2013, p. 36.

assistance. As well as recognising a need for further learning, those working with people with dementia are eager to utilise what they have learned:

Their desire for staff education and seminars and group meetings and so forth has been much greater than we expected. It is a question that they have a sense of need, they have no way of knowing how to satisfy that need but once you give them that they certainly move towards it with considerable enthusiasm.<sup>41</sup>

5.30 The committee heard of a number of initiatives that have been undertaken, such as working with universities, to improve training for staff working with people with dementia.<sup>42</sup> Medical professionals also reported taking time to run dementia awareness and training courses, some of which are undertaken on a pro bono basis.<sup>43</sup>

5.31 HammondCare emphasised that Australia has a good variety of programs to improve dementia care, such as Dementia Care Essentials.<sup>44</sup> Dementia Care Essentials is a Commonwealth-funded initiative providing dementia training to aged care workers throughout Australia. It was reported that approximately 35,000 aged care workers had received accredited dementia training by June 2013 under the program.<sup>45</sup>

5.32 The Department highlighted that \$10 million has been provided over the previous three years to the Dementia Training Study Centre to 'up skill the workforce in terms of dementia care'.<sup>46</sup> The Commonwealth also funded the Encouraging Better Practice in Aged Care program which included 'a range of projects increasing the skills of workers caring for people with dementia'.<sup>47</sup> Alzheimer's Australia provides training and education services<sup>48</sup>, and innovative approaches such as *Spark of Life* courses are provided by Dementia Care Australia.<sup>49</sup> The Wicking Dementia Research and Education Centre was highlighted as an excellent provider of training:

On quite a positive note and on the role of the Wicking centre, they are doing some really amazing stuff with not huge amounts of dosh to assess the needs of people providing care in aged-care settings, recognising things

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41 Mr Stokes, Principal Advisory, Australian Psychological Society, *Committee Hansard*, 16 December 2013, p. 19.

42 Ms Morka, General Manager, Retirement, Ageing and Financial Inclusion, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 10.

43 Dr Kidd, Chair, Australian Medical Association Committee for Health and Ageing, *Committee Hansard*, 14 February 2014, p. 3.

44 Mr Cunningham, Director – The Dementia Centre, HammondCare, *Committee Hansard*, 17 July 2013, p. 15.

45 Department, *Submission 56*, p. 21.

46 Ms Smith, First Assistant Secretary, Ageing and Aged Care Division, Department, *Committee Hansard*, 17 July 2013, p. 47.

47 Ms Smith, First Assistant Secretary, Ageing and Aged Care Division, Department, *Committee Hansard*, 17 July 2013, p. 47.

48 BlueCare, *Submission 32*, p. 10.

49 Dementia Care Australia, *Submission 54*, p. 7.

like transient working populations...and they are starting to actually deliver some really cost-effective education packages specifically around dementia care.<sup>50</sup>

5.33 Services for Australian Rural and Remote Allied Health (SARRAH) suggested the provision of 'dementia training modules similar to those available in the vocational sector such as Aged Care Certificate III and IV training for care workers'.<sup>51</sup> The committee notes that there are dementia-specific Australian Quality Framework certified courses available at this level in some states.<sup>52</sup>

#### *Quality of training*

5.34 Although there are good education resources available to inform the workforce about dementia, it was put to the committee that some of the training for dementia currently on offer was of an unacceptably poor standard:

Significant issues exist in the quality of the training provided throughout training organisations. It is not consistent; it is not always of a high standard; and, in some cases, it is substandard.<sup>53</sup>

5.35 One person who worked in dementia care with a specialised qualification in dementia awareness indicated that some formal qualifications in dementia care do a poor job of preparing workers for actually providing dementia specific care.<sup>54</sup>

5.36 The committee heard that in some cases education providers had actively tried to reduce the number of hours required to become qualified to work in aged care.<sup>55</sup> For training to be effective, and for prospective employers to value qualifications, the standards need to be sufficiently high to ensure that a person qualified in dementia care is capable of completing the work they are employed to do.

5.37 Although dementia training resources are available, those working in the field must be able to access those resources.

5.38 One of the barriers to providing better staff training was facilities not having enough staff or financial resources to simultaneously pay for staff members to attend training, pay their salary, and the salary of a replacement worker during the training

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50 Dr Morrissey, Old Age Psychiatrist, Department of Health and Human Services – Tasmania, *Committee Hansard*, 10 July 2013, p. 24.

51 *Submission 19*, p. 5.

52 For example, Alzheimer's Australia Western Australia offers a Certificate IV in Dementia Practice.

53 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 2.

54 Mr Oldham, private capacity, *Committee Hansard*, 10 July 2013, p. 3.

55 Ms Walters, Innovation and Continuous Improvement Manager, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 12.

course.<sup>56</sup> BlueCare and Dementia Care Australia—among others—recommended that additional funding be available to backfill staff to engage in training.<sup>57</sup>

5.39 SARRAH argued that it was necessary to fund education in rural and remote settings for health professionals and ancillary staff working with people with dementia, noting that regional providers have additional costs in accessing training due to the travel distances involved.<sup>58</sup>

5.40 Funding for up skilling the aged care workforce appears to be effective, albeit sporadic. Yarriambiack Lodge was able to provide training for all their staff due to Health Workforce Australia funding.<sup>59</sup> BlueCare reported being able to develop and offer workshops—'resulting in increased knowledge and expertise in why behaviours occur and how to develop strategies to prevent them'—after winning a grant from the Dementia Training and Studies Centre in Queensland.<sup>60</sup>

### *Committee view*

5.41 The current aged-care workforce does not appear to have the skills and training to adequately support Australians living with dementia and BPSD. There is a need to significantly improve the skills in this sector as a matter of priority. Staff without the necessary skills to provide dementia care can actively exacerbate BPSD creating additional stress for workers, patients and families. Conversely, staff with the appropriate training can facilitate the care and management of people with BPSD who may otherwise have been transferred around the health and aged care system.

5.42 There are a number of excellent examples from around Australia of providers who have taken the necessary steps to ensure that their workforce is appropriately qualified to provide high levels of care to people with dementia and BPSD. There are also innovative and highly effective training tools available to help train the workforce.

5.43 There may be a role for the Commonwealth to better publicise the training that is available and encourage other providers to raise the skills of their workforce, benefitting from the example of the forerunners in dementia care. The Commonwealth has established the Dementia and Severe Behaviours Supplement in Residential Care which provides RACFs over \$6,000 per year, per resident with dementia and BPSD. The purpose of this supplement is to ensure that those residents receive the care that they need. Given the importance of staff training in managing BPSD, it is not

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56 BlueCare, *Submission 32*, p. 8; Dementia Care Australia, *Submission 54*, p. 8.

57 Mrs Edwards, Service Development and Improvement Advisor, BlueCare, *Committee Hansard*, 17 July 2013, p. 12; National Rural Health Alliance Inc, *Submission 45*, p. 6.

58 *Submission 19*, p. 3.

59 Ms Morley, Chief Executive Officer, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 6.

60 Mrs Edwards, Service Development and Improvement Advisor, BlueCare, *Committee Hansard*, 17 July 2013, p. 12.



unreasonable to expect that some of this additional funding is directed toward providing staff training.

### **Recommendation 10**

**5.44 The committee recommends that a phased program of accredited training in dementia and the management of Behavioural and Psychological Symptoms of Dementia (BPSD) be required for all employees of Residential Aged Care Facilities.**

### **Recommendation 11**

**5.45 The committee recommends that the Commonwealth take a proactive stance in highlighting the importance of staff training in dementia care, and develop linkages between care and education providers.**

### **Retaining skilled workers**

5.46 As the percentage of the population with dementia increases, there will be an increasing demand for specialist dementia care. The committee heard that the availability of nurses and other professions with dementia expertise will be the difference between people with dementia remaining in the community or moving into residential care.<sup>61</sup> It was put to the committee that 'the high turnover of care workers with limited training is a core obstacle to successfully managing BPSD'.<sup>62</sup> Once aged care workers have entered the field, received dementia-specific training and begun to gather experience, it is important that those skills are retained.<sup>63</sup>

5.47 The committee heard that it was difficult to retain workers, principally because of low remuneration.<sup>64</sup> Of concern were the wages on offer for the specialist work that is expected:

Generally our aged-care workers are particularly poorly paid and the work that they do is specialist, especially working with people living with dementia. That is absolutely paramount: giving people the adequate training and also compensating them for that.<sup>65</sup>

5.48 The Productivity Commission similarly noted that the 'current remuneration and working conditions are considered strong disincentives to entering and staying in the sector'.<sup>66</sup> The Royal Australian College of General Practitioners (RACGP)

61 Brotherhood of St Laurence, *Submission 40*, p. 8.

62 Royal Australian and New Zealand College of Psychiatrists, *Submission 49*, p. 8.

63 Mr Reed, Assistant Director of Nursing – Mental Health Services, Department of Health and Human Services, *Committee Hansard*, 10 July 2013, p. 23.

64 Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, p. 10; Services for Australian Rural and Remote Allied Health, *Submission 19*, p. 3.

65 Mrs Edwards, Service Development and Improvement Advisor, BlueCare, *Committee Hansard*, 17 July 2013, p. 15.

66 Productivity Commission, *Caring for Older Australians*, Canberra, 2011, p. 354.

remuneration for professional staff involved in dementia care and the status of carers'.<sup>67</sup>

***Committee view***

5.49 Those working in aged care are some of Australia's lowest paid workers. This low level of remuneration is inconsistent with the responsibilities these workers face and the community's expectation of their experience and expertise. The lack of skills and experience in dementia care can be expected to continue until wages are significantly improved and reflect the time and training required. The committee supports the Productivity Commission's view:

An increase in the level of remuneration for aged care workers will have a flow-on effect to other factors affecting the workforce. For example, the image and reputation of the sector as an area where caring work is valued would be enhanced by better wages. In addition, the quality and continuity of care may be increased as workers are more content to stay in the sector and turnover is reduced. In turn, this may allow more funding for education and training to be targeted towards up skilling the workforce, rather than basic training for new entrants who are unlikely to stay for long under current conditions.<sup>68</sup>

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67 *Submission 52*, p. 7.

68 *Caring for Older Australians*, Canberra, 2011, p. 365.

# Chapter 6

## The use of restraints in dementia care

A restraint free environment means no words, devices or actions will interfere with a resident's ability to make a decision or restrict their free movement...The use of restraint confronts a resident's rights and dignity and, in some cases, may subject the resident to an increased risk of physical harm. – *Decision-making tool: supporting a restraint free environment in residential aged care*, published by the Department of Health and Ageing [(Department)]<sup>1</sup>

I am increasingly concerned about the use of restraint in aged-care facilities as a means of responding to behaviours of concern. The use of restraint is a significant infringement on human rights and the lawful authority for the use of restraint in aged-care settings is ambiguous at best. – Office of the Public Advocate Queensland<sup>2</sup>

6.1 A key issue throughout this inquiry was the use of restraints in the management of dementia and Behavioural and Psychological Symptoms of Dementia (BPSD). Restraints can be divided into two categories: physical and chemical. Physical restraints include locked facilities<sup>3</sup>, the removal of mobility aids such as scooters<sup>4</sup>, binding patients to furniture<sup>5</sup>, and preventing patients from socialising with certain people.<sup>6</sup> Chemical restraints are typically medications that act to calm residents or prevent certain behaviours.<sup>7</sup> This chapter discusses the reasons and appropriateness of the use of restraints and monitoring and conditions placed on their use. The chapter concludes with the discussion of whether restraints are necessary in caring for people with dementia.

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1 Department of Health and Ageing (Department), *Decision-making tool: supporting a restraint free environment in residential aged care*, 2012, p. 40.

2 Ms Cook, Public Advocate, Office of the Public Advocate Queensland, *Committee Hansard*, 17 July 2013, p. 1.

3 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 36.

4 Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, p. 7.

5 Mrs Nicholl, Advocate, Elder Rights Advocacy, *Committee Hansard*, 16 December 2013, p. 24.

6 Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, pp 7–8.

7 Ms Cook, Public Advocate, Office of the Public Advocate Queensland, *Committee Hansard*, 17 July 2013, p. 6.

## The rights of patients and considerations in using restraints

6.2 The committee heard that one of the impacts of a diagnosis of dementia in a residential aged care facility (RACF) was a seemingly automatic erosion of personal rights:

It is quite surprising and disappointing to see the number of staff members we train who do not understand that the people who live in the homes have rights. To me, what is lacking is a general rights based approach. That just not seem[s] to exist at all, and people do not understand that. They think, 'Well, they get to a certain age; they have a form of dementia, and that means we have to make decisions for them and don't have to take into consideration what they want.'<sup>8</sup>

6.3 Extrapolating from the Universal Declaration of Human Rights, the United Nations Principles for Older Persons encourages governments to incorporate certain principles into their national programmes whenever possible, including:

Older persons should be able to utilise appropriate levels of institutional care providing protection, rehabilitation and social and mental stimulation in a humane and secure environment.<sup>9</sup>

6.4 In its submission to this inquiry, the Australian Medical Association (AMA) provided guidance on how and why restraints are used in an aged-care setting:

The need for physical or medical restraint is based on the medical practitioner's assessment of the issues. The medical practitioner has to determine the right balance between:

- A patient's right to self-determination;
- The need to protect the patient from harm; and
- The possibility of harm to others.

The decision to use restraint is not made in isolation. It involves a process of: request; assessment; team involvement; and consent within an ethical and legal framework.<sup>10</sup>

6.5 Some people derive great benefits from medication and need it to enable management of their condition.<sup>11</sup> The Royal Australian and New Zealand College of Psychiatrists (RANZCP) noted that 'the *appropriate* use of psychotropic medications is an essential element in improving the quality of life for some older people with mental illness'.<sup>12</sup> One of the experiences related to the committee highlights the

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8 Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, p. 4.

9 See: <http://www.ohchr.org/EN/ProfessionalInterest/Pages/OlderPersons.aspx> (accessed: 26 March 2014).

10 *Submission 39*, pp 2–3.

11 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 36.

12 *Submission 49*, p. 12.

positive impact appropriately used psychotropic medication can have on a sufferer of dementia:

I know everybody has been talking about how bad the drugs have been, but mum was only ever on one drug: Aricept. It really helped her a lot for the first nine months. We kept it up because we did not know how bad she would be without it, and it did help her. Before she was diagnosed she was all tearful and stopped doing her artwork, but after two weeks on Aricept she was back to painting again. It lasted for about nine months, and then the disease progressed.<sup>13</sup>

6.6 Alzheimer's Australia, a staunch advocate for those people living with dementia, also recognised that 'from time to time there are emergencies and we do accept that these drugs have a role'.<sup>14</sup> The committee similarly heard that while it was important to prevent the inappropriate use of medication, it was important that those who did need medication still received it. As Professor Draper noted:

[Whatever] consideration we give to how we in some way try to minimise the inappropriate use of these drugs, we need to also make sure we do not capture in that people who are appropriately being treated for serious mental disorders like schizophrenia or serious mood disorders like depression, manic depressive disorders, bipolar disorders.<sup>15</sup>

6.7 Unfortunately, the committee also heard allegations that restraints were used for the convenience and protection of the facility, rather than the clinical needs of the patient.<sup>16</sup>

### **Chemical Restraints**

6.8 The evidence received by the committee points to a troubling trend in which there is an increased use of restraints as a management tool for BPSD, often used in the absence of guidelines about their appropriate use and management.<sup>17</sup> The committee heard that:

...anecdotally we are getting and seeing increasing reports of the use of restraints, particularly chemical restraints in aged-care settings. That is and of itself, particularly the use of antipsychotic medications, is of particular concern to me.<sup>18</sup>

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13 Dr Smith, Private Capacity, *Committee Hansard*, 17 December 2013, p. 22.

14 Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 34.

15 Professor Draper, private capacity, *Committee Hansard*, 17 July 2013, p. 50.

16 Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, pp 5–7; Ms Cook, Public Advocate, Office of the Public Advocate Queensland, *Committee Hansard*, 17 July 2013, pp 5–7.

17 Ms Cook, Public Advocate, Office of the Public Advocate Queensland, *Committee Hansard*, 17 July 2013, p. 6.

18 Ms Cook, Public Advocate, Office of the Public Advocate Queensland, *Committee Hansard*, 17 July 2013, p. 6.

6.9 Alzheimer's Australia estimated that only one-in-five dementia sufferers currently on antipsychotics currently need to be on them.<sup>19</sup> One nurse contended however that:

Chemical restraints I believe are only prescribed by a doctor and given when all else has failed in managing the person's behaviour, for their safety. It is not just given out because it can [be].<sup>20</sup>

6.10 The committee heard that the over prescription of antipsychotic medication can present more risks to the health of a person than the behaviour that the medication was introduced to control.<sup>21</sup> As one witness related:

She was a risk of falls, because of the over-medication; she was drowsy and really unable to do any of the personal care and so forth, so required a lot more support from us...Sometimes medication that is over-prescribed can have a huge detrimental effect on the person and create more concerns for that person than they would if they had the behaviour.<sup>22</sup>

6.11 Morbidities that may come with these medications include cardiac deaths, strokes, falls and other injuries.<sup>23</sup> The committee also heard of cases where patients were given combinations of medication to control behaviours resulting in hospitalisations as a consequence of adverse reactions to those medications.<sup>24</sup>

6.12 HammondCare emphasised that there remains a grey area between the risks posed by restraints and the risks posed by a patient's behaviours:

One of the things HammondCare is passionate about is balancing people's knowledge about the risk of restraint versus what risk a person may pose to themselves or others without restraint. I think the grey area there has to be acknowledged, and that grey area is only managed with the right expertise at a medical level.<sup>25</sup>

6.13 The committee received evidence from stakeholders that restraints are being used too readily in aged-care to cover staff and resourcing constraints.<sup>26</sup> Some argued

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19 Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 34.

20 NSW Nurses and Midwives' Association, *Submission 55*, p. 2.

21 Mrs Edwards, Service Development and Improvement Advisor, BlueCare, *Committee Hansard*, 17 July 2013, p. 11.

22 Ms Astete, Senior Manager – Day and Respite Programs, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 13.

23 Dr Cleary, Geriatrician, Dementia Behaviour and Management Advisory Service, *Committee Hansard*, 10 July 2013, p. 23.

24 Mrs Potter, *Submission 20*, p. [7].

25 Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 14.

26 Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 14; Mrs Edwards, Service Development and Improvement Advisor, BlueCare, *Committee Hansard*, 17 July 2013, p. 14.

that there is an overreliance on medication to manage the behaviour of residents that could be dealt with without resorting to chemical restraints.<sup>27</sup> The Australian Psychological Society (APS) argued that there is a pharmacological 'knee-jerk response' to many conditions associated with dementia—especially BPSD—rather than managing those conditions through non-medical pathways.<sup>28</sup> This position was echoed by the Young People in Nursing Homes National Alliance (YPINH) who stated:

What we have often seen is that the use of drugs becomes a response of first resort, not last resort, because of escalation of behaviour or because other residents may be being endangered, or even just because noise levels are unbearable.<sup>29</sup>

6.14 Elder Rights Advocacy (ERA) argued that General Practitioners (GPs) are prescribing drugs at the behest of facilities who are insufficiently staffed to deal with people with dementia:

As staffing pressures appear to mount – that is the message from the industry – they are using it as a soft restraint, it would seem to me. It is not that soft but you do not see it and that is the only difference in it. Mostly GPs are doing it, we believe at the behest of aged care facilities saying, 'we don't have an option. We can't cope with the person.'<sup>30</sup>

6.15 The AMA seemed to implicitly argue that the use of restraints is often a reflection of resourcing limitations rather than clinical need, noting:

In the environment of an under resourced residential aged care facility, with limited qualified nursing staff and sufficient numbers of carers, the need for restraint is an unfortunate reality.<sup>31</sup>

6.16 The committee heard that the use of restraints in residential care was often poorly managed with people placed on a restraint long-term, rather than using restraints as an intervention with start and finishing dates. Alzheimer's Australia explained to the committee how drugs can be undermanaged:

What tends to happen is that once somebody is on a drug they tend to stay on it. A lot of these drugs are recommended for regular review and they are not. Some of the prescribing practices seem to be learnt in hospitals, so the person comes back from acute care having been restrained by one

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27 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, pp 35–6; Mr Stokes, Principal Advisory, Australian Psychological Society, *Committee Hansard*, 16 December 2013, p. 21.

28 Mr Stokes, Principal Advisory, Australian Psychological Society, *Committee Hansard*, 16 December 2013, p. 16.

29 Dr Morkham, National Director, Young People in Nursing Homes National Alliance, *Committee Hansard*, 17 July 2013, p. 34.

30 Ms Lyttle, Chief Executive Officer, Elder Rights Advocacy, *Committee Hansard*, 16 December 2013, p. 25.

31 *Submission 39*, p. 3.

antipsychotic or another and it is maintained in the residential care facility and not questioned.<sup>32</sup>

6.17 HammondCare suggested that:

In my view, an antipsychotic should be viewed in the same way that an antibiotic is. It should have a start time, a review time and a finish time. It is treatment for a particular intervention and is not something that should be used long term.<sup>33</sup>

6.18 The use of mandatory reviews of antipsychotic medication was another suggestion put to the committee to improve the management of medication. It was reported that the Australian Geriatric Society recommend that there should be a revision within three to six months.<sup>34</sup> The committee heard that:

Three months is what we tend to think is a time frame at which, if a drug is appropriately prescribed in the first place and seems to be assisting the situation, it is worth trying to stop the drug. And research suggests that up to 50 per cent or so can be stopped successfully.<sup>35</sup>

### **Recommendation 12**

**6.19 The committee recommends that the use of antipsychotic medication should be reviewed by the prescribing doctor after the first three months to assess the ongoing need.**

### **Recommendation 13**

**6.20 The committee recommends that residential aged care facilities, as part of their existing Aged Care Standards and Accreditation Agency annual audit process, report:**

- **circumstances where an individual has been prescribed antipsychotic medication for more than six months, together with the reasons for and any steps taken to minimise that use; and**
- **general usage patterns of antipsychotic medications in each facility.**

6.21 One of the reasons put forward to explain the under-management of medication was poor links within the care ecosystem. The committee heard that communication between doctors and different parts of the health system was, at times, poor, and meant that GPs working in residential facilities did not have sufficient information to cease a medication. As Professor Pond explains:

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32 Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, pp 33–34.

33 Mr Cunningham, Director – The Dementia Centre, HammondCare, *Committee Hansard*, 17 July 2013, p. 18.

34 Dr Cleary, Geriatrician, Dementia Behaviour and Management Advisory Service, *Committee Hansard*, 10 July 2013, p. 23.

35 Professor Draper, private capacity, *Committee Hansard*, 17 July 2013, p. 51.



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There is a gap when, as a new GP, I take over the care of someone in a nursing home. I often only have some written information about them and do not have any actual discussion or much detail from their former GP. [Discharge summaries] are often difficult to interpret for GPs, so we do not know why someone is on the medication. We really need a better way of gathering a history and improving that communication between acute and aged care. We as GPs might be reluctant to cease something when we are not quite sure what it is and when in a percentage of cases – around 20 per cent, I believe, from the literature – you will get a resurgence of behaviours if you stop the medication. That might be very difficult. I have certainly had a patient who ended up in a specialised unit having had her medication ceased. That is something that makes you very reluctant to follow that path again.<sup>36</sup>

6.22 The decision to start or cease a drug relies on the 'clinical professionalism of the doctor's prescribing behaviour and in the monitoring of the client over time'.<sup>37</sup> The committee also heard however, that doctors rely heavily on the facility to advise them on how the patient has reacted to medication, or for a history of that patient's past behaviour. As was explained to the committee:

[The] GPs often say that they feel powerless to do anything other than fulfil the nursing staff's requests, because the nursing staff are at their wits' end about how they can manage a situation that to them is causing huge problems in their facility, either with some form of aggression or agitation or other forms of disruption. So it becomes a bit of a chain even, if you like: there are the nursing staff, and maybe there are not enough of them, or not enough skills to deal with the problem; they hassle the doctors, and the doctors cannot think of much else to do, because the doctors themselves may not have many other skills beyond the prescription pad for this type of problem. And it continues on that way. Many doctors feel that if they do not prescribe then the patient will be sent by the facility to an emergency department because the facility cannot cope. These kinds of pressures happen.<sup>38</sup>

6.23 The committee was informed that GPs will see patients on medication at least every 12 weeks to write up medication charts.<sup>39</sup> It is not clear though, how doctors who only intermittently see dementia patients can accurately make the decision to start or cease a medication.

6.24 The Pharmaceutical Benefits Scheme (PBS) only records the number of medications dispensed, not necessarily to which patient, which has resulted in

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36 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 35.

37 Dr Towler, Principal Medical Adviser, Population Health Division, Department, *Committee Hansard*, 17 July 2013, p. 43.

38 Professor Draper, private capacity, *Committee Hansard*, 17 July 2013, p. 52.

39 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 35.

difficulty in monitoring drug use across Australia. It was not clear how many individuals were receiving treatment as one person may have been on several drugs concurrently.<sup>40</sup>

6.25 Evidence received from the Department appears to confirm the suspicions of a number of submitters to this inquiry: that the use of drugs in dementia is higher than would be expected on clinical grounds alone. The committee heard:

The drug utilisation subcommittee has become concerned about the use of antipsychotic medication in comparison with the prevalence of depression or schizophrenia at the population level. They undertook a comparison at the end of last year and at the beginning of this year. The reports show that the use of PBS-listed antipsychotics is growing at a higher than expected rate. It is growing at a higher rate in the elderly...In February 2013 it found that there is a high and inappropriate utilisation of antipsychotics in the elderly, especially in the case of two drugs: quetiapine and olanzapine, which are prescribed at a rate inconsistent with the age-specific prevalence of bipolar disease.<sup>41</sup>

6.26 Dr Towler went on to say:

There is no doubt that some of these medications that we suspect, because of the data that do not line up here, are being used inappropriately in terms of their funded indications on the PBS.<sup>42</sup>

6.27 Although the Department's submission argues that:

The Government has in place a range of initiatives to help ensure that anti-psychotic medicines are used only as a last resort and that the prescription of anti-psychotic medicines is closely regulated.<sup>43</sup>

6.28 The evidence indicates that more can be done to minimise the use of drugs in aged care and increase the efficacy of the oversight regime.

6.29 The Australian Institute of Health and Welfare (AIHW) reported to the committee that the 2014 edition of *Australia's Health* will provide greater granularity of dementia drug prescribing practices than has previously been available.<sup>44</sup>

6.30 Alzheimer's Australia called for the accreditation standards agency to take a leading role in improving the transparency of prescribing practices within aged care.<sup>45</sup>

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40 Mr Cooper-Stanbury, Head – Ageing and Aged Care Unit, Australian Institute of Health and Welfare, *Committee Hansard*, 16 December 2013, p. 32.

41 Ms Platona, Assistant Secretary, Pharmaceutical Benefits Division, Department, *Committee Hansard*, 17 July 2013, pp 40–41.

42 Dr Towler, Principle Medical Adviser, Population Health Division, Department, *Committee Hansard*, 17 July 2013, p. 41.

43 Department, *Submission 56*, p. 8.

44 Mr Cooper-Stanbury, Head – Ageing and Aged Care Unit, Australian Institute of Health and Welfare, *Committee Hansard*, 16 December 2013, p. 32.

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## Recommendation 14

**6.31** The committee recommends that the Commonwealth develop, in consultation with dementia advocates and service providers, guidelines for the recording and reporting on the use of all forms of restraints in residential facilities.

## Recommendation 15

**6.32** The committee recommends that the Commonwealth collect and report:

- the number of residents in aged care and acute care facilities with a diagnosis of dementia;
- the number of these residents who are taking, or have taken, antipsychotic medication;
- the number of instances where a patient has been prescribed multiple anti-psychotic medications;
- the reason the medication was prescribed; and
- the average duration of a course of prescribed antipsychotics.

## Physical restraints

**6.33** It was put to the committee that the use of restraints is often for the necessary protection of patients:

Many facilities have a locked dementia unit so people cannot actually get out, where the might be a busy road or something like that. For the night people may be put in a low bed that is a little bit difficult to get out of so that they cannot wander easily. It is not actually a restraint as such but it does provide a physical barrier to wandering. So there are some things like that that do not feel anything like being tied up but that do minimise behaviour that might cause that resident some harm.<sup>46</sup>

**6.34** The committee received some particularly disturbing evidence from ERA detailing the use of physical restraints in some facilities:

His daughter contacted us when she went to visit dad – bearing in mind he is 93 years old – and she found him strapped into a wheelchair. This is in a psychiatric facility, so one we would expect to have a high ratio of staff. She was told that they did this to keep him safe, because he would not settle, and they felt that he was a high falls risk and it would be best to strap him into the wheelchair. When challenged on this by me they said, 'No, it's

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45 Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 33.

46 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 36.

not restraint, because he can still move his feet and pull the chair along.' This is a psychiatric team who told me this.<sup>47</sup>

6.35 It was further reported that the same facility managed another patient by locking him into an isolated corridor area.<sup>48</sup>

6.36 As well as overt restraint, the committee heard of a number of situations that may be deemed a restraint in that they limit a person's rights to information and association. The committee was informed that residents were sometime restricted from engaging in sexual relationships at the request of their families.<sup>49</sup> The committee heard that there was a need to balance the rights of consenting adults with dementia to associate with whomever they please, and the wishes of the family who may find the relationship painful to observe:

Another scenario similar to that which I really want to highlight and which upsets a lot of people is where you have a person who has dementia who has forgotten who their living spouse is and forms a relationship with another person who might have dementia in the residential aged-care home. This is really, really difficult...What [providers] tend to do is separate the two.

...

Even if you have dementia, even if this is hurting someone, you still have a right to choose who you have relationships with. This is a difficult issue. I sympathise with people who are caught up in that type of scenario, but the rights are still there and they will never disappear.<sup>50</sup>

6.37 ERA recommended to the committee that Australia explore 'deprivation of liberty safeguards' such as those used in the United Kingdom.<sup>51</sup>

### ***Committee view***

6.38 While the committee is not in a position to verify the accuracy and currency of these claims of physical restraint, the committee takes these claims seriously. The committee believes that this case serves as a cautionary warning of the harm that can occur where dementia care practices do not focus on the patient.

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47 Mrs Nicholl, Advocate, Elder Rights Advocacy, *Committee Hansard*, 16 December 2013, p. 24.

48 Mrs Nicholl, Advocate, Elder Rights Advocacy, *Committee Hansard*, 16 December 2013, p. 24.

49 Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, pp 7–8.

50 Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, pp 7–8.

51 Mrs Nicholl, Advocate, Elder Rights Advocacy, *Committee Hansard*, 16 December 2013, p. 30.

## Guidelines for the use of restraints

6.39 The Department reported that there are guidelines and advices provided by the authorities to RACFs:

For some years, staff in aged care homes have had access to a decision-making guide to help them make decisions about minimising the use of physical and chemical restraint in the care of older people with dementia.<sup>52</sup>

6.40 The official guidelines were updated and in 2012 two new decision-making tools were reportedly provided to all residential and community care services: *Responding to Issues of Restraint in Aged Care in residential care* and *Responding to Issues of Restraint in Aged Care in community care* (Guidelines).<sup>53</sup> The Guidelines replaced and updated the previous guidelines published in 2004. As the Department explains:

[The guidelines] emphasise that: a restraint-free environment is a basic human right for all care recipients and chemical restraint should not be implemented unless alternatives are explored; and a review of the use of chemical restraint should be carried out in consultation with the care recipient's medical practitioner and an accredited pharmacist.<sup>54</sup>

6.41 In addition, the National Prescribing Service has produced over ten publications on the management of behavioural problems related to dementia that include guidance on minimising the use of drugs, as well as conducted outreach education programs.<sup>55</sup>

6.42 A diversity of opinions was put to the committee regarding the current guidelines. One service provider 'strongly [recommended] more robust guidelines be written to prevent long-term use of antipsychotic medications'.<sup>56</sup> This view was not universal. Another provider posited that 'there are very good and solid guidelines', but these need to be properly implemented.<sup>57</sup> This position was echoed by Benetas which argued that the Guidelines 'provide an excellent model but again the problem is to have health professionals attend aged care facilities to undertake medication reviews'.<sup>58</sup>

6.43 Despite the availability of guidelines and official guidance on the use of restraints, different providers were reported to still have differing ideas of what constitutes a restraint:

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52 *Submission 56*, p. 7.

53 Department, *Submission 56*, p. 7.

54 *Submission 56*, p. 8.

55 Department, *Submission 56*, p. 9.

56 Mrs Edwards, Service Development and Improvement Advisor, BlueCare, *Committee Hansard*, 17 July 2013, p. 11.

57 Mr Cunningham, Director – The Dementia Centre, HammondCare, *Committee Hansard*, 17 July 2013, p. 18.

58 *Submission 21*, p. [4].

I would even go so far as to say that I believe that there are differences in the definitions that different providers are using of what constitutes a restraint. In my travels over the years I have heard people saying, 'Oh, well, if you have got a person who has a diagnosis of dementia, you do not have to class it as a chemical restraint because the person has an antipsychotic.' That is where it starts to get problematic.<sup>59</sup>

6.44 This confusion should not exist. The Guidelines are clear regarding what constitutes a restraint and under what circumstances they may be used, and emphasises that restraints 'must not be implemented until alternatives are explored extensively through assessment'.<sup>60</sup> The committee, unsurprisingly, heard calls for greater publicity and training to be provided around the Guidelines and other advices.<sup>61</sup>

### *Committee view*

6.45 The adequacy of the existing Guidelines is obviously a concern based on the evidence presented above. The committee was surprised that many people appear to be unaware that Guidelines exist, let alone what they contain. The Guidelines appear to be of a high quality and recommend various alternatives to the use of restraints. The committee notes however that there do not appear to be any penalties for the over use of medication, or incentives for providers to minimise the use of restraints.

6.46 Unfortunately the lack of granularity in the data limits the scope of these considerations. In the first instance, the committee considers it important that the use of medication that could be considered as a restraint is quantified and reported to enable a clearer picture of how restraints are being used.

6.47 The committee recognises that the government has produced a number of guides and advices, in addition to the Guidelines, regarding the use of restraints in managing dementia and other conditions. This information however does not seem to have percolated through the sector, especially to doctors who are responsible for prescribing and managing these drugs.

### **Recommendation 16**

**6.48 The committee recommends that the Commonwealth undertake an information program for doctors and residential aged care facilities regarding the guidelines *Responding to Issues of Restraint in Aged Care in Residential Care*.**

### **Are restraints necessary?**

6.49 A number of contributors argued that when the time was taken to understand the causes of BPSD the use restraints was typically unnecessary:

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59 Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 17.

60 Department, *Decision-making tool: supporting a restraint free environment in residential aged care*, 2012, p. 26.

61 Benetas, *Submission 21*, p. [4].

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I think that knowing the person, working with them and understanding them is a much more effective way to go. Communicating with them and understanding what their behaviours are about is a much more effective way to go than using chemicals restraint.<sup>62</sup>

6.50 Alzheimer's Australia emphasised that when the causes, rather than just the behaviours, were considered it was easier to understand why the person is acting the way they do:

I think the secret to dementia care is actually very simple, and that is to look at the cause of a person's symptoms and not to respond to the symptoms themselves. If somebody is violent, they are not being violent because they are a nasty person. They are being violent because they are frustrated. They feel no purpose in life...They do not know where they are. They feel disorientated. They may feel very depressed. They may be suffering psychosis. They may be losing their words. They may not be able to communicate. You put all those things together and think of how you would react and then you can start to translate it into your own behaviours.<sup>63</sup>

6.51 A person's behaviour may also be as a result of their own personal history. Demonstrating the importance of understanding a person's background is well demonstrated in the following example:

I have a patient who is looking at nursing home care, and I know she was in Europe during World War II and was bombed, and she gets very upset when there is a low-flying aircraft and will probably exhibit behaviours in the nursing home that might be very difficult for people to understand unless they know that particular issue.<sup>64</sup>

6.52 The Brotherhood of St Laurence argued that with a sufficient understanding of the patient, most antipsychotic medications were unnecessary:

We very rarely have a need to use antipsychotic medication. There may be a use of anxiety-reducing medication, but generally that might be undertaken for a short period where you are getting the anxiety brought under control but you are looking at all those other things that we have just been speaking about, which was understanding the person.<sup>65</sup>

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62 Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, p. 6.

63 Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 31.

64 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 35.

65 Ms Morka, General Manager, Retirement, Ageing and Financial Inclusion, Brotherhood of St Laurence, *Committee Hansard*, 16 December 2013, p. 12.

6.53 Wintringham reported great success in transitioning patients off medication when the time was taken to understand the root cause of their behaviours.<sup>66</sup> Similarly, HammondCare reported that their dementia-specific facility 'with appropriate design principles and specially trained staff' has successfully implemented a no-restraint policy.<sup>67</sup> Rural Northwest Health reported large reductions in the number of patients on medication following their conversion to the Montessori method of care.<sup>68</sup>

6.54 Speaking from a medical perspective, Professor Pond agreed that there was scope for reducing the reliance on medication through additional staff training and resources:

I think it would be so much better if the nursing home staff had the training and resources to provide some simple distracting activities [for residents]. Some nursing homes are excellent at this, but all too often residents are left to their own devices for huge swags of the day and then they turn to pacing and rattling doors and wanting to go home, and calling out.<sup>69</sup>

6.55 This view was echoed by Professor Brian Draper:

I think there is clearly an overuse of drugs, and I think a lot of this relates to poor design of facilities and training of staff, inadequate numbers of staff and lack of suitable activity programs. I think that if a lot of that could be improved then the use of medications would be much less.<sup>70</sup>

6.56 Based on this evidence, it appears that the use of restraints can be significantly reduced from their current levels. Providing personalised care; ensuring staff members have the appropriate training; and that facilities are designed and managed with the needs of dementia in mind appear to be three of the foundations to build a better care model upon.

6.57 The RANZCP provides an important caveat to this viewpoint:

A recent systematic review into the ability to implement non pharmacological management of BPSD within residential aged care concluded that there are several non-pharmacological interventions that may be effective, but *most interventions required significant resources from services outside of long term care or significant time commitments from long term care nursing staff for implementation.*<sup>71</sup> (emphasis in original)

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66 Ms Small, General Manager of Operations, Wintringham Specialist Aged Care, *Committee Hansard*, 16 December 2013, p. 5.

67 *Submission 25*, p. 4.

68 Ms Walters, Innovation and Continuous Improvement Manager, Rural Northwest Health, *Committee Hansard*, 17 December 2013, p. 5.

69 Professor Pond, representative, Royal Australian College of General Practitioners, *Committee Hansard*, 16 December 2013, p. 36.

70 Professor Draper, private capacity, *Committee Hansard*, 17 July 2013, p. 50.

71 *Submission 49*, p. 9.



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6.58 It is possible to significantly reduce reliance on restraints provided that the resources in the form of training, time and facilities are available:

For the desirable goal of reduced use of restraint and pharmacological interventions in people with BPSD to be achieved, increased access to trained staff with adequate time and resources within residential aged care facilities will be required.<sup>72</sup>

### **Committee view**

6.59 The evidence provided by the Department of Health and Ageing seems to confirm that there is significant overuse of psychotic medication in aged care to control BPSD. This overuse must not be allowed to continue. The existence of several providers who manage BPSD without reliance on chemical or physical restraints highlights what can be achieved with the current resources available.

6.60 This chapter, and those preceding it, have shown that aged care professions know how to reduce the impacts of BPSD. Chapters three and four highlighted the importance of appropriate facilities and environments and a person-centred focus in reducing unnecessary BPSD. Chapter five discussed the importance of adequate staff training in managing BPSD. This chapter brings together these tools—education, appropriate facilities, adequate staff numbers, partnerships with carers, and a person-centred focus—to demonstrate that some service providers are already managing dementia and BPSD without resorting to restraints unnecessarily.

6.61 The use of medication is a symptom of the aged care system not placing enough emphasis on staff training and providing a person-centred focus that engages the patient in meaningful activities. Reliance on restraints to manage dementia and BPSD is not an acceptable model of care, especially as more and more Australians are diagnosed with dementia. It is necessary to make the necessary investments in training and facilities to ensure that the rights of people with dementia are respected and they are free from unnecessary restraints.

6.62 The Commonwealth has recently made significant changes to the aged care system under the *Living Longer, Living Better* reforms. It is hoped that some of these reforms, such as the Dementia and Cognition Supplement, will improve the quality of life for people living with dementia. If the ratio of dementia patients on antipsychotics does not decrease, there will be a need for further government involvement.

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72 Royal Australian and New Zealand College of Psychiatrists, *Submission 49*, p. 12.



# Chapter 7

## Younger Onset Dementia

I think for younger people in particular there is a sense of loss. There is a sense of loss with dementia anyway but for younger people it is a little more acute because they are seen as not having had a bite at living their life yet. That sense of loss for their immediate family is often not addressed.

– Dr Morkham, Young People in Nursing Homes National Alliance

7.1 The issues faced by people with Younger Onset Dementia (YOD) have many parallels with those faced by older people with dementia. Issues around staff training, the use of restraints, assistance for carers, and other matters previously discussed in this report all hold true for people with YOD. The purpose of this chapter is to highlight some of the unique challenges faced by people with YOD.

7.2 Although dementia is often seen as a disease of the elderly, an estimated 23 900 Australians under the aged of 65 suffer from YOD. YOD typically refers to the onset of dementia before the aged of 65.<sup>1</sup> The progression of the disease is reported to be faster in YOD than in other forms of dementia.<sup>2</sup> It was reported by the Royal Australia and New Zealand College of Psychiatrists (RANZCP) that:

Younger onset dementia has a more diverse range of causes than later onset dementia. Alzheimer's disease is less common. Frontotemporal dementia is more frequent, and 'secondary dementias' due to issues such as alcohol, traumatic brain injury, HIV, multiple sclerosis and a large range of metabolic, infection, neoplastic and autoimmune disorders. Current epidemiology regarding the prevalence of younger onset dementia from all causes is poor.<sup>3</sup>

7.3 The Australian Institute of Health and Welfare (AIHW) reported that over seventy per cent of those with dementia under the age of 65 were profoundly limited in core activities and needed substantial support.<sup>4</sup> Around 6800 young Australians presently occupy around five per cent of residential aged care beds nationally with the majority of these being classified as high dependency.<sup>5</sup> Behavioural and Psychological Symptoms of Dementia (BPSD) is also more prevalent in YOD.<sup>6</sup>

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1 Young People in Nursing Homes National Alliance, *Submission 48*, p. 4.

2 Mr Cunningham, Director – The Dementia Centre, HammondCare, *Committee Hansard*, 17 July 2013, p. 19.

3 *Submission 49*, p. 7.

4 Young People in Nursing Homes National Alliance, *Submission 48*, p. 5.

5 Young People in Nursing Homes National Alliance, *Submission 48*, p. 4.

6 Royal Australian and New Zealand College of Psychiatrists, *Submission 49*, p. 7.

7.4 Due to both a lack of understanding of dementia and the prevalent notion that it is an ailment of the aged, diagnosing YOD can be slower than ideal.<sup>7</sup> The long process and difficulties involved in a diagnosis of YOD was related to the committee:

There is still a considerable gap in terms of younger people getting access to diagnosis and into services. It is similar to older onset but has a few key differences. If you are a younger person who presents with symptoms that may be related to dementia, we try and eliminate every other possible cause first. That makes sense but it complicates the journey for those individuals. It is not uncommon for people with YOD to have unusual forms of dementia as well as the garden variety, for want of a better phrase, so it can be more difficult to determine what the actual diagnosis is. But a key problem is that we do not think people under 65 will have dementia.<sup>8</sup>

### **Interaction between Acute-, Disability-, and Aged-care**

7.5 Due to their age and diagnosis, YOD tend to fall between the responsibilities of the aged- and disability-care sectors. The Young People in Nursing Homes National Alliance (YPINH) expressed their frustration at the lack of coordination between the aged-, community- and disability-care sectors:

Young people with dementia continue to enter an endless merry-go-round of bureaucratic avoidance where various arms of the service system not only diminish their responsibility for the care and support these young people require, but actively shift their responsibility to other sectors.<sup>9</sup>

7.6 National Disability Services (NDS) similarly noted the impact on service delivery created by the present administrative demarcations:

At present the needs of this group we believe are not well met, in part because they do not fit neatly into any of the existing service systems: the disability system, the health system, the mental health system or indeed the aged-care system.<sup>10</sup>

7.7 The interaction between State, Territory and Commonwealth systems can cause additional problems for people with YOD. The committee was informed that before a person under 65 can receive a Commonwealth Aged Care Assessment Team (ACAT) assessment (in Queensland, Victoria and South Australia) they need a letter from the State disability services 'stating that there is no suitable disability support for this person. Obtaining this letter can be a complicated, lengthy process.'<sup>11</sup> The delays in gaining access to ACAT and the services they can provide, at a time when people are 'in need of urgent assistance', may contribute to people being admitted into acute

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7 Royal Australian and New Zealand College of Psychiatrists, *Submission 49*, p. 7.

8 Professor McInerney, Professor of Aged Care, Mercy Health and the Australian Catholic University, *Committee Hansard*, 14 February 2014, p. 32.

9 *Submission 48*, pp 5–6.

10 Dr Baker, Chief Executive, National Disability Services, *Committee Hansard*, 14 February 2014, p. 8.

11 Alzheimer's Australia, *Submission 42.2*, p. 3.

care or a residential aged care facility (RACF).<sup>12</sup> The committee heard evidence that ACAT often do not see YOD as part of their responsibilities and refer people back to the disability sector.<sup>13</sup> Such are the difficulties of accessing services, it was reported to the committee that some people end up homeless due to a lack of support.<sup>14</sup>

7.8 The committee heard that providers of acute care (hospitals, mainly) are often the first port of call when a crisis develops in the health of a person with YOD. Once a patient's health has stabilised or is being managed appropriately, the acute care provider will look to discharge the patient. If the person with YOD has informal care in the community they will return there. If community care is not available, the acute care provider will look to discharge the patient either to the disability- or aged-care system.<sup>15</sup>

7.9 Neither the disability- nor aged-care sectors appear to be appropriately equipped to deal with YOD. It was reported that:

Disability Services' funding limitations and its design of funding rules thus means that the YOD group – like those with progressive neurological conditions more generally – continues to struggle to access increasing levels of service in a timely manner.<sup>16</sup>

7.10 In addition to accessing the available care, it was reported that the disability sector more generally does not have the expertise to deal with YOD.<sup>17</sup> When the limits of this assistance are reached, the person is often sent back to acute care.<sup>18</sup> The other 'exit' from acute care is to the aged-care sector. Evidence provided by YPINH highlights the problems associated with this outcome:

Resource for a very different cohort of frail older Australians in the end stages of life, aged care services are ill prepared to manage the different and dynamic health and other supports needed by [young people in nursing homes] generally and individuals with YOD especially. While their aged dementia services provide some assistance, these services are not geared to the different requirements of those with YOD.

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12 Alzheimer's Australia, *Submission 42.2*, p. 3.

13 Dr Baker, Chief Executive, National Disability Services, *Committee Hansard*, 14 February 2014, p. 9; Professor McInerney, Professor of Aged Care, Mercy Health and the Australian Catholic University, *Committee Hansard*, 14 February 2014, p. 27; Mercy Health, *Submission 29*, p. 4; Consumers Health Forum of Australia, *Submission 35*, p. 2.

14 Royal District Nursing Service, *Submission 24*, p. 4.

15 Young People in Nursing Homes National Alliance, *Submission 48*, p. 7.

16 Young People in Nursing Homes National Alliance, *Submission 48*, p. 7.

17 Dr Baker, Chief Executive, National Disability Services, *Committee Hansard*, 14 February 2014, p. 8.

18 Young People in Nursing Homes National Alliance, *Submission 48*, p. 7.

The result is often the start of a revolving door of hospital admissions involving discharge from acute care to aged care to acute care again to aged care again and so on, none of which provides an enduring solution, but consumes significant health and aged care resources in the process as it fails.<sup>19</sup>

7.11 The acute care sector creates a trio of administrative divisions unable to meet the needs of YOD:

For the acute care service, it is a disaster. Already struggling with inadequate funding, sky rocketing demand for health services and the escalating cost of providing health care, hospitals are now increasingly facing provision of long term accommodation to growing numbers of young people they are unable to discharge to other services.<sup>20</sup>

7.12 As evidenced by the above discussion, each sector holds a portion of the expertise required to address the needs of YOD: they need to be brought together.<sup>21</sup> In the opinion of the Productivity Commission and some service providers, the aged-care sector will remain the key provider of services to this group of people.<sup>22</sup>

### **Caring for people with younger onset dementia**

7.13 It was reported to the committee that there is a general lack of appropriate services for people with YOD, with YPINH reporting:

...a distinct lack of specialised services for this group remains and the dedicated accommodation, clinical or other services these young people require are nowhere to be found. Even services that, while not necessarily YOD specific, are still capable of providing targeted responses are extremely rare.<sup>23</sup>

7.14 Mercy Health highlighted that community care is most appropriate for YOD:

For those with YOD, care provided in the community setting is most appropriate (ideally consumer directed care). This allows them to remain with their family, and eliminates the additional stress to themselves and their family involved in moving into a residential aged care facility.<sup>24</sup>

7.15 The carers of YOD tend to be younger including working carers and children living with the person.<sup>25</sup> Many families have to meet a significant financial burden from providing consumables such as incontinence aids, as well as deal with the financial costs associated with foregone labour and one member of the family out of

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19 *Submission 48*, p. 8.

20 Young People in Nursing Homes National Alliance, *Submission 48*, p. 9.

21 Young People in Nursing Homes National Alliance, *Submission 48*, p. 9.

22 Productivity Commission, *Caring for Older Australians*, Canberra, 2011, p. 46; HammondCare, *Submission 25*, p. 6.

23 *Submission 48*, p. 5.

24 *Submission 29*, p. 4.

25 Helping Hand, *Submission 11*, p. 1.

the workforce.<sup>26</sup> The RANZCP argued that more supports need to be available for carers of people with YOD, noting that: 'carer depression and other psychological issues are common in this group of people'.<sup>27</sup>

7.16 Social and support programs for people with dementia are typically targeted at the elderly. People living with YOD may feel isolated as 'they commonly know few others with the same condition and often cope primarily within their own resources'.<sup>28</sup> The committee heard that 'there really was not anything around for younger people'.<sup>29</sup> YPINH and Mercy Health reported that the lack of age-appropriate care is a problem across Australia.<sup>30</sup> While there is no reason why older and younger people should not engage in activities together<sup>31</sup>, there does appear to be a significant shortfall in the provision of social activities that specifically cater to YOD.

7.17 Younger people with dementia are also physically different from older sufferers. The committee heard that YOD experiencing BPSD:

...are not be able to be managed at home because of either violent outbursts or challenging physical abilities where people are younger and stronger, and that can cause real problems for families.<sup>32</sup>

7.18 When BPSD manifests, families report difficulties organising income support and 'respite options are almost non-existent'.<sup>33</sup> The committee was given a glimpse of the challenges of providing care at home for someone experiencing BPSD:

For the whole week he was up 24 hours a day – all week. He dozed on the chairs but would not go to bed. He wanted to break out of the house and break windows, and he jumped on me and dived on me. By that stage he had gone for my neck and I knew that I just could not have him back home, and there was nowhere else for him to go except into an aged-care facility.<sup>34</sup>

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26 Helping Hand, *Submission 11*, p. 1; Dr Baker, Chief Executive, National Disability Services, *Committee Hansard*, 14 February 2014, p. 11.

27 *Submission 49*, p. 8.

28 Mercy Health, *Submission 29*, p. 5.

29 Ms Woolstencroft, Carer, Carers ACT, *Committee Hansard*, 17 July 2013, p. 22.

30 Dr Morkham, National Director, Young People in Nursing Homes National Alliance, *Committee Hansard*, 17 July 2013, p. 32; Professor McInerney, Professor of Aged Care, Mercy Health and the Australian Catholic University, *Committee Hansard*, 14 February 2014, p. 27.

31 Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 37.

32 Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 19.

33 National Disability Services, *Submission 43*, p. 3.

34 Ms Woolstencroft, Carer, Carers ACT, *Committee Hansard*, 17 July 2013, p. 21.

7.19 Evidence provided by Alzheimer's Australia highlighted that access to respite care is often limited as service providers are reluctant to take on the care of people who are 'fitter and younger than other residents'.<sup>35</sup>

7.20 HammondCare similarly highlighted the challenges faced by YOD in relation to respite care:

What we have found in that service is that the [respite] service options for people with younger onset dementia are not adequate to meet the needs that people have. There is a large gap in terms of what is provided out in the community for people with younger onset dementia. It is a different set of needs to those of people who are older. Respite services in particular are different; their family members still need to be in full-time work because there are still mortgages to pay. The person with dementia does not need an hour of personal care in the morning and an hour of personal care in the evening—the person needs eight hours during the day when their spouse is going to work and making sure that the world goes around for the family. Those services are not adequate at the moment.<sup>36</sup>

7.21 Carers Australia noted that day care is particularly important for carers of YOD, but the hours of operation do not take into account carers having a full time job or significant other responsibilities such as children.<sup>37</sup>

7.22 As well as different hours, people with YOD have different requirements for respite care that are not presently met:

Younger people and their carers require different types of respite services than older people and their carers do. They are at greater risk of boredom and isolation and need activities to keep the connected and motivated. For instance, they may be in the early stages of a relationship and what to have time alone over a weekend with their partner.<sup>38</sup>

7.23 The majority of people with YOD receive services through the aged-care system.<sup>39</sup> The residential care they are offered however—designed as it is to cater for the elderly—is different from what they need:

...people need to be given the opportunity to continue to engage in normal life in a broader sense, and have more personal freedoms – which also comes with more personal risks.<sup>40</sup>

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35 *Submission 42*, p. 7.

36 Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 18.

37 Ms Elderton, Policy Manager, Carers Australia, *Committee Hansard*, 17 July 2013, p. 20.

38 Carers Australia, *Submission 46*, pp 12–13.

39 Dr Baker, Chief Executive, National Disability Services, *Committee Hansard*, 14 February 2014, p. 8.

40 Ms Raguz, General Manager – Residential Care, HammondCare, *Committee Hansard*, 17 July 2013, p. 14.



7.24 The committee also heard that it is more expensive to provide accommodation infrastructure for YOD:

Younger people have different accommodation requirements for example to providers to adequately accommodate younger people there is a significant capital cost, younger people require greater access to open space, these people often need to move around freely.<sup>41</sup>

7.25 Families with people with YOD in residential care still want that time to be a quality life where they can do things together they would have done at home.<sup>42</sup> It was suggested to the committee that YOD should be provided with areas that provide 'opportunities for families to come together if they are not staying there all the time'.<sup>43</sup>

7.26 The institutionalisation of people with YOD with residents who are 20 or 30 years older, with no common interests, may exacerbate their BPSD.<sup>44</sup> It was explained to the committee that residential aged-care facilities (RACFs) are not equipped to deal with YOD<sup>45</sup>:

Younger people with young onset dementia present a particular conundrum for aged-care providers, who, with the best intend and best will in the world, are not resources for them. Younger people are bigger, heavier and more demanding.<sup>46</sup>

7.27 The evidence received by the committee highlighted that the residential care model as it exists for dementia, even what is considered best practice, may not be suitable for YOD exhibiting BPSD:

Even residential care services dedicated to younger people with dementia may not be appropriate for residents if they are based on existing models. HammondCare began pioneering a 15-place (14 permanent beds and one respite) cottage for young people with dementia. However, this cottage model, based on our cottages for older people with dementia, is not suitable for people with very severe and persistent BPSD.

HammondCare is currently reviewing a smaller house-based model that would cater for five to six younger people with dementia. As part of this review, we are exploring the possibility of adapting a number of group living models used to support people with intellectual disabilities.<sup>47</sup>

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41 Helping Hand, *Submission 11*, p. 1.

42 Mercy Health, *Submission 29*, p. 5.

43 Dr Morkham, National Director, Young People in Nursing Homes National Alliance, *Committee Hansard*, 17 July 2013, p. 37.

44 BlueCare, *Submission 32*, p. 3.

45 Professor Draper, private capacity, *Committee Hansard*, 17 July 2013, p. 53.

46 Dr Morkham, National Director, Young People in Nursing Homes National Alliance, *Committee Hansard*, 17 July 2013, p. 33.

47 HammondCare, *Submission 25*, p. 5.

7.28 Due to facilities not being appropriately staffed or equipped to deal with YOD, chemical and physical restraints are more likely to be used as YOD 'are more active and can be physically strong.'<sup>48</sup> There is also the potential for YOD to make other residents in RACFs feel uncomfortable.<sup>49</sup>

### **Recommendation 17**

**7.29 The committee recommends that a review of the adequacy of respite facilities for Younger Onset Dementia patients be carried out urgently.**

### **Recommendation 18**

**7.30 The committee recommends that the Commonwealth fund the development of a pilot Younger Onset Dementia specific respite facility at either the Barwon or Hunter area National Disability Insurance Scheme trial sites.**

### **Improving care for people with younger onset dementia**

7.31 HammondCare recommended two macro-level changes to caring for younger people:

So I think one of the things we need to look at in the younger onset context is being able to make sure that, firstly, the services are available and appropriate to their needs and that, secondly, we are able to respond to those needs.<sup>50</sup>

7.32 There is a need to ensure there are services available, and that those services must proactively manage YOD, rather than waiting until a crisis point is reached. Professor Draper emphasised that there is a need to address the shortfalls across community-, acute-, and residential-care as services will be provided by all of them.<sup>51</sup>

7.33 As part of the Commonwealth's *Living Longer, Living Better* reforms Younger Onset Dementia Key Workers (key workers) are being trialled in order to improve coordination of services for people with YOD. As of 18 February 2014 there are 40 key workers operating nationally.<sup>52</sup> The key worker pilot will be an important step in this direction provided that they can achieve their stated objectives:

The younger onset dementia key worker acts as a primary point of contact for people with younger onset dementia, their families and carers. The key worker provides information, support, counselling, advice and helps consumers effectively engage with service appropriate to their individual needs.

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48 Alzheimer's Australia, *Submission 42*, p. 8.

49 Ms Small, General Manager of Operations, Wintringham Specialist Aged Care, *Committee Hansard*, 16 December 2013, p. 7.

50 Mr Cunningham, Director – The Dementia Centre, HammondCare, *Committee Hansard*, 17 July 2013, p. 19.

51 Professor Draper, private capacity, *Committee Hansard*, 17 July 2013, p. 53.

52 Department of Social Services, *2013–14 Supplementary Estimates*, answer to question on notice (written): 433, (received 18 February 2014).

This program ensures that the needs of people with younger onset dementia are being met in the community by increasing awareness and education, building capacity in the disability, aged care, community and residential care sectors and improving coordination of services across agencies. Key workers identify and address gaps in services and build capacity through consultation, networking and collaboration with service providers and consumers.<sup>53</sup>

7.34 Although there are doubtless benefits in providing information, support, counselling and advice, it is unclear how many of the service gaps identified by the contributors to this inquiry can be met through the better coordination of services when those services do not appear to exist. Whereas dementia services for older Australians may be insufficient, especially for people with BPSD, they seem to be non-existent for YOD.

7.35 Brightwater Care Group highlighted a model of support they have developed to provide services to people with Huntington's disease that they suggested may be applied to YOD:

Brightwater has provided support for those families from point of diagnosis. They were working quite closely with the Huntington's Disease Association and with the neurosciences to almost providing a case management model identifying where the person is on their journey, when there are challenges in the family in providing support, and looking at education, and we carry that through when those people require residential accommodation and support. We certainly provide education and training to staff in supporting those people with Huntington's disease and we see that potentially that could be a good model for supporting people with younger onset dementia.<sup>54</sup>

7.36 Mercy Health reported they are working on a similar YOD-specific initiative involving their organisation, Alzheimer's Australia Victoria and the Lovell Foundation. As they explain: 'This consortium has been formed with the intent of developing a leading edge service for those living with younger onset dementia'.<sup>55</sup> These approaches appear to have many parallels between the key worker pilot, with the added benefit that the service provider has the ability to improve staff training and minimise disruption for the person with the illness as there is greater continuity of care. The committee notes that this model appears highly applicable to all dementia sufferers.

7.37 Many stakeholders appeared positive that *National Disability Insurance Scheme* (NDIS) could facilitate improved access to

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53 Alzheimer's Australia, *National Younger Onset Dementia Key Worker Program*, <http://www.fightdementia.org.au/services/younger-onset-dementia-key-worker-program.aspx>, (accessed: 19 February 2013).

54 Ms Hudson, Wellbeing and Dementia Support Coordinator, Brightwater Care Group, *Committee Hansard*, 14 February 2014, p. 33.

55 *Submission 29*, p. 2.

YOD specific services as the market begins to cater those needs.<sup>56</sup> It will take time for the necessary skills to develop in the disability sector. As NDS explained:

The disability service system is at present not well equipped to support this group of people. Although there is experience in supporting people, for example, with Down syndrome who acquire dementia and early-onset dementia is more probable among people with Down syndrome than the general population, there is not wide experience within the sector of supporting people with dementia.<sup>57</sup>

7.38 There is capacity under NDIS to purchase expertise from the aged-care sector where much of the necessary expertise resides.<sup>58</sup> Mercy Health noted that consumer directed care will improve YOD care:

Consumer Directed Care will provide significant benefits for those with YOD and their family. Support received in the home may not be direct care for the consumer, but be the provision of home support or respite which allows the spouse to leave the house to shop, or attend children's sporting events. For the children of those with YOD, counselling could be provided.<sup>59</sup>

7.39 NDS cautioned however that although participants in NDIS will have greater choice over the service they could receive, organisations may not wish to provide services to this group; as is often the case presently.<sup>60</sup>

7.40 As YOD cross over the boundaries of several areas, advanced care planning is of crucial importance to ensure that immediate and future needs can be prepared for.<sup>61</sup> It was noted by the Office of the Public Advocate Queensland that: 'In addition to empowering the person, this may also be a cost-effective way to enhance quality of care.'<sup>62</sup> The committee was informed that there was insufficient emphasis on the importance of advanced care planning:

I believe that there is not enough being done in this area. First and foremost, we completely support [advanced care planning]. We think it is very

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56 Dr Morkham, National Director, Young People in Nursing Homes National Alliance, *Committee Hansard*, 17 July 2013, p. 38; Mr Rees, Chief Executive Officer, Alzheimer's Australia, *Committee Hansard*, 17 July 2013, p. 38; Professor McInerney, Professor of Aged Care, Mercy Health and the Australian Catholic University, *Committee Hansard*, 14 February 2014, p. 27.

57 Dr Baker, Chief Executive, National Disability Services, *Committee Hansard*, 14 February 2014, p. 8.

58 Dr Baker, Chief Executive, National Disability Services, *Committee Hansard*, 14 February 2014, p. 10.

59 *Submission 29*, p. 5.

60 National Disability Services, *Submission 43*, p. 5.

61 Ms Cook, Public Advocate, Office of the Public Advocate Queensland, *Committee Hansard*, 17 July 2013, p. 2.

62 Ms Cook, Public Advocate, Office of the Public Advocate Queensland, *Committee Hansard*, 17 July 2013, p. 2.

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important, particularly with people who have early onset dementia. But the issue is that there is not a lot of awareness about it. That needs to be augmented so that people know what it is about, how they can do it and how they can get their wishes recorded.<sup>63</sup>

7.41 Engaging the person with the illness in their care planning while they are still able to will make it easier for service providers to understand and meet the goals and needs of that person in the future. Providing the person-centred approach previously discussed in this report relies on having an understanding of who the person is, what their preferences are, and how they want to live out their life. Advanced care planning is a key tool to facilitate this care approach.

### **Committee view**

7.42 Australia's disability sector, aged care sector, and acute care facilities are, through no fault of their own, systematically failing younger people diagnosed with dementia. The changes emerging from NDIS and *Living Longer, Living Better* should improve access and availability of services for people with YOD. Improving coordination between the aged- and disability-sectors through the key worker program is an important initiative, and the advent of person directed care through NDIS will create a marketplace of services.

7.43 As has been seen throughout this inquiry however, the most promising trends often come from the service providers themselves who go out of their way to create innovative and effective models to provide care for all Australians. Brightwater Care Group's and Mercy Health's model of working with patients, peak bodies, carers and staff to provide holistic and appropriate support is one that needs to be applied more broadly. HammondCare's efforts to provide YOD specific housing similarly stands out as a model of care with great potential. The Commonwealth has an important role to play in advertises these successes to allow other providers to emulate that successful care.

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63 Mrs Di Mezza, Advocacy Coordinator, Australian Capital Territory Disability, Aged and Carer Advocacy Service, *Committee Hansard*, 17 July 2013, p. 9.



## Concluding comments

8.1 Dementia is a significant and growing problem in Australia. In 2012, the Australian Institute of Health and Welfare (AIHW) reported there were 321,000 Australians diagnosed with the illness. Of this number, more than 90% were aged over 65 and more than 60% were women.<sup>1</sup> The incidence of the illness is also pronounced in government-funded residential aged care facilities (RACFs) where more than half the residents live with dementia. With projections that the number of Australians living with dementia will increase to 400,000 by 2020 and almost 900,000 by 2050, it will be necessary to provide care to people with dementia in the community and in RACFs.

8.2 This report has been concerned with the care and management of Australians living with dementia and the behavioural and psychological symptoms of dementia (BPSD). Its focus has been on assessing Commonwealth, State and Territory government services and supports for persons living with dementia in both community care and residential care. The committee's recommendations are based on an understanding that people living with dementia need personalised care from well trained staff and, while there are certainly leaders in service provision, there is no single correct model of care for those with dementia.

8.3 There are pressing challenges for governments, health advocates and the aged care sector to ensure effective care and management of dementia sufferers, for example:

- improving early and accurate diagnosis of the condition, including enabling specialists and family members to become involved in the diagnosis process;
- ensuring there are proper support systems in place for people living with dementia to remain at home;
- ensuring that carers have adequate support, including respite, training, and guidance in accessing dementia services; and
- ensuring a high standard of care for dementia sufferers through adequate funding, innovation and design. While the model of delivery may differ from one provider to the next, the standard of care should be based on:
  - a person-centred approach that takes into account the individual's qualities, abilities, interests, preferences and needs;
  - recognition that dementia alters perceptions and appropriate environments can minimise BPSD;
  - respect for their rights as patients, offering activities that are engaging and stimulating rather than chemicals and restraints to suppress the outward signs of the illness;

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1 *Dementia in Australia*, 2012. AIHW noted that 24,400 sufferers were aged under 65.

- training and retaining high-quality residential and community care workers; and
- facilitating greater community awareness and understanding of the illness.

8.4 These challenges, and the response to date, have been themes of this inquiry and report. While the challenges are significant and complex, this inquiry has identified a number of areas where access to, and coordination of, information would greatly assist patients, their families and carers. In this context, the committee has found notable examples of RACFs delivering leadership, innovation and success in response to each of the challenges listed above. The committee believes it is important that government recognise these achievements, and act to promote and publicise this work.

8.5 The committee emphasises the key role that carers play to facilitate the community care system must be supported. Community care is valuable not only in itself but in taking pressure off the more expensive option of RACFs. The committee emphasises that those reliant on community care need to be able to access information on all their options for support as simply and efficiently as possible. The Commonwealth-funded Home Care Packages Program and Home and Community Care Services are both important funding measures. The continuing shortage of BPSD appropriate respite facilities is of real concern to the committee. The lack of respite options for people with younger onset dementia (YOD) and people in regional and remote areas are also areas of particular concern.

8.6 This report has identified residential aged care providers such as Wintringham, Rural Northwest Health, HammondCare and the BrightWater Group as providing a high standard of living for people with dementia. Their models differ but a common theme is their commitment to person-centred care (PCC), high levels of staff training and investment in new ideas and appropriate facilities. These providers have benefitted greatly from managers who take the initiative to explore new ideas in PCC and adapt these new practices to their organisation. They explain the changes to staff and encourage staff involvement as they are implemented. They also demonstrate that existing RACFs can be retrofitted in a way to provide PCC.

8.7 The committee believes that the examples of these leading RACF providers must be more widely acknowledged. The providers deserve a good reputation and should attract strong community interest. The Commonwealth should play a role to publicise the work of these providers and explain to the community what it is about their service for people with dementia that is exemplary. It is to be hoped that these messages will encourage other providers to compete by lifting their standards.

8.8 Skilled and committed staff is crucial to care effectively for people with dementia in RACFs and the community. This inquiry has noted a number of leaders in training and retaining staff with innovative and highly effective training tools. The committee believes that the Commonwealth has a role to facilitate more effective ways to publicise training courses that are available, and to ensure that staff working



with people with dementia have the skills necessary to provide person centred, dementia appropriate care.

8.9 There is important work being done to educate the Australian community about the experience of living with dementia and care for those with the condition. Alzheimer's Australia's newly established Perc Walkley Dementia Learning Centre in Melbourne is a world-class facility. The committee gained considerable insights from its visit to the centre in December 2013 and was most impressed with the staff and the use of technology. As a tool to showcase the sensory experience of those living with dementia, and to highlight how workspaces, homes and public spaces can become more dementia friendly, the centre is an outstanding public resource and deserves wide public attention.

**Senator Rachel Siewert**

**Chair**



# **APPENDIX 1**

## **Submissions and additional information received by the Committee**

### **Submissions**

- 1** Mrs Julie Drury
- 2** Ms Anne Dickens
- 3** Ms Kyla Mathers
- 4** Mr Glen Oldham
- 5** White Wreath Assoc Ltd
- 6** Mr Ron Ebdon
- 7** Dr Kim Wylie
- 8** Dr John Tooth
  - Response from Tasmanian Government to submission 8
- 9** GLBTI Retirement Association Inc
- 10** Private Mental Health Consumer Carer Network (Australia)
- 11** Helping Hand
- 12** National Prescribing Service
- 13** ACT Disability Aged Carer and Advocacy Service
- 14** Catholic Health Australia
- 15** Confidential
- 16** Mission Australia
- 17** Professor Brian Draper
  - Attachment
- 18** Australian Institute of Health and Welfare
- 19** Services for Australian Rural and Remote Allied Health
- 20** Mrs Jenny Potter
- 21** Benetas
- 22** Emeritus Professor Rhonda Nay

- 23** Alzheimer's Australia NSW
- 24** Royal District Nursing Service
- 25** HammondCare
- 26** Aged Care Crisis
- 27** Ms Susan Henderson
  - Attachment
- 28** Minister's Dementia Advisory Group
  - Attachment
- 29** Mercy Health
- 30** Elder Rights Advocacy
  - Attachment
- 31** Australian Psychological Society
- 32** Blue Care
- 33** Confidential
- 34** Name Withheld
  - Response from Presbyterian Care Tasmania to submission 34
- 35** Consumers Health Forum of Australia
- 36** National LGBTI Health Alliance
- 37** Office of the Public Advocate Queensland
- 38** Australian College of Nursing
- 39** Australian Medical Association
- 40** Brotherhood of St Laurence
- 41** Mr Lionel Parrott
- 42** Alzheimer's Australia
  - Attachment 1
  - Attachment 2
  - Attachment 3
  - Attachment 4
  - 42.1 Supplementary submission
  - 42.2 Supplementary submission
- 43** National Disability Services
- 44** Endeavour Foundation

- 45 National Rural Health Alliance Inc.
- 46 Carers Australia
- 47 Carers ACT
  - Attachment
- 48 Young People In Nursing Homes National Alliance
- 49 Royal Australian and New Zealand College of Psychiatrists
- 50 Brightwater Care Group
- 51 Mental Health Council of Australia
- 52 Royal Australian College of General Practitioners
- 53 National Mental Health Commission
- 54 Dementia Care Australia
  - Attachment
- 55 NSW Nurses and Midwives' Association
- 56 Department of Health and Ageing
- 57 Adssi Home Living Australia
- 58 Royal Australasian College of Physicians and Australian and New Zealand Society for Geriatric Medicine
- 59 Wintringham
- 60 Tasmanian Government
- 61 Mrs Doreen Hill
- 62 Dr Karen Macpherson

**Additional Information**

- 1** The use of antipsychotic medication for people with dementia: Time for action report (October 2009), by Professor Sube Banerjee, from Blue Care, received 17 July 2013
- 2** An economic evaluation of alternatives to antipsychotic drugs for individuals living with dementia report (October 2011), by Matrix Evidence, from Blue Care, received 17 July 2013
- 3** United Nations Principles for Older Persons, tabled by ACT Disability Aged Care and Advocacy Service, at Canberra public hearing 17 July 2013
- 4** Atypical Antipsychotic Use in Patients With Dementia: Managing Safety Concerns journal article, by Martin Steinberg and Constantine Lyketsos, from Blue Care, received 18 July 2013
- 5** Decision-making tool: Supporting a restraint free environment in Residential aged care, by Department of Health and Ageing, from ACT Disability Aged Care and Advocacy Service, received 18 July 2013
- 6** Decision-making tool: Supporting a restraint free environment in Community aged care, by Department of Health and Ageing, from Department of Health and Ageing, received 9 August 2013
- 7** Caring for carers research summary, tabled by Brotherhood of St. Laurence, at Melbourne public hearing 16 December 2013
- 8** Preliminary evaluation of the Short Break Stay Program research summary, tabled by Brotherhood of St. Laurence, at Melbourne public hearing 16 December 2013
- 9** Putdowns and uplifts: signs of good or poor dementia care article, tabled by Dementia Care Australia, at Melbourne public hearing 16 December 2013
- 10** Discover the person, not the disease article, tabled by Dementia Care Australia, at Melbourne public hearing 16 December 2013
- 11** Statement by Sandy Crowe from Southern Cross Care WA, from Dementia Care Australia, received 19 December 2013
- 12** Spark of Life brochure, from Dementia Care Australia, received 20 December 2013
- 13** Journal of Clinical Nursing article: Hospital discharge planning for frail and older people and their family, from Rural Northwest Health, received 19 December 2013

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- 14** SAGE article: How family carers view hospital discharge planning for the older person with a dementia, from Rural Northwest Health, received 19 December 2013
  - 15** Alzheimer's Australia research final report, from Rural Northwest Health, received 19 December 2013
  - 16** Australian Health Review article: Hospital discharge: recommendations for performance improvement for family carers of people with dementia, from Rural Northwest Health, received 19 December 2013
  - 17** Submission by ACON to NSW Health on the Draft NSW Dementia Services Framework 2010-2015 (August 2010), from National LGBTI Health Alliance, received 13 February 2014
  - 18** Document by Gay and Lesbian Health Victoria, Matrix Guild of Victoria and Vintage Men Inc.: My Story – My People, Stories about older gay, lesbian, bisexual and transgender people's experiences of aged care, Extracts from the My People study (November 2012), from National LGBTI Health Alliance, received 13 February 2014
  - 19** Paper by Alzheimer's Australia: Dementia, Lesbians and Gay Men (October 2008), from National LGBTI Health Alliance, received 13 February 2014
  - 20** Inclusive Language Guide, from National LGBTI Health Alliance, received 13 February 2014
  - 21** Letter regarding access to assessment and support for people with younger onset dementia, from Alzheimer's Australia, received 26 February 2014

**Correspondence**

- 1** Correspondence from Department of Health and Ageing correcting evidence given at Canberra public hearing 17 July 2013, received 9 August 2013

**Answers to Questions on Notice**

- 1** Answers to Questions on Notice received from Dementia Tas, 10 July 2013
- 2** Answers to Questions on Notice received from Tasmanian Department of Health and Human Services, 10 July 2013
- 3** Answers to Questions on Notice received from Department of Health and Ageing, 9 August 2013
- 4** Answers to Questions on Notice received from Department of Social Services, 9 December 2013
- 5** Answers to Questions on Notice received from Australian Psychological Society, 19 December 2013
- 6** Answers to Questions on Notice received from Department of Social Services, 28 February 2014



# **APPENDIX 2**

## **Public hearings**

*Wednesday, 10 July, 2013*

*Parliament of Tasmania, Hobart*

### **Witnesses**

#### **Presbyterian Care Tasmania**

BROOKS, Mr John, Chief Executive Officer

WEEDING, Ms Felicity, Manager South

#### **Department of Health and Human Services, Tasmania**

BUCHER, Ms Hazel Frances, Nurse Practitioner, Psychogeriatrics, Older Persons  
Mental Health Service

CLEARY, Dr Allison, Geriatrician

DAVIDSON, Mr Brendon Paul, Principal Policy Consultant

MORRISSEY, Dr Martin, Senior Old Age Psychiatrist, Older Persons Mental Health  
Service

REED, Mr Stewart, Assistant Director of Nursing, Mental Health Services

#### **Dementia Tas**

CALVERT, Ms Roslyn Ann, Manager

**DICKENS, Mrs Anne, Private capacity**

**HUNT, Mr Rodney John, Private capacity**

**MATHERS, Ms Kyla Anne, Private capacity**

**OLDHAM, Mr Glen Andrew, Private capacity**

**Woman A, Private Capacity**

**Woman B, Private Capacity**

*Wednesday, 17 July, 2013*

*Parliament House, Canberra*

**Witnesses**

**Department of Health and Ageing**

MARTINE, Mr David, Deputy Secretary

PLATONA, Ms Adriana, Assistant Secretary, Pharmaceutical Benefits Division

BROWNE, Ms Shirley, Assistant Secretary, Ageing and Aged Care Division

SMITH, Ms Carolyn, First Assistant Secretary, Ageing and Aged Care Division

HUNT, Dr Susan, Senior Adviser, Office of Aged Care Quality and Compliance

TOWLER, Dr Bernie, Principal Medical Adviser, Population Health Division

**Office of the Public Advocate Queensland**

COOK, Ms Jodie, Public Advocate

**HammondCare**

CUNNINGHAM, Mr Colm, Director, The Dementia Centre

RAGUZ, Ms Angela, General Manager, Residential Care

**Australian Capital Territory Disability, Aged and Carer Advocacy Service**

DI MEZZA, Mrs Sonia, Advocacy Coordinator

**DRAPER, Professor Brian, Private capacity**

**Blue Care**

EDWARDS, Mrs Denise, Service Development and Improvement Adviser

**Carers Australia**

ELDERTON, Ms Sue, Policy Manager

**Young People In Nursing Homes National Alliance**

MORKHAM, Dr Bronwyn, National Director

**Minister's Dementia Advisory Group**

PIETERS-HAWKE, Ms Sue, Co-Chair

YATES, Associate Professor Mark, Member

**Alzheimer's Australia**

REES, Mr Glenn, Chief Executive Officer

**Carers ACT**

WOOLSTENCROFT, Ms Judy, Carer

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***Monday, 16 December, 2013***

***State Netball and Hockey Centre, Melbourne***

**Witnesses**

**Brotherhood of St Laurence**

MORKA, Ms Christine, General Manager, Retirement, Ageing and Financial Inclusion

ASTETE, Ms Lisa, Senior Manager, Day and Respite Programs

**Australian Institute of Health and Welfare**

COOPER-STANBURY, Mr Mark, Head, Ageing and Aged Care Unit

**Dementia Care Australia and Spark of Life**

VERITY, Mrs Jane, Founder and Chief Executive Officer

LEE, Ms Hilary, President

DELMONTE, Ms Helen Elaine, Allied Health Manager and Spark of Life Practitioner, Mercy Parklands

**Australian Psychological Society**

STOKES, Mr David, Principal Adviser

LI, Mr Bo, Senior Policy Adviser

**Wintringham Specialist Aged Care**

LIPMANN, Mr Bryan, Chief Executive Officer

SMALL, Ms Helen, General Manager of Operations

**Elders Rights Advocacy**

LYTTLE, Ms Mary, Chief Executive Officer

NICHOLL, Mrs Debra Ann, Advocate

**Royal Australian College of General Practitioners**

POND, Prof. Constance Dimity, Representative

**YOUNG, Mr Matthew John, Private capacity**

*Tuesday, 17 December, 2013*

*Yarriambiack Lodge, Warracknabeal*

**Witnesses**

**Rural Northwest Health**

MORLEY, Ms Catherine, Chief Executive Officer

FISCHER, Ms Alison, Nurse Unit Manager

WALTERS, Ms Wendy, Innovation and Continuous Improvement Manager

RAMSDALE, Ms Katie, Rehabilitative Therapist

**BROWN, Mr Edward James, Private capacity**

**OSBORNE, Mr Graham, Private capacity**

**SMITH, Dr Jennifer Gay, Private capacity**

**WALKER, Mr Maxwell John Henry, Private capacity**

**WALKER, Ms Angela, Private capacity**

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*Friday, 14 February, 2014*

*Parliament House, Canberra*

**Witnesses**

**Australian Medical Association**

KIDD, Dr Richard, Chair, Committee for Healthy Ageing  
TRIMMER, Ms Anne, Secretary General

**National Disability Services**

ANGLEY, Ms Philippa, National Policy Manager  
BAKER, Dr Ken, Chief Executive

**Aged Care Crisis**

SALTARELLI, Ms Lynda, Communications Advisor  
SPARROW, Ms Linda, Committee Member

**National LGBTI Health Alliance**

ANSARA, Dr Y. Gavriel, Senior Health Policy Officer  
REYNOLDS, Ms Rebecca, Executive Director

**Brightwater Care Group**

HUDSON, Ms Wendy, Wellbeing and Dementia Support Coordinator  
ZEEMAN, Ms Tonia Lynda, General Manager, Strategy

**Mercy Health**

McINERNEY, Professor Frances Julia (Fran), Professor of Aged Care