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 Ageing¹ (Department) reported 'nearly 1.5 million Australians are affected by dementia including the families and carers of people living with dementia'. 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.³

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.⁴

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).⁵ Indigenous Australians are also more likely to

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).

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. 6

- 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
Mild or early	Deficits are evident in a number of areas (such as memory and personal care) but the person can still function with minimal assistance.
	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.
Moderate or middle	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.
	Symptoms include: severe memory loss, considerable difficulty orienting to time and place, obvious difficulties if inding 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).
Severe or late	Characterised by almost total dependence on the care and supervision by others.
	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.
	By this stage the majority of people with dementia are in residential care.

Sources: Draper 2011; Morris 1993.7

- 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. 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:

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.

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.

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.⁹

- 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.¹⁰
- 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. 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.¹²

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). 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.¹⁴

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

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

⁹ Department, Submission 56, p. 6.

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

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

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. ¹⁵

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

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. 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. 17
- 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. ¹⁸ 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. ¹⁹
- 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.²⁰

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, OBE²¹
- 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

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

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

¹⁶ Department, Submission 56, p. 6.

¹⁷ *Submission 49*, p. 3.

¹⁹ Department, Submission 56, p. 6.

²⁰ *Submission 49*, p. 3.

pressing public health issues. In August 2012, all Australian Health Ministers recognised dementia as the ninth National Health Priority Area (NHPA). 22 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. ²³

- 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. 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. ²⁵
- 2.22 The number of Australians living with dementia is projected to rise to about 900,000 in 2050 as the population ages. ²⁶ Dementia prevalence rates are relatively low until the age of 70 years and over when the prevalence rates start to increase exponentially. ²⁷ After the age of 65 the probability of receiving a diagnosis of dementia doubles every five to six years. ²⁸ There is likely to be little change in this pattern, with the AIHW reporting:

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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.

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.

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

Department, Submission 56, p. 6.

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

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.²⁹

- 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. The number of women with dementia outnumbers men, accounting for more of the projected disease burden (63% compared to 37%). 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. The state of the problem in Australia and linguistically diverse communities.
- 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). The average cost of hospital care for people with dementia was \$2,500 more per episode than those without dementia. 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. The strength of the significant in th
- 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.³⁶ 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.³⁷

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

- Mr Cooper-Stanbury, Head Ageing and Aged Care Unit, Australian Institute of Health and Welfare, *Committee Hansard*, 16 December 2013, pp 31–32.
- 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.
- Australian Institute of Health and Welfare, Dementia in Australia, 2012, p. 15.

²⁹ Dementia in Australia, 2012, p. 5.

³¹ 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.³⁸

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.³⁹ 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.⁴⁰

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. 41

- 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.⁴²
- 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. 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.

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

⁴⁰ *Submission 31*, p. 5.

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

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

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

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.⁴⁴

The committee similarly heard of the importance of carer and family input to 2.31 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'. 45

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.⁴⁶

In addition to time constraints, the committee heard that the omission of a 2.33 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.47

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.

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

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

Professor Pond, representative, Royal Australian College of General Practitioners, Committee 47 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. 48

- 2.35 The APS stressed the need for expert knowledge to evaluate dementia diagnoses. ⁴⁹ 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. ⁵⁰ 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'. ⁵¹ The committee heard that there presently was no mechanism for a GP to refer a person to psychological experts for assessment under Medicare. ⁵²
- 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.⁵³ 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.⁵⁴ 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'.⁵⁵
- 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

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

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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.

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

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.

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

Mercy Health, Submission 29, p. 3.

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. ⁵⁶

- 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.⁵⁷
- 2.40 The committee heard evidence that there remains a stigma associated with dementia that can create barriers to community engagement.⁵⁸ 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. ⁵⁹

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. 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.⁶¹

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.

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

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

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

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

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

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