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.[1] 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.[2]

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.[3]

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.[4] 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'.[5]

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.[6]

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'.[7]

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.[8]

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'.[9]

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.[10]

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.[11] 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 or 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.[12]

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.[13]

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.[14]

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.[15]

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.[16]

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.[17]

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'.[18] It should be noted that the receipt of ACFI funds does not come with any staffing ratio requirements.[19] 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.[20]

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.[21]

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.[22] 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.[23]

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.[24]

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,[25] 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.[26]

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.[27]

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.
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> …
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> 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

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.[28]

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.[29]

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![30]

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.[31]

4.27 The facility was designed by Dr John Tooth OAM, the then Tasmanian State psychogeriatrician, and two experienced psychogeriatric nurses.[32] 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.[33]

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.[34] 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.[35] 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.[36]

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, 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.

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

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.[38]

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.[39]

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'.[40] The committee heard that facilities need to have around 90 beds in size in order to be financially viable.[41]

4.37 Smaller self-contained units within a larger facility were one suggested means of providing high quality care while remaining economically viable.[42] 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.[43]

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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.[44]

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.
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> 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).
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> 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.[45]

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.[46]

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.

> 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.[47]

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.[48]

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.[49]

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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.[50]

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.[51] 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.[52]

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.[53]

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'.[54]

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.[55] 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.[56] 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 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.

are 'still real people behind a bit of fog'.[57] 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.[58]

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 cares, as well as RACF staff.[59]

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.[60]

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.[61]

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.[62]

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.[63]

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.[64]

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.[65] 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].

> 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.[66]

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.[67] 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.[68]

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.
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> …
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> 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.[69]

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.[70]

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'.[71]

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.[72]

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.[73]

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.[74]

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.[75] 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.[76]

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.[77]

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.[78]

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.[79]

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.[80]

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.[81]

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.[82]

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.[83] Some providers reported to the committee success in reducing the incidence of BPSD through improved training and management in a non-dementia specific environment.[84]

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.