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.[1] 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.[2] It is estimated that delaying the entry to residential aged-care saves the government significant amounts of money.[3] 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].[4]

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.[5] 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.[6]

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

---

[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).[7] 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.[8] 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.[9]

3.6 While these packages are targeted at 'frail older people', there is no minimum age limit to access HCPP.[10] 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.[11] 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'.[12]

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.

---

[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.[13]

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

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,[15] 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.[16] HACC services provide access to a broad range of services from domestic assistance to transport, counselling, centre-based care, and respite care.[17] 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.[18]

---

[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.[19]

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.[20] Since 2007, eight organisations have been delivering DBMAS activities in each State and Territory.[21]

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.[22]

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.[23] Illustrating the importance of equipping carers to undertake their

---

[19] Dementia Behaviour Management Advisory Services, *What we do*, 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.[24]

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.[25]

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'.[26] 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'.[27]

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.[28] The committee heard that Massive Open Online Courses[29] for dementia training, which are facilitated by the University of Tasmania, had attracted over 9,000 enrolees.[30] 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.

---

[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.[31]

3.23 Following a referral by a GP, ACAT visits the person in their home and assesses their eligibility for available services.[32]

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.[33]

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

---

[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.[35] 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.[36]

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.[37]

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.[38]

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'.[39]

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

---

[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.

trialling a Younger Onset Dementia Key Worker Program (KWP) which is being implemented by Alzheimer's Australia.[40] 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.[41]

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'.[42] 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'.[43] 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.[44]

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.[45]

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'.[46] 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'.[47]

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:

---

[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.

> 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.[48]

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[49]—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.[50]

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.

---

[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.[51] 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.[52]

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.[53]

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.[54] 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.[55]

---

[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'.[56]

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.[57]

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.[58]

3.48 The limited resources of ACAT affect access to respite care.[59] 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.[60] In crisis

---

[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.[61]

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.[62] 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'.[63] 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.[64]

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 been patients and services available.[65] 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

---

[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.[66]

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.[67]

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.[68] 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.[69]

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

---

[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.[70]

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.[71] 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.[72]

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.[73]

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.[74]

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

---

[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.[75]

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.[76]

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 Respire Care.[77] 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.[78]

---

[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.[79]

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.[80]

3.68 In developing the CHSP, there will also be a large-scale review of the services offered through the program.[81]

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.[82] The committee heard that the stress of providing care can result in the carer themselves being hospitalised.[83] 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.[84]

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.[85] (emphasis added)

---

[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.[86]

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.[87]

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'.[88] 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'.[89] 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'.[90] 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.[91]

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.[92]

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

---

[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.[93]

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.[94]

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.[95] 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.[96] Unfortunately, it was reported that these options are 'thin on the ground and very expensive'.[97] 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.[98]

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

---

[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.[99] 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.[100]

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'.[101] 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.[102] 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.[103]

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.[104]

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

---

[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.[105]

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.[106]

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.[107]

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'.[108] Recognising the importance on maintaining the continuum of care, several stakeholders suggested that greater use of short-stay and day respite should be encouraged.[109] 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

---

[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.

> dementia. We know that the demand for dementia care will increase as the prevalence of dementia increases.[110]

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.[111] 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.[112] 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.[113]

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.[114]

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.[115]

---

[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.[116] 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.[117]

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.[118]

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.[119]

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 suffers 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.

---

[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.

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.[120] Residential care and its related issues is the topic for the next chapter of this report.

---

[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.