

Dementia in Australia – demographics and services

- 2.1 This chapter offers key data on the prevalence of dementia in Australia. It is not a comprehensive account, but simply provides sufficient context to enable consideration of matters raised in later chapters.
- 2.2 The chapter also presents an overview of core government supports and services available to people living with dementia, their families and carers. The chapter concludes by acknowledging the contribution by the non-government sector.
- 2.3 The chapter draws on a range of the available literature, which is vast. Readers interested in a more thorough account should look to the Australian Institute Health Welfare's 2012 publication *Dementia in Australia* which provides a much more comprehensive review of dementia demographics and the delivery of dementia care services.¹

Impact of dementia

- 2.4 Dementia is a leading cause of death in Australia. In 2010 (the most recent year for which the data is available) it was the third most common cause of death (after ischaemic heart disease and cerebrovascular disease), with an average of 25 people dying of it each day.² This accounts for 6 per cent of all deaths.³

1 Australian Government Australian Institute of Health and Welfare (AIHW) 2012, *Dementia in Australia*, catalogue no. 70.

2 Australian Bureau of Statistics (ABS) 2012, *Causes of Death: 2010*, reference number 3303.0, Canberra, p.6.

3 AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 9.

- 2.5 Noting the longer life expectancy of women compared to men, it not surprising that data for 2010 indicates that twice as many women died from dementia. The number of deaths directly due to dementia increased by an order of magnitude: 2.4 times between 2001 and 2010. This was due in part to the ageing of the population, but there were also changes in how dementia is recorded on death certificates which may have increased the figures.⁴
- 2.6 Furthermore, it should be understood that people with dementia also die of other illnesses. Dementia may compound any number of other conditions; thus dementia was recorded as the underlying or an additional cause of 14 per cent of deaths in 2010.⁵
- 2.7 Medical analysts also rely on a concept called 'burden of disease'. The Australian Institute of Health and Welfare (AIHW) states:
- Estimates of burden of disease quantify the amount of healthy life lost due to premature death and prolonged illness or disability. Estimates for 2011 suggest that dementia was the fourth leading cause of overall burden of disease, and the third leading cause of disability burden. For people aged 65 and over, dementia was the second leading cause of overall burden of disease and the leading cause of disability burden, accounting for a sixth of the total disability burden in older Australians.⁶
- 2.8 The severity of the condition varies. Dementia was classified as 'mild' in 163,900 people (55 per cent of people with dementia), 'moderate' in 89,400 people (30 per cent) and 'severe' in 44,700 (15 per cent).⁷
- 2.9 Dementia is also a leading cause of disability and dependency, particularly among older people.⁸
- 2.10 Dementia has wide ranging implications for carers, families and friends of people living with the condition. For these individuals dementia imposes all manner of stresses and costs, including the cost of opportunities foregone and careers, education or retirement neglected.

4 AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 9.

5 AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 9.

6 AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 10.

7 AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 9.

8 World Health Organisation (WHO) and Alzheimer's Disease International (ADI), *Dementia: A Public Health Priority*, 2012.

What is dementia?

- 2.11 Dementia is not a single condition. Rather it is an umbrella term that encompasses a range of conditions that affect memory, thinking, behaviour and ability to perform everyday activities.
- 2.12 Although dementia occurs more commonly in older people, contrary to popular belief it is not an inevitable or 'normal' part of the ageing process. Therefore it is often ignored, rather than viewed as a condition requiring active attention. Furthermore, dementia is not limited to older people. Dementia occurring in people under 65 years is referred to as Younger Onset Dementia (YOD). In 2011, there were an estimated 23,900 Australians under the age of 65 who had dementia, with men accounting for 53 per cent of those diagnosed. Those under 65 represented 8 per cent of all people with dementia in Australia.⁹
- 2.13 Dementia has been broadly described in the following testimony from Alzheimer's Australia (Victoria):
- Dementia describes a collection of symptoms that are caused by disorders affecting the brain. Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person's normal social or working life. Most people with dementia are older, but not all older people get dementia and it is not a normal part of ageing.¹⁰
- 2.14 Dr Fiona Bardenhagen defined dementia as:
- ... a term used to refer to an acquired impairment in memory and cognition. Dementia can take many different forms, can arise from a number of conditions, and while memory impairment is the most common feature, some forms of dementia involve changes in behaviour and language rather than memory in the early stages. As a result, there are a number of different diagnostic criteria for dementia. Some are based on clinical features, and some are based on pathology.¹¹
- 2.15 There are over 100 illnesses and conditions that can result in dementia.¹² The most common types of dementia in Australia are:
- dementia in Alzheimer's disease, estimated to be responsible for around 50–70% of dementia cases, involving abnormal plaques and tangles in the brain;

9 AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 15.

10 Alzheimer's Australia (Victoria), *Submission 35*, p. 2

11 Dr Fiona Bardenhagen, *Submission 46*, p. 1.

12 AIHW 2007, *Dementia in Australia: National data analysis and development*, catalogue no. 53, p.5.

- vascular dementia (formerly known as arteriosclerotic or multi-infarct dementia), resulting from significant brain damage caused by cerebrovascular disease – onset may be sudden, following a stroke, or gradual, following a number of mini-strokes or because of small vessel disease;
- dementia with Lewy bodies, in which abnormal brain cells (Lewy bodies) form in all parts of the brain. Progress of the disease is more rapid than for dementia in Alzheimer’s disease;
- frontotemporal dementia (e.g. Pick’s disease), in which damage starts in the front part of the brain, with personality and behavioural symptoms commonly occurring in the early stages;
- mixed dementia, in which features of more than one type of dementia are present. For example, many people with dementia have features of both Alzheimer’s disease and vascular dementia.¹³

2.16 There are also a number of less common types of dementia, including (but not limited to):

- dementia in Parkinson’s disease, resulting from the loss of the neurotransmitter, dopamine, in the brain (dopamine is implicated in the control of voluntary movements) – dementia is common in people with Parkinson’s but not everyone with Parkinson’s develops dementia;
- alcohol-induced dementia (e.g. Wernicke/Korsakoff syndrome), in which brain function deterioration is associated with excess alcohol consumption, particularly in conjunction with a diet low in Vitamin B1 (thiamine);
- drug-related dementia, where neurological deficits result from substance abuse, such as petrol sniffing;
- head injury dementia, which involves brain damage resulting from head injuries;
- Huntington’s disease, an inherited disorder of the central nervous system, which is characterised by jerking or twisting movements of the body and is usually eventually accompanied by dementia;
- other forms of dementia such as that developing in the course of human immunodeficiency virus (HIV), or Creutzfeldt-Jakob disease;
- reversible forms of dementia, such as dementia from B12 deficiency or hypothyroidism, which, although rare, are important to identify.¹⁴

13 AIHW 2007, *Dementia in Australia: National data analysis and development*, catalogue no. 53, pp. 5–6.

14 AIHW 2007, *Dementia in Australia: National data analysis and development*, catalogue no. 53, p. 6.

- 2.17 Conditions causing dementia are typically progressive, degenerative and irreversible.¹⁵

Signs and symptoms of dementia

- 2.18 The common characteristics of dementia involve impairment of brain functions, including speech, memory, perception, personality and cognitive skills. Onset is typically gradual, progressive (in that as the condition develops, the patient deteriorates, and does not improve) and irreversible.¹⁶
- 2.19 In the early stages of dementia, individuals may experience difficulty with familiar tasks such as shopping, driving or handling money. As the disease progresses, more basic or core activities of daily living such as self-care (e.g. eating, bathing, dressing, reading, using numbers) may be affected. In some cases dementia results in the affected individual displaying uncharacteristic behaviours (e.g. agitation, apathy or aggression).¹⁷
- 2.20 The specific cognitive, psychiatric and behavioural manifestations of dementia may include:
- memory problems, especially for recent events (long-term memory usually remains in the early stages);
 - communication difficulties through problems with speech and understanding language;
 - confusion, wandering, getting lost;
 - personality changes and behaviour changes such as agitation, repetition, following; and
 - depression, delusions, apathy and withdrawal.¹⁸
- 2.21 For the majority of people with dementia, assistance will eventually be required for activities such as making decisions, managing relationships, coping with feelings or emotions, and undertaking cognitive or emotional tasks.¹⁹ As the condition progresses, people with dementia become increasingly dependent on their care providers in most or all areas of daily living. The AIHW reports that:

Among the older population, dementia is more likely than other health conditions to be associated with a severe or profound

15 Access Economics 2009, *Keeping dementia front of mind: incidence and prevalence 2009-2050*, p.2.

16 AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 2.

17 AIHW 2007, *Dementia in Australia: National data analysis and development*, catalogue no. 53, p. xiii-xiv.

18 AIHW 2007, *Dementia in Australia: National data analysis and development*, catalogue no. 53, p. 5.

19 AIHW 2007, *Dementia in Australia: National data analysis and development*, catalogue no. 53, p. xiii-xiv.

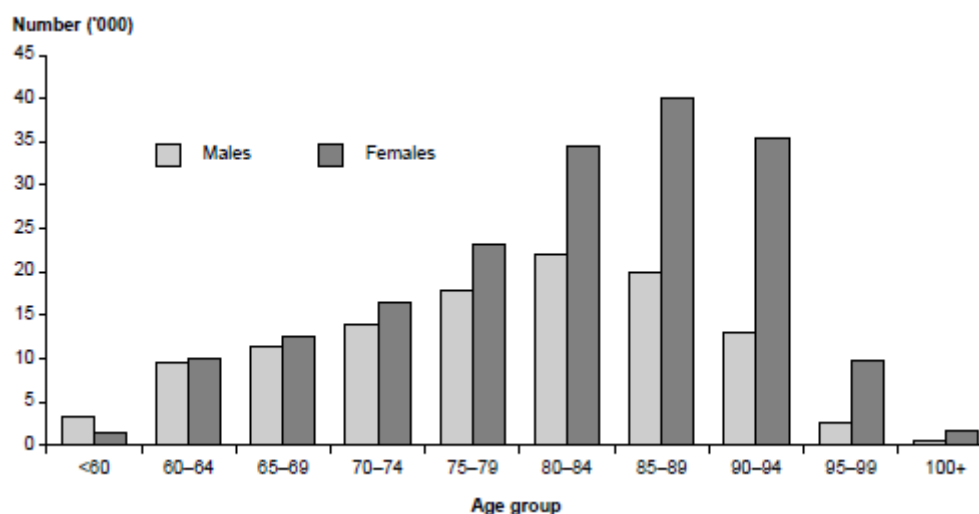
limitation in self-care, mobility or communication, to be a main disabling condition and to be associated with multiple health conditions.²⁰

Prevalence of dementia

2.22 In 2011, there were an estimated 298,000 people with dementia, of whom 62 per cent were women and 70 per cent lived in the community. Among Australians aged 65 and over, almost 1 in 10 (9 per cent) had dementia, and among those aged 85 and over, 3 in 10 (30 per cent) had dementia. There were also an estimated 23,900 Australians under the age of 65 with dementia.²¹

2.23 Old age is the greatest risk factor for dementia. After the age of 65, the likelihood of being diagnosed with dementia doubles every five years.²² This is indicated by dementia prevalence rates, in which dementia prevalence is relatively low until the age of 70 years, after which prevalence rates increase exponentially.²³ Besides age-related risk, dementia prevalence rates also suggest that females are at greater risk of developing dementia than males, particularly at older ages (Figure 2.1).²⁴

Figure 2.1 Estimated number of people with dementia, by age and sex, 2011



Source Australian Institute of Health and Welfare (AIHW); *Dementia in Australia*, catalogue No. AGE 70, 2012, p. 15.

20 AIHW 2007, *Dementia in Australia: National data analysis and development*, catalogue no. 53, p. xiii–xiv.

21 AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 11.

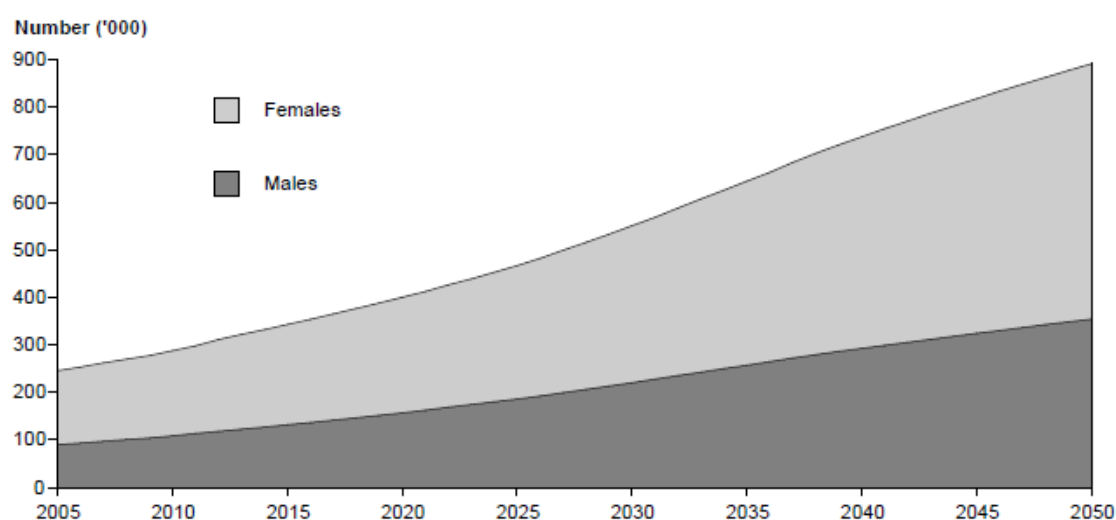
22 Access Economics 2009, *Keeping dementia front of mind: incidence and prevalence 2009–2050*, p. 4.

23 Deloitte Access Economics 2011, *Dementia across Australia: 2011–2050*, p.14.

24 Access Economics 2009, *Keeping dementia front of mind: incidence and prevalence 2009–2050*, p. iv.

- 2.24 The most recent figures from the Australian Bureau of Statistics (ABS) indicate that deaths due to dementia and Alzheimer's disease have more than doubled in the period 2001 to 2010, rising from 2.2 per cent to 6.3 per cent of all deaths.²⁵ Dementia and Alzheimer's disease are now the third leading cause of death overall. When assessed by gender, dementia and Alzheimer's disease are the third leading cause of death amongst females, compared to sixth for males.²⁶
- 2.25 The prevalence of dementia in Australia is projected to triple to around 900,000 Australians by 2050 (Figure 2.2). The projected tripling will coincide with a doubling of the population aged over 65 years. The largest growth in prevalence is expected to occur in the decade leading up to 2020 which coincides with the 'baby boomer' generations moving into the older age groups, which have a higher risk of dementia. By 2050, it is expected that women will continue to account for around 60 per cent of people living with dementia.²⁷

Figure 2.2 Estimated number of people with dementia, by sex, 2005-2050



Source Australian Institute of Health and Welfare (AIHW); *Dementia in Australia*, catalogue No. AGE 70, 2012, p. 18.

- 2.26 Rates of dementia are higher for Indigenous people than other Australians. In Indigenous communities of Australia, particularly in the Northern Territory and Western Australia, the prevalence of dementia is at least five times that of the general population. The rate of dementia is 26

25 ABS 2012, *Causes of death 2010*, catalogue no. 3303.0, Canberra, p.6.

26 ABS 2012, *Causes of death 2010*, catalogue no. 3303.0, Canberra, pp. 7-8.

27 AIHW 2012, *Dementia in Australia*. catalogue no. 70, p. 11.

times higher in the 45 to 69-year-old age group and about 20 times higher in the 60 to 69-year-old age group.²⁸

Data limitations

2.27 Whilst estimates of dementia prevalence can provide some indication of the extent of the condition, there are limitations on how the data is interpreted. For example, as the World Health Organization (WHO) has observed:

The way in which the diagnosis of dementia is defined and applied may be among the most important sources of variability [amongst data].²⁹

2.28 In relation to projections for the prevalence of dementia in Australia, the AIHW cautions:

Changes in risk factors and in the prevention, management and treatment of the condition may affect the accuracy of these estimates. For example, improved medical and social care might increase prevalence by allowing more people to survive longer with dementia The estimates are also sensitive to deviations from projected changes in the age-sex structure or total size of the projected populations. Therefore, these estimates (especially those further into the future) should be interpreted with caution.³⁰

2.29 With regard specifically to estimates of prevalence in Indigenous communities, the AIHW states:

Due to the lack of national data on the prevalence of dementia among Indigenous Australians, most information is drawn from a small number of localised, largely community-based studies.³¹

Ageing Australia and demand for services

2.30 In 2010 the Productivity Commission published its report on *Caring For Older Australians*. Key findings from the report relating to projected future demands for aged care services include the following:

- The number of people aged 85 and over is projected to more than quadruple (from 0.4 million to 1.8 million) between 2010 and 2050. This

28 Mr Brian Gleeson, Office of the Coordinator General for Remote Indigenous Services, *Official Committee Hansard*, 8 February 2013, p. 1.

29 WHO 2012, *Dementia: A Public Health Priority*, p. 31.

30 AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 19.

31 AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 38.

is expected to drive a major increase in the demand for aged care services over the next 40 years.³²

- The people demanding care services will be increasingly diverse, with a relative rise in proportion of older people who are culturally and linguistically diverse, Aboriginal and Torres Strait Islander people and living in regional and rural areas.³³
- There is already a growing demand by consumers for higher quality services, as well as a growing demand for control and choice, since many older people want to age in their own home, while the relative availability of family and informal carers is expected to decline. This decline is expected to add to the demand for residential aged care.³⁴
- Developments in information and assistive technology have the effect of enhancing the ability of people to meet their own needs for longer.
- Adjusting policy settings in areas such as the provision of alternatives to hospitalisation for frail older people who do not have acute care needs is important.³⁵

Dementia services and supports

2.31 The Australian health system is complex. Dementia services are delivered within the well-established institutional and professional context of the health care system, and the closely related aged care system. While these systems are used by people with dementia, the systems deal with a diverse range of morbidities and ageing in general.

2.32 Responsibility for funding and provision of services is shared across all levels of government and the private sector. In broad terms, the Australian Government sets national policy and contributes to health funding, primarily through Medicare, the Pharmaceutical Benefits Scheme and Private Health Insurance rebates. The Australian Government also funds some services directly and provides payments to state and territory governments for the delivery of other services.

32 Productivity Commission Inquiry Report, *Caring For Older Australians*, No. 53 June 2010, 'Drivers for future demand', volume 1, p. 37.

33 Productivity Commission Inquiry Report, *Caring For Older Australians*, No. 53 June 2010, 'Drivers for future demand', volume 1, p. 37.

34 Productivity Commission Inquiry Report, *Caring For Older Australians*, No. 53 June 2010, 'Drivers for future demand', volume 1, p. 37.

35 Productivity Commission Inquiry Report, *Caring For Older Australians*, No. 53 June 2010, 'Drivers for future demand', volume 1, p. 37.

- 2.33 State and territory governments are also responsible for the funding and delivery of public health services through hospitals and a range of community settings. Private sector involvement in primary care and the delivery of community services also adds to the complexity.

Medicare and the Pharmaceutical Benefits Scheme

- 2.34 As noted above the Australian Government is responsible for two significant national health subsidy schemes:
- Medicare; and
 - the Pharmaceutical Benefits Scheme (PBS).
- 2.35 Dementia-focussed medical services increasingly concentrate on prevention. Medicare provides a new item for general practitioners, the 45–49 year old health check, which is available to all general practitioners whose patients are identified as at risk for a chronic disease. This complements Medicare items for comprehensive annual health assessments for those 75 years of age and over (and for Indigenous Australians 55 years of age and over).³⁶
- 2.36 Some patients with mild to moderate Alzheimer’s disease are eligible for a six month supply of subsidised cholinesterase inhibitors (i.e. donepezil hydrochloride, galantamine hydrobromide and rivastigmine hydrogentartrate) under the PBS.³⁷ For access beyond six months, there must be evidence of clinical improvement.³⁸ Memantine hydrochloride is another dementia specific drug available under the PBS for people with more severe Alzheimer’s.³⁹
- 2.37 The anti-psychotic medication risperidone is also available under the PBS for ‘behavioural disturbances characterised by psychotic symptoms and aggression in patients with dementia where non-pharmacological methods have been unsuccessful’.⁴⁰

Primary care and acute care services

- 2.38 Primary care providers, most notably general practitioners, play a key role in the initial identification and management of dementia. A survey of
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36 Brodaty and Cummings, *Dementia Services in Australia*, International Journal of Geriatric Psychiatry, 2010, 25: 887-895, p. 889. See also: DoHA, *Submission 89*, pp. 7-8.

37 Brodaty and Cummings, *Dementia Services in Australia*, International Journal of Geriatric Psychiatry, 2010; 25: 887–895, p. 889.

38 Brodaty and Cummings, *Dementia Services in Australia*, International Journal of Geriatric Psychiatry, 2010; 25: 887–895, p. 889.

39 AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 81.

40 Brodaty and Cummings, *Dementia Services in Australia*, International Journal of Geriatric Psychiatry, 2010; 25: 887–895, p. 889.

carers for people with dementia suggests that over 80 per cent of GPs were the first health professionals approached when the symptoms of dementia emerged.⁴¹ Recognising the vital role for primary care providers, the 2012 *Living Longer. Living Better.* package has provided additional support for educating and training primary health care providers to diagnose dementia in a more timely manner.⁴²

- 2.39 People with dementia are also over represented in the acute care setting. Dementia was the principal diagnosis in 21 per cent of those aged over 75 years who were hospitalised. This figure increases to 36 per cent for people aged over 85 years.⁴³ The *Living Longer. Living Better.* package provides additional funding to improve hospital services for people with dementia. Funding will be used to help staff in the acute care setting to identify the signs of dementia and apply appropriate protocol.⁴⁴

Community aged care services

- 2.40 There are a number of community care services available to help older people to manage daily activities and remain living in their own homes. Services provided may be general or dementia specific.⁴⁵
- 2.41 The Aged Care Assessment Program (ACAP) provides assessments of older people to ensure that they access the most appropriate types of care to meet their specific needs. Assessment is conducted by Aged Care Assessment Teams (ACATs). As explained by the Australian Government Department of Health and Ageing (DoHA):
- The role of ACATs is to determine the overall care needs of frail older people and to assist them to gain access to the most appropriate types of care services. In doing this, ACATs comprehensively assess older people taking account of the restorative, physical, medical, psychological, cultural and social dimensions of their care needs.
- This includes determining whether a person has dementia or other cognitive conditions, or behavioural problems related to these or other conditions and/or the presence of depression or delirium.⁴⁶
- 2.42 The outcome of the ACAT assessment determines eligibility for a range of government subsidised aged care services including:

41 AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 63.

42 Australian Government, *Living Longer. Living Better.*, April 2012, p. 22.

43 AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 70.

44 Australian Government, *Living Longer. Living Better.*, April 2012, p. 24.

45 For discussion regarding Community Care Packages, see Life Care, *Submission 29*.

46 Department of Health and Ageing (DoHA), *Submission 89*, p. 9.

- Home and Community Care (HACC);
 - Community Aged Care Packages (CACPs);
 - Extended Aged Care in the Home packages (EACH);
 - Extended Aged Care in the Home Dementia packages (EACHD); and
 - Access to Residential Aged Care Facilities (RACF).
- 2.43 These services offer different levels of assistance ranging from low-level care provided to people in their own homes through HACC or the CACP program, to more intensive home-based care through the EACH and EACHD packages, through to residential care in aged care facilities.
- 2.44 From 1 July 2013, subject to legislative reform, there will be four levels of Home Care Packages, to allow a seamless continuum of care at home and catering to the full spectrum of care needs. These reforms were summarised by DoHA as follows:
- Level 1 – a new package to support people with basic care needs;
 - Level 2 – a package to support people with low level care needs, similar to the existing CACP;
 - Level 3 – a new package to support people with intermediate care needs; and
 - Level 4 – a package to support people with high level care needs, similar to the existing EACH package.
- It will no longer be necessary to have a separate EACHD level, as a new Dementia Supplement will be available to all consumers who meet the eligibility criteria for the Dementia Supplement (across any of the four levels of Home Care Packages).⁴⁷
- 2.45 From July 2015, the Australian Government will establish the national Commonwealth Home Support Program. The CHSP will combine under the one program all the services currently providing basic home support, including the HACC services for older people and services provided under the NRCP.⁴⁸
- 2.46 Culturally appropriate aged care services are also available for Indigenous Australians under the National Aboriginal and Torres Strait Islander Flexible Aged Care Program.

47 DoHA, *Living Longer. Living Better.*, 'Home Care Packages Program', <<http://www.livinglongerlivingbetter.gov.au/internet/living/publishing.nsf/Content/Consumer-Directed-Care-Home-Care-Packages>> viewed 12 June 2013.

48 Australian Government, *Living Longer. Living Better.* April 2012, p. 3.

2.47 Veterans, war widows and widowers can also access home assistance through the Veterans' Home Care program provided through the Department of Veterans' Affairs.⁴⁹

Home and Community Care

2.48 The HACC program is the largest national community care program providing support for frail older people in Australia. Since 2012 the Australian Government has taken full funding, policy and operational responsibility for HACC services for older people in all states and territories (except Victoria and Western Australia).⁵⁰

2.49 Commonwealth HACC services are available to:

- People aged 65 years and over (or 50 and over for Aboriginal and Torres Strait Islander people) in all states and territories (except Victoria and Western Australia);
- People who are at risk of premature or inappropriate admission to long term residential care; and
- Carers of older Australians eligible for services under the Commonwealth HACC Program.⁵¹

2.50 The range of services available under HACC include:

- Clinical care (e.g. nursing care and allied health services);
- Domestic assistance (e.g. cleaning, washing, shopping, food preparation);
- Personal care (e.g. bathing, dressing, grooming and eating);
- Social support;
- Home maintenance and modifications;
- Transport;
- Assessment, client care coordination and case management;
- Counselling, information and advocacy services;
- Centre-based day care; and
- Support for carers including respite services.⁵²

49 For further information on dementia-related programs for veterans, see Department of Veterans' Affairs, *Submission 90*.

50 In Victoria and Western Australia the state governments continue to deliver services for older people under joint funding arrangements with the Australian Government. HACC services for younger people with disabilities continue to be the responsibility of state and territory governments.

51 DoHA, *Living Longer. Living Better.*, 'Commonwealth HACC Program', <<http://www.health.gov.au/internet/main/publishing.nsf/Content/hacc-index.htm>> viewed 6 June 2013.

Community Aged Care Packages

- 2.51 Community aged care packages (CACP) are designed to provide flexible support which is tailored to individual needs. The CACPs target older people living in the community with care needs equivalent to at least low-level residential aged care. The types of services available through CACPs include:
- Help with personal care;
 - Meals;
 - Domestic assistance; and
 - Transport.
- 2.52 Extended Aged Care at Home (EACH) packages target older people living at home with care needs equivalent to high-level residential aged care. EACH packages generally include qualified nursing input, particularly in the design and ongoing management of the package. Services available through EACH include:
- Clinical care;
 - Help with personal care;
 - Meals;
 - Domestic assistance;
 - Assistance to access leisure activities;
 - Emotional support;
 - Therapy services; and
 - Home safety and modification.⁵³
- 2.53 Similar to the EACH packages, Extended Aged Care at Home Dementia (EACHD) packages offer a range of services that are tailored specifically to meet the needs of older Australians with behavioural concerns or psychological symptoms associated with dementia. The criteria for obtaining a package are that the applicant:
- Is experiencing behaviours and psychological symptoms associated with dementia that is significantly impacting upon their ability to live independently in the community;
 - Requires a high level of residential care;

52 DoHA, *Living Longer. Living Better.*, 'Commonwealth HACC Program', <<http://www.health.gov.au/internet/main/publishing.nsf/Content/hacc-index.htm>> viewed 6 June 2013.

53 DoHA, *Living Longer. Living Better.*, 'Home-based care', <<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-commcare-comcprov-eachdex.htm>> viewed 6 June 2013

- Prefers to receive an EACHD package; and
 - Would be able to live at home with the support of an EACHD package.⁵⁴
- 2.54 The packages provide a range of services including:
- Clinical care (e.g. nursing care and allied health services);
 - Personal care;
 - Transport to appointments;
 - Social support;
 - Home help; and
 - Assistance with oxygen and/or enteral feeding.⁵⁵
- 2.55 A new Dementia Supplement of 10 per cent on top of base level funding for home care packages is included under the *Living Longer. Living Better.* package.⁵⁶
- 2.56 Indigenous Australians may be able to access a range of residential and community care services available through the National Aboriginal and Torres Strait Islander Flexible Aged Care Program. The aim of the program is provide quality, flexible and culturally appropriate aged care for older Indigenous Australians. The *Living Longer. Living Better.* package provides additional funding to support more aged care places under this program.⁵⁷
- 2.57 The Veterans' Home Care (VHC) program aims to assist veterans and war widows and widowers who wish to continue living independently in their own home and local community by providing low level home care services. The range of services include:
- Domestic assistance;
 - Personal care;
 - Safety-related home and garden maintenance; and
 - Respite care for carers who have responsibility for a person who requires ongoing care, attention or support.⁵⁸

54 DoHA, *Living Longer. Living Better.*, 'Home-based care', <<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-commcare-eachd.htm>> viewed 6 June 2013.

55 DoHA, *Living Longer. Living Better.*, 'Home-based care', <<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-commcare-eachd.htm-copy3>> viewed 6 June 2013.

56 Australian Government, *Living Longer. Living Better.*, April 2012, p. 23.

57 Australian Government, *Living Longer. Living Better.*, April 2012, p. 26.

58 Department of Veterans Affairs, Fact sheets, <<http://factsheets.dva.gov.au/factsheets/>> viewed 6 June 2013.

Respite services

2.58 Support for families and carers is essential if people with dementia are to be supported to live in their own homes for as long as possible.⁵⁹ As outlined by the AIHW in its *Dementia in Australia* report:

Respite care offers support to older people and their carers who may need a break or who require some extra care for a short period (such as during, or while recovering from, illness). Care may be provided for a few hours on a one-off or regular basis, for a couple of days or for a few weeks. Respite can occur in a variety of settings, including homes, centres, residential aged care services and other locations, with care provided by volunteers and/or paid respite workers. Respite is especially important for people caring for someone with dementia ... the demands of the caring role may involve the provision of substantial amounts of physical, psychological, cognitive and social support, while behaviour changes may add to the complexity of caring.⁶⁰

2.59 The Australian Government funds the National Respite for Carers Program (NRCP) which targets carers of four groups: frail older people, younger people with disabilities, people with dementia, and people with dementia who have 'changed behaviours'.⁶¹

2.60 The program provides direct respite care in a number of settings, including day respite in community settings, in the home and in respite 'cottages' (but not in residential aged care facilities). Indirect respite care, such as domestic assistance, social support and personal care for the care recipient, is also provided by the NRCP. An ACAT assessment is not required to access the NRCP, but the program has assessment procedures focussing on the needs of the carers and the people for whom they care.⁶²

Residential aged care services

2.61 The Australian Government provides funds to support aged care facilities for older Australians whose needs are such that they are no longer able to remain in their own homes. Eligibility for publicly funded residential care places is typically determined by an ACAT assessment.

2.62 Residential care varies in the type of accommodation and the level of support for residents. It may be available on a permanent basis or simply

59 See for example, Life Care, *Submission 29*; East Lake Macquarie Dementia Service Inc, *Submission 99*.

60 AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 111.

61 AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 112.

62 AIHW 2012, *Dementia in Australia*, catalogue no. 70, p. 112.

used for respite care as required. Typically, residential care in Australia is described as either low level or high level care.

- 2.63 Low level care facilities may assist residents with the basic activities of daily living such as dressing, eating and bathing, as well as support services such as cleaning, laundry and meals. They may offer some allied health services, such as physiotherapy. Nursing care can be given when required.
- 2.64 High level care provides people who need almost complete assistance with most activities of daily living with 24 hour care, either by registered nurses, or under the supervision of registered nurses. Nursing care is combined with accommodation, support services, personal care services and allied health services.⁶³
- 2.65 Significant reforms to residential aged care are proposed under the *Living Longer. Living Better.* package, including:
- More residential facilities being built,
 - Supporting the viability of services in regional, rural and remote areas,
 - Trialling Consumer Directed Care in residential aged care,
 - Strengthening means testing for residential care by combining the current income and asset tests,
 - Establishing a new Aged Care Financing Authority, and
 - Improving the Aged Care Funding Instrument.⁶⁴

Dementia Behaviour Management Advisory Services

2.66 The Dementia Behaviour Management Advisory Services (DBMAS) initiative commenced in 2007. Its main purpose is to provide support to those who provide care for people with dementia associated behavioural and psychological problems. This is achieved by improving the dementia care capacity of care workers, family carers and service providers. DBMAS services include:

- Assessment of the person with dementia;
- Provision of clinical support, information and advice;
- Care planning, case conferences and short term case management;
- Mentoring and clinical supervision; and

63 DoHA, *Aged Care Australia*, <<http://www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/Content/Types%20of%20care>> viewed 7 June 2013.

64 DoHA, *Living Longer. Living Better.*, 'Residential Care', <<http://www.livinglongerlivingbetter.gov.au/internet/living/publishing.nsf/Content/Residential-care#5>> viewed 12 June 2013.

- Education and training.⁶⁵

2.67 Under the *Living Longer. Living Better.* package additional funding has been provided to extend DBMAS into acute and primary care settings.⁶⁶

National Dementia Support Program

2.68 The National Dementia Support Program (NDSP) was established in 2005 under the Dementia Initiative (*Making Dementia a National Health Priority*) to provide and promote education programs, services and resources that:

- Improve awareness and understanding about dementia and the services available to people living with dementia, their carers, families, service providers and health professionals; and
- Increase the skills and confidence of people living with dementia, their carers, families, health professionals, volunteers and community contacts.⁶⁷

State/territory governments and the non-government sector

2.69 As noted earlier in the chapter, funding and provision of services for people living with dementia and their families/carers is shared across all levels of government and the private sector.

2.70 While drawing on health and aged care funding from the Australian Government, state and territory governments manage services delivered through public hospitals and fund a range of community health services. In addition many localised and community based services for dementia patients are delivered directly by the state and territory governments, or by subcontracted non-government agencies.

2.71 The contribution of non-government agencies to the aged care sector, and to the provision of services for people with dementia and their families is diverse. While some are focused on representation, support and advocacy (e.g. Carers Australia and the Consumers Health Forum of Australia), others deliver services directly those living with dementia or those caring for them (e.g. Brotherhood of St Laurence and Baptcare), while yet others do both (Alzheimer's Australia).

2.72 For example, organisations typically provide supports and services for people with dementia and their families/carers, including:

65 Australian Government DBMAS, <<http://dbmas.org.au/>> viewed 6 June 2013.

66 Australian Government, *Living Longer. Living Better.* April 2012, p. 23.

67 DOHA, *Dementia*, <<http://www.health.gov.au/internet/main/publishing.nsf/Content/dementia-support#National%20Dementia%20Support>> viewed 6 June 2013.

- Advocacy;
- Information and referral services;
- Counselling;
- Support groups;
- Recreational and social activities;
- Education; and
- Care services, such as respite and residential care.

2.73 It is beyond the scope of the report to provide a comprehensive and detailed description of the full range of services and supports available. However, while many non-government organisations rely heavily on funding from public sources in order to provide these supports and services, it is equally the case that without the valuable contribution of the private sector governments would struggle to meet demand. The ensuing synthesis between the public and private sectors can be complex, but administrators in both sectors work to ensure that the system operates effectively.

