



Royal Commission
into Aged Care Quality and Safety

DEMENTIA IN AUSTRALIA: NATURE, PREVALENCE AND CARE

BACKGROUND PAPER 3

MAY 2019

The Royal Commission into Aged Care Quality and Safety was established on 8 October 2018 by the Governor-General of the Commonwealth of Australia, His Excellency General the Honourable Sir Peter Cosgrove AK MC (Retd). Replacement Letters Patent were issued on 6 December 2018.

The Honourable Richard Tracey AM RFD QC and Ms Lynelle Briggs AO have been appointed as Royal Commissioners. They are required to provide an interim report by 31 October 2019, and a final report by 30 April 2020.

The Royal Commission intends to release consultation, research and background papers. This background paper has been prepared by staff of the Office of the Royal Commission, for the information of Commissioners and the public. The views expressed in this paper are not necessarily the views of the Commissioners.

This paper was published on 3 May 2019.

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ISBN 978-1-920838-74-4 (online)

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Introduction

This paper provides a high-level introduction to dementia, including its nature, prevalence in Australia, and research about how to best care for people living with dementia. It has been prepared by staff of the Office of the Royal Commission into Aged Care Quality and Safety but does not represent a direction or position of the Royal Commission in relation to these areas. Any views expressed are not necessarily the views of the Commissioners.

Dementia is a complex and broad set of conditions which can have a devastating impact on people's lives—those living with dementia, their families, close friends and carers. It is significant in Australia's health and aged care systems, with dementia contributing to approximately 15.8% of all deaths in 2015¹, and over half (52%) of people living in residential aged care in 2016, having a diagnosis of dementia.²

People living with dementia will have different experiences of care, from the time of diagnosis and living at home, to care in residential aged care, and palliative and end-of-life support. Improving dementia care drives research into prevention, assessment and diagnosis, intervention and treatment, living with dementia, and models of care. However, there are challenges in conducting research with vulnerable people that may impact on research conclusions. With the exception of pharmacological treatments, much of the evidence and many of the recommendations about dementia care come from single studies or consensus, based on expert opinion.³

There is some research-based evidence for interventions (i.e. changes or modifications to current practices or the introduction of new practices) to:⁴

- prevent and detect dementia;
- support early diagnosis;
- manage cognitive and behavioural and psychological symptoms through the use of medicines and other structured interventions, such as music;
- support families and carers;
- improve the quality of living and dying for people with dementia.

¹ Australian Bureau of Statistics, *Dementia and Death in Australia, 2015*, (Catalogue 3303.0), viewed 24 April 2019, <https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2015~Main%20Features~Dementia~10002>.

² Australian Institute of Health and Welfare. *Australia's Welfare 2017: In Brief*, 2017, p 182.

³ Guideline Adaptation Committee, *Clinical Practice Guidelines and Principles of Care for People with Dementia*, Sydney Guideline Adaptation Committee, 2016.

⁴ G Livingston, A Sommerlad, V Orgeta, S G Costafreda, J Huntley, D Ames, C Ballard, S Banerjee, A Burns, J Cohen-Mansfield, C Cooper, N Fox, L Gitlin, R Howard, H Kales, E Larson, K Ritchie, K Rockwood, E Sampson, Q Samus, L Schneider, G Selbæk G, L Teri, and N Mukadam, 'Dementia prevention, intervention, and care' (2017) 390 *Lancet* 2673–2734. doi:10.1016/S0140–6736(17)31363–6.

There are also research findings to support the quality of life and quality care for people living with dementia through positive relationships, social engagement and providing functional ability interventions.⁵ This includes support for small domestic models of care.⁶

This paper has been informed by rapid review and narrative analysis of published systematic research reviews, non-peer reviewed publications, and select single studies sourced from a global policy forum, an Australian peak organisation on dementia, and Australian dementia and cognitive research collaborations.

The paper does not address population diversity, innovations, clinical guidelines,⁷ or models of care in detail. While the needs of families, friends and others who provide informal care to the person living with dementia are acknowledged throughout, they too are not specifically examined. The employment, education, training and regulation of the dementia workforce is also not examined here.

What is dementia?

Dementia is an umbrella term which describes symptoms associated with a group of major neurocognitive conditions or disorders of the brain. It is characterised in medicine as a diagnosable, abnormal condition with organic causes and progressive stages. It results in deterioration in memory, thinking, behaviour, communication and the ability to perform day-to-day activities.⁸ Dementia is not a normal part of the ageing process.⁹

There are several medical definitions for dementia¹⁰, including the International Classification of Diseases (ICD), which defines it as:

a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capability, language, and judgement.¹¹

There is uncertainty about the number of people living with dementia in Australia. The Australian Institute of Health and Welfare acknowledges that there is no national data on the number of people in Australia affected by dementia. It estimated the number at 376,300 in 2018.¹²

⁵ A Martyr, S Nelis, C Quinn and Y T Wu, 'Living well with dementia: a systematic review and correlational meta-analysis of factors associated with quality of life, well-being and life satisfaction in people with dementia' (2018) 48(3) *Psychological Medicine* 2130–2139. <https://doi.org/10.1017/S0033291718000405>.

⁶ E S Gnanamanickam, S M Dyer, R Milte, E Liu, J Ratcliffe and M Crotty, 'Clustered domestic model of residential care is associated with better consumer rated quality of care' (2018) *International Journal for Quality in Health Care* 1–7. doi: 10.1093/intqhc/mzy181. S M Dyer, E Liu, E S Gnanamanickam, R Milte, T Easton, S L Harrison, C E Bradley, J Ratcliffe and M Crotty 'Clustered domestic residential aged care in Australia: fewer hospitalisations and better quality of life' (2018) 208(10) *The Medical journal of Australia* 433–438. doi: 10.5694/mja17.00861.

⁷ Guideline Adaption Committee, above n 3.

⁸ Department of Health, *National Framework for Action on Dementia 2015–2019*.

⁹ World Health Organisation, Dementia Key Facts, 2017, viewed 24 April 2019, <https://www.who.int/news-room/fact-sheets/detail/dementia>.

¹⁰ See ICD-10 and DSM-5.

¹¹ ICD-10, Organic, including symptomatic, mental disorders (F00-F09), viewed 24 April 2019, <https://icd.who.int/browse10/2016/en#/F00-F09>.

¹² Australian Institute of Health and Welfare, *Australia's health 2018*, 2018, Chapter 3.14.

Age is the strongest known non-modifiable risk factor¹³ for dementia with the majority of people developing dementia aged 65 years or more. Dementia also affects people under the age of 65 years and this is commonly referred to as ‘younger onset dementia’. The characteristics of younger onset dementia are distinct and thought to require different interventions and services.¹⁴ For example, younger people with dementia are generally stronger and fitter, may still be working and have dependent families.

There are about 100 conditions or disorders that cause the symptoms of dementia.¹⁵ Table 1 shows the most common of these as Alzheimer’s disease, vascular dementia, frontotemporal dementia, and dementia with Lewy bodies.

Table 1: Most common types of dementia, with prevalence and characteristics

Most common types of dementia	Prevalence	Distinguishing characteristics
Alzheimer’s disease	50–75%	A physical brain disease characterised by progressive degeneration of brain cells. Early stages include short term memory loss, apathy and depressive symptoms. Later stages may include behavioural and psychological symptoms.
Vascular (multi-infarct) dementia	20–30%	Associated with problems with blood circulation to the brain (stroke). Onset can be sudden with less predictable progression. Memory loss may not be as significant as for Alzheimer’s disease.
Frontotemporal dementia	5–10%	More common in males and younger onset dementia. Characterised by early signs of changes in personality, mood, disinhibition and language.
Dementia with Lewy bodies	5%	Associated with the development of abnormal cells in the brain. Characterised by fluctuating cognition, visual hallucinations, tremor, and rigidity. Progression may be more rapid than Alzheimer’s disease.

Source: prevalence figures drawn from: Australian Institute of Health and Welfare, *Dementia in Australia*, Cat. No. AGE 70, 2012, p 2.

Since the 1980s, dementia has been recognised as more than a medical diagnosis, particularly for the people who live with it, their families, close friends and those who care for them. More recently, critical social gerontology has further critiqued biomedical approaches to dementia, proposing that it be understood through a social model of disability.¹⁶ The social approach to understanding dementia reframes it from a medical diagnosis to part of living

¹³ A ‘non-modifiable risk factor’ is a risk factor that cannot be changed.

¹⁴ Organisation for Economic Cooperation and Development Health Policy Studies, *Care Needed: Improving the Lives of People with Dementia*, OECD Health Policy Studies, 2018, Paris. <http://dx.doi.org/10.1787/9789264085107-en> p 29.

¹⁵ Dementia Australia, *Types of Dementia*, viewed 24 April 2019, <https://www.dementia.org.au/information/about-dementia/types-of-dementia>.

¹⁶ A Innes and J Manthorpe, ‘Developing theoretical understandings of dementia and their application to dementia care policy in the UK’ (2012) 12(6) *Dementia* 682–696. doi: 10.1177/1471301212442583.

D Gove, J Andrews, A Capstick, C Geoghegan, J Georges, S Libert, G McGettrick, H Rochford-Brennan, H Rohra, S Vehmas and T Williamson, ‘Dementia as a disability: Implications for ethics, policy and practice. Ethical Discussion Paper’ (2017), viewed 24 April 2019, <https://www.alzheimer-europe.org/Ethics/Ethical-issues-in-practice/2017-Dementia-as-a-disability-Implications-for-ethics-policy-and-practice>.

and ageing successfully. This approach places a greater focus on the potential for adaptability, reablement, rehabilitation and restorative care to maximise the quality of life for the person with dementia.¹⁷ The evidence source for these approaches and models are the experiences of people.¹⁸

In 2012, dementia was added to the list of Australian national health priority areas; focused on understanding and measuring the impact of disease on the population.¹⁹ Since 2015, the Australia Coding Standard has required that dementia be recorded in hospital records if it is present on the person's admission, regardless of whether it was the reason for admission or required treatment.²⁰

What triggers the need for care for people with dementia?

A number of factors influence the experience of living with dementia. These include the progressive nature of the conditions that cause dementia, the facts that people respond individually to all stages of their disease, have varied access to quality support and care at home, in the community and in health and aged care facilities, and may have needs that require more intensive care, for example in the advanced and end-of-life stages of dementia.

People living with dementia may experience changes in:

- cognition, such as memory, language and reasoning;
- the ability to perform activities of living, such as mobility, hygiene, and nutrition (often referred to as ADLs);
- behavioural and psychological symptoms, such as depression, anxiety, agitation and apathy (often referred to as BPSD).²¹

Table 1 summarised some of the key characteristics of the most common types of dementia and signalled some of the care needs that may need to be met by family members, close friends, and the health and aged care systems.

Recent analysis of population level data shows that of the 180,417 people living in Australian aged care facilities in 2017–18, those with dementia had higher cognition and behaviour care needs (81%), and higher activities of daily living needs (64%) than those who did not have dementia (46% and 53% respectively).²²

¹⁷ S Górska, K Forsyth and D Maciver. Living with Dementia: A Meta-synthesis of Qualitative Research on the Lived Experience *Gerontologist*. (2018) May, 58(3): e180–e196. doi: 10.1093/geront/gnw195.

C Poulosa, A Bayerc, L Beaupred, L Claree, R Poulos, R Wang, S Zuidemag, K McGilton K. A comprehensive approach to reablement in dementia *Alzheimer's & Dementia (2017) Translational Research & Clinical Interventions*, 3 450–458.

¹⁸ S Górska, K Forsyth and D Maciver, above n 17.

¹⁹ Australian Institute of Health and Welfare, *Improving Australia's burden of disease (including references to National Health Priority Areas)*, media release, Canberra, 9 January 2018, viewed 24 April 2019, <https://www.aihw.gov.au/getmedia/28c917f3-cb00-44dd-ba86-c13e764dea6b/Improving-Australia-s-burden-of-disease-9-01-2019.pdf.aspx>.

²⁰ Organisation for Economic Cooperation and Development, above n 14, p 22.

²¹ *Ibid*, p 12.

²² Australian Institute of Health and Welfare, *GEN fact sheet 2017–18: People's care needs in aged care*, 2018.

Dementia diagnosis

Dementia is different to the mild and variable decline in learning, memory, and ability to make decisions that may occur with age.²³ Initial symptoms are often very mild, slow to develop and difficult to recognise.²⁴ With many different forms and no single conclusive test, the diagnosis of dementia can be a difficult and lengthy process, anticipated to take about three years from first symptoms to diagnosis by a health professional.²⁵ A diagnosis of dementia is reserved for a significant decline from a previous level of performance in one or more of the cognitive areas outlined in Table 2. The decline needs to not be attributable to other conditions, and with the exception of early Alzheimer's disease, is determined to interfere with undertaking day-to-day activities independently.²⁶ Research into Alzheimer's disease indicates a pre-clinical stage that may have a different disease trajectory.²⁷

Table 2: Functional limitations associated with impairment in different cognitive domains

Cognitive domain	Examples of changes in the activities of daily living
Complex attention	Normal tasks take longer, especially when there are competing stimuli; is easily distracted; tasks may need to be simplified; has difficulty holding information in mind to do mental calculations or dial a phone number.
Executive functioning	Difficulty with multi-stage tasks, planning, organising, multi-tasking, following directions, keeping up with shifting conversations.
Learning and memory	Difficulty recalling recent events; repeats themselves; misplaces objects; loses track of actions already performed; increasingly reliant on lists, and reminders.
Language	Word-finding difficulty, use of general phrases or wrong words, grammatical errors, difficulty with comprehension of others' language or written material.
Perceptual-motor/ visuospatial function	Getting lost in familiar places, more use of notes and maps, difficulty using familiar tools and appliances.
Social cognition	Disinhibition or apathy, loss of empathy, inappropriate behaviour, loss of judgment.

Source: J Hugo and M Ganguli, 'Dementia and Cognitive Impairment: Epidemiology, Diagnosis, and Treatment' (2014) 30(3) *Clinical Geriatric Medicine* 421–442.

²³ National Collaborating Centre for Mental Health (UK), *Dementia: A NICE-SCIE Guideline on Supporting People with Dementia and Their Carers in Health and Social Care*, 2007.

²⁴ L Perry-Young, G Owen, S Kelly and C Owens, 'How people come to recognise a problem and seek medical help for a person showing early signs of dementia: A systematic review and meta-ethnography' (2018) 17(1) *Dementia* 34–60. doi: 10.1177/1471301215626889.

²⁵ National Health and Medical Research Institute (NHMRC) National Institute for Dementia Research, *Australia's Boosting Dementia Research Initiative: Report on early outcomes*, 2018, Canberra.

²⁶ Dementia Australia, *Diagnostic criteria for dementia*, viewed 24 April 2019, <https://www.dementia.org.au/information/for-health-professionals/clinical-resources/diagnostic-criteria-for-dementia>.

²⁷ *Ibid*, p 3.

Misunderstandings about dementia are common and knowledge about dementia treatments among the Australian public is reported as poor.²⁸ While Australia is one of at least 16 Organisation for Economic Co-operation and Development (OECD) countries with clinical guidelines for dementia care²⁹, a 2018 review of 45 research studies found that approximately half of the people with dementia were not told their diagnosis.³⁰

Various screening, imaging and clinical laboratory technologies can be used to diagnose dementia.³¹ General practitioners in Australia can make cognitive assessments where there is a suspected impairment, and clinical guidelines recommend that people with a possible diagnosis of dementia be referred to memory assessment specialists.³² This is because a timely diagnosis assists people with dementia, and their families, to access information and actively participate in decisions that influence the quality of the care.³³

Behavioural and psychological symptoms of dementia

The behavioural and psychological symptoms of dementia are a varied group of non-cognitive behaviours and symptoms that are common to many people as the severity of their dementia advances.³⁴ The causes and risk factors for the symptoms are multiple and include biological, psychological and environmental variables, with their combination, rather than any specific factor, potentially explaining the occurrence.³⁵

The range, type and severity of behavioural and psychological symptoms varies though the natural course of over time is still largely unknown.³⁶ Wandering is reported as persistent³⁷, with depression the most prevalent, followed by apathy/indifference and irritability.³⁸

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- ²⁸ M Cations, G Radisic, M Crotty and K Laver, 'What does the general public understand about prevention and treatment of dementia? A systematic review of population-based surveys' (2018) 13(4) *Public Library Of Science (PLOS) One*. doi.org/ 10.1371/journal.pone.0196085, p 12.
M Rahja, K Laver, T Comans and M Crotty, 'What Does the Australian General Public Know About Treatments for Dementia? A Population Survey' (2018) 4 *Gerontology & Geriatric Medicine*. doi.org/10.1177/2333721418793442.
- ²⁹ Organisation for Economic Cooperation and Development, above n 14, p 22.
- ³⁰ L Low and M McGrath, 'Communicating a diagnosis of dementia: A systematic mixed studies review of attitudes and practices of health practitioners' (2018) *Dementia*. doi.org/10.1177/1471301218761911.
- ³¹ Dementia Australia, *Diagnostic criteria for dementia*, above n 26.
J McCleery, L Flicker, E Richard and T Quinn, 'When is Alzheimer's not dementia—Cochrane commentary on The National Institute on Ageing and Alzheimer's Association Research Framework for Alzheimer's Disease' (2019) 48 *Age and Ageing* 174–177. doi :10.1093/ageing/afy167.
- ³² Guideline Adaptation Committee, above n 3.
- ³³ S M Dyer, E S Gnanamanickam, E Liu C Whitehead and M Crotty, 'Diagnosis of dementia in residential aged care settings in Australia: An opportunity for improvements in quality of care?' (2018) 37(4) *Australasian Journal on Ageing* E155-E158. doi.org/10.1111/ajag.12580.
- ³⁴ Organisation for Economic Cooperation and Development, above n 14, p 139.
- ³⁵ O P Tible, F Riese, E Savaskan and A von Gunten, 'Best practice in the management of behavioural and psychological symptoms of dementia' (2017) 10(8) *Therapeutic Advances in Neurological Disorders* 297–309 doi.org/10.1177/1756285617712979.
- ³⁶ Ibid.
- ³⁷ R M Van der Linde, T Denning, B C M Stephan, A M Prina, E Evans and C Brayne, 'Longitudinal course of behavioural and psychological symptoms of dementia: systematic review' (2016) 209(5) *British Journal of Psychiatry* 366–377. dx.doi.org/10.1192%2Fbjp.bp.114.148403.
- ³⁸ M Steinberg, H Shao, P Zandi, C G Lyketsos, K A Welsh-Bohmer, M C Norton, J C S Breitner, D C Steffens, J T Tschanz and Cache County Investigators, 'Point and 5-year prevalence of neuropsychiatric symptoms in dementia: the Cache County Study' (2008) 23(2) *International Journal of Geriatric Psychiatry* 170–177 doi.org/10.1002/gps.1858.

Difficulty in communicating may result in people with dementia expressing their needs through actions and behaviours which may not be readily understood by family and carers. Challenging behaviours, or behaviours of concern may include agitation or extreme restlessness, physical and verbal aggression, wandering, social and/or sexual disinhibition, delusions, apathy, depression and/or anxiety.³⁹ These actions and behaviours may be mild, moderate or severe in nature. Symptoms are generally unique to the person and their circumstances and may be made worse by factors such as pain, fear, feelings of being threatened, or stress associated with confusing environments.

Behavioural and psychological symptoms require specific training to appropriately recognise and manage.⁴⁰ There is evidence that a range of supports and interventions can help to manage them. Severe symptoms may require pharmacological management, using antipsychotic or other medicines, to prevent the person from harming themselves or others. However, research suggests that antipsychotic pharmaceutical use can increase the risk of stroke, falls and pneumonia, and hasten cognitive deterioration.⁴¹ Further discussion about the use and effectiveness of pharmacological interventions for managing the behavioural and psychological symptoms of dementia is available in *Background Paper 4: Restrictive practices in residential aged care in Australia*.

Behavioural and psychological symptoms can be stressful for families and friends, particularly where a person requires a move to residential care to secure a level of care that they need.

Approaches to dementia policy and planning in Australia have been influenced by the Brodaty Triangle—a seven-tiered model of management of symptoms that divides people living with dementia into an ascending order of symptom severity and decreasing levels of prevalence (Figure 1 below). This model, first proposed in a 2003 publication, cites six studies as the source of behavioural and psychological symptom rates in settings of most relevance to Australia: community settings and residential facilities.⁴² The cited references date from 1996 to 2001 and do not have large sample sizes.

In the absence of more recent data, this commonly cited model proposes that approximately 40% of people have no behavioural and psychological symptoms and approximately 1% of people experience severe symptoms as represented in Tier 6. The very severe behaviours of Tier 7 are deemed to be rare. The authors note that the ‘boundaries between tiers are not distinct, and movement between levels is not necessarily stepwise’.⁴³

³⁹ Organisation for Economic Cooperation and Development, above n 14, p 35.

⁴⁰ Ibid, p 139.

⁴¹ Ibid, p 139.

⁴² CG Lyketsos, M Steinberg, JT Tschanz, MC Norton, DC Steffens and JC Breitner, ‘Mental and behavioural disturbances in dementia: findings from the Cache County Study on Memory in Aging’ (2000) 157 *American Journal of Psychiatry* 708–714.

M S Mega, J L Cummings, T Fiorello and J Gornbein, ‘The spectrum of behavioral changes in Alzheimer’s disease’ (1996) 46 *Neurology* 130–135.

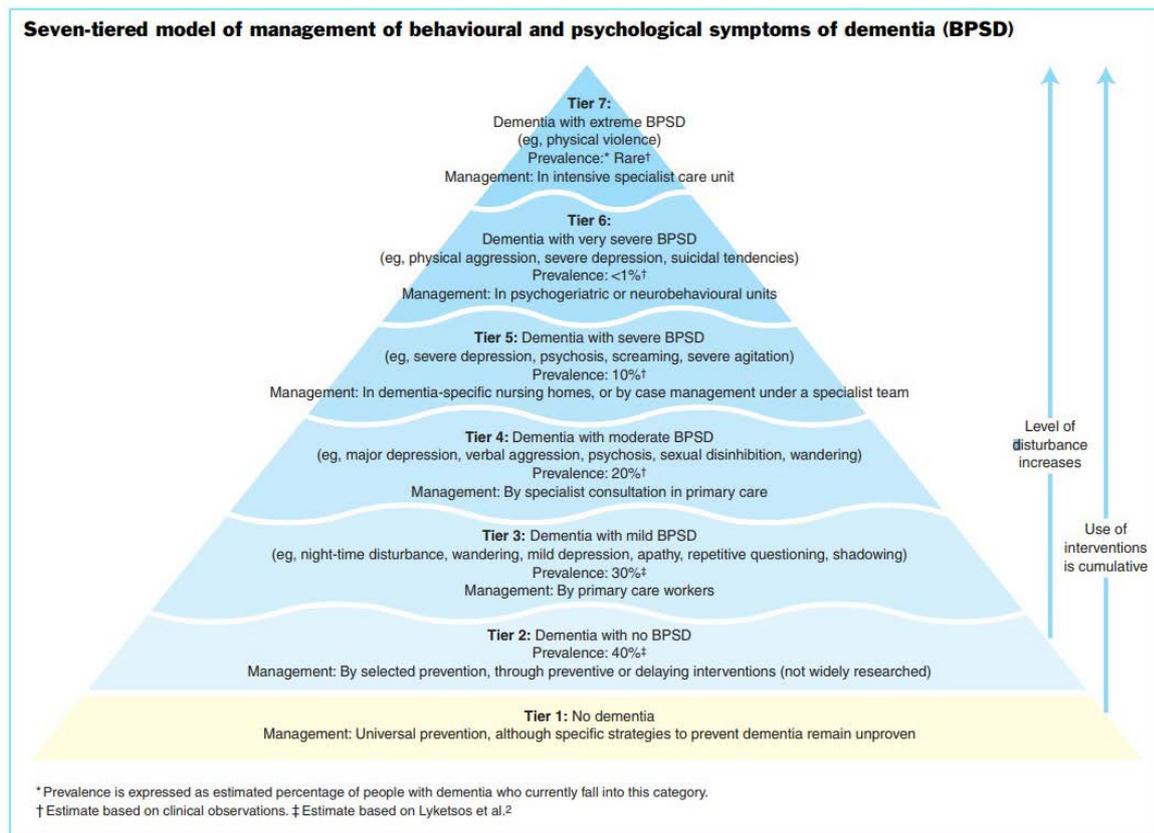
J Snowden, R Miller and R Vaughan, ‘Behavioural problems in Sydney nursing homes’ (1996) 11 *International Journal of Geriatric Psychiatry* 535–541.

Brodaty H, Draper B, Saab D, et al. Psychosis, depression and behavioural disturbances in Sydney nursing home residents: prevalence and predictors. (2001) *Int J Geriatr Psychiatry*; 16: 504–512.

Sourai R, McCusker J, Cole M, Abrahamowicz, Agitation in demented patients in an acute care hospital: prevalence, disruptiveness and staff burden. (2001) *Int Psychogeriatr*; 13: 183–197.

⁴³ H Brodaty, B Draper, and L Low, ‘Behavioural and psychological symptoms of dementia: A seven-tiered model of service delivery’ (2003) 178(5) *Medical Journal of Australia* 231–234.

Figure 1: The Brodaty Model



Source: H Brodaty, B Draper, and L Low, 'Behavioural and psychological symptoms of dementia: A seven-tiered model of service delivery' (2003) 178(5) *Medical Journal of Australia* 231–234.

What are the physical and social consequences of dementia?

Globally, dementia is one of the leading causes of disability for older people, with implications for individuals and populations. A diagnosis of dementia will invariably have a significant impact on a person's life; physically, psychologically and socially. As dementia progress there is generally a decline in health with increased need for help from informal carers and aged care services. There are also impacts for families and close friends, and the health and aged care sectors.⁴⁴

The 'burden of disease'—a measure of healthy life lost due to prolonged illness, disability or early death—associated with dementia is significant. Australian estimates place it as the second leading cause of total burden (accounting for 7.8% of years of life lost due to illness or death), and the leading cause of non-fatal burden (accounting for 10% of years of life lost due to living with the disease).⁴⁵ Population based policies for disease prevention, intervention and treatment are typically informed by burden of disease measures.

⁴⁴ Australian Institute of Health and Welfare, *Dementia in Australia*, Cat. No. AGE 70, 2012, p 2.
Australian Institute of Health and Welfare, *Australia's welfare 2017*, Australia's welfare series no. 13, AUS 214, Canberra: AIHW, p 183.

⁴⁵ Australian Institute of Health and Welfare, *Australia's health 2018*, Chapter 3.14, 2018.

The median age of those who died from dementia in Australia in 2015 was 88.6 years, compared with 81.9 years for all deaths. Around 70% of all dementia deaths occurred in those 85 years of age or more and about another quarter occurred among people aged 75 to 84.⁴⁶ People with dementia in residential aged care also have a greater likelihood of hospital admissions, which is recognised to bring additional health risks.⁴⁷

Dementia can lead to difficulties with mobility, continence, nutrition and immune system function. These can lead to frailty, infections and difficulty breathing, with pneumonia the most common complication leading to deaths in Australia in 2015 (2707 cases, or 21.4%).⁴⁸

Decreased mobility and attention to personal care and diet, together with psychological disturbance and communication difficulties, may also result in people with dementia resisting, or appearing to resist, care or medical treatments. This can cause distress for the person and their family and carers. It can also challenge providing treatment and care, and may result in the person being more susceptible to other illnesses. Dementia is by far the strongest risk factor for delirium, which is a serious yet potentially reversible acute confusional state that commonly occurs in hospitalised older people. Delirium can lead to poor outcomes and even death.⁴⁹

The logic framework in Figure 2 (below) delineates dementia, its clinical symptoms and progression, and possible or hypothesised consequences. It demonstrates how the cognitive symptoms, and behavioural and psychological symptoms can affect a person's physical, psychological and social health.

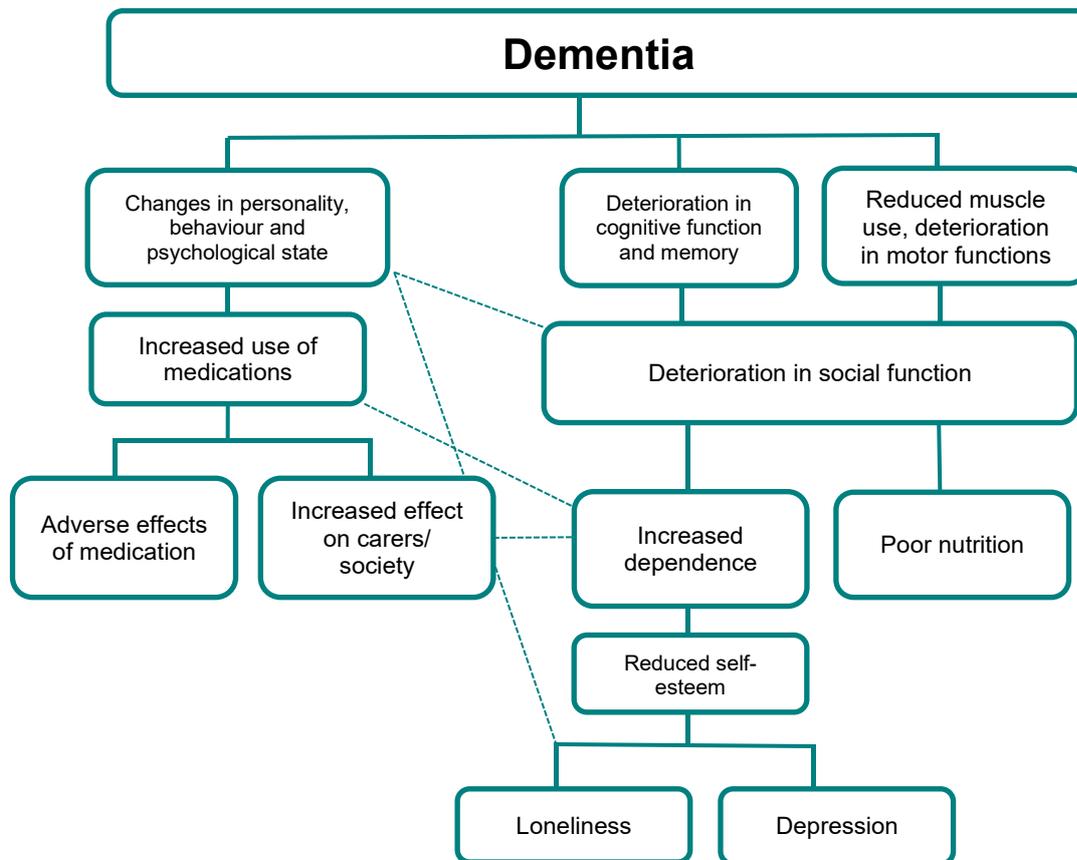
⁴⁶ Australian Bureau of Statistics, *Dementia and Death in Australia, 2015*, (Catalogue 3303.0), <https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2015~Main%20Features~Dementia~10002>.

⁴⁷ Australian Commission on Safety and Quality in Health Care. A better way to care: Safe and high-quality care for patients with cognitive impairment (dementia and delirium) in hospital—Actions for health service managers. 2014 Sydney, ACSQHC.

⁴⁸ Ibid.

⁴⁹ J McCrow, E Beattie, K Sullivan and D M Fick, 'Development and review of vignettes representing older people with cognitive impairment' (2013) 34(2) *Geriatric Nursing* 128–137 doi.org/10.1016/j.gerinurse.2012.12.012.

Figure 2: Logic framework model of progressive clinical manifestations and possible consequences of dementia.



Source: Adapted from N M Lai, S M W Chang, S S Ng, F Stanway, S L Tan, N Chaiyakunapruk. Animal-assisted therapy for dementia. (2019) *Cochrane Database of Systematic Reviews* 1. Art. No.: CD013243.

How prevalent is dementia in Australia?

Australia does not have national data that can provide reliable prevalence estimates of dementia.⁵⁰ Internationally, less than 40% of OECD countries have national rates of dementia diagnosis, and only two countries—Denmark and the United Kingdom—have specific targets to improve the rates of dementia diagnosis.⁵¹

Estimates about the current and future prevalence of dementia are primarily based on continued ageing of the population and the assumption that the age specific prevalence of dementia will remain consistent.⁵² The data in Figure 3 (below) are modelled on all available international data on the prevalence of dementia.⁵³ The shaded areas represent the 95% credible interval on the prevalence estimates. The error ranges are significant because very few comprehensive dementia prevalence studies have been undertaken in Australia.

⁵⁰ Australian Institute of Health and Welfare, above 48.

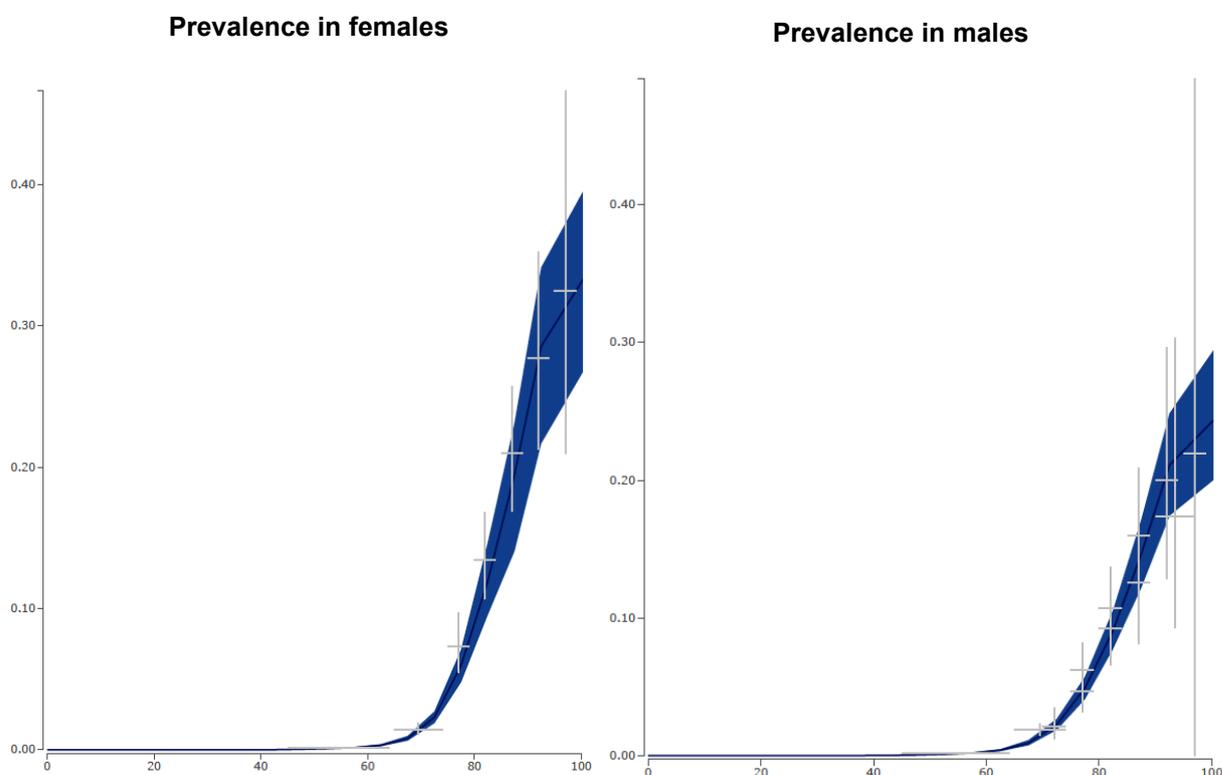
⁵¹ Organisation for Economic Cooperation and Development, above n 14, p 12.

⁵² Organisation for Economic Cooperation and Development, above n 14.

⁵³ The data are modelled using a complex Gaussian Process Regression.

Figure 3 illustrates that the incidence of dementia increases dramatically after the age of 70 years, approximately doubling every five years. About 0.1% of the population under 65 years of age has dementia, compared with about 5.2% of the population aged between 65 and 70, and 28.8% of the population aged 85 years or older. The prevalence increases to 41% for those over 90 years of age.⁵⁴

Figure 3: Estimated prevalence of dementia, Australia, 2017, by age, by sex



Source: Institute of Health Metrics and Evaluation (IHME). (2019) Epi Visualisation. Seattle, WA: IHME, University of Washington. Available from <http://ihmeuw.org/4q1k>.

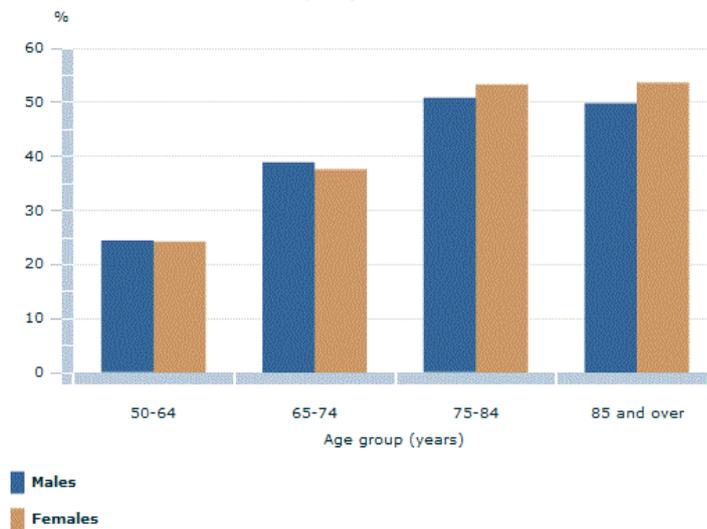
While acknowledging the lack of national data, the Australian Institute of Health and Welfare estimated that, in 2018, about 376,000 Australians had dementia and 61% of people with dementia were female.⁵⁵ Dementia Australia commissioned research from the National Centre for Social and Economic Modelling which suggested that in 2019, 447,115 people live with dementia, with the majority of these people being women.⁵⁶

⁵⁴ Organisation for Economic Cooperation and Development Health Policy Studies, above n 14, p 12.

⁵⁵ Australian Institute of Health and Welfare, above 48.

⁵⁶ Dementia Australia, *Dementia Key facts and statistics 2019*, 2019, viewed 24 April 2019, <https://www.dementia.org.au/files/documents/2019-Dementia-Key-facts-stats.pdf>.

Figure 4: People with dementia in Australia in 2015 in residential aged care, by age and sex



Source: Australian Bureau of Statistics, *Dementia and Death in Australia, 2015*, (Catalogue 3303.0), <https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2015~Main%20Features~Dementia~10002>.

There is also little comprehensive information about prevalence among specific populations. However, one in five people with dementia reportedly has a cultural and linguistically diverse background.⁵⁷ The Aboriginal and Torres Strait Islander population is reported to have a much higher incidence and prevalence, with younger onset of dementia, and higher rates of the risk factors for dementia (such as heart disease, diabetes and tobacco use).⁵⁸

Compounding this issue, the prevalence of undetected dementia is also high. There are studies in Australia and internationally reporting that knowledge about dementia is poor, and that there may be many people living with dementia that is not detected.⁵⁹

Figure 5 shows the number of Australians projected to have dementia between 2010 and 2030. By 2030, about 550,000 Australians are expected to have dementia, and 42.8% of those aged 85 or older. By 2057, this number is expected to extend to about 1 million Australians.⁶⁰

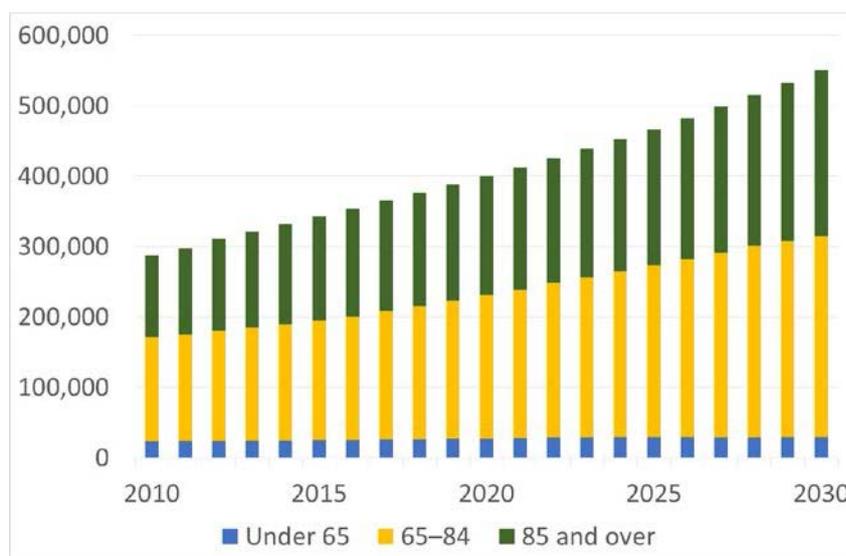
⁵⁷ University of Canberra National Centre for Social and Economic Modelling (NATSEM), *Economic Cost of Dementia in Australia 2016–2056*, 2017.

⁵⁸ S Q Li, S L Guthridge, P E Aratchige, M P Lowe, Z Wang, Y Zhao and V Krause, 'Dementia prevalence and incidence among the Indigenous and non-Indigenous populations of the Northern Territory' (2014) 200 (8) *Medical Journal of Australia* 465–469. doi.org/10.5694/mja13.11052. L Flicker and K Holdsworth, above n 44.

⁵⁹ M Rahja, K Laver, T Comans and M Crotty, above n 28. L Lang, A Clifford, L Wei, D Zhang, D Leung, G Augustine, I M Danat, W Zhou, J R Copeland, K J Anstey and R Chen, 'Prevalence and determinants of undetected dementia in the community: a systematic literature review and a meta-analysis' (2017) 7 *British Medical Journal Open*. doi.org/10.1136/bmjopen-2016-011146.

⁶⁰ Australian Institute of Health and Welfare, above n 44.

Figure 5: Estimated number of Australians with dementia, by age group, 2010 to 2030



Source: Australian Institute of Health and Welfare, *Australia's health 2018*, Chapter 3.14, 2018.

In Australia, the estimated 27,247 people with younger onset dementia is expected to rise to 29,353 people by 2028 and 41,249 people by 2058.⁶¹ This is a decreased projection from the 2018 estimates.⁶²

There have been some reports over the last five years of a decline in the incidence and prevalence of dementia in Australia and other high-income economies.⁶³ A 2019 publication, reportedly the largest and most comprehensive study in Australia of people aged 65 years and over using aged care services, analysed dementia prevalence trends.⁶⁴ This was a retrospective study of long-term care use by older people between 2008 and 2013 and of home care use by older people between 2005 and 2014. It reported that the prevalence of dementia for people accessing long-term care decreased from 50.0% to 46.6% between 2008 and 2014, while dementia prevalence for people accessing home care decreased from 25.9% in 2005 to 20.9% in 2014. Dementia related health conditions were not related to this decline.⁶⁵ The study authors note that the decline in prevalence:

...may be due to a decline in incidence of dementia or an increase in people dying with dementia before they access aged care services ... stable mortality rates for people with dementia accessing long-term care in this study indicate that the prevalence of dementia may be due to a decline in incidences rates, but this is not clear from this study.⁶⁶

⁶¹ Dementia Australia, *Dementia Key facts and statistics*, above n 55.

⁶² Ibid.

⁶³ Alzheimer's Australia, *Is the Incidence of Dementia Declining*, Paper 39, 2014.

S Roehr, A Pabst, T Luck and S Riedel-Heller, 'Is dementia incidence declining in high-income countries? A systematic review and meta-analysis' (2018) 10 *Clinical Epidemiology* 1233–1247 doi.org/10.2147%2FCLEP.S163649.

⁶⁴ S L Harrison, C Lang, C Whitehead, M Crotty, J Ratcliffe, S Wesselingh and M C Inacio, 'Trends in Prevalence of Dementia for People Accessing Aged Care Services in Australia' (2019) *Journals of Gerontology: Series A*. doi.org/10.1093/gerona/glz032.

⁶⁵ Ibid, p 4.

⁶⁶ Ibid, p 7.

These rates are understood to be occurring at the same time as an increase in home care dementia services, with improvements in cardiovascular health possibly contributing as well. The prevalence of dementia for people accessing aged care services in Australia is critical to the accurate planning of services, particularly for the needs of people with moderate to severe dementia.⁶⁷

What does the literature say about dementia care?

The systematic research on how to best care for people living with dementia spans a range of areas, including early diagnosis in primary care settings through to end-of-life and palliative care at home, hospital or residential aged care facilities. The following discussion provides an overview of the reviews of research and some key studies and reports that address dementia prevention, support and interventions.

Dementia risk and prevention

Research suggests that there is a range of dementia risk factors that can be changed or reduced—known as modifiable risk factors'. These include hearing loss, adequate education, smoking cessation, maintaining physical activity, avoiding social isolation and managing depression, high blood pressure, obesity and diabetes.⁶⁸ In general, healthier lifestyles are associated with declining prevalence of cognitive impairment and dementia⁶⁹.

However, the potential to reduce risk factors does not mean that all dementia is preventable or treatable.⁷⁰ In relation to the latter, there is no conclusive evidence that exercise, diet, cognitive training, medications or vitamins have effects on mild cognitive impairment. There is also no evidence that social activity prevents cognitive decline or dementia.⁷¹ Some literature suggests, however, that addressing diabetes may slow the progression from mild cognitive impairment to dementia.⁷²

Support and interventions

The care of people living with dementia is generally focussed on preventing, recognising and managing common behavioural and psychological symptoms. As discussed earlier, the progression of dementia changes the ability of people with dementia to interact with others and their environment, and makes them increasingly dependent. This deterioration may include symptoms and complex care needs arising from biological brain dysfunction, unmet needs, environmental triggers, and interactions between the person, their carers and the environment.⁷³

⁶⁷ Ibid.

⁶⁸ G Livingston, et al., above n 4, p 1.

⁶⁹ K Laver, SM Dyer, C Whitehead, L Clemson and M Crotty, 'Interventions to delay functional decline in people with dementia: a systematic review of systematic reviews' (2016) 6(4) *British Medical Journal Open*. doi.org/10.1136/bmjopen-2015-010767.

⁷⁰ G Livingston, et al., above n 4, pp 2677–2683.

⁷¹ G Livingston, et al., above n 4, pp 2673–2734.

⁷² G Livingston, et al., above n 4, pp 2688–2689.

⁷³ H Kales, 'Assessment and management of behavioural and psychological symptoms of dementia' (2015) 350 *British Medical Journal*. doi.org/10.1136/bmj.h369.

The research evidence for the care of people living with dementia falls broadly into pharmacological and non-pharmacological interventions. This evidence suggests that no single treatments, either pharmacological or non-pharmacological, are recommended for behavioural and psychological symptoms, with multiple approaches providing the best outcomes.⁷⁴

Pharmacological interventions for dementia

While there are no medicines currently available to cure dementia, there are some that aim to delay or prevent progression, reduce dementia symptoms and improve quality of life. In general, the efficacy of these medications is limited.⁷⁵ Pharmacological interventions for behavioural and psychological symptoms include antidepressants, cognitive enhancers, benzodiazepines, mood stabilizers, antipsychotics, anxiolytics (inhibits anxiety), analgesics, or melatonin (which regulates sleep-wake cycles).⁷⁶ Many studies highlight the risk-to-benefit ratio and question, in particular, the use of antipsychotics for people with dementia.⁷⁷ Further discussion about the use and effectiveness of pharmacological interventions for managing behavioural and psychological symptoms is available in *Background Paper 4: Restrictive practices in residential aged care in Australia*.

Non-pharmacological interventions

There is no consistency in the way that non-pharmacological interventions for behavioural and psychological symptoms are classified. People with these symptoms cross the full range of dependency, from mobile and needing minimal assistance to having varying degrees of severe and challenging behaviours that may include physical and verbal aggression, depression, disinhibition, unpredictable moods and/or suicidal tendencies. There are many reports of trials and evaluations of various non-pharmacological interventions for symptoms, most of which acknowledge the limitations to producing findings that can be generalised to other people or settings. This is often because the research has been conducted with small groups of people receiving variable interventions often over a short duration.

The research evidence for non-pharmacological interventions are described here as they relate to the person, the environment and the families and carers, with a particular focus on residential aged care.

⁷⁴ G Livingston, et al., above n 4, pp 2673–2734.

⁷⁵ Ibid p 11.

⁷⁶ S M Dyer, S L Harrison, K Laver and C Whitehead, 'An overview of systematic reviews of pharmacological and non-pharmacological interventions for the treatment of behavioural and psychological symptoms of dementia' (2018) 30(3) *International Psychogeriatrics* 295–309. doi.org/10.1017/S1041610217002344.

⁷⁷ J Westbury, P Gee, T Ling, A Kitsos and G Peterson G. More action needed: Psychotropic prescribing in Australian residential aged care, (2019) *Australian & New Zealand Journal of Psychiatry* 53(2) 136– 147 DOI: 10.1177/0004867418758919.

N Jokanovica, N Ferrah, J Lovell, C Weller, L Bugejab, S Bella, and J Ibrahim. A review of coronial investigations into medication-related deaths in residential aged care, (2019) *Research in Social and Administrative Pharmacy*, 15, (4) April, 410–416 doi.org/10.1016/j.sapharm.2018.06.007.

Cognitive training and rehabilitation

Despite widespread use, there is limited evidence for common approaches to improve the cognition of people with dementia. Cognitive approaches fall into the following three categories:⁷⁸

- cognitive stimulation, which aims to improve cognition and social functioning through a range of activities and discussions, usually in a group;
- cognitive training, that aims to assist with performing standard tasks related to particular cognitive functions to suit the individual level of ability.
- cognitive rehabilitation, where a therapist works with the person who has dementia and their family members to build on the person's strengths and develop ways to manage any impairments.

Studies indicate that cognitive training and rehabilitation do not assist people with mild to moderate Alzheimer's disease or vascular dementia with cognitive functioning, mood or undertaking day-to-day activities.⁷⁹ However, in 22 reviews, cognitive stimulation was reported to improve thinking, memory and concentration, and therefore improve communication and quality of life.⁸⁰

Tailored activities, exercise and other therapy

Similarly, there is little research evidence to support the idea that personally-tailored activities for people with dementia are any more effective in managing behaviour than non-tailored activities. Activities that have been investigated include music, modified sporting programs, bingo, storytelling, exercise, pet therapy, trivia and watching movies. All participants in the reviewed studies, with the exception of one, had demonstrated challenging behaviours.⁸¹

While there is no evidence that exercise itself improves cognition, psychological symptoms and depression, some research suggests that exercise of sufficient intensity can improve the ability of people with dementia to perform daily activities.⁸² In general, exercise is often

⁷⁸ B Woods, E Aguirre, AE Spector and M Orrell, 'Cognitive stimulation to improve cognitive functioning in people with dementia' (2012) 2 *Cochrane Database of Systematic Reviews*. doi: 10.1002/14651858.CD005562.pub2.

⁷⁹ A Bahar-Fuchs, L Clare and B Woods, Cognitive training and cognitive rehabilitation for mild to moderate Alzheimer's disease and vascular dementia (2013) *Cochrane Database of Systematic Reviews*, Issue 6. Art. No.: CD003260. doi: 10.1002/14651858.CD003260.pub2.
B Woods, E Aguirre, AE Spector and M Orrell. Cognitive stimulation to improve cognitive functioning in people with dementia. (2012) *Cochrane Database of Systematic Reviews*, Issue 2. Art. No.: CD005562. doi: 10.1002/14651858.CD005562.pub2.

⁸⁰ O McDermott, G Charlesworth, E Hogervorst, C Stoner, E Moniz-Cook, A Spector, E Csipke and M Orrell. Psychosocial interventions for people with dementia: a synthesis of systematic reviews, (2018), *Aging & Mental Health*, doi: 10.1080/13607863.2017.1423031.
B Woods, E Aguirre, AE Spector and M Orrell. Cognitive stimulation to improve cognitive functioning in people with dementia. (2012) *Cochrane Database of Systematic Reviews*, Issue 2. Art. No.: CD005562. doi: 10.1002/14651858.CD005562.pub2.
B Woods, L O'Philbin, EM Farrell, AE Spector and M Orrell M. Reminiscence therapy for dementia. (2018) *Cochrane Database of Systematic Reviews*, Issue 3. Art. No.: CD001120. doi: 10.1002/14651858.CD001120.pub3.

⁸¹ R Möhler, A Renom, H Renom and G Meyer, 'Personally tailored activities for improving psychosocial outcomes for people with dementia in long-term care' (2018) 2 *Cochrane Database of Systematic Reviews*, doi: 10.1002/14651858.CD009812.pub2.

⁸² D Forbes, S C Forbes, C M Blake, E J Thiessen and S Forbes, 'Exercise programs for people with dementia' (2015) 4 *Cochrane Database of Systematic Reviews*, doi: 10.1002/14651858.CD006489.pub4.

recommended for people living with dementia because it is not associated with any adverse side effects.

While music therapy has been shown as beneficial in the short-term in reducing depressive symptoms, improving behavioural problems, emotional wellbeing, quality of life and anxiety, there is differences in assessment of music on agitation, aggression or cognition.⁸³

Some interventions, such as aromatherapy or light therapy, have little or no evidence base. Others, such as pet therapy, show promise in reducing depressive symptoms in the short-term, and improving overall behavioural problems, emotional wellbeing, quality of life, and reduced anxiety. Like music therapy, they may have little or no effect on agitation, aggression or cognition.⁸⁴

Despite a lack of research evidence supporting these as effective non-pharmacological interventions, they have been found to cause little or no harm. Best practice suggests making them available as part of an individualised assessment of other factors such as of pain, hearing, vision and the potential for stress or overstimulation that may contribute to behavioural and psychological symptoms.⁸⁵

Nutrition, hydration and oral health

The psychological symptoms or behaviours that people with dementia can develop may cause them to eat or drink less. In turn, this can cause the potential for unexpected weight loss, dehydration and declining oral hygiene. Some studies have established a positive link between healthy eating patterns and better brain health in older adults.⁸⁶ However, research into keeping people with dementia eating and drinking as well as possible found that there was too much variation in the study interventions or outcomes to provide consistent conclusions.⁸⁷ The findings from interventions to maintain or improve oral health in people with dementia have been generally inconclusive, suggesting only that professional mouth

K Laver, SM Dyer, C Whitehead, et al., above n 69.

⁸³ C Travers, O Brooks, S Hines, M O'Reilly, M McMaster, W He, M MacAndrew, E Fielding, L Karlsson, E Beattie, 'Effectiveness of meaningful occupation interventions for people living with dementia in residential aged care: a systematic review' (2016) 14(12) *JBI Database System Rev Implement Rep* 1631.

J T van der Steen, H J A Smalin, J C van der Wouden, M S Bruinsma, R J P M Scholten and A C Vink, 'Music-based therapeutic interventions for people with dementia' (2018) 7 *Cochrane Database of Systematic Reviews*, doi: 10.1002/14651858.CD003477.pub4, et al p 2685.

J Abraha, F Rimland, G Trotta, A Dell'Aquila, M Cruz-Jentoft, A Petrovic, R Gudmundsson, D Soiza, A O'Mahony, A Guaita and A Cherubini 'Systematic review of nonpharmacological Interventions to treat behavioural disturbances in older patients with dementia The SENATOR-OnTop series' (2017) 7 *British Medical Journal Open* doi: 10.1136/bmjopen-2016-012759.

⁸⁴ G Livingston, et al., above n 4, pp 2673–2734.

J T van der Steen, H J A Smalin, J C van der Wouden, M S Bruinsma, et al., above n 71.

⁸⁵ K Scales, S Zimmerman and S Miller, 'Evidence-Based Nonpharmacological Practices to Address Behavioral and Psychological Symptoms of Dementia' (2018) 58 *Gerontologist*, doi:10.1093/geront/gnx167.

G Livingston, et al., above n 4, pp 2673–2734.

J T van der Steen, H J A Smalin, J C van der Wouden, M S Bruinsma, et al., above n 71, p 2705.

⁸⁶ X Chen, B Maguire, H Brodaty and F O'Leary, 'Dietary patterns and cognitive health in older adults: A systematic review' (2019) 67 *Journal of Alzheimer's Disease*, doi.org/10.3233/JAD-180468.

⁸⁷ M Herke, A Fink, G Langer, T Wustmann, S Watzke, A Hanff and M Burckhardt, 'Environmental and behavioural modifications for improving food and fluid intake in people with dementia' (2018), 7 *Cochrane Database of Systematic Reviews* doi: 10.1002/14651858.CD011542.pub2.

care may reduce the number of deaths caused by pneumonia, compared to usual mouth care.⁸⁸

Communication

Some literature suggests that effective communication skills that individualise care to specific needs and preferences may decrease agitation in people with dementia.⁸⁹ Single studies have shown that agitation and other symptoms for people with advanced dementia can be reduced by effective communication, identifying and responding to the person's preferences and needs, providing stimulation and occupational interventions such as exercise, walks, or folding laundry, and social and sensory interventions such as music, art, gardening or cooking.⁹⁰

Person-centred care models

To date, the effectiveness of person-centred care has been measured through psychological and functional status, infection rates, levels of depression and agitation, quality of care, approaches to person-centred care, capacity of staff to deliver individualised care and the roles of carers.⁹¹ Differences in the individual progression of dementia and nuances of personalised care challenge attempts to identify and measure outcomes.⁹² Further challenges exist as research in this area can vary in the emphasis on rights, choice, control, individual care planning and personalisation.⁹³

However, a number of person-centred care models have been established as valid and reliable in aligning the principles of person-centred care with quality dementia care. This includes in staffing and organisational development, in health and personal care, in resident lifestyle, and in supportive and inclusive physical and social environments.⁹⁴

⁸⁸ E Siegel, M Cations, C Wright, V Naganathan, A Deutsch, L Aerts and H Brodaty, 'Interventions to improve the oral health of people with dementia or cognitive impairment: A review of the literature' (2017) 21 *Journal of Nutrition, Health and Aging*, <http://dx.doi.org/10.1007/s12603-016-0851-6>.

C Liu, Y Cao, J Lin, L Ng, I Needleman, T Walsh and C Li, 'Oral care measures for preventing nursing home-acquired pneumonia' (2018) 9 *Cochrane Database of Systematic Reviews*, doi: 10.1002/14651858.CD012416.pub2.

⁸⁹ G Livingston, et al., above n 4, p 2705.

L Chenoweth, M King, Y H Jeon, H Brodarty, J Stein-Padbury, R Norman, M Haas and G Luscombe, 'Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a Cluster randomized trial' (2009) 8 *The Lancet Neurology* doi:10.1016/S1474-4422(09)70045-6.

⁹⁰ L Chenoweth, M King, Y H Jeon, et al., above n 89.

G Livingston, A Sommerlad, V Orgeta, et al, above n 4, p 2702.

⁹¹ Ibid, p 7.

⁹² A Martyr, S Nelis, C Quinn and Y T Wu, above n 5.

⁹³ L Trigg, 'Improving the quality of residential care for older people: a study of government approaches in England and Australia' (2018) London School of Economics and Political Science, PhD thesis p 47.

D Brooker, 'What is person-centred care in dementia?' (2004) 13 *Reviews in Clinical Gerontology* 13, doi:10.1017/S095925980400108X.

S Brownie and S Nancarrow, 'Effects of person-centered care on residents and staff in aged-care facilities: a systematic review' (2013) 8 *Clinical Interventions in Aging*, doi: 10.2147/CIA.S38589.

⁹⁴ S Fazio, D Pace, J Flinner and B Kallmyer B, *The Fundamentals of Person-Centered Care for Individuals with Dementia*, (2018), 58 *Gerontologist*, doi:10.1093/geront/gnx122.

S Kim and M Park, 'Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis' (2017) 12 *Clinical Interventions in Aging* doi: 10.2147/CIA.S117637.

J Røsvik, D Brooker, M Mjorud and O Kirkevold, 'What is person-centred care in dementia? Clinical reviews into practice: the development of the VIPS practice model, (2013) 23 *Reviews in Clinical Gerontology*, doi.org/10.1017/S0959259813000014.

There is some evidence that implementing person-centred care at the organisational level may increase the quality of life for people living with dementia, and potentially improve wellbeing and reduce behavioural and psychological symptoms.⁹⁵ Person-centred care has also been shown to positively influence staff satisfaction and the capacity to provide individualised care, improve residents' perceptions of boredom and feelings of helplessness, and affect levels of agitation in people living with dementia.⁹⁶ This approach has also been reported to decrease the use of psychotropic medicines for people with dementia living in long-term care facilities.⁹⁷

End-of-life and palliative care

The phrase 'end-of-life' in dementia care refers to the time when a person is living with, and impaired by, their dementia (a fatal condition), even if there is no certainty about how long they may live.⁹⁸ Generally, people are 'approaching the end-of-life' when they are likely to die within the next 12 months. Palliative care is providing relief for symptoms such as pain, difficulty in breathing, hydration and nutrition, and delirium.

A third of older people die with dementia, yet there is no international evidence of frameworks for delivering palliative care to people with dementia. There are some quality studies, but little about advanced care planning and end-of-life care.⁹⁹ In addition, many people with dementia die in aged care facilities. Research suggests that carers in these settings infrequently have training in dementia or end-of-life and palliative care, which potentially leads to poor quality pain relief and inappropriate use of antipsychotic medicines.¹⁰⁰

Aboriginal and Torres Strait Islander people with dementia can face barriers to quality palliative care because of a cultural belief that palliative care only relates to the 'last few days of life'.¹⁰¹

The physical and social care environment

People living with dementia are likely to receive care at home, in hospitals, post-acute or respite facilities and residential aged care settings. A small number of people with very severe behavioural and psychological symptoms may also be cared for in specialist dementia units. Recent Australian research reports that about 46% of people living with dementia live in the community with only informal assistance, 29% receive both informal and formal care, 16% receive formal assistance only, and 9% have no assistance at all.¹⁰²

⁹⁵ L Chenoweth, J Stein-Parbury, S Lapkin, A Wang, Z Liu and A Williams, 'Effects of person-centered care at the organisational-level for people with dementia. A systematic review' (2019) 14 *PLoS ONE* doi.org/10.1371/journal.pone.0212686.

⁹⁶ S Brownie and S Nancarrow, above n 93.

⁹⁷ J Li and D Porock, 'Resident outcomes of person-centered care in long-term care: A narrative review of interventional research' (2014) 51 *International Journal of Nursing Studies*, doi:10.1016/j.ijnurstu.2014.04.003.

⁹⁸ D Parker, J Lewis and K Gourlay, *Palliative Care and Dementia*, Dementia Australia paper no. 43, 2017.

M Raymond, A Warner, N Davies, N Nicholas, J Manthorpe and S Iliffe, 'Palliative and end of life care for people with dementia: lessons for clinical commissioners' (2014) 15 *Primary Health Care Research & Development* doi:10.1017/S146342361300039X.

E Murphy, K Froggatt, S Connolly, E O'Shea, E L Sampson, D Casey and D Devane, 'Palliative care interventions in advanced dementia' (2016) 12 *Cochrane Database of Systematic Reviews* doi: 10.1002/14651858.CD011513.pub2.

¹⁰⁰ G Livingston, A Sommerlad, V Orgeta, et al., above n 4, p 2714.

¹⁰¹ L Flicker and K Holdsworth, above n 58.

¹⁰² University of Canberra, above n 57.

Family members and informal carers of people with dementia provide care along with health care workers or paid carers, practitioners or health practitioners (i.e. general practitioners, specialists, nurses and allied health). Medical specialists in the care of people with dementia may include geriatricians, neurologists, psychiatrists, psychogeriatricians or neuropsychiatrists.

Care transitions

People with cognitive impairment including dementia move between different locations of care. Transitions can be unplanned, disruptive, and stressful for people with dementia and their families. They involve an increased risk of poor health outcomes, including complications, morbidity, and mortality.¹⁰³ Those who are in hospital are at a significantly increased risk of adverse outcomes such as functional decline, and preventable complications such as falls, or infections.¹⁰⁴ Medication problems are also a feature, including unintentional medication discrepancies, preventable adverse events, lack of an informative discharge summary and unforeseen medication access problems.¹⁰⁵

When a person has to move between care settings there is a risk of communication breakdown, including inaccuracies in information exchange, ineffective coordination between providers and a lack of follow-up care. This can increase the risk of poor health outcomes, particularly for people with dementia who are already at risk because of the nature of their condition. Research suggests that when health care team members communicate effectively with one another across care settings and with caregivers, people with dementia can be safely transitioned with minimal complications.¹⁰⁶

Effective transition approaches involve people with dementia and their carers establishing: goals of care; education about the likelihood of transitions in different care settings; timely communication of information; and connecting inter-professional teams of medical, social and supportive carers and caregivers.¹⁰⁷ Despite a very low level of evidence that case management and care coordination may provide a person-centred approach¹⁰⁸, practice guidelines recommend that health services include a care coordinator to assist with communication, coordination, referrals and transitions for people with dementia.¹⁰⁹

Care environments

The environments in which people with dementia receive care are integral to quality and safety, including appropriately managing behavioural and psychological symptoms.¹¹⁰ Living at home is often a personal preference that is cost-effective for the aged care system. As dementia progresses however, people usually require the higher level of assistance that is available in residential aged care. Dementia care environments may also include 'dementia

¹⁰³ K Hirschman and N Hodgson, 'Evidence-Based Interventions for Transitions in Care for Individuals Living With Dementia' (2018) 58 *Gerontologist*, doi:10.1093/geront/gnx152.

¹⁰⁴ Australian Commission on Safety and Quality in Health Care, *Evidence for the safety and quality issues associated with the care of patients with cognitive impairment in acute care settings: a rapid review*, 2013 Sydney.

¹⁰⁵ G Cooper, D Gibson, B Draper, S Kurrle and L Deeks, *Medication management and dementia in the acute care sector and during care transitions*, Dementia Collaborative Research Centre— Assessment and Better Care,(2015) University of New South Wales, final report.

¹⁰⁶ K Hirschman and N Hodgson, above n 103.

¹⁰⁷ Ibid.

¹⁰⁸ S Reilly, C Miranda-Castillo, R Malouf, J Hoe, S Toot, D Challis, and M Orrell, 'Case management approaches to home support for people with dementia. *Cochrane Database of Systematic Reviews*' (2015) doi:10.1002/14651858.CD008345.pub2.

¹⁰⁹ Guideline Adaptation Committee 2016, above n 3.

¹¹⁰ S Reilly, C Miranda-Castillo, R Malouf, J Hoe, et al., above n 108.

friendly communities' with awareness raising and other strategies implemented to reduce stigma and make communities safer for the people with dementia who live there.¹¹¹

Specific design elements have been shown to be beneficial to people with dementia.¹¹² Higher quality of life is reported, well into the advanced stages of dementia, in small-scale environments with private inside and outside spaces that are shared by a small number of like-minded residents.¹¹³ The literature suggests that small-scale care environments with low social density are positively associated with improved behaviour and functionality.¹¹⁴ Features such as homelike appearances, sufficient lighting, good acoustics, room climate, use of colour and visual access assisted people's orientation, social abilities and care outcomes.¹¹⁵

Designs for home and residential settings that have person-centred values for people living with dementia are:

- visually and acoustically controlled smaller spaces with fewer people;
- homely, considering territoriality, awareness and orientation;
- safe and supportive of functional abilities and balance preferences, activities and the design of the indoor and outdoor spaces;
- stimulating, offering a choice of meaningful activities, enabling people to make decisions about where and how they want to spend their time;
- engaging, providing meaningful activities and resources for memories, conversation and sharing.¹¹⁶

Small local dementia-friendly community initiatives exist in most Australian states and territories. Internationally, countries such as Denmark, Ireland, Norway and the United Kingdom have embedded such findings in dementia-friendly design principles to inform the development or adaption of buildings and homes.

While these environments are helpful in general, there is no research supporting a particular environment type as any better for people with different types of dementia,¹¹⁷ or that environmental design affects cognition in dementia.¹¹⁸

¹¹¹ Organisation for Economic Cooperation and Development, above n 34, p 40. See also, Australia—Dementia Friendly Communities Alzheimer's Disease International.

¹¹² G Marquardt, K Bueter and T Motzek, 'Impact of the design of the built environment on people with dementia: An evidence based review' (2014) 8 *Health Environments Research and Design*, doi: 10.1177/193758671400800111.

¹¹³ Organisation for Economic Cooperation and Development, above n 34, p 35. R Fleming, B Goodenough, L Low, L Chenoweth and H Brodaty, The relationship between the quality of the built environment and the quality of life of people with dementia in residential care, (2016) *Dementia*, 15(4) 663–680 doi: 10.1177/1471301214532460.

¹¹⁴ G Marquardt, K Bueter and T Motzek, above n 112, p 146.

¹¹⁵ E Gnanamanickam, S M Dyer, R Milte, E Liu, J Ratcliffe and M Crotty, above n 6.

¹¹⁶ M P Calkins, 'From research to application: Supportive and therapeutic environments for people living with dementia' 58 (2018) *The Gerontologist*, DOI:10.1093/geront/gnx146.

¹¹⁷ Ibid.

¹¹⁸ G Marquardt, K Bueter and T Motzek, above n 112, p 147.

Why is support for families and carers part of dementia care?

The needs of family, friends and informal carers of people living with dementia are significant.¹¹⁹ Informal or unpaid care can be a substitute or supplement for domestic, personal care or nursing work.¹²⁰ While the provision of care is a testament to love and duty, the negative impact and detrimental effects of providing care for people with dementia are well established in the literature.¹²¹ Caregiver stress, be it financial, family, physical or psychological, can be significant; affecting the health and wellbeing of the carer and increasing the likelihood that the person they care for may need more intensive support in a residential setting.

The costs for informal or unpaid carers include unpaid labour, lost salary or earnings and direct out-of-pocket expenses.¹²² Many OECD countries provide support in the form of leave, allowances or other benefits either to the carer or to the person needing the care. Of the 35 OECD countries, 27 countries have workplace policies to support carers, with 19 of these countries offering some paid leave, though mostly for only a few days.¹²³ Germany provides family care leave to support a relative with long-term care, and up to three months of leave specifically for end-of-life care. Employees can also access interest-free loans (conditional on employer size) while their income is reduced.¹²⁴

Financial support is available to small numbers of people in Australia, Ireland, New Zealand and the United Kingdom through means tested benefits. Canada provides federally-legislated tax credits for carers.¹²⁵ Cash allowances that are available to an eligible few in the UK and Ireland are reported as difficult to administer and open to abuse.¹²⁶

There is research evidence to support the effectiveness of caregiver training and skill-building to assist with caregiver burden, stress levels, and the quality of care that they can deliver.¹²⁷ Psychosocial interventions such as counselling, behavioural management and participation in support groups is reported to reduce carers' stress by changing beliefs about their responsibilities to the person with dementia, their own need for support, and understanding about their relatives or friends behaviour.¹²⁸

¹¹⁹ T Hill and T Broady, 'Understanding the social and emotional needs of carers: Final report', Sydney: *Social Policy Research Centre*, UNSW Sydney, 2019, doi.org/10.26190/5c59202697201.

¹²⁰ F Colombo, A Llena-Nozal, J Mercier, F Tjadens, 'Help Wanted?: Providing and Paying for Long-Term Care' in OECD Health, 2011, *Policy Studies*, OECD Publishing, Paris, <http://dx.doi.org/10.1787/9789264097759-en>.

¹²¹ K Seeher, L F Low, S Reppermund and H Brodaty, 'Predictors and outcomes for caregivers of people with mild cognitive impairment: A systematic literature review' (2013) 9 *Alzheimer's and Dementia*, pp 346–355, <http://dx.doi.org/10.1016/j.jalz.2012.01.012>.

¹²² Organisation for Economic Cooperation and Development, above n 34, p 106.

¹²³ *Ibid*, p 109

¹²⁴ *Ibid*.

¹²⁵ *Ibid*, p 119

¹²⁶ *Ibid*.

¹²⁷ L N Gitlin, K Marx, I H Stanley and N Hodgson, 'Translating Evidence-Based Dementia Caregiving Interventions into Practice: State-of-the-Science and Next Steps', (2015) 55 *The Gerontologist*, pp 210–226 <https://doi.org/10.1093/geront/gnu123>.

¹²⁸ M Vernooij-Dassen, I Draskovic, J McCleery and M Downs, 'Cognitive reframing for carers of people with dementia' (2011) 11, *Cochrane Database of Systematic Reviews*, doi: 10.1002/14651858.CD005318.pub2.

K Laver, SM Dyer, C Whitehead, et al. Interventions to delay functional decline in people with dementia: a systematic review of systematic reviews. (2016) *BMJ Open*, doi:10.1136/bmjopen-2015-010767.

Overall, there is evidence that when family and carers are educated about dementia, develop positive communication patterns with the person with dementia, and are involved in that person's care, then the person with dementia benefits.¹²⁹

What do we know about the dementia care workforce?

Internationally, workforce is a critical feature of care for people with dementia. Just four countries (Denmark, the Netherlands, Norway, and Sweden) have developed financial incentives targeted to care facilities or local authorities for further dementia training. Frameworks to recognise dementia care competencies, such as those developed in New Zealand and the United Kingdom (England), can help to better monitor care workers' skills and identify where further training is needed.¹³⁰ Norway and New Zealand have financial incentives for individuals to undertake dementia specific training.

There is research about education and training for different parts of workforce, such as health practitioners and paid carers. A systematic review of education for the workforce found that workforce training resulted in some improvement in the functional ability of people living with dementia in carrying out activities of living. However, nurse and care staff education had limited impact on residents' agitation, anxiety, mood and quality of life.¹³¹

Training for paid carers and health practitioners may be broad across the scope of dementia care, or specific to one aspect. Two recent systematic reviews report evidence that staff training improves the quality of dementia care. One review found evidence that training can reduce behavioural and psychological symptoms.¹³² The other examined how staff variables were associated with the quality of life and the quality of care of people with dementia who were living in aged care facilities.¹³³ This review found that relationships, residents' moods and food intake were improved and psychotropic use was decreased when staff were adequately educated and skilled in being empathetic and acting humanely.¹³⁴

¹²⁹ Organisation for Economic Cooperation and Development, above n 34, p 12.

¹³⁰ Ibid, p 33.

¹³¹ M Bauer, D Fetherstonhaugh, E Haesler, E Beattie, K D Hill and C J Poulos, 'The impact of nurse and care staff education on the functional ability and quality of life of people living with dementia in aged care: A systematic review' (2018) 67 *Nurse Education Today* doi: 10.1016/j.nedt.2018.04.019.

¹³² A Spector, M Orrell and J Goyder, 'A systematic review of staff training interventions to reduce the behavioural and psychological symptoms of dementia' (2013) 12 *Ageing Research Reviews* p 354–364.

¹³³ K Anderson, M Bird, S MacPherson and A Blair, 'How do staff influence the quality of long-term dementia care and the lives of residents? A systematic review of the evidence' (2016) 28 *International Psychogeriatrics* doi: org/10.1017/S1041610216000570.

¹³⁴ Ibid.

There is support in the literature for the education and training of people providing care to those living with dementia. Improvements were shown in:

- the assessment of behavioural problems and care for people with behavioural and psychological symptoms;¹³⁵
- communications associated with coping behaviours, and environments, dementia, or end-of-life and palliative care;¹³⁶
- knowledge and skills in behavioural management without physical or pharmacological restraint, recognition of delirium and dementia, Montessori activity training¹³⁷, and de-escalating aggressive incidents.¹³⁸

There are some specific challenges associated with the education and training for carers of Aboriginal and Torres Strait Islander people living with dementia. Although higher rates of dementia have been reported in Aboriginal and Torres Strait Islander people, the condition has different cultural interpretations and may be overlooked often in communities—including by local health workers and service providers. Geographical constraints in the provision of services, a lack of education and awareness in communities and by health workers, as well as the prevalence of other chronic diseases all pose considerable barriers to the recognition of dementia as an emerging health issue.¹³⁹

Conclusion

Dementia is a significant issue for the Australian community, and particularly the aged care and health systems. It can have a devastating impact on people's lives, both those living with dementia and their families, friends and carers.

With no medical treatments available to stop the brain diseases that cause it, treatment and care is directed at the prevention or delay of progression, reduction in symptoms and improvement in the quality of life.¹⁴⁰

Producing research findings that can be generalised across settings is challenging, particularly due to the ethical and research considerations that are necessary for this vulnerable population. The growing body of evidence and consensus about best practices indicates that throughout all stages of dementia, people can respond favourably to exercise, eating well, and staying as independent and socially connected as possible¹⁴¹, with caring and supportive relationships, and meaningful activities provided in safe and pleasant environments.¹⁴²

¹³⁵ S Fazio, D Pace, J Flinner and B Kallmyer, 'The Fundamentals of Person-Centered Care for Individuals with Dementia' (2018) 58 *Gerontologist*, doi:10.1093/geront/gnx122.

¹³⁶ G Livingston, A Sommerlad, V Orgeta, et al, above n 4, p 2693.

¹³⁷ Montessori activities support the person's independence through meaningful activities, roles and environmental cueing. Dementia Australia, viewed 24 April 2019, <https://www.dementia.org.au>.

¹³⁸ M Masso, C Duncan, P Grootematt, L Phillipson, P Samsa, D Fildes, and R Gordon, 'Specialist dementia care units: an Evidence Check rapid review' Sax Institute for the Commonwealth Department of Health, 2017.

¹³⁹ Flicker and Holdsworth, above n 58.

¹⁴⁰ G Livingston, A Sommerlad, V Orgeta, et al., above n 4.

¹⁴¹ Guideline Adaptation Committee, above n 3.

¹⁴² M Vernooij-Dassen and Y Jeon, 'Social health and dementia: the power of human capabilities' (2016) 28(5) *International Psychogeriatrics* 701–703. doi.org/10.1017/S1041610216000260.

There is broad agreement that the best practice care of people with dementia not living at home requires multiple approaches including:

- an individualised or person-centred unit philosophy;
- a supportive physical environment;
- a workforce that is educated and experienced in the care of people with behavioural dysfunction;
- medical and allied health staffing providing a broad program of therapeutic and meaningful activities;
- individualised and multidisciplinary assessment and care planning;
- a focus on timely assessment and care planning from a multidisciplinary team to avoid unnecessary transfers and missing important medical and psychiatric diagnoses.¹⁴³

¹⁴³ M Masso, C Duncan, P Grootematt, L Phillipson, P Samsa, D Fildes, and R Gordon, above n 138.