
National Framework for Action on Dementia 2015 - 2019

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Introduction

Dementia has a profound life-changing impact - not only on the person with dementia, but their carers, family members and friends.

In 2011, dementia was estimated to be the fourth leading cause of the overall burden of disease and the third leading cause of all deaths in Australia, with an estimated 298,000 people living with dementia. In the absence of effective prevention or cure options, estimates suggest that by 2020 around 400,000 people will be living with dementia in Australia. The number of people with dementia is projected to triple by 2050, reaching around 900,000 people.¹

In August 2012, Australian Health Ministers agreed to designate dementia as the ninth National Health Priority Area due to the increased burden of disease and the rising prevalence of dementia in Australia. Recognising dementia as a National Health Priority Area creates opportunities to improve the health status and wellbeing of people with dementia and their carers.

This *National Framework for Action on Dementia 2015 - 2019* (the Framework) has been developed under the auspices of the Australian Health Ministers Advisory Council (AHMAC) following an extensive national consultation process involving people with dementia, their carers, families, peak bodies that represent them, clinicians and service providers. This Framework builds on the achievements of the previous *National Framework for Action on Dementia 2006 – 2010* and aims to further improve the quality of life for those living with dementia and their carers.

The purpose of the Framework is to guide the development and implementation of actions, plans and policies to reduce the risk of dementia and improve outcomes for people with dementia and their carers. It does this by drawing on current evidence to promote dementia friendly societies and delivery of consumer-focused care.

The Framework presents seven priority areas for action:

1. Increasing awareness and reducing risk
2. The need for timely diagnosis
3. Accessing care and support post diagnosis
4. Accessing ongoing care and support
5. Accessing care and support during and after hospital care
6. Accessing end of life and palliative care
7. Promoting and supporting research.

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

The Framework will continue to bring the Australian, State and Territory governments together to create a strategic, collaborative and cost effective response to dementia across Australia. Each priority area focuses on significant aspects of care and support needed by a person with dementia over their lifetime and their carers. There are specific outcome and action statements for each priority area to assist jurisdictions to achieve improved outcomes for people with dementia and their carers. It also provides a framework for governments to review activity and progress under the seven priority areas.

It will be important that the impact of national policy direction and major initiatives, including the National Disability Insurance Scheme (NDIS), are considered over the duration of this Framework. The NDIS addresses the chronic unmet needs of people with significant non age-related disabilities. The scheme is not intended to replace the health or aged care systems. In its report, the Productivity Commission advocated that adequate support should be available in both the disability care and aged care systems.

People who have a diagnosis of dementia may be able to access the NDIS if their impairment results in substantially reduced functional capacity to undertake activities of daily living.

Vision

Improve the quality of life for people living with dementia and their support networks.

Intent

The Framework is designed to inform strategies and initiatives to:

- improve the community's understanding of dementia, including the risk factors of dementia, so they may take advantage of opportunities to reduce the risk of developing dementia, or delay its onset
- improve access and provision to appropriate assessment and timely diagnosis services by skilled and knowledgeable professionals
- improve access and provision to post-diagnosis information and support services for people with dementia
- ensure that services are person centred and support engagement, good health, well-being and enjoyment of life
- Increase understanding that dementia is a life-limiting condition that diminishes cognitive capacity over time. People with dementia require appropriate end of life and palliative care services tailored to their needs and preferences.

Principles

The Framework is underpinned by the following key principles:

- People with dementia are valued and respected, including their rights to choice, dignity, safety (physical, emotional and psychological) and quality of life.
- Carers and families are valued and supported, and their choices are respected.

- Social participation is actively supported, and an approach that promotes enablement, wellness and inclusion is adopted.
- People with dementia, their carers and families have access to competent, affordable, timely care and support services.
- Services are provided within a consumer-directed care philosophy, delivered in a person-centred way where individual needs and preferences are identified and met where possible.
- People with dementia, their carers and families receive care and support services when needed without discrimination.
- A knowledgeable and skilled workforce is essential in providing quality care.
- A collaborative approach is adopted to inform change and improve services.
- Evidence-based approaches, policies and practices are adopted for all dementia-related activities and services. Areas where the evidence base is inadequate should be prioritised for future research.

Understanding Dementia

Dementia includes more than 100 different diseases that affects the brain and leads to a progressive decline in functioning including: memory; thinking; orientation; awareness; comprehension; emotional control; sociability; calculation; learning capacity; language, and judgement.

There are numerous causes and types of dementia. The most common, Alzheimer's disease, accounts for more than 50 to 75 per cent of all dementia cases. Vascular dementia is the second most common representing 20 to 30 per cent of cases. Other forms of dementia include: fronto-temporal dementia; Pick's disease; dementia with Lewy bodies and alcohol-related dementia. There are, however, conditions that may manifest as dementia but that are not dementia – these include stress, delirium, depression and side effects of some medications.

While a relationship exists between age and dementia, dementia is not inevitable as one grows old; dementia is not a natural part of ageing. Although ageing is a contributing factor, dementia is a standalone condition which is affected by various other factors and can also affect younger people.

There are a number of factors which affect the reported incidence and prevalence of dementia in Australia. The projected rates of dementia are based on the rates released by Alzheimer's Disease International (ADI 2009) in the World Alzheimer Report 2009. These rates are based on estimates as there is currently no Australian population based study that collects this information. This is complicated by the substantial gap between when symptoms are first being noticed and time of diagnosis. The occurrence of under-diagnosis and under-disclosure means that data on prevalence does not accurately reflect the presence of dementia and is likely to be an under-estimation of the total number of people with dementia in Australia. Whilst noting these limitations, in 2011 an estimated 298,000 people were living with dementia, and this estimate is expected to grow to almost 400,000 by 2020 and 900,000 by 2050. ²

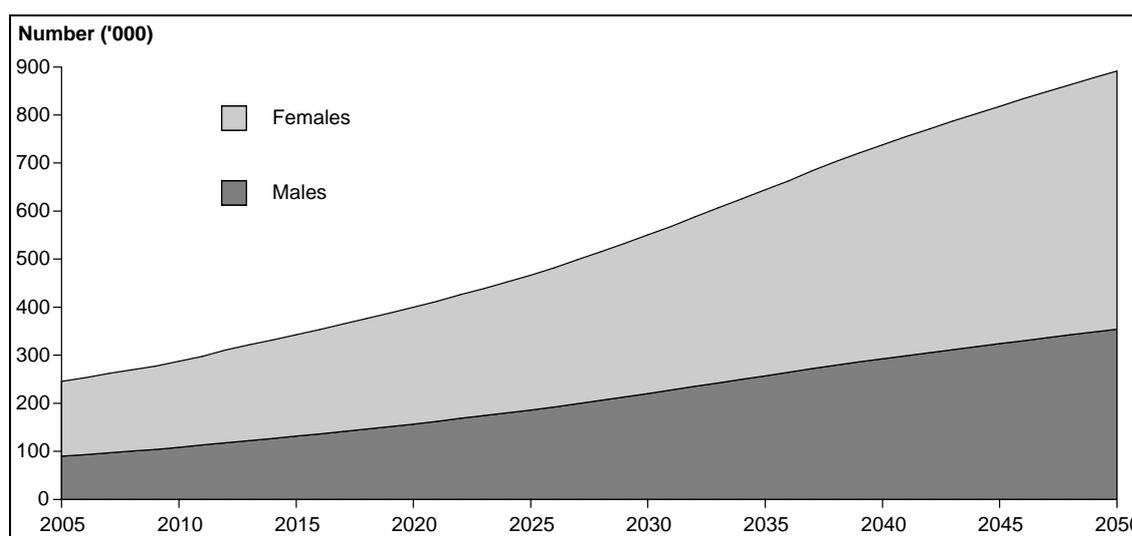


Figure 1: Estimated number of people living with dementia by sex, 2005 to 2050 (AIHW)

² Ibid

The burden of disease (a measure of healthy life lost) for people with dementia, is significant. In 2011, dementia was estimated to be the fourth leading cause of overall burden of disease and the second leading cause for people over the age of 65 in Australia. Dementia contributed to 6.3 per cent of all deaths in 2010 being the third leading cause of all deaths (after ischaemic heart and cerebrovascular disease) in Australia.³

Diverse needs groups

Like the rest of the population, people with dementia are not a homogeneous group. Frequently, it is the combination of the nature of the disease and diverse or special needs that create unique individual circumstances. While each person's experience with dementia is unique, there are population groups who have particular service needs and preferences.

Aboriginal and Torres Strait Islander people

In some regions of Australia such as the Northern Territory and Western Australia, studies indicate that the prevalence of dementia in the Aboriginal and Torres Strait Islander populations is over five times greater than the general population.⁴

While prevalence of dementia is likely to be greater in Aboriginal and Torres Strait Islander communities, awareness of dementia in these communities is lower than in the overall Australian population.⁵ Also, the perception of dementia can be quite different across Aboriginal and Torres Strait Islander communities. It is often not viewed as a medical condition, and consequently medical treatment or support is not often sought. Access to services may also be challenging due to a lack of services that take into consideration language, cultural or other circumstances unique to Aboriginal and Torres Strait Islander people and their communities.⁶

Younger onset dementia

Younger onset dementia refers to the onset of dementia in people under the age of 65 and under the age of 50 for Aboriginal and Torres Strait Islander people. It is estimated that in 2011 there were 23,900 Australians with younger onset dementia, representing nine per cent of all people with dementia in Australia.⁷

Younger Australians with dementia may face many challenges similar to those of older people with dementia, however the non-normative timing of the disease and different practical considerations present challenges different to those faced by older people with dementia. Younger people may face barriers to accessing appropriate services as dementia services tend to be designed around the interests and physical abilities of older people.

³ Australian Institute of Health and Welfare 2012, *Dementia in Australia (catalogue no. 70)*, AIHW, Canberra.

⁴ Office of the Coordinator General for Remote Indigenous Services 2013, *Official Committee Hansard 8 February 2013*, Canberra.

⁵ Garvey, G et al. 2011, Making sense of dementia: understanding amongst indigenous Australians, *International Journal of Geriatric Psychiatry*. vol. 26, no. 6, pp. 649–656.

⁶ National Rural Health Alliance 2012, *Submission to the House of Representatives Standing Committee on Health and Ageing - Inquiry into Dementia: early diagnosis and intervention (submission.036)*, National Rural Health Alliance, Deakin West.

⁷ Department of Family and Community Services 2012, *Service and support requirements of people with younger onset dementia and their families – final report*, viewed July 2013

Younger onset dementia is more likely to affect an individual's employment, family-raising responsibilities and other life stage roles, and is likely to have significant impact on carers and family members.

People from Culturally and Linguistically Diverse backgrounds

Different cultural perceptions of dementia are present in culturally and linguistically diverse (CALD) communities. In some communities, dementia is a taboo issue which is not openly discussed, resulting in even higher levels of stigma and negative community perceptions. These cultural perceptions impact on individual willingness to access services and decrease the likelihood of accepting support. In addition, individuals and their carers and families from CALD backgrounds often have limited knowledge of services, lower utilisation rates of community services and lower access to respite care. They may also prefer services that provide care and support in the home, for safety as well as cultural reasons, and are less likely to use residential care services. It is projected that the prevalence of dementia in CALD populations will increase to 45,651 in 2020 and 119,582 in 2050.⁸

People with disability

People with physical and intellectual disabilities are increasingly surviving to older age and therefore are vulnerable to age-associated disorders such as dementia. It is reported that one in five people, with an intellectual disability, aged 65 and older, have dementia.⁹

People living in rural and remote areas

People living in rural and remote communities face many challenges including access to primary and specialist health care. There may be a shortage of specialists and established multi-disciplinary teams, particularly in regional, rural and remote communities of Australia. In these locations, distance often presents a significant barrier to accessing primary and specialist care services. There is a requirement for service responses to support regional, rural and remote communities of Australia. This includes: access to primary health care, specialist medical care where necessary, as well as care and support services with flexible modes of delivery.

Other diverse needs groups

People who are financially and socially disadvantaged, homeless people, people living alone without suitable supports, veterans, care-leavers and those people who identify as Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) require specific supports and services that are sensitive and respectful to their needs.

⁸ Access Economics 2009, *Final report for Alzheimer's Australia- Keeping dementia front of mind: incidence and prevalence 2009–2050*, Access Economics.

⁹ Strydom, A et al. 2007, Prevalence of dementia in intellectual disability using different diagnostic criteria, *British Journal of Psychiatry*, vol. 191, pp.150-157.

The Framework

The Framework will continue to bring Australian governments together, to create a strategic collaborative and cost effective response to dementia across Australia. Each priority area focuses on significant aspects of care and support needed by a person with dementia over their lifetime and their carer. There are specific outcome and action statements for each priority area to assist jurisdictions to achieve improved outcomes for people with dementia and their carers.

1 Priority area for action – Increasing awareness and reducing risk

While dementia is the third leading cause of all death in Australia it is estimated that only one in five Australians are aware that the disease is terminal. It has also been reported that almost one-third of Australians feel uncomfortable spending time with people with dementia.¹⁰ This lack of awareness and understanding of dementia contributes to communities functioning in a way that is not always inclusive of people with dementia and their carers. These negative perceptions and the stigma surrounding dementia originates from a lack of understanding and the common misbelief that dementia is a natural part of ageing.

Negative perceptions of dementia in the community contribute to a level of marginalisation for people with dementia and their carers. Increased awareness and understanding of dementia and addressing risk reduction factors may promote and enhance health and social outcomes and quality of life for people with dementia and the broader community.

1.1 A collaborative approach to dementia friendly communities

The development of dementia friendly services and approaches may help to promote awareness and create communities which are more inclusive and accepting of people with dementia. For this to occur, the communities, including local businesses, health care professionals and other service providers should improve their understanding and awareness of dementia. The provision of amenities, goods and services in a user-friendly manner that meets the needs (including co-vulnerabilities) of people with dementia and their carers may help to facilitate inclusion.

Although, there are currently efforts to increase community awareness, further effort is required to make awareness-raising activities comprehensive, meaningful and effective.

Many of the awareness concepts, risk factors and risk reduction strategies are common across other National Health Priority Areas. This provides a good basis for collaboration as well as knowledge sharing among peak bodies and stakeholders. In their daily practices, health professionals can highlight risk reduction strategies that are universal across major diseases including dementia. For example, health professionals could proactively consider dementia when they are conducting risk reduction counselling for smoking, nutrition, alcohol and physical activity for a range of chronic diseases.

1.2 Tailored evidence-based approaches

Information and programs must be specific and tailored to target audiences. Particular attention is required for diverse needs groups where the approach adopted needs to be culturally sensitive.

Risk reduction and awareness strategies should be evidence-based and seek to improve and build on the current body of evidence. Messages about risk reduction and dementia awareness must be easy to read and encourage the public to seek further information and help if needed.

¹⁰ Standing Committee on Health and Ageing 2013, *Thinking Ahead- Report on the inquiry into dementia: early diagnosis and intervention*, Department of the House of Representatives, Canberra.

Increased awareness and understanding of dementia in the community will lead to better living experiences for people with dementia, their carers and families, and a more inclusive community. Improved outcomes include delays in disease progression and enabling people with dementia to participate in the community and maximise their independence through improved social engagement.

1.3 Outcome and Actions – Awareness and Understanding of Dementia

Australians have a greater awareness, acceptance and understanding of dementia and the actions they can take to reduce the risk of developing dementia

Dementia friendly communities
➤ Develop dementia friendly communities, where all aspects of the community’s built environment and approaches are dementia friendly, inclusive, promote respect, and acceptance and enable participation.
➤ Support and resource community based programs and initiatives to promote social engagement and develop dementia friendly environments.
➤ Develop communities and workplaces that are dementia friendly.
Collaborative awareness and risk reduction approaches
➤ Conduct awareness activities that highlight the need to understand and respect the rights of the person with dementia and treat people with dementia with dignity and respect.
➤ Adopt a collaborative evidence-based approach for awareness and risk reduction activities having regard to other relevant National Health Priority Areas.
➤ Link and promote population health strategies to support a healthy and physically active lifestyle for all Australians including people with dementia and their carers.
➤ Provide accurate and evidence-based information on risk factors and risk reduction strategies for dementia are readily available to the community ensuring that it is easy for individuals to seek further information and adopt risk reduction behaviours.
➤ Develop, deliver and promote programs to support health professionals and care workers increase their awareness and understanding of dementia.

2 Priority area for action – The need for timely diagnosis

The diagnosis of dementia provides a basis for accessing appropriate services, including support services and may assist with responding to and accepting the diagnosis. It is estimated that approximately 50 per cent of cases of early dementia are not detected on first contact with the primary care system.¹¹ Timely and accurate diagnosis also increases opportunities for continued social engagement, workforce and community participation; and gives people the power to control their life and plan for their future.

Lack of timely diagnosis may be attributed to limited knowledge and understanding of dementia as well as the stigma surrounding dementia and the general belief that memory loss is a normal part of ageing. People with dementia and their families may have difficulty distinguishing the early signs of dementia (e.g. memory loss, cognitive and emotion changes, functional disability) from their perception of ‘normal’ ageing. These barriers can be addressed by national public awareness activities, circulating communications and resources through organisations such as Alzheimer’s Australia to help people recognise the early signs and symptoms of dementia. Increased awareness and recognition amongst health professionals may help to detect the early signs of memory loss and appropriately monitor changes in order to make an accurate judgement about the need for further investigation.

People with dementia, their carers and families require access to high quality and appropriate early detection services, which includes access to knowledgeable primary care practitioners, specialists and diagnostic processes.

A timely and accurate diagnosis of dementia may facilitate early care and support responses, and help people with dementia, their carers and families to plan ahead. Diagnosis of dementia and advance planning may assist people with dementia to maximise their independence and enable continued choice and decision-making that contributes to a fulfilling and rewarding life.

2.1 Role of general practitioners

Although dementia can be diagnosed in a number of different settings, a general practitioner is often the first point of contact when people are concerned about the signs and symptoms of dementia. As a person’s main healthcare provider, a general practitioner is likely to have an important role in recognising, assessing, diagnosing and providing support. Establishing an accurate diagnosis of dementia can encompass several consultations over weeks or months, and long-term planning and support arranged with the person with dementia and their family.

To be effective in this role, general practitioners require ongoing support, this includes access to ongoing professional education to inform their practice, including:

- Dementia: its impact, prevalence and manifestation
- The use of evidence-based diagnostic tools

¹¹ Milnea, A et al. 2008, Screening for dementia in primary care: A review of the use, efficacy and quality of measures. *International Psychogeriatrics*, vol. 20, no.5, pp. 911-26.

- Awareness of services for patients and their carers, in response to sustained and emerging needs
- Clinical decision making tools, including referral systems and pathways.

General practitioners also need, at times, to be able to refer patients to specialist services and multi-disciplinary teams. These teams are usually led by a clinical specialist, who can use their combined expert skills and knowledge of dementia to support the individual patient and their family.

In-home assessments, conducted by a nurse practitioner or other clinicians, can be an important component in diagnosis. This information may supplement information identified in a general practice environment.

In addition, the role of nurse practitioners is increasing in rural and remote areas as a means of providing assessment and diagnosis for a person with dementia.

2.2 Multi-disciplinary teams and the role of carers

Dementia is a multifaceted condition, where diagnosis requires the input and expertise of multiple stakeholders, including carers, families and clinicians (such as general practitioners, psychologists, psychiatrists, psychogeriatricians, geriatricians, specialist nurses and allied health professionals).

Family and carers have a major role in the early detection of dementia, because they will often recognise early signs and symptoms which may not be apparent to the individual themselves. This recognition of symptoms by carers highlights the importance of the carer during the early stages of dementia, and their role in seeking medical investigation, care and support services.

People who live alone and who are socially isolated may not have family and carers who can monitor and respond to their changing cognitive function. The support of multi-disciplinary teams, together with appropriate linkages to community supports, is an important aspect of providing assessment, care and support to people with dementia who are living alone and without carers or family.

2.3 Tools to support the diagnostic process

A diagnosis of dementia requires the results of a suitable assessment process, a practitioner's clinical judgment, and information gathered from the person being assessed, their carers and families. The aim of the assessment is to gather sufficient information about changed behaviours, functional capacity, psychosocial issues and relevant medical conditions to allow for a diagnosis to be made. There are a range of diagnostic tools available to medical practitioners and other health professionals to assist in making an accurate diagnosis of dementia. The assessment process may vary according to who is conducting it and the symptoms with which the person presents.

There are challenges associated with achieving an accurate diagnosis in some population groups, including but not limited to people with an intellectual disability, people from CALD backgrounds, and Aboriginal and Torres Strait Islander people. Although there are specific dementia diagnostic instruments for people with CALD backgrounds and Aboriginal and Torres Strait Islander people, there is a need to further consider where separate guidelines and assessment methods are required.

2.4 Outcome and Actions – The need for timely diagnosis

Australians will have access to skilled and knowledgeable health professionals who can support and provide an accurate and timely diagnosis of dementia.

Access to high quality early detection services
➤ Provide diagnostic processes that are delivered according to best available evidence/practice.
➤ Encourage the appropriate and consistent use of validated clinical assessment and diagnostic tools.
➤ Improve links to specialist diagnostic services through the development of referral pathways in all settings
➤ Provide education and ongoing training for GPs and nurse practitioners to ensure a knowledgeable and skilful workforce regarding the diagnosis of dementia.
➤ Provide support and training in dementia for all levels of health professionals, including allied and community health professionals and paramedics.
➤ Undertake diagnosis of dementia using a multi-disciplinary approach where available, involving a range of health professionals and value the participation and views of carers.
➤ Support the use of telehealth and advances in information technology to improve access to timely diagnosis.
➤ Expand the use of Aboriginal and Torres Strait Islander specific diagnostic instruments and assessment methods in rural and remote communities where applicable.
Access to information and supports
➤ Support people to have access to information regarding the early signs of dementia.
➤ Support people with dementia, their carers and families, to access relevant information that enables them to make an informed decision about their care and treatment options.
➤ Provide information, advice, counselling and support for people with dementia, their families, carers and community members.
➤ Provide people with dementia, their carers and family members support as required to respond to grief, loss, conflict and relationship breakdown.

3 Priority for action – Accessing care and support post diagnosis

Following a diagnosis, people with dementia, their carers and families should be able to access information and support services to enable effective planning for their future. Care and support services may assist in improving the quality of life and independence for people with dementia, including the ability to exercise choice and decision-making that impacts on independence and lifestyle. Effective planning and decision-making during this period may help to support both immediate individual needs and to plan for longer term priorities and preferences.

3.1 Needs and preferences of people with dementia and their carers

Referral pathways and mechanisms differ between states and territories at local and regional levels. People with dementia require access to high quality care, which is seamless, interdisciplinary, involves appropriate referral pathways, is based on a person-centred approach, and is delivered by a skilled and knowledgeable workforce.

Interdisciplinary care

Interdisciplinary care and support encompasses a ‘whole of community’ approach, which focuses on partnership within the health sector and across other sectors as required. People with dementia may have varied pathways of progression and require care and support from a wide range of agencies. Addressing these needs requires a commitment to action, both from key stakeholders within the health and aged care sectors and services from outside these sectors.

Appropriate referral pathways

Appropriate referral by general practitioners to specialist dementia services can facilitate timely access to assessment, care and support. Specialist clinics and ACATs will facilitate access to a range of service including, but not restricted to:

- Geriatricians or psychogeriatricians (and adult psychiatry)
- Counselling and other allied health and nursing support
- Access to HACC, Home Care Packages and residential aged care
- Access to the resources and services of Alzheimer’s Australia

General practitioners and other health professionals need clear practice guidelines and information about local services and referral pathways to assist them to direct people to appropriate specialist support and care following a diagnosis.

Primary health care networks can also play an important role in improving the coordination and integration of primary health care in local communities which may address service gaps and assist people to navigate the local health care system.

Person-centred care

A person-centred approach assists services to see the person with dementia as an individual, rather than focusing on their illness or on the abilities that they may have lost. Instead of treating people with dementia as a collection of symptoms and behaviours, person-centred care considers the whole person and their individual characteristics. Adopting a person-centred approach enables people with

dementia to maximise their independence and exercise choices about accessing services according to their individual needs and preferences and results in a higher level of client satisfaction.

Access to a skilful and knowledgeable workforce

To deliver care and support, the workforce requires access to ongoing training and education, and encouragement to look beyond the technical aspects of care to identify and implement improvements that enhance the quality of life of people with dementia. People with dementia expect to receive care and support from a workforce who can demonstrate competence in the care of people with dementia based on dignity and respect.

Diverse needs groups

Tailored early support services are required for people with diverse and special needs who face particular challenges when accessing services. For example, CALD and Aboriginal and Torres Strait Islander communities often have lower levels of awareness of dementia which result in later diagnosis and poorer access to support services. Approaches to enhance access to services for these groups in a culturally sensitive and linguistically appropriate way are required.

People with younger onset dementia also have specific information, support and counselling needs. Information and support is required to enable them to discuss their current situation with their family, work, colleagues, community and social groups. They may need to discuss their abilities, changing needs and, potentially arrange flexible work conditions.

Future planning

Dementia is a progressive, degenerative disease that, at present, does not have a cure. However, if a timely diagnosis is made, people with dementia may have the opportunity to determine their future care plans and to undertake decision making relating to their future (including their future care, living, legal and financial arrangements), while they still have capacity to do so, and record these decisions through valid legal documents.

People with dementia and their carers should be encouraged to plan for the future and take advantage of advance care planning options.

3.2 Support for carers

Caring for a person with dementia may be time consuming and demanding for the carer. Informal carers (such as family members and friends) can play a vital role in the lives of people with dementia. Carers may assist with personal care, transport, housework and other activities, as well as understanding unmet needs that can lead to behavioural problems. Carers are likely to have knowledge and information that is critical to developing of effective and relevant care and support plans. Accordingly carers should be considered essential partners in the planning and provision of care in all settings. It should also be noted that being a primary carer may affect the relationships that the carer has with others.

Carers should have access to support tailored to their needs in order to effectively respond to and manage the pressures associated with the physical, mental and emotional demands of their caring role.

The provision of information and support services to carers may help to make the caring experience less stressful, and more rewarding. Online resources, such as the *My Aged Care* website, may assist

people to navigate Australia’s aged care system. Organisations such as Alzheimer’s Australia are funded to deliver services including the National Dementia Helpline, help sheets, a resourced website, counselling services, support groups as well as education and training for informal and formal carers. In addition, there are a range of carer organisations that can assist carers, including Carers Australia. These national organisations often have affiliated bodies in jurisdictions that people may access.

3.3 Outcome and Actions – Accessing care and support post diagnosis

Accessible, flexible and quality dementia care is available to people living with dementia and their carer’s are supported in their care role.
➤ Provide people with dementia, their carers and families with access to person-centred care and support post diagnosis, which is delivered by a skilled and knowledgeable workforce.
➤ Improve support for people with younger onset dementia through the provision of a link or key worker.
➤ Develop dementia specific interdisciplinary teams to coordinate the assessment and management of dementia service provision across all health care settings.
➤ Develop clinical referral and care pathways that are flexible including for people with dementia from diverse needs groups and people with younger onset dementia.
➤ Provide education, training and support for carers to enhance their skills to assist them in their caring role and connect carers and families to essential information about dementia and dementia services.
Planning for the future
➤ Provide support for people with dementia, their carers and families to plan for the future including in relation to lifestyle and living arrangements (such as proximity to services and family, future loss of driver’s licence) and advance care planning.
➤ Maximise opportunities for people with dementia and their representatives to plan for the future by raising their awareness of options relating to enduring guardianship and enduring powers of attorney and wills.

4 Priority area for action – Accessing ongoing care and support

The progressive nature of dementia means that the care needs and support requirements of a person with dementia change over time. The stage of the illness, the person's general health, life circumstances and living arrangements all affect the type and level of service and support that is required and where and when it is needed.

The impact of dementia on cognition, function and behaviour means that people with dementia, their carers and families require access to various support services including community, respite, residential and end of life and palliative care services.

4.1 Living at home

People with dementia, their carers and families need to be able to access the necessary care and support to continue living at home for as long as possible. When aligned with the preferences of people with dementia and their carers and families, such care and support has been shown to improve health outcomes and reduce healthcare costs.

In order to facilitate care at home, there is a requirement for an adequate amount of support and for this support to be distributed equitably across Australia, including to rural and remote locations. This support includes care services delivered by formal community care providers through a range of government subsidised programs such as the home support programs, Veteran's Home Care (VHC) program, the Department of Veterans Affairs (DVA) Community nursing program, and Home Care Packages (HCP). In addition, more informal personal supports may be provided by carers, care providers, local health services, pharmacies, government agencies, and community organisations such as Alzheimer's Australia and Carers Australia. For the person with dementia to continue living at home, carers should be effectively supported and services coordinated and integrated as much as possible.

Assessment and response tools

Access to medical, nursing and allied health assessment and advice is an important element of care for people with dementia. This enables them to live in their own home safely, and for as long as possible. Allied health professionals, such as physiotherapists, occupational therapists, speech pathologists, social workers, dieticians and psychologists, can assist carers to safely care for people living with dementia as the disease progresses.

Community engagement

Continued social engagement and community participation have benefits for people with dementia, their carers and families and the broader community. Maintaining adequate levels of community engagement and involvement is a goal of home care.

People with dementia progressively disconnect from activities and relationships in their lives. Community support and networks are needed to promote social engagement in activities that have been part of the person's life before diagnosis. People with dementia require access to a variety of daily activities which are interesting, meaningful and assist in meeting their social, physical, mental and spiritual needs.

Community participation for all people with dementia may be facilitated through the use of an enablement approach, which focuses on what they can do rather than on what they cannot do. Appropriate service structures may provide assistance to people with dementia to identify and pursue personally important, relevant and meaningful goals in their daily lives.

4.2 Respite care

Respite is of equal importance for the person with dementia as well as for their carer, and the outcomes for both should receive equal consideration when respite services are developed and delivered. Early uptake of respite services contributes to the wellbeing of both the person with dementia and their carer and may assist in developing links with future care services as the illness progresses.

4.3 Residential care

When people with dementia move into a residential care facility, their individual needs and preferences need to be understood and their overall wellbeing addressed. People with dementia living in residential aged care facilities may continue to be socially engaged if the environment is enriching and meaningful. For people with dementia, social engagement opportunities will come from both within residential care facilities and from the broader community.

Within residential care facilities, the best dementia care is about meeting people's need and creating opportunities for residents to use their abilities. People with dementia require access to activities which are similar to their experiences in the community. Interests which were important to the person before onset of dementia should also be seen as important to them now. Everyday activities, such as eating and bathing, and culturally significant activities provide opportunities for promoting self-esteem, dignity and feelings of self-worth and independence.

Environment

People with dementia require a safe living environment that provides physical comfort while mitigating the risk of undue harm. A safe, secure and homely environment can reduce confusion and agitation, improve way finding and encourage social interaction. It is facilitated by a good relationship between the service provider and the person with dementia. An efficient and effective environment includes family, friends, volunteers, and the broader community providing a genuine sense of partnership in care among all people involved in the care of the person living with dementia. Adoption of dementia friendly guidelines can assist with the establishment of physical environments better suited to the needs of people with dementia.

Assessment

Access to specialist psychogeriatric assessment and advice can be an important element of care for people with dementia living in residential facilities. There are specific assessment tools which may be used to monitor the signs and symptoms and progression of dementia. The assessment and advice provided by allied health professionals, such as physiotherapists, occupational therapists, speech pathologists, social workers, dieticians or psychologists, is essential for attaining the best quality of life for the person with dementia.

A collaborative approach

Formal relationships between residential care facilities, local hospital and community networks, primary health care networks and private practitioners may help to reduce unnecessary hospitalisation for people with dementia. These partnerships may involve arrangements where geriatricians, psychogeriatricians and other health professionals visit residential aged care facilities to provide outreach services. The Dementia Behaviour Management Advisory Service (DBMAS) may also be a valuable resource, particularly in relation to prevention and management of the behavioural and psychological symptoms of dementia (BPSD).

Telehealth and eHealth technologies may be used to undertake virtual consultations where onsite consultation is not possible. The use of these technologies may be especially beneficial in rural and remote locations.

Partnerships between residential aged care facility staff, the person with dementia and their carer are important to ensure that a consistent approach is adopted in the provision of care and supporting people to live well. This approach provides opportunities for the carer to advocate on behalf of the person with dementia, to ensure their needs and preferences are met.

Support for carers

It is vital to recognise that the caring role does not cease when the person with dementia enters a residential facility. The caring role changes and support should be in place to assist the carer with the transition from home care to residential care. This support needs to remain in place whilst the person with dementia continues to live in the facility.

4.4 Behavioural and Psychological Symptoms of Dementia

Behavioural and Psychological Symptoms of Dementia (BPSD) can be distressing and have a severe impact on the person with dementia, their carers and families, care workers, and the broader health system. BPSD may occur in any care setting including home, respite care, hospital or residential care. The aim of care should always be to try and prevent the emergence of BPSD, particularly focussing on biopsychosocial approaches.

If not effectively managed, BPSD may reduce quality of life, increase carer burden, and risk premature entry into residential care or inappropriate admission to hospital.

Care and treatment should focus on identifying the triggers of BPSD including unmet needs (e.g. hunger, pain, comfort). Comprehensive assessment of a person exhibiting BPSD by an appropriately skilled and resourced care team may identify whether there are triggers for BPSD such as staff practices, pain, discomfort, environmental stressors or over stimulation, and apply tailored strategies to prevent, overcome or deal with distress. The services offered by the Dementia Behaviour Management Advisory Service may assist development of individual and organisational BPSD prevention and management strategies, including offering relevant training and education.

Advice from a medical specialist, such as a psychogeriatrician, may improve outcomes for the person with BPSD, particularly where it is necessary to eliminate other causes of BPSD such as delirium. This may include obtaining a differential diagnosis that eliminates other causes such as delirium (refer to section 5.2) that require further investigation for cause.

Carer support such as increasing time available to carers and providing carer education and training in relation to BPSD may be effective in decreasing burden and reducing the impact on the carer, and the individual's behaviour. In addition, ongoing education and training is required for all members of multi-disciplinary teams that help to support and respond to people exhibiting BPSD. This training, coupled with the use of established guidelines, will enable service delivery that is in line with evidence based guidelines.

Medication management and review

People with dementia often have co-morbidities and may take multiple medications to manage those illnesses. A decision about the use of medicine to treat BPSD is a clinical one made by the prescriber based on individual circumstances. It is vital to adopt a collaborative approach to the management of medications for people with dementia as many medicines may induce or worsen BPSD. Feedback should be obtained from people with dementia, their carers and families and regular pharmaceutical reviews by pharmacists and prescribers conducted.

Antipsychotic drugs are, at times, prescribed to assist with controlling the challenging behaviours displayed by people with BPSD. Consideration should be given to the side effects and potential risks of antipsychotic drugs for people with BPSD before prescription and administration. Pharmaceutical care provides one treatment alternative and consideration should be given to behavioural, psychological and environmental therapies.

A seven tiered model

The seven tiered model of service delivery for BPSD¹² provides an evidence based practice model of management. Ideally, support provided for people exhibiting BPSD is based on this seven tiered model, where support is cumulative: people at the bottom end of the spectrum, with less developed signs and symptoms, receive the least intervention and people at the top end of the spectrum, with further developed symptoms, receiving the most. Methods of treatment should include non-pharmacological management of BPSD irrespective of where the BPSD may be positioned in this seven tiered model.

Within residential settings, effective responses to BPSD include the right mix of dementia friendly organisational policies, leadership, facility design, staff and resources.

4.5 Diverse needs groups

Aligned with a person-centred approach, tailored delivery of longer term and continuing care is required for diverse needs groups. Diverse needs groups with dementia experience challenges in all aspect of care, including limited access to residential and respite services. This largely results from their diverse needs, limited access to services and the limited awareness of services and service options. The quality and availability of services for diverse needs groups can be enhanced through improved education and training for the workforce.

¹² Brodaty H, Draper, B & Low, LF 2003, Behavioural and Psychological Symptoms of Dementia: A Seven Tiered Model of Service Delivery, *Medical Journal of Australia*, vol. 178, pp 231 – 34.

For people with younger onset dementia, ongoing care needs are directly related to life stage. Independence is closely related to maintaining relationships with family and friends and maintaining work arrangements for as long as possible.

People with younger onset dementia are likely to have different needs and preferences for respite and residential care and are not easily aligned with aged care services. New service models, policy and practice will need to respond to this challenge. Disability services, historically the primary service providers for people with younger onset dementia, are increasingly moving towards a person-centred approach, linked to individualised funding options.

4.6 Outcome and Actions – Accessing ongoing care and support

People with dementia and their carers will have access to quality dementia care and support
➤ Provide people with dementia, their carers and families access to home care services that are person-centred, and are delivered by a knowledgeable and skilful workforce.
➤ Assist carers to access support services and education programs to support them in their care role.
➤ Assist people with dementia, their carers and families to access the advice and support they need.
➤ Provide people with dementia and their carers and families access to appropriate and responsive respite services.
➤ Provide and promote dementia training and ongoing education for all staff that care for people living with dementia.
➤ Support people with dementia in residential aged care facilities to continue to be socially engaged both within and outside the facility (in the broader community) to retain their choice and involvement in decision-making.
➤ Support people with dementia in residential aged care facilities to have access to specialist medical and non-medical services, care and support.
Behavioural and Psychological Symptoms of Dementia
➤ Support system wide, organisational and workforce awareness of BPSD together with evidence-based prevention and management strategies, including the provision of dementia friendly environments.
➤ Provide opportunities to staff, family and carers of people with dementia to learn skills to prevent and respond to BPSD using psychological, behavioural and environmental techniques.
➤ Provide access to quality mental health services as required for people with BPSD.
Diverse needs groups
➤ Support culturally appropriate care for people with dementia from diverse needs groups including Aboriginal and Torres Strait Islander and CALD communities.
➤ Provide support for people with younger onset dementia and their carers to remain in employment for as long as possible and to maintain family and community participation.
➤ Provide age appropriate home, residential and acute care support services to meet the needs and preferences of people with younger onset dementia, their carers and families.

5 Priority area for action – Accessing care and support during and after hospital care

The presence of people with cognitive impairment, including dementia, is common in acute care settings. People with dementia often present in acute care settings (hospitals) due to a medical emergency, exacerbation of a chronic illness or following the onset of an acute illness, but rarely for dementia itself. Approximately 21 per cent of those in hospital over the age of 75 are found to have a diagnosis of dementia and 47 per cent of people with dementia may not have dementia documented after admission into hospital.¹³ Despite its prevalence, cognitive impairment (including dementia) is not always readily recognised or effectively responded to in all acute care settings.

Multiple bed moves, an unfamiliar environment and invasive procedures may exacerbate confusion, agitation, behavioural problems and falls. These effects may be detrimental to a person with cognitive impairment or dementia, and its impact may have ongoing negative effects well after discharge.

5.1 Acute care setting

The role of carers and families is essential in acute care settings. Often, dementia may go unrecognised, especially if the person with dementia, their carers and families are not consulted. Carers and families usually have the most contact with the individual and may be able to provide the most accurate and complete history.

Engaging the person with dementia, their carers and family in the planning of care may help to facilitate more rapid, accurate assessment, diagnosis and support for the person with dementia. This engagement may also provide opportunities for carers and families to gain a better understanding of the care plan developed with the care team.

Adequate support for people with BPSD remains a significant challenge in an acute setting. Symptoms such as anxiety, agitation, aggression, wandering, disinhibited behaviour, delusions and hallucinations significantly reduce the ability to provide quality care in acute settings. These behaviours pose significant barriers for health care professionals in their efforts to effectively respond to a person's dementia and other health concerns. Possessing the appropriate skills and knowledge to recognise BPSD and respond effectively will significantly improve the outcomes for people with dementia.

To enable the delivery of better health care for people with dementia in an acute setting, training and education programs are required to assist the acute health care workforce build their knowledge base.

There is a case for dementia training to be incorporated in all undergraduate and postgraduate health professional programs. In doing so it will raise awareness and help build workforce understanding of dementia, which will be beneficial to acute care practice over time. Greater

¹³ Australian Institute of Health and Welfare 2013, *Dementia care in hospitals costs and strategies*, AIHW, Canberra.

understanding by care providers of the challenges confronting people with dementia and their carers will assist in improving care and outcomes.

Age friendly design principles should be adopted to create a dementia friendly environment within acute care settings. This may include the establishment of specific units in hospitals which can improve the care of people with dementia. These units can provide specialist care in a safe and less restrictive environment that maximises a person's functional capacity. It also creates opportunities for training and education in dementia-related care for health care professionals. Dementia specific units may enhance hospital practice in other units through improved access to specialist dementia programs and specialist support for people with dementia and co-morbidities.

In some cases, it may be possible to provide acute care in a non-hospital environment. Hospital substitution programs, such as Hospital in the Home or Hospital in the Nursing Home, along with emerging hospital avoidance programs, may be beneficial as they encourage care in the familiarity of 'home'. For the person with dementia this can avoid the disorientation and stress associated with transfers between settings and unfamiliar environments.

5.2 Delirium

Delirium is an acute and reversible confusional state and, although it is not dementia, it is commonly experienced by people with dementia. In Australia, it is estimated that approximately 56 per cent of people aged over 65 who are admitted to hospital are affected by delirium.¹⁴ Delirium may cause behavioral and psychological symptoms that are difficult for staff to effectively respond to in the acute care setting and is often associated with an increased length of stay in hospital.

Delirium can be caused by infection, pain, dehydration, constipation, sensory deprivation (poor eye sight and/or hearing), polypharmacy and poor food intake. The cause of delirium may be pinpointed by engaging in careful and thorough assessment and treated accordingly. The identification of the cause of delirium can help to provide support immediately and appropriately and to promote better clinical outcomes. Health care professionals require training so that they are able to identify and respond to delirium effectively and appropriately in the acute care setting. *Delirium Care Pathways*¹⁵, developed by Australian Health Ministers, can assist with improving the coordination of care and minimising adverse outcomes for people during delirium.

5.3 Whole of hospital response

A national approach to dementia care standards in acute care settings and the introduction of standards for quality dementia care into institutions will promote better awareness, recognition and care of dementia in hospital and ensure consistent care and support as a person moves between different care settings. The implementation of mandatory safety and quality standards for hospitals may facilitate greater levels of accountability and compliance, and promote consistency in service delivery. This has the potential to improve the level of quality, diagnosis and care for people with cognitive impairment (including dementia) in hospitals and acute care settings.

¹⁴ Department of Health and Ageing, *Delirium in older people* (2006)

¹⁵ Australian Health Ministers' Advisory Council (AHMAC), *Delirium Care Pathways* (2010)

Support for acute hospital admissions and multi-disciplinary discharge planning (including medication and follow up treatment) may be improved by establishing systems between the acute and other care settings, such as care in the community and in residential aged care facilities. For example, effective discharge planning may help to ensure appropriate support continues when people return to their usual care environment.

5.4 Outcome and Actions – Accessing care and support during and after hospital care

People with dementia in an acute care setting receive quality care

Acute care health professionals are able to recognise and respond to people living with dementia
➤ Improve assessment for cognitive impairment and identification of dementia on admission in the acute health care setting.
➤ Develop and promote the use of an evidence based clinical care pathway when caring for people with dementia in an acute care setting.
➤ Develop and implement training for relevant health care professionals in the acute care setting to recognise BPSD and respond effectively.
➤ Support training and education programs to assist the acute health care workforce to provide evidence based dementia care.
➤ Support carers and families to be included as part of a team and ensure that their roles in assisting diagnosis and in the planning and provision of care are recognised and fully utilised.
Standards for quality care of people with dementia in an acute setting
➤ Develop standards for quality dementia care to promote better awareness, recognition and response to people with dementia in the acute setting.
➤ Develop processes to ensure standards are applied.
➤ Support consistent use of admission and discharge planning initiatives for people with dementia entering and leaving an acute care setting.
➤ Explore the expansion and utilisation of telemedicine to enable access to dementia specific follow-up post discharge from an acute setting, particularly for people with dementia living in regional or rural and remote communities.
➤ Examine options for hospital care in other settings, e.g. Hospital in the Home, Hospital in the Nursing Home.
➤ Ensure that people with dementia have access to a safe and secure hospital environment which is suitable for their needs.

6 Priority area for action – Accessing end of life and palliative care

Accessing appropriate end of life care and palliative care is essential for people with dementia and their carers, and the presence of an advance care plan may facilitate delivery of care that meets their expressed preferences. End of life care and palliative care have many aspects that are unique to people with dementia, specifically as a result of the disease trajectory of dementia which differs to that of many other chronic diseases.

6.1 Planning for end of life

Advance care planning is a series of steps people take to help them think about and plan for their future medical care, enabling the person living with dementia to communicate decisions about wishes for their end of life care.

Planning for end of life care in the earlier stages of dementia means that people with dementia may contribute to their care planning, and be confident about the care they receive as their condition deteriorates. When a person with dementia arrives at the end of life stage, advance care planning and other planning arrangements may be implemented as agreed, ensuring that the person's preferences and wishes can be met.

6.2 Adoption of a palliative approach

The terms “end of life” and “palliative care” are sometimes used interchangeably. In this Framework, a distinction is drawn between end of life and palliative care. End of life is an overarching term that describes the stage of life leading up to death for people with dementia (and impacts on their carers and families).

The World Health Organisation (WHO) describes palliative care as “providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement”. This Framework encourages that a palliative approach be adopted. Components of a palliative approach include support for dealing with symptoms of dementia and other health concerns; psychological, social and spiritual care for people with dementia, their carers and families; and bereavement and respite services for carers and families.

Many health needs faced by people with dementia are already present prior to the end of life stage. Symptoms may increase as the disease progresses, reaching very high levels in the end of life stage. Some of the health related needs and symptoms include under-recognition and support to deal with pain, nutritional needs and support, infections, BPSD and personal comfort.

For carers, the end of life stage can be a period filled with grief and loss. Bereavement services, including counselling and support relating to the death of a loved one, should be promoted and available to carers and families.

Carers and families provide the majority of care, which often intensifies in later stages of dementia. Carer health and wellbeing requires recognition and support.

6.3 High quality service provision during end of life care

There is evidence to suggest that services to support end of life in dementia can be improved. Issues include access to palliative care at the end of life, under and over treatment of symptoms and complications, and inadequate policies and workforce to support quality care. To address these issues, it is desirable that services be delivered in a person-centred and holistic manner.

Health professionals and other care providers play a lead role in the delivery of quality services. Optimal service delivery requires an adequate level of awareness and understanding surrounding a palliative approach to end of life care.

Providing options for end of life care outside the hospital setting, at home and in residential care may improve quality of life and help to retain dignity for people with dementia. Remaining in their familiar surroundings may positively impact on feelings of orientation, comfort and safety, as well as reducing the risk of infections and unnecessary medical treatments.

6.4 Outcome and Actions – Accessing end of life and palliative care

People with dementia have access to high quality care that supports a palliative approach during end of life

Advance care planning
➤ Promote advance care planning in the early stages following a diagnosis of dementia.
➤ Support advance care plans to be actively reviewed, refreshed and implemented in the care provided.
➤ Provide training and education regarding advance care planning options.
Adoption of a palliative approach
➤ Provide training and education regarding a palliative approach.
➤ Develop effective care and referral pathways to enable seamless transition to palliative care services for people with dementia.
➤ Support development of services and programs to meet the needs of people with dementia requiring end of life and palliative care living in rural and remote communities.
High quality end of life care
➤ Develop and implement strategies to increase the awareness and understanding of end of life needs and preferences.
➤ Provide education, training and information for carers to access and utilise culturally specific information to improve end of life care for people with dementia.
➤ Develop links between research and practice to improve the quality of end of life care for people with dementia.
➤ Provide options for end of life care outside the hospital setting, including at home and in residential care.

7 Priority area for action – Promoting and supporting research

Research into risk reduction strategies, treatments and a cure for dementia is necessary to address the increasing prevalence. The research effort should be complemented by ensuring the current and future research is translated into practice to ensure better outcomes for people with dementia and their family and carers. Research activities are the collective responsibility of all jurisdictions and all levels of government.

There is a substantial research base and current research agenda on how to improve service responses to dementia. For example, the National Health Medical and Research Council (NHMRC) funds research into all National Health Priority Areas, including dementia. Also, in May 2014, the Australian Government committed \$200 million over five years specifically for dementia research, including \$50 million for the establishment of a National Institute for Dementia Research. The research to be undertaken, as well as research already underway, corresponds to the scope of the Framework including: timely detection; assessment and diagnosis; care and support, post diagnosis and for the long term, and in acute care settings; and end of life and palliative care.

Overall, the research agenda for dementia is broad. It ranges from laboratory-based science to practice-based studies. Some of the focus areas for dementia research include:

- the provision of more timely diagnosis in primary care and through advances in technology such as neuroimaging
- laboratory-based science which aims to discover the cause of Alzheimer's disease, including development of blood tests to enable more accurate and earlier diagnosis, and identification of medicines to halt or reverse dementia
- provision of optimal care and support for people with dementia care in the home and in residential care settings
- assistance for carers and families to reduce stress and improve quality of life for themselves as well as for those with dementia.

The causes of dementia are complex and influenced by many factors acting in combination. Reducing the risk of dementia, and delaying disease onset and progression depends on a greater understanding of these determinants. Many risk and protective factors have been identified however, relatively few of these factors have been definitively established, with most considered either probable determinants or inconclusive.

7.1 Outcome and Actions – Promoting and supporting research

Health care providers and the community have access to evidence based research into dementia to inform prevention, care and treatment across all care settings

Evidence based research
<ul style="list-style-type: none">➤ Conduct dementia research, including into:<ul style="list-style-type: none">– causes– diagnosis– care– treatment– carers– identification of risk factors and risk reduction strategies– end of life care– cure.
<ul style="list-style-type: none">➤ Explore opportunities for collaborative research particularly in relation to other National Health Priority Areas.
<ul style="list-style-type: none">➤ Promote the translation of current and future evidence based research into the practice of dementia care from diagnosis to end of life.
<ul style="list-style-type: none">➤ Improve hospital data collection of dementia, including clinical coding to better inform research activities.

7.2 Acronyms and terms

Acronym/Term	Definition
Advance Care Planning	Advance care planning is the process of planning for a person's future health and personal care. Advance Care Planning helps ensure that an individual's choices are respected for future medical treatment. Their beliefs, values and preferences are made known, in order to guide future care in the event that the person is unable to make decisions or communicate. ¹⁶
AHMAC	Australian Health Ministers' Advisory Council
BPSD	Behavioural and Psychological Symptoms of Dementia
CACP	Community Aged Care Packages
CALD	Culturally and Linguistically Diverse
Care-Leaver	A person who was in institutional care or other form of out-of-home care, including foster care, as a child or youth (or both). Care-leavers include Forgotten Australians, former child migrants and people from the Stolen Generations.
DBMAS	Dementia Behaviour Management Advisory Service
DFE	Dementia Friendly Environments
Diverse needs groups	This includes a wide range of diverse population groups including but not limited to; Aboriginal and Torres Strait Islanders; people from culturally and linguistically diverse backgrounds; those living in rural and remote areas; and people with disability.
DVA	Department of Veterans' Affairs
HCP	Home Care Packages
Jurisdictions	Australian Government, State and Territory governments
LGBTI	Lesbian, Gay, Bisexual, Transgender and Intersex
MBS	Medicare Benefits Scheme
NHMRC	National Health and Medical Research Council's
VHC	Veterans' Home Care
WHO	World Health Organisation

¹⁶ Department of Health, Victoria 2013, Advanced Care Planning

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