Supporting people with dementia and their families and carers
Victorian dementia action plan 2014–18
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Some words from people with dementia

- We can forget where we put things.
- We can forget what we have been doing, even recently.
- We can forget people's names, even people close to us.
- We can forget we have done something and repeat doing or saying things.
- Our strongest memories may be for events from the past.

**It impairs our reasoning:**
- We can find abstract notions like money and value confusing.
- We can find the results of actions hard to predict.
- We can misunderstand the pattern on the floor.

**It impairs our ability to learn:**
- We can find new places disorienting.
- We can have difficulty getting used to unfamiliar objects or routines.
- We forget where basic things like the toilet are.

**It raises our levels of stress:**
- We can find large groups difficult.
- We can become anxious in situations we coped well in before.
- Too much noise makes us confused.

**It makes us very sensitive to built and social environments:**
- We can be very sensitive to the emotional atmosphere.
- We benefit from calmness.
- We need good lighting to give us as much information as possible about our surroundings.

**It makes us more and more dependent on all our senses:**
- We may need to be able to smell, feel and see things.
- We can get agitated if we get too hot.
- We can get confused if there is not enough light.
Five major needs of people with dementia shape person-centred care (Kitwood 1997):

1. **Comfort**
   People living with dementia may have a sense of loss, causing anxiety and insecurity. They need an environment of comfort and empowerment.

2. **Attachment**
   The need for attachment is strong in each of us, more than ever when we feel like a stranger in someone else’s environment. People with dementia need to feel a sense of belonging.

3. **Inclusion**
   People with dementia can find it hard to be included in situations where others do not have the same impairment. Individualised care and physical settings help people feel they are part of a group.

4. **Occupation**
   Being occupied means being involved in everyday life. Carers and designers need to create conditions that support social involvement, drawing on people’s experiences, strengths and abilities.

5. **Identity**
   A person with dementia is unique. A person’s life-story should be built into all interactions in the care setting.

‘Being at home works. It’s a familiar environment. Mum can access the bathroom when she wakes up at night. The neighbours know Mum and Dad and how to support them – do you need a lift?’

Carer, Alzheimer’s Australia Vic, March 2014
What is dementia?

Dementia is not a single specific disease, but an umbrella term describing a syndrome – or group of symptoms – associated with more than 100 different diseases. It is characterised by the impairment of brain functions, including language, memory, perception, social awareness, reasoning and cognition. Although the type and severity of symptoms and their pattern of development varies with the type of dementia, it is usually of gradual onset, progressive in nature, and irreversible.

Australian Institute of Health and Welfare, Australia’s health 2014

The progress of dementia, from early to final stages of the disease, varies from person to person. People with dementia have various abilities and capacities depending on the individual, type of dementia, how far the dementia has progressed and other influences. A focus on each person’s individual capacities and maximising their abilities is essential throughout all stages.

Appendix 1 defines terms and concepts.
Introduction

Vision

Improve the quality of life for Victorian people with dementia and their families and carers.

The main focus of the Victorian dementia action plan is people with dementia, and their families and carers. Improving their quality of life requires better awareness, knowledge and responses from all service, community and business sectors and the population as a whole.

Government, the private sector, hospitals, legal entities, transport providers, planners and community groups all have a role to play in creating communities and environments that are friendly for older people including people with dementia.

‘Educate the public, not just medical people. People need to know we look just like them, but we have different needs. People should respect us.’

Person with dementia, Alzheimer’s Australia Vic, March 2014

Change depends on partnerships between government, non government organisations, schools and most of all people with dementia and their families and carers. Although the health sector takes a lead in some areas related to dementia, it does not have direct responsibility for many things that could improve quality of life for people with dementia.

The health sector can, however, lead or promote partnerships that encourage different industries and organisations to take action in physical and social environments in which they play a lead role. Dementia-friendly communities and environments can benefit people of all ages.

Partnerships with people with dementia and their families and carers enable people to have a say in their care and support. People with dementia need to be engaged early in discussions about care, including their end-of-life care, while they can still make decisions.

This action plan also focuses on reducing risk factors for dementia. These risk factors are the same as for many other chronic conditions. Once again, promoting health and reducing risk factors for dementia has benefits for everyone.

All older people, including people with dementia, should be healthy, able to participate in the community and be active as they get older. The World Health Organization (WHO) defines active ageing as ‘a process of optimizing opportunities for health, participation and security for quality of life as people age, allowing people to realise their potential for physical, social and mental well-being throughout their lives’.

A shared understanding of person-centred holistic support and care, coordinated services, partnerships, enablers and outcomes is integral to facilitating and shaping meaningful action. This plan aims to bring consistency to these concepts, and provide a strong platform for achieving the vision.
The context for the Victorian dementia action plan includes:

- National Framework for Action on Dementia (NFAD)
- Seniors Count 2014–2019: Victoria’s Seniors Participation Action Plan
- Commonwealth-state jointly funded Home and Community Care (HACC) program
- responsibilities at federal, state and local government levels.

A note on the Victorian service system while the Victorian dementia action plan is being implemented: The Victorian Government is working with the Commonwealth Government to implement major national changes to the Home and Community Care (HACC) program to retain the benefits of Victoria’s current HACC service system. Many of these benefits contribute to supporting people with dementia and their carers. The resources in the HACC program are to be split on 1 July 2015, so that the Commonwealth takes funding and administration responsibility for services for people aged 65 and over. Victoria retains the responsibility for services for people aged under 65. The HACC program continues to be funded jointly by Commonwealth and Victorian Governments, and administered by the Department of Health Victoria, until 1 July 2015.
Seniors Count! heralds a shift in how we think about ageing and sets a new course for ageing well in Victoria. It will support seniors to have their voices respected, keep healthy and well, stay active within age-friendly communities and share their skills and contribute to the community.

The seven priority action areas of the Victorian dementia action plan are:

- Increase awareness of and responsiveness to dementia, and improve the health and wellbeing of older people.
- Support timely assessment and diagnosis.
- Plan for diversity in the delivery of support and services.
- Maximise independence, health and wellbeing of people with dementia.
- Promote dementia friendliness in age-friendly communities.
- Support families and carers of people with dementia.
- Support people with dementia at the end of their lives.

Who this document is for

The Victorian dementia action plan is for organisations and individuals who can help implement the vision of improving quality of life for people with dementia and their families and carers. This includes service system organisations, non-government organisations, policy makers in local, state and federal governments, practitioners, and consumers and their representative organisations.
1 What we currently do

International collaboration seeks to support people with dementia and their families and carers. In Australia, many organisations share responsibility for action on dementia. This includes organisations funded by the Commonwealth, Victorian and local governments such as service providers, peak bodies, and advocacy groups.

Global context

Dementia affects an estimated 35 million people worldwide, a figure set to almost double every 20 years. The world’s first G8 dementia summit was held in London on 11 December 2013, bringing together government ministers, researchers, pharmaceutical companies and charities to discuss what can be done to:

- stimulate greater investment and innovation in dementia research
- improve the prevention and treatment of dementia
- improve quality of life for people with dementia.

Ministers from each of the G8 countries delivered prepared statements during the first session of the summit. In the declaration and communiqué resulting from the summit, the G8 ministers agreed to:

- set an ambition to identify a cure, or a disease-modifying therapy, for dementia by 2025
- significantly increase the amount spent on dementia research
- increase the number of people involved in clinical trials and studies on dementia
- establish a new global envoy for dementia innovation, following in the footsteps of global envoys on HIV and AIDS and on climate change
- develop an international action plan for research
- share information and data from dementia research studies across the G8 countries to work together and get the best return on investment in research
- encourage open access to all publicly funded dementia research to make data and results available for further research as quickly as possible.

Commonwealth responsibilities

As well as jointly funding the Aged Care Assessment Service (ACAS) and, up to July 2015 the HACC program with the state government, the Commonwealth Government funds healthcare provided in general practice and hospitals, pharmaceuticals, residential aged care, home care packages, respite, and research into the cause, prevention and cure of dementia. The Commonwealth and jurisdictions have developed the National framework for action on dementia 2014–18 (NFAD).

The NFAD has 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 on-going 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.
The Commonwealth also funds:

- $200 million to boost dementia research from 2013–2018. The funding is for Australian scientists and medical researchers to continue working on prevention or cure of dementia. The Commonwealth is establishing a National Institute for Dementia Research which will be hosted by the National Health and Medical Research Council.

- Alzheimer’s Australia Vic to deliver the Living with Memory Loss Program. The program informs people with early stage dementia and family members about dementia pathways, how to access personal and home services, community services, activities for people with dementia and their families and carers, and how to make plans for the future, including appointing a substitute decision maker.

- Dementia Behaviour Management Advisory Service (DBMAS) to improve the quality of life for people with dementia whose unmet needs impact on their support and care. DBMAS provides advice and support to care workers, family carers and service providers.

- National Respite for Carers Program\(^1\) to provide community-based and residential respite options for families and carers.

- Dementia training study centres to provide professional development opportunities for practitioners, including general practitioners, nurses, aged care and dementia service providers, medical specialists, psychologists, psychiatrists, allied health professionals and tertiary institutions.

- Other initiatives, such as the National Dementia Support Program (NDSP). The Commonwealth funds Alzheimer’s Australia state and territory offices to provide the following services under the NDSP:
  - National Dementia Helpline and Referral Service
  - support and counselling
  - information, awareness, education and training
  - support for people with special needs

- the Commonwealth Aged Care Reform package includes new supplements to provide additional financial assistance to approved providers, through:
  - Dementia and Cognition Supplement in Home Care Packages
  - Dementia and Severe Behaviours Supplement in Residential Care
  - Veterans’ Supplement in Home Care Packages
  - Veterans’ Supplement in Residential Care.

Additional financial assistance for dementia and veterans’ care is also provided in Transition Care, Multi-Purpose Services and Innovative Care (Ageing in Place) Programs, and the Aboriginal and Torres Strait Islander Flexible Aged Care Program.

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\(^1\) The National Respite for Carers Program, together with the Home and Community Care Program and the Day Therapy Centres Program, will become part of the Commonwealth Home Support Program from July 2015.
**Victorian responsibilities**

The Victorian Department of Health has the lead for actions supporting people with dementia and their families and carers. Much has been achieved in Victoria to more effectively integrate and link aged care services and health services. Integration aims to keep people as well as possible, provide support and care in community settings, and avoid unnecessary hospital admissions.

Key services funded by the Victorian Department of Health include:

- Cognitive, Dementia and Memory Service (CDAMS), which provides diagnosis, advice, support and referral for people with cognitive difficulties causing confusion, memory loss or thinking problems, and support for families and carers
- Information, support, counselling, education and training services through Alzheimer’s Australia Vic
- the Aged Care Assessment Service (ACAS), jointly funded by the Commonwealth and Victorian Governments, assesses the needs and capabilities of older people. An ACAS assessment is required to access residential aged care, respite, Commonwealth-funded home care packages and the Transition Care Program
- Home and Community Care (HACC) program, jointly funded by the Commonwealth and Victorian Governments, supports people, including those with dementia, to live as well as possible at home. Services include dementia specific planned activity groups (PAGs)
- Support for Carers of People with Dementia delivers flexible, innovative support, respite, counselling, education and leisure activities
- Café-style support services where older people in care relationships, including people with dementia and their carers, can meet to share their experiences, access information, and create networks with people in similar circumstances
- Hospitals providing services to people with dementia, and promotion of hospital environments that provide dementia-friendly care in admitted and non-admitted settings
- Resources, such as the web-based and hardcopy *Dementia-friendly environments: a guide for residential aged care services*, to support dementia-friendly environments in residential aged care services, subacute services and hospital settings
- Aged persons mental health assessment and treatment services, which provide specialist expertise.

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2 Alzheimer’s Disease International (2013, p. 10) suggests information should be available to people with dementia, their families and friends on the condition, treatment, care and support options, including having people’s voices heard.
Many researchers see the kitchen as the central hub of a residential facility. Well-located kitchens can support services and benefits, including supporting the dining area, promoting a home-like feel and being used for staff events.

Some dementia-friendly facility designs place the kitchen centrally, with the dining room an extension of the kitchen and the living room or sitting area nearby. Kitchens that visibly open directly onto dining areas encourage people to join informal kitchen activities. In cluster designs, people’s rooms are often directly off a central public area, making the kitchen a replacement for old style nursing station.

Kitchens can have most appliances, cupboards and work surfaces found in home kitchens, giving a sense of familiarity for people with dementia, staff and visitors.

One new facility design using the kitchen as a key feature of everyday living has universal staff prepare meals in an open, central kitchen, easily accessible to people with dementia and visitors. People with dementia, family members and friends can join in all activities relating to food preparation and eating. They are thought of as social activities, and this is written into the facility’s policies <www.health.vic.gov.au/dementia/changes/dining.htm>.

‘Bendigo Health provides Café-style support for geographically isolated people. People participate and enjoy a range of activities, the opportunity to socialise with others in similar situations, and receive information and support. Local service providers present information, and mingle with participants to answer questions. Partners include Alzheimer’s Australia Vic, Bendigo TAFE, a local pharmacist and others. Participants have visited Bendigo TAFE for cooking classes, as well as music and dancing. Participants feel they are accepted as couples, rather than being labelled as a person with dementia and a carer.’

*Café-style support services, Practice guidelines for Home and Community Care Services in Victoria, Department of Health 2013*

‘My husband aged 70 was diagnosed with vascular dementia and Alzheimer’s disease last year. We live in a rural farming area. Alzheimer’s Australia has been a tremendous support as we progress on our journey.’

*Carer, Alzheimer’s Australia Vic website, 2014*
Office of the Public Advocate

The Office of the Public Advocate provides last resort guardianship services for people whom VCAT determines unable, by reason of disability, to make reasonable judgements, and who need a guardian to make key decisions for them.

The Office of the Public Advocate provides a telephone advice service for people seeking information about guardianship and enduring powers of attorney.

The Victorian Department of Health has an advocacy role with other levels of government to support people with dementia and their families and carers, including:

- the HACC program so that benefits for Victorians of the HACC program are maintained into the future
- the NFAD to help determine future directions in dementia care and support, and so that it reflects Victorian initiatives for people with dementia and their families and carers
- the National Disability Insurance Scheme (NDIS), given Victorians 65 years of age and older are not eligible for the NDIS
- various service systems so that transition for people with dementia and their carers through different service systems can maintain continuity of support and care.

‘Dad and I go outside to the men’s shed and it’s just like old times. He seems more himself and we chat like we used to. He can’t really build much but he loves to hammer nails into wood and take screws out. Dad is much happier and is more a part of our life because we spend more time in his home. Yeah, we see it more like his home than a nursing home.’

Dementia-friendly environments: a guide for residential aged care services, Department of Health 2012
Local government responsibilities

In Victoria local government is made up of 79 councils. Local government is responsible for implementing many diverse programs, policies and regulations set by the Commonwealth and Victorian Governments.

Victorian councils seek to meet local issues in their communities through active ageing and aged care services. Areas of focus are:

- delivering HACC services
- access and equity for culturally and linguistically diverse communities
- positive and active ageing
- community transport.

Positive ageing initiatives include age-friendly cities and communities, improved liveability for older people in small towns, local positive ageing networks, older persons’ reference groups, projects on positive ageing in local communities and positive ageing planning. Other local services provided or supported by local government support older people and their carers.

Many opportunities and activities exist in local governments to link Seniors Count! 2014-2019, Victoria’s Seniors Participation Action Plan priorities and Victorian dementia action plan priorities.
2 The case for action

Dementia as a chronic disease presents issues for people with dementia and their families, friends and carers, and presents challenges for researchers, the service system and communities. There are also many opportunities to better support people and provide care. There is a very strong case for many types of action by many organisations, both public and private.

Approaches including public policy, awareness raising, timely diagnosis, acknowledging and responding to diversity and longer life expectancy, and evidence-based support and services can help improve quality of life for people with dementia and their families and carers.

The number of Victorians affected by dementia is increasing each year as the population ages and life expectancy increases. In 2013, around 74,600 people in Victoria were estimated to have dementia. It is predicted that by 2020 around 98,100 people will have dementia. Some 62 per cent of Australians with dementia are women, and 38 per cent are men (see Figures 1 and 2).

While dementia is not the leading cause of death, it contributes to disability and burden of disease, and its role will increase. In 2010–11, dementia was the third-leading cause of death and fourth leading cause of burden of disease in Australia, accounting for six per cent of deaths. In 2011, the leading underlying cause of death was coronary heart disease (11,733 men or 8 per cent of deaths and 9,780 women or 6.7 per cent). The next most common causes of death in women in Australia were cerebrovascular diseases including stroke (6,824 or 4.6 per cent of deaths), and dementia and Alzheimer’s disease (6,596 or 4.5 per cent of deaths); for men the next most common causes were lung cancer (4,959 or 3.4 per cent) and cerebrovascular diseases (4,427 or 3 per cent).

Figure 1: Estimated numbers of Australians with dementia aged 65 and over (AIHW 2012)
Longer life expectancy

Longer life expectancy may increase the risk of developing dementia. However, a recent study in the United Kingdom comparing dementia prevalence between two cohorts over two decades showed a substantial decrease in the prevalence of dementia. This study provides further evidence that dementia prevalence is different for different cohorts. That is, later-born populations have a lower risk of prevalent dementia than those born earlier in the past century.

‘The scale in the reduction of dementia that we identified is substantial and is in line with major reductions in risk factors in higher income countries, which have been modified by societal changes such as improvements in education, and prevention and treatment strategies in recent decades.

Whether or not the gains that we have identified for the present older population will be borne out in later generations will probably depend on whether further improvements in primary prevention and effective health care for disorders that increase the risk of dementia can be achieved, including addressing inequalities.

Although many factors could have increased dementia prevalence at specific ages (such as those associated with diabetes, survival after stroke, and vascular incidents), other factors, which could decrease prevalence, such as improved prevention of vascular morbidity and higher levels of education, seem to have had a greater effect.’

Living longer is a great achievement, particularly if this means continued health, wellbeing and participation in the community. Older people continue to participate in paid and volunteer work for longer, often with greater flexibility. Therefore there will be people who continue to be very active in the workplace and community who may display early signs and symptoms of dementia.

‘Future generations may not have the same risk for Alzheimer’s, for a given age, as the current generation. It is possible that environmental and lifestyle factors, such as diet and exercise, could make a significant contribution to reducing the risk of developing dementia.’

Professor Perminder Sachdev, Alzheimer’s Australia, Centre for Healthy Brain Ageing 2014

In 2008, 37 per cent of Australians with dementia did not receive formal care and were supported by families and carers. The estimated cost of replacing family carers of people with dementia with paid carers equated to $5.56 billion a year nationally, and the lost productivity for individuals, business and government was estimated at $881 million.

In 2011 about 25 per cent of Melbourne households consisted of one person. One-person households are growing at the rate of 1.6 per cent a year. Inevitably some single-person households are and will be an older person, some of whom will be a person with dementia without a live-in carer.

Studies show that dementia increases the cost of direct medical and social care, and indirect costs. Victorian data shows the estimated percentages of HACC-assessed people with memory and behavioural difficulties (see Figure 3). As numbers and percentages increase there will be additional increases in total costs.

Figure 3: Estimated percentages of HACC-assessed people with memory and behaviour difficulties (HACC Minimum Dataset 2011–12)
Hospital environments and residential aged care

In Australia, the average length of stay for all hospitalisations is three days, compared with an average of 18 days for people with dementia. Data shows the prevalence of dementia in hospitalisations (see Figure 4).

Approximately 71 per cent of people with dementia live in their own homes and 29 per cent in care accommodation. Of those living in their own homes, about 30 per cent are men with moderate to severe dementia, and 20 per cent are women with moderate to severe dementia.

Data shows the extent of cognitive impairment in supported residential services (SRS) (see Figure 5). When people with dementia are out of their familiar environment and have difficulty understanding where they are, the social and physical elements of the environment need to be more supportive.

Figure 4: Estimated percentages – hospitalisations in Australia with dementia as principal diagnosis (AIHW 2012)

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3 A three-year National Health and Medical Research Council (NHMRC)-funded project is currently under way to look at outcomes for people with dementia admitted to hospital, the Hospital Dementia Services Project. The project is a collaboration between AIHW, University of Canberra, and University of New South Wales.
Diversity

The Victorian population is diverse and includes Aboriginal people, people of culturally and linguistically diverse backgrounds, people who live in remote and rural areas, people with intellectual disabilities, people who identify as gay, lesbian, bisexual, transsexual and intersex, and people who are homeless or at risk of homelessness.

There is no accurate data on dementia among Aboriginal people in Victoria. Most Aboriginal Australians live in urban or regional areas like these, with only about 30 per cent living in remote areas. The number of older Aboriginal Australians is increasing rapidly, and yet little is known about their health and dementia rates. A recent study in the remote Kimberley region of Western Australia found higher rates of dementia at younger ages, but research in the majority urban population has been lacking.

However information is available from national sources and other states and territories:

- Dementia is a significant problem in Aboriginal communities, with some communities estimated to experience dementia at a rate five times higher than the general Australian population.
- As life expectancy increases for Aboriginal people, so does the risk of developing dementia. Factors that increase the chance of Aboriginal people getting dementia include: high rates of chronic diseases like diabetes and stroke; childhood infections such as periodontal disease; head injuries and cognitive damage due to drug and alcohol use. These findings relate to Western Australian and remote communities, and may not reflect Victorian Aboriginal communities.
- Far greater percentages of Aboriginal people need dementia and aged care services before 55 years of age than people of non-Aboriginal background.

Increased awareness about dementia among Aboriginal people, and ways to support Aboriginal people with dementia within their communities, can make a huge difference to people’s quality of life.

Different patterns of migration over the years have led to different population profiles within different groups. For instance cultural groups that arrived in Australia in the 1950s may have a larger population of older people than newer arrivals.
Dementia services can be under-used by older people from culturally and linguistically diverse backgrounds. Dementia may be seen in some communities as a normal part of ageing or a form of madness, rather than a disease. Stigma may be a major barrier to support and services as people may have feelings of shame and deny their condition. Consequently dementia is often diagnosed at a more advanced stage when people reach a crisis point. Nevertheless, data shows that some people of cultural and linguistic diversity are accessing certain services (see Figure 6).

**Figure 6: Estimated percentages – dementia and culturally and linguistically diverse communities**

<table>
<thead>
<tr>
<th>Category</th>
<th>Percent</th>
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<tbody>
<tr>
<td>2012–2013 CDAMS contacts who needed an interpreter – communities with higher CALD presence</td>
<td></td>
</tr>
<tr>
<td>2012–2013 CDAMS contacts who needed an interpreter – communities with lower CALD presence</td>
<td></td>
</tr>
<tr>
<td>2011–2012 Victorian ACAS referrals for culturally and linguistically diverse people</td>
<td></td>
</tr>
<tr>
<td>2009 Victorians with dementia who speak a language other than English at home</td>
<td></td>
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</tbody>
</table>

The Ethnic Communities Council of Victoria (ECCV) discussion paper, *Meant to care*, examines culturally relevant dementia care. It shows that culturally and linguistically diverse (CALD) people under-use dementia services due to:

- varying levels of English
- lack of knowledge
- cultural perceptions and stigma
- experience of discrimination with health services
- lack of culturally appropriate services.

The ECCV discussion paper makes recommendations on empowering, informing and resourcing people from culturally and linguistically diverse backgrounds.
Timely diagnosis

Unlike other chronic diseases, most people with dementia do not connect with the health system to have dementia addressed. Instead, they may go to a general practitioner (GP) or a falls and mobility clinic, or to hospital for a medical need other than dementia. It may be staff from services going into a person’s home who have the first hint that the person has changed, or they have a change in cognition. Service providers can often see early signs of dementia in people who may not be eating meals, or not attending a planned activity group.

A timely diagnosis occurs within six months of symptoms. People with pre-dementia or mild cognitive impairment may need monitoring, as many (30–50 per cent) could develop dementia, or may need a more detailed assessment for other things.

Without a timely and correct diagnosis, other expensive tests may be used, leading to inappropriate and expensive treatment that may or may not help the person or the family and carers. Whether or not dementia is diagnosed a person can still get appropriate responses, support and referrals.

Identifying and reporting dementia is often poor in hospitals, possibly due to several medical conditions, such as delirium and polypharmacy affecting cognition. Other possible issues in hospitals may be inability of people with dementia to report symptoms of cognitive impairment and clinical, coding and administrative issues such as inconsistent reporting.

Between 50 per cent and 80 per cent of people in early stage dementia who attend primary care services are not diagnosed. Of those people diagnosed with dementia in primary care, many do not receive a diagnosis until three years after they first notice symptoms. Diagnosis of dementia may be delayed because of community and health practitioners’ misconceptions that nothing can be done to assist people with dementia or their families and carers. Sometimes difficulties with memory appear opportunistically, for example, through repeat forgetting of medical appointments, or repeated conversations.

The report *Thinking ahead: report on the inquiry into dementia – early diagnosis and intervention* suggested that GPs sometimes have difficulty making a diagnosis of dementia and do not always understand referral pathways for treatment and support.

Guidelines for the Royal Australian College of General Practitioners state that practitioners should be alert to the symptoms and signs of dementia in people over 65 years of age. After excluding other disorders that can contribute to memory difficulties, a GP might refer a person for diagnosis to a Cognitive Dementia and Memory Service or a specialist, such as a geriatrician, neurologist or psychiatrist. GPs may also be concerned about how to communicate the diagnosis.

General practice nurses are a key part of a changing primary healthcare system. Their role includes aged care and chronic disease management. In Victoria, practice nurses are increasingly administering the Medicare Benefits Scheme 75+ years assessment, and associated cognitive assessment tools in the home.
Supporting people with dementia and their families and carers

The Alzheimer’s Disease International BUPA Global Dementia Charter states that people with dementia should have a say in their care and support, and their end-of-life wishes should be discussed with them while they can make decisions. With timely diagnosis, people can make informed choices about current and future care needs, for example through advance care planning, make decisions about their legal and financial affairs and consider the use of technology, family connections and support.

A preliminary evaluation of the Short Break Stay Program: respite care for people with dementia examined the benefits of person-centred respite. It found that person-centred respite is of most value when it meets the needs and preferences of people with dementia, including efforts that replicate care received at home. Other valued features of person-centred respite include:

- people with dementia being able to identify with each other
- matching staff and people with dementia
- regular communication with the person with dementia
- smooth and seamless transitions into respite and back home.

Caring for people with dementia has unique challenges, especially as cognition degenerates. Supporting people in care relationships and people without carers is important to keep people living at home for as long as they desire and is possible.

Early access to support and services is likely to mean better outcomes for both the person with dementia and their carer, and delays entry into residential aged care. These supports can lead to more participation and better quality of life for all.

People with dementia need additional support when accessing the health and aged care system, beyond their presenting medical need. The health and aged care system therefore needs to continue to improve its ability to support the needs of people with dementia and their families and carers.

‘It’s not all doom and gloom. Focus on what we like to do, can do, enjoy doing. Tell people about that.’
Person with dementia,
Dementia-friendly communities,
Alzheimer’s Australia Vic 2014

‘You need the right staff and volunteers to relate to and communicate with a person with dementia, someone who understands. That is critical.’
Carer, Alzheimer’s Australia Vic 2014

For people living by themselves, a timely diagnosis may mean making decisions about living arrangements. A person with dementia who is living alone may have limited social connections, or reliable and regular connections with family and/or friends.
The wide range of different living arrangements, including single-person households, can be supported by innovative use of technology, home-care support models, use of volunteers and housing options with built-in care trajectories, for example cooperative communities and retirement villages. Diversity of options and pathways can help maximise independence and semi-independence for as long as desirable.

For some families and carers, the care role reduces capacity to participate in the workforce. Nationally in 2009, people aged 15 to 64 years who provided care to people with dementia had a labour force participation rate of 56 per cent; the rate for primary carers of people with dementia was 38 per cent.

Families may be better able to plan for the future and prepare themselves knowing that the person they care for is experiencing cognitive change. Over the course of a person’s life with dementia, a carer can experience grief and loss of both the person with dementia and the relationship they previously had with the person. Grief and loss counselling may be important for carers from the time of a dementia diagnosis to the end of life. Other ways to support carers are also likely to be valuable.
3 People and places

There is great diversity within the Victorian population, including a wide range of cultures and languages across geographic locations. There are also different settings and environments, as well as multiple service system pathways that people with dementia and their families and carers need to navigate. This presents opportunities and challenges in planning and implementing actions to improve the quality of life of people with dementia and their families and carers.

Populations

Some population groups are at greater risk of experiencing poor quality of life with dementia. These groups include Aboriginal people, low-income earners, people in rural and remote communities, people from culturally and linguistically diverse backgrounds, people who are gay, lesbian, bisexual, transsexual or intersexual, and others with special needs or who are disadvantaged or at risk of discrimination.

Improving the quality of life of older people within these population groups requires a range of different and appropriate approaches, with input from the appropriate representatives, groups and individuals.

It’s very important to get into a support group of like-minded people – when they work, they work well.

Carer, Alzheimer’s Australia Vic 2014

While some actions, such as reducing risk factors for dementia, are relevant for the whole population, different methods and pathways may be more successful for people of different ages, stages, cultural backgrounds or socioeconomic backgrounds. Some actions may be directed at particular or minority population groups.

Environments and settings

The places in which people with dementia and their families and carers gain information, receive a diagnosis, access support and services, and conduct their daily lives are critical for influencing and improving their quality of life.

These places include communities, at home, hospitals, support groups, government-funded services, private sector industries and businesses, local council environments, leisure and recreation venues and holiday destinations.

Although a focus on supporting people to remain in their own homes is vital, it is not the only strategy for supporting people with dementia to maintain quality of life.

A more concerted focus on choice and person-centred care can provide clearly defined pathways and options from which people can choose to receive support. This can include remaining at home with formal or informal support, moving in with a carer, moving into a retirement village, serviced apartment or other group housing or entering residential aged care.
Challenges associated with demography and access, particularly in rural and regional areas also need to be considered.

Key elements in all these forms of accommodation and support are:

- combatting social isolation
- empowering individuals to participate in and make decisions about their lives
- maintaining a focus on mobility.

Homeless people with cognitive impairment due to alcohol, drugs and dementia need different models of service to support them. These services may include outreach, meals, housing, care and support and combined services.

No matter what the environment or setting, the person with dementia and their family and carers need to be central in planning, implementing, monitoring and evaluating support and services.

'Strive, struggle, and sometimes, when you do, just get up and think, "Well, what can I achieve today? Which is the best way to live, not to worry?"'

Person with dementia, Dementia Engagement and Empowerment Project, UK, March 2014

Supporting homeless people including people with dementia

Wintringham Housing provides an extensive range of safe, secure and affordable housing and care options allowing people to exercise control over their lives and maintain their chosen lifestyle. The housing is for older people who are homeless or at risk of becoming homeless, and are financially disadvantaged. Wintringham Housing residents have an over-representation of people with various forms of dementia, including severe and complex behaviours and psychological symptoms of dementia. Residents have many opportunities to be part of local community activities and events, for example visiting the Tall Ships, membership at the Melbourne City Baths, visiting the Royal Melbourne Show and weekends away.

Wintringham Specialist Aged Care www.wintringham.org.au
Pathways through care and support

Pathways for individuals through the service system and community may be different. These include pathways to diagnosis and treatment, through to palliative and end-of-life care.

People with dementia and their families and carers are likely to use various services during the course of dementia. Services can include primary care and general practice, acute services, community care, respite and support services and residential care. People may not know why they are meeting different health professionals or services, what each service does, or what questions they should ask of each different health professional or service.

Support should be available, or pathways identified, so that a person’s pathway is clear and easy to navigate with relevant responses at appropriate times. People with dementia and their families and carers need to be supported when making decisions about transition points, for example organising powers of attorney, seeking support as a carer, or considering residential aged care.

Victoria has examples of successful service coordination. For example, the Guidelines for streamlining pathways between ACAS and HACC assessment services 2011 strengthen referral pathways, so that older people with care needs receive timely assessment. Continuous quality improvement can improve system responsiveness to people with dementia and their families and carers.

People with dementia and their families and carers can best be served by a coordinated service system of partnerships and networks, undertaking continuous improvement to meet changing needs and preferences.

‘The problem is getting the right services at the right time. There are many entry doors, and people get treated differently, get different information, different services.’

Carer, Alzheimer’s Australia Vic 2014

‘... develop a vision of what we want to achieve, such as seeing the whole person and not the disease of dementia alone, coordinated services, partnerships, enablers and outcomes (so we’re all on the same page).’

Participant, roundtable discussion, Department of Health, November 2013
Person-centred approach

Person-centred care means a whole-of-system approach to the needs and preferences of individuals. Holistic healthcare and support focus on the whole person, rather than on dementia as a disease. Upholding and respecting the rights of Victorians with dementia and their families and carers also requires a focus on what people are still able to achieve.

Considerations in person-centred, holistic support and care include:

- recognising everyone is different – older people have diverse needs, preferences and life experiences that may be related to their cultural background, language, generation, spiritual beliefs, hobbies and interests, family structure, employment history, gender and much more. Importantly though, everyone has similar basic everyday needs, including the need for respect and dignity at all stages of dementia
- promoting a person’s independence as much as possible
- supporting social connections and physical and emotional wellbeing
- developing dementia-friendly communities, places and services that support people with dementia, and their families and carers
- maximising functional ability through all the above, and recognising the contributions and inter-dependence of people with dementia.

Dementia is a terminal disease. A person’s abilities will deteriorate, sometimes rapidly over a few months, in other cases more slowly over a number of years.

‘John would not talk when he came to us … He was withdrawn and refused to participate in any activity … but since doing tai chi he talks … he engages with us and the other residents … and is participating in tai chi and other activities … This has been such a surprise for me, staff, other residents and his family.’

Tai chi leader, evaluation of Arthritis Victoria pilot project 2009

From diagnosis to the end-of-life, the quality of life of a person with dementia and their family and carers is paramount. A person-centred approach means a holistic focus on each person’s individual capacities and maximising their abilities.

While the symptoms of dementia worsen over time, the experiences and needs of a person with dementia are unlikely to be linear, and may be related to matters other than dementia. For instance, a person with dementia may interact with the health service system for other conditions, diseases or illnesses not related to dementia, such as admissions to hospitals, visits to community health services, and dental appointments. These services need to have communication, physical environments, timing and an integrated and coordinated approach that are appropriate for people with dementia.

Many people with dementia may experience behavioural and psychological symptoms of dementia (BPSD). BPSD includes disturbed perception, thought content, mood or behaviour, with a person’s symptoms changing over time.
The reasons for BPSD in an individual may be complex and need to be explored. They can be due to a change in the person’s environment or routine, to experiences from their past at work, in war or childhood, or to frustration about the cognitive, personal or functional changes they are experiencing. Multicomponent non-pharmacological responses to BPSD need to be considered.

Environments can be changed to support the improvement in a person’s functional ability – increasing independence by having a bathroom and kitchen visible from the bedroom and living room, or creating an outdoor gardening space that a person can access by themselves.

Resources can be provided to the person, or a routine restored or created. For example, there could be a place in the house where the person does an activity they have always loved doing, or have been used to doing.

Non-pharmacological responses can also include music, aromatherapy, and other types of relaxing and enjoyable activities that provide meaningful and possibly productive occupation. Pharmacological responses may be appropriate in some cases.

Standards of care should be based on:

- a person-centred approach that takes into account the individual’s qualities, abilities, interests, preferences and needs
- recognition that dementia alters perceptions and appropriate environments can minimise BPSD
- respect for their rights as people, offering activities that are engaging and stimulating rather than chemicals and restraints to suppress the outward signs of illness
- training and retaining high-quality residential and community care workers
- facilitating greater community awareness and understanding of the illness.

Senate Community Affairs Committee Secretariat 2014

For people with dementia, having services coming to them, rather than attending appointments in unfamiliar locations may be a better way of providing care and support. This is particularly the case for people in the later stages of dementia.

The Victorian health and aged care system consists of services funded through multiple sources and across various settings. The range and mix of services is typically described as a continuum of support and care.

Developing a system responsive to people’s needs requires capacity building in all services, from initiatives to promote and support maximum functional ability, health and wellbeing to the delivery of health and aged care services, and end-of-life care. People connect with services at various points in their lives depending on need. It is not a linear journey or a continuum of support and care (see Figure 7).
Advance care planning

The Victorian Advance care planning: have the conversation – a strategy for Victorian health services 2014–2018 provides information and support for staff in health services to broach the often difficult conversations with people about their end-of-life wishes and care. The strategy sets key measures in four priority action areas:

— establishing robust systems so organisations can have the conversation
— ensuring an evidence-based approach to have the conversation
— increasing workforce capacity to have the conversation
— enabling the person being cared for to have the conversation.

This strategy aims to ensure all Victorians accessing health services will have opportunities to express their preferences for future treatment and care.

Figure 7: Person-centred dementia action
4 Enablers

Enablers include the means, knowledge and opportunity to support quality of life of people with dementia, their families and carers, such as:

- partnerships and networks
- service coordination and referral
- legislation supporting individual rights and responsibilities
- education and training
- continuous quality improvement
- resources.

Partnerships

Different organisations across different sectors contribute to developing a comprehensive response to people with dementia and their families and carers. Partnerships between organisations can achieve a more coordinated, responsive approach, and recognise and address service gaps.

The success of the Victorian dementia action plan depends on engaging communities and strengthening partnerships across the private and public sectors. Peak bodies are key stakeholders in these partnerships. Most importantly, people with dementia and their families and carers are key to the success of partnerships and progress in Victoria to improve quality of life.

Peak bodies already involved include Alzheimer’s Australia Vic, Carers Victoria, Ethnic Communities Council of Victoria, Aboriginal organisations, representatives of gay, lesbian, bisexual, transgender or intersex people, and Networking Health Victoria.

Other organisations to be approached include private sector industry and business, and public sector organisations within and outside the health sector, for example education, justice, housing, transport and libraries.

Partnerships within statewide organisations, local governments and communities are equally important to improve quality of life among people with dementia and their families and carers. For instance fully dementia-friendly communities only occur if local business and local government, along with local charities and public health services, coordinate their efforts and seek input from people with dementia and their families and carers at each step.

Communities are working on various ways of developing sustainable and productive partnerships. For example, the ‘collective impact’ approach requires the commitment of a group of stakeholders from different sectors to a common agenda for addressing the needs of people with dementia and their families and carers.

This approach means agreeing to a common agenda of primary goals, developing a shared measurement system of success, undertaking mutually reinforcing activities, continuous communication between stakeholders, and a structured process of support for the participating organisations.
Service coordination and referral

Service coordination places people at the centre of service delivery and creates opportunities for early access to services and health promotion. It supports smooth referral pathways between services for quality, coordinated care, which is particularly important for people with complex and multiple needs.

Service coordination includes collecting and sharing consumer information according to agreed protocols. The Victorian service coordination practice manual 2012 defines the common practices, processes, protocols and systems that support service coordination. Information standards, Service Coordination Tool Templates (SCTT) and guidelines aid coordination efforts through registration of people, initial needs screening, making referrals, getting consent to share information and coordinating care.

Service coordination can smooth a person’s transition from one sector to another. For example, a shared support plan shows person-centred and relationship-centred goals, the main issues, planned actions, who is involved in the care, and who is responsible for each action. Documenting person-centred goals focuses the efforts of service providers to work towards a common goal.

HACC and subacute care ambulatory services, including Cognitive Dementia and Memory Services, participate in the system-wide coordination approach.

The department encourages the use of e-referral for secure transmission of health related information between service providers in health and human services sectors, and better referral practices.

Legislation

The impact of dementia is dynamic. Capacity may be impaired one day and not another. The impact changes during various stages of the disease, and from one person to another.

Commonwealth and state legislation and regulation protect the rights of individuals, and helps reduce discriminatory practice.

Relevant acts at the Commonwealth level include:

- Aged Care Act 1997
- Age Discrimination Act 2004
- Carer Recognition Act 2010
- Disability Discrimination Act 1992
- Racial Discrimination Act 1975
- Sex Discrimination Act 1984

Relevant acts at the Victorian level include:

- Charter of Human Rights and Responsibilities Act 2006
- Carers Recognition Act 2012
- Equal Opportunity Act 2010
- Freedom of Information Act 1982
• Guardianship and Administration Act 1986
• Health Records Act 2001
• Information Privacy Act 2000
• Medical Treatment Act 1988

The Victorian Equal Opportunity and Human Rights Commission can provide further information about appropriate avenues for individuals seeking assistance in relation to any of the acts.

**Education and training**

Individual staff members bring their own experiences and values to the workplace. The people they support and care for probably have different life experiences, preferences and values from staff. For example, some health and aged care workers may come from countries where changes in memory and cognition are viewed as normal ageing, requiring no additional consideration or support.

This belief may limit the use of simple supports that can improve outcomes for people with dementia – for example access to meaningful objects or experiences from earlier adult life.

The department promotes a support and care approach focusing on the needs of the person and their family and carers, regardless of the experiences or values of staff. This person-centred approach underpins all policy and program activity of the department, and is a focus for development of the workforce.

Pain, injury, illness, medication and environmental factors influence all of us, including people with dementia. People with dementia and their families and carers have social, physical, spiritual and emotional needs and preferences that should be considered.

Developing workforce skills is also critical to recognise possible dementia, provide assessment, diagnosis and access to services, and support families and carers (see Appendix 2).

**Continuous quality improvement**

On-going review of the support and care provided to people with dementia and their families and carers assists continuous improvement in the quality care and support.

Many service providers develop and implement their own continuous quality improvement processes and tools. Other quality review tools available from both the Victorian and Commonwealth jurisdictions include the following resources.

**Community Care Common Standards**

The Community Care Common Standards were developed jointly by the Commonwealth and state and territory governments. They set out standards for the delivery of services, including HACC, community care packages and the National Respite for Carers Program.

The quality standards are:

• effective management
• appropriate access and service delivery
• service user rights and responsibilities.
The standards are measured against 18 expected outcomes:

• eight management outcomes
• five service delivery outcomes
• five service user rights outcomes.

In Victoria, most organisations use service user surveys to measure results against the standards. A small number of CALD organisations collect data through focus groups.

The department produced the Victorian Home and Community Care Quality Review Resource 2012 to provide the context for implementation of the standards, and to outline specific Victorian policy and program requirements for HACC-funded organisations.

**National Safety and Quality Health Service Standards**

The Australian Commission on Safety and Quality in Health Care implements the National Safety and Quality Health Service Standards and Accreditation scheme.

The scheme includes ten standards to improve the level of care that people can expect from health services, including public hospitals, day procedure services and dental services.

Standard 2 is ‘Partnersing with consumers’. This standard is about creating systems and strategies that foster a person-centred health system by including consumers in developing and designing quality healthcare.

**Quality indicators**

All public sector residential aged care services in Victoria report regularly against the following quality indicators:

• medication use
• falls
• pressure ulcers
• use of physical restraints
• unplanned weight loss.

The department has developed consensus evidence-based reference ranges for each quality indicator. This enables services to compare their performance with statewide benchmarks, and set realistic targets for improvement.

**Australian Aged Care Quality Agency accreditation standards**

Four accreditation standards apply to residential aged care. They relate to:

• management systems
• staffing and organisational development
• health and personal care
• resident lifestyle
• physical environment and safe systems.

Each standard includes an expected outcome that the organisation actively pursues continuous improvement.
Elder abuse

The Elder abuse prevention and response guidelines for action 2012–14 (the guidelines) outline the Victorian Government's priorities and actions to help older Victorians live safely, free from harm and abuse. The guidelines link to the government’s Victorian health priorities framework 2012–2022, which includes priorities that enable the health system to better support an ageing population. The main areas of focus in the Elder abuse prevention and response guidelines for action 2012–14 are professional education, community education, the provision of legal, referral and advocacy services, and the coordination of service responses.

Through these guidelines, our aim is to ensure a statewide, integrated response to elder abuse, with measures in place to help prevent incidents of abuse and improve the safety and wellbeing of older Victorians. The guidelines also address areas of specific need, such as targeted community and professional education for older people from culturally and linguistically diverse (CALD) communities and from Aboriginal communities, as well as older people with a disability.

Elder abuse: reporting by approved providers of residential aged care

The Commonwealth Government has safeguards against elder abuse that apply to aged care providers subsidised under the Aged Care Act 1997. The compulsory reporting requirements aim to increase the safety and protection of people living in residential care.

Services need to report incidents alleging physical assault and/or unlawful sexual contact with residents, and incidents of residents missing without reasonable explanation. These incidents are reported to the Commonwealth Aged Care Complaints Scheme, Victoria Police and the family as soon as practicable within 24 hours.

Information about these requirements is available at: www.health.vic.gov.au/hospitalcirculars/circ14/circ0514.htm

Resources

Information about maintaining and improving health and wellbeing, and accessing supports and services is important for the community, people with dementia, their families and carers, service providers and practitioners.

Resource development and production occurs through government departments, peak bodies, service providers, researchers and others. Although older people are the fastest growing group of new adapters to online technology, many still do not use computers or access the internet, and alternative modes of communication need to be available.
Resources for people with dementia and their families and carers should include information about maintaining a healthy and active lifestyle, what dementia is, tips on living with dementia, how families and carers can best support a person with dementia, making homes and gardens dementia-friendly, and accessing available services and support. While most information is available on the internet, hardcopy documents should be available for distribution to people with dementia, and their families and carers.

Existing resources for workers who support people with dementia and their families and carers should include online training modules and courses, service and program manuals and guides. Management and staff of services should be able to access resources on making their service environments, approaches and processes dementia-friendly, whether delivering community based services, or in doctors’ surgeries, hospitals, respite facilities or residential aged care.

Residential environments for people with dementia

- Position toilets appropriately in relation to doors. When people with dementia can easily see a toilet, they are more likely to use it.
- Train staff in appropriate communication during personal care and bathing to maintain dignity and privacy.
- Personal items in a bedroom, such as photos, lamps and vases, enhance a home-like environment and provide information about a person.
- In one facility, staff members prepare meals in an open, central kitchen, so people with dementia, their families and visitors, can all join in the food preparation and eating.
- Staff at Lyndoch Nursing Home attend workshops on the sexuality of people with dementia, and have procedures and information for staff and families on sexuality.
- St Laurence Care Farm in Lara has different animals that people with dementia, staff and volunteers care for, vegetable and herb gardens, fruit groves and a shed with tools for farm activities.
- Allawah Lodge in Yarrawonga records people’s life stories, including a family tree, leisure assessment, interests, likes and dislikes. A men’s group of people with dementia and people from the local community meet regularly.

_Dementia-friendly environments: a guide for residential aged care services_,
Department of Health 2012

Businesses and other organisations keen to attract people with dementia and their families and carers as part of their clientele can increasingly access information on the internet on how to be dementia-friendly. Volunteers, neighbours, friends and work colleagues of people with dementia can access resources on the internet to help them support people with dementia.

In addition to internet and hardcopy resources, networks of people with dementia and their families and carers can support individuals and their families and carers to live as well as possible. Similarly networks of health professionals can support and assist individual practitioners (see Appendix 2).
5 Priority areas for action

Seven priority action areas have been identified for improvements in responsiveness of the health system and the wider community for people with dementia, their families and carers:

- Increase the awareness of and responsiveness to dementia, and improve the health and wellbeing of older people
- Support timely assessment and diagnosis
- Plan for diversity in the delivery of support and services
- Maximise independence, health and wellbeing of people with dementia
- Promote dementia friendliness in age friendly communities
- Support families and carers of people with dementia
- Support people with dementia at the end of their lives.

Work has already begun with many strategies being implemented in the seven action areas. Building on this strong start, activities will be conducted in each of the priority action areas. This will be achieved through collaboration between peak bodies, public and private primary care and health services, education, industry and government.

While there are opportunities to do new and different things, we can also improve what is already being done. We are investigating how current services and activities can be improved, and how what we already do can be improved.

For instance, a dementia-friendly component can be included in work already being done on age-friendly communities without adding to the cost or inconvenience. Service providers can improve access by increasing and targeting information for people with dementia and their families and carers. We can also improve knowledge and referrals among service providers for smooth transitions for people with dementia between services, and we can respond more appropriately to individual and family needs.

These improvements rely on partnerships between services within and across public and private sectors. Some examples that demonstrate this include:

- resources for dementia-friendly environments in residential aged care
- support and links between local services through Alzheimer’s Australia Vic dementia service hubs
- information through Seniors Online and Better Health Channel
- A guide to services for people with dementia and their carers – a resource for services to help them provide information, support and referrals that meet the expressed needs of people with possible dementia and their families and carers.

Art classes for people with dementia

‘Elizabeth rarely spoke or joined in activities except for knitting. She was keen, however, to paint independently. She began painting flowers on wet paper, added tree trunks and more flowers, and finished with grass and a purple background. Her wide smile and wide eyes revealed pride at her accomplishment. Her painting was called Forest of flowers.’

The hen that laid the golden omelette: a guide to art classes for people with dementia, Davison and Potter 2013
Priority 1: Increase awareness of and responsiveness to dementia, and improve the health and wellbeing of older people

Expected outcome Raise dementia awareness among the whole population, and improve health and wellbeing of older Victorians, reduce risk factors for dementia and prepare for future health events.

Increasing awareness and responsiveness:
- increases awareness of the whole community about signs and symptoms of dementia
- means reducing risk factors for dementia by informing and supporting activities such as physical activity, literacy and learning, emotional wellbeing, social participation and nutrition
- confirms the importance of supportive social and physical environments for people with dementia
- includes supportive actions such as organising powers of attorney, advance care planning, and making and up-dating wills.

Needs and demands

The Victorian Public Health and Wellbeing Plan 2011–15 (VPHWP) aims to improve the health and wellbeing of Victorians by engaging communities in prevention, and strengthening systems for health protection, health promotion and preventive healthcare across all sectors and levels of government. Several VPHWP priority areas promote the health of Victorians Some of these relate to reducing the risk of dementia.

Although age is the main risk factor for dementia, research identifies modifiable risk factors. Possible risk factors include a history of stroke and other cardiovascular diseases, smoking, low exercise levels, midlife obesity, insulin-dependent diabetes and hypertension. Physical activity, good nutrition and social connection can reduce risk factors, reinforcing the importance of early primary prevention. Brain stimulation is also showing to have a positive effect on reducing the risk of cognitive decline and dementia.

Prevention strategies are cost effective, can deliver savings to the community, and should begin in early and middle life stages. The department delivers various health promotion and disease prevention strategies. These strategies raise awareness of disease risk factors, and encourage people to maintain their health and wellbeing.

Increasing awareness about dementia in the community helps destigmatise the disease leading to open discussion, and better understanding of and more support for people with dementia, their families and carers.

Completing advance care plans and nominating powers of attorney and guardianship when people are healthy and well enables them to express their preferences and choices for future care, support and treatment. Planning gives a voice to a person’s beliefs and values. An appointed guardian acts as a substitute decision maker, when a person cannot make decisions.

Opportunities should be maximised for people diagnosed with dementia to discuss these important issues as soon as possible. People should still be included in decision making as much they can be, as cognition declines.
### Aims, actions, measures and responsibility

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<th>Aims</th>
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| **Promote a better understanding of dementia within the community, general practitioners and other health professionals** | Continue to promote the fact that modifiable risk factors for vascular dementia are shared with other lifestyle diseases such as type 2 diabetes, cardiovascular disease and stroke:  
- develop and provide information on Seniors Online  
- include vascular dementia risk in analysis of risk-factor information, for example, the Victorian Population Health Survey Report  
- review and update Well4Life resources  
- continue to liaise with Alzheimer’s Australia Vic (AAV) on the Your Brain Matters program and other such initiatives.  
Improve health literacy among older Victorians, including dissemination of relevant AIBL study findings. | Number of hits on Seniors Online  
Well for Life resources updated  
Information on Seniors Online, Fifty Plus, ECCV Golden Years, HAnet and like organisations | Department of Health – System Intelligence and Analytics  
– Ageing and Aged Care  
AAV                                                                 |
| **Promote action on reducing modifiable risk factors**               | Provide information to older people about reducing social isolation and increasing participation in physical activity, healthy eating and continuous learning.  
Seniors Count! seeks to: empower older people, acknowledge their contributions and enhance perceptions about older people, provide opportunities for participation, support age-friendly environments, and facilitate support and access to services.  
Improve awareness and integration of evidence-based falls-prevention initiatives within departmental programs, including for people with dementia.  
Provide information for Seniors Online and relevant Victorian publications. | Information on Seniors Online, Fifty Plus, ECCV Golden Years, and HAnet. Information and activities in Victorian Seniors Festival  
Dissemination of findings of NHMRC Partnership Project, Reducing Falls Among Older People In Victoria: Better Evidence, Better Targeting, Better Outcomes, to relevant Department of Health programs such as Health Independence Program, Home and Community Care, Primary Care Partnerships, Primary Health.  
Number of hits on Seniors Online | Department of Health – Ageing and Aged Care  
– Prevention and Population Health  
Commissioner for Senior Victorians  
Ministerial Advisory Committee for Senior Victorians  
Department of Health – Ageing and Aged Care                                                                 |

*Australian Imaging, Biomarkers and Lifestyle Study of Ageing*
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<tr>
<td>Implement healthy ageing funding in departmental regions to promote healthy ageing by improving nutrition, physical activity, emotional wellbeing, and social connection through funding ten projects.</td>
<td>Projects completed in Gippsland, Grampians, Hume and Loddon Mallee Regions by the end of 2014</td>
<td>Department of Health – Ageing and Aged Care – Gippsland Region – Grampians Region – Hume Region – Loddon Mallee Region</td>
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<td>Continue to support and deliver anti-smoking social marketing, smoking cessation support programs and legislative reform, to encourage people to quit smoking and reduce the community’s exposure to secondhand smoke.</td>
<td>Tobacco control programs and reform delivered</td>
<td>Department of Health – Prevention and Population Health</td>
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<tr>
<td>Deliver Life! Diabetes and Cardiovascular Disease Prevention Program, providing tailored lifestyle management programs for people at high risk of type 2 diabetes, heart disease and stroke, to adopt healthy behaviours and a more active lifestyle.</td>
<td>Number of people identified at high risk commencing the Life! Program to June 2015</td>
<td>Department of Health – Prevention and Population Health</td>
<td></td>
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<tr>
<td>Deliver Healthy Together Victoria (HTV) initiatives, addressing the underlying causes of poor health across children’s settings, workplaces and communities to impact health at the population level. This whole-of-community initiative aims to keep all Victorians healthier for longer. Inform evidence-based health promotion interventions across multiple settings through evaluation of HTV.</td>
<td>Concentrated coordinated prevention effort delivered by Healthy Together Communities (HTCs) Evaluation of Healthy Together Victoria</td>
<td>Department of Health – Prevention and Population Health</td>
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<td>Aims</td>
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<td>Support the Heart Foundation Victoria’s expansion of their existing program of assisting councils to implement urban design principles that create healthy and active local communities.</td>
<td>Targeted technical support provided to HTCs and Victoria’s Health Attack Hot Spots, together accounting for 20 local government areas.</td>
<td>Department of Health – Prevention and Population Health</td>
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<td>Support planning for future care needs and preferences</td>
<td>Promote the appointment of appropriate substitute decision makers through use of enduring powers of attorney.</td>
<td>Number of hits on web Number of community education presentations</td>
<td>Office of the Public Advocate Seniors Rights Victoria</td>
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<td>Implement the statewide advance care planning strategy to guide health services about involving people in decisions about their care, assisting people to develop advance care plans, and guiding appropriate responses from clinicians that respect people’s wishes regarding level of healthcare and quality of life. Develop resources in 2014 (and beyond) to support the implementation of advance care planning.</td>
<td>Implementation from 2014 of Advance care planning: have the conversation. A strategy for Victorian health services 2014-2018</td>
<td>Department of Health – Continuing Care Health services Other service providers including general practitioners, residential aged care services and Ambulance Victoria</td>
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<td>Support research into risk reduction strategies, treatments and cure for dementia</td>
<td>Coordinate statewide support for and lead in the development of the Victorian Dementia Research Initiative submission to the NHMRC.</td>
<td>Funding and in-kind support provided to research</td>
<td>Department of Health Transformational Initiatives Unit The Florey Institute of Neuroscience and Mental Health AAV National Ageing Research Institute</td>
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Priority 2: Support timely assessment and diagnosis

Expected outcome Better access to dementia assessment, support, advice and specialised services.

Timely assessment and diagnosis:
- improves the opportunity to engage with people with dementia while they can make decisions about their care
- enables early service response and support that can improve outcomes for people with dementia
- gives families an opportunity to plan for the future and prepare themselves, knowing that the person they care for is experiencing cognitive change.

Needs and demands

Lack of knowledge about dementia among service providers, general practitioners and other health professionals can be a barrier to early assessment, diagnosis, referral and access to support and services.

Diagnosis of dementia may be delayed because of a perception that nothing can be done to assist people with dementia, their families and carers.

Families may delay seeking help because they lack understanding about the early signs of dementia. Diagnosis can also be delayed because of community or cultural reluctance to raise the issue, for example because of the way dementia is perceived in some culturally and linguistically diverse communities, or because the tools to diagnose dementia are not relevant to communities.

Early diagnosis improves the opportunity to engage with people with dementia while they can make decisions about their care and support, and for early service response and support that can improve outcomes for people with dementia. Families can better plan for the future and prepare themselves with the knowledge that the person they care for will experience cognitive change. Early diagnosis and early access to support and services likely lead to better outcomes for both the person with dementia and their carer, and delay entry into residential aged care. Diagnosing dementia later reduces the opportunity for early support and services, contributes to isolation of people with dementia and their families, and increases the likelihood of people needing more costly services due to increased dependence and morbidity.
# Aims, actions, measures and responsibility

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<tr>
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<tbody>
<tr>
<td><strong>Promote and strengthen assessment and diagnosis</strong></td>
<td>Continue to monitor improved access to Cognitive Dementia and Memory Services (CDAMS) as per the subacute services planning and capability framework, with a focus on improved access to CDAMS particularly in regional and rural areas. Strengthen assessment and diagnosis processes through the revised <em>Best practice guidelines for CDAMS</em>.</td>
<td>Monitoring of implementation of capability and access framework, and innovative models of healthcare provision such as telehealth</td>
<td>Department of Health – Continuing Care Health services</td>
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<td>Continue implementation of the Service Coordination Tool Templates (SCTT) to identify cognition and memory problems for screening.</td>
<td>Implementation demonstrated in annual System Service Coordination Survey</td>
<td>Community care and health service providers Department of Health – Primary Health</td>
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<td></td>
<td>Promote awareness and recognition of dementia through HACC assessment services.</td>
<td>HACC assessment protocols implemented</td>
<td>Department of Health – Ageing and Aged Care</td>
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<td></td>
<td>Continue to focus on identifying early stages of dementia by HACC assessment services through implementation of <em>Strengthening assessment and care planning</em>, as well as the <em>Dementia practice guidelines for HACC assessment services</em>.</td>
<td><em>Dementia practice guidelines for HACC assessment services</em> implemented</td>
<td>Department of Health – Ageing and Aged Care</td>
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<tr>
<td></td>
<td>Work with Networking Health Victoria and state, regional and local primary healthcare networks to provide information to GPs on assessment, referral, support and services.</td>
<td>Information available and accessible to GPs on support for people with dementia and their carers</td>
<td>Department of Health – Ageing and Aged Care Networking Health Victoria Primary care networks</td>
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<td>Educate ACAS clinical staff in the use of validated assessment and screening tools for dementia, for example, RUDAS, SMMSE, GDS tools[^1] based on recommendations of an Expert Clinical Reference Group convened by the Commonwealth Department of Health.</td>
<td>All clinical staff trained in the administration of selected tools from the toolkit</td>
<td>Department of Health – Ageing and Aged Care</td>
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[^1]: RUDAS – Rowland Universal Dementia Assessment Scale is designed for use with people from CALD backgrounds
SMMSE – Standardized Mini-Mental State Examination
GDS – Geriatric Depression Scale
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<tr>
<td>Support ACAS(^6) to maintain geriatricians as part of the multidisciplinary ACAS team.</td>
<td>Geriatrician support to 85 per cent of ACAS teams</td>
<td>Department of Health – Ageing and Aged Care</td>
<td></td>
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<tr>
<td>Promote timely assessment and diagnosis by ACAS for people with dementia.</td>
<td>ACAS protocols implementation supported</td>
<td>Department of Health – Ageing and Aged Care</td>
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<tr>
<td>Support dissemination of <em>Advancing practice in the care of people with dementia</em> to all ACAS and other relevant stakeholders.</td>
<td>Hardcopy and web-based resource available to all ACAS</td>
<td>Department of Health – Ageing and Aged Care Dementia Training Study Centre, Victoria and Tasmania</td>
<td></td>
</tr>
<tr>
<td>Support AAV in developing a series of toolkits that address the development of dementia as part of HIV, diabetes, and other chronic diseases.</td>
<td>Toolkits developed and published</td>
<td>Department of Health – Ageing and Aged Care AAV</td>
<td></td>
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<tr>
<td>Support AAV in the pilot of an education module relating to cognitive screening by Aboriginal health workers.</td>
<td>Education module developed, piloted, evaluated and completed</td>
<td>AAV</td>
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</table>

\(^6\) ACAS is jointly funded by the Commonwealth and Victorian Governments.
Priority 3: Plan for diversity in the delivery of support and services

Expected outcome Diversity planning is embedded into organisational policy, programs and services.

Planning for diversity:
- acknowledges the extreme diversity within age ranges and various population cohorts, and that older people are not an homogenous group
- recognises that needs and preferences for support and services vary from person to person
- promotes access of Victorians to the support and services they need and want
- meets the expectation that department-funded programs should provide a flexible response for individual and diverse needs and preferences, including those of people of diverse backgrounds, such as Aboriginal and CALD communities; people with intellectual disabilities; people who identify as gay, lesbian, bisexual, transgender or intersex; and younger people with dementia.

Needs and demands

Victorians should have access to the support and services they require. All department-funded programs are expected to provide a flexible response to meet diverse needs and preferences.

Older people are not an homogenous group. Needs and preferences for support and services may vary among people from diverse backgrounds, for example, Aboriginal and CALD communities; people with intellectual disabilities; people who identify as gay, lesbian, bisexual, transgender or intersex (GLBTI); and younger people with dementia. For example, dementia is much maligned and stigmatised in some CALD communities. This has implications for raising awareness about dementia and may limit people from CALD communities seeking information and support, leaving them and their families isolated. The department continues to focus on improving services to increase access for CALD communities.

Because of their stage of family lifecycle, the preferences of younger people with dementia and their families for supports are likely to be different to those of older people. For example, there may be financial implications for a family with young children and a significant mortgage, when a parent with early onset dementia, and perhaps their carer, have to leave paid employment.
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<tr>
<td>Improve service planning to include the needs and preferences of people from diverse backgrounds</td>
<td>Continue to support implementation, including annual reviews, of the regional and agency HACC diversity plans up to 2015, to improve accessibility and responsiveness to diverse groups including people with dementia, their community networks, families and carers. Use regional HACC diversity advisors to support regions and organisations to implement their diversity plans. Support HACC-eligible people who have difficulty, due to their diversity, accessing HACC and related services, through the support of Access and Support Workers.</td>
<td>Regional plans updated annually, agreed by Department of Health Ageing and Aged Care, and uploaded to the HACC website Organisation plans reviewed annually in discussion with regions Implementation of diversity plans included in the Community Care Common Standards (CCGS) triennial review</td>
<td>Department of Health – regions HACC funded organisations until 30 June 2015 Department of Health – Ageing and Aged Care</td>
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<tr>
<td>Improve understanding of diversity and associated issues with the aged care and other relevant workforces</td>
<td>Continue to engage with AAV through the HACC Diversity Working Group that provides input to HACC diversity projects and initiatives, and is a networking forum for key sector stakeholders.</td>
<td>HACC Diversity Working Group meetings, including AAV</td>
<td>Department of Health – Ageing and Aged Care</td>
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<tr>
<td>Support the HACC workforce to respond to the needs and preferences of people with dementia and their families and carers</td>
<td>Fund AAV to provide education and training to the community care workforce. Meet the demand for HACC workforce training in the accredited course ‘Provide support to people with dementia’, through the HACC Statewide Training Calendar.</td>
<td>Outputs agreed with AAV Training take-up monitored, and training units modified to meet changing needs</td>
<td>Department of Health – Ageing and Aged Care AAV Victorian HACC Education and Training Service (Chisholm)</td>
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<td>Aims</td>
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<td>Support a Royal District Nursing Service (RDNS) nurse-led dementia trial across Melbourne, Dementia Care in Community: Access for CALD Communities to support people at risk of being overlooked by the health system because of language or cultural differences.</td>
<td>Trial complete and findings disseminated by October 2015</td>
<td>RDNS Diverse stakeholders including AAV, CDAMS, ECCV, Department of Health Ageing and Aged Care</td>
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<td>Encourage initiatives by stakeholders to further dementia research, policy, resources and practice, such as the joint AAV, National Ageing Research Institute, and Victorian Aboriginal Community Controlled Health Organisation Incorporated submission for a partnership grant for Evaluation of Victorian Health Services for Older Aboriginal People to determine the prevalence of dementia, chronic disease and geriatric syndromes in Victoria.</td>
<td>Grant achieved for project</td>
<td>AAV National Ageing Research Institute Victorian Aboriginal Community Controlled Health Organisation Incorporated Other stakeholders</td>
</tr>
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Priority 4: Maximise independence, health and wellbeing of people with dementia

Expected outcomes Improved quality of life for people with dementia living at home, in the community, in hospital or in residential aged care facilities. Improved experience of using health services for people with dementia.

Maximising independence, health and wellbeing:
- means person-centred and relationship-centred approaches that meet different needs
- promotes social connection
- supports dementia-friendly communities and environments including physical and social environments
- improves service coordination, referral and transition between services.

Needs and demands
People with dementia have different interests and pastimes. Designing daily life around these interests gives people pleasure; makes use of their skills and abilities; forges important links with people and places that were or are important in their lives; adds variety and interest; and creates stimulation, thereby reducing boredom, anxiety, stress and frustration. The focus should be on being alive, healthy and contributing rather than on being a person with dementia.

The department seeks to support the independence, health and wellbeing of people with dementia, at home, in the community, in residential care, and when accessing health and aged care services. Approaches that maximise independence, health and wellbeing: are person-centred and relationship-centred; promote social connection; meet different needs; and improve service coordination, referral and transition between services.

People want a life free from stigma and access to the information, support and services they need.
Tools and resources can assist care planning, mainstream health services caring for people with dementia, and services that provide care in the home and in residential aged care. People with dementia commonly need to transition from living independently to living with extra support and, for many, living with support through community and home-based packages. A person with dementia returning from hospital may require additional supports. When a person can no longer live at home, they may transition to residential aged care.
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| Promote a person-centred approach among service providers | Support research and project initiatives seeking to improve the lives of people living with dementia, such as:  
- Monash University Accident Research Centre (MUARC) partnership research into people with dementia and transport/driver, if the MUARC proposal is funded through Australian Research Council (ARC) Linkage Grant Scheme  
- AAV Lifestyle Project, on applying dementia risk reduction strategies to enhance quality of life of people living with dementia, and potentially affect the progression of dementia. | Funding and in-kind support provided to the research project  
Resource developed and disseminated | Department of Health – Ageing and Aged Care  
MUARC and partners  
AAV and stakeholders |
| Continue to embed the HACC active service model (ASM) approach to care and supporting people in care relationships, including goal directed care planning and flexible service responses. | | Annual ASM implementation plans developed by all HACC-funded agencies  
Implementation of HACC ASM monitored, currently through the Commonwealth Community Care Standards | Department of Health – Ageing and Aged Care |
| Review implementation of the ASM, to identify progress in implementation, and sustainable and comprehensive changes in services. | | Sustainable and comprehensive changes identified, or ways to achieve sustainability and a comprehensive approach identified and disseminated | Department of Health – Ageing and Aged Care |
| Fund café-style support services for people in care relationships, to promote social engagement, connections and networking. | | Funding continued and café-style support services model identified and encouraged where appropriate  
Opportunities for funding growth sought | Department of Health – Ageing and Aged Care |
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<tr>
<td>Improve referral pathways for people with dementia and their carers.</td>
<td><strong>Guide to services for people with dementia and their carers</strong> (Department of Health 2012) localised at a regional level</td>
<td>Department of Health – Ageing and Aged Care – regions HACC alliances until 30 June 2015 Service providers</td>
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| Improve the involvement of older people and their carers in decisions around care and information provided to them:  
  - Support health services to investigate and improve participation of older people and their carers in informing care planning.  
  - Support projects that aim to improve what and how information is provided to people on discharge. | **Clinical Leadership Group on care of older people in hospital** supported to review and develop resources supporting informed care planning. Funding and support provided for project/s on information | Department of Health – Continuing Care Clinical Leadership Group on care of older people in hospital Health services |
| Acknowledge individual rights of people with dementia and their families and carers | Implement priority actions in the *Elder abuse prevention and response guidelines for action 2012–14*, progress strategies to prevent elder abuse, and inform older people of their legal, financial and societal rights. | **Resources developed and disseminated** | Department of Health – Ageing and Aged Care |
| Pilot a Health Services Guardianship Liaison Officer (HSGLO) position at the Office of the Public Advocate (OPA) to provide education and liaison, and develop a toolkit to guide best practice in Victorian health services. | **Toolkit developed and tested through a staged implementation process across Victorian health services**  
  - Increased number of appropriate and relevant guardianship applications submitted by hospitals | OPA Department of Health – Continuing Care |
<p>| Where OPA is appointed as guardian by VCAT, seek the person’s wishes and implement where feasible. | <strong>Practice guidelines implemented</strong> | OPA State Trustees |</p>
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<tr>
<td>Improve treatment, care and support for older people</td>
<td>Develop a discussion consultation paper identifying priorities to be addressed to support the mental health and wellbeing of older people. Develop an <em>Older person’s mental health action plan</em>.</td>
<td>Consultation process conducted with key stakeholders in relation to key priorities Older person’s mental health action plan developed</td>
<td>Department of Health – Mental Health</td>
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<td>Monitor the licensed training provider delivering training in comprehensive health assessment of older people to help screen for delirium, pain and depression, for health professionals in all settings.</td>
<td>Annual reporting by training provider</td>
<td>Department of Health – Ageing and Aged Care</td>
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<td>Support collaboration between AAV, CDAMS and NHV for state, regional and local primary healthcare networks, on: identifying signs of cognitive impairment, referrals to appropriate and timely services and support, and ongoing support in general practices and by practice nurses of people with dementia and their carers.</td>
<td>Guidance made available to general practices and practice nurses</td>
<td>Department of Health – Ageing and Aged Care AAV CDAMS NHV Primary healthcare networks</td>
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<td>Support regional dementia plans and initiatives.</td>
<td>Department of Health Ageing and Aged Care information and advice on regional materials provided to regions Department of Health Ageing and Aged Care presentation to regions as appropriate Regional initiatives achieved</td>
<td>Department of Health – Ageing and Aged Care — regions</td>
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<td>Identify and support innovative approaches to the systematic management of older people and those with dementia that improve outcomes following presentation to hospital: • Fund Melbourne Health/Epicentre to develop a dementia care pathways in acute hospital. • Support health services to develop alternative care settings to manage older people and those with dementia presenting to hospital, including at home.</td>
<td>Funding and support over three years provided for project Uptake by health services of GEM care in a home setting</td>
<td>Department of Health – Continuing Care Melbourne Health/Epicentre Health services</td>
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<td>Support health services to prevent the functional decline of older people in hospital by providing health services with an up-to-date evidence base</td>
<td>Maintain the website <em>Best care for older people everywhere: the toolkit</em> &lt;www.health.vic.gov.au/older/toolkit/index.htm&gt; which provides appropriate tools, resources and simple strategies for all staff, to minimise risks of functional decline of older people in hospital.</td>
<td>Number of hits on website</td>
<td>Department of Health _ Continuing Care NARI Victorian hospital sector and experts</td>
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<tr>
<td>Support people with dementia in supported residential services (SRS)</td>
<td>Support updated annual SRS Proprietor and Staff Training program that incorporates supporting people with a range of cognitive impairment needs including dementia.</td>
<td>Revised SRS training courses provided to SRS proprietors and staff</td>
<td>Department of Health _ Ageing and Aged Care Leading Age Services Australia (LASA)</td>
</tr>
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| Support people to live in residential aged care                      | Promote dementia-friendly residential aged care environments through the use of:  
  • Dementia-friendly environments: a guide for residential aged care services  
  • residential aged care services built environment tool  
  • aged care residential services generic brief  
  • training and education of public sector residential aged care services (PSRACS) management and staff  
  • dementia-friendly projects in PSRACS including therapeutic dementia aids and resources to maximise independence, participation and communication in rural PSRACS for residents with behavioural and psychological symptoms of dementia (BPSD). | Training and education of PSRACS managers and staff delivered PSRACS funded to undertake projects in dementia-friendly environments | Department of Health – Ageing and Aged Care PSRACS                                           |
| Support a research and evaluation project to better understand the quality use of medicines in PSRACS, and explore opportunities for sector-wide quality initiatives. | Support a research and evaluation project to better understand the quality use of medicines in PSRACS, and explore opportunities for sector-wide quality initiatives.                                      | Published reports                                                        | Department of Health – Ageing and Aged Care Centre for Medicine Use and Safety, Faculty of Pharmacy and Pharmaceutical Sciences, Monash University Victorian Institute for Forensic Medicine |
Aims | Actions | Measures | Lead responsibility and partners
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Support the Health Literacy in PSRAC project (Residential Aged Care: Partnering in Care – RAC-PIC) to develop evidence-based consumer information brochures for clinical risks identified in Strengthening care outcomes for residents with evidence (SCORE). | Resources developed and disseminated | Department of Health – Ageing and Aged Care
Support the development of assessment requirements and approaches for PSRACS for the new dementia and severe behaviours supplement introduced in 2013. | Resources developed and disseminated | Department of Health – Ageing and Aged Care
Barwon Health

Features of dementia-friendly practice in a hospital

Ballarat Health:
- runs education sessions for all staff, clinical, and non-clinical, on supporting people with dementia in the hospital
- has a bookmark for staff and visitors on ways to communicate with people with dementia
- puts up posters in lifts and foyers on the hospital’s dementia care initiative, and distributes flyers through the hospital cafeteria and outpatient areas
- consulted with people with dementia and their carers on a local cognitive impairment identifier that prompts staff to pay more attention to communicating with a person, take more time with the person, and modify their expectations.

*Dementia care in hospitals: key findings and ideas from the evaluation of four projects*, Department of Human Services 2005
Priority 5: Promote dementia friendliness in age friendly communities

Expected outcome Increased opportunities for people with dementia and their families and carers to stay connected to community.

Dementia friendliness:
- maximises the abilities that people with dementia have
- acknowledges that people with dementia have individual needs
- seeks to promote the independence of people with dementia

Needs and demands

People with dementia and their carers want to live their life in a way that meets their needs. They want to engage in and contribute to their local communities as long as they are able, and live alongside people who have an awareness and understanding of dementia.

Age-friendly communities can include dementia friendliness, which can benefit everyone. Age- and dementia-friendly neighbourhoods, communities, public places and spaces, and businesses support people with dementia and their carers to continue interacting and moving in their regular routines and environments, with purpose and enjoyment. Dementia-friendly planning and design can result in community amenities, housing, care facilities, transport, way-finding and other features that optimise the participation and engagement of people with dementia and their carers.

The potential for social isolation is high for people with dementia and their carers. Social networks can help people be physically and mentally active leading to improved health and wellbeing.

Frequent emotional support and social activity reduce the risk of cognitive decline. Creating affordable and culturally appropriate opportunities for older people to participate in the community supports their individual health and wellbeing, and strengthens our communities.

‘Peter had been living at a lodge for seniors in New South Wales, but decided to visit the house where he grew up in Melbourne. When Peter arrived in Melbourne he found that the house had been knocked down. He had been wandering the streets for days, mostly sleeping rough during the nights. Peter was finally picked up by police who identified him as a person listed missing in New South Wales. He was brought to Travellers Aid. The Emergency Relief Officer at Travellers Aid made contact with Peter’s carer in New South Wales to confirm he still had his room at the lodge and was expected back there. Travellers Aid helped Peter obtain sufficient identification to travel and booked him on a flight back to New South Wales. Despite his general confusion, Peter seemed relieved that the police and the Emergency Relief Officer took care of him, and he was very grateful when he left the Travellers Aid office to be taken to Melbourne Airport.’

Annual report: making every day travel possible for all people, Travellers Aid Australia 2011
### Aims, actions, measures and responsibility

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<td>Promote dementia-friendly communities and environments</td>
<td>Promote a dementia-friendly Victorian Seniors Festival.</td>
<td>Dementia-friendly environment to feature from 2014 Victorian Seniors Festival</td>
<td>Department of Health – Ageing and Aged Care; RDNS</td>
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<td>Partner with local governments to promote age-friendly communities including dementia friendliness.</td>
<td>Agreed plans with several local governments to create dementia-friendly shopping strips and public spaces</td>
<td>AAV; Municipal Association of Victoria; Council on the Ageing Vic (COTA Vic)</td>
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<tr>
<td>Fund Municipal Association of Victoria (MAV) for dementia-friendly projects in two-three local government areas (LGAs).</td>
<td>Projects in two-three LGAS resulting in sustainable dementia-friendly features in local communities</td>
<td>Department of Health – Ageing and Aged Care; Municipal Association of Victoria</td>
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<td>Develop and promote resources to support age-friendly (including dementia-friendly) shopping precincts and businesses.</td>
<td>Tip sheets developed and disseminated for dementia-friendly precincts and businesses</td>
<td>Department of Health – Ageing and Aged Care</td>
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<td>Promote dementia-friendly businesses through Seniors Card Victoria.</td>
<td>Seniors Card Victoria business supporters identified as being dementia-friendly</td>
<td>Department of Health – Ageing and Aged Care</td>
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<tr>
<td>Explore collaborations with the ANZ bank, Pharmacy Guild and taxi services, based on Alzheimer’s Australia’s Is it Dementia? campaign.</td>
<td>Agreements established between AAV and various businesses, and implemented, including specific supports of people with dementia and their carers</td>
<td>AAV</td>
<td></td>
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<tr>
<td>Work with the City of Melbourne on dementia-friendly communities project to serve as a pilot/model for specific forms of private sector engagement.</td>
<td>Agreement implemented between AAV and City of Melbourne; Specific initiatives to support people with dementia and their carers living and visiting the City of Melbourne</td>
<td>AAV; City of Melbourne</td>
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Priority 6: Support families and carers of people with dementia

Expected outcome Better supported carers.

Supporting families and carers:

- acknowledges that the majority of people in the early and middle stages of dementia in Victoria live at home supported by family or other unpaid carers
- seeks to promote the health and support needs of families and carers who are critical in providing community-based care
- recognises that carers of people with dementia are often partners who may be old and frail, with high levels of carer burden, depression and decreased quality of life
- provides services and supports to carers so that they can continue to provide care.

Needs and demands

The majority of people in the early and middle stages of dementia in Victoria live at home, by themselves or with family. The health and support needs of carers are a critical part of providing community-based care. Carers of people with dementia are often partners who may be old and frail, with high levels of carer stress, depression and decreased quality of life. Many carers need ongoing support to continue in their care role. However, not all carers and people in care relationships seek or desire government support. Not all carers perceive themselves as carers.

As Victoria’s population ages, coupled with probable increases in dementia prevalence, there is likely to be a greater need for care provided by family and friends. As the disease progresses, care needs increase. Carer outcomes improve when carers are fully informed about dementia and its path. Carer support and counselling at diagnosis can delay entry into residential aged care.

A review of Victoria’s social support and respite services, completed in 2011, found that carers would benefit from more practical information to support them in the early stage of their care roles.

Carers identified the need to better understand the stages and changes that dementia brings, as well as how to access and incorporate care and supports into the home (Review of HACC and SCP social support and respite services 2011).

The Victorian Auditor General’s Report 2012, Carer support programs, found that:

- although the department funds a range of carer support programs, such as counselling, respite and training, some carers lack awareness of available supports
- better identification of carers, through referral and assessment processes, would facilitate carer access to support
- a consistent approach to prioritising carer need would provide better equity and timely access to high-demand services for those with greatest need.
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| Inform and support carers | Promote *Carers Recognition Act 2012* and Victorian charter supporting people in care relationships by:  
- providing information on Seniors Online about the Act, charter and services that support carers  
- providing information on HAnet about the Act, charter and services  
- using forums to present on the Act, charter and services. |  
- Number of website hits  
- Number of reads of the dementia-related posts  
- Engagement of carers through Carers Victoria’s website, e-newsletter and advisory telephone line  
- Presentations made at regional forums of service providers, peak bodies etc. | Department of Health  
- Ageing and Aged Care  
- regions  
Carers Victoria  
AAV  
Service providers, HACC until 30 June 2015, and Support for Carers Program |

| Review Support for Carers Program (SCP) guidelines, including support for carers of people with dementia, to take into account the Victorian Auditor General’s recommendations, the Act and charter, and support of carers after the person they care for has died. | SCP guidelines redrafted in consultation with regions and providers  
Guidelines confirmed and disseminated | Department of Health  
- Ageing and Aged Care  
- regions  
Carers Victoria  
Support for Carers Program providers |

| Continue to fund dementia services, and support for carers of people with dementia, including the carers of younger people. | Funding continued and opportunities for funding growth sought | Department of Health  
- Ageing and Aged Care |

| Strengthen the focus on identifying carer needs | Continue to implement the carer assessment guidelines in *Strengthening assessment and care planning: dementia practice guidelines for HACC assessment services*.  
Promote *A guide to services for people with dementia and their carers* to improve service provider awareness of referral pathways and supports for carers. | Carer Assessment Guidelines implemented by all HACC assessment services  
Services guide localised by providers at a regional level | Department of Health  
- Ageing and Aged Care  
Service providers |

| Review and update the HACC, Ageing and Aged Care, Seniors Online and HAnet websites to improve information about support services for carers, and upload relevant publications. | HACC, Ageing and Aged Care, Seniors Online and HAnet updated with relevant publications | Department of Health  
- Ageing and Aged Care |

| Liaise with relevant key stakeholders and peak bodies involved in providing information and support to carers to review and improve information about department-funded support services for carers. | On average, three meetings per year of Department of Health, Department of Human Services and Carers Victoria liaison committee | Department of Health  
- Ageing and Aged Care  
Department of Human Services  
Carers Victoria |
Priority 7: Support people with dementia at the end of their lives

Expected outcome Improved palliative and end-of-life care for people with dementia.

Supporting people at the end of life:

- means respecting a person’s wishes for palliative and end-of-life care
- gives people choice and control
- empowers people with dementia to make decisions early about palliative and end-of-life care
- requires that a person’s wishes are discussed with family, carers and practitioners in the early stages of dementia, and documented in an advance care plan.

Needs and demands

Although dementia is a terminal disease, many people with dementia die from other causes. Those dying of chronic illnesses like dementia are likely to experience prolonged decline, and be supported over a long period of time. Some people with dementia die in their own homes, some in residential aged care, and some in an acute health setting or palliative care service.

A person’s wishes for their end-of-life care are best discussed with family, carers and practitioners in the early stages of dementia and documented in an advance care plan (see Priority 1). Making decisions about end-of-life care early along the dementia pathway can empower people with dementia, enabling choice and control.

Advance care planning: have the conversation – a strategy for Victorian health services 2014–2018 states that:

- Advance care planning is the process of planning for future health and personal care whereby a person’s values, beliefs and preferences are made known so they can guide clinical decision making at a future time when that person cannot make or communicate their decisions due to lack of capacity.
- In palliative and end of life care, advance care plans developed in the early stages of dementia need to be activated.

The Victorian Government’s vision for palliative care articulated in the Strengthen palliative care: policy and strategy directions 2011–2015 is:

- All Victorians with a life threatening illness and their families and carers have access to a high quality palliative care service system that fosters innovation, promotes evidence-based practice and provides coordinated care and support that is responsive to their needs.

Seniors Count! 2014–2019 Victoria’s Seniors participation action plan, overseen by the Commissioner for Senior Victorians, aligns where appropriate with the Victorian dementia action plan.
### Aims, actions, measures and responsibility

<table>
<thead>
<tr>
<th>Aims</th>
<th>Actions</th>
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<td>Assist aged care and health services to care for people at the end of life</td>
<td>Strengthen the relationship between palliative care programs and residential facilities caring for older people and those at home</td>
<td>Number of residential aged care facilities that have introduced end-of-life care pathways Percent of people accessing community palliative care who wish to die at a residential aged care facility, and who die in their place of choice, including at home</td>
<td>Department of Health – Continuing Care – Ageing and Aged Care Aged care service providers</td>
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### Outcomes and reporting

The *Victorian dementia action plan* will result in on-going improvements, increased reach, better networks based on stronger and new partnerships, and new approaches – all to improve the quality of life for people with dementia and their families and carers, and ultimately everyone in Victoria.

Measures are to be identified and reported according to the type of activity and the stage at which it is meaningful to be measured and reported. Measures can relate to process, impact and outcome, at the individual level, organisational level and systemic level and are identified for each action in the *Victorian dementia action plan*.

Each action identifies those with lead responsibility for the action, and partners to support its implementation. Identifying and reporting on outcomes will be a collaborative effort of stakeholders involved in implementing the *Victorian dementia action plan*. The Department of Health, Ageing and Aged Care Branch will co-ordinate annual reporting of the implementation of the plan.

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*Seniors Count! 2014–2019 Victoria’s Seniors Participation Action Plan, overseen by the Commissioner for Senior Victorians, aligns where appropriate with the *Victorian dementia action plan*.**
People in palliative care with different illnesses

‘Before I had palliative care I was very scared about the transition between life and death; what was actually going to happen at that moment. … my whole attitude to life and death and everything has changed since I’ve joined (palliative care). I can’t speak highly enough of them. When hospice first came, they asked me if I wanted to die at home or at hospital; I’d never given it a thought. So we decided I’d die at home, but to do that, (my partner) has to be more prepared, he has to know more; everyone has to be more on their toes. We can change our mind at the end, but that would be one of the dreams, to die at home with all the kids here. That’d be lovely.’

‘In the Aboriginal communities…We look at it as being a beautiful journey, the dreaming flowing along, my ancestors in the background and my family just at the end waiting to hold me. … I want to die in country. Go home to where I was born in Yorta Yorta country. That’s my wish. I’ve lived on Wurundjeri country so I feel that I’ve been accepted and I belong here too, so I can probably die here. I want to be at home if possible and I want my journey to be a very strong but safe cultural journey for me and my family.’

‘Sometimes all it takes is a hand on your shoulder.’

‘When I was diagnosed I thought “Oh well. That’s it.” So I arranged and paid for my funeral. I went to the solicitor and made a new will and gave (my daughter) power of attorney so I didn’t have to worry about anything then. I don’t want fuss. That’s the first thing I did actually. Hospice has been absolutely marvellous; if I’ve got any queries, any worries, they’re always very helpful. They can’t do enough for you.’

*The Dreamers: Life, death and dreams*, Pippa Wischer 2014
Appendix 1: Defining terms and concepts

**Behavioural and psychological symptoms of dementia**

Behavioural and psychological symptoms of dementia (BPSD) are symptoms of disturbed perception, thought content, mood or behaviour that frequently occur in people with dementia. Some health professionals add signs as well as symptoms to this term.

Behavioural symptoms can usually be identified by observation, such as screaming, restlessness, wandering, agitation, hoarding, sexually inappropriate behaviours, shadowing, obsessive and/or repetitive behaviour, and verbal behaviours perceived by a carer as aggressive. Psychological symptoms can usually be identified in an interview or discussion, with symptoms including anxiety, depression, apathy, hallucination and delusions.

Multi-component non-pharmacological responses are increasingly being encouraged to address BPSD. These usually require knowing about a person, for example their family, work and childhood life experiences, their cultural preferences, international events that may have affected them such as wars or the depression of the 1930s. Pharmacological responses may be appropriate in some cases.

**Carers and care relationships**

An unpaid carer is a person providing care to another person requiring that care in a care relationship, for example assistance and support with activities of daily living or personal care. A carer may look after a family member, friend, or someone else who needs support. Carers can be from any culture or country, and any socio-economic background. Carers may be employed or not employed. A carer may not necessarily live with the person they care for.

Some people who provide unpaid care to another person requiring that care do not identify as being ‘a carer’.

In a care relationship, one person gives unpaid care to the other. Sometimes there may be more than one person giving care, or being cared for.

**Delirium and depression**

Delirium, or acute confusional state, is a reversible disorder of cognitive function, an acute disturbance of attention and cognition. Although delirium may have a short duration, symptoms may continue for months. Delirium can be difficult to recognise, lacking a single clear presentation.

Identified risk factors for developing delirium include: ageing, dementia, sensory impairment, ill-health, institutional care such as hospital or residential care, use of physical restraints, malnutrition, more than three medications, infection, sleep deprivation, and immobility.

Depression is a medical condition characterised by feelings of extreme sadness and dejection. It is not just feeling sad. Depression is caused by a combination of physical and psychological factors, and generally results from a mix of recent events and other longer-term or personal factors, causing chemical imbalances in the brain. These factors might include life events, family history, personality, serious medical illness, and drug and alcohol use.

Depression may be mild or severe. Types include major depressive disorder, bipolar disorder, dysthymic and cyclothymic disorders, and seasonal affective disorder. Timely detection and seeking help early may avoid the risk of other mental health problems, and untreated depression can lead to suicide.
Dementia

Dementia describes a collection of symptoms caused by disorders affecting the brain. It is not one specific disease. Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with a person’s normal social or working life.

Various areas of cognitive function may be impaired, such as memory (in Alzheimer’s disease), language, attention, spatial skills or judgement.

There are many different forms of dementia and each has its own causes. The most common types of dementia are: Alzheimer’s disease, cerebrovascular disease, Parkinson’s disease, Dementia with Lewy bodies, frontotemporal dementia, Huntington’s disease, alcohol-related dementia (Korsakoff’s syndrome), Creutzfeldt-Jacob disease, and traumatic brain injury.

Some people experience a level of memory loss greater than that usually experienced with ageing, but without other signs of dementia. This has been termed mild cognitive impairment (MCI).

The term young onset dementia has been used to describe dementia in people younger than 65.

In May 2013, the American Psychiatric Association in its *Diagnostic and statistical manual and mental disorders* (DSM-5):

- replaced ‘dementia’ with the term ‘major neurocognitive disorder’ to reduce stigma surrounding dementia
- added ‘mild neurocognitive disorder’ (not ‘mild cognitive impairment’) providing an opportunity for detection and treatment of cognitive decline before a person’s cognitive impairment becomes more pronounced, and progresses to major neurocognitive disorder
- removed the subcategory referring to younger onset dementia, identifying that the threshold age of 65 is arbitrary.

The terms dementia and mild cognitive impairment are likely to be widely used for some time.

Dementia-friendly communities and environments

A dementia-friendly society has been defined as a cohesive system of support that recognises the experiences of a person with dementia, and supports them to remain engaged in everyday life in a meaningful way (Davis et al. 2009).

The World Health Organization’s *Global age-friendly cities: a guide* identifies the following topic areas of age friendly cities:

- housing
- social participation
- respect and social inclusion
- civic participation and employment
- communication and information
- community support and health services
- outdoor spaces and buildings
- transportation.
Dementia-friendly environments include both social and physical components, and the ways they intersect and support each other. The social environment should support people’s cultural background and experiences, their social and civic participation, respect and social inclusion, engagement, access to community support and health services, and employment, and should seek to eliminate stigma. The physical environment comprises the concrete tangible aspects of settings, such as outdoor spaces and buildings, furniture and décor, housing and transport.

Dementia-friendly communities and environments can be created anywhere, for example in the public and private sectors; at precinct, local, regional or broader geographical levels; in certain industries such as banking, the taxi industry, and hotels; within certain buildings; and in the health and community service system.

Healthy, positive and active ageing

The term ‘healthy ageing’ is often used interchangeably with terms such as active ageing, successful ageing, positive ageing and productive ageing. There is general acceptance that healthy ageing involves more than physical or functional health. The World Health Organization (WHO) defines active ageing as a process of optimizing opportunities for health, participation and security for quality of life as people age, allowing people to realise their potential for physical, social and mental wellbeing throughout their lives.

Reporting measures

Measures are to be identified and reported according to the type of activity and the stage at which it is meaningful to be measured and reported. Measures can relate to process, impact and outcome, at the individual level, organisational level and systemic level and are identified for each action in the Victorian dementia action plan.

The Department of Health, Ageing and Aged Care Branch will coordinate annual reporting of the implementation of the Victorian dementia action plan.
Appendix 2: Education and resources

Education and training

Department of Health supported training opportunities

Community
- Funding Alzheimer’s Australia Vic for education and training of HACC workers, medical and nursing students.
- An interdisciplinary education and training package for nurse practitioners for comprehensive health assessments of older people, developed, delivered and evaluated by La Trobe University.
- Implementing a HACC statewide education and training service including investigating the training needs of the HACC workforce to better support people with dementia.
- Working with the vocational education and training sector to develop key competencies for the community sector around service coordination.

Aged Care Assessment Services
- Delivering face-to-face orientation training for all new Aged Care Assessment Services (ACAS) staff including training in dementia assessment, referral pathways and differential diagnosis: dementia, delirium and depression
  - Update training is provided every two years with online assessment.
  - Some assessment questions relate to dementia.
- Promoting use of the ACAP Toolkit for consistent ACAT assessments and decision making in all assessment areas including cognitive function.
- Providing periodic training and workshops for ACAS teams on topics such as: dementia in Aboriginal and Torres Strait Islander communities and practical advice to clinicians about assessing and supporting people with dementia.
- Recommending that ACAS staff complete the DTSC Time for dementia ten online training modules on dementia assessment and differential diagnosis.
- Convening quarterly training for ACAS managers, senior clinicians and education officers, including training on dementia.
- Developing tip sheets for ACAS, such as assessing people from CALD backgrounds and providing person-centred assessment.

Public sector residential aged care services
To improve safety and quality and implement evidence-based, person-centred care for people living in public sector residential aged care services, the department funded the following projects:
- as part of its SCORE7 initiative, the Australian Centre for Evidence-Based Aged Care developed and piloted evidence-based, standardised care processes on: constipation; physical restraint; unplanned weight loss; choking; oral and dental hygiene; polypharmacy; hypoglycaemic episodes; depression; delirium; and dehydration

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• comprehensive health assessment training to support staff to identify changes in people and make appropriate referrals
• an interdisciplinary education and training package for nurse practitioners for the comprehensive health assessment of older people, developed, delivered and evaluated by LaTrobe University
• education and training on dementia-friendly environments in Public Sector Residential Aged Care Services.

Resources

Websites
• Seniors Online – information for older people about government and other supports and services, and health related information including activities for healthy ageing and brain health: <www.seniorsonline.vic.gov.au>
• The Better Health Channel – quality assured, reliable and up-to-date health and medical information to help people stay healthy, and better understand and manage their health and medical conditions: <www.betterhealth.vic.gov.au>
• Healthy Ageing Online Network – an online, interactive network for health professionals and service providers to work together, and share information, resources, and good practice strategies to support Victorians as they get older: <hanet.health.vic.gov.au>
• The Human Services Directory (HSD) – a database for the community, practitioners and service providers with access to accurate and up-to-date information about health, social and disability services in Victoria. Used to inform consumers and communicate with practitioners, including referring consumers to other services. HSD identifies telehealth locations that may improve access to services for isolated people: <www.humanservicesdirectory.vic.gov.au/Home.aspx>

Other resources
• **Strengthening assessment and care planning: dementia practice guidelines for HACC assessment services** – dementia-specific information and practical guidance for HACC assessment services to improve assessment, care planning and service provision for people with possible dementia and their families and carers.
• **A guide to services for people with dementia and their carers** – a resource for service providers to support timely provision of information, supports and referrals that meet the needs and preferences of people with dementia and their families and carers. The guide is annually updated to reflect new services or changes to existing services, and can be used to create local service directories.
• **Dementia-friendly environments: a guide for residential aged care** – a practical guide to inform the building or renovation of residential aged care facilities, for managers, staff, developers, builders, architects, landscape architects and others involved in creating, building, renovating and managing residential aged care environments
• **Residential aged care services built environment tool** – used to adapt and improve existing aged care environments.8

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8 This tool was adapted from Improving the environment for older people in health services: an audit tool.
• **Aged care residential services generic brief** – informs the systematic development of residential aged care facilities.

• **Best care for older people everywhere toolkit** – clinical information, tools and resources for health services to improve care for older people in hospital and throughout the care continuum, including advance care planning, medication, pain and a palliative approach to care.

• **Strengthening aged care assessments for Aboriginal consumers: a guide for ACAS in Victoria** – for staff to develop culturally responsive services that meet the needs of Aboriginal people.

**Practitioner networking**

Victoria has a statewide Victorian Dementia Network and several local and regional dementia networks. These networks assist local service providers and health professionals across the health and care continuum to work together to support people with dementia and their families and carers.

Network attendance and involvement can include: ACAS, CDAMS, aged persons mental health teams, Alzheimer’s Australia Vic, DBMAS, health services, community services including package providers, dementia and cognition nurses and consultants, educators and academics, public and private residential aged care providers, carer and respite services, Carers Victoria, CALD community organisations, and Victorian and Commonwealth government representatives.

Practitioners share information and discuss support options for people with dementia and their families and carers. The networks provide professional development, and information about government funding, education, research, clinical care and service developments.

The Victorian Carer Services Network (VCSN) is a peak body for regional and state wide carer services. The VCSN comprises Commonwealth Respite and Carelink Centres, Support for Carers Program providers and Carers Victoria. The VCSN aims to create and maintain an accessible, responsive and integrated carer support and community information system.

Members of the statewide Palliative Care Clinical Network (PCCN) have experience across palliative care and related sectors. The PCCN provides clinical leadership in implementation of policy direction and program initiatives, and oversees service improvement projects.

A key role of PCCN is to host community-of-practice forums of service sectors with a common interest in good quality end-of-life care. Topics include: palliative care and aged care; providing palliative care to people with dementia; and offering palliative care in community settings.
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