

Department of Health

health

Strengthening assessment and care planning

Dementia practice guidelines for
HACC assessment services

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Two key pieces of work related to dementia that have informed the development of this project are:

- Dementia services pathways – an essential guide to effective service planning, (KPMG 2011).
- Victorian and Tasmanian Dementia Study Centre – TIME for Dementia education resource.

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Part A

Introduction and context

1 Introduction

1.1 Background

The Home and Community Care (HACC) program is often the first contact for people with possible dementia and their carers who require assistance and support.

The *Dementia practice guidelines for HACC assessment services* provide dementia-specific information and practical guidance for assessors from HACC assessment services to improve assessment, care planning and service provision for people with possible dementia and their carers.

The *Dementia practice guidelines* are a companion document to *Strengthening assessment and care planning: a guide for HACC assessment services in Victoria* (Department of Health 2010; referred to in this document as the *HACC assessment service practice guide*). The *HACC assessment service practice guide* identifies the skills, practices and knowledge required to provide Living at Home Assessments. The *Dementia practice guidelines* build upon this knowledge by applying a 'dementia-specific' lens to assessment and care planning.

The *Dementia practice guidelines* are intended to provide HACC assessors with a baseline knowledge and understanding of dementia and develop a more consistent approach to helping people with possible dementia and their carers to access appropriate clinical and support services.

The *Dementia practice guidelines* will assist HACC assessors to understand their role in assessment and care planning for people with possible dementia and their carers, including when and where to refer to other providers and dementia experts at different points of the care pathway.

An additional resource, *A guide to services for people with dementia and their carers* (Department of Health 2012), is also being developed by the Department of Health to support the *Dementia practice guidelines*. This statewide guide provides detailed information about key services in Victoria that support people with possible dementia and their carers. It is designed to be updated at a regional or sub-regional level with local service information and to support referrals and the care pathways to local dementia and related services.

The *Dementia practice guidelines* should be read in conjunction with *A guide to services for people with dementia and their carers* to gain a better understanding of the available services.

1.2 Policy context

The *Victorian Health Priorities Framework 2012-2022* was released in May 2011. This framework articulates long-term key outcomes, principles and priorities for the Victorian health system. The framework is the basis for three supporting plans: The *Metropolitan Health Plan*, the *Rural and Regional Health Plan* and the *Health Capital and Resources Plan* for further information visit <www.health.vic.gov.au/healthplan2022>.

The HACC program in Victoria is currently implementing three key initiatives which support implementation of the *Victorian Health Priorities Framework 2012-2022*. These quality improvement initiatives are: the Active Service Model, the Assessment Framework and Diversity Planning and Practice. These key areas of work, together, will refocus HACC services in Victoria to a more capacity building, person centred approach.

The following publications provided the context for development of the *Dementia practice guidelines*:

- *Dementia framework for Victoria – pathways to the future, 2006 and beyond: dementia framework for Victoria*, Department of Human Services 2006
- *Strengthening assessment and care planning: a guide for HACC assessment services in Victoria*, Department of Health 2010

- *Victorian HACC program manual* including updates/amendments, Department of Human Services 2003
- *Diversity planning and practice guide*, Department of Health 2011.

In addition, the following two projects have contributed significantly to the dementia management approach referred to in the *Dementia practice guidelines* and the understanding of evidence-based practice.

National Dementia Service Pathways project

In 2010, KPMG carried out a national project, *Dementia services pathways: an essential guide to effective services planning* (KPMG 2011), to inform and assist jurisdictions to improve dementia service for people living with dementia and their carers along the care and support continuum <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-dementia-servicespathways.htm>.

The *Dementia practice guidelines for HACC assessment services* build on the pathways and draw upon the key aspects of dementia care framework developed by KPMG, particularly the guiding principles and the concept of four stages of dementia management.

Out of the Shadows

Out of the Shadows: the development of a best practice model of care for people living with dementia (RDNS 2009) was developed by the RDNS Helen Macpherson Smith Institute of Community Health as part of a project funded by the Wicking Trust. Key components of the dementia model of care are an assessment tool, a care planning process and an education and training package for nursing staff. The evidence base reviewed in relation to community-based dementia care and learnings from the Out of the Shadows project have informed these guidelines.

1.3 Navigating the guidelines

The *Dementia practice guidelines* are set out in three parts:

- Part A: Introduction and context: provides an overview of the types of dementia, risks and comorbidities
- Part B: Assessment and care planning for people with possible dementia: describes the role of HACC assessors across the four stages of dementia management
- Part C: Assessment and care planning for the needs of carers: provides guidelines for assessment and care planning for carers.

Case studies are provided to highlight the different journeys people might experience with dementia and the referral and support options. **All case studies are fictitious.**

Each section of the *Dementia practice guidelines* includes lists of suggested strategies and resources.

1.4 Terminology

Possible dementia

The term 'possible dementia' is used throughout the *Dementia practice guidelines*. It suggests the presence of signs or symptoms that would suggest cognitive impairment. A formal diagnosis of dementia is required to confirm dementia.

Carers and community care workers

The support needs of carers of people with dementia are highlighted throughout the *Dementia practice guidelines*, particularly in Part C. Where the term 'carer' is used, this refers to carers, usually a family member or friend who provides unpaid assistance to a person with support needs. The term 'community care worker' refers to carers who are employed to support the care needs of the person with dementia and their family.

1.5 Key dementia resources for HACCC assessors

The following is a list of key resources and manuals that provide more detail and practical guidance for HACCC assessors about issues faced by people with possible dementia who live at home:

- Alzheimer's Australia
Resources are available on the Alzheimer's Australia website. Help sheets in many community languages can be downloaded from this website or ordered online <www.alzheimers.org.au>.
- *Younger onset dementia: a practical guide*
<<http://www.ftdrg.org/wp-content/uploads/yod-booklet.pdf>>
- Baptist Community Care – NSW & ACT 2008, *Living with dementia: how the environment and technology can help you* <www.dementiatechnology.org.au>
This is online resource funded by the Australian Government under the Dementia Initiative.
Resources include:
 - 33 help sheets
 - a DVD with facilitator's guide
 - a home safety checklist
 - a poster book
 - a promotional brochure and poster.
- Carers Victoria, *Carer information and support kit*
This kit can be ordered from Carers Victoria and is available in a number of languages.
The kit has information sheets on:
 - legal arrangements
 - taking a break
 - feelings
 - managing money
 - services for you
 - safety at home
 - taking care of yourself
 - loss and grief
 - managing health care and medications
 - emergency care plan – including emergency contact details, emergency card and medication.

- Eastern Cognitive Disorders Clinic, *The frontotemporal dementia toolkit*

This toolkit provides essential resources for awareness, diagnosis and management of frontotemporal dementia. It can be downloaded from the Eastern Cognitive Disorders Clinic (ECDC) website <www.ecdc.org.au>.

- Latrobe University, Maximising thinking and memory abilities – factsheets for people with mild cognitive impairment and early dementia, <<http://www.latrobe.edu.au/aipca/projects/mci/>>
- NSW Department of Ageing, Disability and Home Care, 2008 *At home with dementia: a manual for people with dementia and their carers*

The contact list for access to the assistive technologies suggested in this manual applies to NSW only. Refer to the Independent Living Centre in Victoria <<http://www.yooralla.com.au/ilc.php>> for assistive technologies in this state.

A similar guide on creating dementia-friendly environments in the home will be published in 2012 by the Department of Health: <<http://www.health.vic.gov.au/dementia>>.

2 About dementia

2.1 What is dementia?

'Dementia' is an umbrella term that describes a collection of symptoms affecting the brain. It is a process of slowly declining ability resulting from pathological changes in the brain that can affect a person's memory, behaviour, personality and functional capacity until it becomes terminal (refer to page 20 for signs and symptoms of dementia).

A common myth concerning dementia is that the condition is a normal part of growing old. However, dementia is not associated with normal age-related changes. Normal changes to cognition include:

- a generalised decline in the speed of processing information but the accuracy of the person's responses is not affected
- slower, more cue-dependent memory performance; for example, a need to make lists
- a decrease in learning speed and recall, but if the person is given extra time to complete the task their intellectual functioning is adequate.

2.2 Prevalence of dementia

Ageing is the most notable factor in the development of dementia. There is a rising incidence of dementia as a result of our ageing population (AIHW 2007). In Victoria it is estimated that 69,000 people currently have dementia and this is projected to increase to 98,000 by 2020 (Access Economics 2009).

Types of dementia

There are many sub-types of dementia, each with its own causes and risk factors.

The major sub-types of dementia include (Access Economics 2010):

Alzheimer's disease: Accounts for 50 per cent of all dementias. It is a physical disease that attacks the brain, resulting in impaired memory, thinking and behaviour. Alzheimer's disease occurs gradually and initial symptoms may be unnoticed but there is progressive memory decline. Initially there is impaired new learning and poor short term memory. Gradual progression of the disease involves long term memory and other functions such as language, perception and executive function. There are no physical signs or laboratory evidence of other causes of dementia. There are three stages of Alzheimer's disease: mild, moderate and severe. In the severe stage support in residential care is often required (*TIME for dementia: The Victoria and Tasmania Dementia Training Study Centre* 2007). The rate of progression varies from person to person. A person may live from three to twenty years with Alzheimer's disease, with the average being seven to ten years.

Vascular dementia: Accounts for 20 per cent of all dementias. It is a disease process that involves the blood vessels of the brain. It may occur across a broad spectrum of disorders, from major strokes leading to nerve loss and disruption of nerve transmission, to decreased blood flow to the brain from any cause. In some instances there may be a mixture of Alzheimer's disease and vascular dementia. Vascular dementia usually progresses gradually in a step-wise fashion in which a person's abilities deteriorate after a stroke and then stabilize until the next stroke. Sometimes the steps are so small that the decline appears gradual. Memory is often only mildly affected and the person is likely to have better insight in the early stages than people with Alzheimer's disease. Vascular dementia is usually diagnosed through neurological examination and brain scanning: CT (computerized tomography) or MRI (magnetic resonance imaging).

Dementia with Lewy Bodies (LBD): Accounts for 15 per cent of all dementias. It is caused by the degeneration and death of nerve cells in the brain. This type of dementia is diagnosed by excluding other possible causes such as Vascular dementia or Alzheimer's disease. The progression of the disease is more rapid and characterised by visual hallucinations, fluctuation in mental state (the person may be lucid and clear at times or confused and disorientated) or experience tremors and stiffness similar to Parkinson's disease.

2.3 Possible risk factors and risk reduction

While the causes of dementia are unknown, age, lifestyle and, to a lesser extent, genetics are the broad categories of risk factors for the development of dementia.

Age: The risk of developing dementia increases with age but dementia also occurs in younger people.

Genetics: Most of the research about dementia and risk focuses on Alzheimer's disease and there is still much to learn about the genetic basis of dementia. However, less than five per cent of cases of Alzheimer's disease have a direct genetic link (Avramopoulos 2009). People with a predisposition to vascular disease also show a predisposition to vascular dementia. Genetic testing and counselling are available for people concerned about their increased risk of developing Alzheimer's disease.

Risk reduction: As many dementias are of a mixed variety, the behaviours that are suggested to reduce the incidence or delay the onset of dementia are behaviours that would also be promoted in any healthy approach to life. A lifestyle that is generally healthy, promoting cardiovascular, respiratory and cerebro-vascular health may reduce risk for dementia. This includes physical exercise, a healthy diet, mental stimulation and social inclusion (Dementia Collaborative Research Centres 2007).

2.4 Comorbidities and dementia

Comorbidity is defined as a disease or condition that coexists with another disease. Multiple comorbid medical conditions regularly occur in older people and some are more common in people with dementia.

Physical comorbidities that are associated with dementia include falls, delirium, weight loss and malnutrition, epilepsy, frailty, sleep disorders, oral disease and visual impairment (Dementia Collaborative Research Centres 2010).

There is also a relationship between dementia, mental health and neurological conditions. For example, one-third of people with dementia experience moderate to severe mental health problems. These include psychosis, aggression, anxiety, depression, and Post-Traumatic Stress Disorder (PTSD) (Rural Health Education Foundation 2007). Some neurological problems may include Parkinson's disease and Pick's disease.

It is important that comorbidities are managed to lessen risks associated with dementia. This includes arranging for people to be treated for diabetes, blood pressure or psychiatric disorders and assisting them to take medication as prescribed.

2.5 Resources

- Alzheimer's Australia
 - Help Sheets *Section 1: About dementia* includes information about diagnosis, planning, memory changes, research and types of dementia <<http://www.alzheimers.org.au/understanding-dementia/help-sheets-and-update-sheets.aspx>>
 - DVD – 'Understanding the brain and behaviour'
 - Dementia risk reduction program – Mind Your Mind <<http://mindyourmind.org.au/>> includes BrainyApp
- Commonwealth Department of Health and Ageing, *Dementia resource guide* <<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-dementia-resource-guide.htm>>
- Dementia Training Study Centre (Eastern Australia), Dementia Education Online <<http://dementia.uow.edu.au/understandingdementiacare/index.html>>
- Victoria and Tasmania Dementia Training Study Centre TIME for Dementia <<http://www.timefordementia.org/Home/>>.

Part B

Assessment and care planning
for people with possible dementia

3 Assessment and care planning in practice

3.1 Guiding principles of dementia care

The following principles have been developed by KPMG. They outline the important elements for service delivery in respect to dementia care (KPMG 2011):

- When concerns about dementia arise, people with dementia have access to competent, multidisciplinary assessment, diagnosis and case management.
- People with dementia are valued and respected. Their right to dignity and quality of life is supported.
- Carers and families are valued and supported.
- People with dementia, their carers and families are central to making choices about care.
- Service responses recognise each person's individual journey.
- All people with dementia, their carers and families receive appropriate services that respond to their social, cultural or economic background, location and needs.
- A well-trained supported workforce delivers quality care.
- Communities play an important role in quality of life for people with dementia, their carers and families.

3.2 Stages of dementia management

The following four stages of dementia management build on KPMG's dementia services pathways. Built into the KPMG framework are principles of care, key elements of service delivery and distinct service features required for people living with dementia and their carers.

Assessment practice and care planning skills, strategies and referrals are described under each of these four stages to focus on the specific assessment issues in each management stage.

- Stage 1: Awareness and recognition
- Stage 2: Initial dementia assessment, diagnosis and post-diagnosis support
- Stage 3: Management, care, support and review
- Stage 4: Palliative and end-of-life care.

3.3 Case studies

Case studies are presented throughout these guidelines, applying the four stages of dementia management. They have been adapted from the KPMG dementia services pathways. Each case study highlights the individual journey of the person with dementia, and addresses the concerns of their family and/or carer. Possible referrals and supports are also identified for both the person with dementia and their carer. People with dementia from diverse backgrounds with diverse needs are highlighted in some of the case studies, including:

- a person from a culturally and linguistically diverse (CALD) background
- a person with younger onset dementia
- an Aboriginal person¹.

¹ For the purpose of this document 'Aboriginal' refers to people who identify as Aboriginal, Torres Strait Islander, or both Aboriginal and Torres Strait Islander.

3.4 Consent

A person's capacity to consent to care may be affected by the presence of cognitive impairment or possible dementia. It should be assumed an individual has the capacity to give consent unless proven otherwise. Consent must be properly informed, freely given, specific and current. The individual's capacity to consent should be revisited within the assessment or re-assessment. Vulnerable people need to be protected by the presence of an authorised representative or supported to seek advice about appointing an enduring power of attorney (medical treatment), enduring power of attorney (financial) and enduring power of guardianship. People should be encouraged to make an Advance Care Plan in early dementia. (see Section 7: Advance Care Planning).

3.5 Dementia and diversity

Consideration of the needs of different population groups is important as they may have differing dementia care needs and service requirements and a range of experiences in accessing services. For suitable care plans and service responses to be put in place, assessments need to be responsive to people with dementia from diverse backgrounds with diverse needs.

Four diverse needs groups requiring consideration specifically in relation to dementia are discussed below.

Aboriginal people

The experience of dispossession and racism means that exploring a person's needs requires sensitivity and understanding of their historical and cultural context. The success of assessment and service provision for Aboriginal people depends on building trust and rapport from the very first contact with the person with possible dementia and their carer/s.

The poor health status and burden of chronic disease and other risk factors among many Indigenous communities may increase risk of developing dementia at a younger age. For this reason, people from Aboriginal communities may require assessment for dementia care at younger ages and special consideration by health and community professionals working in remote and rural areas where there is little access to specialist dementia services (Alzheimer's Australia 2008a).

Perceptions of dementia in Aboriginal communities vary due to cultural and linguistic differences within and between groups. Knowledge of local Aboriginal communities can assist in understanding the local context, but it is important to be aware that a person from a different community may have different preconceptions about dementia.

Where there is a large family network, the caring role may be shared by more than one person, and most care for more than one person, often for three or four generations of family members with care needs, yet few Aboriginal people formally identify as carers.

When working with Aboriginal people, HACC assessors should ask the person or their family if they would like a support person from an Aboriginal Community Controlled Organisation to attend the assessment. Refer to the *HACC assessment service practice guide* section 11.2 for further information about supporting Aboriginal people.

People from culturally and linguistically diverse (CALD) backgrounds

The perceptions of dementia among people from CALD backgrounds are varied. They range from dementia being considered an illness, a normal part of ageing or a mental illness, to having no meaning at all in some communities. The stigma associated with dementia or the lack of understanding of dementia may result in people being marginalised and isolated from their own communities and sometimes even from family members.

Diagnosis of dementia in CALD communities often occurs at the late stage of dementia. This is often at a crisis point following lack of involvement of services due to people or their families lacking knowledge about the early symptoms of dementia, where to go for help or being ashamed of being labelled. Other issues relate to communication barriers and unfamiliarity with the aged care service system and how to access services (Alzheimer's Australia 2008b).

Refer to the *HACC assessment service practice guide* section 11.3 for guidelines for working with people from CALD backgrounds, including communication techniques and how to work with interpreters.

Younger people with dementia

Dementia is generally considered a disease of older age, however the prevalence of people with younger onset dementia is increasing. Younger people are more likely to present with fronto-temporal dementia than Alzheimer's disease and the causes are different from dementia in older people (AIHW 2007).

The diagnostic process in younger onset dementia is often lengthy. Any younger person presenting with memory loss or changes in communication or behaviour should be referred for specialist assessment. Diagnosis is generally made by a neurologist rather than through a specialist cognitive, dementia and memory service or a psycho-geriatrician. The diagnostic differentials make the process complex and protracted.

There are three specialist diagnostic clinics for people under 65; see section 5.5 for details.

Generally the diagnosis for a younger person is not anticipated. Most people believe dementia is a disease of old age so it challenges community stereotypes. A person diagnosed in their 40s, 50s or early 60s may feel devastated because they think they are losing many productive years. The diagnosis may interfere with plans for future employment, retirement, travel and lifestyle arrangements. The issues of grief and loss are very real.

There are limited age-appropriate services for people with younger onset dementia. Support services for people with dementia under 65 years of age may be provided through disability support and/or HACC services. Consider a referral to an Aged Care Assessment Service (ACAS) for people under 65 with dementia. See *Disability Services – ACAS Protocol* (Department of Human Services 2009).

People with intellectual disability and dementia

Down syndrome is the most common cause of intellectual disability and occurs across all races and cultures. Alzheimer's disease occurs more frequently and at a younger age for people with Down syndrome. Research reports different rates of Alzheimer's disease in people with Down syndrome, but most studies report that about 50 per cent of people with Down syndrome will develop Alzheimer's disease by the age of 60 years.

Down syndrome is associated with a wide range of health issues, for example people with Down syndrome often have a lowered general immunity compared to the general population. More information about Down syndrome can be found at <http://www.downsyndromevictoria.org.au/> and more information about Down syndrome and Alzheimer's disease can be found at <http://www.cddh.monash.org/assets/dsad-booklet-final.pdf>.

Gay, lesbian, bisexual, transgender and intersex (GLBTI) people

Recognising sexuality and gender diversity enables provision of appropriate care. Between 2–15 per cent of the population identify as non-heterosexual. Person-centred care does not treat everyone as if they are the same. Many older people grew up in an era when homosexuality may have been considered criminal, unnatural, deviant or the basis for societal discrimination. This can mean that some older people may not feel comfortable or safe to ‘come out’ or talk about their needs.

A person’s home should be a safe environment. The case study below is an example of the reticence some people may have accessing home care services. They may think a community care worker will judge them, betray confidences or provide poor quality services if they disclose their sexual identity. This can result from a lifetime of being alert to possible negative attitudes.

HACC assessors need to:

- support the rights of people to feel safe in expressing themselves and to respect their privacy
- deliver informed assistance and advice that is GLBTI inclusive
- offer information about support organisations such as Matrix Guild, Vintage Men, and TransGender Victoria.

See the *HACC Diversity planning and practice guide* (Department of Health 2011) for strategies for providing a GLBTI inclusive service.

Bob and Ken’s story

Bob and Ken had been a couple since they met at a gay club in the 1970s. Ken has been providing more and more care for Bob as he forgets things previously taken for granted. Following some tests, Bob has now been diagnosed with Alzheimer’s disease. All their social visitors at home have been men. If female service providers come to their home, Ken knows that Bob will be confused and may become agitated. Ken is very concerned about their relationship becoming ‘public property’. He does not want his private world becoming something that others scrutinise and judge.

During the assessment process, HACC assessors need to show understanding of, and demonstrate, inclusive work practices. An example is to use the term ‘partner’. The absence of a current partner relationship does not negate an individual’s sexuality. Ask who else the person would like to be involved in their assessment. Creating a trusting environment for the person with dementia (and their partner, if appropriate) helps collect information to assist services provide appropriate care that meets identified needs.

When a person becomes unable to make their own decisions, it helps if the substitute decision maker for medical treatment and financial issues is clear. Planning for the future enables the wishes of the person with dementia to be respected and met. Advance Care Planning, appointing an enduring power of attorney (medical treatment), an enduring power of attorney (financial) or an enduring power of guardianship are effective ways for GLBTI people to express their medical treatment, future care, financial and lifestyle preferences.

Further reading:

Well proud: a guide to gay, lesbian, bisexual, transgender and intersex inclusive practice for health and human services <<http://docs.health.vic.gov.au/docs/doc/Well-Proud:-A-guide-to-gay--lesbian--bisexual--transgender-and-intersex-inclusive-practice-for-health-and-human-services>>.

Paper number 15 Dementia: lesbians and gay men <<http://www.alzheimers.org.au/research-publications/alzheimers-australia-numbered-publications.aspx>>.

3.6 Person-centred and family-centred practice in dementia care

Person-centred practice is a HACC assessment principle. Person- and family-centred practice is respect for a person's, family's or carer's right and desires to make their own decisions. The approach focuses on self-determination and empowerment. Family and carers can play a pivotal role in care relationships and in contributing to or making decisions.

The experience of dementia is different for everybody. While there is an understanding of how dementia affects the brain, and of the brain deterioration that can be expected in the various sub-types of dementia, no two persons' experience of dementia is the same. The personal journey of disease progression will vary from person to person.

Given that dementia is a progressive illness, a person may for some time have capacities or be competent in some areas. This will be different for all individuals. Goals may be maintenance-related rather than restorative in some areas of competence affected by the dementia.

Goal-oriented and strength-based assessment focuses equally on what the person with dementia can do and aims to maximise their potential. Goals should be set in consultation with the person and their family and carer, having identified what is important to each of them, in line with a person- and family-centred approach to care.

3.7 Communication skills

Effective communication skills are essential to elicit accurate and meaningful information from a person with dementia.

Issues may arise with word finding, altered fluency of speech, poor conversation skills, and an inability to understand what is being said. Reading and writing skills and the ability to recognise familiar objects may also be affected. These issues may be compounded by co-existing hearing and vision problems. Each person's ability to communicate will vary and people react to stimuli in different ways. It is important when dealing with people with dementia that assessors are more conscious of how to present themselves and give and receive information.

People with dementia may not remember a discussion or any agreements that have been made so it is important to put strategies in place to assist recall of communications – such as a communication book, expanded diary entries and so on.

Reflection on the development of rapport and relationship building with people with dementia and their carers is important. Understanding the life and background of the person with dementia and their reactions to dementia is essential if meaningful assistance is to be offered. Experiencing dementia can be terrifying, funny, sad, hopeful and/or spiritual. Each person has a different journey that assessment staff must try to understand.

In some cultures there is stigma around dementia and depression. This can lead to discomfort or unwillingness to discuss some topics. HACC assessors should be aware of this and sensitive when discussing issues that may have cultural significance. Consider contacting an Aboriginal Community Controlled Organisation or an ethno-specific organisation to help you get a better understanding of cultural issues surrounding health conditions such as dementia.

Below are some useful strategies for communicating with a person with dementia:

- Allow plenty of time for conversations with the person with dementia.
- Keep the environment as calm and quiet as possible when communicating.
- Be sure to communicate directly with the person with dementia as well as with the carer/s.
- Listen carefully to grasp the meaning or tone of the person's conversation.
- Take into consideration a person's usual communication skills and cultural beliefs and attitudes towards dementia.
- Consider cultural differences in communication styles, both verbal and non-verbal.
- Consider any loss of language skills and possible reversion to first language as English may not be the first language of the person with dementia.
- When working with interpreters, brief them prior to the assessment and debrief them after. For example, identify what you would like to get out of the session, talk about culturally relevant issues and clarify terms to be used.
- Access relevant translated information about dementia at appropriate times for the person and carer, for example, Alzheimer's Australia help sheets and dementia risk reduction bilingual tip sheets (Mind Your Mind).
- Always face the person during conversations and be reassuring in your expressions, tone of voice and words.
- Be prepared to change your approach or terminate the interview if the person becomes distressed. You may need to make another time or seek more information from other sources.
- Speak clearly using short sentences, simple vocabulary, avoid jargon and present one concept at a time.
- Take account of hearing or visual problems.
- Check understanding and recall as the conversation progresses.
- Make use of the person's past experiences and life story to assist with communication.
- Use images, pictures, symbols or music to enhance communication and facilitate understanding.
- If the person is already receiving other services, follow communication guidelines that have already been developed to support the person (for example, in their care plan).

Creating a life story

Life stories are an important element of person-centred care. They provide a mechanism for the person with dementia, their family and care workers to talk about and reflect on the person's life and shared memories. Life stories can contain photos, documents, stories, memorabilia. For the person with dementia this can be a source of pleasure as it can assist communication with family and friends and help to build relationships with community care workers.

Life stories can assist care workers to get to know who the person really is – understand what is important to them - their family members, friends, interests, spiritual life, talents, profession, trades, favourite pastimes, holiday destinations, pets etc. A person's life story book might provide a distraction if the person is anxious or becomes upset. It may help care workers to understand why certain behaviours occur repeatedly.

Life stories are usually compiled with assistance from family members at home or as part of an activity in a respite or planned activity group or a residential care facility. Life stories are a great 'way in' to appreciate the person's life journey. However reminiscence and reflection may be distressing, so respect people's right to refuse involvement in an activity such as this.

<http://alzheimers.about.com/cs/treatmentoptions/a/reminiscence.htm>.

3.8 Dario's story

This case study describes a person with dementia from a CALD background.

Stage 1: Awareness and recognition	
<p>Dario is 79 years old. He lives with his wife, Sophia.</p> <p>Over the past year Dario has become increasingly uninterested in family activities, gardening and going to his Italian senior citizens club. He has frequent memory loss, particularly of recent conversations and events. He is more short tempered than normal and becomes frustrated when he can't do things.</p> <p>Sophia discusses her concerns with Dario. Initially he is reluctant to admit there is a problem, but he acknowledges that he hasn't been acting himself lately and knows his wife is worried about him. He agrees to see his doctor for a check up.</p>	<p><i>Possible referral and support:</i></p> <ul style="list-style-type: none"> • GP and practice nurse • CO.AS.IT (Italian Assistance Association) • Alzheimer's Australia Vic Helpline or counselling • Alzheimer's Australia Vic: Help Sheet <i>Worried about your memory</i> (translated help sheets available)
Stage 2: Initial dementia assessment, diagnosis and post diagnosis support	
<p>During the assessment process the practice nurse screens for depression and cognition with help from an interpreter and finds that Dario is not depressed. As a result, the doctor refers Dario to the Cognitive Dementia and Memory Service (CDAMS) for diagnosis. CDAMS confirms a diagnosis of Alzheimer's disease and recommends Dario and his family seek advice and assistance from Alzheimer's Australia Vic.</p> <p>In consultation with the Alzheimer's Australia Vic counsellor and the local doctor, the practice nurse refers both Dario and Sophia for an assessment with the local HACC assessment service. Respite and culturally appropriate support options are recommended. Information, education and support are provided and they are encouraged to commence planning for the future.</p>	<p>Possible referral and support:</p> <ul style="list-style-type: none"> • GP and practice nurse: initial screening for depression • Interpreter service • Cognitive Dementia and Memory Service • Alzheimer's Australia Vic – counselling • HACC – Living at Home Assessment • Access and support worker (where available)
Stage 3: Management, care, support and review	
<p>Dario attends an Italian planned activity group one day a week and some respite services run by the Migrant Resource Centre.</p> <p>Over the coming years Dario's symptoms of dementia progress and Sophia finds it difficult to manage him all the time. Dario speaks little English and he has some problems expressing and understanding Italian. He repeats questions and is continually asking Sophia for the day and time. The HACC assessor carries out a reassessment suggesting increasing the existing home supports using Italian speaking staff.</p> <p>A referral is also made to the local ACAS to explore future options for more intensive support. ACAS approve an Extended Aged Care At Home Dementia (EACHD) package.</p> <p>A plan is developed by the EACHD package provider for ongoing care.</p>	<p>Possible referral and support:</p> <ul style="list-style-type: none"> • HACC: respite and support with activities of daily living (ADLs) • Access and support worker (where available) • Migrant Resource Centre: HACC planned activity group • Carer support group • ACAS • EACHD package • Interpreter service • Alzheimer's Australia Vic – counselling
Stage 4: Palliative care and end-of-life	
<p>With support from the package of care (EACHD) Sophia cares for Dario at home for the next 10 years. Sophia's strong preference is for Dario to be cared for and die at home. All parties agree that a palliative approach is needed to support his care at home. A plan is developed by palliative care in collaboration with the EACHD provider so that Dario's physical and cultural needs are met as well as Sophia and their daughters' emotional and spiritual needs.</p> <p>The counsellor from the community palliative care service visits them to support Sophia and her daughters to better understand the changes that are occurring with Dario. Sophia and her daughters have requested that Dario is not told about his prognosis. Dario's condition deteriorates and he is treated at home. Dario dies as a result of his illness.</p>	<p>Possible referral and support:</p> <ul style="list-style-type: none"> • GP • Community palliative care service • Grief counselling • Alzheimer's Australia Vic – counselling

3.9 Resources

- Alzheimer's Australia Vic, *Perceptions of dementia in ethnic communities*
<http://www.alzheimers.org.au/common/files/VIC/Perceptions_of_dementia_in_ethnic_communities_-_project_report.pdf>
- Alzheimer's Australia Vic. 'Mind Your Mind', dementia risk reduction bilingual tip sheets,
<<http://www.mindyourmind.org.au/resources/bilingual-tip-sheets>>
- Australian Indigenous HealthInfoNet: Dementia section
<<http://www.healthinfonet.ecu.edu.au/dementia>>
- Centre for Cultural Diversity in Ageing, *Dementia care practice guide*,
<<http://www.culturaldiversity.com.au/practice-guides/dementia-care>>
- Commonwealth Department of Health and Ageing and Alzheimer's Australia 2007
Dementia learning resource for Aboriginal and Torres Strait Islander communities
<[http://www.health.gov.au/internet/main/publishing.nsf/Content/AEB6FEFC2F8E7CD3CA25781700156872/\\$File/facilitators-guide.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/AEB6FEFC2F8E7CD3CA25781700156872/$File/facilitators-guide.pdf)>
- Commonwealth Department of Health and Ageing, *Dementia resources for special needs groups*,
<<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-dementia-info-hp.htm>>
- Department of Health 2012, *A guide to services for people with dementia and their carers*
- Department of Health 2011, *Strengthening diversity planning and practice – a guide for Victorian Home and Community Care services*
<http://www.health.vic.gov.au/hacc/downloads/diversity/diversity_guide.pdf>
- Helen Sanderson & Associates 2007, *Person centred thinking with older people*, HAS Press, Cheshire UK 2007
- KPMG 2011, *Dementia services pathways: an essential guide to effective service planning*,
<[http://www.health.gov.au/internet/main/publishing.nsf/Content/48EFBFA3F0CE468DCA25790B000B6FDA/\\$File/Dementia-services-pathways\(ext2\).pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/48EFBFA3F0CE468DCA25790B000B6FDA/$File/Dementia-services-pathways(ext2).pdf)>.

4 Awareness and recognition – stage one

Stage 1 incorporates recognition by the general public and service providers of dementia signs and symptoms requiring referral for further investigation, assessment, diagnosis and support. Education, training and awareness-raising are also included (KPMG 2011):

- **Awareness** – understanding the signs and symptoms of dementia.
- **Recognition** – acknowledging dementia as a chronic progressive and terminal disease.
- **Referral** – timely recognition of symptoms that relate to a possible diagnosis of dementia and timely referral to other services and/or medical or health professionals.

4.1 HACC assessment services role in awareness and recognition

HACC assessors play an important role in early recognition and awareness of dementia. HACC services may often be the first contact for the person with possible dementia. Community care workers may be the first to become aware of people demonstrating signs of memory or thinking problems. HACC MDS data for 2010–11 shows that approximately 26 per cent of HACC clients assessed by HACC assessment services reported memory problems (Department of Health, unpublished).

HACC assessors need to be aware of, and alert to, the early signs of memory problems, confusion and depression. The opportunity for observation and reporting of a person's functioning in the home environment provides important information about how a person behaves and communicates in familiar surroundings and identifies early signs of memory problems, confusion and depression.

This is a vital aspect of a Living at Home Assessment.

HACC assessors, together with HACC service delivery coordinators, need to ensure that:

- Community care workers are aware of their responsibility to observe, pick up and report possible signs of dementia, including changes in memory and behaviour.
- Community care workers know what to do if they believe that the person they are caring for is showing changes in behaviour or if the carer expresses concerns.
- Monitoring and review processes have prompts for reporting concerns about memory or behaviour change, and protocols for acting on those concerns.

Initial needs identification, holistic needs assessment, monitoring and review are components of the Living at Home Assessment and HACC service delivery where recognition and identification of possible dementia may occur.

4.2 Initial contact and initial needs identification

Asking an individual a simply-worded screening question such as 'How is your memory?' or 'Are you concerned with memory loss, changes in thinking or changes in mood?' should be considered at initial contact. Information from carers or other reliable informants is often needed at this stage as well. The person with possible dementia may be eligible for HACC services, but because of their specific needs and circumstances they may require assessment by another service provider (for example, ACAS, disability services or a mental health service).

If assessment by another service is required, the organisation should be contacted to discuss the most appropriate response, such as joint assessment. See *Guidelines for streamlining pathways between ACAS and HACC assessment services* (Department of Health 2011) for further information.

4.3 Early signs and symptoms of dementia

Alzheimer's Australia Vic has identified signs of early dementia that may assist with recognition for further investigation. The person may:

- appear more apathetic, with less sparkle
- lose interest in hobbies or activities
- seem unwilling to try new things
- struggle to adapt to change
- make decisions they wouldn't normally make
- be slower to grasp complex ideas or take longer with routine jobs
- blame others for 'stealing' lost items
- seem to be more self-centred and less concerned with others and their feelings
- become more forgetful of details of recent events
- be more likely to repeat themselves or lose the thread of their conversation
- be more irritable or upset if they fail at something
- have difficulty handling money
- revert back to their first language (in the case of people from different cultural backgrounds).

These symptoms may also be applicable to other medical conditions (for example, delirium) so a referral to the GP is recommended (refer to section 5 for information about diagnosis).

Other possible signs for the community care worker and HACC assessor to look for are:

- increased difficulty with memory – more forgetful, asking the same question repeatedly
- increased difficulty handling problems – an increased reliance on others to solve problems or to make plans, for example, asking you to make appointments
- increased difficulty managing finances – maintaining a cheque book, paying bills, making complicated financial decisions, for example, asking you to do their banking and pay bills
- more difficulty handling emergencies – making unsafe decisions, needing increased support, for example, locking themselves in or out of the house
- increased difficulty performing household tasks – cooking, using appliances, for example, leaving a gas burner on, and putting plastic pots on the stove
- changes in the person's ability to perform hobbies – decreased participation in complex hobbies, increased difficulty following the rules of games, reading less or needing to re-read more
- requiring increased prompting in self-care, for example, remaining in dirty clothes and being unwilling to shower.

Where possible it is important to establish information about the person and how they managed in the past. The assessor's role is to look for evidence of **change**, for example a change in functioning from 10 years ago.

4.4 Behavioural and psychological symptoms of dementia (BPSD)

Other common changes that may occur in a person with possible dementia are recognised as behavioural and psychological symptoms of dementia. These symptoms can be grouped together into:

- psychological issues, such as depression, anxiety, hallucinations, delusion (a false belief that is held despite evidence to the contrary)
- behaviours of concern, such as aggression, wandering, sundowning (where the person becomes more confused, restless or insecure late in the afternoon or early evening), shadowing (when a person follows or mimics the carer), hoarding, agitation, sexual disinhibition, calling out, apathy and insomnia.

Anxiety and depressed mood may occur early on in dementia. Aggression, wandering, restlessness, agitation, shadowing, sexual disinhibition, hoarding and delusions are behaviours that may occur in more progressed dementia. These symptoms are common and affect up to 90 per cent of people with possible dementia.

Behavioural and psychological symptoms are related to dementia and, in some instances, may be a response to unsuitable care approaches or environmental stimuli. They are not the fault of the person with dementia, who may be exhibiting the behaviour to communicate with those around them.

Factors that may contribute to behaviours are:

- health status and physical or physiological issues – delirium, medical conditions, pain, hunger, thirst, heat or cold, tiredness, boredom
- psychological issues – fear, anxiety, grief, loss, depression, post-traumatic stress disorder
- cognition status – level of dementia and cognitive functioning
- cultural or social issues – background, language, habits, rituals
- personal history – education, experiences such as war, abuse, torture and trauma, pre-migration and settlement experiences
- environmental issues – unfamiliar environments, shared environments, lack of privacy, noise, light, altered routines
- task/activity related issues – amount, appropriateness and structure
- the behaviour and responses of others.

4.5 Strategies for behavioural and psychological symptoms

A person displaying behavioural and psychological symptoms requires an early, considered and coordinated response of various measures, including risk minimisation. HACC assessors should:

- try to determine what is causing the behaviours, in what context they occur and what may be contributing factors
- refer to a GP for medical investigation, particularly if there has been an abrupt and significant behavioural change; this could indicate an underlying medical problem such as a delirium
- determine level of risk by establishing the nature and degree of behaviour being demonstrated and act accordingly. Delirium, physical danger to self and others, profound mental illness and loss of accommodation should all be considered serious risk
- look at possible environmental causes, for example, overstimulation, boredom, inconsistent routine, lack of continuity of community care worker
- encourage carers to seek support from services, for example, Dementia Behaviour Management and Advisory Service (DBMAS) and Alzheimer's Australia Vic
- secondary consultation with, and possible referral to, DBMAS for phone-based assessment and advice (metropolitan Melbourne) and face-to-face assessment (regional Victoria)
- consider a referral to ACAS for a comprehensive specialist assessment and discussion of care options
- secondary consultation with and possible referral to psychiatric triage, such as aged persons mental health service, when severe behavioural difficulties associated with dementia or psychiatric disorder occur
- provide detailed information from family and carers when making referrals. Understanding and knowing the person can assist in preventing behaviours and/or provide insight into appropriate initiatives regarding behaviours.

4.6 Hilary and Angela's story

Stage 1: Awareness and recognition	
The presenting issues according to Hilary	<p>'I am becoming a bit forgetful and often run late for appointments and find myself lost in my local community. I say it's old age. My daughter (Angela) is worried about me and visits three days a week to help me with my shopping and checks I'm OK. She thinks I may need some help.'</p> <p>With Hilary's consent the HACC assessor contacts Angela, who is Hilary's carer, so that she is present at the assessment, which is scheduled at a time that suits her.</p>
What is revealed in conversation (as part of the Living at Home Assessment process)	<p>Tell me about yourself and how things have changed for you.</p> <p>Hilary tells of how she always had a good memory but lately has been forgetful. She is distressed when she recounts forgetting her grandchildren's birthdays. 'I nearly forgot to buy Kirsty a card and present last year, Angela had to remind me.' She misplaces things such as her keys, handbag, clothes and then finds them in the strangest of places. 'I once found them (keys) in the fridge.'</p> <p>She no longer reads and only goes shopping with her daughter as she doesn't 'feel safe' to drive. 'With all the new roads I get lost easily.'</p> <p>When talking to the HACC assessor, Angela tells of how her mother's friends have noticed over the past few months that Hilary has become quiet and is not her usual chatty self. When she does talk, she tends to repeat herself. At the swimming class she does not participate in the exercises and sometimes can't find the changing room.</p>
Observation by the HACC assessor	It is apparent that Hilary has experienced some cognitive changes over the past months and she is becoming distressed about changes to her memory. Angela is also anxious about her mother.
Main goal	<p>Hilary, what would make you feel better in yourself? Is there something you would like us to do?</p> <p>Hilary replies, 'I want to know if there is something wrong or if it is just old age that makes me feel this way'</p>
Possible referrals and supports	<p>The HACC assessor:</p> <ul style="list-style-type: none"> • encourages Hilary and Angela to see the GP about her symptoms • discusses the benefits of having an assessment (and possible diagnosis of a disease) either through CDAMS or a medical specialist • provides details of the National Dementia Helpline and Alzheimer's Australia Vic 'Worried about your memory' information, given Hilary's concern about her memory and accessing local services • provides Angela with details of the Carers Victoria Advisory Line for information about issues to consider in caring for an ageing parent and about local services • suggests assistance with shopping and delivered meals twice a week so that Hilary can get sufficient nutrition and monitoring. This will also provide some support to Angela.
Anticipated outcome	Hilary and Angela discuss Hilary's concerns with the GP and are both provided with written information about support options and ongoing education.

4.7 Questions

HACC assessors may ask the following questions:

- Tell me about yourself and how things have changed for you.
- Are you concerned about your memory loss?
- Do other people such as family or friends ever complain about your memory or tell you that you are repeating yourself?
- How do you spend your week?
- How often do you see family, friends and neighbours?
- What is the most important thing for you right now?
- What would make you feel better about yourself?
- Is there something you would like us to do for you?

4.8 Strategies

If signs and symptoms are identified:

- Talk to the family about GP involvement and other services or agencies that may already have been involved in the investigation of signs and symptoms of possible dementia
- Involve the person in a discussion about possible referrals (with consent) to the GP and/or Cognitive Dementia and Memory Service (CDAMS) for further investigation of symptoms and diagnosis. Include in the referral any information gathered about the person such as changes in memory and behaviour
- Suggest contact with the person's GP to discuss concerns
- Discuss needs for written information, for example, Alzheimer's Australia Vic help sheets, educational programs for improving understanding of the dementia, for example counselling or a referral to Alzheimer's Australia Vic's Living with Memory Loss program
- Provide phone numbers for support, for example, National Dementia Helpline 1800 100 500, Carer Counselling and Advisory Service 1800 242 636, DBMAS 1800 699 799
- If the person is receiving ongoing HACC services, alert the HACC team leader and community care worker(s) to monitor issues or risks and set a review date to discuss further changes.

4.9 Resources

- Alzheimer's Australia help sheets
Section 1: About dementia
<<http://www.alzheimers.org.au/understanding-dementia/section-1-about-dementia.aspx>>
Section 5: Changed behaviours and dementia <<http://www.alzheimers.org.au/understanding-dementia/section-5-changed-behaviours-and-dementia.aspx>>
- Commonwealth Carer Resource Centre *Carer Information and Support Kit, including Emergency Care Kit* <<http://www.carersaustralia.com.au>>
- Dementia Behaviour Management Advisory Service (DBMAS) Victoria
<http://dbmas.org.au/Your_state/Victoria>
Northern Territory: Northern Territory Dementia Behaviour Management Service *Aboriginal and Torres Strait Islander cultural considerations for best practice guidelines for behaviour management frontier services 2008* <http://dbmas.org.au/Your_state/northern_territory>
- Department of Health Victoria *Guidelines for streamlining pathways between ACAS and HACC assessment services*
<http://www.health.vic.gov.au/agedcare/downloads/pdf/acas_has_guidelines.pdf>.

5 Initial dementia assessment, diagnosis and post-diagnosis support – stage two

Stage 2 incorporates the spectrum of service providers that may assist with and/or undertake initial dementia assessment and diagnosis of dementia. Services and specialists involved in diagnosis provide post-diagnosis information and referral to appropriate support services (KPMG 2011).

5.1 HACC assessment services role in initial dementia assessment, diagnosis and post-diagnosis support

The role of the HACC assessor in this stage is to discuss any concerns about memory loss with the person with possible dementia and the family, and suggest that they see their GP and/or a specialist to discuss their concerns and for initial dementia assessment and possible diagnosis. Referrals to GPs should provide a detailed description of signs, symptoms, behaviours and other changes that may suggest memory loss and confusion or other cognitive impairments that are not part of normal ageing.

HACC assessors (with the exception of RDNS and some other district nursing services) do not currently carry out initial dementia assessment using validated cognitive screening tools. The use of dementia screening tools requires a significant level of training and clinical support in administering the tools and in the correct interpretation of the results.

As a result of consultations and discussions during the development of these guidelines, the Department of Health has determined that initial dementia assessment and the use of validated dementia screening tools (as described below) will **not** be a requirement of a Living at Home Assessment.

5.2 Who undertakes the initial dementia assessment?

Services that may currently undertake dementia-specific assessment include aged care assessment services, GPs, practice nurses, occupational therapists and some district nursing services. These agencies use a number of tools to screen for cognitive impairment in different population groups. However, screening tools are not a diagnostic test and no tool used in isolation can confirm a diagnosis of dementia. Medical specialists and CDAMS use a comprehensive range of assessment tools and tests to achieve a diagnosis.

The two most commonly used dementia screening tools are the MMSE (Mini-Mental State Examination) and the RUDAS (Rowland Universal Dementia Assessment Scale). The MMSE is the screening tool that is used to assess people's eligibility for government funding for subsidised medications. These medications offer some relief from the symptoms of Alzheimer's disease for some people for a limited time. The RUDAS is the preferred screening tool for use with people from CALD communities. Diagnosis of the disease needs to be made by a medical specialist. More information is available in the Alzheimer's Australia Vic help sheets.

Standard tests may not be applicable for Aboriginal peoples. The KICA tool is validated for use in remote areas of the Kimberly (Western Australia) but is not necessarily appropriate for Victorian Aboriginal peoples. ACAS, CDAMS or Aboriginal Community Controlled Organisation can provide further information. Further studies on modified forms of the KICA are underway, and may be appropriate for Victoria, but all assessments need to take an individual approach.

5.3 Diagnosis of dementia

HACC assessors need to understand information about diagnostic processes and the purpose of getting a confirmed diagnosis. This can assist HACC assessors to inform the person and their family about what steps to expect when undergoing dementia assessment and diagnosis, and the benefits.

Diagnosis of dementia is important to:

- explain the condition to the person with dementia and their family
- learn about the condition, understand its biological basis and behavioural change in order to cope with the changes
- determine appropriate treatments and the range of therapeutic responses
- enable planning for the future, understand community supports and how to access them.

Dementia is a clinical diagnosis and there is no single test to diagnose the syndrome.

The International Statistical Classification of Diseases (ICD-10) definition of dementia states that there must be:

- a six-month minimum timeframe over which symptoms have developed
- progressive intellectual decline with impaired activities of daily living (ADLs)
- multiple cognitive domains affected.

The definition also states that memory involvement is not mandatory.

Development of multiple cognitive deficits can be manifested by memory impairment and impairments in one or more of language, skilled motor activities, recognition of familiar objects or people, and executive functioning for planning, organising and reasoning.

A diagnosis can only be made if the cognitive impairment is progressive and not due to drugs, other medical conditions or delirium. Before a diagnosis of dementia can be made, differential diagnoses must be considered and other causes of cognitive impairment excluded.

5.4 Differential diagnoses – dementia, delirium and depression

Identifying another reason for the symptoms of dementia is known as 'differential diagnosis'.

A differential diagnosis of cognitive impairment is the first step towards diagnosing dementia as many causes of cognitive impairment are reversible and should be identified and excluded before dementia is diagnosed. Mild cognitive impairment may not always progress to dementia.

Delirium is a reversible disorder of cognitive function. It is a transient mental disorder with a relatively rapid onset that typically fluctuates and has a brief duration. Delirium is difficult to diagnose and urgent medical treatment is required to treat the cause. Symptoms of delirium may be altered attention, disorganised thinking, hallucinations, sudden mood changes, rambling speech and sleep disturbances. Delirium can be caused by almost any medical condition or pharmacological treatment (and occasionally nothing at all). Risk factors for delirium may include: infection, existing cognitive impairment, unrecognised medical conditions such as thyroid problems, medical conditions, urinary retention, dehydration (and constipation), drug effects (and interactions), sensory impairment and pain (Department of Health and Ageing 2006).

Symptoms of **depression** may be low mood, loss of interest, feelings of hopelessness or worthlessness, insomnia, weight loss or gain, reduced physical activity, diminished ability to think or concentrate or recurrent thoughts of death. Underlying cognitive status cannot be accurately assessed in the presence of depression. Table 1 highlights the differences between delirium, depression and dementia.

Table 1: Differentiating between delirium, depression and dementia

Features	Delirium	Depression	Dementia
Onset	Acute	Variable	Insidious
Duration	Hours, days or weeks	Weeks, months or years	Months to years
Course	Fluctuates	Variable	Progressive
Alertness	Fluctuates – variable	Normal	Generally normal
Orientation	Impaired – difficult to engage	Generally normal	Initially normal – deteriorates as dementia progresses
Memory	Variable – often impaired short-term memory	Short-term memory may be impaired	In some forms of dementia, initially short-term memory impaired then long-term memory impaired as dementia progresses
Thinking	Confused. Suspiciousness is common	May be preoccupation with negative ideation. Slowing of thoughts may be evident	Confused and disordered. Often delusions with behavioural and psychological symptoms are common
Perception	Hallucinations. Misinterpretation of environmental stimuli common	Delusions may be present	Usually normal until later stages
Emotions	Withdrawn, agitated	Flat, unresponsive or sad. May be irritable. Early morning awakening.	Usually blunted. Irritability as condition advances.
Sleep patterns	Nocturnal confusion.	Often disturbed. Nocturnal wandering and confusion.	Disorientation to time.

Source: Victorian and Tasmanian Dementia Training and Study Centre, TIME for dementia

5.5 Who can diagnose dementia?

Formal diagnosis of dementia usually requires referral to, and evaluation by, a medical specialist, particularly if medication is required (for example, geriatrician, neurologist or psychiatrist) or a specialist service (for example, CDAMS).

There are three specialist diagnostic clinics for people under 65 years of age:

- The Centre for Developmental Disability Health Victoria, OMNICO, Business Centre Monash Building 1, 270 Ferntree Gully Road, Notting Hill Victoria 3168 tel: 03 9902 4467 fax: 03 8575 2270 email: cddh@monash.edu website <<http://www.cddh.monash.org>>
- Eastern Cognitive Disorders Clinic, Eastern Health Clinical School, Monash University tel: 03 98953353
- Neuropsychiatry Unit, Royal Melbourne Hospital tel: 03 9342 8750; <www.neuropsychiatry.com.au>.

5.6 Diagnostic tools, steps and tests

There is no single test that will diagnose dementia; it is a clinical diagnosis. The ideal clinical approach is to obtain the person's history together with reports from others (for example, family and carers who know the person well). This is followed by a detailed physical examination before proceeding to simple non-invasive cognitive tests.

Important considerations in diagnosis:

- Dementia is difficult to diagnose early (the ceiling effect of some screening tests means that high test scores suggest lack of impairment despite people having obvious cognitive impairment; for example, MMSE). More detailed cognitive tests are required across all domains.
- Informant or carer reports are critical to diagnosis.
- A detailed medical history is vital to exclude depression or other conditions.
- Physical examination including neurological examination.
- Neuropsychology assessment for complex cases or to support management.
- Pathology tests:
 - full blood count, electrolytes, urea and creatinine, liver function tests, B12, folate, calcium, thyroid stimulating hormone
 - urine examination: midstream urine sample; microscopy, culture and sensitivity
 - in certain people: syphilis serology, HIV testing.
- Imaging:
 - computerised tomography (CT) is routinely done
 - magnetic resonance imaging (MRI).

5.7 Treatment options

A person with dementia needs a specific diagnosis as treatment options vary according to the type of dementia and wrong treatments may be harmful. Medication such as cognitive enhancers may be prescribed by a medical specialist according to strict criteria if there is potential to slow the progress of the disease. Drug therapies may also be used to manage comorbid conditions, modify risk factors (for example, lowering blood pressure) and to treat behavioural and psychological symptoms.

Health improvement strategies, other than drug therapies, may include quitting smoking, reducing weight, exercising and obtaining nutrition advice. Other common therapies that may improve the quality of life of people with dementia are:

- music therapy
- reality orientation
- validation therapy
- recreation therapy
- reminiscence therapy.

See the Glossary for a brief description of these therapies.

Refer to the Alzheimer's Australia Help Sheet 2.2 *Therapies and communication approaches* for more information.

5.8 Hilary and Angela's story

Stage 2: Initial dementia assessment, diagnosis and post-diagnosis support	
The presenting issues	<p>The GP is concerned that Hilary's symptoms are more than just normal ageing or related to another cause and refers Hilary to a specialist (geriatrician).</p> <p>Further investigations and tests are conducted and after a third visit to the geriatrician, it is confirmed that Hilary has dementia.</p> <p>Angela decides to contact Alzheimer's Australia Vic on behalf of her mother, Hilary, for further information. She is given general information about memory loss and details on support services and groups available in her area. On reading the information, Angela and Hilary decide to see her local GP.</p> <p>Angela decides to contact the Carers Victoria Advisory Line for information and support. She receives a Carer Information Kit and contact details for support services and carer support groups in her area.</p>
What is revealed as part of the assessment process	<p>Following diagnosis, the specialist discusses the cause and likely course of dementia with Hilary and Angela and states that the dementia is at an early stage and is likely to be Alzheimer's disease.</p> <p>The specialist also discusses the safety implications of the diagnosis and course of the disease on Hilary's ability to continue driving. Hilary does not want to give it up. The specialist informs Hilary of her duty of disclosure to Vic Roads and her insurer with regard to any condition that might affect driving, including dementia. He advises Hilary that a medical report should be submitted to Vic Roads recommending an OT driving assessment but that ultimately it is the Vic Roads medical review section that makes this determination.</p> <p>The specialist suggests that they return for a review in six months to monitor Hilary's progress and refers her back to her GP for ongoing care.</p>
Main goal	<p>Hilary feels that she will be able to continue with her life as before, but she is keen to find out the reason for her change in memory and thinking:</p> <p>'I'm more concerned about Angela looking after me – I'm fine. I can do my own housework – I don't need anyone coming into my home to help me with that.'</p>
Possible referrals and supports	<p>Alzheimer's Australia Vic:</p> <ul style="list-style-type: none"> • provides general information about memory loss, details on support services and groups available in the area • provides the Alzheimer's Australia Vic Living With Memory Loss program as a way to further educate Hilary (and Angela) on dementia and its progression. This encourages planning for the future and use of service system resources. <p>HACC – Living at Home Assessment:</p> <ul style="list-style-type: none"> • suggests that a review of both Hilary's and Angela's needs can help Hilary to be as independent as possible • provides a referral to an occupational therapist for a home-based assessment to identify ideas and possible equipment • suggests other transport options to deal with Hilary's concerns about lost independence if she is unable to continue driving • asks Hilary and Angela whether they have considered Advance Care Planning and/or appointing an enduring power of attorney (medical treatment) or an enduring power of attorney (financial). Links to resources are available at <www.health.vic.gov.au/acp>.
Anticipated outcomes	<p>Psychological and practical support in place for Angela and Hilary:</p> <ul style="list-style-type: none"> • Hilary's wishes become known through discussions with Angela. An enduring power of attorney (medical treatment) is appointed • Angela is part of the local Carers' Support Group • Angela has arranged for Hilary to attend a day centre respite program once a week.

5.9 Resources

- Alzheimer's Australia help sheets:
 - 8.2 *Early planning*
 - 8.4 *Driving and dementia*
 - 8.8 *Talking about diagnosis*
 - 8.9 *Talking with your doctor.*

<<http://www.alzheimers.org.au/understanding-dementia/section-8-about-you---information-for-people-with-dementia.aspx>>
- Carers Victoria: *Information for Carers Fact Sheet – Legal arrangements*
<<http://www.carersvic.org.au/file-assets/factsheet/carers-information-pack/>>
- Department of Health, *Best care for older people everywhere – the toolkit*
This was developed by the Department of Health to assist staff working in health services to identify and minimise functional decline amongst older people. The toolkit reflects current evidence-based practice spanning ten key domains: person-centred care, assessment, skin integrity, continence, mobility, nutrition, delirium, dementia, depression and medication. Although the primary focus of the toolkit is hospital settings, many of the resources and principles contained within it are applicable across the care continuum.
<www.health.vic.gov.au/older/toolkit>
- VicRoads *Medical review – assessing fitness to drive*
<<http://www.VicRoads.vic.gov.au/Home/Licences/MedicalConditions/MedicalReview.htm>>.

6 Management, care, support and review – stage three

Stage 3 addresses the role of ongoing management (health and community care), review and support across the spectrum of services and across care settings (such as in the home, in the community and in residential care – high and low care). Services range from post-diagnosis support, addressing fluctuations in needs for care and support services, and the need for care coordination if people are receiving care from different services, to more intensive case management such as Hospital Admission Risk Program (HARP), Extended Aged Care at Home Dementia (EACHD) or residential care, as the disease progresses (KPMG 2011).

This section addresses the needs of a person with dementia. For issues related to carers refer to Part C.

6.1 HACCC assessment services role in management, care, support and review

The role of HACCC assessment services during this stage is to assist both the person with dementia and their carer to get the right supports to help deal with everyday issues, and get timely information and assistance to navigate the services within and beyond those provided by the HACCC program.

6.2 Living at Home Assessment

A Living at Home Assessment provides the basis for planning appropriate care for the person with dementia, supporting the family and supporting the community care workers.

Because dementia is a complex disease with symptoms that can impact on many aspects of a person's life, the assessment may require more than one visit and more frequent reviews. Services need to be introduced and information provided at a pace and in a format appropriate to the person and their family.

Assessors need to be aware they are working in an interdisciplinary environment where the family may already be linked into a range of services including specialist medical and diagnostic services. Understanding which agency is coordinating the person's care and gaining consent to share information between agencies is very important as it will mean less duplication and a more coordinated approach.

The following considerations are central to assessment and care planning:

- Aim to assist the person to maintain their sense of identity and include them in decision making wherever possible. Getting to know the person, their past history, family, working life, interests and special talents is very important. Find out if another agency has already collected this information, for example, a Cognitive Dementia and Memory Service.
- Plan care arrangements on the basis of improving people's functioning, building on interests, strengths and their lifestyle patterns. Be mindful of risks and discuss realistic and safe care options.
- Be conscious of communication styles and strategies. For example, discuss the benefits of developing a memory book or life story book to assist people who come into the house to understand and communicate meaningfully with the person (see page 16: Creating a life story).
- Who is managing any comorbid conditions? Coordinate HACCC service responses with other agencies and work on common goals where possible.
- Make sure you understand and deal with immediate problems or issues that the family is telling you about. Be flexible - you may not cover all the areas that you thought you would in one or two visits.
- When appropriate, outline all the options for supports at home and allow the family to set their own goals. Find out their views about moving to residential care in the future.

- Keep in mind the need for timely referrals to specialist service such as CDAMS and Aged Care Assessment Services (ACAS). Referrals that are 'too late' may have significant consequences that limit treatment and support options.
- Provide contact numbers for advice on behavioural and psychological symptoms of dementia, for example, Dementia Behaviour Management Advisory Service (DBMAS), Alzheimer's Australia Vic, Aged Care Assessment Services, or Aged Persons Mental Health Services (APMHS).
- Encourage contact by the person with dementia and their family with Carers Victoria and with Alzheimer's Australia Vic for further information, support and education.

6.3 Service-specific assessments

HACC assessment services will carry out service-specific assessments for HACC services to support the person with possible dementia and their carer. Community care workers providing support to the person may encounter a range of challenges. Regular monitoring of service plans by the assessor, HACC team leader or coordinator is necessary to discuss emerging issues or problems and identify possible solutions. For information on strategies for service-specific assessment refer to section 6.3 Maintaining health, wellbeing and independence and the *HACC assessment service practice guide*, section 12 on service-specific assessments.

6.4 Care planning

Understanding a person in the context of their life history assists with planning appropriate dementia care and support. This approach, also known as 'life story work', is useful with people with cognitive problems. For care to be person- and family-centred, it is important to listen to the person and their family who can provide insight into the persons past and present. This aids understanding of the impact of past and present experiences on care provision, and provides a history to share with other care staff and services for assessment and care planning. The person's life history may include things like their profession, work, family background and relationships, what they enjoy and what their leisure interests are. Discussion with the person with dementia and their family or carer elicits what the person usually gets enjoyment from. These activities may be set as goals in the care plan. For example, taking part in group activities may be helpful for some people; however, not all people function well in groups.

6.5 Strategies for care planning

Goal setting can be used in care planning for people with dementia and their carers. Different strategies may need to be used to identify goals and the most appropriate approach to achieving those goals.

A problem-solving approach may be useful. This approach assists with meeting the needs of the person with dementia whilst considering the needs of their carer. Principles of a problem solving approach are:

- Build on strengths – maximise autonomy by identifying the person's skills. For example, changes should encourage rather than restrict a person's involvement in their own personal care and household tasks.
- Try simple solutions first – use a trial and error approach.
- Try to achieve a balance between safety and autonomy – weigh up the risks.
- Provide a safe working environment for community care workers, family carers and other services.

Suggested strategies include the following (NSW Department of Ageing Disability and Home Care 2008):

- Involve the person with dementia to identify problems and possible changes to the home environment. When communication is more difficult, careful observation of how the problem affects the person is important.
- Respond to specific problems with specific solutions. Changes to the home environment should encourage independence, however changes may have unintended consequences. For example, installing a fence to keep the person secure may cause the person to be frightened, feel trapped and possibly climb and wander.
- Take into account the person's usual preferences and dignity when suggesting modifications. For example, introducing a tracksuit for someone who can't manage zippers and buttons may make them feel uncomfortable to go out in if they are not accustomed to wearing this type of clothing.
- Maintain a comforting, familiar atmosphere in the home where possible.
- Consider whether any suggested changes to the environment are culturally appropriate; modifications should be home-like using styles or equipment the person is familiar with.
- Change as little as possible – preserving the familiar home environment is critical in maintaining skills and independence. For example, household items should not be removed or changed unless they present a problem or obstacle to the person's independent functioning. If needing to change a stove top kettle because it is becoming unsafe to use, consider the design of an automatic kettle before purchasing as it may be difficult for the person to learn how to use. Traditional 'comfort' food, plants and music may bring back happy memories.
- Recycle ideas – be flexible and creative, keep trying and retrying old strategies.
- Respect the right of the person with dementia to make decisions about their care that may be contrary to the advice of the health professional.

Table 2 outlines an example of a care plan developed for a person with possible dementia.

Table 2: Sample content for care plan

Issue/problem	Agreed goal	Action(s) to be taken and by whom	Target date
Unable to dress and cook for herself	To enable the person to maintain her ability to dress and cook for herself	<i>HACC assessor</i> <ul style="list-style-type: none"> • Secondary consultation with or referral to occupational therapist for ideas to support independence in ADLs 	4–6 weeks
Unable to attend social club weekly gatherings demonstrated by confusion with day, date and time	To enable the person to attend her social club weekly gatherings	<i>HACC assessor and carer</i> <ul style="list-style-type: none"> • Discuss approaches to minimising confusion with time and day • Develop a plan that includes friends, family and neighbours to assist her to access more social events 	4–6 weeks
Reluctance to undergo further cognitive assessments	To improve understanding of future options and what is involved in dementia assessment and diagnosis	<i>HACC assessor and GP</i> <ul style="list-style-type: none"> • Provide family with information about the benefits of cognitive assessment; obtaining a diagnosis and future treatment options • Refer to a cafe-style support service where the family can talk to other people in similar circumstances and share stories. 	4–6 weeks

6.6 Transitions in care

People with dementia commonly need to transition from HACC services to a higher level of in-home care offered by packaged care services or to a residential aged care facility. As increasing care needs, such as signs of dementia are identified, a referral to ACAS should be considered in discussion with the person and their family and carers.

The move to residential care means significant change and transition and can be difficult for all. Issues that may arise include finding a suitable facility, and the level of acceptance by the person with dementia, their carers and family. An ACAS assessment will determine whether the person's needs would be best met through a package of care or a move to a residential care facility. Refer to *Guidelines for streamlining pathways between ACAS and HACC assessment services in Victoria* (Department of Health 2011) for further information.

A person with dementia who is returning home from hospital is especially vulnerable and may require additional supports. A referral to ACAS for a transition care package should be considered in conjunction with a range of other supports such as HARP and Hospital in the Home available through the health service.

Communication and sharing of assessment and care plans are important when a person with dementia is transitioning between care providers. HACC assessment services can support a seamless process by communicating relevant information with other service providers involved in the person's care.

6.7 Information in the referral

HACC assessors should include a detailed description of how memory loss and other changes related to dementia affect everyday functioning of the person. Information about care relationships and carer stress should also be included when referring to services for carer support.

Refer to Part C (page 55) for more information about addressing the needs of carers.

Services receiving a HACC referral to investigate symptoms of dementia will benefit from information that shows how the person is coping (or not) in their home environment, potential risks, and changes occurring with memory and behaviours.

6.8 Review

Review and reassessment should be carried out as outlined in the *HACC assessment service practice guide* (sections 15.3 and 18). The care plan should be revisited and amended as appropriate. HACC assessment services should consider when feedback about changes in functioning or behaviour should be provided to assist other services involved in the person's care.

7 Maintaining health, wellbeing and independence – stage three continued

The following topics are considerations to be explored during assessment and care planning that may impact on the health, wellbeing and independence of the person with dementia (see Part C for assessment of carer needs).

Pain management and palliative care are included in Stage 4 of the dementia pathway (see section 8, Palliative and end-of-life care). For some people, pain management may be required in all stages of dementia management. For people with comorbidities, palliative care may be required at an early stage of dementia management because the dementia may only be recognised very late in life.

7.1 Domestic assistance

Deteriorating memory can affect a person's ability to perform daily activities. Careful planning of household tasks and the use of memory aids can assist with these activities. The resource *At home with dementia: a manual for people with dementia and their carers* (NSW Department of Ageing, Disability and Home Care) provides solutions and suggestions for the home environment. Some strategies related to memory, wandering and safety are dementia-specific while others are more general.

Assessment and care planning for domestic assistance should take into consideration the person's wishes and build on people's strengths. Under the Active Service Model approach, the care plan will support community care workers to work with the person to carry out activities or element of tasks or activities that the person can and wants to continue doing. This is the 'doing with, not for' philosophy. See the *HACC assessment service practice guide* (section 12.2).

It is important to build in sufficient time for assessors to explain the care plan to the community care workers so they understand the context, rationale and goals that lie behind the care plan tasks.

Strategies

- Observe and discuss with the person the way they perform activities and tasks around the house.
- Discuss with family and carers how the person performs tasks and ways for improving independence and building on past strengths and interests.
- Promote options to help with managing tasks, including use of memory aids and assistive technology, for example, easy-to-read clocks and large calendars, reminder timers, labelling and shopping lists.
- Consider a secondary consultation or referral to an occupational therapist to maximise the person's independence and safety with a task or activity. Recommendations may be made for aids and equipment, such as grab rails and ramps.
- Consider the role of the community care worker. For example, break down activities, work out which the person enjoys doing, and identify how the community care worker can act as a guide and coach to enable the person to keep doing these tasks themselves.

Resources

- *HACC assessment service practice guide*: see sections
 - 10.1 Domestic activities of daily living
 - 12.2 Domestic assistance and ASM
- Independent Living Centre in Victoria for equipment <<http://www.yooralla.com.au/ilc.php>>
- NSW Department of Ageing, Disability and Home Care, *At home with dementia: a manual for people with dementia and their carers*.

7.2 Personal care

HACC personal care assessment and service delivery must be conducted in accordance with the HACC Personal Care Policy (see *Victorian HACC program manual*, including amendments and updates). This policy includes the requirement for personal care assessment and care planning and staff support by registered nurses or other relevant health professionals where clients have, for example:

- unstable health status and/or complex care
- PEG feeding and other invasive procedures
- medicines management
- assistance with hygiene
- foot care.

As people with dementia would generally be considered to have complex care needs assessors should refer to the *Victorian HACC program manual* and amendments/updates for assessment requirements for people with **unstable health status or complex needs**. In such circumstances, clinical assessment, care plan and evaluation of the person's needs are required. A clinical assessment is usually provided by a registered nurse or other health professional.

HACC assessment services will have protocols with district nursing services which detail the circumstances in which registered nurses will be involved in personal care assessment and service delivery. Personal activities of daily living can include:

- bathing, showering
- dressing
- eating
- toilet use
- managing continence (bowels and bladder)
- personal hygiene (shaving, hair care, grooming)
- limited nail care (only after professional assessment)
- mobility (transfers in and out of chairs, bed, wheelchair, vehicle)
- assistance with prescribed exercise or therapy programs
- fitting aids and appliances
- monitoring self-medication
- escorting to medical or other related appointments or activities.

Below are personal care tasks or activities of particular relevance to people with dementia.

Personal care tasks

The ability to perform personal care tasks, including hygiene and dressing, diminishes as dementia progresses. In advanced dementia a person becomes totally dependant on carers to meet these needs. The need to perform personal care tasks such as bathing and dressing can be difficult and stressful for carers and is often the trigger for family and carers seeking support from external services.

Service-specific assessment and care planning for personal care needs to take account of the person's wishes and what is important to them. The assessment needs to identify any sensitivities surrounding personal care tasks for the person with dementia. Be creative and use a problem-solving approach to minimise stress or confrontation. Observe when and where agitation and distress arise and try to avoid or find ways around these situations.

Assessors need to spend time explaining the care plan to the community care workers so they understand the context, rationale and goals that lie behind the care plan tasks. Community care workers need to be well prepared and well supported in the provision of personal care.

Strategies

- Consider gender and cultural considerations in care planning
- Use prompts or reminders to help the person dress independently.
- Introduce clothing with Velcro instead of zippers and buttons.
- Break down tasks into simple and manageable steps.
- Organise a secondary consultation with, or referral to, an occupational therapist for appropriate aids and equipment.
- Consider a commode for overnight toileting or equipment like an over-toilet frame.

Resources

- Alzheimer's Australia help sheets:
 - *2.15 Dressing*
 - *2.17 Hygiene*
- *Victorian HACCC program manual* and updates and amendments.

Continence

Maintaining continence or bladder and bowel control requires the cognitive ability to recognise the need to empty your bladder or bowel, to remember how to respond to the sensation, and to be able to locate the toilet. As cognition declines, people with dementia are more susceptible to both urinary and faecal incontinence. As in any person, reversible causes of incontinence must be investigated prior to accepting incontinence as being associated with dementia.

Strategies

- Consider a referral to a GP, nursing service or continence clinic for further assessment or secondary consultation. (This is consistent with the practice guide.)
- Contact the National Continence Helpline 1800 330 066 for secondary consultation.
- Based on the information gained from the continence assessment, the following strategies may be recommended:
 - education of the community care worker and family carer on prompting the person to go to the toilet or, if the person is not able to respond to prompting, encourage or guide them to the toilet regularly
 - education of the community care worker and family carer to look out for physical cues of a need to go to the toilet, for example, restlessness, agitation, flushed face
 - clothing that allows ease of undressing and dressing
 - adjustments to the environment: make the location of the toilet more recognisable, leave the door open, leave the light on at night, and use signs (pictures and words).

Medicine management

Treatment of dementia focuses on the use of drug therapy and other strategies to relieve or minimise the impact of symptoms or enhance the quality of life of the person with dementia. Medicines available include cognitive enhancers, medicines to treat symptoms including behavioural and psychological symptoms of dementia, and medicines to modify risk factors. Poor memory is the most common reason for people with dementia failing to take medicine.

Strategies

- Refer for a home medicines review if the person is taking more than five medicines or is concerned or confused or forgets medications. Other triggers may be a significant change to the medicine in the last three months including recent hospital discharge.
- Consider use of use of interpreters and translated medicine information when working with people from CALD backgrounds.
- Consider a referral to the GP for a review of medications or to the district nurse for assessment regarding the level of assistance required to monitor and take medications. The GP or nurse assessment may result in the use of prompts for taking medications, including the use of appropriate dose boxes according to dexterity or simplifying the medication regime, for example, linking with the person's established routines.
- If assistance with medicines is given by a HACC community care worker they must have the relevant competencies and follow the HACC guidelines.

Resources

- *Assistance with medication by HACC community care workers*, Victorian Department of Health, September 2009
- *Guiding principles for medication management in the community* Ph (02) 62897753 for copies
- *HACC assessment service practice guide: 8.9 Medication management*
- *Victorian HACC program manual* and amendments and updates.

7.3 Oral health

Optimal oral health is essential for the overall wellbeing of a person. Because dementia is a progressive condition, oral health needs to be improved as early as possible. Safe and appropriate dental treatment for the person with dementia must be based on a comprehensive assessment of their oral health, current medical status and degree of cognitive impairment. Strategies include:

- investigate when the person had their last oral health check up
- refer to a dentist or community dental clinic for a dental check up
- consider a secondary consultation with the person's dentist or community dental clinic to discuss appropriate strategies for inclusion in the care plan.

Assistance with oral hygiene

If a person with dementia needs assistance with oral hygiene, a clinical assessment will be required. This may result in a number of interventions as listed below. If a community care worker is delivering this care, they need to have the relevant oral health competencies. Oral hygiene may include:

- brushing teeth and/or dentures
- using a high-fluoride toothpaste
- using a soft toothbrush on gums, tongue and teeth
- applying a low strength antibacterial product after lunch, for example, chlorhexidine gel
- keeping the mouth moist, for example, sipping water frequently, applying water-based lip moisturiser, and eating tooth-friendly lollies
- reducing sugar intake from food and drinks, for example, use tooth-friendly sugar substitute products.

Resources

- Alzheimer's Australia help sheet 2.14 *Dental care* <<http://www.alzheimers.org.au/understanding-dementia/section-2-caring-for-someone-with-dementia.aspx>>
- *HACC assessment service practice guide*: 8.10 Oral health
- *Victorian HACC program manual* and amendments and updates.

7.4 Nutrition and hydration

The nutritional status of a person with dementia may be compromised due to the symptoms of dementia. Impaired cognition leads to an inability to prepare meals, forgetting to eat, forgetting how to chew or swallow or being unable to recognise the food placed in front of them. Commonly there is a loss of interest in food but in some cases the person may experience extreme hunger and craving for sweets.

Strategies

- Assess the ability of the person to shop for and buy food.
- Assess the ability of the person to prepare food, including the safe use of kitchen equipment, for example, turning on taps, boiling the kettle and using a toaster or a gas or electric stove or oven.
- Consider the impact of culture and religion on diet.
- Verify with the family, carer, dietician or GP any concerns about the person's nutritional status.
- Refer to a GP to exclude other medical causes and for review of medications as these may affect appetite or cause nausea.
- Consider a secondary consultation with, or referral to, a nutritionist, dietician to identify risks and strategies for inclusion in the care plan. Dieticians may recommend:
 - using finger food and having small, frequent meals
 - eating healthy snacks
 - nutritional supplements
 - keeping fluids visible throughout the day
 - using uncomplicated table settings and contrasting and unpatterned crockery
 - keeping a calm and quiet environment at meal times.
- Consider a referral to a speech pathologist for swallowing difficulties; thickened fluids may be required.

Resources

- Alzheimer's Australia
 - Help sheets 2.13 Nutrition and 2.12 Eating
 - Update sheet What you eat and drink and your brain <<http://www.alzheimers.org.au/understanding-dementia/section-2-caring-for-someone-with-dementia.aspx>>
- HACC assessment service practice guide:
 - 8.7 Nutrition and hydration
 - *Victorian HACC program manual* (2003) including updates and amendments
- Victorian Continence Resource Centre 2008: *Water for Wellbeing: promoting adequate fluid intake for the frail older person* <<http://www.continencevictoria.org.au>>.

7.5 Mobility

Most dementias affect areas of the brain responsible for movement and balance. A person may at first walk more slowly and after a while their walking may become more uncoordinated. Loss of mobility may cause people with dementia to be unsteady, at risk of falls or other injury related to unstable gait, and eventually chair- or bed-bound.

Strategies

- Refer to a physiotherapist to work on the person's range of movement with exercises to maintain flexibility and strength.
- Refer to an occupational therapist for assessment of the home environment and any modifications required.
- Follow up on recommendations from the physiotherapist or occupational therapist relating to suitable mobility aids and equipment and modifications to improve the person's mobility and make the home environment safe, for example, install bathroom equipment grab rails and hoists.

Resources

HACC assessment service practice guide:

10.3 Mobility

12.2 Personal care and ASM.

7.6 Falls prevention

Risk factors for falls are compounded by impaired cognition as people with dementia may not have insight to appreciate that they may fall or have the ability to use mobility aids. Widely used falls prevention initiatives may not be easily implemented for people with dementia. Fractures (for example, hip fractures) can be far more difficult for people with dementia to recover from. There is a high prevalence of delirium (increased confusion) post-operatively, which means formal rehabilitation by allied health (physiotherapy and occupational therapy) is difficult as the person with dementia is unable to follow a structured exercise program. Minimising falls risk in people with dementia relies on environment change and reducing intrinsic factors wherever possible.

Strategies

- Suggest improvements for lighting in the home and removal of trip hazards.
- Be alert for signs of dehydration, delirium, low blood pressure and low blood sugar.
- Refer to the GP for investigation of falls risks.
- Refer to the Falls and Balance Clinic for a comprehensive assessment of complex cases.
- Refer to allied health (physiotherapist, occupational therapist, podiatrist) for balance and gait problems, equipment, home modifications and concerns with foot care and footwear.
- Organise a case conference with the relevant services to discuss issues and care coordination.

Resources

- Department of Health: Falls prevention web page
<http://www.health.vic.gov.au/agedcare/maintaining/falls_dev/index.htm>
- *HACC assessment service practice guide:* 10.4 Falls prevention.

7.7 Physical activity

Physical activity promotes healthy blood vessels, improving blood flow to the brain and the supply of glucose and oxygen that it needs to function well. Physical activity also promotes growth and survival of nerve cells in the brain. Some studies have linked sedentary behaviour with increased risk of dementia while others have demonstrated the positive effect of exercise on measures of mild cognitive impairment and executive function. For people with dementia, physical activity can help prevent muscle weakness, mobility problems and other health problems associated with inactivity. It can also help promote a normal day–night routine, improve mood and increase social participation. Physical activity can also help reduce the stress, anxiety and depression that may also be experienced (Alzheimer's Australia 2010).

Strategies

- Encourage the person to continue with the activities they enjoy, helping where needed.
- Organise a secondary consultation with, or referral to, the GP and a physiotherapist for recommendations on appropriate structured exercise programs. Consider using personal care workers to assist with increasing the person's level of physical exercise.

Resources

- Alzheimer's Australia update sheets:
 - *Keep on moving: physical exercise and dementia*
 - *Safer walking for people with dementia: approaches and technologies*
- HACC assessment service practice guide: 10.5 Physical activity.

7.8 Emergency planning and safety

For people with dementia, environments can become more difficult to deal with during and after an emergency; for example, threat from fire or flood or other natural disaster. They may have reduced ability to get to accessible exits, personal items and emergency supplies. People with vision and hearing loss and people with speech problems often encounter many more communication barriers. Emergency planning includes preparing the person with dementia and their carer to deal with emergencies that may arise.

Strategies

- Encourage and assist the person with dementia and their carer to develop an emergency care plan.
- Refer the person and their carer to the Country Fire Authority (CFA) *Fire Ready Kit* or the *Emergency REDiPlan: Household preparedness for seniors* booklet, available from Australian Red Cross.
- Consult with the relevant fire service (Metropolitan Fire Brigade or CFA) concerning home fire safety strategies, particularly if the person with dementia has problems with hoarding.
- Identify and manage risks in and around the home, for example, the use of a timer for cooking, appliances that turn off automatically, gas detectors, working smoke detectors, alarms or sensor equipment if people wander, and reduction of clutter where there is a high level of hoarding.

Resources

- For all hazards planning tools see the following websites:
 - Red Cross resources <www.redcross.org.au/emergency-resources.aspx>
 - Bush fire plans – Leaving early: <www.redcross.org.au/files/Bushfires_leaving_early.PDF>
 - CFA resources/kits: <www.cfa.vic.gov.au/firesafety/bushfire/firereadykit.htm>
- ACH Group, Planning Ahead: an information guide for people with dementia and their families' <http://www.ach.org.au/webdata/resources/files/Planning_AheadGuideforFamilies_Web.pdf>
- Alzheimer's Australia help sheets:
 - 2.3 Safety issues
 - 8.5 Living alone
 - Section 9: The environment and dementia (kitchen, laundry, living room, bathroom and toilet, bedroom, building, furnishings and decor, utilities, outside, new housing and renovations, memory aids, creating a calming environment, pets, health and safety for carers)
- Better Health Channel: Dementia – safety issues
- *HACC assessment service practice guide*: 10.6 Emergency planning and home fire safety
- Independent Living Centres Australia <<http://www.ilcaustralia.org/home/default.asp>>.

7.9 Transport options

The issue of driving competence is complex and requires special assessment. Many people view driving as a right rather than a privilege and as the last external sign of independence. Driving is also seen as essential to maintaining a person's social activities and lifestyle, particularly in rural and isolated settings. Illness and physical changes that are more common with ageing increase the risk of older drivers being involved in a crash (VicRoads 2010).

All drivers have a responsibility to inform Vic Roads and their insurer about any condition that might affect driving, including dementia. GPs may be asked to provide a medical report for VicRoads or recommend a driver occupational therapist assessment.

Strategies

- Refer to the GP or medical specialist for assessment of fitness to drive. The GP or specialist may recommend a driving assessment by an occupational therapist specialist driving assessor. Following a driving assessment, conditions may be recommended rather than revocation of the licence. Examples of conditions or restrictions could be that the person only drives in daylight hours or that driving is restricted to a given distance from the home.
- Refer to VicRoads for driver assessment where there are concerns about the ability of a person to drive safely, where the person does not agree to a referral to a health professional or where a person continues to drive against advice.
- In consultation with the family, carers and GP, document strategies to minimise risk and prevent a person from driving.
- Discuss alternative transport options, for example, eligibility for a multi-purpose taxi program.

Resources

- Alzheimer's Australia help sheet 2.7 *Driving*
- Austroads Inc 2006 *Assessing fitness to drive* <www.austroads.com.au/assessing-fitness-to-drive>
- Department of Infrastructure 2007 *Maintaining mobility – the transition from driver to non- driver* <www.transport.vic.gov.au/_data/assets/pdf_file/0019/31195/MaintainingMobilityPolicyReport.pdf>
- HACC assessment service practice guide: 10.7 Transport options
- VicRoads: <<http://www.vicroads.vic.gov.au>>
 - *The Victorian Older Driver's Handbook*
 - *Fitness to drive* (brochure)
 - Getting around without a car.

7.10 Psychological and emotional wellbeing

People with dementia and their carers encounter many losses and will experience grief at many stages as the condition progresses. Loss of future plans, loss of independence and loss of the past as memory deteriorates are a few examples of triggers for grief. Major milestones, such as moving to residential care, are also extreme causes of grief. Grief and loss may manifest in the later stages as changes in behaviour such as restlessness or agitation.

For some people living with dementia, problems and losses from the past (for example, old or unresolved trauma or grief) can also resurface creating additional psychological or emotional difficulties or pathological grieving. The resurfacing of a traumatic experience can result in people reliving the experience through 'flashbacks'.

Sleep disturbances such as early wakening, night time wandering and restlessness, reversed day/night cycles and disorientation frequently occur in people with dementia. An inpatient hospital admission may be required to address sleeping issues. Sleep disturbances can also cause great distress and burden to carers. It is stressful for the carer to care for a person with dementia when they are sleep-deprived. Night time wandering may trigger the need for the person to move to a residential aged care facility.

Strategies

- Consider referral to a respite or day centre that offers music, reminiscence, validation, recreation or reality therapy to provide comfort and reinforce the person's identity. The key features of these therapies can be implemented simply at home. For example:
 - have the person's favourite music on hand to reduce stress and bring back memories. The association should be a pleasant one; some music may bring back negative or sad memories
 - encourage the family to compile a 'life story' book (see page 16).
 - encourage exercise as it is a great way of reducing stress
 - maintain social supports wherever possible.
- Refer to Alzheimer's Australia Vic for counselling.
- Refer the carer for counselling and support including respite care.
- Refer to the GP for treatment of any underlying causes such as illness, pain, depression or sleep apnoea.

Resources

- Alzheimer's Australia help sheets:
 - 2.16 *Sleeping*
 - 8.3 *Looking after yourself*
 - 8.6 *Feelings and adjusting to change*
- Commonwealth Respite and Carelink Centre Southern Region, *Creative Ways to Care – Strategies for carers of people living with dementia*, DVD and facilitator training manual, <<http://carersouth.org.au/creative-ways-care>>
- Department of Health: *Well for Life – improving emotional wellbeing for older people at home* <http://www.health.vic.gov.au/agedcare/downloads/wellforlife/ewb_home_complete.pdf>
- *HACC assessment service practice guide*: 9.1 Psychological and emotional wellbeing.

7.11 Social wellbeing

During early stages of dementia mood or personality changes may make the person feel that they are not themselves, and misinterpret their environments and other people's words and actions. Some may find being among groups of people overwhelming. Too much noise or activity can also create anxiety or confusion. As a result, the person may begin to withdraw or become disconnected from social situations.

The potential for social and emotional isolation is high for people with dementia. The impact of a diagnosis of dementia may itself cause isolation as the person and their family carer come to terms with it.

Strategies

- Encourage the person with dementia to continue with social activities, within usual groups or, if possible, modify the group size to provide more individual attention within the group as needed.
- Use natural supports, such as existing friends, neighbours, family and clubs, to maintain the person's connection to life and involvement with others.
- Plan and involve the person with dementia in activities and social situations that continue past interests and lifestyle even though the activity may need to be adapted.
- Advise other organisations, carers and family to seek advice about discreet ways to alert others in social situations that the person has dementia.
- Consider ways community care workers can support the person to keep participating in activities they enjoy both in and outside the home. For example, social group activities, physical activities such as going to the gym, visiting friends or assistance with preparing a meal.
- Consider referral to a café-style support program or memory lane café
- Consider age-appropriate activities for a person with younger onset dementia.

Resources

- Alzheimer's Australia help sheet *8.7 Keeping involved and active*
- *HACC assessment service practice guide*:
 - 9.2 Family, friends and community
 - 12.2 Planned Activity Groups and ASM.

7.12 Legal and ethical considerations

During the early stages of dementia, a person's capacity to make legal, financial and lifestyle decisions may not be impaired. Over time, however, dementia increasingly affects memory and other cognitive abilities, and may impact on their capacity to make important decisions. It is important, in the early stages, to encourage the person with dementia to consider making an enduring power of attorney (medical treatment), enduring power of attorney (financial) and/or enduring power of guardianship. The Office of the Public Advocate (OPA) web site has detailed descriptions of each of these powers of attorney and guardianship documents for downloading and completing. *Take control: A Kit for making powers of attorney and guardianship* is a very useful resource, <<http://www.publicadvocate.vic.gov.au/publications/121/>>.

A person must have sufficient capacity to appoint an attorney or guardian. Capacity, or legal capacity, means you have the ability to reason things out. You can understand, retain, believe, evaluate (that is, process) and weigh up relevant information' (*Take Control*, Victoria Legal Aid and Office of the Public Advocate 2011, page 7).

An adult is presumed to be competent. When a person makes an Advance Care Plan they can be asked open-ended questions to determine whether they do understand the matters in the previous paragraph. A person challenging competence must produce evidence of incompetence.

It is not the HACC assessor's role to determine legal capacity. Refer the family to the Victoria Legal Aid and Office of the Public Advocate resource *Take Control* and if further advice is needed, to the Office of the Public Advocate.

Other issues HACC assessors may face include:

- identifying and responding appropriately to situations of alleged psychological or emotional abuse (see *HACC assessment services practice guide* section 9.6 Elder abuse)
- balancing issues of risk with autonomy
- addressing situations where family members limit or control the person's freedom of movement
- addressing situations of self-neglect when a person fails to see they are not looking after themselves
- addressing a person's, and sometimes their family's, refusal to accept services and assistance when they have limited capacity and the situation is putting them at significant risk.

Strategies

- Talk to the person with dementia and their family about their rights and responsibilities.
- Consider referral to the GP or secondary consultation with the ACAS intake worker for advice about issues of risk or autonomy
- Organise a case conference with appropriate services that may be involved in care to discuss the issues.
- Work with the person who holds enduring power of attorney (medical treatment) or enduring power of attorney (financial) or enduring power of guardianship, if applicable.
- People may require a geriatrician or neuropsychology assessment regarding their capacity to make decisions and appoint substitute decision makers.
- Consult the Office of the Public Advocate to seek advice if there are no enduring powers of attorney and there exists reasonable doubt as to whether the person has capacity to appoint a power of attorney.

- An application to VCAT (Victorian Civil and Administrative Tribunal) is required for the appointment of a guardian or administrator. Before making an application consider if there is a decision which needs to be made and whether the person has a disability under the Guardianship and Administration Act. The Public Advocate can be appointed as a guardian as a last resort when there is no appropriate alternative.

Resources

- Alzheimer's Australia help sheet *8.2 Early planning*
- Office of the Public Advocate (Vic.) <<http://www.publicadvocate.vic.gov.au/medical-consent/>>
Take control <<http://www.publicadvocate.vic.gov.au/publications/121/>>
- Protocol between the Aged Care Assessment Service and Office of the Public Advocate 2011 <http://www.health.vic.gov.au/agedcare/downloads/pdf/acas_opa_protocol.pdf>
- Department of Health, *With respect to age – 2009, Victorian Government practice guidelines for health services and community agencies for the prevention of elder abuse* <<http://www.health.vic.gov.au/agedcare/publications/respect/index.htm>>
- *HACC assessment service practice guide*: 9.5 Family violence; 9.6 Elder abuse; 9.7 Financial and related considerations.

7.13 Advance Care Planning

Advance Care Planning is the process for identifying wishes for future treatment and care whereby a person's values, beliefs and preferences are made known. An Advance Care Plan is only used when the person can no longer make or communicate their own decisions. It works as a guide to substitute decision makers and health professionals who plan treatment and care.

An Advance Care Plan records values, life goals and preferred outcomes of care. People with dementia and their family or carer should be encouraged to make Advance Care Plans. The Advance Care Plan enables the person to influence treatment and care even when they can't fully participate in decision making. The process can take place in an informal family setting or via an established Advance Care Planning program within a health service, aged care setting or with a GP. Advance Care Planning discussions are recommended at the onset of initial symptoms or when a diagnosis is confirmed. Contact details of some health services that provide assistance with Advance Care Planning in their catchment is on the department's Advance Care Planning website <www.health.vic.gov.au/acp>.

Advance Care Planning helps maximise autonomy; in particular, a person's right to consent to or refuse medical treatment. It can also

- help minimise the likelihood of people receiving unwanted treatment at a time when, due to incapacity, they cannot make decisions about their medical treatment
- help those who treat and care for people by giving them greater confidence to make decisions responsive to the **person's** needs and respectful of **their** values
- help people to access and use the law to express their wishes about their **future** treatment, including deciding **who** they want to appoint to make treatment decisions if they no longer can.

An Advance Care Plan can include:

- nomination of another person to make decisions. In Victoria this can be done formally by completion of formal documentation to appoint an Enduring Power of Attorney (Medical Treatment).
- an oral discussion
- a letter written by the person to document their wishes.

Listing detailed medical interventions that the person consents to, or refuses, is discouraged. Studies suggest that medical treatment preferences change over time, whereas values and life goals generally remain consistent. Medical directions are best written by a medical practitioner but are informed by the person's values and beliefs or preferences as outlined in their Advance Care Plan. It is important to note in implementing the Advance Care Plan that expressed wishes are advisory and cannot be met if background requirements are not available. For example, a particular type of accommodation cannot be provided if it is not available.

Strategies

- Ask if the person has expressed their wishes about future care to family members.
- Check if there is a substitute decision maker. Assisting with the appointment of an enduring power of attorney (medical treatment) may be the primary aim of the Advance Care Plan, followed by a discussion of the person's wishes for future care.
- Provide information about Advance Care Planning. Check the information available on the department's web site <www.health.vic.gov.au/acp>
- Consider a referral to the GP, Alzheimer's Australia Vic for support in Advance Care Planning. Check the department's Advance Care Planning website to find out which Health Services offer assistance.
- If the person's wishes have been expressed or written down, find out where this document is kept. Does the GP have a copy? Does the substitute decision maker, enduring power of attorney (medical treatment) or family member have a copy? Convey advance care information to other service providers and the GP (with permission).

Resources

- *A national framework for advance care directives*, September 2011, The Clinical Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, <http://www.ahmac.gov.au/cms_documents/AdvanceCareDirectives2011.pdf>
- Department of Health, Advance Care Planning www.health.vic.gov.au/acp
- Office of the Public Advocate (Vic.) <<http://www.publicadvocate.vic.gov.au/medical-consent/>> and *Take control* <<http://www.publicadvocate.vic.gov.au/publications/121/>>
- Alzheimer's Australia help sheet 2.20 *Later stages of dementia*
- Respecting Patient Choices program <<http://www.respectingpatientchoices.org.au/>>.

7.14 Hilary and Angela's story

Stage 3: Management, care, support and review	
The presenting issues according to Hilary and her family	<p>Over the past two and a half years Hilary's condition has gradually deteriorated and is complicated by underlying medical conditions.</p> <p>More recently Hilary has had a couple of accidents around the home, one where she spilt a pot of boiling water and burnt her foot and another where she fell in the shower and bumped her head. Her daughter, Angela, is worried about her safety.</p> <p>Angela wishes to continue caring for Hilary but is finding it increasingly difficult. Over the past two years she has had to reduce her employment from full-time to part-time (three days per week). Angela has decided that as she has to visit every day she will have to stop working completely. Hilary is always agitated and asking questions about relatives who have passed away, and her needs have increased, requiring more constant supervision and assistance with daily activities. She won't settle at a task anymore and often needs to be assisted with dressing and hygiene. Angela's health has also been declining and she finds the carer role exhausting. 'I can't leave her for a minute without fearing that there will be some trouble – I worry about her all the time.' Kirsty, Angela's daughter, is juggling a full-time job and a growing family and tries to support her mum where she can.</p> <p>Hilary's condition worsens and a reassessment by the HACC assessor shows that her care requirements have increased.</p> <p>The reassessment reveals that over time Hilary has lost mobility and continence and is no longer able to sleep through the night. Following the discussion with Hilary and Angela an agreement is reached that she needs more intensive care and support. A referral to ACAS is made by the HACC assessor. Following an assessment by ACAS, Hilary is assessed as high care and approved for an Extended Aged Care at Home Dementia (EACHD) package. She goes onto a waiting list for allocation of the package by a packaged care provider. Angela moves into Hilary's home. In the interim HACC continues to provide services to support Angela and Hilary.</p>
What is revealed in the HACC assessment review process	<p>With the assistance of packaged care services Hilary and Angela can be supported in the home. Hilary requires assessment for falls risk and continence management</p> <p>Angela is experiencing carer burden, including financial burden due to her resigning from her employment and is in need of counselling.</p>
Main goals	To maintain Hilary in her home for as long as possible and support the care relationship
Possible referrals and supports	<p>Hilary:</p> <ul style="list-style-type: none"> • The GP continues to maintain contact with Hilary. • ACAS: <ul style="list-style-type: none"> – assesses for an EACHD package – organises other services and referrals to improve, for example, her continence and mobility. <p>Angela:</p> <ul style="list-style-type: none"> • HACC: <ul style="list-style-type: none"> – provides regular in-home respite and home care (assisting with shopping, cleaning and preparing meals) and expands the service to providing personal care for Hilary as her needs increase – provides two days per week respite care for Hilary to provide her with social support and give Angela some time to herself – refers Angela to a carer support service for information regarding financial and other care supports including advice on the carer allowance. • Alzheimer's Australia Vic provides Angela with counselling to assist her with the psychological impacts of the care role.
Anticipated outcomes	<ul style="list-style-type: none"> • Angela feels better supported with the assistance she and Hilary receive and is able to continue in her carer role. • Hilary is supported to continue to live at home, maintain a level of independence and delay thinking about moving to residential care. • Hilary receives home-based care services and manages to live at home for a further two years.

8 Palliative and end-of-life care – stage four

Stage 4 addresses the spectrum of service providers, medical and allied health professionals and community-based supports involved in the planning and provision of quality palliative and end-of-life care in different settings (such as home or community-based, hospitals and hospices and residential care facilities) (KPMG 2011).

8.1 Palliative care

Dementia is a progressive and ultimately terminal condition. Palliative care is the specialised care of people who have life-threatening illnesses. The aim of palliative care is to provide the best possible quality of life for the person, their family and carers. Palliative care is provided in many settings; for example, private homes, residential services, hospitals and palliative care facilities. Decisions about where to provide palliative care are based on the needs and wishes of the person who has a terminal illness in consultation with their family as appropriate. Clarification around end-of-life decisions is best undertaken early to include the individual in planning their end-of-life-care. In advanced dementia individuals usually have limited ability to participate, which can increase the responsibility on staff and families.

Strategies

- Refer the person to a palliative care service for appropriate care in relation to personal comfort, pain and symptom management, nutrition and hydration, psychosocial and carer support.
- Support the carer and refer them where necessary to counselling services to deal with grief and loss.

Resources

- Alzheimer's Australia help sheet 2.21 *Palliative care and dementia*
- Victorian Aboriginal Palliative Care Program
Migrant Information Centre (Eastern Melbourne) 2009, *Palliative care for culturally and linguistically diverse communities: cultural profiles to assist in providing culturally sensitive palliative care*, <http://www.miceastmelb.com.au/documents/pdaproject/Palliative_care_resource_for_workersAug2009.pdf>
- *HACC assessment service practice guide*: 8.11 Palliative care.

8.2 Care requirements

Family carers face many challenges in trying to provide care for a dying person with dementia at home. Care of a high intensity can be required for an indeterminate time period. Carers may feel they need to honour commitments made to look after their family member at home until they die and may experience significant guilt and grief if they are unable to do this.

If the person with dementia wishes to remain at home and the family wishes to continue to support the person to die at home, a range of services is required to ensure appropriate supports are in place. Palliative care is the key service that provides end-of-life care. However, traditionally palliative care has been perceived as a service for people dying with cancer and not for those with a terminal illness such as dementia.

At end-of-life, high intensity care is often needed for the person with dementia. This would typically mean 24-hour care as the person is usually totally dependent; use of hoists and special bed equipment; and care for pain management, nutrition, hydration, continence management and personal hygiene needs.

Other supports may include assistance from the HACC program for the carer, such as in-home respite; district nursing for ongoing care of pre-existing health conditions for the person with dementia; and residential respite care. If the person is receiving a CACP, EACH or EACHD package, the case manager will coordinate the relevant care and supports.

However, these home-based services may not be able to meet the person and carer's needs and wishes. HACC services can only provide basic support and maintenance and there are often significant waiting lists for packaged care services. In many cases transition into residential aged care is the most realistic option.

8.3 HACC assessment services role

HACC assessors may be required to assess or review service provision to a person with dementia who is palliative in conjunction with palliative care services and the person's family or carer. For example, HACC assessors may:

- ask the person and their family if they have discussed end-of-life issues with their GP. Questions might be: How are you going to manage into the future? Have you talked to anyone about this? What sort of things are important to you and your family?
- work with the GP and the palliative care provider to ensure the family and carer understand the options for care of the person with dementia at end-of-life and support them in understanding those options
- discuss appropriate responses to the cultural, linguistic or spiritual needs of the person and the carer
- check that planned care reflects existing Advance Care Plans
- refer family and carers to appropriate services if they need support to manage grief or change
- consider the training and support needs of support staff who will be providing HACC services.

8.4 Pain management

Pain is under-assessed and under-reported in people with dementia. It is still often thought that people with dementia do not experience pain. Pain in people with dementia can show as disturbed sleep or behaviour symptoms such as aggression and agitation. Pain should be appropriately assessed and managed, particularly when there are communication difficulties. Management of pain includes non-pharmacological approaches and/or adequate use of pain killers.

Strategies

- Monitor changes in the person's behaviours that may suggest pain (for example, withdrawal, lethargy, frustration, agitation, sleeping more than usual, crying, facial or verbal expressions, poor mobility).
- Consider and address other issues that may be contributing to pain (for example, osteoarthritis, osteoporosis, hip fracture history, back pain, constipation, dental problems, infections, migraines, headaches, pressure sores).
- Refer the person to a palliative care/pain service for appropriate pain assessment and management.

Resources

- Alzheimer's Australia help sheet: *2.11 Pain*.

8.5 Hilary and Angela's story

Stage 4: End-of-life	
The presenting issues, according to Hilary and her family	<p>Hilary has been living at home for two years with support provided by an EACHD package. Over the past few months Hilary's condition has deteriorated and Angela can no longer support Hilary's care at home. Angela contacts ACAS for a reassessment for Hilary to enter a residential aged care facility. The impact of this decision on Angela is profound and she requires ongoing counselling.</p> <p>Angela has enduring power of attorney (financial) and enduring power of attorney (medical treatment) for her mother. Hilary signed and completed an Advance Care Plan after a discussion with Angela many years ago. According to the Advance Care Plan Hilary's wishes were to not undergo invasive treatment should her condition deteriorate.</p>
Main goal	Hilary's wishes for no invasive treatment are respected and Angela is supported.
Possible referrals and interventions	<p>ACAS:</p> <ul style="list-style-type: none"> reassesses for high-level residential aged care. <p>Palliative Care Service:</p> <ul style="list-style-type: none"> provides palliative care and support to Hilary and Angela in the residential aged care facility provides care staff to support Angela and her family. <p>GP:</p> <ul style="list-style-type: none"> assists the residential aged care facility to provide Hilary with a dignified death. <p>Alzheimer's Australia Vic:</p> <ul style="list-style-type: none"> provides Angela with counselling. <p>Carers Victoria:</p> <ul style="list-style-type: none"> provides counselling and support for Angela to re-discover a life for herself after caring for her mother for a number of years.
Anticipated outcomes	<ul style="list-style-type: none"> Hilary has a dignified death. Angela feels supported.

Part C

Assessment and care planning
for the needs of carers

9 Assessment and care planning for the needs of carers

This section provides information to guide HACCC assessors when undertaking a holistic needs assessment of the needs of carers of people with dementia. Carers are a specific target group in the HACCC program, acknowledging their need for support, services, recognition and assistance.

9.1 Carers and dementia

It is important to recognise that carers of people with dementia have a pre-existing relationship with that person; as a husband, wife, brother, sister, son or daughter. This pre-existing relationship, its strengths and challenges need to be understood when considering how best to support the care relationship.

Dementia is predominantly associated with people of older age and often carers themselves are older. Informal carers can be family members or friends but the majority are partners or spouses and offspring (often daughters or daughters-in-law). Younger people are more likely to be carers when a parent has early onset dementia. In Aboriginal communities, carers are usually immediate or extended family members. Where there is a large family network, the caring role may be shared between two or more people, usually women (Department of Health 2011).

Carers often provide the majority of care and are often the link to formal services and care assistance for the person with dementia. These carers are distinct from paid carers or community care workers who are paid to look after people with care needs.

Co-resident carers are carers who live in the same household as the person they are caring for. Carers of people with dementia tend to be co-resident with the person, possibly reflecting the need for continuous rather than episodic care and supervision.

Carers who do not live with the person may have other care responsibilities and workforce obligations. They can have quite different experiences of the care role and different needs compared to co-resident carers. They may also face different pressures and therefore may need flexible support.

The progression and changes associated with dementia can place ever-changing demands on carers as the level of dependency increases over time. Caring for someone with dementia is associated with greater difficulties and higher levels of carer stress than caring for a person who is not cognitively impaired.

Carer needs can change along with the needs of the person they are caring for. These may be affected by health, ageing, family, carer circumstances or sudden emergencies. Typical challenges faced by families or carers are physical and emotional tiredness, their own medical issues, financial strain and isolation, and access to general support and respite care.

9.2 Assessment of the care relationship

Carers may receive HACC assessment and care planning to address their needs and support them in their caring role. Assessment and care planning may occur either together with the person with dementia and their family or carer, or individually with the carer as a person in their own right.

Assessment of the care relationship should include the strengths, resources and needs of the person with possible dementia and the carer, and of the care relationship. This includes exploring their formal and informal support systems.

Life domains to explore in assessment are:

- other care responsibilities – for example, caring for more than one parent or in-law, or caring for a spouse, sons and daughters or grandchildren
- family relationships – with the older person and immediate and extended family
- social connectedness – with friends, community involvement, recreational interests
- employment/education – paid and volunteer work and/or studies
- financial circumstances – including eligibility for income support
- physical health – including chronic illness management, risk of injury
- emotional health – any strong positive or negative feelings about the care role
- quality of life and future goals.

HACC assessors should explore with carers any risks to maintaining the care relationship.

Possible risks include:

- being new to the care role and/or lacking information and support
- signs of stress and burden, for example, anxiety and depression
- high intensity co-resident care
- multiple competing role demands, for example, balancing work and care
- conflict in relationships, for example, with other family members or with service providers
- changes in the health of the carer or person cared for
- limited or changing support networks
- major changes in family circumstances.

Questions HACC assessors may ask could be:

- What are things like for you? (in each of these life domains.)
- Have there been major changes since taking on a care role and what are they?
- How do you feel about the current situation?
- Are there difficulties? If so, how you could you bring about positive change?

9.3 Maintaining health, wellbeing and independence of carers

The following strategies for improving the health, wellbeing and independence of the carer should also be considered in assessment and care planning.

Health management

Carers may neglect their own health due to their care responsibilities. Health issues for carers can include depression, physical and emotional exhaustion or fatigue, as well as injuries sustained from care tasks such as lifting. Carers of people with dementia may be older and subject to age-related health problems or disabilities. Carers who are children of people with dementia may be concerned about their own risk of developing dementia.

Strategies

- Consider the carer's own perception of their health.
- Consider past or present illnesses, disability, recent hospital admissions, treatments and medications.
- Consider sleep disturbance and exhaustion, risk of injury and any cognitive problems the carer is experiencing.
- Consider the stability of the carer's health and its impact on their capacity to care.
- Support or encourage the carer to monitor and look after their health and associated needs.

Emotional and social wellbeing

The role of caring for a person with dementia, while rewarding in many ways, can place an enormous stress burden on the carer. Carers can derive a sense of satisfaction and fulfilment from caring through being needed, receiving recognition or fulfilling a sense of duty. Carers often provide most of the emotional support to a person with dementia. This support can cause tremendous strain for carers and is one of the major reasons for carers seeking help.

Caring for someone with dementia can become a 24 hours a day, seven days a week role as the person with dementia may experience sleep disturbance, nocturnal increase in confusion and nocturnal wandering. The person with dementia may not be able to be left alone in the home during the day due to concerns about their safety.

The carer may often decline support when they would benefit from respite care or other services. HACC assessors may find it difficult to understand why someone seems unwilling or unable to accept help. Cultural issues may play an important part in carers' acceptance of support.

Some of the reasons why a carer may not accept help include:

- having a sense of duty and obligation to the person they are caring for
- feeling the need to fulfil the expectations of family and community
- not wanting to be seen as demanding or a trouble to people
- not having the energy to prepare (emotionally and otherwise) the person with possible dementia for the change
- feeling uncomfortable about other people helping
- feeling that another person may not do the caring as well
- feeling that it is a sign of weakness or not coping
- feeling guilty about needing help
- knowing the person being cared for does not want others to know how much support they need
- knowing the person being cared for does not want another person to help.

Carers can find it difficult to plan ahead beyond the day-to-day matters of constantly monitoring wellbeing and behaviour and feeling worried about leaving the person with dementia with others for a period of time.

Strategies

- Consider appointments to see the carer on their own, as the carer may need personal time to express their worries and issues about care without the person with dementia present.
- Identify where a carer may benefit from assistance as carers may not raise their feelings of not being able to manage and not report stress or 'carer burden'.
- Consider using a validated tool, for example, the Carer Strain Index to assist in identifying the presence and degree of carer stress.
- Be aware of potential signs of elder abuse.
- Provide gentle reminders that the carer may need breaks and help if they are to continue to provide care.
- Encourage self-care and stress management techniques.
- Encourage carers to seek emotional and psychological support from their family and personal support networks.
- Support the carer to participate in their preferred social, leisure and/or employment activities.
- Consider referring the carer for professional counselling, for example, National Carer Counselling Program, National Dementia Helpline.

Building capacity of carers

For many people in the earlier stages of dementia, carers may need to supervise and prompt rather than step in to assist with the task. There may be a need to assist in areas like organising time and appointments, managing finances and organising or using transport.

As dementia progresses and the person becomes more dependent, carers will need to provide assistance with activities of daily living, including continence, dental care, dressing, hygiene, meals, nutrition, pain management and sleep.

Personal care is an intimate action and carers are often faced with what is called 'resistance to care'. The person with dementia may become angry and aggressive when carers attempt to undress them or take them into the shower or bath. This can place great strain on relationships.

Strategies

- In consultation with the carer, identify their needs and the supports that would be of benefit, for example, home care with cleaning.
- Suggest practical and timely supports to assist carers with the tasks of caring, such as meals, home care, personal care and respite services.
- Develop a separate care plan in consultation with the carer.
- Refer the carer to carer support services for more support options, particularly with planned regular respite (see section 8.7 Services assisting carers for a list of carer support services).
- To encourage day centre attendance by the person with dementia, suggest that the carer accompany them on the first few visits, until the person is comfortable with staff and the new environment.

- Identify how much information the carer needs at a given point in time. Information should be tailored to the individual.
- Provide carers with knowledge about dementia to enable understanding of how dementia might impact on the person concerned and the sorts of things carers can expect.
- Refer to Carers Victoria for support.
- Provide information to promote understanding of the changing nature of dementia; explain that future needs will vary depending on individual experience and the effectiveness of early strategies of the carer and support services.
- Provide information and refer to Alzheimer's Australia Vic to assist the carer to cope with end-of-life decisions and planning, such as coping with admission to residential care and end-of-life.
- Suggest strategies to the carer about how best to communicate with the person as cognition deteriorates, for example, talking in a calm, gentle manner using short sentences and positive body language such as hand gestures and facial expressions.
- Encourage the carer to access expert advice about any behaviours or psychological symptoms of dementia by calling the Dementia Behaviour Management Advisory Service (DBMAS) line. A telephone consultation about the specific behaviour (for example, resistance to showering) can help the carer identify what might be driving this particular behaviour, and practical strategies can be implemented to reduce the behaviour.

9.4 Emergency planning

Carers should be supported to plan for emergencies in and around the home and for emergencies where they will not be able to continue the care of the person with dementia due to illness or injury.

Strategies

- Encourage the carer to develop emergency care arrangements if something were to happen to the carer.
- Consider a home emergency evacuation and action plan.
- Provide information to educate the carer and family about the risks associated with leaving the person alone and how best to manage risks.
- Check with the family that smoke detectors in the home are active (see *HACC assessment service practice guide* page 99).

9.5 The care journey

There are many milestones through the journey of caring for a person with dementia, and the needs of the carer vary at each milestone. Table 3 provides a summary of possible milestones and the possible needs of carers.

Table 3: Possible milestones and needs of carers

Possible milestone	Possible needs
Pre-diagnosis and diagnosis	<ul style="list-style-type: none"> • Information • Counselling • Referral to GP, CDAMS, medical specialists • Referral to Alzheimer's Australia Vic • Referral to Carers Victoria • Assistance with forward planning
Seeking assistance from external support services	<ul style="list-style-type: none"> • Assistance with identifying appropriate supports e.g. Living at Home Assessment or ACAS assessment • Financial and legal advice • Advance Care Planning
Seeking assistance from informal supports <i>For example, extended family, faith community</i>	<ul style="list-style-type: none"> • Assistance with identifying appropriate family, friends and community supports • Financial and legal advice
Making decisions about employment <i>For example, from full-time to part-time work, or to full-time caring</i>	<ul style="list-style-type: none"> • Referral to employment-related care services • Financial and legal advice • Assistance with applications to Centrelink • Advice on maintaining social contacts
Making decisions about, and the process of, moving the person with dementia into residential care	<ul style="list-style-type: none"> • Information and advice about the process of moving to residential care • Support in dealing with emotions such as loss and grief, guilt and fear • Advice on: <ul style="list-style-type: none"> – planning for and choosing an appropriate facility well in advance due to often lengthy waiting lists – maintaining a relationship with the person with dementia after admission – developing relationships with facility staff
Death of the person with dementia	<ul style="list-style-type: none"> • Support to come to terms with the situation • Advice on returning to social or workforce participation • Financial and legal advice

Source: Based on Victorian and Tasmanian Dementia Training and Study Centre, TIME for dementia

9.6 Peter and his family's story

The following case study describes the life journey of a younger man with younger onset dementia and looks at the impact of this on his life and family.

Stage 1: Awareness and recognition	
<p>Peter is an engineer and has worked in engineering for the past 20 years. He has a variety of interests and particularly enjoys cycling, reading and practising his guitar. He is married with two children – one in primary school, the other in high school. His wife, Claire, works part-time and they are both active in their children's school activities.</p> <p>Recently Peter has been struggling at work – he has been finding it difficult to remember things and to communicate what he thinks and feels. He initially puts this down to stress and tiredness. Claire also notices an increase in the number of falls he has when cycling his familiar route to work and that he has not been reading as much as usual.</p> <p>Peter confides to his wife that he is struggling at work and finds it stressful that he is as 'not on top of his game' as he used to be. His behaviour has become increasingly difficult and erratic at home and he seems irritable towards his children. Claire has noticed the change in her husband for some time. She encourages him to see his GP.</p>	<p>Possible referral and support:</p> <ul style="list-style-type: none"> • GP • Counselling service
Stage 2: Initial dementia assessment, diagnosis and post diagnosis support	
<p>The GP conducts an initial assessment and based on the results refers Peter to a specialist for further investigation. This upsets Peter as he thought he was just tired and stressed and he becomes anxious as he waits for his specialist appointment.</p> <p>The specialist conducts various tests and rules out other potential causes for the changes, and after a period of time diagnoses Peter with fronto-temporal dementia (FTD). The specialist discusses with Peter what this means for him and his family. Peter is in disbelief and Claire feels anxious for the future. The specialist recommends they contact Alzheimer's Australia Vic for information and support. They do not tell anyone of the diagnosis, not even the children.</p>	<p>Possible referral and support:</p> <ul style="list-style-type: none"> • Specialist diagnostic service for people under 65 • Cognitive Dementia and Memory Service (CDAMS)
Stage 3: Management, care, support and review	
<p>As Peter's condition worsens, the impact on the family becomes greater. Peter can no longer work and Claire takes over running the household, looking after the children and working full-time to keep the family going. They have difficulty meeting their mortgage repayments, the children are feeling unsettled and the youngest is misbehaving in school. Claire becomes overwhelmed and depressed. Peter is not as engaged with life as he used to be and no longer cycles or plays guitar.</p> <p>At this point, their GP refers them again to Alzheimer's Australia Vic. As a result Peter and Claire attend a Younger Onset Living with Memory Loss program. Peter also attends a younger onset social/activity group, giving Claire some respite. Alzheimer's Australia Vic encourages accessing age-specific day respite care and to consider active planning for residential respite. Peter's two children also access counselling to discuss their thoughts and feelings about the changes in their dad. Claire investigates receiving some in-home assistance to help with the pressures of running the household.</p> <p>The financial planner recommends that Peter and Claire seek financial advice/assistance from Centrelink (such as accessing a disability pension and/or carers allowance). They are then referred for specialist legal advice given the complexities around Peter's early ill health retirement in the context of a terminal diagnosis.</p> <p>Over time, Peter displays increasing behavioural and psychological symptoms of dementia and Claire seeks advice and assistance from DBMAS to manage chronic and acute episodes, including brokered support for residential respite care.</p>	<p>Possible referral and support:</p> <ul style="list-style-type: none"> • Alzheimer's Australia Vic – counselling service/ support group • Enduring power(s) of attorney • Advance Care Planning • GP • Centrelink • HACC – Living at Home Assessment • Dementia Behaviour Management Advisory Service • Legal, financial and superannuation • Respite
Stage 4: Palliative care and end-of-life	
<p>Over time Peter's condition deteriorates and Claire can no longer manage him at home. Peter is assessed by ACAS as requiring high-level care and moves from home into a residential care facility. This process is extremely stressful for the family.</p> <p>After five years Peter's condition deteriorates. He is no longer able to communicate his needs verbally; he is not drinking or eating. Using his Advance Care Planning wishes and Claire's appointment as enduring power of attorney (financial and medical treatment), Peter has no medical intervention. His pain is managed and over the next few weeks, Peter receives palliative care and dies with dignity.</p> <p>Claire and the children are supported by Alzheimer's Australia Vic through counselling and support networks.</p>	<p>Possible referral and support:</p> <ul style="list-style-type: none"> • ACAS • Residential aged care facility • Alzheimer's Australia Vic – counselling

9.7 Services assisting carers

Support services available to carers are described briefly here; for a comprehensive description of these and other services refer to *A guide to services for people with dementia and their carers* (Department of Health 2012).

- **Carers Victoria:** support services for family and friend carers. Services include referral to support groups, counselling, information sessions and education workshops. Carers Victoria also has a series of fact sheets for carers.
- **Alzheimer's Australia Vic:** support services for people with dementia and their carers. Services include counselling, information sessions, education seminars, memory lane cafes and a range of early intervention programs. Alzheimer's Australia Vic also has help sheets for carers.
- **Commonwealth Respite and Carelink Centres:** provides information about available services including all types of respite care for older people, family and friend carers and workers. They also provide a range of respite and flexible support services for carers.
- **Dementia Behaviour Management Advisory Service:** a free service providing advice and support to carers and health professionals about management of behavioural symptoms of dementia.
- **Respite care and support services:** helps the carer 'take a break' from their care responsibilities. Respite services are either in a community setting or in residential aged care facilities.
 - Community respite and support: short-term respite either in a person's home or in day centres. Short-term respite allows carers to participate in hobbies, go shopping or attend social functions.
 - Residential respite: an assessment by ACAS is required to access residential care respite. The assessed person can have up to 63 days respite each financial year in a residential aged care facility.

9.8 John and his family's story

This case study presents an Aboriginal Elder with dementia and his family.

Stage 1: Awareness and recognition	
<p>John is a 61-year-old Aboriginal man who lives with his extended family in rural Victoria. John is not in good health and his family is having trouble looking after him. They are reluctant to seek services outside their locality as John has rarely travelled outside his community. He is a valued and respected Elder in the community.</p> <p>The family needs support to get him to appointments.</p> <p>John says: 'I don't seem to remember things the way I used to. I guess I'm getting on and these things happen as you get older but I'm afraid that soon I won't remember the stories to pass on to my children...'</p>	<p>Possible referral and support:</p> <ul style="list-style-type: none"> • Local Aboriginal Health Service or GP
Stage 2: Initial dementia assessment, diagnosis and post diagnosis support	
<p>The GP assessment identifies some memory loss, which prompts further investigation. John is diagnosed with vascular dementia. In addition a degree of Alzheimer's disease cannot be ruled out. The geriatrician from Cognitive Dementia and Memory Service (CDAMS) recommends John commences some memory medication with the aim of improving the symptoms of dementia.</p> <p>John's family is concerned about his fragile health and worried about the diagnosis of dementia and what it means for him. The local Aboriginal Health Service's health worker visits John and his family, gives them some information about dementia and discusses some of the symptoms and difficulties John is experiencing. They also discuss the options available to John within the community and what to expect as his dementia progresses.</p> <p>The regional worker from Alzheimer's Australia Vic visits John's community and arranges to meet with the family and local health clinic. The Alzheimer's Australia Vic worker provides additional education and support to the family and advice to the health worker about ongoing management.</p>	<p>Possible referral and support:</p> <ul style="list-style-type: none"> • Aboriginal Health Service or GP • CDAMS • Alzheimer's Australia Vic • Local Aboriginal Community Controlled Organisation
Stage 3: Management, care support and review	
<p>John's extended family decides to put services in place so that he can remain at home as long as possible with the support of the local Aboriginal Health Service. HACC services are provided by their local council and a referral to ACAS is made for a CACP assessment.</p> <p>John and the family are made aware there are Aboriginal services available for respite, HACC services and CACPs and they can have their choice of service provider. The family make sure John is still able to participate in local community events and activities.</p> <p>John's needs continue to increase. His family accesses respite in the community. Some years later John's treating doctor identifies that his condition is palliative and discusses plans for end-of-life care with the family.</p>	<p>Possible referral and support:</p> <ul style="list-style-type: none"> • Aboriginal Health Service • ACAS • Local Aboriginal Community Controlled Organisation • Local council HACC services including respite • GP • Alzheimer's Australia Vic
Stage 4: Palliative care and end-of-life	
<p>Aided by the CACP, the local health service and the consultative support of the Aboriginal palliative care program, John is supported to pass away at home. The family share the care responsibilities throughout the community, recognising that it is culturally vital that John die on his home soil in the company of his extended family.</p>	<p>Possible referral and support:</p> <ul style="list-style-type: none"> • Aboriginal palliative care community service • HACC services including respite

9.9 Resources

- Alzheimer's Australia help sheets:
 - *Section 2: Caring for someone with dementia*
 - *Section 3: Looking after families and carers*
- Alzheimer's Australia: Living with Memory Loss program
<<http://www.alzheimers.org.au/services/living-with-memory-loss-program.aspx>>
- Carers Victoria: *Putting carers in the picture – improving the focus on carer needs in aged care assessment*
<<http://www.carersvictoria.org.au/file-assets/publication/putting-carers-in-the-picture/>>
- Commonwealth Department of Health and Ageing, *Dementia Resource Guide*
<<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-dementia-resource-guide.htm>> and <<http://www.health.gov.au/internet/main/publishing.nsf/Content/Dementia-1>>
- Department of Health, *Recognising and supporting care relationships for older Victorians*,
<http://www.health.vic.gov.au/agedcare/downloads/agedcare_action_plan_0806.pdf>
- Department of Health, *A Victorian charter supporting people in care relationships*
<http://www.health.vic.gov.au/agedcare/downloads/pdf/carers_charter.pdf>
- National Dementia Helpline 1800 100 500: a 24-hour telephone information and support service available across Australia <<http://www.alzheimers.org.au/content.cfm?infopageid=348>>
- Validated carer assessment tool, such as the Carer Strain Index Assessment Tool
- Wicking Dementia Research and Education Centre, University of Tasmania: Carers' CARE – self help DVD and resource package <<http://www.carers-care.edu.au/>>.

Glossary

Refer to the glossary in the *HACC assessment service practice guide* for assessment and service coordination terms used in this guide. Refer also to *A guide to services for people with possible dementia and their carers* (Department of Health 2011) for a full descriptions of services relevant to people with dementia and their carers.

Term	Definition
Advance Care Planning	Advance Care Planning is the process of identifying wishes for future treatment and care whereby a person's values, beliefs and preferences are made known. This assists in guiding decision making at a time when that person cannot make or communicate their decisions. < www.health.vic.gov.au/acp >
Attorney	A person appointed to make financial, legal or medical treatment decisions for another person.
behavioural and psychological symptoms of dementia	An umbrella term for a group of non-cognitive symptoms used to describe a range of symptoms associated with disturbed perception and thought content, such as anxiety, depression, hallucinations, delusions, misidentifications, mania and personality changes.
comorbidity	A disease or condition that coexists with another condition.
co-resident carer	A carer who lives in the same household as the care recipient.
dementia-friendly service	A service response that recognises people's individual journeys and is alert to the signs and symptoms of dementia. People with dementia are valued and respected and are central to making choices about care. Carers and families are valued and supported. Also known as 'dementia appropriate service'.
dementia behaviour management advisory service	Dementia Behaviour Management Advisory Service (DBMAS) provides specialised services to family members, care workers and health professionals who are supporting people with behavioural and psychological symptoms of dementia (BPSD) DBMAS Vic provides the following support services: <ul style="list-style-type: none">• a statewide Freecall 24 hour phone advisory service• phone-based assessment, care planning, advice and referral services in metropolitan Melbourne• face-to-face assessment and intervention services in regional Victoria
end-of-life	Refers to the stage of a life-threatening illness when the person is dying or near death.
general practice	Refers to the practice of general medicine by a GP or doctor.
independent living centres	Independent living centres provide information, advice and trial of independence equipment to enhance the quality of life for people with disabilities or age related difficulties. It is staffed by occupational therapists and physiotherapists.

Term	Definition
carer	Anyone who provides unpaid assistance to a person with support needs based upon a previously existing relationship. Usually a partner or family member.
medical specialist	A medical practitioner that specialises in an area of medicine.
mild cognitive impairment	Usually defined as significant memory loss without the loss of other cognitive functions. People with mild cognitive impairment have more memory problems than would be expected in someone of a similar age. People with mild cognitive impairment are able to function independently and do not usually show other signs of dementia, such as problems with reasoning or judgment.
music therapy	The use of music and/or its musical elements (sound, rhythm, melody and harmony) by a qualified music therapist, with a client or group, in a process designed to facilitate and promote communication, relationships, learning, mobilisation, expression, organisation and other relevant therapeutic objectives in order to meet physical, emotional, mental, social and cognitive needs.
National Dementia Helpline	Phone 1800 100 500. A service funded by the Australian Government and run by Alzheimer's Australia to provide information and support for people with dementia, their carers and families, as well as for service providers, health professionals and members of the public who have an interest in dementia.
neurologist	A medical practitioner who studies and treats injuries and diseases affecting the brain, spinal cord, peripheral nervous system and muscle tissue.
palliative care	Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
practice nurse	A nurse working in a general practice clinic with a GP.
prevalence	The total number of cases of a particular disease in a population at a given time.
reality therapy	Aims to orientate the person with dementia to their surroundings and situation. Usually involves verbal prompting, reminding, explaining and repetition of information and/or visual cues such as orientation boards and signs.

Term	Definition
recreation therapy	Providing recreation resources and opportunities to improve health and wellbeing. Formal recreation therapy is guided by assessment of the individual and the development of appropriate and individualised activities.
reminiscence therapy	The use of familiar objects, photographs or music from the past to prompt discussion of a person's past life and experiences. The limited research in this area indicates that mood, cognition and function did improve and that carers reported lower levels of strain following this therapy.
residential care	Care provided in an aged care facility, such as a nursing home or hostel.
respite	Temporary care arrangements provided by someone other than the usual carer. May also include short-term residential care.
shadowing	A common anxious behaviour where people with dementia follow the carer closely around the house like a shadow.
sundowning	A condition in which people with dementia become more confused, restless or insecure late in the afternoon or early evening. It can be worse after a move or a change in their routine. They may become more demanding, restless, upset, suspicious and disoriented, and even see, hear or believe things that aren't real, especially at night. Attention span and concentration can become even more limited. Some people may become more impulsive, responding to their own ideas of reality that may place them at risk.
transition care	After a hospital stay, the person receives rehabilitation care and support for some weeks either in an aged care facility or at home before returning to regular care arrangements at home or being considered eligible for permanent placement in an aged care facility. Eligibility for transition care is determined by an Aged Care Assessment Service.
validation therapy	Therapy that facilitates communication with older people with dementia and involves acceptance of the other person's reality.
younger onset dementia	Used to describe any form of dementia diagnosed in people under the age of 65 years.

Acronyms

AAV	Alzheimer's Australia Vic
ACAS	Aged Care Assessment Service
ACP	Advance Care Planning
ADLs	Activities of daily living
ASM	Active Service Model
APMHS	Aged Person's Mental Health Service
CACP	Community Aged Care Package
CALD	Culturally and linguistically diverse
CDAMS	Cognitive Dementia and Memory Service
DBMAS	Dementia Behaviour Management Advisory Service
EACH	Extended Aged Care at Home package
EACHD	Extended Aged Care at Home Dementia package
GP	General practitioner or doctor
HACC	Home and Community Care
HARP	Hospital Admission Risk Program
HAS	HACC Assessment Service
MMSE	Mini-Mental State Examination
NRCP	National Respite for Carers Program
OT	Occupational therapist
PAG	Planned Activity Group
RDNS	Royal District Nursing Service
RUDAS	Rowland Universal Dementia Assessment Scale
SCTT	Service Coordination Tool Template

References

- Access Economics 2009, *Keeping dementia front of mind: incidence and prevalence 2009–2050*, Final report by Access Economics for Alzheimer's Australia, <http://www.fightdementia.org.au/common/files/NSW/2010NSWFront_of_Mind_Full_Report1.pdf>
- Access Economics 2010, *Caring places: planning for aged care and dementia 2010–2050*, volume 1, Report by Access Economics for Alzheimer's Australia, <http://www.fightdementia.org.au/common/files/NAT/20100700_Nat_AE_Vol1CarePlaces2010-2050.pdf>
- Alzheimer's Australia 2008a, *Dementia facts and statistics*, <<http://www.fightdementia.org.au/help-sheets-and-update-sheets.aspx>>
- Alzheimer's Australia 2008b, *Perceptions of dementia in ethnic communities*, <<http://www.fightdementia.org.au/help-sheets-and-update-sheets.aspx>>
- Australian Institute of Health and Welfare (AIHW) 2007, *Dementia in Australia: national data analysis and development*. Cat. No. AGE 53. AIHW, Canberra
- Avramopoulos D. 2009, 'Genetics of Alzheimer's disease: recent advances', *Genome Medicine*, 1:34 (doi:10.1186/gm34)
- Dementia Collaborative Research Centres (DCRC) 2007, 'Dementia risk reduction: The evidence', *Alzheimer's Australia Paper no. 13*
- Dementia Collaborative Research Centre – University of New South Wales 2011, *Physical co-morbidities of dementia*, Presentation by Associate Professor Susan Kurle
- Department of Ageing Disability and Home Care 2008, *At home with dementia: a manual for people with dementia and their carers*, NSW State Government, Sydney
- Department of Health, unpublished HACC MDS data 2008–09, State Government of Victoria, Melbourne
- Department of Health, unpublished HACC MDS data 2010–11, State Government of Victoria, Melbourne
- Department of Health 2010, *Strengthening assessment and care planning; a guide for HACC assessment services in Victoria*, State Government of Victoria, Melbourne
- Department of Health 2011, *Strengthening diversity planning and practice - a guide for Victorian Home and Community Care Services*, State Government of Victoria, Melbourne
- Department of Health and Ageing, 2006, *Delirium in older people*, Commonwealth of Australia, Canberra
- KPMG 2011, *Dementia services pathways – an essential guide to effective service planning*, for the Australian Government, Canberra <<http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-dementia-servicespathways.htm>>
- Rural Health Education Foundation 2007, *Dementia, mental health and neurological co-morbidities*, Program ID 616c
- TIME for dementia: The Victoria and Tasmania Dementia Training Study Centre 2007 <www.timefordementia.org>
- VicRoads 2010, *The Victorian Older Driver's Handbook*, VicRoads, Melbourne

