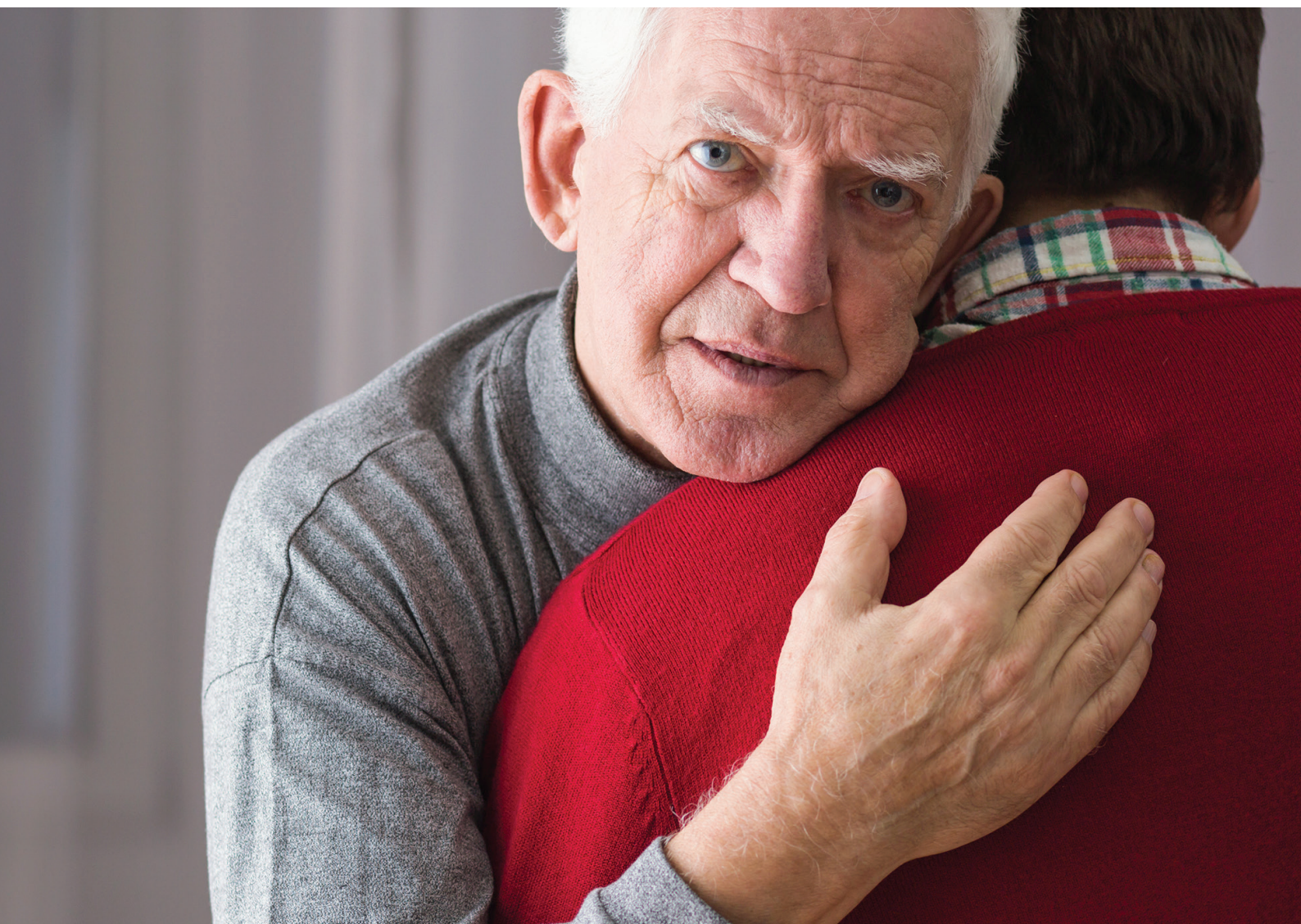


Palliative Care **AND DEMENTIA**



Dementia Australia

Paper Number 43

A report for Dementia Australia, prepared in collaboration with Palliative Care Australia.



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Introduction

Australia, like many developed countries, has an ageing population. The proportion of older people aged 65 and above has tripled over the last fifty years to 3.4 million in 2014. Furthermore, projections suggest there will be 9.6 million people aged 65 and over, and 1.9 million people aged 85 and over by 2064.¹

Current estimates indicate that there are 425,416 people with dementia in Australia. Prevalence is projected to increase to 536,164 by 2025 and to more than 1,100,890 by 2056.²

Today, most people with dementia who live in the community receive informal care (46%). Only 29% receive both formal and informal care, 16% receive formal care only and 9% receive no care.²

Around 80% of Australians who died between 2010 and 2011 aged 65 or over used aged care services in the eight years prior to their death. Three-quarters of this group used an aged care service during the 12 months before they died.³ This suggests that aged care services are an important partner in the provision of end-of-life care for older Australians, particularly for those living with dementia.



Background

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. The condition is fatal. There is a typical pattern of increasing symptoms for the person living with dementia. These symptoms can impact a person's ability to recognise people, places and events, communicate, eat, get dressed, walk and move about independently, control their bladder and bowel, and swallow food and fluids. Supports for the person living with dementia will vary over time, and can be impacted by co-occurring health conditions.

Dementia is now the leading cause of death for women in Australia, and the second leading cause overall, accounting for 8% of all deaths. This has increased from 4% in 2005. In real figures this equates to 37 Australians dying each day from dementia. However, this rate underestimates the much larger proportion of people who die from other causes and have dementia.² In Australia

and internationally dementia is now recognised as a terminal condition for which palliative and end-of-life care is appropriate.⁴

This discussion paper provides guidance for health professionals on palliative and end-of-life care for people with dementia and those who support them.



Philosophy of Care

DEMENTIA

Support for people living with dementia and their families has been influenced by a range of initiatives designed to put the person first. The most influential is the concept of person-centred care, first conceived by Tom Kitwood.⁵ In this model a person has absolute value and is worthy of respect regardless of disability.

Brooker, building on Kitwood⁶, uses the acronym **VIPS** to identify that people with dementia and their families should be **valued**; people with dementia must be treated as **individuals**; the **perspective** of the person with dementia must inform our understanding; and the person's **social environment** must be attended to.

The concept of person-centred care is embedded in aged care standards in Australia and has been widely influential in changing the culture in aged care services including for those without dementia. Most recently, the *Dignity in Care* initiative focused on reinforcing the importance of treating patients with dignity and respect across care settings.⁷

PALLIATIVE CARE

Palliative care is care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness. Palliative care is an approach that improves the quality of life of patients and their families facing the challenges associated with before terminal condition illness. Quality of life is improved through prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain, and other problems including physical, psychosocial and spiritual.⁸

Palliative care is for people of any age who have a serious illness that cannot be cured. Dying is a normal process, with palliative care offering a support system to help people to live their life as fully and as comfortably as possible until death, and to help families cope during this illness and in their bereavement.⁹

While palliative care has traditionally been an approach associated globally with people with cancer, there is support for expanding palliative care early in the course of chronic conditions, including for people with dementia. The term **'palliative approach'** refers to care provided by any healthcare professional that adapts palliative care knowledge and expertise to meet the needs of people with chronic life-limiting conditions.

A palliative approach recognises the importance of patient and family-centred care that focuses on the person and where quality of life is the primary goal.¹⁰ A palliative approach is consistent with the philosophy of person-centred care and the VIPS model.

In Australia, there are some specific terms that need clarification:

'End-of-life' is the period when the person is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. People are 'approaching the end-of-life' when they are likely to die within the next 12 months.⁹

'Specialist palliative care' is a subset of palliative care provided by clinicians who have advanced training in palliative care. The role of the specialist palliative care service includes providing direct care to patients with complex palliative care needs, and providing consultation services to support, advise and educate non-specialist clinicians who are providing palliative care.⁹

This discussion paper recognises the importance of everyone involved in the care and support of people living with dementia.

Prognosis

A question that health professionals may be asked by either a person with dementia or their family is around prognosis – *How long have I/they got?*

This question is difficult to answer. While dementia is a terminal condition, the **need** for a palliative approach, palliative care, end-of-life, or specialist palliative care will vary with each individual, mainly because of co-existing health conditions.

Diagnosis of dementia can occur some years after the onset of symptoms. Average survival times range from three to ten years and differ depending on whether they are calculated from diagnosis or the onset of symptoms. Factors such as age, sex, other co-existing conditions, type of dementia and severity at diagnosis have been found to influence reported survival.

While survival time is similar for men and women, women, due to their longer life expectancy, lose more years of their remaining life span than men. Age at diagnosis has a negative impact as does severity of dementia, with survival for those with mild dementia ranging from 2.9 to 7 years, moderate 1.5 to 3 years and severe 1.4 to 2.4 years.¹¹

Survival time for people living with younger onset dementia is longer than for people who are aged 65 and over. For younger onset dementia this varies from 1.3 years to 7.9 years after diagnosis and from 6.1 to 14.7 years after disease onset. Time from symptom onset to institutionalisation is also longer for people living with younger onset dementia; 9 years compared to 4 years for those aged 65 and over.¹²

While symptoms will vary individually, a systematic review of prognostic indicators of 6-month mortality for people with advanced dementia¹³ found that decreased appetite, insufficient food intake, malnutrition, weight loss and anorexia were common prognosticators identified across studies. Other indicators were increased risk as measured by a valid and reliable dementia severity scale, such as the Functional Assessment Staging Tool (FAST) and presence of co-morbidities.

Currently, there is no single prognostication tool for accurately predicting the need for palliative or end-of-life care. Understanding the three phases of dementia – early, moderate and advanced – taken with a comprehensive clinical assessment may provide guidance of appropriateness of palliative or end-of-life care or referral to specialist palliative care services.

Phases of dementia

EARLY DEMENTIA

Often this phase is only apparent in hindsight. At the time it may be missed, or put down to ageing or overwork. The onset of dementia is usually very gradual and it is often impossible to identify the exact time it began. The person may:

- Appear more apathetic and to have less ‘sparkle’
- Lose interest in hobbies and activities
- Be unwilling to try new things
- Show reduced capacity to adapt to change
- Show poor judgement and make poor decisions
- Be slower to grasp complex ideas and take longer with routine jobs
- Blame others for “stealing” lost items
- Become 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 challenges handling money.¹⁴

A person with early dementia may require a palliative approach, palliative care or end-of-life care if other conditions indicate this is required.

MODERATE DEMENTIA

At this stage the challenges are more pronounced and disabling. The person may:

- Be more forgetful of recent events. Memory for the distant past generally seems better, but some details may be forgotten or confused
- Be confused regarding time and place
- Become lost if away from familiar surroundings
- Forget names of family or friends, or confuse one family member with another
- Forget saucepans and kettles on the stove or may leave gas unlit
- Wander around streets, perhaps at night, sometimes becoming lost
- Behave in a disinhibited way, for example going outdoors in nightwear
- See or hear things that are not there
- Become very repetitive
- Be forgetful of hygiene or eating and drinking

- Become angry, upset or distressed through frustration.¹⁴

A person with moderate dementia may require a palliative approach, palliative care or end-of-life if other conditions indicate this is required.

ADVANCED DEMENTIA

At this third and final stage, the person is severely disabled and needs total care. The person may:

- Be unable to remember occurrences for even a few minutes, for instance forgetting that they have just had a meal
- Lose their ability to understand or use speech
- Be incontinent
- Show no recognition of friends and family
- Need help with eating, washing, bathing, toileting and dressing

- Fail to recognise everyday objects
- Be disturbed at night
- Be restless, perhaps looking for a long-dead relative
- Be aggressive, especially when feeling threatened or closed in
- Have difficulty walking, perhaps eventually becoming confined to a wheelchair
- Have uncontrolled movements
- Have permanent immobility, and in the final weeks or months.¹⁴

A palliative approach, palliative care and end-of-life care is appropriate for a person with advanced dementia. Referral to specialist palliative care services may be required.



Care settings

A person with dementia may receive care across different settings and should not be excluded from any health care services because of their diagnosis, regardless of age. Health professionals vary on their level of knowledge and expertise in providing care for people with dementia.

A range of government initiatives (*The Palliative Approach Toolkit*, *PalliAged*, *Program of Experience in the Palliative Care Approach*, *Improving Dementia End-of-life Care at Local Aged Care*) have been developed to support aged care services to provide palliative and end-of-life care and access to specialist palliative care support. More information on these programs is available from Caresearch – <https://www.caresearch.com.au>

SERVICES IN THE HOME

There are a number of government programs to support people with dementia who require assistance living at home. The *My Aged Care Contact Centre* provides information on how to be assessed to determine what program a person with dementia is eligible for. <https://www.myagedcare.gov.au/>

People with dementia may receive support from the *Commonwealth Home Support Program* or *Home Care Packages Program*. The *Commonwealth Home Support Program* provides support services at low intensity on a short-term or ongoing basis, or higher intensity services delivered on a short-term or episodic basis.

The *Home Care Packages Program* provides patients with higher intensity, ongoing services as well as an individualised budget that the patient controls. There are four levels of support ranging from low (Level 1) to very high (Level 4).

As the majority of people with dementia are living in the community it is important for community providers to understand the needs of people living with dementia and their families, and how these may change if palliative or end-of-life care is being provided at home.

People living with younger onset dementia are eligible for services under the National Disability Insurance Scheme (NDIS): <https://www.ndis.gov.au/index.html>. The *Dementia Australia Younger Onset Dementia Key Worker Program* is available to support people living with younger onset dementia and their families.¹⁵ These key workers could play an important role in advance care planning and identification of palliative care choices.

Access to specialist palliative services are not funded under the NDIS. People living with younger onset dementia may have access to, or be eligible for specialist palliative care

services, depending on referral criteria and service availability.

RESPIRE SERVICES

Respite is a form of support for all people living at home who have dementia, and their families and carers. Our position is that respite is of benefit to both the person with dementia and the carer. For the person living with dementia, respite can be an opportunity to enjoy relationships and meaningful activities separate from their family or carer, and can be within their own home or elsewhere. A range of respite care options is available including in home respite, centre based respite and residential respite. For people with dementia living at home who require palliative and end-of-life care, regular use of respite services is recommended. Further details of respite services are available from the Carer Gateway: <https://www.carergateway.gov.au/>

DEMENTIA BEHAVIOUR MANAGEMENT ADVISORY SERVICE

The Dementia Behaviour Management Advisory Service (DBMAS) is a free Australia-wide service improving quality of life for people with dementia. DBMAS is available for those living in the community or in residential aged care facilities. Changes in behaviour for a person with dementia may occur when the person requires palliative or end-of-life care and may be exacerbated by symptoms related to end-of-life needs. Referral to DBMAS may be required independent of or in addition to referral to a specialist palliative care service. For more information on DBMAS, visit <http://dbmas.org.au/>

SERVICES IN RESIDENTIAL AGED CARE

Residential aged care facilities provide accommodation and 24/7 care for people unable to remain living at home. Approximately 50% of residents have an Aged Care Funding Instrument (ACFI) classification of dementia. These residents are more likely to be assessed as requiring high care (90% compared with 70% residents that do not have dementia). A classification of high care implies greater reliance on carers to undertake activities of daily living (ADL) such as showering and dressing, and managing the behavioural and psychological symptoms of dementia.¹⁶

Palliative Care Australia has developed eight principles for palliative and end-of-life care in residential aged care.¹⁷ The principles reflect the need to:

- recognise when an aged care patient is approaching the end-of-life

Care settings



- assess, document and meet changing care requirements
- ensure equitable access to high quality end-of-life care
- ensure residential aged care services are adequately resourced to provide high quality palliative care
- ensure staff are adequately trained and supported in delivering end-of-life care
- ensure care is holistic and seamless
- ensure respect, dignity, privacy and diversity, including spiritual, cultural and gender diversity
- understand and meet the needs of patients with dementia
- support families and carers in bereavement
- acknowledge the contribution of the patient.

SERVICES IN ACUTE HOSPITALS

People with dementia are frequent users of acute services, with one in four people with dementia being admitted to hospital every year, twice the rate of people of the same age who do not have dementia.¹⁸ While

dementia may be the principal cause of admission (15%), most hospitalisations are for other conditions such as hip fracture or urinary tract infections.¹⁹ Higher mortality, readmission rates and longer lengths of stay are also reported for people with dementia.^{20, 21}

The Dementia Australia's report *Dementia Care in the Acute Hospital Setting: Issues and Strategies*²² identified that approximately 50% of people with dementia do not have their diagnosis documented during admission. It was also found that there is a lack of adequate training in caring for someone living with dementia for staff working in acute hospitals. The report proposes six strategies to improve care for people with dementia in the acute hospital:

1. Identify and manage dementia, recognising that care management should be individually tailored and appropriate discharge planning is required.
2. Involve carers in developing care plans by using tools such as *TOP5*. This program enables carers to communicate the top five care strategies for the person with dementia which can be used by staff

particularly when a family member is not present. You can find out more by visiting

http://www.cec.health.nsw.gov.au/_data/assets/pdf_file/0004/295978/TOOLKIT-FOR-COMMUNITY-SERVICES.pdf

3. Communicate effectively with simple strategies, such as, staff introducing themselves, maintaining eye contact, remaining calm, keeping sentences short, involving carers and not presenting patients with too many choices at once.
4. Provide alternative care to antipsychotic drugs, such as, psychosocial interventions.
5. Create an appropriate physical environment that reduces distractions and helps orientate patients with dementia, which can reduce disorientation and distress.
6. Reduce avoidable hospital admissions through the use of services such as hospital-in-the home, dementia units within residential aged care facilities, and access to medical and allied health services including specialist palliative care.

Other initiatives for improving care for people living with dementia admitted to acute care include:

- the *Confused Hospitalised Older Persons* (CHOPs) model of care (<https://www.aci.health.nsw.gov.au/chops>)
- The Dementia Care in Hospitals Program (<https://www.bhs.org.au/services-and-clinics/dementiacare-in-hospitals-program/>).

While not all of these strategies are specifically focused on people living with dementia requiring a palliative approach, palliative or end-of-life care, they are appropriate for all phases of dementia and other reasons for admission.

With over 50% of all deaths in Australia occurring in an acute care setting²³, there is a high likelihood that people living with dementia will be admitted to and die in an acute care setting. Increased recognition of the importance of palliative or end-of-life care for people living with dementia in this setting is required.

SPECIALIST PALLIATIVE CARE SERVICES

People with dementia being cared for at home or in a residential aged care facility may receive specialist palliative care services. However, in comparison to patients with cancer, the proportion of people with a diagnosis of dementia using specialist palliative care services is low (75.4% versus 2.4%).²⁴ While there are models of support from specialist palliative care services through dedicated teams or consultancy services, there are no current dedicated programs for specialist palliative care specific to dementia available.

Advance care planning

Advance care planning allows individuals to express their desires and choices for future health and personal care when a person cannot make or communicate their decisions. This may result in a person completing an advance care plan (ACP), an advance care directive (ACD) or appointing a substitute decision-maker (SDM).

An **advance care plan** states preferences about health and personal care and can be oral or written. It may be made on a person's behalf but should reflect the person's values, beliefs and preferences. An **advance care directive** is one type of written ACP and depending on where the person resides is recognised either by common law or authorised legislation. It must be signed by a legally defined competent adult. It can describe wishes for future care and appoint a substitute decision maker. A **substitute decision maker** is someone that is appointed or identified by law to make decisions on behalf of a person when decision making capacity is impaired. The names of this substitute decision maker vary from state to state in Australia but will be a variation of Enduring Attorney (Health), Enduring Guardian or Person Responsible.²⁵

A person with dementia should be involved in discussions and decision making as much as possible. Competence and ability to participate in discussions should be assumed, unless it is clear this is not possible. Advance care planning should be done as soon as possible after the person has been diagnosed with dementia.²⁵ Assumptions should not be made that all family members should be included in advance care planning discussions. If possible the person living with dementia should decide who is to be involved in advance care planning conversations. People living with dementia who do not have a family advocate should be provided with access to independent advocacy support to ensure that any aspect of their care is upheld.¹⁷

Advance care plans should be reviewed on a regular basis, in particular following a significant change in health condition or circumstances.²⁶ People living with dementia, and their family members if appropriate, should be supported to discuss and understand the implications of treatment options and different end-of-life care choices, including their right to request or decline life-prolonging care.¹⁷ Dementia Australia's resource, *Start2Talk* (<https://www.dementia.org.au/living-dementia/what-next-after-your-diagnosis/planning-ahead>), provides practical and comprehensive resources to assist in planning ahead. A help sheet called *Planning Ahead* is also available from the Dementia Australia website (<https://www.dementia.org.au/living-dementia/what-next-after-your-diagnosis/planning-ahead>).

People with dementia may require care in different settings. It is important that a person's ACP is transferred to all relevant settings. A range of strategies can assist with this including:

- Encouraging the family of the person with dementia to keep multiple copies of the most recent plan
- Transferring care providers ensuring that copies are given to new providers
- Discharge summaries from any service noting any ACP discussions
- Health and aged care providers having policies and procedures to ensure that a person's ACP and SDM are recorded
- Ambulance services having procedures to identify and follow a person's wishes
- Health care organisations developing systems for storing, updating and retrieving ACPs.²⁵

Practice points

- *People living with dementia can be involved in ACP discussions and decision making.*
- *People living with dementia where possible should be consulted about what family if any should be included in ACP discussions.*
- *Health professionals should raise the issue of ACP and not wait for the person living with dementia or their family to ask.*
- *Strategies for inclusion in ACP and decision-making include:*
 - *Providing clear explanations*
 - *Avoiding medical jargon*
 - *Minimising noise and distractions during discussions*
 - *Narrowing options to avoid confusion.*

Care planning

Care planning for people with dementia and their caregivers is important across all phases of dementia. For people requiring end-of-life care, the use of case conferences or family meetings provides an opportunity to improve quality of care for the person with dementia and their family.

A review by Phillips et al²⁷ found that case conferencing for people with advanced dementia can improve medication management, advance care planning, psychological support, family support and terminal care. Triggers to identify people with advanced dementia where they or their family may benefit from a facilitated case conference include:

- new or worsening symptoms
- functional or clinical decline
- return to the residential aged care facility following discharge from acute care or an emergency department presentation
- poor appetite or reduced oral intake, and
- family distress or disagreement about care.

The aims of convening a facilitated case conference are to:

- Allow the person with dementia and their family to set the agenda for discussion
- Embed a person-centred approach based on each individual's needs, within decision-making and all aspects of care
- Establish a system that identifies when a person's conditions change and allows for timely review of care goals to ensure support for current and changing needs
- Help create a culture of quality improvement that grows staff and family expertise and satisfaction in providing person-centred palliative care to persons with advanced dementia.

An outcome of the *Improving Dementia End-of-life Care at Local Aged Care* (IDEAL) study is online resources to support facilitated case conferencing for people with advanced dementia in residential aged care (<https://www.caresearch.com.au>).



Symptom management

Symptoms experienced by people with dementia will vary depending on the stage of the disease and other conditions. This section covers some of the main symptoms relevant to palliative and end-of-life care. This includes pain, dyspnoea or shortness of breath, issues around nutrition and hydration, and delirium.

Pain

Pain is a common symptom in dementia with prevalence rates reported in some studies to be around 36–50%, with the incidence and severity of pain increasing in advanced disease.²⁸ The causes of pain in the population of people with dementia can include musculoskeletal disease, central neuropathic disorders and previous fractures. Altered responses to pain stimuli, due to neuropathology, is reported in chronic pain syndromes. Evidence of increased attention to noxious and painful stimuli, highlights increased levels and duration of pain in this group.^{29, 30} The neuropathology of dementia and difficulties expressing and communicating pain requires attention to regular, systematic assessment and management.

Pain is expressed verbally, through body language, emotional responses, behaviours and physiological changes. Knowledge of the range of pain responses enables a more accurate and comprehensive assessment. Cognitive impairment and communication difficulties in people with dementia requires the utilisation of a dementia-specific pain tool. Some commonly used pain scales in dementia include:

- Assessment of Discomfort in Dementia Protocol (ADD);
- Abbey Pain Scale (APS); DOLOPLUS-2;
- Discomfort in Dementia of the Alzheimer's Type (DS-DAR);
- Pain Assessment in Advanced Dementia Scale (PAINAD);
- Face, Legs, Activity, Cry, Consolable (FLACC) Scale;
- Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC).

These scales should be used in conjunction with a comprehensive clinical assessment of the person.

Treatment of pain requires consideration of reversible causes and often a combination of non-pharmacological and pharmacological approaches. Reversible causes might include problems such as constipation, ill-fitting aids or supports, immobility, metabolic abnormalities and infections. A trial of non-pharmacological strategies should be considered where indicated and then

reviewed. These strategies can include walking, positioning and repositioning, massage, bathing alternatives, assistive devices, environmental modifications, comfortable and supportive furniture, mindfulness meditation, music, adequate sleep, practicing spiritual or faith activities, social and relational engagement.^{31, 32}

A trial of analgesics, using principles of appropriate prescribing for an older cognitively impaired population assessed as having pain, should be considered. Analgesic prescribing must be based on a medical history with commencement of lowest doses and titration of doses slowly to effect.³³

Use of prescribing guidelines is recommended, recognising that pharmacological approaches have the potential to make cognition and function worse in the context of dementia. A careful and stepwise approach to analgesic prescribing and titration is required, with further evaluation of a range of analgesic medications for safety and efficacy.³⁴ Education of healthcare staff in assessment, management and prescribing of opioids is essential.

Terminally ill patients who have never used opioids before require the most conservative approach to prescribing and dose titration, with careful and ongoing monitoring for both analgesic response and adverse outcomes such as agitation.³³ An individualised approach to pain management is required, along with consultation of specialist pain clinicians when pain is poorly responsive to management.

The experience of psychological and functional signs and symptoms in the likely context of pain is being increasingly reported in people with dementia. Chronic pain and its association with depression in people with dementia have heralded interest in research to understand and describe the clustering of these symptoms in this group.

Achterberg et al³⁰ reported that depression was 2.6 times more likely in patients with dementia reporting pain in a residential aged care facility. Impaired capacity to perform ADLs and reduced activity was also reported in patients with dementia reporting pain.³⁵ Additionally, interruptions to a person's sleep pattern as a result of unmanaged pain was found to exacerbate behavioural and psychological symptoms of dementia and reduce cognitive function.³⁶ Further research into clustering of signs and symptom and expression of pain in people with dementia is required.

Practice points

- Pain is prevalent in advanced dementia.
- Pain relief is not intended to sedate.
- People with advanced dementia are at risk of under-treatment of pain and other symptoms due to cognitive impairment and communication difficulties.
- Managing pain requires routine and ongoing assessment utilising a dementia specific pain assessment tool. Appropriate assessment is essential to care and where possible include self-reporting of pain.
- Therapeutic Guidelines for Palliative Care can assist with prescription of opioids and other analgesics.
- Understanding of the safety and efficacy of opioid use in patients with dementia requires more research.
- It is important to note that pain is reported to be clustered and expressed with other signs and symptoms in people with dementia. These signs and symptoms include depression, disrupted sleep, impaired capacity to perform ADLs and changed behaviours.

Dyspnoea

Dyspnoea (shortness of breath) prevalence in people with dementia who are close to death varies widely, with rates between 8% and 80%.³⁷ A retrospective observational study by Henriks et al³⁸ reports dyspnoea rates of 35%, with pharmacological management being the most common treatment. Dyspnoea is a subjective experience and due to the complexity of symptoms and behavioural responses it is difficult to assess with a standard tool. Self-reporting is the best approach to assessment, where possible.

There are many contributing factors that lead to dyspnoea: a range of diseases, functional decline, fatigue and frailty, side effects of treatment, respiratory infections or acute cardiac events. Respiratory infections cause the greatest symptom burden in this group.³⁹ The high rates of pneumonia in end-stage dementia and the associated respiratory distress further identify the requirement for focussed attention for management of dyspnoea in this population.³⁹ Despite evidence for prevalence there

remains limited research on approaches to assessment and management in the dementia population. The application of best evidence for dyspnoea symptom management in COPD and cancer populations can be considered. This management includes:

- Treating reversible causes where possible. This approach requires consideration of the stage of disease and weighing up the capacity for benefit. Treatment of reversible causes can potentially improve dyspnoea and will likely also improve burden and risk related to hospital admission, treatment side effects and increased monitoring and assessment.
- Non-pharmacological interventions, including respiratory exercises, circulating air to the face (fan or fresh air), positioning and breathing techniques. There is presently no strong evidence for the use of oxygen over medical air.
- Pharmacological interventions such as the use of regular oral or parenteral opioids for symptom management are supported by robust evidence. The use of benzodiazepines is not supported by adequate evidence.^{40, 41}

Practice points

- Assessment of dyspnoea is difficult without self-reporting.
- Consideration for those at risk for dyspnoea is important for assessment. Risk factors include: diagnosis of pneumonia, aspiration, advanced heart disease or COPD and terminal phase.
- The use of non-pharmacological management strategies should be considered.
- The prescribing and titration of opioids for dyspnoea requires commencement at low dose with careful titration to effect.

Symptom management

Nutrition and hydration

Maintaining nutrition and hydration are the most common clinical complications in advanced dementia and involve the most contested treatment decisions. The evidence in relation to artificial feeding reveals no increase in survival for the person with dementia. In addition, it can cause risks and harms for increased hospitalisation, and complications such as infection and bleeding from tube placement, diarrhoea, constipation and reflux, aspiration and fluid overload leading to respiratory distress.⁴²

At the end-of-life clinicians considered that artificial nutrition in patients with advanced dementia created more ethical dilemmas than other interventions, such as, artificial hydration and antibiotic treatment.⁴³ Artificial hydration can improve the experience of dry mouth and should be considered on an individual basis. Administration of fluid by subcutaneous route is recommended to manage symptoms of dehydration at a rate that does not cause symptoms of fluid overload.

Food and water can have important meaning and value for religious, cultural or personal reasons around people with dementia and their families. It is therefore important to engage in early discussion around these issues. Fears and concerns are for dehydration, starvation and suffering, and denial of life-prolonging treatment. Informing families and patients of risks and supporting collaborative, flexible approaches to the provision of sustenance can often manage contested views of artificial hydration and nutrition practices at the end-of-life.⁴² An outline of preferences for nutrition and hydration in an advance care plan is important and will enable clarity to achieve consensus in decision making in this area.

Practice points

- *Artificial feeding and hydration pose some of the most difficult ethical and practical dilemmas in advanced dementia. Artificial hydration poses the greatest concern.*
- *Artificial nutrition and hydration does not prolong life and can pose risk and harm for the person with advanced dementia.*
- *Provision of fluids subcutaneously to manage symptoms of dry mouth or dehydration can be considered on a case by case basis.*
- *Conversations to pre-empt concerns around feeding and hydration at the end-of-life should occur early and be addressed further in follow-up conversations. Inclusion of preferences for feeding and hydration in an advance care plan is important. Additionally, understanding the basis of the concerns of families is valuable to ensure sensitivity to these concerns.*

Delirium

Delirium is a serious medical condition and a common symptom for a person with dementia. Despite the seriousness of the condition, for increased morbidity and mortality, it is poorly recognised and often misdiagnosed. Delirium presents as acute changes in consciousness, attention and cognition. In particular, a person may present with inattention, disorganised thinking and altered or fluctuating levels of consciousness. Sub-types of delirium are identified by patient behaviour: persons with a delirium may present with agitation and restlessness (hyperactive delirium), withdrawal (hypoactive delirium), or a combination of these (mixed delirium).

Dementia is the most frequent predictor of delirium and yet Australian data on the incidence of delirium in people with dementia is limited. There is one Australian observational study which reported rates of delirium at admission to an acute setting of 23.5% in patients with dementia and rates of incident delirium of 14.7% for people with dementia.⁴⁴

Patients presenting to hospital with a diagnosis of dementia require routine assessment for delirium using a validated tool. In addition, preventative approaches and monitoring of hospitalised patients with dementia should occur.⁴⁵

The etiology of delirium is considerable and includes, but is not limited to, serious illness, dehydration, infection, sensory impairment, medication side effects, immobility, metabolic disturbances and surgery. Diagnosis therefore requires careful history and investigations for identification of underlying causes, as precipitating factors for delirium are often identifiable through these measures.⁴⁶

The use of brief validated tools for assessment of delirium is required. Some of the brief tools include:

- Abbreviated Mental Test (AMT-10) the Brief Confusion Assessment Method (bCAM);
- DSM-V delirium checklist;
- Assessment test for delirium and cognitive impairment (4AT);
- Nursing Delirium Screening Scale (NuDESC);
- Single Question in Delirium (SQiD) ‘Do you think [name of patient] has been more confused lately?’ is asked of family or friends.

The 4AT test performed best in a dementia delirium population.⁴⁷

The impact of a delirium diagnosis is profound, with the experience itself a precursor to distress, fear and anxiety for the person with dementia, and also for their family. Other adverse outcomes for delirium in the person with dementia include worsening cognition, increased risk for falls, increased risk for premature mortality and the increased likelihood to require higher dependency care. Early diagnosis and management of delirium therefore is important to improve outcomes for patients and their families.

Management of delirium should focus on non-pharmacological management strategies which include: family involvement, communication and reassurance, adequate hydration, improved sleep and relaxation strategies, safe and soothing environments, management of sensory deficits, review of medications, and regular mobilisation.⁴⁸ There are a number of multifaceted intervention frameworks that constitute non-pharmacological management. Those that include mobilisation, noise reduction strategies and sleep strategies have been found to have the greatest benefit for improved delirium outcomes.⁴⁸ The implementation of multifaceted interventions is best achieved through interdisciplinary collaboration.⁴⁹

Pharmacological interventions to manage delirium have demonstrated limited evidence for reducing adverse events.⁵⁰ Commencing pharmacotherapy should only be considered in the patient with a delirium when it is accompanied by severe behavioural or emotional disturbance, when their changed behaviours threaten their own safety or the safety of others, and when non-pharmacological interventions have proven ineffective. The use of psychoactive medications (e.g. benzodiazepines) should not be considered as substitute for antipsychotic medication, as the evidence for efficacy and safety of these medications in the context of dementia and delirium is also limited.⁴⁵

Practice points

- Clinicians should be alert to the elevated risk for delirium in people with dementia.
- Assessment of delirium utilising a dementia specific tool is required.
- When delirium is present diagnostic investigations are undertaken where appropriate.
- A management plan for delirium is developed in consultation with the person with dementia (wherever possible), family and healthcare team. The plan considers preventative strategies.
- Care for the person with delirium includes treatment of the underlying cause. Strategies to prevent or manage risks to safety (physical, psychological and dignity) are implemented and the environment is modified where possible to enable care that manages the risks to safety.
- Evidence suggests non-pharmacological strategies are best practice when managing behavioural changes. Pharmacological strategies should only be considered when other strategies are ineffective and the person poses risk to self and others.
- If antipsychotic medication is indicated, commence at the lowest clinically appropriate dose with careful titration according to symptoms and use only for a short period.

Personal comfort measures

Mouth care

People with moderate and advanced dementia are at significant risk of oral pathology.⁵¹ Poor oral health and periodontal disease is more prevalent among older people. Reasons for this include:

- increasing levels of inattention to oral hygiene due to cognitive decline
- more restricted access to regular oral hygiene practice inclusive of dentist review
- as symptoms increase with time, chewing and swallowing abilities decline.⁵²

Poor oral hygiene can result in changes in oral mucosa and saliva production and it is these changes that can impact chewing, swallowing, breathing, comfort and dignity.

Xerostomia or dry mouth is common in people with dementia due to poor oral hygiene and the side effects of medication. Xerostomia can cause halitosis, difficulty chewing and swallowing food, and increases the risk of secondary bacterial, fungal and/or viral infections.⁵³

Stomatitis is inflammation of the oral mucosa resulting from poor oral hygiene and dry mouth. Stomatitis often causes pain, adversely impacts quality of life for the person with dementia and can result in the development of aphthous ulcers and gum disease. Patients with dentures (full or partial) are at greatest risk for denture stomatitis.⁵⁴

Family and carer training in oral assessment and hygiene is important and requires regular scheduling when executing care plans, inclusive of prevention strategies and use of an oral health assessment tool. Professional dental treatment, use of an electric tooth brush and staff training were all found to improve aspects of oral health for people with dementia. Assistance with oral hygiene produced the most pronounced results.⁵⁵

Oral care has been found to be neglected by care staff due to their prioritising of other care needs, limited knowledge of oral hygiene practice, and difficulties accessing a resident's mouth, especially if there is a risk of injury associated with the task.⁵¹ Training of staff and family by specialist staff is beneficial and can address some of the challenges posed for care staff and family. Oral assessment by a dentist at regular intervals is also necessary for prevention and management of changes to the oral mucosa and pathologies. There are some dentists with dementia awareness in the community, and Dementia Australia is developing video resources to support dental professionals.

Practice points

- *Ensure the mouth is clean and moist for adequate oral hygiene.*
- *Use saliva substitutes to manage dry mouth.*
- *Electric tooth brushes are more effective and often more acceptable for the person with dementia and their care provider.*
- *Dentures (full or partial) need to be routinely cleaned and sterilised.*
- *A reliable and validated screening tool for use in residential care facilities with residents with dementia, for example, Oral Health Assessment Tool (OHAT): <https://www.nice.org.uk/guidance/ng48>*

Personal care and bathing

Bathing, personal hygiene and skin care are important aspects of caring for people with dementia and their families. Personal care is important for maintenance of hygiene, wellbeing and dignity. Assistance is often required with personal hygiene tasks and it is important to engage people with dementia to gain agreement about what supports are acceptable, and to promote the person's independence in these activities for as long as possible.

Cultural, religious, gender and sexuality differences need to be considered in practices around personal hygiene. Family members undertaking personal hygiene tasks for the person with dementia may be contributing to the person's distress due to the intimacy of the task. Training for carers, formal and informal, is required to address the practical issues for bathing and personal care, and distress for loss of independence and privacy experienced by the person with dementia.⁵⁶

Preferences for bathing activities and timing need to be ascertained and, where possible, negotiated with the person with dementia. Keeping instructions simple, clearly communicating the task, seeking agreement and allowing the person to maintain as much control as possible in bathing and personal care is more likely to reduce distress.⁵⁷ Modified approaches to bathing and improvements to the bathing environment have been found to reduce the incidence of distress for the person

with dementia. Correct water and room temperature, soothing washing products, distraction and use of soothing music, and avoiding water in the face and eyes are some strategies to reduce distress. Perception of safety for the person with dementia is also important with accessible grab rails, secure positioning, and feet placed on a firm and non-slip surface.^{57, 58} Correct positioning will additionally assist with discomfort. Pain medication should be considered prior to bathing for individuals assessed as having pain or exhibiting pain responses during the bathing routine.

People with advanced dementia will require full care, with increased attention to pressure care and skin care due to restricted mobility. Daily bathing may not be required when people with dementia are bed bound and assessment of discomfort during hygiene care and pressure area management at this time in particular is required. Family involvement in personal care at the end-of-life can be meaningful.

It is important to encourage a person living with dementia to select their own clothing for as long as possible and to acknowledge that this should be the goal. The need for a palliative approach, palliative or end-of-life care does not negate the need for maintaining individuality and usual style of dress.

Practice points

- *Bathing and personal care for the person with dementia is important to maintain hygiene and dignity.*
- *A person with dementia can experience distress around bathing and personal care which can trigger behavioural responses. Negotiating preferences around these tasks early in the caring relationship will maximise a person's independence, dignity and comfort.*
- *Encourage preferences to be included in an Advance Care Plan.*
- *Religious, cultural, gender and sexuality differences for the person with dementia and their carers should be considered in bathing and personal care routines.*
- *Modification of the bathing routine may be required with the use of non-water bathing options as one example.*

- *Assess and manage discomfort and pain in the bathing and personal care routine.*
- *Individuality and style of dress should always be maintained.*

Bowel care

Constipation is a common symptom in aged care populations related to normal ageing and co-morbidities. Common causes in older people include slowed colonic peristalsis related to normal ageing, irritable bowel syndrome, pelvic floor dysfunction, medications (opioids, diuretics, antipsychotics, certain antihypertensive and antidepressants), haemorrhoids, metabolic disorders, dehydration and reduced fluid intake, Parkinson's disease and stroke.⁵⁹

People with dementia are increasingly at risk of constipation due to ageing, ill-health and challenges with cognition and memory. People with dementia can often delay the urge to use the toilet due to difficulties finding the toilet, difficulties removing their clothing, disorientation, and changes in their ability to communicate the need to use the toilet due to primary progressive aphasia.

Literature reveals prevalence of faecal incontinence over constipation in dementia populations. Continence issues in dementia are overall related to the social and physical limitations for accessing and using the toilet. In advanced dementia cognitive impairment additionally limits neurological signals of a full rectum and nerve muscle responses to control defecation.⁶⁰

Constipation impacts of quality of life and dignity, and can cause symptoms such as pain, delirium, urinary retention, faecal incontinence, haemorrhoids, and anal fissures. Serious complications include faecal impaction, bowel obstruction and bowel perforation. Evidence of constipation might include halitosis, reduced appetite, lethargy and restlessness, and faecal overflow. Treating constipation with oral and rectal aperients can further impact on discomfort due to the side effects of medications which can cause abdominal cramping, rectal pain and impact a person's dignity. Proactive bowel care by preventing constipation is therefore a priority.

Personal comfort measures

The frequency and volume of bowel movements varies for each person with the range being one to three times a day, to three times per week. Bowel management must be individualised and include a comprehensive history, documentation of usual bowel pattern, physical exam and use of a valid and reliable assessment scale. Diagnosis of constipation can be made on the basis of an assessment and history or require an abdominal x-ray. Management of bowel health requires adequate fibre and fluid intake and physical activity. The person's need for privacy and ease of access to the toilet can be met by using appropriate signage and installing a high contrast toilet seat.⁶¹

Pharmacological treatment of constipation requires the use of oral and/or rectal aperients and sometimes these may be required in addition to lifestyle strategies. Oral aperients are considered appropriate as first line management when constipation is not severe. Rectal aperients are necessary to treat moderate or severe constipation, such as faecal impaction, but should not be considered for regular management of constipation.⁶² Prophylactic aperients must be considered for patients who have been prescribed opioids.

Practice points

- Use an assessment tool such as the Bristol Stool Form Scale/ Norgine© Risk Assessment Tool for Constipation or Norgine Risk assessment Tool for Constipation
- Take a careful history and review of medications known to cause constipation.
- First line management of constipation is aimed at non-pharmacological management and oral aperients.
- Rectal aperients are often required for intractable constipation and faecal impaction.

Spiritual care

According to the ABS (2011), 81% of people over 65 years identify as having a connection with a religion or some other form of spirituality.⁶³ Spirituality is described as integral, but not limited to, religion and faith. For some individuals, spirituality is the source of meaning and hope, which is intimately related to connectedness at many levels. Communication styles are core elements of spiritual care. McSherry and Smith⁶⁴ define spirituality as:

'...universal, deeply personal and individual; it goes beyond formal notions of ritual or religious practice to encompass the unique capacity of each individual. It is at the core and essence of who we are, that spark which permeates the entire fabric of the person and demands that we are all worthy of dignity and respect. It transcends intellectual capability, elevating the status of all humanity to that of the sacred'.⁶⁴

McSherry⁶⁵ identifies internal (person related) and external (environmental) barriers to providing spiritual care. From an internal perspective, identifying and providing spiritual care by health care providers is often impeded by a lack of confidence to provide such care and knowledge about how these needs can be assessed and met.⁶⁶ Also, a working environment where death is a regular occurrence places a very large emotional burden on staff. Communication with the person with dementia can be difficult once their sensory and cognitive symptoms are in the moderate to severe categories. External barriers include workplace management support, privacy, workload, education and relocation of residents.

The literature suggests that spiritual wellbeing can have a positive impact on the mental health of people living with dementia, and act as a buffer for anxiety and depression.⁶⁷ Having a religious belief specifically has been identified in creating higher levels of meaning and mental wellbeing.⁶⁸ Spiritual wellbeing has the potential to ameliorate the impact of the onset of disability and dementia, and additionally the transition to a care environment or to a palliative care phase.^{69, 70}

Other outcomes of spiritual wellbeing include improvements in social connectedness, dignity, pain management and preparation for the end-of-life.⁷¹ Recognising and maintaining spiritual care in the palliative care phase enhances quality of life through the maintenance of meaning for existence until the time of death. Palliative approaches will likely privilege openness for expression of meaning in death and dying and enable exploration of fears.

A sense of spirituality is not limited by cognitive decline. The search for meaning, belonging, hope and desire for fulfilment is still relevant for the person with dementia. The challenge when implementing a spiritual care focus for those who provide care does however remain.

Dalby et al (2012) noted a number of opportunities where spirituality could be explored in dementia: the experience of faith, the search for meaning, changes and loss in the experience of self, staying intact, and pathways to spiritual connection and expression⁷². MacKinlay⁷³ described ways to identify and engage spiritual elements for a person with dementia: uncovering meaning through reminiscence, being present, actively listening, acknowledging the spiritual dimension of the older person, and to allowing meaning to be uncovered. Multidisciplinary and interdisciplinary involvement is required to achieve these aims. A thorough knowledge of the person's life is very important and can be part of advance care planning to allow different staff to know the person with dementia.

Assessment of spirituality is complex in the literature. The National Guidelines for Spiritual Care in Aged Care state that spiritual care is considered essential to the carer role. They identify a number of strategies for assessment and practice: that care staff are trained and equipped in awareness of spirituality and in particular their own spirituality; staff use their skills in non-verbal assessment of needs for spirituality; staff communicate compassionately and facilitate a culture of connectedness and presence; staff identify and refer to specialised spiritual or religious care providers where required; and organisations prioritise recruitment and training of staff for the identification and development of spiritual care.⁷¹

Practice points

- *Understand that every person has spiritual needs irrespective of physical or cognitive symptoms.*
- *Spirituality can encompass religious faith and practice.*
- *Learn about the person and what constitutes meaning for them.*
- *Understand that spiritual care will likely improve the psychosocial and physical needs of people with dementia and their family carers.*
- *Cognitive impairment does not negate capacity for spirituality, but people with dementia require approaches to spiritual care that address their cognitive impairment.*
- *Healthcare staff require education and training in the assessment of spiritual needs and knowledge of how these needs are met for the individual.*

Supporting people who are culturally and linguistically diverse

Australia is a culturally and linguistically diverse country, with over 300 languages and 100 different religions, and beliefs from over 120 different countries.⁶³ This diversity is projected to increase in the future and will be most pronounced amongst older age groups. Training in cultural safety for healthcare staff in all healthcare settings is therefore a priority to ensure the provision of the most appropriate care for people from culturally and linguistically diverse (CALD) groups. Consideration and accommodation of cultural needs in dementia care is essential for quality care outcomes for the person with dementia; but equally important for family caregivers who face challenges while providing care and also when accessing resources and support.⁷⁴

Aged care in community and residential care settings in Australia is delivered typically according to western values of a nuclear family focus. This is in contrast with non-western cultures who can perceive family in a far more extended way.⁷⁵ Family communication styles, decision making and gender roles can be in contrast to western values around autonomy, open communication, equity in caregiving and advance care planning. Cultural and religious customs and rituals, language issues (and the need for interpreters), diet and personal care practices are also considerations for dementia care in people from CALD populations. Awareness, sensitivity and responsiveness of care sites to these cultural differences and needs are therefore important.

Cultural safety or awareness training for staff is essential to focus broadly on being sensitive and responsive to diverse needs. Awareness training aims for participants to achieve understanding of how culture informs a person's values, beliefs and assumptions. Most importantly, awareness training examines the healthcare providers own values, biases and beliefs and how these could potentially be in conflict with those of the people for whom they are caring. Awareness training aims to develop cultural sensitivity and acceptance, and encourages care staff to be actively mindful and respectful of difference(s). Cultural awareness can be enacted in areas such as person-centered assessment and care planning (including spiritual care), life-story work, using interpreters, multidisciplinary care planning and providing translated information.

Practice points

- *Australia's culturally and linguistically diverse (CALD) population is pronounced in older age groups.*
- *Cultural awareness training equips healthcare staff to be sensitive and responsive to the needs of culturally diverse groups.*

Supporting Aboriginal and Torres Strait Islander people

Culturally safe and responsive care for Aboriginal and Torres Strait Islander people with dementia and the family is essential. Prevalence of dementia in Aboriginal and Torres Strait Islander communities is at a much higher rate compared with non-Indigenous Australians and occurs at an earlier age.⁷⁶ Aboriginal and Torres Strait Islander people with dementia and their families typically have cultural differences around health beliefs, health practices and possibly a need for an interpreter.

Aboriginal and Torres Strait Islander people are impacted by the effects of colonisation and racism at individual and institutional levels which impact directly on trust and feelings of safety. Cultural safety and cultural awareness training specific to Aboriginal and Torres Strait Islander people is available in most states in Australia through Indigenous health services and professional organisations. Appropriate and culturally relevant screening tools and programs for Aboriginal and Torres Strait Islanders are also available and are important resources to assist in responsive care for this population.⁷⁷

For Aboriginal or Torres Strait Islander people with dementia it is important that a person's wishes are communicated so that when the person is unable to make decisions the family, Aboriginal health workers and health professionals provide care that is in keeping with the person's values and requests. Having these conversations is called 'advance care yarning' and while these may be difficult conversations to start, planning for dying enables peoples wishes to be respected. Completing an advance care plan helps with communicating these wishes to people who do not know the person.⁷⁸

While death is confronting, understanding the meaning of death for Aboriginal or Torres Strait Islander people helps health professionals to provide appropriate care. Due to Aboriginal and Torres Strait Islander spiritual beliefs around the life cycle, the term 'passing' is more acceptable when discussing death or dying. Providing palliative and end-of-life care for Aboriginal and Torres Strait Islander people with dementia is complex and Queensland Health has an excellent resource guide – *Sad News, Sorry Business: Guidelines for Caring for Aboriginal and Torres Strait Islander people through death and dying*. This resource specifically provides information for staff to acquire cultural capability around the final stages of life and time after passing⁷⁹ for Aboriginal and Torres Strait Islander communities.

Further resources on supporting Aboriginal or Torres Strait Islander people with dementia who require palliative care is available from the *Caresearch* Aboriginal and Torres Strait Islander Hub.

Practice points

- *Aboriginal and Torres Strait Islander people have higher rates of dementia and require care that is responsive to cultural beliefs and practices and the impact of colonisation and racism.*



Supporting lesbian, gay, bisexual, transgender and intersex people

There is recognition of the importance of advance care planning, palliative and end-of-life care for people who identify as lesbian, gay, bisexual, transgender and intersex (LGBTI) but limited attention specifically in this regard for LGBTI people living with dementia.

While these groups are not homogenous, issues that health professionals should be aware of include communication around disclosure and possible exclusion or marginalisation of partners in decision making and advance care planning. Completion of an advance care plan or advance care directive for LGBTI people with dementia may be particularly important to protect their partner who may not be recognised by health professionals as decision maker.

Health professionals providing care for people with dementia who identify as LGBTI should promote acceptance, facilitate disclosure of sexual orientation and gender identity and minimise heterosexual assumptions inherent in assessments and care planning.^{80, 81}

Practice points

- *Promote acceptance, facilitate disclosure of sexual orientation and gender identity' and minimise heterosexual assumptions inherent in assessments and care planning.*

Family carers

There are more than 200,000 Australians providing informal unpaid care for someone with dementia. A study conducted by the Australian Institute of Health and Welfare (AIHW) in 2012 identified that caregivers are primarily spouses (44%) or adult children (42%).⁸² The needs of these carer groups vary due to their work, family and social demands. The vast majority of informal carers are living in the community and are usually the sole providers of care. The level of disability of the person with dementia for whom they are caring, recorded as 'profound' in over 80% of respondents⁸² to the study.

The effects of caring for someone with dementia are beginning to be explored in the literature. Co-habiting carers, were on average, providing 40 or more hours of care a week.⁸² Not surprisingly, as the severity of dementia increases, the demands of care also increase and this places further strain on carers.

The length of the care relationship, often due to the slow decline in physical and cognitive function, impacts carers financial, health and social wellbeing. The limited social awareness of dementia and the stigma of the diagnosis place carers at further risk of social isolation and distress. Rates of depression in carers of people with dementia are reported to be 15–30%.⁸³

Research on the impact of interventions to support carers identify that structured multifaceted interventions, inclusive of individual psychosocial and educational interventions, are the most effective. Interventions which include case management, support groups and respite care demonstrate carer satisfaction, but they remain inconclusive.⁸⁴ Strategies to enhance resilience in carers have been explored as an approach to enable sustainability in informal caring, but have demonstrated limited or no improvement.⁸⁵

Caring for someone with dementia requiring palliative or end-of-life care may impact on a carer's physical and emotional wellbeing. Dementia Australia⁸⁶ has general tips for self-care which are applicable across the course of the dementia. These include:

- A consistent schedule for the person living with dementia
- Recognition that when the person with dementia is displaying difficult behaviour that this is a result of their dementia
- Being knowledgeable about dementia and encouraging other people who support the carer to be knowledgeable about the impact of living with dementia and on the carer

- Being able to discuss issues with family or friends that understand the impact of caring for someone with dementia
- The importance of the carer maintaining their health with a good diet, regular exercise and social engagements
- Having realistic goals of how much care can be provided.

Use of regular respite should be encouraged. Support services are available from Dementia Australia and Carers Australia. The Carer Gateway (<https://www.caregateway.gov.au/>) offers a national online and phone service that provides practical information and resources to support carers. The interactive service finder helps carers connect to local support services.

Research indicates problems with communication between family members and staff about dementia and dying. When families do not understand that dementia is a terminal illness, this impacts on their capacity to make informed decisions about active treatment and end-of-life care and prepare for the death of their loved one.⁸⁷ Limited preparation for loss is a risk factor for complicated bereavement.⁸⁸

Practice points

- *Encourage carers to engage in self-care activities.*
- *Plan multicomponent educational and psychosocial strategies to support home-based carers.*

Terminal care/recognising dying

Terminal care is care provided in the last days or weeks of life. Determining that a patient is in the terminal phase of their illness is difficult even for experienced palliative care and aged care clinicians. Recognising dying is beneficial when aligning care to the patient's needs and is more important than predicting how long the person has to live.

The last or terminal stage of dementia is characterised by:

- Loss of ability to communicate meaningfully
- Difficulty swallowing and very poor nutritional intake
- Incontinence of bowel and bladder
- Sleeping most of the time
- Inability to change position, sit unsupported, hold head up or smile
- Episodes of fever and infection
- High risk of pressure injury, hip fracture, pneumonia and urinary tract infection; all of which are associated with the risk of death within six months (inconsistent with days and weeks).⁸⁹

The following signs of dying are often more accurate for predicting the imminent terminal phase of dementia.

These signs include:

- Retained and noisy respirations, related to the inability to clear oral and tracheal secretions; aspiration pneumonia; or loss of gag reflex
- Abnormal breathing patterns – apnoea, Cheyne-Stokes respirations, agonal breaths
- Agitation, restlessness
- Decreased level of consciousness – the person becomes unresponsive
- Peripheral and central cyanosis and mottling of the skin.⁹⁰

The goals of care change again in the terminal phase with interventions reduced to only what is necessary to maintain comfort and dignity for the person with dementia, and achieve a supportive environment for the family and staff. Adequate support and services for people being cared for in the community is essential for a home-based death. Provision of palliative care for the individual with dementia in an acute-care setting is the most challenging, therefore enabling the person to remain in their residential facility or at home is preferred.⁹¹

Care priorities in the terminal phase are driven by the signs and symptoms in this phase. Regular mouth care and eye care is important as the mucosa can become dry and cause discomfort. Mouth care should be done hourly with soaked swabs (non-alcohol) and lubricant eyes drops used to keep the eyes moist. Regular turning

and use of a pressure relieving mattress, where possible, is important to relieve discomfort due to immobility. Family involvement in this care is important for maintaining connection and intimacy with the dying person.

Pharmacological management in the terminal phase is often required and this needs to be pre-empted in the community setting for a home death. Exacerbation of symptoms in the terminal phase is not common but pre-emptive prescribing of 'as required' medications to manage pain, breathlessness and agitation should be considered. Staff training and competency in assessment and pharmacological management of terminal symptoms is essential.

Subcutaneous drug administration is often necessary in the terminal phase due to the person with dementia not being able to swallow or swallow safely. Pain medication should be converted to an equivalent parenteral dose for patients already taking opioids, and for opioid naïve patients these doses are dependent on the patient's age, other conditions and clinical status. In older, frail patients the starting dose or dose conversion should be considered at the lower end. In the terminal phase, agitated delirium can be refractory and the judicious use of palliative sedation is often required.⁹² Specialist review is necessary for patients with unmanaged symptoms in the terminal phase. Expert consensus on prescribing in the terminal phase and dose conversions can be found in the Palliative Care Therapeutic Guidelines.⁹³

Practice points

- *Provide families with clear clear information written in plain English about the terminal nature of dementia.*

Grief and bereavement support

Family and carers of people with dementia experience grief and loss multiple times with several of these losses likely to occur before their loved one dies of the disease or co-existing health conditions. They experience sadness, grief and loss when the person with dementia starts to decline cognitively and functionally. They experience loss, sadness and/or guilt if they place their relative into care and they experience loss and grief when their relative dies from their disease. Grief from these losses is called anticipatory grief. This may occur at any stage following the person's diagnosis.⁹⁴

Grief is a normal psychological and emotional reaction occurring in response to a significant loss. Complicated grief occurs where someone experiences cognitive, behavioural and emotional symptoms or separation distress to a disabling degree, causing impairment in social or occupational functioning for more than six months after bereavement.⁹⁴ People at risk of complicated grief are those who are spousal carers and for those with depression prior to the person's death. Grief is more pronounced for family when the person with dementia is in the moderate and severe stage and the impacts may be exacerbated on admission of the person with dementia to a residential aged care facility.⁹⁴

Research is yet to adequately examine the effects of psychosocial interventions on the experience of family carers of grief, loss and bereavement.⁹⁵ Research in this area is very important considering the projections for aged populations.

The evidence of grief support in cancer populations receiving palliative care suggests that good networks of support, ongoing communication by healthcare providers, involvement in decision making and good care in the terminal phase often herald good bereavement outcomes. Most bereaved people accommodate grief through support from family, friends and community supports. A small number of bereaved people require professional counselling in bereavement. Models of bereavement support which are responsive to the impact of loss throughout the progression of dementia are therefore required.⁴

Practice points

- *Acknowledge that families suffer multiple losses when a person has dementia.*
- *Identify family and community supports that will help families in their bereavement.*
- *Identify carers who may be at risk of complicated grief.*

Conclusion

This discussion paper focused on the difficult topic of palliative and end-of-life needs amongst people with dementia including support for family and carers. Australia, like many developed countries, faces an exponential demand for high-quality person-centred dementia services including timely recognition of palliative needs or end-of-life care. Promotion of individual autonomy and respecting the person's wishes when capacity is failing or lost is paramount and can be best achieved by early planning. As such the promotion of advance care planning in the early stage of dementia, or even earlier, will help facilitate care that is in keeping with the person's wishes and values and facilitates decision making for families. Impeccable assessment and management of symptoms and co-ordination of care across settings are the cornerstones of high quality palliative and end-of-life care.



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Glossary

Acute hospital

A hospital providing healthcare services to patients for short periods of acute illness, injury or recovery.

Advance Care Planning (ACP)

The process of planning for future health and personal care where the person's values, beliefs and preferences are made known so they can guide decision making at a future time when that person cannot make or communicate their decisions.

Advance care plan

Advance care plans state preferences about health and personal care and preferred health outcomes. They may be made by, with or for the person. They may be made on the person's behalf and should be prepared from the person's perspective to guide decisions about care. They may be oral or written. A person with diminished competence may complete an advance care plan or be assisted to complete one. Advance care plans can nominate a preferred decision maker but they may not be legally recognised.

Advance care directive

An advance care directive is one way of formally recording an advance care plan. It is recognised by common law or authorised legislation and is signed by a competent adult. The directive can describe a person's wishes regarding future care or appoint a substitute decision maker.

Anticipatory grief

Grief which occurs before the person dies.

Agonal breathing

An abnormal, shallow breathing pattern which is often a precursor to cardiac arrest and death.

Aperient

A substance (medicine or food) which stimulates evacuation of the bowel.

Apnoea

A period of cessation of breathing.

Aspiration Pneumonia

Pneumonia caused by entry of secretions or foreign material into the trachea and lungs.

Artificial feeding and hydration

Artificial feeding or nutrition and artificial hydration are means for the provision of food and/or fluid to someone who is unable to achieve oral intake. Enteral tube feeding

and hydration is the delivery of nutrients and fluids through a gastrointestinal tube. Intravenous feeding and hydration is the delivery of nutrient fluid or fluids alone through a vein.

Bereavement

Refers to the event of death of a person with whom there has been an enduring relationship.

Cheyne-Stokes breathing

Cheyne-Stokes breathing is an abnormal pattern of breathing that occurs when death is imminent and is characterised by progressively deeper and sometimes faster breathing, followed by a gradual decrease that results in a temporary halt in breathing called an apnoea (loss of breathing). The pattern repeats, with each cycle usually taking 30 seconds to two minutes.

Co-morbidity

A medical condition that exists simultaneously with another.

Complicated grief

Complicated grief is recognised where someone experiences cognitive, behavioural and emotional symptoms or separation distress to a disabling degree, causing impairment in social or occupational functioning for more than six months after bereavement.

Culturally and Linguistically Diverse (CALD)

People who identify themselves as having a specific cultural or linguistic identity in relation to their place of birth, ancestry, ethnic origin, religion, preferred language, or language(s) spoken at home.

Cyanosis

Cyanosis describes the bluish discoloration of the skin and mucosal membranes and is caused by a lack of oxygen in the circulatory system.

Dyspnoea

Dyspnoea or shortness of breath is the sensation of difficulty in breathing, disordered or inadequate breathing.

Dying

The terminal phase of life, where death is imminent and likely to occur within hours or days, or occasionally weeks.

End-of-life care

Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the person's body after death. People

are approaching the end of life when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean they are expected to die within one month
- existing conditions, if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events

Family

Those who are closest to the person in knowledge, care and affection. This may include biological family, the family of acquisition (related by marriage or contract), and the family and friends of choice.

Family meetings

(See also Palliative care case conference)

A meeting that can be used for coordinating care across a multidisciplinary team where team members, the person with dementia (where possible), and family identify and discuss end-of-life care needs and goals.

A plan of care reflecting the person with dementia and their families' values with regard to end-of-life care is the outcome of the palliative care case conference.

Goals of care

The aims for the person's medical treatment, as agreed between the person, family and health team. Goals of care will change over time, particularly as the person enters the terminal phase. Medical goals may include attempted cure of a reversible condition, a trial of treatment to assess reversibility of a condition, treatment of deteriorating symptoms or the comfort of a dying person. Non-medical goals may include returning home or reaching a particular milestone, such as participating in a family event.

Grief

Grief is a normal psychological and emotional reaction occurring in response to a significant loss.

Halitosis

Odorous breath or 'bad breath'.

Interdisciplinary team

A team of providers who work together to develop and implement a plan of care.

Life-limiting illness

Used to describe people with a chronic condition that may seem life-threatening but can continue for many years or even decades.

Multidisciplinary team

A group of health care workers who are members of different disciplines (professions e.g. Psychiatrists, Social Workers, etc.), each providing specific services to the patient.

Opioid naïve

A person who has never taken an opioid medication or has not received repeated opioid dosing for a period of two weeks.

Palliative care

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.

Palliative approach

An approach linked to palliative care that is used by primary care services and practitioners to improve the quality of life for individuals with a life-limiting illness, their caregiver/s and family. The palliative approach incorporates a concern for the holistic needs of patients and caregiver/s that is reflected in assessment, in primary treatment of pain and in the provision of physical, psychological, social and spiritual care.

Person-centred care

A philosophy where the person has absolute value and is worthy of respect. It promotes the importance of people to make choices about the type of health services and care they access and how and when it is delivered.

Primary progressive aphasia

Primary progressive aphasia is the slow and progressive impairment of speech and/or language. The impairment is evidenced by limitations in the ability to comprehend or use language presenting as problems with naming items, fluency of speech, poor articulation and profound word finding difficulties.

Palliative care case conference

A meeting that can be used for coordinating care across a multidisciplinary team where team members, the person with dementia (where possible), and family identify

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and discuss end-of-life care needs and goals.

A plan of care reflecting the person with dementia and their families' values in regard to end-of-life care is the outcome of the palliative care case conference.

Quality of life

Refers to the general well-being of individuals or society.

Respite

Provision of care for a person by an organisation or another non-family member for a temporary period so the family can have a break from caring.

Specialist palliative care

Services provided by clinicians who have advanced training in palliative care. The role of the specialist palliative care services includes providing direct care to patients with complex palliative care needs, and providing consultation services to support, advise and educate non-specialist clinicians who are providing palliative care.

Stomatitis

Inflammation of the mucosa lining the mouth that may also involve the tongue, lips and gums.

Substitute decision-maker

A person who is appointed by law as the person able to make decisions on behalf of someone whose decision making capacity is impaired. Depending on the state this person may also be termed the Enduring Attorney (Health), Enduring Guardian or Person Responsible.

Terminal

Stage of an illness when death is likely within days.

Titration

The adjusting of the dosage of a medication following regular assessment of symptom response and medication requirements in the previous 24 to 72 hour period.

Xerostomia

Dry mouth resulting from absent or reduced saliva.

Notes

National Dementia Helpline
1800 100 500

dementia.org.au

