



Government of **Western Australia**
Department of **Health**



End-of-Life and Palliative Care for People with Dementia Framework

A framework for developing local palliative care
service delivery guidelines for people with dementia

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Executive summary

The *End-of-Life and Palliative Care for People with Dementia Framework* (the Framework) offers a guide to planning, developing and implementing local processes and solutions to support the end-of-life and palliative care needs of people with dementia, including support to address their advance care planning needs. It outlines principles for providing quality and appropriate end-of-life care for people with dementia, aligning with the six priorities in the [WA End-of-Life and Palliative Care Strategy 2018–2028](#)¹.

The Framework provides guidance for health services to address the needs of people with dementia within two different contexts:

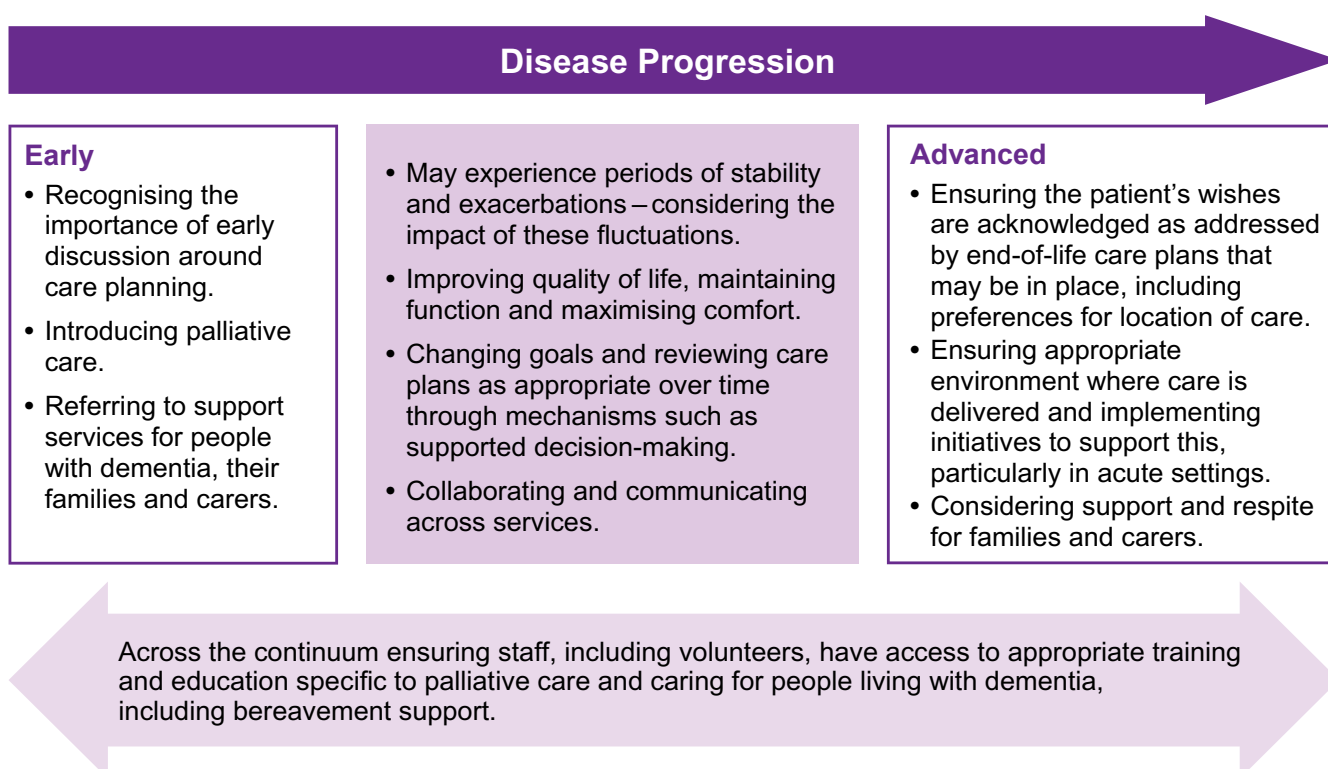
1. service considerations by priority area
2. care considerations for people with dementia during phases of palliative care – via the [Dementia Care Model](#).

In addition to supporting service delivery, other ways in which the Framework can be used include:

- advocacy at an individual and organisational level to promote a shared understanding of the importance of enabling timely access to palliative care for people living with dementia
- promotion of key messages
- informing education and training for consumers and professionals
- supporting policy, legislation and program and service design and provision
- directing, prioritising and driving relevant research
- assisting services to work collaboratively by sharing knowledge and resources and building systemic relationships.

[Appendix 1](#) of the Framework provides a list of further resources that may be helpful for people with Dementia, their carers and to guide service improvement and delivery.

Key end-of-life and palliative care considerations in relation to people living with dementia



Service considerations by WA End-of-Life and Palliative Care Strategy 2018–2028 priority area

Priority One: Care is accessible to everyone, everywhere

I have access to good quality end-of-life and palliative care, regardless of who I am, or how I live

People with dementia and their family and carers should be involved in early discussions about advance care planning to create familiarity and build trust and promote choice and control over their care. Health services should be equipped to meet the needs of people with dementia, providing appropriate and effective end-of-life care in the person's location of choice. Facilitating access to specialist advice and support may help to enhance palliative care capacity in primary care, aged care and community services.

Priority Two: Care is person-centred

I am seen as an individual, and I have the opportunity to be involved in honest discussions with those important to me about my care. My values, culture and spirituality are respected and taken into account.

Services should adopt a collaborative approach to developing care and end-of-life care plans, involving health care professionals and the person with dementia and their family and carer, with an emphasis on co-designing care where possible. People with dementia should be supported to be as involved as possible in advance care planning discussions, including addressing legal matters such as Enduring Power of Guardianship. Treatment plans should be regularly reviewed in collaboration with relevant care providers to ensure the care being provided aligns with the person's values and preferences.

Priority Three: Care is coordinated

I receive the right care at the right time, in the right place, from the right people. My care occurs within a coordinated/collaborative approach, enabling care to be delivered seamlessly.

Services should consider the impact that changes in care setting can have on people with dementia, and consider integrating formal care pathways and creating linkages to local health services to promote their use and prevent avoidable hospital admissions. Appropriate policies and procedures to support documentation of a person's advance care planning discussions and end-of-life plans, comprehensive discharge summaries and strengthened referral pathways will improve communication and care coordination between care settings.

Priority Four: Families and carers are supported

Those close to me and/or caring for me are supported and involved in my care. The contributions made by my family and carer are recognised and valued by those providing my care, including their need to be supported during and after my death.

Efforts should be made to raise awareness that both the person who has dementia and the carer experience progressive losses over an extended period as death approaches. Families and carers should be informed early of the option of establishing enduring power of guardianship and should be involved in care and end-of-life care discussions with health professionals where possible. The development of care pathways may increase access for families and carers to practical advice and information resources, psychosocial, respite and bereavement support.

Priority Five: All staff are prepared to care

Wherever/whenever I am cared for, all relevant staff have expertise, empathy and compassion. All staff provide confident, sensitive and skilful care before, during and after my death

Staff should have access to learning resources and training for dementia and palliative care topics. Staff should be encouraged to use appropriate, inclusive and non-stigmatising language and consistent terminology around dementia, end-of-life care and palliative care. Developing education standards to clarify the level of training and education required for different professions and roles involved in caring for people with dementia and their families/carers will help ensure staff are prepared to care.

Priority Six: The community is aware and able to care

I feel supported and empowered to make decisions. My individual preferences are expressed through Advance Care Planning (ACP) and reflected in my end-of-life and palliative care. My community is aware and able to support me and those close to me.

Services should aim to promote an understanding of palliative care and increase awareness that dementia is a terminal condition for which palliative care is appropriate. Raising awareness of palliative care and palliative care services helps build capacity within communities to better support people with dementia requiring end-of-life and palliative care. Service providers and community groups can also collaborate to develop models such as Compassionate Communities and Dementia Friendly Communities.

Introduction

All Western Australians should have access to high-quality, person-centred end-of-life and palliative care services that aims to improve quality of life of people, their families and carers facing life-limiting conditions through a holistic approach to care and management. An increased demand for services, combined with an ageing population with complex needs, means that the Western Australian (WA) health system needs to continue to strengthen the way end-of-life and palliative care services are delivered.

WA Health is committed to improving end-of-life and palliative care services across the State. The [WA End-of-Life and Palliative Care Strategy 2018–2028](#)¹ (the Strategy) and the corresponding [Implementation Plan One 2020–2022](#)² (IP1), outlines the values and priorities for WA to improve statewide end-of-life and palliative care services and a plan for how to achieve this.

Further, the 2018 Joint Select Committee (JSC) Report [My Life, My Choice](#)³ outlines 12 recommendations specifically addressing improvements to access and the delivery of end-of-life and palliative care services across the State.

These documents highlight the importance of improving access to appropriate and respectful care for all people with life limiting illness, their families and carers, including people with dementia. Well supported and informed end-of-life planning is of particular importance to those with dementia, to prepare for a time when they may no longer be able to express their wishes. Access to education, training and resources for health, community and aged care providers is essential as an enabler for the provision of responsive, person-centered palliative care for people with dementia and their families and carers.

Many people are unaware that dementia is a terminal condition. Dementia, including Alzheimer's disease, remains the second leading cause of death of Australians, accounting for over 15,000 deaths in 2019.⁴ It has remained the leading cause of death in women since 2016, with overall deaths due to dementia increasing by 66.8 per cent from 2010 to 2019.⁴ In 2021, there was an estimated 34,400 people living with dementia in WA.⁵ Further to this, research to date indicates that Aboriginal and Torres Strait Islander people experience dementia at a rate of 3 to 5 times higher than the general Australian population⁶. Going forward, dementia will continue to present increasing challenges to the community as Australians continue to age and survival rates for other diseases continue to improve.

Palliative care for people with dementia requires specific considerations because dementia is different from other life-limiting illnesses. The potential for a long and unpredictable course of the disease, the requirement for supported decision-making and the loss of decision-making capacity presents significant barriers to accessing palliative care that appropriately responds to the person's needs and respects their wishes.⁶ Sensory and cognitive impairment leading to difficulties in communication and lack of community understanding of the disease⁶ can create further barriers. Access to appropriate care can be further complicated for people from culturally and linguistically diverse and other minority communities, and those with significant behavioural and psychological symptoms of dementia. The model of delivery of palliative care services for people with dementia may therefore differ significantly from that delivered to people with other illnesses more commonly associated with palliative care, such as cancer.

About the Framework

Purpose

The *End-of-Life and Palliative Care for People with Dementia Framework* (the Framework) offers health service providers and administrators a guide to planning, developing and implementing local processes and solutions to address the needs of people with dementia, to help ensure they have timely access to appropriate end-of-life and palliative care services, including support to address their advance care planning needs.

The Framework aims to increase awareness and understanding of the specific needs associated with caring for people with dementia and other forms of cognitive decline so that health services are better equipped to address their unique end-of-life care needs. The ultimate goal is to improve access to appropriate end-of-life care for people living with dementia.

The Framework is applicable to all services in WA that support and care for people with dementia or other forms of cognitive decline, their families and carers. Such services may include:

- public, private, community, aged care services and non-government organisations, including primary healthcare teams
- educational, training and research institutions.

It outlines the principles for providing quality and appropriate end-of-life care for people with dementia, aligning with the six priorities outlined in the [WA End-of-Life and Palliative Care Strategy 2018–2028](#)¹ (Figure 1), and the recommended actions under IP1². It also provides a care model to guide those involved in caring for people with dementia to consider important factors throughout the disease trajectory from early stages of dementia through to advanced stages.

The Framework provides examples of best practice and acts as a tool to support the implementation the [WA End-of-Life and Palliative Care Strategy 2018–2028](#)¹, to assist with continued improvement in the delivery of palliative care for people with dementia.

Figure 1: Priorities of the WA End-of-Life and Palliative Care Strategy 2018–2028¹



Using the Framework

It is intended that the Framework provides a focus on palliative care for people with dementia, specifically highlighting the importance of palliative care-related service considerations at the early stage and in the more advanced stages of the disease. By addressing dementia as a terminal condition, it highlights the importance of ensuring adequate end-of-life care plans are in place to empower the consumer and ensure their wishes are addressed when they no longer have the cognitive capacity to make decisions themselves.

It should be noted that this is not a clinical guideline and should be used as a complementary resource specific to the end-of-life and palliative care needs of people with dementia.

A list of additional resources is outlined in [Appendix 1](#) which provides more in-depth information and guidance on certain topics related to caring for people with dementia and information for families and carers. These have been grouped into main themes and service settings for ease of navigation.

WA Health will support the implementation of the Framework by communicating it across the WA health system and to all relevant external stakeholders. It will be available via the Department of Health website.

Potential uses for the Framework include:

- advocacy at an individual and organisational level to promote a shared understanding of the importance of enabling timely access to palliative care for people living with dementia
- promotion of key messages
- informing education and training for consumers and professionals
- supporting policy, legislation and program and service design and provision
- directing, prioritising and driving relevant research
- assisting services to work collaboratively by sharing knowledge and resources and building systemic relationships.

Users of the Framework can build in measures of success into their individual implementation plans. WA Health will monitor and evaluate the use of the Framework in line with the evaluation and monitoring of the [WA End-of-Life and Palliative Care Strategy 2018–2028](#)¹.

Language and key concepts

End-of-life and palliative care terms

It is important to differentiate between the terms palliative care and end-of-life care, in the WA context. The following definitions are utilised in this document and are based on the definitions provided in the *WA End-of-Life and Palliative Care Strategy 2018–2028*¹; terms used by the Australian Institute of Health and Wellbeing and the Australian Commonwealth Government.

End-of-life

End-of-life is the timeframe during which a person lives with, and is impaired by, a life-limiting/fatal condition, even if the prognosis is ambiguous or unknown. Those approaching end of life will be considered likely to die during the next 12 months.

End-of-life care

End-of-life care is care needed for people who are likely to die in the next 12 months due to progressive, advanced or incurable illness, frailty or old age. During this period, people may experience rapid changes and fluctuations in their condition and require support from a range of people, including health services, as well as family and carers.

Palliative care

Palliative care is an approach that improves the quality of life of individuals, their families and carers facing problems associated with life-threatening illnesses/conditions, through the prevention and relief of suffering. Palliative care recognises the person and the importance and uniqueness of their family and carer. It serves to maximise the quality of life and considers physical, social, financial, emotional, and spiritual distress. Such distress not only influences the experience of having a life-limiting illness but also influences treatment outcomes.

Specialist palliative care

Specialist palliative care is undertaken by a professional palliative care team or service with recognised qualifications or accredited training in palliative care. The role of the specialist palliative care services includes providing consultation services to support, advise, educate and mentor specialist and non-specialist teams to provide end-of-life and palliative care and/or to provide direct care to people with complex palliative care needs.

Terminal care

Terminal care refers to the care of a person in the last days or weeks before they die (i.e. the final part of palliative care).

Dementia

Dementia is the umbrella term for a number of neurological conditions, of which the major symptom includes a global decline in brain function. It affects thinking, behavior and the ability to perform everyday tasks. There are many different forms of dementia including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease.

Dementia is one of the major causes of disability and dependency, particularly amongst older people worldwide. It can be overwhelming, not only for the people who have dementia, but also for their carers and families. There is often a lack of awareness and understanding of dementia, resulting in stigmatisation and barriers to diagnosis and care. The impact of dementia on carers, family and wider society can be physical, psychological, social and economic.⁴

Palliative care for people with dementia

Palliative care has a well-developed conceptual framework and evidence-base when it comes to cancer and some chronic diseases but the notion of palliative care for people with dementia has traditionally received less attention.⁷ Consequently, there may be inconsistencies in the way these services are delivered.

Palliative care is considered an appropriate type of care for people with dementia at any stage of the disease.⁸ It 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.⁹ It recognises the importance of patient and family-centered care that focuses on the person and where quality of life is the primary goal.⁹

Providing palliative care means focusing on:

- the overall quality of life
- reducing suffering by early recognition and treatment of pain and other distressing symptoms
- affirming life and treating dying as a normal process
- caring for spiritual, psychological and cultural needs as well as physical needs
- offering a support system to help the family cope during their relative's illness and in their own bereavement
- using a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.

While dementia is a terminal condition, the need for palliative care services and the level of services required vary with each individual and will be dependent on factors such as the severity of the disease and co-existing health conditions. Because the trajectory of disease for people with dementia is complex, unpredictable and dependent on individual experience, their palliative care needs may change according to individual preferences and the progression and nature of symptoms. This will likely involve care in different settings and may not always be provided through specialist palliative care services.

Evidence suggests that overall, families feel less burdened by care decisions and people with dementia have less burdensome interventions when families are included and informed during the course of the disease.⁸ The use of supported decision-making aims to provide help and assistance for people with cognitive decline, in making decisions about their lives and enables the person to be involved in decisions that affect their care. This is extremely important as good communication and information sharing between health professionals and carers and families may help them make appropriate care decisions that prioritise the interests, comfort and dignity of their relatives, and help families deal with grief and loss.⁸

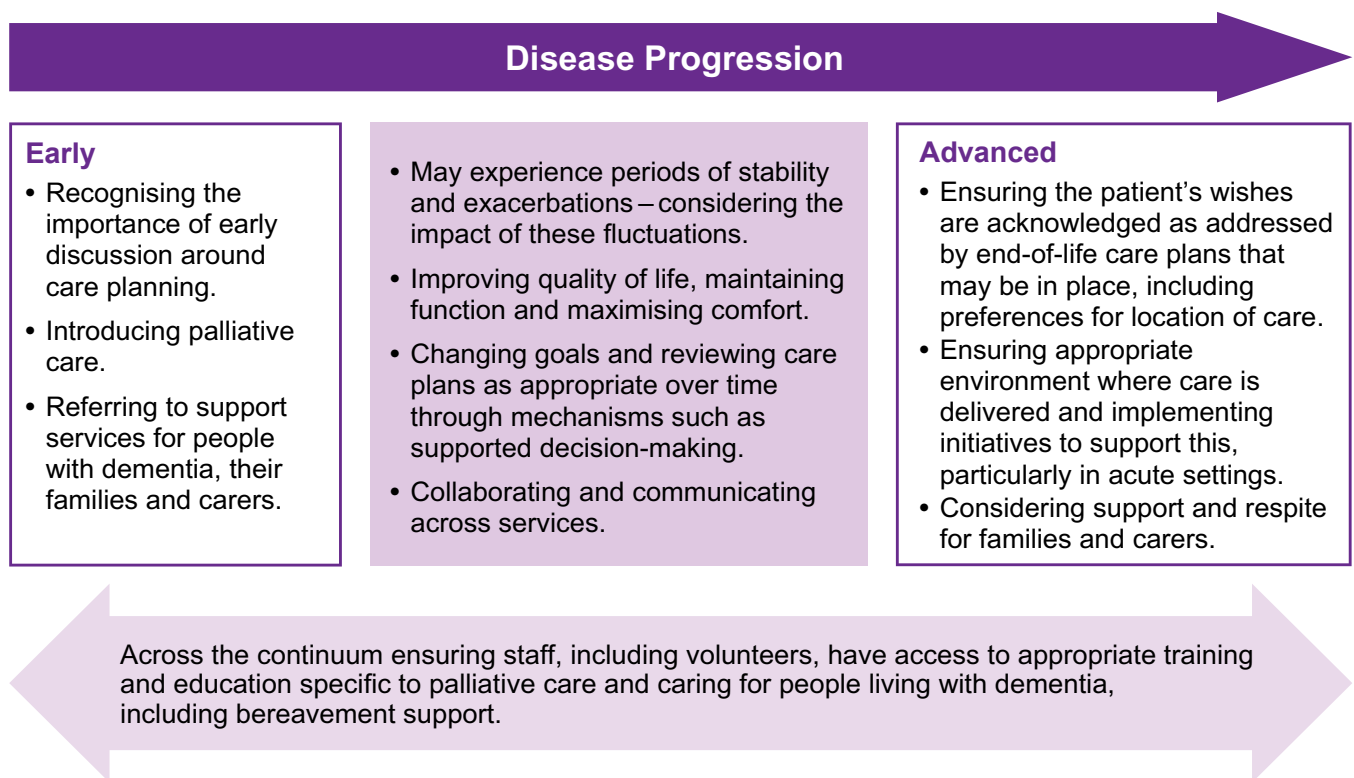
The Framework

The Framework provides guidance for health services to address the needs of people with dementia within two different contexts:

- service considerations by priority areas
- care considerations for people with dementia during phases of palliative care – via the Dementia Care Model.

Figure 2 provides a summary of the key service considerations across the stages of dementia as outlined by the Framework.

Figure 2. Key end-of-life and palliative care service considerations in relation to people living with dementia



Service considerations by WA End-of-Life and Palliative Care Strategy 2018–2028 priority area



Priority One: Care is accessible to everyone, everywhere

I have access to good quality end-of-life and palliative care, regardless of who I am, or how I live my life.

In Australia and internationally, dementia is now recognised as a terminal condition for which palliative and end-of-life care is appropriate.⁹ As dementia is less understood than other terminal conditions, people with dementia often struggle to access appropriate palliative care that responds to their needs and respects their wishes. Aboriginal and Torres Strait Islander people, those from diverse backgrounds and those with behavioural symptoms of dementia can experience even greater difficulties in accessing palliative care services.¹⁰ Support for Aboriginal people and other priority populations may include increasing awareness of existing resources such as the Palliative Care WA (PCWA) Information and Support Line, [Palliative Care Australia's Aboriginal and Torres Strait Islander resources](#)²⁸ and [resources for people from culturally and linguistically diverse backgrounds](#)²⁹. The palliative care needs of those with younger onset dementia are also an important consideration.

While dementia is a terminal condition, the palliative care needs of individuals will vary because of differing co-existing health conditions and variations in the disease trajectory.⁶ Currently, there is no single prognostication tool for accurately predicting the need for palliative or end-of-life care for those living with dementia. However tools such as the [Supportive and Palliative Care Indicators Tool \(SPICT™\)](#)¹¹ or the [Gold Standards Framework \(GSF\) Prognostic indicator guidance](#)¹² may be helpful in assessing prognosis. Other valuable sources of information in this area include the assessment guidance within the [New Zealand Framework for Dementia Care](#)¹³ and the [ELDAC resource on common clinical tools for end-of-life care](#)¹⁴.

As the needs of people with dementia often do not fit within traditional models of palliative care, the palliative care requirements of people with dementia will differ from someone with another chronic condition. Early assessment and diagnosis is critical to enable timely access to support services, particularly where needs are or may become complex. Elements of palliative care should be available in different settings as appropriate to the needs of the consumer including at home, in residential aged care facilities, through community service organisations and in hospital services. Referral to outreach palliative care services should be considered, especially in regional, rural, and remote areas.

In their guidance document for health professionals, Dementia Australia, in collaboration with Palliative Care Australia outline the three phases of dementia and the symptoms you may observe at each stage. Understanding these 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 and referral to specialist palliative care services.⁹ Validated assessment tools may be useful for initial clinical assessment and monitoring, for example for the assessment of pain ([Abbey pain scale](#)¹⁵), nutrition ([Mini Nutritional Assessment](#)¹⁶), cognition ([Montreal Cognitive Assessment](#)¹⁷), and depression ([Cornell Scale for Depression in dementia](#)¹⁸).

Service considerations for Priority One

- Ensuring health services in acute and community settings are equipped to meet the needs of people with dementia, providing appropriate and effective end-of-life care in the person's location of choice. This may require:
 - raising awareness of the need for palliative care in dementia, and in particular the need for early assessment, planning and regular reassessment
 - teaching communication and assessment skills
 - fostering an understanding of the criteria for referral to specialist palliative care and other support services
 - developing systems and behaviours that ensure a multidisciplinary, collaborative approach to assessment and intervention to optimise function and wellbeing.
- Starting conversations about advance care planning early to identify an individual's values and goals to help guide their care plan, including their end-of life care and choices. Health and care services should build systems that acknowledge the importance of supported decision-making into relevant policies and procedures. Completed advance care planning documents should be shared with relevant care providers, and where possible uploaded to the person's electronic My Health Record.
- Engaging and communicating with care providers in different service settings throughout the disease trajectory to increase awareness of the importance of completing and checking advance care plans, and to encourage timely transfer of information between care providers to ensure continuity and appropriateness of care.
- Providing education and training tailored to the needs of each profession in the workforce on the unique palliative care needs of people with dementia.
- Ensuring access to resources to support newly diagnosed patients and their families.
- Facilitating access to specialist advice and support to help enhance palliative care capacity in primary care, aged care and community services.
- Prioritising ongoing research in this space to enhance the evidence base for interventions and models of care for the provision of palliative care in dementia.
- Further information and resources can be found in [Appendix 1](#).



Priority Two: Care is person-centred

I am seen as an individual, and I have the opportunity to be involved in honest discussions with those important to me about my care. My values, culture and spirituality are respected and taken into account when care is given.

People with dementia have the right to die peacefully when the time comes, with dignity and in a way that respects their wishes. Providing a person-centred, holistic approach which involves their families and carers is an integral part of palliative care service delivery in order to support their right to live and die in their preferred setting. Palliative care, particularly for people with dementia, should also affirm life, supporting their quality of life as the lifespan of the condition varies significantly between people. Care planning is important across all phases of dementia and a person with dementia should be involved in discussions and supported in decision making as much as possible.⁹ Providing person-centred care helps to identify what matters most to the person living with dementia, for instance their routines and personal preferences, which is particularly important if their ability to communicate fails.

Health service providers across all settings are encouraged to build care pathways that ensure healthcare professionals initiate timely discussions (and ideally close to the point of diagnosis), about advance care planning (ACP) with a person with dementia and their family.⁶ This is key to providing care that aligns with the values, preferences and wishes of people with dementia at the end-of-life. It is important that people with dementia are encouraged and supported to exercise choice and control over the treatment they wish to receive. Discussions therefore need to be initiated and recorded at the right time, with involvement from family and/or carers, where appropriate.⁶ Care plans should also be regularly reviewed by the person and their family or carers to take account of any changes in the needs and wishes of the person as their condition progresses.

People living with dementia, and their family members and carers, 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. Case conferences, where available, provides an opportunity to improve palliative care outcomes for older people with dementia by engaging family and all relevant internal and external health providers in prospective care planning.¹⁹

Aboriginal and Torres Strait Islander people have higher rates of dementia and require care that is responsive to cultural beliefs and practices and takes into consideration the impact of colonisation and racism.⁵ Development of care pathways that consider the individual's social, emotional and cultural wellbeing in the provision of end-of-life and palliative care is just as important as their physical needs and symptom management. Other population groups that may have specific needs include the LGBTI community, Veterans, people from culturally and linguistically diverse and refugees. A focus on person/family/carer centred assessment, providing opportunities to discuss and understand the values, needs, concerns and preferences of the person and those important to them, should enable delivery of appropriate, individualised care for all.

Service considerations for Priority Two

- Providing access and support in decision making for persons who require it for them to make, communicate and participate in decisions that affect their lives.²⁰ Supported decision-making is a practice that enables people to make decisions about their own life and enables the person to be involved in decisions that affect their care.
- Adopting a collaborative approach to developing care and end-of-life care plans involving health care professionals and the person with dementia and their family and carer. This should be a dynamic process that explores all manners of preferences including location of care, providers of care and preferred decision-making supports.
- Co-designing care with health teams to include culturally respectful and comprehensive care that considers the individual's social, emotional and cultural wellbeing as well as their physical needs and symptom management.
- When discussing ACP and end-of-life decision-making, providing clear explanations, avoiding medical jargon, minimising noise and distractions, and narrowing choices to avoid confusion. Health professionals should raise the issue of ACP rather than waiting for the person living with dementia or their family to ask.
- Encouraging the person and their family to discuss legal matters including ACP, Advance Health Directives, Enduring Power of Guardianship and Enduring Power of Attorney. They should also be encouraged to share these details with family, close friends and health professionals and have these details readily accessible in a safe place (e.g. My Health Record).
- Regularly reviewing the treatment plan in collaboration with relevant care providers to ensure the care being provided aligns with values and preferences outlined in advance care plans or other relevant documents, in the setting of choice.
- Providing education and training to workforce on a person-centred approach to the unique palliative care needs of people with dementia and access to resources to support newly diagnosed patients and their families.
- Further information and resources including those on ACP, and supported decision-making can be found at [Appendix 1](#).



Priority Three: Care is coordinated

I receive the right care at the right time, in the right place, from the right people. My care occurs within a coordinated/collaborative approach, enabling care to be delivered seamlessly.

People with dementia may also have other illnesses and disabilities and will therefore require care in different settings at some stages of their care pathway. As with dementia, multi-morbidity correlates with age, representing the most common ‘disease pattern’ found among older people, and is characterised by complex interactions of coexisting diseases for which a medical approach focused on a single disease is not enough.²¹ Multiple conditions not only have a cumulative effect but also require interaction from different service providers and settings.

A flexible model of care is required which enables health and care professionals to provide the right care, at the right time, and within the right setting to accommodate the changing needs of people living with dementia, and their carers, as the disease progresses.⁶ During the different stages of their treatment, individuals may require care in different settings. It is important for these transitions to be adequately managed and that there are mechanisms in place to ensure a person’s end-of-life care plans are transferred and communicated throughout. It should also be noted that the type of care available to people with dementia may vary between settings.

Whether the person with dementia is being cared for at home or in a residential aged care facility, avoiding or minimising admission to hospital is strongly advised where possible. Hospitals are generally not a suitable setting for people with dementia and can be very frightening as they are usually loud, noisy, busy places, with unfamiliar staff and routines. If the person does require hospitalisation, minimising the amount of movement between wards is recommended as this can cause increased levels of distress and harm for people with dementia.²² Where appropriate, it is generally better for them to remain at their place of residence, especially at the very end stage of life, if that is their preference.⁸

Important elements to address Priority Three: Care is coordinated include a workforce that is appropriately trained and skilled, an adequate supply and distribution of specialist and community nursing services and appropriate funding to support palliative care at all levels in metropolitan and in rural and regional areas.

Service considerations for Priority Three

- Encouraging healthcare providers to consider integrating formal care pathways for those with advanced life limiting illnesses, including advanced dementia, and creating linkages to local health services to promote their use and prevent avoidable hospital admissions.
- Managing illness/symptoms of multiple chronic conditions to avoid unnecessary hospitalisations and transfer between health service settings.
- Strengthening referral pathways and handover between end-of-life and specialist palliative care teams and aged care facilities, primary care and community services. Consider introduction and monitoring of appropriate key performance indicators.
- Encouraging health and aged care providers to have policies and procedures to ensure that a person's end-of-life plans are recorded and transferred. This includes systems for storing, updating and retrieving advance care plans. Consider introduction and monitoring of appropriate key performance indicators.
- Considering the impact that changes in care settings have on people with dementia and the optimal care location. While these individuals may require care in different settings the following strategies can assist in ensuring their end-of-life plans are communicated throughout:
 - Transferring care providers ensuring that copies are given to new providers during handovers
 - Encouraging the family of the person with dementia to keep multiple copies of the most recent plan. e.g. [Focus on the Person Form](#)³⁰
 - Ensuring discharge summaries from any service providers note any ACP discussions, and changes in cognition and function.
- Ensuring ambulance services having procedures to identify and follow a person's wishes.
- Providing adequate resources to support health, community and aged care providers delivering end-of-life and palliative care. Monitoring to ensure resources are sufficient and fit for purpose and identifying gaps and priorities for improvement.
- Encouraging services to focus on being person/family centred and collaborative, with a focus on timely and appropriate transfer of information as needed, rather than organisation/geographical boundary centred.
- Considering identification of a keyworker with responsibility for coordinating care, who will ensure regular review of care needs and facilitate multidisciplinary decision-making
- Prioritising ongoing research into optimal care for dementia, including palliative care in all settings.
- Further information and resources can be found at [Appendix 1](#).



Priority Four: Families and carers are supported

Those close to me and/or caring for me are supported and involved in my care. The contributions made by my family and carer are recognised and valued by those providing my care, including their need to be supported during and after my death.

The role of the primary care giver, which may be families or other carers, is key in promoting good lives and good endings for people with dementia.²³ It is generally acknowledged that families feel less burdened by care decisions and people with dementia have less burdensome interventions when families understand the course of advanced dementia.⁸ Therefore, people living with dementia, their families and carers need to be supported throughout their palliative care journey. Carers are likely to have knowledge and information that is critical to developing effective and relevant care and support plans. Accordingly, carers should be considered essential partners in the planning and provision of care in all settings.²⁴ This is a good reason to make sure that all those caring for the person with dementia – especially families – understand that dementia is a terminal condition and that best care will focus on palliative care. By engaging in early and continuous discussion with the person living with dementia and their families and carers, they will feel supported and informed to make appropriate care decisions that prioritise the interests, comforts and dignity of their relatives, and help families deal with grief and loss.

In the development of a framework for service delivery and planning, it is important to formally recognise the contributions of primary carers, and to ensure that they do not feel obliged to contribute in a way that places an overwhelming burden upon them.²¹ Primary carers should have access to responsive support that meets their needs and helps them manage the pressures associated with the physical, mental and emotional demands of their caring role.²⁴ This includes encouragement to engage in self-care activities and access to respite care if needed. It is recognised that access to carer support is varied, and an important priority for development, in particular for carers with their own health needs and carers of people with advanced dementia, where increasing social isolation can be a significant concern.

Carer burnout can often be a trigger for hospitalisation. The provision of information and support services to carers may help to make the caring experience less stressful, and more rewarding, reducing the need for emergency care needs.

It is also important to be aware that both the person who has dementia and their carer, will experience progressive losses over an extended period of time and as death approaches. Bereavement for families and carers of people with dementia can often be very complex. Providing timely links to bereavement and grief support is an important component of palliative care.

Service considerations for Priority Four

- Raising awareness that both the person who has dementia and the carer experience progressive losses over an extended period as death approaches.
- Maximising opportunities for people with dementia and their families and carers to plan for the future by raising their awareness of options relating to enduring guardianship, enduring powers of attorney and wills.
- Involving families and carers in end-of-life care discussions with the health professionals to ensure these are documented and communicated to relevant parties.
- Developing care pathways to facilitate access to psychosocial, respite and bereavement support for carers, including support from volunteers. This is extremely important to prevent avoidable hospitalisations and carer burn out. Consider access to appropriate in-home respite (including overnight) for those for whom it may be too overwhelming to be moved to access respite elsewhere.
- Improving access to practical advice, support and resources for families and carers of people living with dementia including encouragement to engage in self-care activities.
- Planning multicomponent educational and psychosocial strategies to support home-based carers.
- Improving awareness of health, community and aged care providers regarding family access to bereavement support.
- Understanding and respecting spiritual and cultural needs following death and supporting families and carers in undertaking death and grief related practices and rituals.
- Further information and resources can be found at [Appendix 1](#).



Priority Five: All staff are prepared to care

Wherever and whenever I am cared for, all relevant staff involved in my care have expertise, empathy and compassion. All staff provide confident, sensitive and skilful care before, during and after my death.

A person with dementia is likely to receive care across different settings and should not be excluded from any health care services because of their diagnosis.⁹ Across these settings, health professionals have different levels of knowledge and experience in providing care for people with dementia. In order to care and support families and carers, service providers should have a fundamental understanding of the specific implications and requirements for caring for a person living with dementia. Through improved health, community and aged care provider understanding of dementia and end-of-life care, appropriate referrals to palliative care (including specialist palliative care) can be made, which can have significant benefits to the patient. Understanding the benefits of palliative care is an essential component for those caring for people with dementia.

Palliative care is not just for patients at the final stages of death, particularly for people with dementia. Rather it is a supportive approach to care that aims to improve the quality of life of individuals, families and carers facing problems associated with life-threatening conditions.⁸ Elements of palliative care can be adapted and delivered through multiple settings by different health service providers, at all points of the disease trajectory. It is important to know that specialist palliative care may be needed, but there are different methods of service delivery available including community services, inpatient and consultative specialist palliative care. Just as dementia is a continuum, staff training is also a continuum in order to develop the required skills and expertise to care for people living with dementia.

There is much benefit to be realised by increasing health professionals' access to additional training in palliative care, end-of-life care and advance care planning (ACP), including legal options at end-of-life. Other important recommendations for health professionals, are increased education and training in caring for people living with dementia. Symptoms experienced by people with dementia will vary depending on the stage of the disease, other co-morbidities or conditions and other factors. Some of the main symptoms relative to end-of-life and palliative care include pain, dyspnoea or shortness of breath, issues around nutrition and hydration, and delirium.⁹ Education and training should focus on strategies to engage and support people living with dementia, their families and carers, in addition to other aspects of care and treatment, including assessment of symptoms such as pain and distress, and how to identify, care for and manage the behavioural and psychological symptoms of dementia.²⁵

Service considerations for Priority Five

- Ensuring the use of appropriate, inclusive and non-stigmatising language when talking or writing about dementia and people with dementia. Dementia Australia have published their Dementia language guidelines to assist with this, available in [Appendix 1](#).
- Promoting consistent use of end-of-life and palliative care definitions and awareness of the different types of palliative care services available, including social networks and community services. These services play an important role in supporting people with dementia and their families and carers throughout their journey.
- Promoting consistent and accurate use of terminology around dementia and its diagnosis.
- Developing care pathways that incorporate the time and resources required to complete effective ACP.
- Considering regularly circulating information within health services regarding the availability of palliative care services and referral pathways to them to increase awareness and facilitate timely referral to appropriate services. The ability to access palliative care services when needed is of particular importance due to the prolonged and fluctuating trajectory of dementia.
- Ensuring staff have access to learning resources and training for dementia care and palliative care-specific topics including:
 - Legal options at the end of life including the right to refuse medical treatment
 - ACP processes and options
 - Pain management for people with dementia
 - Communication for people with dementia and their families/carers.
- Including both palliative care and dementia-specific education and training for aged care workers, GPs, community workers, other health professionals and support staff such as cleaners and cafeteria staff who may be involved in caring for a person with dementia.
- Recognising the importance of cultural awareness training to equip staff to be sensitive and responsive to the needs of culturally diverse groups which considers their social, emotional, spiritual and cultural wellbeing alongside their physical needs.
- Recognising the importance of education on the specific needs of people living with dementia from minority groups, such as LGBTI, Veterans, Aboriginal or refugee communities.
- Recognising, at an organisational level, the amount of time taken to deliver person-centred care for people living with dementia.
- Developing education standards to clarify the level of training and education required for different professions and roles involved in caring for people with dementia and their families/carers.
- Considering a [Dementia Change Champion](#)³¹ that will have the knowledge and leadership skills to develop staff within their own organisation in the field of dementia care, using a person-centred approach.
- Providing access to specialist advice and support for health care professionals.
- Considering the impact of the environment in which people with dementia are being cared for. Introducing cost-effective changes to processes and the physical environment that are supported by best practice. Examples of these include changes to communication processes, the use of cognitive indicators, sensory components and implementing dementia friendly areas within the facility.
- Further information and resources can be found at [Appendix 1](#).



Priority Six: The community is aware and able to care

I feel supported and empowered to make decisions. My individual preferences are expressed through Advance Care Planning (ACP) and reflected in my end-of-life and palliative care. My community is aware and able to support me and those close to me.

A key component of ensuring people with dementia receive appropriate end-of-life and palliative care is ensuring the community is informed of care options and services and their role in supporting the individual. This will be achieved through increased awareness and understanding of what end-of-life and palliative care is and the benefits of this to patients with life-limiting conditions and their families and carers. This includes understanding the importance of ACP, particularly for people with dementia.

A flexible approach to end-of-life conversations is important as the patient's condition and preferences may change, and this should be reflected in evolving plans. These discussions may take place in different forms including formal appointments with health professionals and family, informal discussions as their condition progresses and may involve different family or community members.

Any significant decisions should be documented in health records, with copies distributed to relevant parties including family members, carers and relevant health professionals and service providers. Ideally, these conversations should commence close to the point of diagnosis to enable the person to exercise choice and some form of control over their care. Following a supported decision-making model, enables the person with dementia to feel empowered to continue making decisions about their life and care for as long as possible as their condition progresses.

Communities can play a vital part in supporting the delivery of palliative care services not only to people with dementia but to the wider population requiring palliative care services. *Compassionate Communities* recognises that care for one another at times of crisis and loss is not simply a task solely for health and social services, rather, it is everyone's responsibility.²³ This approach builds capacity within individual communities to support people approaching the end of their lives. Linking a palliative care component as part of other initiatives such as Dementia Friendly Communities, Dementia Alliances and Dementia Friendly Organisations may also increase community acknowledgement of dementia as a terminal illness.

Through increased understanding of end-of-life and palliative care and developing a network of support, the community will appreciate the role they have in a patient's palliative care journey and ways in which they can support them, their families and carers during their palliative care journey and following their death.

Service considerations for Priority Six

- Increasing awareness that dementia is a terminal condition for which palliative care is appropriate.
- Promoting the importance of early discussion and ACP including the concept of supported decision-making throughout the disease trajectory.
- Involving relevant parties in discussions about end-of-life care planning including ACP through the concept of supported decision-making.
- Promoting a better understanding of palliative care and awareness of the different types of services that provide palliative care across all service settings, not just limited to specialist or specialist inpatient services.
- Developing *Compassionate Communities* and *Dementia Friendly Communities* models in collaboration with service providers and community groups to build capacity within communities to better support people requiring end-of-life and palliative care, their families and carers.
- Developing care pathways to increase awareness of and facilitate access to support services for patients, their families and carers, including volunteers and community groups. Monitoring any gaps and addressing them as identified.
- Improving awareness of health, community and aged care providers regarding family access to bereavement support.
- Ensuring spiritual and cultural needs following death are understood and respected and families and carers supported in undertaking death and grief related practices and rituals.
- Further information and resources can be found at [Appendix 1](#).

Dementia Care Model – Palliative care considerations

This Framework acknowledges that the trajectory of disease for people with dementia is complex and unpredictable. The Framework has already considered a model of dementia defined by progression from early to advanced over time.

The following Dementia Care Model^{26 27} outlines care considerations for people with dementia during phases of palliative care as described by the Palliative Care Outcomes Collaboration²⁹. These phases may not be linear. Dementia is typically characterised by a fluctuating course with periods of stability, periods with unstable care needs and other periods of more predictable deterioration, prior to reaching the terminal phase of the illness. Deterioration may be slow or rapid, and where fluctuation occurs, decisions regarding treatment and care will need careful consideration and frequent review.

Palliative care phase of person with dementia

Point of care	Stable palliative care phase	Unstable palliative care phase	Deteriorating palliative care phase	Terminal palliative care phase	Bereavement
Education for professionals	Refer to <i>WA Education and Training Framework</i> for further support.	Refer to <i>WA Education and Training Framework</i> for further support.	Refer to <i>WA Education and Training Framework</i> for further support.	Refer to <i>WA Education and Training Framework</i> for further support.	Refer to <i>WA Education and Training Framework</i> for further support.
	Breaking bad news.	Communicating uncertainty.	Symptom control and ethical decision-making in advancing dementia.	Symptom control at end-of-life.	Grief and bereavement.
	Holistic assessment.		Anticipatory prescribing.	Care in the last days of life.	Bereavement support.
	Explaining the role of each multidisciplinary team (MDT) member to patients, their families and carers.			Alternatives to the oral route may need to be considered, including sublingual, subcutaneous bolus and continuous subcutaneous infusion'.	Post death significant event analysis.
	Advance care planning/ Goals of care.			Opioid conversion.	
Trigger for review	Diagnosis.	Existing problems rapidly increasing in severity.	Functional decline, increasing dependency.	MDT agree patient is in the last days or weeks of their life (as per Key Concepts).	MDT identify bereavement support required prior to death.
		New, unanticipated problems arise.	New, anticipated problems arise.		Verification of death.

Point of care	Stable palliative care phase	Unstable palliative care phase	Deteriorating palliative care phase	Terminal palliative care phase	Bereavement	
Trigger for review		Family or carer circumstances may change suddenly and impact on patient care.	Family or carer may experience gradually increasing distress that impacts on patient care.			
		Admission to hospital.	Admission to hospital.			
Goals of Care (GoC)	Discussed early to optimise realistic GoC and quality of life.	Symptom control; functional/ emotional/ practical support.	Anticipating and preparing for death.	Comfort, dignified and compassionate care in the last days/weeks of life.	After death bereavement support for family and carers.	
Decision-making	Person and agreed others are involved in decisions about treatment and care as they want and are able.	Person and agreed others are involved in decisions about treatment and care as they want and are able.	Person and agreed others are involved in decisions about treatment and care as they want and are able.	Dying person and agreed others are involved in decisions about treatment and care as they want and are able.	Agreed others are involved in decisions about funeral care.	
	Consider the use of supported decision-making where appropriate.	Consider the use of supported decision-making where appropriate.	Consider the use of supported decision-making where appropriate.	Consider the use of supported decision-making where appropriate.		
	Identify opportunities to offer Advance Care Planning discussions with the patient if competent (AHD, EPG, EPA, Goals of care, Preferred place of care), and with a responsible person if not competent: Goals of care, Preferred place of care.	Review or offer Advance Care Plan discussion; share information with patient's consent.	Review or offer Advance Care Plan discussion; share information with patient's consent.	Review or offer Advance Care Plan discussion; share information with patient's consent.		
	Consider Goals of Care and appropriate level of escalation.	Review Goals of Care and appropriate level of escalation.	Review Goals of Care and appropriate level of escalation.	Review Goals of Care and appropriate level of escalation.		
	Limitations of care and treatment may be appropriate: CPR, defibrillation, intubation and ventilation not usually recommended. Must be proportionate to goals of care and acceptable to the patient.	ICU admission or transfer to a high care facility may be appropriate for treatment of potentially reversible causes of acute deterioration. Must be proportionate to goals of care and acceptable to the patient.	Limitations of care and treatment appropriate: CPR, defibrillation, intubation and ventilation not usually recommended. Must be in line with goals of care and acceptable to the patient.	Limitations of care and treatment appropriate: CPR, defibrillation, intubation and ventilation not recommended.		

Point of care	Stable palliative care phase	Unstable palliative care phase	Deteriorating palliative care phase	Terminal palliative care phase	Bereavement
Decision-making	<p>Surprise question.</p> <p>Prognostic indicators.</p> <p>Prognosis may be months or years.</p> <p>National Gold Standards Framework Centre's guidance for clinicians to support earlier recognition of patients nearing the end of life¹².</p>	<p>Limitations of care and treatment may be appropriate: CPR, defibrillation, intubation and ventilation not usually recommended.</p>		<p>Surprise question - this week.</p>	
Communication	<p>Clear, sensitive communication with the patient and those identified as important to them.</p>	<p>Clear, sensitive communication with the patient and those identified as important to them.</p>	<p>Clear, sensitive communication with the patient and those identified as important to them.</p>	<p>Clear, sensitive communication with the patient and those identified as important to them, with the use of supported decision-making where appropriate.</p>	<p>Clear, sensitive communication with those identified as important to the patient.</p>
	<p>Discussion with patient and family should focus on diagnosis, treatment plan, prognosis and support, and advance care planning³².</p>	<p>Discussion with patient and family should focus on uncertainty of prognosis and goals of care/wishes regarding escalation of care.</p>	<p>Discussion with patient and family should focus on progression of illness and importance of symptom control and anticipation of death and dying.</p>	<p>Discussion with patient and family should focus on imminent death and importance of comfort care.</p>	<p>Provide bereavement information to family/carer.</p>
					<p>What to do when someone dies – Australian Government³³.</p>
					<p>Australian Centre for Grief and Bereavement information sheets³⁴.</p>

Point of care	Stable palliative care phase	Unstable palliative care phase	Deteriorating palliative care phase	Terminal palliative care phase	Bereavement
Key clinical process	Holistic assessment.	Identify likely prognosis.	Focus on symptom control and anticipation of death and dying.	Focus on comfort, dignified and compassionate care in the last days / weeks of life.	Identify and provide bereavement support for family and carers.
	Advance care planning.	Agree/communicate Goals of care.			
		Case coordination and monitoring.	Case coordination and monitoring.		
MDT involvement	Needs of those identified as important are explored, respected and met as far as possible.	Needs of those identified as important are explored, respected and met as far as possible.	Needs of those identified as important are explored, respected and met as far as possible.	Needs of those identified as important are explored, respected and met as far as possible.	Bereavement support for family and carers.
	Referrals to allied health.	Referrals to allied health.	Referrals to allied health.	Referrals to allied health.	
Investigation, monitoring and treatment		Recovery uncertain. May recover to stable phase or transition to deteriorating/ terminal phase.			
	Palliative treatment of disease may be considered.	Medical review.	Medical review.	Medical review.	
		All reversible causes of decline explored.	All reversible causes of decline explored.	All reversible causes of decline explored.	
	Referrals to allied health.	Referrals to allied health.	Referrals to allied health.	Referrals to allied health.	
	Agree ongoing monitoring to avert a crisis.	Agree ongoing monitoring to avert a crisis.	Agree ongoing monitoring to avert a crisis.	Agree ongoing monitoring to avert a crisis.	
	Holistic needs assessment: physical, psychological, social, spiritual.	Holistic needs assessment: physical, psychological, social, spiritual.	Holistic needs assessment: physical, psychological, social, spiritual.	Individual plan of care for the dying person and those identified as important to them, including review of nutrition and hydration, symptom control, psychological and spiritual needs.	

Point of care	Stable palliative care phase	Unstable palliative care phase	Deteriorating palliative care phase	Terminal palliative care phase	Bereavement
Investigation, monitoring and treatment	Treatment-related adverse effects must be proportionate to goals of care and acceptable to the patient.		Discontinue non-essential routine medical, nursing and allied health interventions. Should only be undertaken if clinically indicated to guide symptom control or support quality of life. Interventions must be acceptable to the patient.	Discontinue invasive medical, nursing and allied health interventions including observations, blood tests, pathology, radiology etc. Only continue of contributing to comfort.	
	Review non-essential treatments	Review non-essential treatments.	Review non-essential treatments.	Review non-essential treatments.	
Symptom management	Maintenance of symptom control, function and quality of life within the context of illness.	Symptom management and support of possible functional decline to sustain quality of life.	Symptom management and support of functional decline to sustain quality of life.	Oral sips and feeding at patient's request.	
		Anticipatory medication prescribed and available to prevent a crisis, following attempts of non-pharmacological management.	Even if at risk of aspiration, oral intake may be appropriate to support quality of life.	Regular and effective mouth care.	
			Alternative route for medication administration may be required as deterioration occurs.	Alternative route for medication administration may be required as deterioration occurs.	
			Anticipatory medication prescribed and available to prevent a crisis, following attempts of non-pharmacological management.	Anticipatory medication prescribed and available to prevent a crisis, following attempts of non-pharmacological management.	
			Referral to allied health for a coordinated approach to mitigate risk.	WA Cancer & Palliative Care Network Evidence based clinical guidelines for adults in the terminal phase ³⁴ .	
				WA Cancer & Palliative Care Network Opioid Conversion Guideline ³⁵ .	

Point of care	Stable palliative care phase	Unstable palliative care phase	Deteriorating palliative care phase	Terminal palliative care phase	Bereavement
Needs/ benefits review	ACAT or NDIS referral/review package of care if necessary.	ACAT or NDIS referral/review package of care if necessary.	ACAT or NDIS referral/review package of care if necessary.	Review package of care if necessary.	Bereavement follow up/ referral of those important to the patient to bereavement counselling as necessary.
	Benefits review for patient and carer.	Benefits review for patient and carer.	Benefits review for patient and carer.	Assess bereavement risk of those identified as important to the patient.	Return of loaned equipment.
	ACROD parking permit eligibility. Access to driving assessment and Taxi Users Subsidy Scheme.	ACROD parking permit eligibility. Access to driving assessment and Taxi Users Subsidy Scheme.	ACROD parking permit eligibility. Access to driving assessment and Taxi Users Subsidy Scheme.		
	Equipment assessment.	Equipment assessment.	Equipment assessment.	Equipment assessment.	
Referral pathways	Referral to other services as required, e.g. allied health, dementia support services and specialist palliative care services.	Referral to other services as required, e.g. Specialist palliative care, allied health, support services.	Referral to other services as required, e.g. Specialist palliative care, allied health, support services.	Referral to other services as required, e.g. Specialist palliative care, allied health, support services.	Referral to bereavement and support services.
Collaboration across sector	Communication with GP and/or relevant professionals.	Communication with GP and/or relevant professionals.	Communication with GP and/or relevant professionals.	Communication with GP and/or relevant professionals.	Inform all relevant agencies: social care, allied health, equipment store, specialist palliative care team, involved allied health professionals, dementia care nurse.
					Staff supported.

Table developed based on the Far West NSW Palliative and End of Life Model of Care and the Fylde Coast North West End of Life Care Model UK^{26 27}.

Definitions

Advance Health Directive

An Advance Health Directive is a legal document completed by an adult with full legal capacity which contains decisions regarding future treatment. It specifies the treatment(s) for which consent is provided or refused under specific circumstances.

Advance care planning

A voluntary process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known to guide decision-making at a future time when that person cannot make or communicate their decisions.

Dementia

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

End-of-life

End-of-life is the timeframe during which a person lives with, and is impaired by, a life-limiting/fatal condition, even if the prognosis is ambiguous or unknown. Those approaching end-of-life will be considered likely to die during the next 12 months.

End-of-life care

End-of-life care is care needed for people who are likely to die in the next 12 months due to progressive, advanced or incurable illness, frailty or old age. During this period, people may experience rapid changes and fluctuations in their condition and require support from a range of people, including health services, as well as family and carers.

Palliative care

Palliative care is an approach that improves the quality of life of individuals, their families and carers facing problems associated with life-threatening illness/condition, through the prevention and relief of suffering. Palliative care recognises the person and the importance and uniqueness of their family/carer. It serves to maximise the quality of life and considers physical, social, financial, emotional, and spiritual distress. Such distress not only influences the experience of having a life-limiting illness but also influences treatment outcomes.

Palliative approach

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.

Terminal care

Terminal care refers to the care of a person in the last days or weeks before they die (i.e. the final part of palliative care).

Acronyms

ACAT	Aged Care Assessment Team
ACP	Advance care planning
AHD	Advance Health Directive
EOL	End-of-Life
EPA	Enduring Power of Attorney
EPG	Enduring Power of Guardianship
GoC	Goals of care
GP	General Practitioner
LGBTI	Lesbian, gay, bisexual, transgender and intersex
MDT	Multidisciplinary team
NDIS	National Disability Insurance Scheme

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Appendix 1: Supporting documentation and resources

The following links provide further information and resources for palliative care and dementia.

Please note this is not an exhaustive list and intended as a guide only for service considerations and further development.

Peak bodies

Palliative Care WA – <https://palliativecarewa.asn.au>

Palliative Care Australia – <https://palliativecare.org.au>

Dementia Australia – <https://www.dementia.org.au>

Dementia Training Australia – <https://dta.com.au>

Alzheimer's WA – <https://www.alzheimerswa.org.au>

General resources – Dementia

Dementia Australia – The Dementia Guide: For people living with dementia, their families and carers

<https://www.dementia.org.au/sites/default/files/resources/The-Dementia-Guide-2019-v2.pdf>

National Framework for Action on Dementia 2015-2019

https://www.health.gov.au/sites/default/files/documents/2020/01/national-framework-for-action-on-dementia-2015-2019_0.pdf

General resources – Palliative care

A guide to palliative care service development: A population-based approach (Palliative Care Australia)

<https://palliativecare.org.au/wp-content/uploads/2015/05/A-guide-to-palliative-care-service-development-a-population-based-approach.pdf>

End of Life Directions for Aged Care (ELDAC)

<https://www.eldac.com.au>

“What Matters Most” Resources for Older Australians

<https://dyingtotalk.org.au/what-matters-most-for-older-australians/>

Early planning (including Advance Care Planning)

Dementia Australia – Early planning Helpsheet

https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-AboutDementia07-EarlyPlanning_english.pdf

Advance Care planning and dementia (Advance Care Planning Australia)

<https://www.advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-in-specific-health-settings/advance-care-planning-and-dementia>

Aged care facilities

Talking About Dementia and Dying - A Discussion Tool for Residential Aged Care Facility Staff
https://eprints.utas.edu.au/17257/1/Stirling_et_al_Talking_about_dementia_discussion_tool_for_RACF_staff.pdf

Palliative Care Australia. Guiding Principles for Palliative Care in Aged Care 2017
https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2017/05/PCA018_Guiding-Principles-for-PC-Aged-Care_W03-002.pdf

Residential Care Line
https://ww2.health.wa.gov.au/Articles/N_R/Residential-Care-Line

Metropolitan Palliative Care Consultancy Service (MPaCCS)
<https://www.bethesda.org.au/facilities-services/mpaccs>

Clinical guidelines

Clinical Practice Guidelines and Principles of Care for People with Dementia
https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/CDPC-Dementia-Guidelines_WEB.pdf

Resources for families and carers

Dementia Australia – Caring for Someone with Dementia Helpsheet
https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-CaringForSomeone21-PalliativeCare_english.pdf

Carer Help
<https://www.carerhelp.com.au/tabid/5856/Default.aspx>

Diagnosis, treatment and care for people with dementia: A consumer companion guide to the clinical practice guidelines and principle of care for people with dementia
<https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/Dementia-Guideline-Guide-2017-WEB.pdf>

Supported decision-making

Supported Decision-making: A guide for people living with dementia, family members and carers
https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/SDM_Handbook_Online_Consumers-ReducedSize.pdf

Supported decision-making in aged care: A Policy Development Guideline for Aged Care Providers in Australia
<https://cdpc.sydney.edu.au/wp-content/uploads/2019/06/SDM-Policy-Guidelines.pdf>

Supported decision-making: University of Sydney Cognitive Decline Partnership Centre
<https://cdpc.sydney.edu.au/research/planning-decision-making-and-risk/supported-decision-making>

Compassionate Communities

Palliative Care WA: Compassionate Communities Resources

<https://palliativecarewa.asn.au/compassionate-communities>

Compassionate Communities resources (PCWA)

<https://palliativecarewa.asn.au/resources/compassionate-communities>

Compassionate communities: An implementation guide for community approaches to end of life care

https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/09/An-implementation-guide-for-community.pdf

Compassionate Communities Network

<http://www.compassionatecommunities.net.au>

Dementia Friendly Communities

<https://www.dementiafriendly.org.au/dementia-friendly-communities>

This document can be made available in alternative formats on request for a person with disability.

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