

# Policy Statement

## Palliative Care and Dementia



**Dementia  
Australia®**



**PalliativeCare**  
AUSTRALIA

July 2023

**This is a joint policy statement from Palliative Care Australia (PCA) and Dementia Australia.**

**Palliative Care Australia** (PCA) is the national peak advocacy body for palliative care. PCA represents those who work towards high quality palliative care for all Australians who need it. Working closely with consumers, our Member Organisations and the palliative care workforce, we aim to improve access to and promote palliative care.

**Dementia Australia** is the national peak body for people of all ages living with all forms of dementia, and their families and carers. It provides advocacy, support services, education and information. An estimated 400,000 people have dementia in Australia. This number is projected to reach more than 800,000 by 2058. Dementia Australia's services are supported by the Australian Government.

### Summary

- There are more than one hundred different types of dementia with a range of symptoms but all are progressive and terminal.
- Dementia can have a variable trajectory so discussions about palliative care must be initiated as early as possible after diagnosis.
- People living with dementia have the right to appropriate, compassionate and timely palliative care, which includes pain relief and symptom management, and the prevention and relief of physical and psychological suffering.
- Educating the health and aged care workforce about dementia and palliative care will make a critical contribution to improving access to timely and appropriate palliative care for people living with dementia.
- Conversations about advance care planning are important to ensure people living with dementia exercise choice and control about health-related matters including their palliative care preferences.
- Supported decision-making is an appropriate approach that encourages the involvement of the person living with dementia in decisions about treatment and care for as long as possible.
- Family members and carers require access to support and services including respite care, and recognition of their role in enabling quality of life for people with dementia.

### Background

Dementia describes a collection of symptoms caused by disorders affecting the brain. It is not one specific disease, and it can affect thinking, memory and behaviour in different ways. While there are symptoms common to certain types of dementia, every person will experience the condition in a unique way.<sup>1</sup> The age at which a person is diagnosed, speed of onset, severity and type of symptoms will vary depending on the individual, but dementia is ultimately a progressive and terminal condition.

Dementia differs from many other terminal conditions in that it is characterised by a long, unpredictable disease trajectory. The variable rate of cognitive decline, the communication challenges experienced and the associated impacts on decision-making capacity make it essential that discussions about palliative care are initiated as early as possible after diagnosis.

Lack of understanding about dementia as a life-limiting condition in the health and aged care sectors, and the broader community, means that many people living with dementia struggle to access appropriate palliative care that respects their wishes and responds to their specific needs. Access can be particularly difficult for people with complex changed behaviour and communication challenges, those from culturally and linguistically diverse backgrounds, and people living in regional, rural and remote areas.

### Issues

As for any other Australian, a person living with dementia has the right to appropriate, compassionate and timely palliative care, including pain relief, symptom management, and the prevention and relief of physical and

**Palliative care** is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting 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.<sup>3</sup>

People are approaching the **'end of life'** when they are likely to die within the next 12-months.<sup>4</sup>

psychological suffering. Comprehensive palliative care for people living with dementia should be available when and where it is needed, including in community, home-based and residential aged care, hospice care, and acute care settings. However, many aged and community-based services are not equipped to address the unique palliative care needs of people living with dementia, due to limited resources or a lack of appropriate staff education and training. Improving awareness and understanding of dementia, and the specific palliative care needs of people with the condition, will contribute to timely access to appropriate palliative care services for people living with dementia in these settings.

Palliative Care Australia and Dementia Australia strongly support the need for the upskilling of the health and aged care workforce to ensure that staff working in palliative care-related settings, including nursing and care staff, and medical and allied health practitioners, receive tailored dementia education. This should include how to identify and respond to changed behaviour and communication challenges, and the assessment of symptoms such as pain and distress in this context. Improved knowledge about dementia, the associated symptoms and the progressive nature of the condition, will enable accurate and informed decision-making around palliative treatment and care, including end-of-life care. Specialist palliative care services supporting people living with dementia, and their family members and carers, play a crucial role in improving access to and delivery of appropriate palliative care.

Encouraging proactive conversations with appropriately trained health care professionals about advance care planning<sup>2</sup> at the time of diagnosis will support people living with dementia, and their family members and carers, to make informed decisions about the care and treatment the person wishes to receive at the end of life.

Supported decision-making offers an appropriate approach in this context, as it recognises the importance of making decisions with rather than for the person. Supported decision-making enables people with cognitive disabilities to exercise their legal rights about decisions that affect their lives, including health-related matters, with support from a team of people they know and trust. A person living with dementia must also be provided with the opportunity to choose and prepare a substitute decision-maker, who may be required to make decisions when the person is no longer able to communicate their own preferences.

It is important to acknowledge differences in understanding and beliefs about dementia, decision-making and palliative care in the ethnically, culturally and socially diverse communities that characterise contemporary Australia, including vulnerable population groups. Presenting information in accessible formats and in the person's preferred language will encourage engagement in advance care planning and supported decision-making.

Palliative Care Australia and Dementia Australia acknowledge the importance of supporting families and those caring for people living with dementia. Carers must be able to access high-quality respite care and other supports and services that are responsive, respectful, culturally appropriate, and which respect the person's individuality and personal care preferences and promote a good quality of life.

**Palliative Care Australia and Dementia Australia advocate for improved awareness and understanding of the unique palliative care needs of people living with dementia, their families, carers and community.**

**Palliative Care Australia and Dementia Australia make the following recommendations in relation to the provision of timely and appropriate palliative care for people living with dementia:**

- Encourage early involvement of the person with dementia, and their family members and carers, in discussions about palliative care.
- Promote a flexible model of palliative care which enables health and care professionals to provide the right care, at the right time and in the right setting to accommodate the changing needs of people living with dementia, and their carers, as the condition progresses.
- Ensure improved access to specialist palliative care services in the community to address the complex needs of people living with dementia and their carers, and to enable greater choice in the type of care that is provided.
- Support compulsory dementia and palliative care education for all health and care professionals involved in the delivery of care for people living with dementia. This should include how to identify, care for and respond to changed behaviour and communication challenges and the assessment of symptoms such as pain and distress in this context, and approaches to advance care planning and end-of-life care.
- Advocate for all health and aged care facilities to be equipped and supported to provide appropriate care to people with changed behaviour so that no person is excluded from these services on this basis.
- Promote improved access to information and discussions with health professionals, to encourage people living with dementia and their family members and carers to document their end-of-life care wishes in advance care plans as soon as possible following a diagnosis or onset of dementia symptoms.
- Advocate for improved access to respite and other supports and services for families and carers of people living with dementia.
- Support the implementation of nationally consistent advance care planning legislation to reduce jurisdictional confusion, provide protection to health professionals and community members, and allow people living with dementia to transition across borders to be closer to family and their community.
- Encourage individuals to link advance care plans to their My Health Record to ensure they can be accessed by all health professionals involved in the care of the individual in a timely manner.

Last Updated: May 2018  
Original Date: October 2013

**National Dementia Helpline: 1800 100 500**

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**02 6255 0722 | [admin@dementia.org.au](mailto:admin@dementia.org.au) | [dementia.org.au](http://dementia.org.au)**

<sup>1</sup> Dementia describes a collection of symptoms that are caused by disorders affecting the brain. There are many different forms of dementia and each has its own causes. The most common types of dementia include Alzheimer's disease, Vascular dementia, Parkinson's disease and Huntington's disease. Dementia Australia, *What is dementia?* <https://www.dementia.org.au/about-dementia/what-is-dementia>

<sup>2</sup> Advance care planning enables the coordination of access to resources and services, to match anticipated care needs, and offers individuals the opportunity to take control of decisions which affect their care. Advance care planning should be considered as an ongoing conversation between the individual, their care team and as appropriate, their family, significant others and carers. Palliative Care Australia and Advance Care Planning Australia (2018) *Policy Statement: Advance Care Planning & Advance Care Directives*.

<sup>3</sup> World Health Organisation (2017), in Australian Government Department of Health *National Palliative Care Strategy 2018*.

<sup>4</sup> Australian Commission on Safety and Quality in Health Care (2015) *National Consensus Statement: Essential elements for safe and high-quality end-of-life care*. ACSQHC, Sydney.