

Policy Statement

Palliative Care and Dementia



May 2018

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

Palliative Care Australia is the national peak body for palliative care in Australia. PCA provides leadership on palliative care policy and community engagement. Working closely with consumers, its Member Organisations and the palliative care and broader health workforce, PCA aims to improve the quality of life and death for people with a life-limiting illness, their families and carers.

Dementia Australia is the national peak body for people, of all ages, living with all forms of dementia, their families and carers. It provides advocacy, support services, education and information. An estimated 425,000 people have dementia in Australia. This number is projected to reach more than 1.1 million by 2056. Dementia Australia is the new voice of Alzheimer's Australia. Dementia Australia's services are supported by the Australian Government.

While the age of diagnosis, speed of onset, severity and type of symptoms of dementia will vary depending on the individual and the disease that initially caused it, ultimately dementia is a terminal condition. Because of this it is essential that palliative care is discussed and made available from the diagnosis of dementia. A person living with dementia, just as any other Australian, has the right to appropriate, compassionate and timely palliative care, which includes pain relief and symptom management, and the prevention and relief of suffering.

Dementiaⁱ is different from other terminal conditions; in part because of the long, unpredictable course of the disease, issues around capacity for decision making, difficulties in communication and lack of community understanding of the disease. Many people living with dementia struggle to access palliative care that appropriately responds to their needs and respects their wishes. Access can be especially difficult for people from diverse backgrounds and those with behavioural symptoms of dementiaⁱⁱ.

PCA and Dementia Australia highlight that many aged care services and community based services are not equipped to address the unique palliative care needs of people living with dementia due to limited resources or appropriately trained staff. By expanding the awareness and understanding of palliative care and dementia across the community and healthcare sectors PCA and Dementia Australia assert that it is possible to improve the accessibility of appropriate palliative care for people living with dementia.

PCA and Dementia Australia emphasise that comprehensive palliative care for people living with dementia should be available when and where it is needed, including community or home based care, residential aged care, hospice care, and acute care settings. There is a need to improve the provision of palliative care services for people living with dementia in each of these settings, and to increase the ability of health professionals, staff, families and the community to meet the specific palliative care needs of people living with dementia.

PCA and Dementia Australia encourage individuals, their families and health professionals to engage in advance care planningⁱⁱⁱ conversations at the time of diagnosis as this is critical in supporting people living with dementia to exercise choice and control over the care and treatment they wish to receive at the end of life, while they are still able. Even if a person lacks capacity, it is important they are given support to enable them to participate in advance care planning conversations. 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.

PCA and Dementia Australia acknowledge the importance of supporting families and those caring for people living with dementia. It is critical that carers are able to access high-quality respite care that is responsive, respectful, culturally appropriate, and which addresses the needs of the person they care for, respecting the persons individuality, and promoting a good quality of life.

Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life. 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.

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

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

- There must be early involvement of the person, where possible, and their family and carers, where appropriate, in decision making, identification of goals, and delivery of palliative care.
- 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.
- Improved access to specialist palliative care services in the community is needed to address the complex needs of dementia and to enable greater choice in the type of care that is provided.
- Health and care professionals need additional training in palliative care, end-of-life care, advance care planning, the assessment of symptoms such as pain and distress, and how to appropriately identify, care for and manage the behavioural and psychological symptoms of dementia.
- All health and aged care facilities must be equipped and supported to provide appropriate care to people with behavioural and psychological symptoms of dementia so that no person is turned away from these services due to a diagnosis of dementia.
- People living with dementia and their carers need to be supported, through improved access to information and discussions with health professionals, to consider and document their end-of-life care wishes through advance care plans as soon as possible following diagnosis or onset of dementia symptoms.
- Improved access to support and respite is needed for families and carers of people living with dementia.
- Nationally consistent advance care planning legislation is needed to reduce jurisdictional confusion, provide protection to health professionals and community members, and allow care recipients to transition across borders to be closer to family and their community.
- Advance care plans should be linked to My Health Records, if the person living with dementia or their decision maker wishes, to ensure they can be accessed by all health professionals involved in the care of the individual in a timely manner.

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ⁱ 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 (2017) 'What is dementia?' Help Sheet 1.

ⁱⁱ Alzheimer's Australia (2012) 'Consumer Engagement in the Aged Care Reform Process'.

ⁱⁱⁱ 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. PCA and ACPA (2018) 'Policy Statement: Advance Care Planning & Advance Care Directives'