



**Palliative
Care
Australia**

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PALLIATIVE CARE & DEMENTIA



Position Statement

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Palliative Care Australia is the national peak body established by the collective membership of eight state and territory palliative care organisations and the Australia and New Zealand Society of Palliative Medicine. Together the Palliative Care Australia members network to foster, influence and promote local and national endeavours to realise the vision of quality care for all at the end of life.

Alzheimer's Australia administers leading edge national dementia programs and services and provides national policy and advocacy for the 321,600 Australians living with dementia. Alzheimer's Australia's vision is for a society committed to the prevention of dementia, while valuing and supporting people living with dementia, their families and carers.

Dementia and Palliative Care

Many people with dementia struggle to get access to appropriate palliative care that responds to their needs and respects their wishes. Dementia is different from other terminal conditions; in part because of the long, unpredictable course of the disease, difficult issues around capacity for decision making, difficulties in communication and lack of community understanding of the disease. Due to complications such as these, people with dementia may be denied access to palliative care services.

For people from diverse backgrounds and those with behavioural symptoms of dementia, access can be even more difficult.¹ By expanding the awareness and understanding of palliative care and dementia across the community and healthcare sectors, the accessibility of appropriate care for people with dementia will improve. Services need to work collaboratively with a consultative and communally engaging model in order to deliver quality person centred care.

Palliative Care Australia and Alzheimer's Australia believe:

- Dementia is a terminal condition.
- People with dementia have the right to die peacefully, with dignity and in a way that respects their wishes.
- People with dementia deserve quality palliative care, which provides a person centred, holistic and supportive approach.
- Comprehensive palliative care to support people with dementia and their carers should be available when and where it is needed. In many cases this can be achieved through the active teamwork and collaboration of health care professionals, the person with dementia and their family, carers and friends.
- Health care professionals should collaborate with the person who has dementia and their families and carers to develop an end of life care plan. This should incorporate a dynamic process that explores all manners of preferences including venue of care, providers of care and preferred decision making supports.
- Encouraging end of life care planning at the time of diagnosis is important in order to support people with dementia to exercise choice and control over the treatment they wish to receive.

Palliative Care Australia and Alzheimer's Australia call for:

- People with dementia to have access to palliative care that respects their wishes and dignity.
- The early involvement of the person, where possible, and family, carers and close friends, where appropriate, in the decision making and delivery of palliative care.
- A flexible model of care which enables health care workers to provide the right care at the right time to accommodate the changing needs of people with dementia as the disease progresses.
- Increased availability of palliative care services in the community to enable people with dementia and their carers to have greater choice as to where they receive care and the type of care.
- Action to improve access to palliative care services through the expansion of training, knowledge and support in the community, and in areas such as aged care, acute care and primary care (particularly General Practitioners).
- All Health and aged care facilities to provide appropriate care to people with behavioural and psychological symptoms of dementia so that no person is turned away from these services because of their diagnosis of dementia.
- Health professionals to encourage individuals to discuss and document their end of life care wishes when services are commenced.
- Increased availability of information and support around planning end of life care during the early stages of dementia.
- Nationally consistent advance care planning legislation to reduce jurisdictional confusion and provide protection to health professionals and community members.
- Advance care plans linked to the Personally Controlled eHealth Record (PCeHR), if the person with dementia wishes, to ensure they can be accessed by all health professionals involved in the care of the individual.

Background

Dementia is the public health challenge of the 21st century. More than 321,000 Australians are currently affected by this major health epidemic and within 20 years more than half a million people will have the condition.² There is no cure for dementia, and as a result it is already the third leading cause of death for Australians. Dementia is an umbrella term, which describes a collection of symptoms and signs that are caused by more than 100 different diseases that impair brain function, the most common being Alzheimer's disease.³ The severity and type of symptoms varies depending on the disease that caused the dementia, however typically the onset of dementia is gradual, progressive and irreversible. Ultimately, dementia is a terminal condition and therefore, it is essential that a palliative approach to care and support is available to people with dementia and their families from the onset of dementia to the advanced, end of life stage of dementia.

Palliative care is a supportive approach to care that aspires to ensure that people experience the highest quality of life before death and that care is in accord with the person's wishes. It can be difficult to determine the end of life wishes of someone with dementia, as they are likely to lack the ability to express their wishes or make medical and care decisions. For this reason it is important for people with dementia to be encouraged and supported at the right time to discuss and record their end of life care wishes and prepare an advance care plan at the onset of dementia. It is important for the person with dementia and their family to have the choice whether to make informed decisions in regard to their future treatment and care. These plans require regular review by the family and the person to respond to changes in wishes and needs of the person as the dementia progresses.

People with dementia should have access to palliative care in their home when needed and in the form needed.⁴ For those living with behavioural and psychological symptoms of dementia and/or in remote areas, appropriate care can be particularly difficult to access. With the new aged care reforms, Living Longer. Living Better, home care packages will be provided with additional funding to cover the extra costs of caring for someone with dementia. There will also be a significant expansion of the availability of home care packages, nearly doubling within the next ten years.⁵ These changes are designed to support people to remain in their homes for longer. Access to community based palliative care services may still be difficult. There is a need

for a model of care that emphasises a collaborative, multidisciplinary, team approach, which is designed to manage the complexities that can be involved with caring for people with dementia. It is also important to develop and improve access to community based palliative care services that respond to local needs. Funding needs to support both the specialist and generalist palliative care sectors to help develop and improve the accessibility of these services. Health care professionals also need additional information on the types of palliative care services that are available in the local area and how people can contact and access this care.

There is a need to improve the provision of palliative care services. All residential aged care facilities, for example, should be able to provide person centred palliative care to residents when required. This includes facilities having the ability to appropriately care and manage behavioural and psychological symptoms of dementia. Staff need to have training in palliative care, advance care planning, and the assessment of symptoms such as pain and distress for the person with dementia. Furthermore, it is imperative that staff have good communication with the family about the person's advance care plan and wishes and that these preferences are documented at the time when the person enters the facility.

Towards the end of life, it is not uncommon for people with dementia to be sent to hospital, even though it can be a traumatic experience. In 2009-2010, 5600 people with dementia died in a hospital setting.⁶ Even so, only 5% of patients receiving palliative care services in hospitals have a diagnosis of dementia.⁷ It is important that healthcare professionals have the option to refer dementia patients to specialist palliative care when appropriate. The possibility of transfer to hospital must be discussed as part of the advance care plan and decisions should be made early about reasons which would necessitate a transfer. This information should be documented and clearly communicated to relevant aged care staff to reduce unnecessary hospitalisations. Family and health professionals also need to be prepared for symptoms associated with impending death so unnecessary admission to hospitals can be avoided.

For more information on palliative care and support contact:

Palliative Care Australia (02) 6232 4433
www.palliativecare.org.au

For more information on dementia and support contact:

NATIONAL DEMENTIA HELPLINE 1800 100 500
www.fightdementia.org.au

Useful resources and further reading

For more information on advance care planning, and to view lectures by Professor Julian Hughes and Colleen Cartwright on Palliative Care for people with dementia:

<http://www.fightdementia.org.au/services/advance-care-planning-1.aspx>

Abbey, J. *Wrestling with Dementia and Death*. June 2013

<http://www.fightdementia.org.au/sites/default/files/pictures/Paper%2034%20web%20v2.pdf>

Cartwright, Colleen Prof. *Planning for the End of Life for People with Dementia: A Report for Alzheimer's Australia*. Part One Paper 23, March 2011

http://www.fightdementia.org.au/common/files/NAT/20110404_Nat_Paper_23EoLP1.pdf

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http://www.fightdementia.org.au/common/files/NAT/20110503_Nat_Paper_EoLP2.pdf

Hughes, J. *Models of Dementia Care: Person-Centered, Palliative and Supportive: A discussion paper for Alzheimer's Australia on Death and Dementia*. June 2013

<http://www.fightdementia.org.au/sites/default/files/pictures/Paper%2035%20web%20v2.pdf>

Palliative Care Australia. *Why do some people experience pain that can be prevented? End of Life - Vol 1 No 1 - Winter 2009*

<http://www.palliativecare.org.au/Portals/46/EoL%20-%20Winter%202009.pdf>

Palliative Care Australia. *Is access to quality palliative and end-of-life care equitable for all Australians? End of Life - Vol 1 No 2 - Spring 2009*

<http://www.palliativecare.org.au/Portals/46/Corporate%20publications/EoL%20-%20Spring%202009%20-%20web.pdf>

³A supportive approach that aspires to improve the quality of life of a person and their families facing a terminal illness, in accordance to the person's wishes and through the prevention and relief of suffering by early identification and treatment of pain and other problems, physical, psychosocial and spiritual. (World Health Organisation)

¹Alzheimer's Australia. *Consumer Engagement in the Aged Care Reform Process*. 2012

²Australian Institute of Health and Welfare. *Dementia in Australia*. 2012

³Hughes, J. *Models of Dementia Care: Person-Centered, Palliative and Supportive. A discussion paper for Alzheimer's Australia on Death and Dementia*. 2013

⁴Australian Institute of Health and Welfare. *Trends in Palliative Care in Australian Hospitals Cat. No. HWI 112* (AIHW, Canberra: 2011)

⁵*Living longer. Living Better Aged Care Reform Package*. 2012

⁶Australian Institute of Health and Welfare. *Palliative Care Services in Australia*. 2012

⁷Australian Institute of Health and Welfare. *Trends in Palliative Care in Australian Hospitals Cat. No. HWI 112* (AIHW, Canberra: 2011)