Position Statement
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.1 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 brain impairments. It is important to develop and improve access to community based palliative care services that respond to local needs. Funding needs to support both specialist palliative care services and other healthcare professionals to respond to the changing needs of people with dementia. Additionally, it is important to ensure people have the choice to remain in their homes for as long as possible.

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 specialist palliative care and other healthcare professionals to respond to the changing needs of people with dementia. Additionally, it is important to ensure people have the choice to remain in their homes for as long as possible.

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 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 to involve the family and friends of the person with dementia and their family to have the choice to remain in their homes for as long as possible.

People with dementia should have access to palliative care in their home when needed and in the form needed.2 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.3 These changes are designed to support people to remain in their homes for longer.

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 control over the treatment they wish to receive. Due to complications such as these, people with dementia may be denied access to palliative care services.

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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 in the community to enable people with dementia and their families to have greater choice as to where they receive care and the type of care.

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 healthcare 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).

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Palliative Care and Dementia – Position Statement

**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:

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


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

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

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*

A 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)

1Australian Institute of Health and Welfare. *Dementia in Australia*. 2012
2Hughes, J. *Models of Dementia Care: Person-Centered, Palliative and Supportive: A discussion paper for Alzheimer’s Australia on Death and Dementia*. 2013
5Australian Institute of Health and Welfare. *Palliative Care Services in Australia*. 2012