

MEDIA RELEASE



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Education the key to improving end of life care for people with dementia

Palliative Care Australia (PCA) echoes calls from Alzheimer's Australia that more needs to be done to improve end of life care for people with dementia. This follows a survey report which identified a number of barriers to providing quality care at the end of life for people with the condition.

'Dementia is the third leading cause of death in Australia, and the number of people affected by the disease is increasing at an alarming rate,' said Professor Patsy Yates, President of PCA. 'It is vital that people with dementia, their families and carers, have access to palliative care services which help them to live as well as possible at the end of life and to die peacefully, with dignity, in a way that supports their wishes.'

Despite dementia being a terminal condition, it accounts for a very small number of referrals to palliative care. Data from the Australian Institute of Health and Welfare's 2013 report *Palliative Care Services in Australia* showed that just 0.4% of hospital admissions for palliative care were for a diagnosis of dementia.

'New international data shows that the vast majority of people who need palliative care have chronic life limiting illnesses, yet in Australia we have a disproportionately high level of access to palliative care for those with cancer,' said Professor Yates. 'Particularly in an aged care environment, where residents are more likely to have a chronic degenerative disease such as dementia, people could miss out on palliative care simply due to their diagnosis. This is very concerning.'

The survey report, which was commissioned by Alzheimer's Australia, showed that despite 75% of health professionals indicating that people with dementia do have access to palliative care services, family carers say they can't access palliative care specialists, hospice care or services in the community.

'What this survey highlights for me is the need for education about the benefits of palliative care,' said Professor Yates. 'Health professionals should have palliative care as a mandatory component of their education and training across the span of their careers, and we need to educate the community about the types of services available.'

The survey report was launched at a joint Alzheimer's Australia and Palliative Care Australia Parliamentary Friends Event by Ita Buttrose, National President of Alzheimer's Australia and Australian of the Year 2013. Ms Buttrose also highlighted advance care planning as a key area for improvement.

'The lack of advance care planning was identified as one of the barriers to good end of life care. Sixty percent (60%) of carers said their loved one with dementia did not have an advance care plan in place.

'Discussing, planning and documenting our preferences for end of life care is the best way to ensure our wishes will be followed at end of life.'

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PCA is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life

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The report also found that health professionals have a lack of knowledge around advance care planning processes and legalities – something that was also highlighted recently in a study by Southern Cross University.

‘The confusion surrounding advance care planning is something that comes up time and time again,’ said Professor Yates. ‘It is something we need to address urgently – consumers are calling for change and health professionals are asking for guidance. Consistent advance care planning legislation and terminology would go some way to reducing this uncertainty.’

Palliative Care Australia has joined a consortium of leading health and aged care organisations to implement the new national Specialist Palliative Care and Advance Care Planning Advisory Services Project, which aims to educate primary health and aged care providers about palliative care and advance care planning.

The \$14.8 million project, funded by the Australian Government under the *Living Longer, Living Better* strategy, will include a dedicated phone line for GPs and aged care providers around the country to call for immediate access to specialist palliative care advice and information about advance care planning, so they are equipped to provide quality and accurate information to patients and their loved ones about options available to them.

The free service will be available 24 hours a day, 365 days a year, and will be complemented by a suite of web-based resources, with tablet and smart phone access, as well as training and linkage activities, so the information can be obtained where and when it is needed most.

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