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Media Release

A call for better end of life care for people with dementia

Australian of the Year and Alzheimer's Australia National President, Ita Buttrose and Senior Australian of the Year and palliative care physician, Professor Ian Maddocks, have today launched a joint statement by Palliative Care Australia and Alzheimer's Australia that calls for dementia-specific palliative care.

The statement, which was released at the 12th Australian Palliative Care Conference in Canberra, focuses on the need for palliative care that is holistic, multidisciplinary and person-centred and available when and where it is needed.

"End of life care for people with dementia differs in important respects from other terminal conditions. Dementia is a long and unpredictable disease. The difficult issues around capacity complicate end of life care as well," Ms Buttrose said.

A survey commissioned by Palliative Care Australia in May this year found that of all Australians who had recently lost a loved one, only half had discussed their wishes for end of life care and only 15 per cent of those who died had an advance care plan in place which detailed their wishes.

"People put off thinking about their end of life care for as long as they can, but it is important to have these discussions early so that family members can ensure their wishes are carried through," Ms Buttrose said.

"Early planning and discussion is all the more crucial for people with dementia because as the disease progresses it is likely that the person will lose the capacity to participate in decision making about their end of life care.

Both organisations are calling for increased availability of information and support around planning end of life care during the early stages of dementia and consistent national advance care planning legislation.

"Dementia scares us, just like talking about death scares us," Professor Ian Maddocks, Senior Australian of the Year and palliative care physician said.

"Palliative care, aged care and dementia care call for common values, attitudes and practices to ensure best outcomes. All three present uncertainties in what lies ahead. By being better prepared to talk about them, we can handle things better.

"We need to improve access to palliative care services through the expansion of training, knowledge and support in the community at large as well as in the health professions. Those working in acute and emergency care as well as in aged care and primary care, should encourage individuals to discuss and document their end of life care wishes at the time services are commenced.

"Care at home and in community settings is often the place of patient choice, and needs priority in support. Increased availability of palliative care services in the community will be essential, if people with dementia and their carers are to have greater choice as to where care is offered," Professor Maddocks said.



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“Lack of appropriate end of life care and uncertainty about the wishes of the person can lead to suffering in the last moments of life for the person with dementia. It can also lead to a lifetime of guilt and pain for the family,” concluded Ms Buttrose.

“People with dementia have the right to live as well as possible until the end of life, and to die peacefully, with dignity and in a way that respects their wishes. Palliative care should be available where and when people need it and no one should be turned away from palliative care services because of their diagnosis of dementia.”

National Dementia Helpline: 1800 100 500

An interpreter service is available

(The National Dementia Helpline is an Australian Government Initiative)

Dementia is a National Health Priority Area

www.fightdementia.org.au

Palliative Care Australia is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life www.palliativecare.org.au

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Interviews are available:

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