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MEDIA RELEASE

Online resources to assist planning ahead for people with dementia

New resources are now available online to assist community, aged and health care staff to highlight the importance of planning ahead for people in their care, particularly those in the early stages of dementia.

The resources include short videos from carers and a GP discussing their experience of planning ahead and why it is important. There are brochures, which can be used with people living with dementia, and their carers and families, staff and those who will be called on to make decisions when someone is unable to do this themselves.

There are also resources for organisations such as guides for implementing quality improvement initiatives or conducting information training sessions.

The resources, funded through the National Health and Medical Research Council's Cognitive Decline Partnership Centre and hosted on the Alzheimer's Australia website are aimed at complementing the consumer information that is already [available](#).

Professor Meera Agar, Palliative Care Physician and academic, who led the project, says that the resources have been developed based on research looking into how to improve advance care planning for those with dementia and other forms of cognitive decline.

"Our research included interviews with over 80 people with experience in advance care planning in a variety of community, aged and health care settings from across Australia. The resources have also been developed and trialled with a number of organisations".

"It is important to have a professional health and aged care workforce who are knowledgeable and skilled in helping older people plan ahead. The community sector, in particular, has an important role to play in raising awareness and encouraging conversations about what matters most in the years ahead," Professor Agar said.

Kathy Williams, consumer representative from Alzheimer's Australia was also involved in the research and development of resources.

"Planning ahead for those with dementia needs to cover a wide range of issues focussing on how the person wants to live the rest of their life, rather than just a narrow focus on end-of-life issues. I know that for my mum staying in control was really important and early planning helped with this," Ms Williams said.

Associate Professor Josephine Clayton, HammondCare, member of the Stakeholder Advisory Committee, welcomed the resources and the focus on also assisting those who will have to make decisions for others.

“I know that making decisions for others can be very stressful. The resources which have been developed include a pamphlet which can be given to people who find themselves in this position so they better understand their role. There is also information on how to support a person to make their own decisions as far as possible,” Associate Professor Clayton said.

It is important that health and aged care professionals learn how to engage with people who have dementia and raise the issue of planning ahead so that people have the opportunity to think about and discuss issues of importance well ahead of when they might be needed. These tools help them to do this and also to implement them across their organisation in a systematic way.

The online resources are available at: www.start2talk.org.au

The research report is available from
<http://sydney.edu.au/medicine/cdpc/resources/advance-planning.php>

Media inquiries

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Alzheimer's Australia is the charity for people with dementia and their families and carers. As the peak body, it provides advocacy, support services, education and information. An estimated 413,000 people have dementia in Australia. This number is projected to reach more than 1.1 million in 40 years.

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](http://www.fightdementia.org.au)

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