

Palliative Care



for people living with Dementia

www.pallcaretas.org.au

What is Palliative Care?

Palliative care is an approach that improves the quality of life of patients and their families facing the issues associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other issues, physical, psychosocial and spiritual¹.

Who is Palliative Care for?

Palliative care is for people of any age who have been told that they have a serious illness that cannot be cured. Palliative care assists people with illnesses such as cancer, motor neurone disease and end-stage kidney or lung disease to manage symptoms and improve quality of life². Although palliative care has traditionally been an approach associated with other chronic diseases, dementia is becoming better recognised as a life limiting condition for which palliative care is appropriate and necessary³.



Key aspects of Palliative Care for People living with Dementia

A palliative care approach recognises the importance of patient and family-centred care that focuses on the person and where quality of life is the primary goal⁴. A palliative approach is consistent with the philosophy of person-centred care and the concept of VIPS model⁵; which is an acronym to identify that people with dementia and their families should be valued; people with dementia must be treated as individuals; the perspective of the person with



dementia must inform our understanding; and the person's social environment must be attended to⁶.

Key aspects of Advance Care Planning for People Living with Dementia?

Advance care planning promotes an individual's choice, control and decision-making over future medical treatment, for a time when they may lack decision-making capacity. It is a way of ensuring that people living with dementia can plan for the future of their care at a point at which they are still able to make independent or supported decisions⁹.

As dementia progresses, a person's capacity to make and communicate decisions about everyday life, health and end-of-life care will deteriorate. Complex health and personal decisions will then often require the involvement of family members or carers who may be uncertain about the preferences of their loved one.

People living with dementia may receive limited access to palliative care services, inappropriate use of antipsychotic medications and potentially futile treatments including hospitalisation, intravenous therapy, and tube feeding.

Advance care planning is a keyway to improve the quality of care delivered to people with dementia. It has been associated with significant reductions in rates of hospitalisation and increased use of palliative care services among people with dementia¹⁰.

It can also reduce stress, anxiety and depression in relatives. Dementia Australia has developed the Start2Talk website to assist people with dementia and their carers to plan for the future:

start2talk.org.au.

What is Advance Care Planning?

Advance care planning is the process of planning for your current and future health care. It involves talking about your values, beliefs and preferences with your loved ones and doctors. This helps them make decisions about your care when you can't. Ideally these conversations start when you are well and then continue throughout your life⁷. Care planning for people with dementia and their caregivers is important across all phases of dementia⁵. As unfortunately, for someone with dementia the time will almost certainly come when they will no longer be able to communicate their wishes. One way to address this problem is Advance Care Planning⁸.

How to Record Your Choices?

In Tasmania, there are two ways you can record your choices for future medical care:

A- Appoint an enduring guardian

B- Complete an Advance Care Directive

What is Enduring Guardian?

When you appoint an enduring guardian, you are choosing a trusted relative or friend to manage your health care. The person(s) you appoint becomes your substitute decision-maker if you are no longer able to make decisions. Identifying and appointing someone who will make decisions on your behalf, is an important part of planning ahead.

What is an Advance Care Directive?

An individual with decision-making capacity can document their preferences for care, values by completing the relevant jurisdictional advance care directive (ACD) form(s). An ACD is completed and signed by what is termed a 'competent adult', but only comes into effect when the person loses capacity to make medical decisions. All health professionals have obligations to access and implement ACDs that comply with legislation, common law or policy, and support quality palliative and end-of-life care¹¹. Advance care directives should be made when the person with dementia still has

legal capacity— the level of judgment and decision-making ability needed to sign official documents or to make medical and financial decisions.

These documents should be completed as soon as possible after a diagnosis of dementia¹².

What is legal capacity?

Capacity means that a person is able to understand:

- The information they are being told.
- The choices they have.
- The consequences of those choices.
- And can communicate their decisions to others.

As long as you have capacity, you will be asked to make your own decisions about medical care, lifestyle choices and financial affairs. An ACD will only be used if/when you lack capacity. If this happens then others will need to make decisions for you if you do not have an ACD in place.

Who is an appropriate person to speak on behalf of a person who lacks capacity?

The person to speak on your behalf would be (in order of priority):

1. an enduring guardian, however if no enduring guardian has been appointed:
2. a spouse (including de facto) with whom the Person Concerned has an ongoing relationship.
3. an UNPAID carer who has provided support to the Person Concerned at home, (whether or not the Person Concerned is now in institutional care)
4. a family member or friend who has an ongoing relationship with the Person Concerned, believes they understand the person's wishes and is prepared to take a decision based on what they believe to be the person's best interests.

If you complete an Advance Care Directive, it is suggested that you also nominate who you would prefer to act as your Person Responsible.

Note: The people who speak on behalf of a person can ONLY do so if, when and for as long as the Person Concerned lacks capacity.

Full list of resources and references available in the online version at www.pallicaretas.org.au

What Resources are available?

- Advance care planning and dementia <https://www.advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-in-specific-health-settings/advance-care-planning-and-dementia>

- Planning for the end of Life for People With Dementia
https://www.dementia.org.au/sites/default/files/20121009_US_23_Planning_for_the_end_of_life_Part_two.pdf

- Planning for Palliative Dementia Care Resource Guide
<https://www.dementia.org.au/sites/default/files/start2talk/5.0.4.6%20Planning%20for%20palliative%20dementia%20care.pdf>

- National Dementia Helpline 1800 100 500

- Models of Dementia Care: Person-Centred, Palliative and Supportive
<https://www.dementia.org.au/sites/default/files/2020-06/Alzheimers-Australia-Numbered-Publication-35.pdf>

- Planning ahead - Start2Talk <https://www.dementia.org.au/information/about-dementia/planning-ahead-start2talk>

References:

- 1- World Health organization (WHO). (2020). *Palliative Care*. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/palliative-care>.
- 2- Palliative Care Australia. (n.d.). *What is palliative care?* Retrieved from <https://palliativecare.org.au/what-is-palliative-care>.
- 3- Dementia Australia (2019). *Dying Well Improving palliative and end of life care for people with dementia*. Retrieved from <https://www.dementia.org.au/sites/default/files/documents/19013-DA-Dying-Well-Discussion-Paper.pdf>.
- 4- Sawatzky R, Porterfield P, Lee J, Dixon D, Lounsbury K, Pesut B, et al. Conceptual foundations of a palliative approach: a knowledge synthesis. *BMC Palliative Care*. 2016;15(5):doi: 10.1186/s12904-016- 0076-9.
- 5- Dementia Australia (2018). *Palliative Care and dementia*. Retrieved from <https://www.dementia.org.au/sites/default/files/documents/Dementia-Australia-Numbered-Publication-43.pdf>.
- 6- Brooker D (2007). *Person-Centred Dementia Care: Making Services Better*. London: Jessica Kingsley; 160 pages.
- 7- Australian Government department of Health (2019). *Advance Care Planning*. Retrieved from <https://www.health.gov.au/health-topics/palliative-care/planning-your-palliative-care/advance-care-planning>.
- 8- Alzheimer's Australia (2011). *Planning for the end of life for people living with dementia*. Retrieved from https://www.dementia.org.au/sites/default/files/20121009_US_23_Planning_for_the_end_of_life_Part_one.pdf.
- 9- Advance care Planning Australia (2020). *ACPA and Dementia Australia Position Statement: Advance Care Directives for people with dementia*. Retrieved from <https://www.advancecareplanning.org.au/about-us/news-case-studies-and-blog/article/2020/03/10/acpa-and-dementia-australia-position-statement-advance-care-directives-for-people-with-dementia>
- 10- Advance care Planning Australia (n.d.). *Advance care planning and dementia*
<https://www.advancecareplanning.org.au/understand-advance-care-planning/advance-care-planning-in-specific-health-settings/advance-care-planning-and-dementia>.
- 11- Fountain S, Nolte L, Wills M, Kelly H, Detering K. (2018). *Review of advance care planning laws across Australia: short report*. Austin Health, Melbourne: Advance Care Planning Australia.
- 12-Alzheimer's Association (2016). *End of Life Decisions*. Retrieved from http://www.alz.org/national/documents/brochure_endoflifedecisions.pdf#:~:text=Advance%20directives%20should%20be%20made%20when%20the%20person,soon%20as%20possible%20after%20a%20diagnosis%20of%20dementia