

This is a joint policy statement from Palliative Care Australia and Advance Care Planning Australia

Palliative Care Australia is the national peak body for palliative care in Australia. PCA provides leadership on palliative care policy and community engagement. Working closely with consumers, its Member Organisations and the palliative care and broader health workforce, PCA aims to improve the quality of life and death for people with a life-limiting illness, their families and carers.

**Advance Care Planning Australia** is a national program, enabling Australians to make the best choices for their life and health care. ACPA increases advance care planning resources across health sectors and NGOs, improves workforce capability, produces information resources for diverse consumers and communities, and builds the evidence base for advance care planning.

*Dying is a normal part of life, and it is important for all Australians to have discussions about death and dying. By doing so people and their families are able to formulate and communicate their end-of-life preferences. This helps ensure their treatment and care best aligns with their values and preferences regarding both the type and place of care and place of death.*

*Advance care planning promotes care that is consistent with a person's goals, values and beliefs, and is an essential tool in enabling Australians to communicate their preferences regarding their end-of-life care. Whilst advance care planning discussions are valuable in their own right, a written Advance Care Plan or an Advance Care Directive increases the likelihood that the person's preferences will be known and followed.*

In 2015, almost 160,000 Australians died and the leading cause of death was chronic disease<sup>i</sup>. Two-thirds of deaths occurred in people aged 75 or over and around half of all deaths occurred in hospital, with another third occurring in residential aged care facilities<sup>ii</sup>. It is unknown how many people had expressed preferences for care and /or had these preferences followed. Evidence suggests the uptake of advance care planning remains low<sup>iii</sup>.

Advance care planning provides a mechanism to improve the quality of care including end-of-life care for all people. Palliative Care Australia (PCA) and Advance Care Planning Australia (ACPA) highlight that advance care planning enables the coordination of access to resources and services, to match anticipated care needs, and offers individuals the opportunity to take control of decisions which affect their care. Advance care planning should be considered as an ongoing conversation between the individual, their care team and as appropriate, their family, significant others and carers.

PCA and ACPA emphasise that advance care planning is not the exclusive domain of any particular health sector or setting, and should involve all members of the care team. Currently there is limited understanding of, and resources to support advance care planning implementation across sectors. Promoting awareness of and engaging in advance care planning and end-of-life care discussions is also the responsibility of individuals and the wider community, and is not just for people with a life-limiting illness, or those nearing the end of life, but should be considered by everyone.

PCA and ACPA affirm that conversations about advance care planning, dying and end-of-life require significant knowledge, experience and enhanced communication skills and should be delivered with respect, compassion and sensitivity. The competencies of the workforce engaged in advance care planning and end-of-life care discussions needs further attention.

PCA and ACPA believe an integral component of advance care planning is the opportunity to choose and prepare a substitute decision-maker. In situations where an individual is no longer able to communicate their own preferences, it may fall upon a substitute decision maker. The substitute decision-maker role must be promoted and supported, with decisions acknowledged and upheld in all jurisdictions. The capacity of people living with dementia or other types of cognitive impairment to participate in advance care planning must also be considered. Capacity is assumed under law unless there is

evidence to the contrary<sup>iv</sup>. If there is a need to assess capacity, an assessment should be undertaken. Even if a person lacks capacity, it is important that they are given support to enable them to participate in advance care planning conversations as much as possible.

PCA and ACPA highlight that written Advance Care Plans or Advance Care Directives are an important part of the advance care planning process, serving as a vehicle for documentation regarding preferences and values as well as decisions about the type and level of medical intervention people wish to receive during significant illness and at the end of life. Individuals must also be provided with opportunities to continually reassess an Advance Care Plan and/or Advance Care Directive based on current circumstances and anticipated future needs.

Advance Care Directives have legal status and are intended to uphold a patient's previously articulated preferences should the person no longer be able to make or communicate their own decisions<sup>v</sup>. All Australian states and territories currently recognise and support advance care planning and recognise Advance Care Directives under either state legislation or common law/policy, however terminology and provisions vary. Navigating available documents is complex, and this can lead to difficulties in implementation.

There is no one correct way to implement advance care planning. PCA and ACPA maintain that the process should be controlled by the individual, who should be free to choose, without force or coercion, and create an Advance Care Plan or an Advance Care Directive that upholds their preferences and values for care. People who elect to not participate in advance care planning must also be supported to make this choice.

**PCA and ACPA recommend a nationally collaborative approach to advance care planning reform, to promote and monitor advance care planning uptake within Australia. This includes:**

- Consumer and community initiatives such as advance care planning advisory services, resources and awareness campaigns regarding advance care planning and end-of-life care options.
- National guidelines to promote good practice in advance care planning, which should promote whole of health system implementation.
- Investment in workforce development and training (undergraduate and post graduate) to build the capacity of all professionals to engage in end-of-life and advance care planning discussions
- Harmonisation across state and territory legislation (and terminology) governing the scope and implementation of Advance Care Directives, as well as the appointment and status of substitute decision makers.
- Development and implementation of the My Health Record as the national system for recording advance care planning conversations, Advance Care Plans and Advance Care Directives.
- A national Advance Care Directive prevalence data set to monitor uptake and to assist with implementation, policy development and evaluation.

Original Date: December 2012

Last Updated: April 2018

02 6232 0700 | [pcainc@palliativecare.org.au](mailto:pcainc@palliativecare.org.au) | [palliativecare.org.au](http://palliativecare.org.au)  
03 9496 5660 | [acpa@austin.org.au](mailto:acpa@austin.org.au) | [advancecareplanning.org.au](http://advancecareplanning.org.au)

<sup>i</sup> ABS (2016). Causes of Death, Australia, 2015. ABS Cat No. 3303.0 Canberra

<sup>ii</sup> AIHW (2017). National Hospital Morbidity Data and National Aged Care Data Clearinghouse.

<sup>iii</sup> Ruseckaite, R., Detering, K. M., Evans, S. M., Perera, V., Walker, L., Sinclair, C. Nolte, L. (2017). Protocol for a national prevalence study of advance care planning documentation and self-reported uptake in Australia. *BMJ Open*, 7(11), e018024.

<sup>iv</sup> 'Supporting substitute decision makers'. Dementia Australia. [accessed April 2018]

<sup>v</sup> 'Advance Directives'. QUT End of Life Law in Australia. [accessed March 2018]