Advance Care Planning Australia
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OPAN Older Persons Advocacy Network

ACPA and Older Persons Advocacy Network Position Statement: advance care planning for older people

The context

In Australia, a rights-based aged care system is required to protect and enforce the rights of older people. Self-determination, the ability to maintain choice and control over current and future decisions, and to have autonomy and independence, is central to human dignity. The Charter of Aged Care Rights promotes individuals to have control over and make choices about their care and to have a person of their choice support them and speak on their behalf.[1]

Advance care planning and related legislation enables older people to have greater control over their future medical treatment, including who provides that care and how decisions are made.

An individual with decision-making capacity can document their preferences for care, values and/or appoint a substitute decision-maker by completing the relevant jurisdictional Advance Care Directive (ACD) form(s). An ACD is completed and signed by a competent adult, and only comes into effect when the person loses capacity to make their own medical decisions. It is a voluntary process. All health professionals have obligations to access and implement ACDs that comply with legislation, common law or policy, and support quality rights-based care.[2]

The issue

Despite comprehensive legislation, policy, forms, quality standards, resources and guidelines, there is limited awareness and uptake of advance care planning amongst older people.

Nationally, the uptake of advance care planning remains low, with 86% of people aged 65+ years not having an ACD. In residential aged care services, 62% of residents aged 65+ do not have an ACD completed by them in their health record. For older people, their health record frequently contained directions relating to not providing life prolonging treatment (e.g. not for resuscitation or antibiotics) written by someone else, 36% had a doctor completed document and 18% had a family / loved one completed document.[3]

Documents that are not completed in collaboration with the individual impacted could place the person, those completing the documentation, the health and aged care workforce, and/or service providers at risk.

There are also known issues with the accuracy, currency, and validity of ACDs, particularly within aged care. A national study identified only 73% of ACDs included full name, signature of the person, document date, and was adequately witnessed.[3]

For older people there may be additional barriers to making informed choices, particularly given ageism, cognitive abilities can change quite rapidly and abilities to make decisions can be impacted. For optimal outcomes, conversations about advance care planning should occur either early on when planning for aged care services or on immediate commencement of those services as part of the intake process. However, there is known limited advance care planning capability and access at point of entry into care.

Advance Care Planning Australia and the Older Persons Advocacy Network recommend and advocate for improved awareness and understanding of the advance care planning needs of older people to enable their choice and control over future medical treatment decisions.

Advance Care Planning Australia and Older Persons Advocacy Network's position is that:

- Autonomy, self-determination and diversity among older persons in aged care should be recognised and respected. This includes access to advance care planning to enable choice and control in decisions.
- Every older person receiving aged care services should have access to advance care planning and for those willing to undertake advance care planning, their preferences should be known and respected.
- The advance care planning related laws of each Australian jurisdiction are to be respected and upheld. Preference would be given to advance care planning laws being uniform across Australia.
- Documentation of ACD(s) must be by the individual for themselves, when they have decision-making capacity, consistent with jurisdictional legislation and/or policy. Some people may require supported-decision making to enable them to make decisions about their ACD. This should be utilised whenever possible rather than immediately resorting to a substitute decision-maker.
- Individuals should be educated on the importance of appointing substitute decision-makers they know and trust who understand and will respect their wishes. They should be supported and able to appoint a substitute decision-maker, whilst they have capacity, who may be required to make decisions when the person is no longer able to communicate their own preferences.
- Individuals who do not have decision-making capacity and have not developed an ACD, maintain personal choice and control by having the identified substitute decision-maker (default or appointed) involved in their medical treatment decisions via consultation with the treating team, in accordance with jurisdictional legislation.
- Aged care services and health professionals:
    - have obligations to enact quality ACD(s), when a person has lost capacity, to support medical treatment decision-making, palliative care and/or end-of-life care
    - should be familiar with the advance care planning legislation and requirements in their state or territory
    - require ongoing support and education to fulfil their obligations.
- For an individual without decision-making capacity, a medical document (usually completed by a doctor) that outlines the plan of care for emergency treatment or severe clinical deterioration (e.g. not for resuscitation) should be developed in consultation with their substitute decision-maker. In addition, some states have advance care planning documentation that can be completed by a family member. This document should clearly indicate it is a statement completed by someone else and be developed and enacted in line with known preferences of the older person.
- When relevant, ACDs should be uploaded to the person's My Health Record to facilitate safe storage and access across health services. Ideally, they should also be shared with the substitute decision-maker, GP, residential aged care facility and local hospital if appropriate.
- A system-wide and multifaceted approach is needed to better support older people, their families, and carers to understand, complete and review ACDs before loss of decision-making capacity and/or accessing aged care services, especially admission to residential aged care.

Advance Care Planning Australia

Advance Care Planning Australia (ACPA) is a national program, enabling people's choice and control of their life and future health care. ACPA promotes national collaboration and provides an advance care planning resource hub, support service, workforce education resources, and research findings.

Find more information about advance care planning in your state or territory or for advice and support freecall 1300 208 582 or visit advancecareplanning.org.au.

Older Persons Advocacy Network

OPAN is a national network of nine state and territory member organisations that give a voice to older people who are eligible or receiving aged care services. The network has been providing free, confidential, aged care advocacy, information and education services to older people, their families or representatives for over 25 years across Australia. OPAN are independent of the government and aged care providers.

OPAN, the national body, works with the government to influence aged care policy through systemic advocacy.

Our collective vision is of a society where older people are heard, informed and respected, and where they can enjoy and exercise their rights to live fulfilling lives.

OPAN is funded by the Australian Government to deliver the National Aged Care Advocacy Program (NACAP). OPAN aims to provide a national voice for aged care advocacy and promote excellence and national consistency in the delivery of advocacy services under the NACAP.

References

1. Charter of Aged Care Rights. Australian Government. Aged Care Quality and Safety Commission. Available via https://www.agedcarequality.gov.au/consumers/consumer-rights#charter-of-aged-care-rights
2. Haining C, Nolte L. Australian advance care planning laws. Can we improve consistency? Austin Health, Melbourne: Advance Care Planning Australia. 2021.
3. Buck K, Nolte L, Sellars M, Sinclair C, White B, Kelly H, Macleod A, Detering K. 2021. Advance care directive prevalence among older Australians and associations with person-level predictors and quality indicators. Health Expectations doi:10.1111/hex.13264