The Royal Commission into Aged Care Quality and Safety was established on 8 October 2018 by the Governor-General of the Commonwealth of Australia, His Excellency General the Honourable Sir Peter Cosgrove AK MC (Retd). Replacement Letters Patent were issued on 6 December 2018.

The Honourable Richard Tracey AM RFD QC and Ms Lynelle Briggs AO have been appointed as Royal Commissioners. They are required to provide an interim report by 31 October 2019, and a final report by 30 April 2020.

The Royal Commission intends to release consultation, research and background papers. This background paper has been prepared by the staff of the Office of the Royal Commission, for the information of Commissioners and the public. The views expressed in this paper are not necessarily the views of the Commissioners.

This paper was published on 20 June 2019.

© Commonwealth of Australia 2019
ISBN 978-1-925593-14-3 (online)

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## Contents

**Introduction** 1

**What is advance care planning?** 1

**Components of advance care planning** 2

- Advance care plans ................................................. 2
- Advance directives ..................................................... 2
- Substitute decision-makers ......................................... 3

**Advance directives and substitute decision-makers in each state and territory** 3

**Advance care planning in aged care** 4

- Benefits of advance care planning .................................. 4
- Uptake of advance care planning ....................................... 5
- Improving advance care planning practice in aged care ................. 6
  - Implementation of advance care plans ............................. 6
  - The approach to advance care planning discussions ............. 7
  - Advance care planning for people with dementia .............. 7

**Conclusion** 8

**Appendix** 9

- Australian Capital Territory ............................................. 9
- New South Wales ............................................................. 9
- Northern Territory ........................................................... 9
- Queensland ................................................................ 10
- South Australia ............................................................... 10
- Tasmania ...................................................................... 10
- Victoria ...................................................................... 11
- Western Australia .......................................................... 11
**Introduction**

This paper provides a brief overview of the practice of advance care planning in Australia. It has been prepared by staff of the Office of the Royal Commission into Aged Care Quality and Safety but does not represent a direction or position of the Royal Commission in relation to advance care planning. Any views expressed are not necessarily the views of the Commissioners.

This paper provides a high-level description of the components of advance care planning, an overview of the practices in each state and territory and a brief explanation of advance care planning as it relates to aged care. It does not comprehensively examine the differences in advance care planning regimes in each state and territory, or their relative advantages or limitations.

This paper does not examine issues related to supported decision-making or decision-making capacity. Nor does it discuss arrangements for substitute decision-making made by a court or tribunal.

**What is advance care planning?**

Advance care planning is a process of pre-emptive discussions and planning that anticipates a future loss of ability to make or communicate decisions. The practice reflects principles of autonomy, self-determination and dignity. It originates from the United States where the practice developed in the 1970s in response to concerns that people who could not make or communicate their own decisions were not receiving end-of-life care consistent with their preferences.

The objective of advance care planning is to guide future decision-making about a person’s treatment and care so that it is consistent with their goals, preferences and values. The process helps health professionals and a person’s family and friends know what kind of treatment and care the person would want in the future.

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Components of advance care planning

Advance care plans

Advance care planning is a broad concept. It may take the form of structured conversations with health professionals or informal discussions with family and friends.\(^5\) Advance care planning does not always result in written documents.\(^6\) The conversations themselves can be very beneficial.\(^7\) Ideally though, advance care planning leads to a written advance care plan outlining a person’s preferences for future health and personal care.\(^8\)

Advance care plans are relied on only if a person loses their ability to make or express their own decisions.

Advance care plans may be a letter to the person responsible for the decision-making, an entry in a medical report, an oral instruction or any other form of communication.\(^9\) It may also take the form of a more formal document like an ‘advance directive’ or an instrument appointing a substitute decision-maker.

Advance directives

An advance directive is a formal document that records a person’s directions for their future care and treatment. Advance directives are not the same as clinical care plans, treatment plans or resuscitation plans prepared by clinicians to guide clinical care.\(^10\)

Advance directives have traditionally been narrowly focused on specific medical treatment decisions. Increasingly, directives are including broader information about a person’s values, goals and what is important to them in life.\(^11\)

Advance directives are recognised in all states and territories, though there are variations in terminology and scope. In the Australian Capital Territory, Northern Territory, Queensland, South Australia and Western Australia, advance directives are provided for in legislation. New South Wales and Tasmania do not have legislation providing for advance directives, but legally binding advance directives can still be made.\(^12\) All states and territories have specific forms that can be used to make an advance directive.

The differences between states and territories are explored further below.

\(^{5}\) G Yapp, C Sinclair, A Kelly, K Williams and M Agar, above n 3, p 135.
\(^{6}\) Ibid.
\(^{8}\) Australian Government Department of Health and Ageing, above n 2.
\(^{10}\) Australian Government Department of Health and Ageing, above n 2, p 9.
\(^{12}\) These advance directives are made under the common law. See *Hunter and New England Area Health Service v A* [2009] NSWSC 761.
Substitute decision-makers

In all states and territories, a person can appoint someone to make decisions on their behalf in the event they become unable to make their own decisions. This is known as a ‘substitute decision-maker’.

Substitute decision-makers can be empowered to make decisions about financial matters, and personal, lifestyle and medical matters. The precise powers a person can be given, and the principles they must follow when making decisions, depends on the state and territory. ¹³

The instrument used to make the appointment differs between each state and territory. In some jurisdictions, the same instrument is used to appoint a substitute decision-maker for personal, lifestyle, medical and financial matters. In other jurisdictions, there are different instruments; for example, an enduring power of guardianship, for lifestyle and personal matters, and an enduring power of attorney for financial matters. In some jurisdictions, such as South Australia, a substitute decision-maker can be appointed in an advance directive.

The Australian Law Reform Commission, in its 2014 Equality, Capacity and Disability in Commonwealth Laws Report, recommended that Commonwealth laws and frameworks include the concept of a ‘supporter’. Supporters do not make decisions on a person’s behalf (like a substitute decision-maker does) but instead supports people to make their own decisions. ¹⁴ At the state and territory level, Victoria has adopted the concept of a supporter role.¹⁵ In 2018, the New South Wales Law Reform Commission recommended a new framework for assisted decision-making laws in New South Wales that uses the concept of a supporter.¹⁶

Advance directives and substitute decision-makers in each state and territory

As discussed above, every state and territory recognises a form of advance directive and allows people to appoint a substitute decision-maker in case they can no longer make decisions for themselves in the future.¹⁷ The terminology and requirements differ between each state and territory. The Appendix provides a brief overview of the formal mechanisms in each state and territory for advance care planning.

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¹⁵ A support person for medical treatment decisions can be appointed under the Medical Treatment Planning and Decisions Act 2016 (Vic) (Part 3, Division 3). A supportive attorney can be appointed to help a person make personal decisions under the Powers of Attorney Act 2014 (Vic) Part 7. Plan nominees can be appointed under the National Disability Insurance Scheme Act 2013 and a Nominated Person can be chosen by a mental health consumer under the Mental Health Act 2014 (Vic) Part 3 Division 4.
¹⁷ This relates only to substitute decision-makers chosen by the person themselves, not those appointed by a court or tribunal or otherwise recognised under legislation.
A summary of the formal mechanisms for advance care planning is shown in the table below.

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<thead>
<tr>
<th>Formal Advance Care Planning Documents</th>
<th>ACT</th>
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**Advance care planning in aged care**

**Benefits of advance care planning**

There are a number of demonstrated benefits of advance care planning for those receiving aged care.

Advance care planning has been shown to reduce unnecessary transfers from a residential aged care facility to a hospital and decrease a person’s level of worry and anxiety about their future. Advance care planning can also have benefits for the person’s family, by improving the family’s understanding of the person’s wishes, and reducing stress, anxiety and depression in the surviving family by helping them prepare for a death.

Advance care planning is particularly relevant for those approaching the end-of-life. The process allows for preferences for palliative and end-of-life care to be identified, documented, and respected.

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Advance care planning has been shown to positively influence quality end-of-life care, increase compliance with a person’s preferences for their end-of-life care, and increase the likelihood that a person will die in their preferred setting.22 Advance care planning can also be particularly important for people living with dementia. As the condition progresses, people with dementia have a decreased ability to make, and communicate, decisions.26 Advance care planning may decrease depressive symptoms, especially for people in the early stages of dementia.27

Uptake of advance care planning

Despite these benefits, the available research indicates that advance care planning may be an uncommon practice.

Research into the uptake, outcomes and utility of advance care planning in Australia is limited.28 The available research suggests that the practice of advance care planning in Australia is not common, particularly when compared with other planning documents such as wills.29

A 2017 Australian study assessed how many people aged 65 years or over had at least one advance directive on file. The study found a rate of 48% in residential care, 16% in hospitals and 3% in general practices.30 Most of the directives were non-statutory documents. Less than 3% had a statutory advance directive outlining preferences for care, and only 11% had a statutory advance directive appointing a substitute decision-maker.31

These rates are significantly higher than those recorded in previous Australian studies.32 For example, a 2014 study found zero advance directives among 100 elderly patients in a tertiary hospital.33

23 K Detering, A Hancock, M Reade and W Silvester, above n 21.
30 Above n 11, p 4.
referral hospital\textsuperscript{33} and a 2009 study found a 5\% median uptake of advance directives in selected residential aged care facilities.\textsuperscript{34}

The low uptake of advance directives may be explained by a lack of awareness and understanding about advance care planning in the community.\textsuperscript{35} People can also be reluctant to make what are seen as binding decisions about an unpredictable future\textsuperscript{36} and are concerned that advance directives cannot be changed once made.\textsuperscript{37}

There also seems to be a general reluctance to discuss issues around cognitive deterioration, end-of-life and death.\textsuperscript{38} These can be very challenging conversations that require someone to engage with their own mortality and plan for worst case scenarios.

\textit{Improving advance care planning practice in aged care}

Implementation of advance care plans

There is evidence suggesting that advance care plans are not always being implemented in accordance with the preferences set out in the document. Reasons for this may include health professionals or residential aged care facilities being fearful of litigation or conflict where the family is demanding treatment or care inconsistent with an advance care plan.\textsuperscript{39} There also seems to be some confusion about the legal effect of an advance care plan\textsuperscript{40} as well as difficulty locating or accessing advance care plans when they are needed.\textsuperscript{41}

Dr Detering and colleagues identified some of the ways that uptake and implementation of advance care plans and advance directives in the aged care context can be increased.\textsuperscript{42} These include educating health professionals and aged care staff about advance care planning and creating a systematic method for advance care planning in residential aged care facilities. On a practical level, correct storage and filing of documents is important.\textsuperscript{43}

\begin{thebibliography}{10}
\bibitem{36} Ibid.
\bibitem{37} G Yapp, C Sinclair, A Kelly, K Williams and M Agar, above n 3, p 141.
\bibitem{41} JJ Rhee, NA Zwar and LA Kemp, above n 39.
\bibitem{42} G Yapp, C Sinclair, A Kelly, K Williams and M Agar, above n 3, p 142.
\bibitem{43} K Buck, K Detering, A Pollard, M Sellars, R Ruseckaite, H Kelly, B White, C Sinclair and L Nolte, above n 7.
\bibitem{42} K Detering, A Hancock, M Reade and W Silvester, above n 21.
\bibitem{43} Ibid.
\end{thebibliography}
The approach to advance care planning discussions

Research has shown the framing of the conversation is important. Conversations around end-of-life issues can be confronting, and issues outside of medical care can be even more important for some people (for example, where a person will live if their condition deteriorates\(^44\)). Discussing how a person wants to live, not how they want to die, can make the conversation easier. Instead of focusing narrowly on medical interventions, it may be better to have a broader conversation about a person’s values and what is important to them in life.\(^45\) An appropriate person to initiate and facilitate the conversation also seems to be important.\(^46\)

Ideally, advance care planning is a flexible, iterative and ongoing discussion\(^47\) involving regular review.\(^48\)

It is important for family to be involved in advance care planning discussion, but Yapp and colleagues note that this should not be to the detriment of the participation of the focal person. This is particularly important for people with dementia—stigmas around the disease may mean that a person’s views are ignored or not sought.\(^49\)

Advance care planning for people with dementia

Successful advance care planning takes into account the needs of people with dementia and other forms of cognitive decline.\(^50\) The Cognitive Decline Partnership Centre\(^51\) has identified key ways that the uptake and quality of advance care planning for people with cognitive decline can be improved. These include ensuring that:

- Advance care planning occurs as early as possible after diagnosis so the person with cognitive decline can be as meaningfully involved in the process as possible. If left too late, it may not be possible for the person to participate.\(^52\)

- The scope of issues covered in the advance care planning process should be wider than just medical decisions related to end-of-life. It should consider ongoing decisions relating to broader financial, lifestyle and health matters, and focus on the person’s values and beliefs.\(^53\)

\(^44\) G Yapp, C Sinclair, A Kelly, K Williams and M Agar, above n 3, p 141.
\(^45\) Ibid p 144.
\(^46\) K Detering, A Hancock, M Reade and W Silvester, above n 21.
\(^48\) M Sellars, O Chung, L Nolte, A Tong, D Pond, D Fetherstonhaugh, F McInerney, C Sinclair and K Detering, above n 38.
\(^50\) A Waird and E Crisp, above n 23.
\(^51\) G Yapp, C Sinclair, A Kelly, K Williams and M Agar, above n 3, pp 139–140.
\(^52\) The National Health and Medical Research Council Partnership Centre for Dealing with Cognitive and Related Functional Decline in Older People (known as the Cognitive Decline Partnership Centre) brings together clinicians, researchers, aged care practitioners, policy makers and consumers who have expertise in working with older people with cognitive and related functional decline.
\(^53\) Ibid, p 5.
• People with cognitive decline should be informed about prognosis and possible disease progression to help them plan appropriately for the future.54

**Conclusion**

Advance care planning is a broad concept that may include conversations with health professionals, carers, family and friends. It may result in informal written documents, like a letter, or it may be crystallised into a formal directive. Each state and territory recognises a form of advance directive and allows people to appoint a substitute decision-maker in the event they lose capacity.

Essentially, advance care planning is a process of identifying preferences for future care and treatment. It is an important process that helps give people control over what happens to them, even if their decision-making or communication ability is impaired. Despite this, advance care planning is a relatively uncommon practice.

Advance care planning is particularly important for people to maintain control as they approach the end-of-life and there are ways that aged care providers can help increase uptake and implementation of advance care planning.

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*Background Paper 5*

8 of 11
Appendix

This appendix provides a brief overview of the mechanisms in each Australian state and territory for advance care planning.

Although an examination of issues relating to decision-making capacity is outside the scope of this paper, another difference between states and territories is the test used to assess whether a person has sufficient capacity to complete a formal advance care planning document.

Australian Capital Territory

In the Australian Capital Territory, a statutory *Health Direction* allows a person to formally record a direction to refuse, or withdraw, medical treatment.\(^{55}\)

A person can also complete an *Advance Care Plan Statement of Choices*. This is not a legal document, but a supporting document that can provide additional information about a person’s specific wishes regarding healthcare decisions.\(^{56}\)

A substitute decision-maker for financial matters, and personal, medical and lifestyle matters can be appointed under an enduring power of attorney.\(^{57}\)

New South Wales

There is no legislation providing for advance directives in New South Wales. However, advance directives can still be made and are legally binding.\(^{58,59}\)

A substitute decision-maker for personal, medical and lifestyles decisions can be appointed under an enduring power of guardianship,\(^{60}\) and a substitute decision-maker for financial and/or property decisions can be appointed under an enduring power of attorney.\(^{61}\)

Northern Territory

In the Northern Territory, a person can complete a statutory *Advance Personal Plan*.\(^{62}\) This is a legal document that sets out a person’s future health, financial and life choices should they be unable to make those decisions for themselves. The *Advance Personal Plan* has replaced the enduring power of attorney.

The *Advance Personal Plan* allows the appointment of a substitute decision-maker for financial, personal, medical and lifestyle matters.\(^{63}\) It includes an optional legally-binding Advance Consent Decision about future health care, and an optional Advance Care

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55 *Medical Treatment (Health Directions) Act 2006 (ACT)* Part 2.
57 *Powers of Attorney Act 2006 (ACT).*
58 Advance directives in New South Wales are binding under the common law.
60 *Guardianship Act 1987 (NSW)* Part 2.
63 Ibid Part 3.
Statement describing a person’s views, wishes and beliefs as to how they want to be treated in relation to any future health, financial or lifestyle matter. This includes questions such as:

What gives your life meaning? What do you value most in life? For example, independent, being on country/at home, being able to work, food, family etc.  

Queensland

In Queensland, a statutory Advance Health Directive directs substitute decision-makers and doctors about a person’s wishes and preferences for medical treatment.

Queensland also has the option of a Statement of Choices. This is used in some Queensland health facilities, residential aged care facilities and general practices to support advance care planning conversations. The statement can guide family and health care professionals when making medical decisions for a person that cannot make or communicate their own decisions. The statement focuses on a person’s wishes, values and beliefs.

A substitute decision-maker for medical related matters can be appointed under an Advance Health Directive, a substitute decision-maker for financial and/or personal and lifestyle matters is appointed under an enduring power of attorney.

South Australia

In South Australia, a statutory Advance Care Directive allows a person to record their wishes, preferences and instructions for future health care, living arrangements, personal matters, and end-of-life care.

An Advance Care Directive can also be used to appoint one or more substitute decision-makers to make decisions related to health care, residential and accommodation arrangements and personal affairs. A substitute decision-maker for financial decisions is appointed under an enduring power of attorney.

Tasmania

Tasmania does not have legislation providing for an advance directive. However, advance directives can still be made and are legally binding.

Tasmania has developed an Advance Care Directive for Care at the End of Life form to enable people to record their wishes for care at the end-of-life, and outline their values, beliefs and preferences for treatment to maintain quality of life. This is not a statutory advance direction.

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67 Advance Care Directives Act 2013 (SA).
68 Ibid.
A substitute decision-maker for personal, medical and lifestyle decisions is appointed under an enduring guardianship, and a substitute decision-maker for financial decision is appointed under an enduring power of attorney.  

**Victoria**

In Victoria, there is a statutory *Advance Care Directive* where a person can record general statements about values and preferences to guide future medical treatment decisions (values directive), and/or consent or refuse specific types of treatment (instructional directive).

Up to two people can be appointed as a person’s ‘medical treatment decision-maker’, which gives those people legal authority to make medical treatment decisions on a person’s behalf should they become unable to do so.

People in Victoria can also appoint a ‘support person’ who does not have the power to make medical treatment decisions on a person’s behalf (unless they are also appointed as the medical treatment decision-maker). Rather, they can assist the person in making, communicating and giving effect to their medical treatment decisions, including by accessing health information relevant to the person’s medical treatment.

A substitute decision-maker for financial, personal and lifestyle decisions (but not medical treatment decisions) is appointed under an enduring power of attorney. A ‘supportive attorney’ can be appointed to help them make and give effect to decisions related to personal matters, such as access to support services, or financial matters.

**Western Australia**

Western Australia has a statutory *Advance Health Directive* which allows a person to record their treatment decisions in respect of future treatment, including in relation to life sustaining measures and palliative care.

A substitute decision-maker for personal, medical and lifestyle decisions is appointed under an enduring power of guardianship, and a substitute decision-maker for financial and/or property decisions is appointed under an enduring power of attorney.

In Western Australia, a person can complete an advance care plan as a record of advance care planning discussions. It is not legally binding, but is a way of informing relevant people of personal wishes that are not covered in an *Advance Health Directive* or enduring power of guardianship. They may not necessarily be health or treatment related and could include specifying who they would like as visitors and their favourite music.

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72 *Medical Treatment Planning and Decisions Act 2016* (Vic).
73 Ibid.
74 Ibid.
75 *Powers of Attorney Act 2014* (Vic).
76 Ibid, Part 7.
77 *Guardianship and Administration Act 1990* (WA).
78 Ibid.