



1. Introduction
2. History
3. Key arguments
4. Prevalence
5. Outcomes
6. NSW policy
7. NSW law
8. NSW Committee report
9. Legislation in Australia
10. National Framework
11. Conclusion

## Advance Care Directives

by Lenny Roth

### 1. Introduction

End-of-life care has been a topic of debate in Australia for several years and, with a rising aged population, is an issue that will only increase in importance.<sup>1</sup> One part of the debate arises from the fact that persons approaching the end of their life often lose capacity to make their own treatment decisions. It has been suggested that this can result in stress for health professionals and families, who are left with the responsibility for making such decisions; and it can lead to the patient receiving unwanted and unnecessary treatment in acute care settings, with adverse outcomes for the patient and the health system.<sup>2</sup>

Governments in Australia and overseas have promoted Advance Care Planning, including Advance Care Directives, as one way of addressing these issues. This e-brief begins with a brief history of this policy. It then outlines the debate about Advance Care Directives and presents evidence about their uptake and impact on care outcomes. Next, the paper presents a summary of government policy and law in NSW, and it notes a 2010 Parliamentary Committee report's recommendation to consider whether legislation is needed in NSW. The final section outlines key features of legislation in other States and Territories.

#### Key concepts

##### *Advance Care Planning (ACP)*

The process of preparing for likely scenarios near the end of life that usually includes assessment of, and dialogue about, a person's understanding of their medical history and condition, values, preferences, and personal and family resources.

##### *Advance Care Directive (ACD)*

A document that describes one's future preferences for medical treatment in anticipation of a time when one is unable to express those preferences because of illness or injury (has also been called a 'living will').

Source: NSW Health, [Using Advance Care Directives: New South Wales](#), 2004

## 2. History

Seymour and Horne explain:

The concept of a 'living will' was initially proposed in 1969 in the USA, and was subsequently embedded in US legislation which followed high profile cases of the 1970s and 1980s. These involved the withdrawal of life support from young women left in persistent vegetative states...The passage of the Patient Self-Determination Act in the USA during the 1990s...made it mandatory for all patients admitted to a health care institution...to be given written information about their rights on decision making and the right to prepare an advance statement relating to their future medical care. As a result of legislative processes in the US, the emphasis [was initially] on the completion of instructional directives or the nomination of proxies...In the last ten years, this emphasis has begun to change as evidence emerges of what is important to patients and families. A new model has emerged in which emphasis is placed on the potential for ACP discussions to help patients and their families prepare for death, review their immediate goals and hopes for the future and strengthen their relationships...<sup>3</sup>

They note that similar developments have taken place in Canada, Australia and Northern Europe since 1990 but it is only in the last few years that there has been serious debate about whether and how Advance Care Planning should be implemented, and about its risks and benefits.<sup>4</sup>

## 3. Key arguments

O'Neill and Peisah have summarised the arguments for Advance Care Directives:

Advance directives...give people the dignity of making their own decisions. Most people like the idea of making arrangements so that they can die with greater dignity than they otherwise would if life sustaining treatment was continued until the medical decision that further treatment was futile was made. Advance directives have many advantages, not the least of which involves a reflective discussion in a non-crisis situation which can prepare all involved and can diminish subsequent guilt and conflict over later decisions and which can offer a sense of control for people in the dying process. Decision-making at the end of life is an activity often overlaid with high emotion. Accordingly, it often provides a focal point for conflict within and between patients, families and treating staff. The significant variation in the way health care professionals approach situations involving the use of life-sustaining treatment has resulted in accusations of over zealous treatment on the one hand and neglect on the other.<sup>5</sup>

The debate about Advance Care Directives in Australia has been limited but there has been much critical commentary in the United States.<sup>6</sup> O'Neill and Peisah have outlined the main arguments against Advance Care Directives as follows:

Advance directives rely on the concept of patient autonomy – the authority of the former competent self to govern the welfare of their later, non-competent selves. Critics of advance directives have highlighted metaphysical (change in personal identity through physical or mental changes) and epistemic constraints on projecting decisions to future states of ourselves.

Detailed instructional directives are the most controversial due to concerns that people may underestimate their future desire for medical treatment in

the face of death, or be unable to predict every potential condition and circumstance...Degrazia has argued that people sometimes cannot grasp in detail the circumstances in which advance directives will apply and goes on to argue that there can be major changes in a person's values and preferences when they complete their directive and when it comes into effect. This led Degrazia to argue that the pre-dementia person and the same person with dementia were literally two different people and that any advance directive...was effectively directed to someone else...<sup>7</sup>

### 4. Prevalence

Seymour and Horne state that “the frequency of use of ACP records varies markedly across the world, with very low take up reported in most countries except some areas in North America”.<sup>8</sup> There is very little evidence about the use of Advance Care Planning and Advance Care Directives in Australia. A 2000 paper reported on a study on the prevalence of Advance Care Planning measures in residential aged-care in the Hunter region.<sup>9</sup> Less than 1 per cent of residents had a formal Advance Care Directive; 5.6 per cent had a formal guardian; 2.8 per cent had an enduring guardian; and 65 per cent had a ‘person responsible’ recorded to make decisions for them.<sup>10</sup> A 2009 article reported on a study to assess the prevalence of Advance Care Directives in thirty residential aged care facilities in the Northern Illawarra.<sup>11</sup> Of the 24 responding facilities, 13 confirmed the presence of Advance Care Directives for some part of their population (the median result was 5 per cent of the population). Two facilities had 100 per cent of their residents documented with Advance Care Directives.<sup>12</sup>

The reasons for low uptake of Advance Care Planning in Australia were explored in a paper published in 2012.<sup>13</sup> The study involved telephone interviews conducted with 23 participants, comprising representatives of various organisations and healthcare professionals with experience and interest in aged care, and end of life issues. The paper reported:

The reasons behind the low level of uptake of ACP in Australia have been largely unknown. Our study shows that the reasons may be lack of societal awareness and understanding of ACP, as well as lack of health professionals' involvement in ACP a result of time pressures, financial disincentives and inadequate education and training in ACP.<sup>14</sup>

### 5. Outcomes

There has been very little research in Australia on the outcomes associated with Advance Care Planning and Advance Care Directives.<sup>15</sup> A 2011 paper, which discussed the US experience, suggested that few people complete Advance Care Directives, they “are often not available when needed”, and “the treatment that people would choose at the end of life is often very different from the treatment they receive”.<sup>16</sup> A 2014 paper that comprehensively reviewed studies on Advance Care Planning from around the world (most of which came from the United States) concluded:

...there is some evidence that ACP positively impacts the quality of end-of-life care. DNR [Do Not Resuscitate] orders were found to reduce the use of cardiopulmonary support measures, reduce hospitalisations and increase the use of hospice care. DNH [Do not Hospitalise] orders have almost invariably been shown to be related to a reduced number of hospitalisations and an increased use of hospice care. The effects of advance directives [i.e.

Advance Directives and Durable Powers of Attorney] seem more diverse, but they tend to be related to an increased frequency of out-of-hospital care that is aimed at increasing the patient's comfort instead of prolongation of life. Extensive ACP interventions may be more effective than written documents alone. They were found to result in an increased frequency of out-of-hospital and out-of-ICU care and in increased compliance with patient wishes and satisfaction with care. However, research on the outcome of ACP is very diverse. More studies are needed with an experimental design, outside the United States, in different settings, including the community...<sup>17</sup>

### 6. NSW policy

In 2004, the NSW Department of Health published [Using Advance Care Directives: New South Wales](#), which outlined best practice on the use of Advance Care Directives within an Advance Care Planning process.<sup>18</sup> In 2005, the Department published [End of life care and Decision-making guidelines](#), which again emphasised the importance of Advance Care Planning.<sup>19</sup> The 2004 guide noted that an Advance Care Directive "that complies with the requirements set out in this document is legally binding in NSW, and functions as an extension of the common law right to determine one's own medical treatment". The requirements included:

- *Specificity* – It must be clear that an advance directive applies to the clinical circumstances arising. This can include treatment preferences in relation to both conditions existing at the time the ACD is made, as well as future anticipated conditions (including catastrophic injury). The advance care directive should be clear and specific enough to guide clinical care. The specificity of the ACD may be improved if the person discusses it with their doctor.
- *Currency* – An advance care directive prepared a long time before it is referred to may not reflect the current intentions of the patient. Nonetheless, if the person was competent at the time the ACD was made then it should still be treated as legally binding. People should be encouraged to review their directives periodically, for example once a year, after an illness, or with a change in health as treatment preferences may change accordingly.
- *Competence* – The person must have been competent to make their own health care decisions when the advance directive was drafted. A person should be considered competent to make a health care decision if they appear able to comprehend, retain, and weigh up the relevant information and then make a choice. Some situations may pose particular difficulties in assessing competence to make an ACD, such as early dementia or intermittent mental health problems. A second opinion from a suitably qualified health professional is advisable.
- *Witnessing* – It is not essential to have an ACD witnessed. However, there are a number of reasons to encourage a person to do this. It may allow for later follow-up if doubts are raised about the person's competence at the time of drafting. It offers some protection against forgery. It may also allay concerns about undue influence in the expressed treatment choices...<sup>20</sup>

The publication also noted that:

Although the ACD has legal authority, its use in practice should be thought of as an assisting device: an education tool, a 'worksheet', a framework for discussion, or a way of documenting preferences when substitute decision-

## Advance Care Directives

makers may later be unsure or disagree. Its completion is not the only goal, and effective advance care planning does not necessarily require the completion of a directive. The person may instead choose to verbally communicate specific wishes to the doctor and family, or formally appoint a substitute decision-maker (enduring guardian) to make treatment decisions on their behalf in the event of their incompetence.<sup>21</sup>

In 2013, the NSW Ministry of Health released [Advance Planning for Quality Care at End of Life: Action Plan 2013–2018](#), which aims to “normalise Advance Care Planning and improve end of life care by integrating patients’ wishes into and throughout the management of chronic life-limiting illness”.<sup>22</sup> The Action Plan contains six objectives, namely:

1. Patients consider earlier in life and throughout the course of illness who can best make treatment and care decisions on their behalf should they lose the capacity to do so.
2. Patients’ wishes are appropriately documented and understood by their treating health professionals.
3. Patients are provided with care consistent with their wishes, within therapeutic limits, always focused on quality symptom management and best practice.
4. Patients’ preferences about where they want to die are respected and appropriate support and resources are available to provide this.
5. Families and carers are clear about patients’ wishes in advance so that they experience reduced burden of decision-making on patients’ behalf.
6. Health professionals consider Advance Care Planning for end of life as an expected part of clinical care, understand the clinical and other requirements for doing so, and are supported in providing best practice treatment and care to dying patients.

### 7. NSW law

The common law principles in relation to Advance Care Directives were outlined in a 2009 NSW Supreme Court decision: [Hunter and New England Area Health Service v A](#). In that case, Mr A was a patient who had developed renal failure and was being kept alive in a hospital by mechanical ventilation and kidney dialysis. As outlined in the judgment:

On 14 July 2009, the Service became aware that a document apparently prepared by Mr A a year earlier, on 19 August 2008, indicated that he would refuse dialysis. In those circumstances, the Service commenced these proceedings seeking...declarations to the effect that the document...was a valid “Advance Care Directive” given by Mr A, and that it would be justified in complying with his wishes as expressed in that directive.<sup>23</sup>

Mr A was a Jehovah’s Witness and the document was one in which congregations of that faith provided to members so that they could indicate their attitude to various forms of medical treatment.<sup>24</sup> The document (Worksheet 2) stated that “you should have your physician explain exactly what is involved in any proposed procedure to ensure that it is in harmony with Bible principles and with your own conscientious decisions”.<sup>25</sup>

Justice McDougall outlined a number of legal principles including:

A person may make an “advance care directive”: a statement that the person does not wish to receive medical treatment, or medical treatment of specified kinds. If an advance care directive is made by a capable adult, and is clear and unambiguous, and extends to the situation at hand, it must be respected. It would be a battery to administer medical treatment to the person of a kind prohibited by the advance care directive...

.....  
It is not necessary, for there to be a valid advance care directive, that the person giving it should have been informed of the consequences of deciding, in advance, to refuse specified kinds of medical treatment. Nor does it matter that the person’s decision is based on religious, social or moral grounds rather than upon (for example) some balancing of risk and benefit. Indeed, it does not matter if the decision seems to be unsupported by any discernible reason, as long as it was made voluntarily, and in the absence of any vitiating factor such as misrepresentation, by a capable adult.<sup>26</sup>

Applying the relevant principles, Justice McDougall concluded:

I consider that Worksheet 2 in general, and the advance refusal of dialysis in particular, represent Mr A’s prospective exercise of his right of self-determination: his right to decide what should be done to his own body. There is nothing in the evidence to suggest that his expression of intent was vitiated in any way. On the contrary, it seems to me to be clear that it was his own voluntary decision.<sup>27</sup>

Accordingly, Justice McDougall granted the declaration that was sought.

### 8. NSW Committee report

In its February 2010 [report](#) on substitute decision-making for people lacking capacity, the Legislative Council’s Standing Committee on Social Issues noted that there was a difference of opinion among inquiry participants as to whether NSW should have legislative provisions on Advance Care Directives.<sup>28</sup> Some participants considered that legislation was needed to clarify the law and to give Advanced Care Directives a more formal and widely known status. Others took the view that the existing common law and policy guidance was adequate. The Committee concluded that recommendations in this area could only be made after receiving evidence from a broader range of stakeholders. It therefore recommended:

That the NSW Government consider the need for an inquiry focussing specifically on the provisions for end-of-life decision-making and advance care directives in NSW and consider referring such an inquiry to the NSW Law Reform Commission.<sup>29</sup>

The NSW Government’s [response](#) to the report dated March 2011 did not support this recommendation for a number of reasons including:

1. Recent developments in the common law provide guidance and protection for all practitioners who follow an advance care directive, and demonstrate how effectively the common law can sometimes advance policy in line with community thinking. The common law allows flexibility in decision-making for practitioners who are faced with the difficult task of determining whether an advance care directive is valid in an emergency situation which may not be the case if use of an advance care directive is prescribed in legislation...
2. End-of-life decision making is not a black and white area, and legislation can be incapable of allowing for cases to be considered on an individual

basis. A legislative form of advance care directive may not be as effective as envisaged as people wish to express their decision in different ways.

3. Legislation of advance care directives has occurred in several other states and there is currently no evidence to suggest there has been an increase in the use of advance care directives or a marked difference in practice at the frontline level in the community in those places, as opposed to NSW.

4. In NSW there is a range of information available both in case law and policy which adequately provides for the use of advance care directives in NSW.

5. The Australian Health Ministers' Advisory Council is currently in the process of drafting a National Framework for advance care directives with one of the objectives of the framework being to promote "harmonisation" in law and policy.... One of the core standards listed is that legislation should preserve common law standards such that advance care directives should still be recognised under common law, regardless of which form they are written on. The framework does not bring an imperative for introducing uniform advance care directive legislation in all states, only that where legislation exists, it be made more consistent. This has meant that states which have legislation...may now need to review that legislation to make it more consistent and compatible with national standards.<sup>30</sup>

In October 2011, it was reported that a spokeswoman for the then Attorney-General, Greg Smith, told the ABC that "currently, no clear need for further legislation in relation to these issues has been identified".<sup>31</sup>

### 9. Legislation in Australia

#### Overview

All other States and Territories, except Tasmania, have enacted legislation providing for Advance Care Directives (ACDs). South Australia was the first jurisdiction to enact such laws, with the *Natural Death Act 1983* (which was replaced in 1995 by the *Consent to Medical Treatment and Palliative Care Act*). Victoria followed five years later with the *Medical Treatment Act 1988*, as did the Northern Territory with the *Natural Death Act 1988*. Queensland enacted legislation in 1998, the ACT in 2006, and Western Australia in 2008. The main reason for enacting ACD legislation in Australia was uncertainty about whether the common law recognised ACDs.<sup>32</sup>

In 2013, South Australia and the Northern Territory both enacted new legislation on ACDs. The South Australian reforms arose out of a review in 2009 by an Advance Directives Review Committee.<sup>33</sup> The main aim of the reforms was to create "a single form of Advance Care Directive to replace the existing Enduring Power of Guardianship, Medical Power of Attorney and the Anticipatory Direction".<sup>34</sup> The South Australian Act will commence on 1 July 2014. The Northern Territory reforms attempted to fill gaps in the existing legislative framework. As outlined in a 2013 issues paper:

The Northern Territory does not presently have legislation allowing a person to appoint a medical attorney. The *Powers of Attorney Act* is limited to financial and property matters. Issues of health and welfare decisions can only be dealt with by appointment of a guardian under the *Adult Guardianship Act*, which does not allow for competent individuals to appoint substitute decision makers of their own choice if needed in the future.

Additionally, except for the limited provisions of the *Natural Death Act* (which relates to directions around the artificial prolonging of death) there is currently no legislative capacity for individuals to make advance health directives which have binding power on others in the future.<sup>35</sup>

**Current legislation in other States & Territories**

Jurisdiction	Legislation	Terminology
Queensland	<i>Powers of Attorney Act 1998</i> (Pt. 3)	Advance Health Directive
Victoria	<i>Medical Treatment Act 1988</i> (Pt. 2)	Refusal of Treatment Certificate
South Australia	<i>Advance Care Directives Act 2013</i>	Advance Care Directive
Western Australia	<i>Guardianship and Administration Act 1990</i> (Pt. 9B)	Advance Health Directive
Northern Territory	<i>Advance Personal Planning Act 2013</i>	Advance Consent Decision
Australian Capital Territory	<i>Medical Treatment (Health Directions) Act 2006</i>	Health Direction

**Key features of legislation<sup>36</sup>**

Type of Directive: In most jurisdictions, the legislation permits an ACD to include a consent to or refusal of health care, including withholding or withdrawing life-sustaining treatment. In Victoria and the ACT, the relevant legislation only permits the refusal of medical treatment; and in Victoria the refusal must relate to a “current condition”.<sup>37</sup> In South Australia, the statute states that a provision in an ACD comprising a refusal of particular health care is a binding provision but all other provisions are non-binding.<sup>38</sup>

Making a Directive: In all jurisdictions there are certain requirements that apply to the making of an ACD. In all jurisdictions, except Queensland and the ACT, the ACD must be in an approved form. In all jurisdictions, it must be witnessed by one or more persons. In some jurisdictions, the witness must certify his or her satisfaction of certain matters; and in two States (Queensland and Victoria) a doctor must also certify these matters.

In Queensland, the witness and a doctor are required to certify that the principal appeared to have capacity to make the Advance Health Directive.<sup>39</sup> In Victoria, a witness and a medical practitioner are required to certify a number of matters for a Refusal of Treatment Certificate including that the patient is of sound mind, and also that:

the patient has been informed about the nature of his or her condition to an extent which is reasonably sufficient to enable the patient to make a decision about whether or not to refuse medical treatment generally or of a particular kind (as the case requires) for that condition and that the patient has appeared to understand that information.<sup>40</sup>

In South Australia, the witness is required to certify that:

- (i) he or she gave to the person giving the advance care directive any information required by the regulations for the purposes of this section; and
- (ii) he or she explained to the person giving the advance care directive the legal effects of giving an advance care directive of the kind proposed; and



## Advance Care Directives

(iii) in his or her opinion, the person giving the advance care directive appeared to understand the information and explanation given to him or her by the suitable witness under this paragraph; and

(iv) in his or her opinion, the person giving the advance care directive did not appear to be acting under any form of duress or coercion.<sup>41</sup>

In Western Australia, it is a requirement that the maker of an Advance Health Directive be encouraged to seek medical or legal advice (and the approved form must include provision for the maker to indicate whether he or she obtained such advice) but the validity of a Directive is not affected by a failure to comply with this requirement.<sup>42</sup>

Operation of Directive: In Queensland, the Act places restrictions on the operation of an Advance Health Directive that refuses life-sustaining treatment. The Act provides that such a directive cannot operate unless the person who made the directive:

- has a terminal illness and may reasonably expected to die within one year; or
- is in a persistent vegetative state; or
- is permanently unconscious; or
- has an illness or injury of such severity that there is no reasonable prospect he or she will recover to the extent that his or her life can be sustained without life sustaining measures.<sup>43</sup>

In addition, a Directive cannot operate unless the person has no reasonable prospect of regaining decision-making capacity for health matters.<sup>44</sup> A Directive to withhold or withdraw artificial nutrition or hydration cannot operate unless providing the measure would be inconsistent with good medical practice.<sup>45</sup>

In all jurisdictions except the ACT, the legislation outlines general circumstances in which an ACD will not operate, or in which a health provider may refuse to comply with the ACD. In the Northern Territory, a Directive may only be disregarded in accordance with a Court order. The relevant provisions are summarised below.

Jurisdiction	General circumstances in which Directive does not operate
Queensland	A health provider may refuse to comply with a direction in an advance health directive if he or she has reasonable grounds to believe that the direction is uncertain or inconsistent with good medical practice or that circumstances, including advances in medical science, have changed to the extent that the terms of the direction are inappropriate. <sup>46</sup>
Victoria	A refusal of treatment certificate ceases to apply to a person if the medical condition of the person has changed to such an extent that the condition in relation to which the certificate was given is no longer current. <sup>47</sup>
South Australia	A health practitioner may refuse to comply with a provision of an advance care directive if he or she believes on reasonable grounds that: <ul style="list-style-type: none"> <li>(a) the person who gave the advance care directive did not intend the provision to apply in the particular circumstances; or</li> </ul>

	(b) the provision does not reflect the current wishes of the person who gave the advance care directive. <sup>48</sup>
Western Australia	A treatment decision in an advance health directive does not operate if circumstances exist or have arisen that —  (a) the maker of that directive would not have reasonably anticipated at the time of making the directive; and  (b) would have caused a reasonable person in the maker's position to have changed his or her mind about the treatment decision. <sup>49</sup>
Northern Territory	The Court may order that an advance consent decision be disregarded if:  (a) there is no reasonable possibility that the adult would have intended the advance consent decision to apply in the circumstances; or  (b) taking health care action in reliance on the advance consent decision would cause the adult unacceptable pain and suffering; or would otherwise be so wholly unreasonable that it is justifiable to override the adult's wishes. <sup>50</sup>

Preservation of common law: It is important to note that the legislation in Queensland, Western Australia, and the Northern Territory expressly preserves the operation of the common law in relation to ACDs. This would mean that the common law may provide legal authority for an ACD that does not meet the statutory requirements. Similarly, the Victorian and ACT legislation both provide that the Act does not affect any right of a person under “any other law” to refuse medical treatment. It has been suggested that the Queensland and Victoria provisions that expressly preserve the common law may be negated by inconsistent provisions in guardianship laws.<sup>51</sup> The South Australian legislation is silent on the matter.

### Law reform proposals

A 2010 report of the Queensland Law Reform Commission on guardianship laws made several recommendations to reform the provisions on Advance Health Directives.<sup>52</sup> One of the recommendations was to provide that a Directive does not operate if it is uncertain or circumstances, including advances in medical science, have changed to the extent that the person would have considered that the terms of the direction are inappropriate. It also recommended providing that a Directive must be made in an approved form, and making it clear that common law recognition is not affected. The recommendations have not yet been implemented.

A 2012 report of the Victorian Law Reform Commission on guardianship recommended that the Refusal of Treatment Certificate should be replaced by an Instructional Health Care Directive, which would permit directives about medical treatment in a broader range of circumstances.<sup>53</sup> This new Directive would need to be in a prescribed form. The Act would specifically state that the Directive does not operate if the maker would not have intended it to apply to the circumstances that have arisen. The Act should make it clear that any existing common law rights are preserved. These recommendations have also not yet been implemented.

### 10. National Framework

In September 2011, the Australian Health Ministers Advisory Council published [A National Framework for Advance Care Directives](#).<sup>54</sup> It defines an ACD broadly, in that it includes a document that appoints a substitute decision-maker to make decisions about health care and personal life management (i.e. an enduring guardian).<sup>55</sup> The Framework contains a Code for Ethical Practice, “which sets out principles to guide practice where ACDs are applied in health, institutional and aged care settings”.<sup>56</sup> The Code contains 15 principles including that “a refusal of a health-related intervention in a valid Advance Care Directive must be followed, if intended by the person to apply to the situation”. The Framework also incorporates Best Practice Standards that “seek to enable policy, legislation, and practice to become more consistent across Australia over time and allow for the recognition of ACDs across jurisdictional boundaries”.<sup>57</sup>

### 11. Conclusion

Advance Care Directives are legal instruments that can be used in planning for end of life care. They may be completed by a person in isolation or as part of an Advance Care Planning process involving health professionals and family members. It is important to emphasise that effective Advance Care Planning can be carried out without completion of an Advance Care Directive. The person may instead choose to verbally communicate wishes or preferences to the doctor and family and/or formally appoint a substitute decision-maker (guardian) to make treatment decisions on their behalf.

Advance Care Directives are seen to have a number of benefits including giving people control over their end of life treatment. However, debates in the United States suggest that these Directives can be problematic. The evidence in Australia about the impact of Advance Care Directives and Advance Care Planning on care is limited while findings from abroad are mixed. One finding is that extensive Advance Care Planning interventions may be more effective than written documents alone. For various reasons, the uptake of Advance Care Planning in Australia has been low.

In 2013, NSW Health released an Action Plan to promote Advance Care Planning, which has six key objectives. One question that remains unresolved in NSW is whether there is a need for legislative provisions on Advance Care Directives. Most other States and Territories have legislated but in most cases the statute expressly preserves the operation of the common law. In other words, the legislation provides a detailed framework within which persons can have certainty about whether an Advance Care Directive will be valid but it also allows the common law to recognise a Directive which does not meet the statutory criteria.

---

<sup>1</sup> For recent discussion in the media, see: A Corderoy, R Olding, and A Black, [The high cost of holding on](#), *Sydney Morning Herald*, 23 April 2014; L Carroll, [End of life treatment for elderly under question](#), *Sydney Morning Herald*, 24 April 2014

<sup>2</sup> See for example, I Scott et al, NSW Ministry of Health, [Difficult but necessary conversations the case for advance care planning](#) (2013) 199(10) *Medical Journal of Australia* 662; and NSW Ministry of Health [Advance Planning for Quality Care at End of Life: Action Plan 2013–2018](#), 2013, p12

- <sup>3</sup> J Seymour and G Horne, Advance Care Planning for end of life: an overview, Ch 2 in K Thomas and B Lobo (eds), *Advance Care Planning in End of Life Care*, Oxford University Press, 2011, p18
- <sup>4</sup> J Seymour and G Horne, note 3, p19
- <sup>5</sup> N O'Neill and C Peisah, *Capacity and the Law*, Sydney University Press Law Books, 2011, [Ch 13.3](#)
- <sup>6</sup> See A Fagerlin and C Schneider, [Enough: The Failure of the Living Will](#) (2004) 34(2) *Hastings Center Report* 30-42; C Hertogh, [The misleading simplicity of advance directives](#) (2011) 23(4) *International Psychogeriatrics* 511-515; and M Gillick, [Reversing the Code status of advance directives](#) (2010) 362(13) *New England Journal of Medicine* 1239
- <sup>7</sup> N O'Neill and C Peisah, note 5, [Ch 13.3](#)
- <sup>8</sup> J Seymour and G Horne, note 3, p19
- <sup>9</sup> B Nair et al, [Advance care planning in residential care](#) (2000) 30 *Australian and New Zealand Journal of Medicine* 339 Article
- <sup>10</sup> For another study in the Hunter, see M Zib and P Saul, [A pilot audit of the process of end-of-life decision-making in the intensive care unit](#) (2007) 9(2) *Critical Care and Resuscitation* 213. It reported on an audit of 47 cases in the Intensive Care Unit of John Hunter Hospital, Newcastle in which treatment was withdrawn from patients. In none of the audited cases was an ACD available.
- <sup>11</sup> A Bezzina, 'Prevalence of advance care directives in aged care facilities of the Northern Illawarra' (2009) 21(5) *Emergency Medicine Australasia* 379
- <sup>12</sup> See also the findings about the prevalence of ACP plans in Alzheimer's Australia, [End of life care for people with dementia: survey report](#), February 2014, p50, 67
- <sup>13</sup> J Rhee, N Zwar and L Kemp, [Uptake and implementation of Advance Care Planning in Australia: findings of key informant interviews](#) (2012) 36 *Australian Health Review* 98
- <sup>14</sup> J Rhee, N Zwar and L Kemp, note 13, p101
- <sup>15</sup> For an Australian study on a complex ACP intervention, see K Detering et al, [The impact of advance care planning on end of life care in elderly patients: randomised controlled trial](#) (2010) *British Medical Journal* [online: doi:10.1136/bmj.c1345].
- <sup>16</sup> A Wilkinson, *Advance directives and Advance Care Planning: the US Experience*, Ch 17 in K Thomas and B Lobo (eds), *Advance Care Planning in End of Life Care*, Oxford University Press, 2011, p194
- <sup>17</sup> A Brinkman-Stoppelenburg, J Rietjens, and A van der Heide, 'The effects of advance care planning on end-of-life care: A systematic review' (2014) *Palliative Medicine* [online: DOI: 10.1177/0269216314526272], p22
- <sup>18</sup> NSW Department of Health, [Using advance care directives: New South Wales](#), 2004. For earlier policy developments, see B Squires and F Barr, [The Development of Advance Care Directives in New South Wales](#) (2005) 24 *Australasian Journal on Ageing* S35
- <sup>19</sup> NSW Department of Health, [End of life care and Decision-making guidelines](#), 2005
- <sup>20</sup> NSW Department of Health, note 18, p7
- <sup>21</sup> An enduring guardian can be appointed under the *Guardianship Act 1987* (NSW), Part 2.
- <sup>22</sup> NSW Ministry of Health, [Advance Planning for Quality Care at End of Life: Action Plan 2013–2018](#), 2013, p2
- <sup>23</sup> [Hunter and New England Area Health Service v A](#) (2009) 74 NSWLR 88 at [1]-[2]
- <sup>24</sup> [Hunter and New England Area Health Service v A](#), note 23, at [44]
- <sup>25</sup> [Hunter and New England Area Health Service v A](#), note 23, at [46]-[47]
- <sup>26</sup> [Hunter and New England Area Health Service v A](#), note 23, at [40]
- <sup>27</sup> [Hunter and New England Area Health Service v A](#), note 23, at [56]-[57]
- <sup>28</sup> NSW Legislative Council Standing Committee on Social Issues, [Substitute decision-making for people lacking capacity](#), Report 43, February 2010, p202
- <sup>29</sup> NSW Legislative Council Standing Committee on Social Issues, note 28, p202
- <sup>30</sup> NSW Government, [Legislative Council Standing Committee on Social Issues Substitute decision-making for people lacking capacity: Government Response](#), 3 March 2011, p19
- <sup>31</sup> S Smith, *National Laws needed for Living Wills*, *Lateline*, 18 October 2012
- <sup>32</sup> L Willmott, [Advance Directives and the Promotion of Autonomy: a Comparative Australian Statutory Analysis](#) (2010) 17 *Journal of Law and Medicine* 556
- <sup>33</sup> See Advance Directives Review Committee: [Planning ahead: your health, your money, your life - Proposed Changes to Law and Policy](#), First Report of the Review of South Australia's Advance Directives, 2009; and [Planning ahead: your health, your money,](#)

- [your life - Stage 2 Proposals for implementation and communication strategies](#), Second Report of the Review of South Australia's Advance Directives, 2009.
- 34 J Hill, [SA Parliamentary Debates \(HA\)](#), 17 October 2012, p3227
- 35 NT Department of Attorney-General and Justice, [Advance Personal Planning Bill 2013 Issues Paper](#), June 2013, p6
- 36 A more detailed analysis of the provisions can be found in L Willmott, note 32; and in Australian Health Ministers' Advisory Council, [A National Framework for Advance Care Directives](#), September 2011, Appendix A.
- 37 *Medical Treatment Act 1988* (Vic), s 5
- 38 *Advance Care Directives Act 2013* (SA), s 19
- 39 *Powers of Attorney Act 1998* (Qld), s 44(4), (6), (7)
- 40 *Medical Treatment Act 1988* (Vic), s 5
- 41 *Advance Care Directives Act 2013* (SA), s 15(1)(b). Regulations have not yet been made.
- 42 *Guardianship and Administration Act 1990* (WA), s 110Q, 110QA
- 43 *Powers of Attorney Act 1998* (Qld), s 36(2)
- 44 *Powers of Attorney Act 1998* (Qld), s 36(2)
- 45 *Powers of Attorney Act 1998* (Qld), s 36(2)
- 46 *Powers of Attorney Act 1998* (Qld), s 103
- 47 *Medical Treatment Act 1988* (Vic), s 7(3)
- 48 *Advance Care Directives Act 2013* (SA), s 36(2)
- 49 *Guardianship and Administration Act 1990* (WA), s 110S(3)
- 50 *Advance Personal Planning Act 2013* (NT), s 41(2), (3)
- 51 See L Willmott, note 32; and Queensland Law Reform Commission, [A Review of Queensland's Guardianship Laws](#), Report No 67, September 2010, p96ff
- 52 Queensland Law Reform Commission, [A Review of Queensland's Guardianship Laws](#), Report No 67, September 2010, Volume 2, Ch9
- 53 Victorian Law Reform Commission, [Guardianship](#), Final Report No. 24, April 2012, Ch11
- 54 Australian Health Ministers' Advisory Council, [A National Framework for Advance Care Directives](#), September 2011
- 55 Australian Health Ministers' Advisory Council, note 54, p10
- 56 Australian Health Ministers' Advisory Council, note 54, p2
- 57 Australian Health Ministers' Advisory Council, note 54, p2

Information about Research Publications can be found on the Internet at the:  
[NSW Parliament's Website](#)

Advice on legislation or legal policy issues contained in this paper is provided for use in parliamentary debate and for related parliamentary purposes. This paper is not professional legal opinion.

© 2014

Except to the extent of the uses permitted under the *Copyright Act 1968*, no part of this document may be reproduced or transmitted in any form or by any means including information storage and retrieval systems, without the prior consent from the Manager, NSW Parliamentary Research Service, other than by Members of the New South Wales Parliament in the course of their official duties.

ISSN 1838-0204