

# VOICES BEFORE THE BEYOND

Uniform national legislation on advance care plans and directives is needed to protect end-of-life autonomy, argues **Jessica Borbasi**

**T**he debate about how we should face our mortality will not go gently. Well-known spokespeople who promote voluntary euthanasia or assisted dying as ‘death with dignity’ frequently cite negative personal experiences to express their disquiet at the thought of death without autonomy.

Community concerns about self-determination and the intrusive care received from a de-personalised health system arise when people imagine themselves in the future without a voice at the end of life. But before opting for the alternatives to a natural death, we should talk about the way our voices can be heard when our mouths can no longer speak.

Value-driven palliative care in combination with advance care directives (ACDs) can offer autonomy at the end of life, if only ACDs were more accessible and more utilised.

## Perception of death among ageing Australians

People perceive that the experience of ageing, health and death is changing. Older Australians, in particular, are themselves—or by caring for parents and loved ones—coming to appreciate how well the health system promotes longevity but how poorly it manages decline from chronic disease exacerbation and death.

The lack of holistic, integrated, person-centred care towards the end of life has resulted in the common experience of death being one where a patient endures multiple repeat hospital admissions, receives reactive and often inappropriate care or interventions, and dies a hospital death that has not been pre-empted with a compassionate conversation

about values or goals for the end of life. These are deaths without autonomy.

A recent study of people who died in New South Wales (NSW) found that on average in the last six months of life, decedents with cancer visited the emergency department once, had three hospital admissions, participated in 90 clinician visits/procedures, and were prescribed 41 medications at an average cost of \$30,000 per person. In the same study, only 10% of the cancer cohort and 1% of the control cohort received palliative care, and the majority died in hospital.<sup>1</sup>

Despite the best attempts of a series of programs and lobby groups to encourage Australians to discuss ageing, death and dying, this domain has been overwhelmed by fear and personal horror stories because of the inherent inflexibility and unsuitability of our current health system.

One claim pushing an agenda of anxiety and radical reform is that 25% of patients who ended their lives in Oregon under assisted dying laws were concerned about pain. But what is possibly more concerning is that 91% may have sought to end their lives because they feared losing autonomy.<sup>2</sup> Autonomy is the right



**Dr Jessica Borbasi** is a Research Associate in the Healthcare Innovations Program at The Centre for Independent Studies (CIS) and author of the CIS research report *Life Before Death: Improving Palliative Care for Older Australians*, released in November 2017. Copies are available at [www.cis.org.au](http://www.cis.org.au)

to self-determination free of external influence. In our liberal democracy it is a fundamental attribute, one that is sacred and ferociously defended. Palliative care, in combination with advance care planning and directives, can help people achieve end-of-life autonomy.

An Advance Care Directive is otherwise known as a living will, written in the present by a competent person to direct medical treatment in the future should they become unable to communicate.

### **Palliative care and advance care planning**

Palliative care—defined as quality care directed by patient values—offers choice and ensures life before death is based on what patients and their families want and need. Palliative care provides support for patients to live ‘as actively as possible until death’ by using an interdisciplinary team approach that acknowledges dying as a normal process, but affirms life.

Palliative care upholds the values of individual autonomy,<sup>3</sup> and addressing the lack of palliative care in this country—as recently identified by the Productivity Commission<sup>4</sup>—should be a priority for policy reform.

Advance care planning is another avenue for Australians to exercise self-determination. However, its utilisation is low across the country, the underlying framework and legal underpinnings are inconsistent between states, and the legal and medical implications are poorly understood by health professionals and citizens alike. Despite this, calls for reform in light of these shortcomings have been hand-balled by policymakers in Canberra to the states to sort out.

Advance care planning is a ‘process by which people plan for future health and personal care by making their values, beliefs, and preferences known’.<sup>5</sup>

An Advance Care Directive (ACD) is a component of an Advance Care Plan (ACP), which occurs within the setting of advance care planning. It is otherwise known as a living will, written in the present by a competent person to direct medical

treatment in the future should they become unable to communicate. Most ACPs also enable the nomination of a substitute decision-maker.

### **State-based variation**

Advance care directives differ between states and territories. Where some state governments have specific forms, others accept any written or even oral directive. In Queensland, an Advance Health Directive can be created using a specific form that must be signed by a competent individual, a doctor and an independent witness. It is recommended the form then be stowed away safely and reproduced as required in the future when a person is rendered incapable of making their own decision.<sup>6</sup>

In NSW, advance care planning is promoted as involving a conversation between family members or health professionals that creates an advance care directive, although there is no specific form that must be used. An enduring guardian is also appointed who can legally make decisions. The advance care directive makes reasonably explicit what the person considers quality of life and what they would and would not find acceptable; for example, artificial feeding. Unlike in Queensland, the directive does not have to be signed by a health professional or a witness to be ‘legal’,<sup>7</sup> although similarly it is to be ‘kept safe’ until required.

In Victoria, an advance care plan consists of an enduring power of attorney for medical treatment, an advance care directive that informs the substitute decision-maker, and a ‘refusal of treatment certificate for a competent or incompetent person’.<sup>8</sup> Early next year, the Medical Treatment Planning and Decisions Bill 2016 will commence. The Act ‘establishes a single framework for medical treatment decision making for people without decision making capacity’ so that ‘Victorians will be able to create a legally binding advance care directive’.<sup>9</sup>

Advanced care directives are legal instruments that can be used to enable self-determination at the end of life when an individual is not able to communicate their wishes. The Australian Capital Territory (ACT), Northern Territory (NT), Queensland (QLD), South Australia (SA), Victoria and Western Australia (WA) have statutory documents or legislation that legitimises

the care directive, although these are recognised under a number of different titles and with varying requirements. For example, an oral directive is legally binding in the ACT if two health professionals are present at the same time and at least one is a doctor, whereas in Queensland the approved form must be witnessed by a doctor documenting the capacity of the person at the time of writing and a witness.

In NSW, there is no legislation for a statutory document and common law is relied upon to bind care directives. Travellers who find themselves interstate will have their statutory documents from other states recognised under common law in NSW, whilst the ACT, QLD, Tasmania and WA will not recognise a statutory document from another state and will treat the directive under common law instead, meaning it informs decision-making but is not legally binding.<sup>10</sup>

Whilst all states facilitate the appointment of substitute decision-makers, they recognise them under varying titles such as enduring power of attorney (medical treatment) in Victoria, enduring guardian (NSW), substitute decision-makers (SA), and decision-maker (healthcare matters) (NT), either through legislation or common law.

The requirements of these decision-makers also vary. So, in the NT, QLD and SA the principle of substituted judgment is used. This means decision-makers, based on what they know of the person, act according to what they reasonably believe the person would have wanted. In Tasmania, Victoria and WA, decision-makers are instructed to make decisions based on the 'best interests of the patient'. However, if you have appointed your substitute decision-maker in Sydney but find yourself in need of advocacy in Perth, WA does not recognise your substitute decision-maker until assessed on an individual case by case basis.<sup>11</sup>

Some jurisdictions also limit the refusal of treatments in a directive by stipulating that refusal must relate specifically to medical conditions present at the time of completing the advance care directive rather than refusal extending to any or all conditions in the future.

The circumstances under which a directive would not operate also vary between states. So as articulated in QLD, if a health provider has

reasonable grounds to believe that circumstances have changed—for example, the directive is no longer consistent with good medical practice—they are able to revoke the directive compared to the NT where, if following the care directive would cause unacceptable pain and suffering it can be discredited.<sup>12</sup> Ultimately, however, advance care directives cannot demand treatment which is not in accordance with good medical practice or is illegal.<sup>13</sup>

Advance care directives, when completed and available, have a myriad of positive effects for patients and their families. Healthcare is more consistent with a person's preferences and so patient and family satisfaction improves. Families are less likely to be overwhelmed by the task of substitute decision-making if preferences are clearly documented, and this relieves carer stress.<sup>14</sup> ACDs also increase the likelihood of a death at home and access to palliative care or hospice care, especially for those in residential aged care facilities.<sup>15</sup>

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### Low on the uptake

Despite these benefits, it is not surprising that confusing and legally inconsistent paper-based advance care plans haven't been widely taken up by the vulnerable population they should serve. Across the country, a lack of advance care directives in nursing homes causes unwarranted emergency hospital transfers, which for almost half of transfers results in hospital admission.<sup>16</sup> Up to 75% of residents transferred to hospital subsequently die within five days of admission.<sup>17</sup>

Advance care directives can prevent unwanted medical treatment. For example, in an Australian randomised controlled trial where the intervention was comprehensive, advance care planning by trained nurses or allied health professionals resulted in 86% of those in the intervention group having their wishes known and followed at the end of life, compared to only 30% of the control group. Of those without advance care planning, 15% died in an intensive care unit.<sup>18</sup>

A national telephone survey found that only 14% of the entire population has an advance care directive, with South Australia and Queensland having the highest uptake.<sup>19</sup> Other studies have revealed in NSW only 5% of residential aged care residents had an ACD.<sup>20</sup> In Victoria of 12 residential aged care facilities studied only half had a policy for advance care planning and even these did not adhere to best practice.<sup>21</sup>

The use, understanding and legal framework of advance care directives across the country is extraordinarily varied and the legal ramifications are poorly understood by health professionals and the community alike. A national survey of palliative care services found even among these professionals only 30% felt confident in their understanding of the state laws regarding advance care planning.<sup>22</sup>

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The directives themselves are often clouded with uncertainty and poorly documented.<sup>23</sup> Given the mobility of the Australian population the variation between states raises serious concerns. Moreover, navigating the bureaucracy and paperwork seems a significant burden for vulnerable groups—not to mention that in an emergency situation, arguably when these decisions are most pressing, it is unlikely these forms or documents are on hand.

There have been a number of attempts to increase the uptake of ACDs within Australia, including from the Royal Australian College of General Practitioners, various websites, interest groups and the NSW Health Advance Planning for Quality Care at End of Life Action Plan 2013–2018. However, their widespread implementation remains to be seen—even among health professionals only 21% had a documented advance care directive.<sup>24</sup>

There are systemic and cultural barriers to the uptake of advance care planning in Australia. With an ageing population and rising rates of dementia, however, the need for reform is growing. The medical community themselves are confused about

who is responsible for initiating a conversation about advance care planning, leaving little hope for patients and their families who are similarly unsure what the concept involves and its benefits.<sup>25</sup>

### Ensuring voices are heard

In response to a Senate inquiry this year, the Australian government rejected the recommendation to create a harmonised national model of legislation, citing the National Framework for Advance Care Directives (the Framework) commissioned in 2011, which provides guidance on policy and best practice in relation to advance care directives for the states and territories. Clearly, six years later this is not enough.

It is not often that I would encourage more legislation or more government intervention. However, instead of infringing on individual autonomy like most legislation does, consistent nationwide legislation regarding advance care directives would instead serve to protect the end-of-life autonomy of a growing number of Australians. Uniform legislation won't improve the uptake of advance care directives overnight, but it will be one less barrier to end-of-life self-determination. It should also foster cultural reform as the medical profession, once the legal underpinnings are understood, will need to define their position and responsibility in this space. This is imperative as cultural reform of attitudes towards death and dying within the wider Australian public will likely take a generation.

The standard ploy of buck passing between the state and federal governments isn't good enough when a growing number of people are looking to radical end-of-life-reform. Voluntary euthanasia is not the only way to exercise self-determination at the end of life.

It is essential older Australians feel assured that their decisions, wants and desires won't be lost in a seemingly endless roundabout of doctors, specialists, hospitals and admissions. Australians value autonomy, and this attachment grows stronger when the prospect of autonomy being lost increases. A world class 21st century health system shouldn't facilitate this fear any longer. Patients' voices should always be heard even if they can no longer speak for themselves.

## Endnotes

- 1 Julia M. Langton et al, 'Health service use and costs in the last 6 months of life in elderly decedents with a history of cancer: a comprehensive analysis from a health payer perspective', *British Journal of Cancer* 114:11 (May 2016), 1293–1302.
- 2 Oregon Public Health Division, Center for Health Statistics, *Oregon Death with Dignity Act: Data Summary 2016* (10 February 2017).
- 3 Cristina Monforte-Royo et al, 'What Lies behind the Wish to Hasten Death? A Systematic Review and Meta-Ethnography from the Perspective of Patients', (14 May 2012), <https://doi.org/10.1371/journal.pone.0037117>
- 4 Productivity Commission, *Introducing Competition and Informed User Choice into Human Services: Identifying Sectors for Reform, Preliminary Findings Report* (Canberra: 2016).
- 5 Rachel Z. Carter, Karen M. Detering, William Silvester and Elizabeth Sutton, 'Advance care planning in Australia: what does the law say?', *Australian Health Review* 40 (2016), 405-414.
- 6 Queensland Government, <https://www.qld.gov.au/law/legal-mediation-and-justice-of-the-peace/power-of-attorney-and-making-decisions-for-others/advance-health-directive>
- 7 NSW Ministry of Health, 'Making an Advanced Care Directive' (2017), <http://www.health.nsw.gov.au/patients/acp/Publications/acd-form-info-book.pdf>
- 8 Australian Government, Department of Health, 'Advance care planning by state and territory' (2017), [https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/05\\_2017/lgbti\\_-\\_advance\\_care\\_planning\\_by\\_state\\_and\\_territory.pdf](https://agedcare.health.gov.au/sites/g/files/net1426/f/documents/05_2017/lgbti_-_advance_care_planning_by_state_and_territory.pdf)
- 9 Victorian Department of Health, 'Medical Treatment Planning and Decisions Act 2016', <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning/medical-treatment-planning-and-decisions-act>
- 10 Carter et al, 405-414.
- 11 As above.
- 12 Lenny Roth, 'Advanced Care Directives', e-brief 6/2014, NSW Parliamentary Research Service (May 2014).
- 13 National Advanced Care Directive Working Group, 'A National Framework for Advanced Care Directives' (Adelaide: Australian Health Ministers Advisory Council, 2011).
- 14 Arianne Brinkman-Stoppelenburg et al, 'The Effects of Advance Care Planning on End-of-Life Care: A Systematic Review', *Palliative Medicine* 28:8 (2014), 1000–1025.; Marcus Sellars et al, 'Advance Care Planning in Palliative Care: A National Survey of Health Professionals and Service Managers', *Australian Health Review* 39:2 (2015), 146–53.
- 15 D. William Molloy et al, 'Systematic Implementation of an Advance Directive Program in Nursing Homes: A Randomized Controlled Trial', *Journal of the American Medical Association* 283:11 (2000), 1437–44; J. M. Teno et al, 'Association between Advance Directives and Quality of End-of-Life Care: A National Study', *Journal of the American Geriatrics Society* 55:2 (2007), 189–94.
- 16 Alyce S. Ashcraft and Donna C. Owen, 'From Nursing Home to Acute Care: Signs, Symptoms, and Strategies Used to Prevent Transfer', *Geriatric Nursing* 35:4 (July-August 2014), 316–20; C. R. Levy, R. Fish and A.M. Kramer, 'Site of Death in the Hospital versus Nursing Home of Medicare Skilled Nursing Facility Residents Admitted under Medicare's Part A Benefit', *Journal of the American Geriatrics Society* 52:8 (2004), 1247–54.
- 17 Levy et al, 'Site of Death'.
- 18 Allyson Waird and Elaine Crisp, 'The role of advance care planning in end-of-life care for residents of aged care facilities', *Australian Journal of Advanced Nursing* 33:4 (2016), 26-34; Karen M. Detering et al, 'The impact of advance care planning on end of life care in elderly patients: randomised controlled trial', *British Medical Journal* 340 (2010), 1345.
- 19 B. White et al, 'Prevalence and predictors of advance directives in Australia', *Internal Medicine Journal* 44:10 (2014), 975-980.
- 20 Andrew J. Bezzina, 'Prevalence of advance care directives in aged care facilities of the Northern Illawarra', *Emergency Medicine Australasia* 21 (2009), 379–85.
- 21 William Silvester et al, 'Quality of Advance Care Planning Policy and Practice in Residential Aged Care Facilities in Australia', *BMJ Supportive and Palliative Care* 3:3 (September 2013), 349–57.
- 22 Marcus Sellars, William Silvester, Malcolm Masso and Claire E. Johnson, 'Advance Care Planning in Palliative Care: A National Survey of Health Professionals and Service Managers', *Australian Health Review* 39:2 (2015), 146–53.
- 23 Joel J. Rhee, Nicholas Zwar and Lynne A. Kemp, 'Uptake and implementation of Advance Care Planning in Australia: Findings of Key Informant Interviews', *Australian Health Review* 36 (2012), 98-104.
- 24 Suzanne Rainsford and Nicholas Glasgow, 'Personal Advance Care Planning Uptake amongst Australian and New Zealand Palliative Care Medical and Nursing Professionals', *Progress in Palliative Care* 24:3 (3 May 2016), 153–58, <https://doi.org/10.1080/09699260.2015.1115605>.
- 25 Manisha Chandar et al, 'Variability of physician perspectives toward advance care planning for patients with incurable cancer and congestive heart failure', *Journal of Clinical Oncology* 33 (October 2015), 12-12; Waird and Crisp (see note 18), 26-34.