Transitions in decision-making authority at the end of life: a problem of law, ethics and practice in deceased donation

Shih-Ning Then 1, Dominique E Martin 2

ABSTRACT
Where a person is unable to make medical decisions for themselves, law and practice allows others to make decisions on their behalf. This is common at the end of a person’s life where decision-making capacity is often lost. A further, and separate, decision that is often considered at the time of death (and often preceding death) is whether the person wanted to act as an organ or tissue donor. However, in some jurisdictions, the lawful decision-maker for the donation decision (the ‘donation decision-maker’) is different from the person who was granted decision-making authority for medical decisions during the person’s life. To date, little attention has been given in the literature to the ethical concerns and practical problems that arise where this shift in legal authority occurs. Such a change in decision-making authority is particularly problematic where premortem measures are suggested to maximise the chances of a successful organ donation. This paper examines this shift in decision-making authority and discusses the legal, ethical and practical implications of such frameworks.

INTRODUCTION
Making decisions for patients who cannot make decisions for themselves is common in healthcare. Legal frameworks provide for legally authorised substitute or surrogate decision-makers (SDMs) to make decisions on behalf of these patients. These SDMs can be called on to make difficult decisions, including deciding whether life-sustaining treatment should be initiated, continued or withdrawn for a patient at the end of life. Sometimes these decisions will lead to the patient’s death. End-of-life decision-making may also require consideration of opportunities for organ and tissue donation after death. Some such opportunities are necessarily explored prior to death, when decisions to cease life-sustaining interventions are followed by consideration of opportunities for donation after circulatory determination of death (DCD). In contrast, if a person is determined to be dead by neurological criteria (‘brain death’), the decision to proceed with donation may be taken after death is declared.

In addition to the ethical complexities of such end-of-life decision-making, problems may arise due to uncertainty regarding lawful authorisation of donation. Following the death of the patient, in some jurisdictions, the lawful decision-maker for the donation decision (the ‘donation decision-maker’) is different from the person who was granted decision-making authority during the patient’s life (the SDM) (see figure 1). To date, little attention has been given in the literature to the ethical concerns and practical problems that arise where this shift in legal authority occurs. However, as demonstrated by a recent Australian case, these situations do arise.

Further complications arise where interventions are introduced or suggested to increase the chances of successful donation and transplantation, but before the patient has died (‘premortem measures’).

Most countries have laws in place that regulate a system of deceased organ donation. Systems of ‘opt in’ as compared with ‘soft’ or ‘hard’ ‘opt out’ are extensively discussed in the literature with ongoing debates as to the preferable model in terms of social acceptability, ethical justification and impact on rates of deceased donation. Within these different consent frameworks, the significant role of ‘next of kin’ or those closest to the deceased in allowing or preventing deceased donation from going ahead has also been well explored.

However, less well recognised and largely absent from the literature is the discussion of the common change in legal authority that occurs in the transition from a person’s end-of-life treatment to their death and possible donation of organs and tissue. These two sets of decisions are often regulated by separate legal regimes in different pieces of legislation. As we discuss below, the development of distinct legal frameworks at different times and with different agendas has led to an undesirable situation with significant consequences for patients, families and healthcare professionals. This situation is particularly pronounced in Australia, which we draw on for examples to illustrate the challenges.

This paper examines this difficult nexus where the law requires transitions of decision-making power at the end of a person’s life. The resultant legal complexity and uncertainty may complicate decision-making during end-of-life care and following a person’s death, potentially impeding opportunities for organ donation and exacerbating psychological distress for families and ethical and legal anxiety for clinicians. While only a small proportion of patients who die will be clinically suitable to donate organs or tissues the huge benefit that can come about from even one successful deceased donor means that any barriers to that happening are worthy of consideration.

1 Australian Centre for Health Law Research, Faculty of Law, Queensland University of Technology, Brisbane, Queensland, Australia
2 School of Medicine, Deakin University, Geelong, Victoria, Australia

Correspondence to: Associate Professor Shih-Ning Then, Australian Centre for Health Law Research, Faculty of Law, Queensland University of Technology, Brisbane, Queensland, Australia; shih-ning.then@qut.edu.au

Received 9 June 2020
Revised 12 October 2020
Accepted 13 October 2020

To cite: Then S-N, Martin DE. J Med Ethics 2020;0:1–6. doi:10.1136/medethics-2020-106572

© Author(s) (or their employer(s)) 2020. No commercial re-use. See rights and permissions. Published by BMJ.

See also, articles in Volume 44, Issue 5 of the Journal of Medicine and Philosophy (2019) devoted to ‘Family-Based Consent to Organ Transplantation’.
CLINICAL DECISIONS AT THE END OF A PERSON’S LIFE

First, we consider the laws governing decision-making for a patient who is at the end of life. The simplest situation is that of a competent patient who retains the ability to make their own decisions. For example, a person with a high-level spinal injury who is dependent on mechanical ventilation may choose to cease life-sustaining treatment and consent to organ DCDD. Legally and ethically, it is relatively uncontroversial that such a patient has freedom to choose what treatment to accept or reject.10–14

When discussions regarding the possibility of donation occur between the competent patient and health professionals, the patient is able to make an informed decision about whether they would like to donate following their impending death and whether they consent to premortem measures that may increase the chance of donation being successful.

However, the more common situation is that of a patient who is at the end of life and has lost the ability to make decisions for themselves. Decisions regarding ongoing treatment and palliative care options must be made for such patients. While the person(s) asked to make decisions on behalf of patients who lack decision-making capacity are often colloquially or informally known as ‘next of kin’, in reality, most countries’ laws provide a legal framework to enable these decisions to be made. These types of laws are often referred to as ‘guardianship’, ‘substituted decision-making’ or ‘medical decision-making’ laws. We will refer to them collectively as ‘substitute decision-making laws’.

Legal systems often recognise decision-making authority either through a patient’s previously made advance directive; or through an SDM (see figure 2). The SDM is a person (or persons) either chosen by the patient prior to their loss of capacity to make medical decisions on their behalf, or else a person specified by law—either appointed by a court or tribunal, or someone deemed by legislation to be the most appropriate person to make decisions in the absence of any others.

Outside of emergencies, clinicians are not usually able to make unilateral treatment decisions (ie, without consulting a person’s SDM) for a person who lacks decision-making capacity (England and Wales being the exception).15 16 SDM laws are complex and clinician knowledge of these legal frameworks, and consequently, the ability to identify the legally authorised decision-maker, is variable in different countries.17–19 In practice, determining the existence of a valid advance health directive, or determining who the legally authorised SDM is can also be difficult. However, the law does—at least on paper—offer mechanisms to determine who has authority to make treatment decisions.

A few points should be noted about the options provided by most legal systems in this context. The first is the variety of mechanisms that exist for a competent adult to plan ahead for a time when treatment decisions may need to be made but they have lost decision-making capacity.15 16 20 Legally binding advance health directives are documents recognised in most Western countries that generally allow a patient’s decisions to consent or refuse treatment in particular circumstances to be made known and applied when they lack decision-making capacity.21 A further mechanism for planning ahead consists of the ability to appoint someone in advance to make healthcare decisions on your behalf if you lose capacity—often through documents such as Lasting Powers of Attorney or Enduring Powers of Attorney. The law also recognises that sometimes no such forward planning will have taken place and so enables courts and tribunals to appoint a person to the SDM role where applications are made from concerned persons for a formal substitute decision-making appointment.

Figure 1 Lawful decision-makers for a person’s medical treatment decisions before death and organ and tissue donation decisions after death.

Figure 2 Summary of legal mechanisms for decision-making when a patient has lost capacity to make decisions for themselves.
Lastly, to ensure that decisions are able to be made in a timely manner on behalf of patients who lack decision-making capacity, most countries have legislation that ‘deems’ a person (a legislative default SDM) close to the patient to have legal authority where no other advance directives or appointments are in place. One example of a provision from Queensland, Australia that empowers a default SDM to act is section 63 of the Powers of Attorney Act 1998 (QLD). This provision allows the first in an identified list of people to act where no other SDM appointment or advance health directive exists (see column 1 of table 1). That provision, like many others in Australia,22–27 prioritises those in a close relationship with the patient who are most likely to know the patient well. These SDMs are often required by legislation to follow a set of human rights principles or making decisions on behalf of a person who cannot make decisions for themselves.28 The last decade has seen the principles within the United Nations Convention on the Rights of Persons with Disabilities increasingly becoming relevant to how decisions are made with or on behalf of others—with an emphasis on decisions consistent with that person’s ‘will’ and ‘preferences’.29

This brief summary shows that the law has developed a range of ways to enable decisions to be made on behalf of adult patients who do not have decision-making capacity. Many of these have enabled mechanisms for more autonomous forward planning for adults (although resulting in more complicated regulatory systems). Given the relatively low uptake of advance directives30–32 and the limited numbers of self-appointed or tribunal/court appointed health decision-makers, in practice, there is a heavy reliance on the default SDM identified under legislation. One thing the law does attempt to promote, is that it will be a person close to the patient—either one they have selected themselves, or one deemed via legislation—who will make decisions on their behalf.

**DECISIONS TO DONATE TISSUE AND/OR ORGANS AFTER DEATH**

In contrast to the range of legal mechanisms for decision-making at the end of life, there are limited legal mechanisms to guide decision-making about deceased donation. As noted above, the laws governing tissue and/or organ donation are generally separated from substitute decision-making law. Instead, dedicated ‘human tissue’ legislation tends to govern all aspects of death, deceased organ and tissue donation, and use of tissues for research and other purposes (eg, medical school use of anatomy parts). Historically, these laws have been developed separately, both temporally and conceptually, from substitute decision-making laws. This is despite the fact that they may operate alongside each other in day-to-day hospital practice.

One regulatory problem evident in some Australian jurisdictions is the comparatively ‘blunt’ way in which a lawful donation decision-maker is determined in situations where the person has not provided written consent to donation during their lifetime. Unlike the situation during life where a person can plan ahead through legally binding documents appointing an SDM for medical decisions, there is often no similar mechanism to elect someone in advance to make a decision about deceased donation on your behalf. While this is possible, for example, in New Zealand and England and Wales where a person can appoint a ‘nominated representative’ or ‘nominee’ while alive to authorise or refuse donation following a person’s death,33–35 there is no similar mechanism under the human tissue legislation throughout Australia. Instead, in Australia there is a designated ‘list’ of people who can provide legal authority for the removal of organs for transplantation where the patient had not formally indicated their wishes prior to death.36

There are obvious parallels in the legislative default decision-maker and the donation decision-maker mechanisms. In both cases, legislation ‘deems’ a person who has a relationship with the patient as the appropriate lawful decision-maker. Under the substitute decision-making legislation, the default SDM is able to make decisions (as guided by legislative principles) regarding healthcare and treatment prior to death. Under the human tissue legislation, the donation decision-maker is able to make decisions regarding the donation of organs and tissue after the patient’s death. However, when these two roles are compared, it is apparent that the definition of a donation decision-maker relies heavily on traditionally defined familial relationships, without consideration of current closeness of those relationships. This is evident when we compare the two roles side by side in table 1 (using the Queensland legislation referred to above). This example is largely representative of the situation in most Australian States and Territories.

Arguably the Australian legislation governing substitute decision-making on behalf of a person lacking decision-making capacity is more attuned to social realities, with priority given to those in closer social relationships with the patient. It seems ethically appropriate to give decision-making authority to those who have the strongest relational ties to the person; those who are most likely to know the person and their likely values, beliefs and preferences regarding treatments (although there is evidence to suggest that some SDM may have difficulty predicting what a person would have wanted, or respecting their choices if these may be emotionally burdensome on SDMs).36

In contrast the human tissue legislation, being older in origin in Australia, is less nuanced and simply identifies categories of genetic or familial relationships with no regard to the actual social closeness of those persons with the recently deceased.36

**Table 1** Comparison of how to determine the appropriate legislative default SDM as compared with donation decision-maker

| Legislative default decision-maker (for healthcare decisions of the patient) | Donation decision-maker (after the patient’s death) |
|---|---|
| The first of the following people who is readily available and culturally appropriate to exercise power:  
  - A spouse of the adult if the relationship between the adult and the spouse is close and continuing.  
  - A person who is 18 years or more and who has the care of the adult and is not a paid carer for the adult.  
  - A person who is 18 years or more and who is a close friend or relation of the adult and is not a paid carer for the adult. (Power of Attorney Act 1998 (QLD), s 63) | The first of the following persons who is reasonably available:  
  - The spouse of the person.  
  - A child, who has attained the age of 18 years, of the person.  
  - A parent of the person.  
  - A sibling, who has attained the age of 18 years, of the person. (Transplantation and Anatomy Act 1979 (QLD), s 4) |

SDM, substitute or surrogate decision-maker.
A further complication may occur in the context of decision-making regarding non-therapeutic interventions for the purpose of facilitating donation as would appear to be the case in some Canadian jurisdictions and some Australian States. In addition, a donation decision-maker’s authority does not extend to decisions during a person’s life-time. None of the human tissue legislation in Australian States and Territories mentions a role for donation decision-makers during the end-of-life care of the person who may wish to act as a deceased donor after their death. Necessarily, when decisions about use of pre-mortem interventions to facilitate donation are made by an SDM, this will entail discussions about donation. However, this may be inappropriate if the SDM is not also the legally authorised donation decision-maker. If the latter person has the right to refuse donation and chooses to do so after the patient has died, then pre-mortem interventions for donation approved by the SDM may be in vain. There are several undesirable consequences of undermining the respect for patient autonomy that is normally fostered by allowing an SDM to make decisions on behalf of the patient that are reflective of their expected values and preferences with regard to donation. First, valuable healthcare resources including the time of donation specialists may be wasted. Second, the patient and their family may potentially be harmed by the ‘intrusion’ of a non-therapeutic intervention during the end-of-life period that will not be outweighed by the potential benefits of donation.

Table 2 Hypothetical examples demonstrating changes in lawful decision-making authority for end-of-life decisions versus donation decisions

| Case 1: The patient who has planned ahead | Case 2: The patient who has not planned ahead |
|-----------------------------------------|---------------------------------------------|
| Consider patient C, a former teacher living in Victoria who had strong views about what treatment she did and did not want to receive at the end of life. C made an advance directive (known in Victoria as an ‘advance care directive’) that outlined her wishes, including specific treatment decisions (‘instructional directives’), for a time when she did not have decision-making capacity. She also appointed her best friend and neighbour JS as a substitute decision-maker (‘medical treatment decision-maker’) for all other treatment decisions. C had extensive discussions with JS about her wishes and preferences at the end of life and the kind of death she wanted. Although she never formally joined the national organ donor registry, C clearly communicated to JS that she wanted to donate her organs and tissues after death, if it were possible. C was single, but was survived by her brother, G. While they saw each other every year around Christmas time, her brother held different views about organ donation based on his differing religious values. Assuming that C lost capacity to make decisions at the end of her life, and she was a potential organ or tissue donor candidate, the table below outlines who would normally be given legal decision-making authority for her end-of-life care, and for deceased donation. | Consider patient T, a former electrician who lives in New South Wales who experienced a traumatic head injury in a car accident 3 months ago. T had not planned ahead and did not have an advance directive and had not appointed an SDM in the event he lost decision-making capacity. T was single but had an adult child, S, whom he rarely saw. He was not close to any other family members. T and S had argued 5 years ago and since that time had seen little of each other. T shared a house with B. They had lived together for the past 4 years and T considered B his best friend. Since the accident B had been T’s main visitor and carer, spending significant amounts of time at the hospital and talking to T’s treating team. S had visited once but did not engage with the treating team. B told the treating team that T had said on a number of occasions that he thought everyone should be an organ donor. T’s condition deteriorates and he is determined to be dead by neurological criteria. Assuming that T lost the capacity to make decisions at the end of his life, and he was a potential organ or tissue donor candidate, the table below outlines who would normally be given legal decision-making authority around treatment before death, and donation after death. |
| **SDM for medical decisions (before death)** | **SDM for medical decisions (before death)** |
| C’s advance directive (if applicable); if advance directive not applicable—JS | B |
| **Legally donation decision-maker (for organ/tissue donation after death)** | **Legally donation decision-maker (for organ/tissue donation after death)** |
| G | S |
| Medical Treatment Planning and Decisions Act 2016 (Vic), ss 12, 55(1), Human Tissue Act 1982 (Vic), ss 3 (definition of ‘senior available next of kin’), 26. | See Guardianship Act 1987 (NSW), ss 3B, 33A(4), 36(1)(a). |
| The situation could play out very differently in England where C would have had the option of appointing JS as her nominated representative before she lost capacity. If appointed, JS would also be the legal decision-maker regarding organ/tissue donation after C’s death in England, rather than G. | See Human Tissue Act 1983 (NSW) ss 4 (definition of ‘senior available next of kin’), 23(3). |

While this is, in part, due to the age of some of these laws, it can lead to some troubling consequences. The starkest examples of this discord between legal regimes are the transitions in decision-making authority that can occur for patients at the end of life regarding who can make decisions about deceased donation. This scenario recently arose on the facts of Millard v Australian Capital Territory where a patient was ultimately declared brain dead. During the situation described by the Court, at one point the person holding an enduring power of attorney for health matters for the patient had a different view regarding donation of organs and tissue as compared with the person who was initially identified as the ‘senior available next of kin’ under the ACT legislation. This discord is also illustrated by the hypothetical examples in table 2.

FURTHER COMPLEXITIES: THE ISSUE OF PREMORTEM INTERVENTIONS

A further complication may occur in the context of decision-making about pre-mortem interventions designed to increase the viability of donation is explored. As these interventions necessarily occur prior to death, a question of law arises regarding who, if anyone, is able to consent to these interventions on behalf of the patient if the primary goal of such interventions is to facilitate donation rather than to therapeutically benefit the patient. This question is not easily answered and is dependent on how domestic substitute decision-making laws are interpreted. For example, laws authorising SDM to make treatment decisions on behalf of patients lacking capacity may not be applicable to decision-making regarding non-therapeutic interventions for the purpose of facilitating donation as would appear to be the case in some Canadian jurisdictions and some Australian States. In addition, a donation decision-maker’s authority does not extend to decisions during a person’s life-time. None of the human tissue legislation in Australian States and Territories mentions a role for donation decision-maker during the end-of-life care of the person who may wish to act as a deceased donor after their death. Necessarily, when decisions about use of pre-mortem interventions to facilitate donation are made by an SDM, this will entail discussions about donation. However, this may be inappropriate if the SDM is not also the legally authorised donation decision-maker. If the latter person has the right to refuse donation and chooses to do so after the patient has died, then pre-mortem interventions for donation approved by the SDM may be in vain. There are several undesirable consequences of undermining the respect for patient autonomy that is normally fostered by allowing an SDM to make decisions on behalf of the patient that are reflective of their expected values and preferences with regard to donation. First, valuable healthcare resources including the time of donation specialists may be wasted. Second, the patient and their family may potentially be harmed by the ‘intrusion’ of a non-therapeutic intervention during the end-of-life period that will not be outweighed by the potential benefits of donation.

would cover those ‘closest’ to the deceased. In some ways, this reflects the assumption of familial authority that exists in practice.
The legal and ethical uncertainties posed by premortem interventions have prompted at least one country to reform the law to provide clarity to health professionals and the public. In Switzerland, changes to the law that came into effect in 2017 clarify who can consent to premortem measures, when this is possible, and what procedures are allowed.43 According to Levy, the Swiss legislation clarifies the timing of when consent for premortem measures can be sought, from whom it is sought, and to what they can consent. In circumstances where the patient herself has not expressed consent (ie, due to being unconscious, lacking decision-making capacity), a ‘next of kin’ is able to give consent as long as the premortem measures are: (1) ‘essential for successful organ transplantation’ and (2) ‘impose only minimal risks and burdens on the donor’.44 Premortem measures that ‘hasten the patient’s death or risk leading the patient into a vegetative state’ are also not allowed under the legislation. The legislation provides for the government to create a list of interventions that are, essentially prohibited and would not satisfy the conditions for a lawful premortem measure.

Legal certainty of some kind, whether of the form adopted by Switzerland or other means, is certainly desirable in other countries for a number of reasons. Without a legally certain way of authorising non-therapeutic premortem measures, some people will have their wishes of potentially becoming an organ donor thwarted, with the consequent loss of benefit for potential transplant recipients. This may be the case even when those closest to them know of a person’s views and attempt to act—by advocating for premortem measures—in accordance with those wishes. For healthcare providers who currently provide premortem interventions for potential donors, the uncertainty in the law may also lead to stress and potential liability.39

CONCLUSION

It remains to be seen if other countries will provide more explicit guidance relating to lawful decision making and practice in the context of premortem interventions for donation, and resolve potential conflicts between the roles of SDMs and donation decision-makers. There is also work to be done in some countries on whether the law should provide for more flexibility in mechanisms to appoint a person to become a donation decision-maker, in the same way that adults can currently appoint an SDM. While currently allowed in New Zealand and England and Wales, no mechanism for this exists in Australia.

Although SDMs and donation decision-makers may frequently be different people, and less frequently disagree about donation decisions, the possibility of such situations occurring may deter or prevent healthcare professionals and SDMs from pursuing some opportunities for organ and tissue donation. Such missed opportunities not only undermine efforts to save and improve the lives of those in need of transplantation, but also undermine respect for those individuals who have expressed a preference to become a donor if possible. This is particularly concerning in the context of widespread efforts by governments and health authorities in many countries to promote the use of advance care planning and use of SDMs as a means to enable people to have their preferences and values upheld at the end of their lives when they are no longer able to make decisions for themselves.

Twitter Shih-Ning Then @NingThen

Acknowledgements The authors would like to acknowledge the research assistance of Kristina Chelberg, Australian Centre for Health Law Research, Queensland University of Technology.

Contributors S-NT conceptualised and wrote the first draft of the paper. Both S-NT and DM drafted and reviewed the final version of the paper.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Disclaimer The views expressed in this paper are the views of the authors and do not represent the views of any other group.

Competing interests S-NT and DM were members of the Australia National Health and Medical Research Council’s (NHMRC) Organ and Tissue Working Committee. DM has received consultancy fees from the Australian Organ and Tissue Authority (AOTA). The views presented here are the authors’ own.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

ORCID iDs
Shih-Ning Then http://orcid.org/0000-0002-8211-1868
Dominique E Martin http://orcid.org/0000-0001-9363-0770

REFERENCES

1 Dalle Ave AL, Shaw DM. Controlled donation after circulatory determination of death: ethical issues in withdrawing life-sustaining therapy. J Intensive Care Med 2017;32(3):179–86.
2 MacDonald Sf, Shemie SD. Ethical challenges and the donation physician specialist: a scoping review. Transplantation 2017;101(5 Suppl 1):S27–40.
3 Millard v Australian Capital Territory [2020] ACTSC 138.
4 Rosenblum AM, Horvat LD, Siminoff LA, et al. The authority of next-of-kin in explicit and presumed consent systems for deceased organ donation: an analysis of 54 nations. Nephrol Dial Transplant 2012;27(6):3531–46.
5 Arshad A, Anderson B, Shafir A. Comparison of organ donation and transplantation rates between opt-out and opt-in systems. Kidney Int 2019;95(6):1453–60.
6 MacKay D, Robinson A. The ethics of organ donor registration policies: nudges and respect for autonomy. Am J Bioeth 2016;16(1):3–12.
7 Saunders B. Opt-out organ donation without presumptions. J Med Ethics 2012;38(2):69–72.
8 Farsides B. Respecting wishes and avoiding conflict: understanding the ethical basis for organ donation and retrieval. Br J Anaesth 2012;108(Suppl 1):73–9.
9 den Hartogh G. The role of the relatives in opt-in systems of postmortal organ procurement. Med Health Care Philos 2012;15(2):195–205. See also articles in J Med Philos 2019;44(5) devoted to ‘Family-Based Consent to Organ Transplantation’.
10 Re B (Adult: Refusal of Medical Treatment) [2002] 2 All ER 449.
11 Brightwater Care Group (Inc) v Rossiter (2009) 40 WAR 84.
12 Schindlendorf’s Society of New York Hospitals 211 NY 125 (1914).
13 Powell T, Lowenstein B. Refusing life-sustaining treatment after catastrophic injury: ethical implications. J Law Med Ethics 1996;24(1):54–61.
14 Downar J, Shemie SD, Gillrie C, et al. Deceased organ and tissue donation after medical assistance in dying and other conscious and competent donors: guidance for policy. CMAJ 2019;191(22):E604–11.
15 Mental Capacity Act 2005 (UK) section 5.
16 Office of the Public Guardian. Making decisions: a guide for people who work in health and social care, 2009. Available: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data_file/348440/OPG063-Health-care-workers-MCA-decisions.pdf [Accessed 8 June 2020].
17 White B, Willmott L, Cartwright C, et al. The knowledge and practice of doctors in relation to the law that governs withholding and withdrawing life-sustaining treatment from adults who lack capacity. J Law Med 2016;24(2):356–70.
18 DeMartino ES, Dudzinski DM, Doyle CK, et al. Who Decides When a Patient Can’t? Statutes on Alternate Decision Makers. N Engl J Med 2017;376(15):1478–82.
19 McCrory SV, Swanson Jw, Couliean J, et al. Physicians’ legal defensiveness in end-of-life treatment decisions: comparing attitudes and knowledge in states with different laws. J Clin Ethics 2006;17(1):15–26.
20 White B, Willmott L, then SN. Adults who lack capacity: substituted decision-making. In: White B, McDonald F, Willmott L, eds. Health law in Australia. 3rd edn., Sydney: Lawbook, 2018: 207–70.
21 Beauchamp TL, Childress JF. Principles of biomedical ethics. 8th edn. New York: Oxford University Press, 2019: 155–216.
22 Medical Treatment Planning and Decisions Act 2016 (Vic) section 55(3).
23 Guardianship Act 1987 (NSW) section 33A(4).
24 Guardian and Management of Property Act 1991 (ACT) sections 32B(1), 32F(1)(b).
25 Guardianship and Administration Act 1995 (Tas) section 41(1)(c).
26 Consent to Medical Treatment and Palliative Care Act 1995 (SA) section 14(1).
27 Guardianship and Administration Act 1990 (WA) section 1102D(2), (3).
28 Then SN. Evolution and innovation in guardianship laws: assisted decision-making. Syd Law Rev 2013;35(1):133–66.
29 United Nations Convention on the Rights of Persons with Disabilities (CRPD).
30 Ystad KN, Gabler NB, Cooney E, et al. Approximately one in three us adults completes any type of advance directive for end-of-life care. Health Aff 2017;36(7):1244–51.
31 White B, Tille C, Wilson J, et al. Prevalence and predictors of advance directives in Australia. Intern Med J 2014;44(10):975–80.
32 Compassion in Dying. Plan well, live well: learning from an information service, 2015https://compassionindying.org.uk/library/plan-well-die-well/ [Accessed 8 June 2020].

33 Human Tissue Act 2004 (Eng) sections 3, 4.

34 Human Transplantation (Wales) Act 2013 sections 3, 8.

35 Human Tissue Act 2008 (NZ) sections 31, 39.

36 Wendler D. The theory and practice of surrogate decision-making. Hastings Cent Rep 2017;47(1):29–31.

37 Bastami S, Krones T, Biller-Andorno N. Whose consent matters? controlled donation after cardiac death and premortem organ-preserving measures. Transplantation 2012;93(10):965–9.

38 Gardiner D, Shaw DM, Kilcullen JK, et al. Intensive care for organ preservation: a four-stage pathway. J Intensive Care Soc 2019;20(4):335–40.

39 Downie J, Rajotte C, Shea A. Pre-mortem transplantation optimizing interventions: the legal status of consent. Can J Anaesth 2008;55(7):458–69.

40 NSW Health. Discussion paper: the use of ante mortem (before death) interventions for organ donation in NSW, December, 2016. Available: https://www.health.nsw.gov.au/legislation/Documents/discussion-paper-organ-donation.pdf [Accessed 8 June 2020].

41 Levy M. Pre-mortem interventions facilitating organ retrieval: the new Swiss legal framework. In: Massey EK, Ambagtsheer F, Weimar W, eds. Ethical, legal and psychosocial aspects of transplantation: global challenges. Lengerich. Westphalia: Pabst Science Publishers, 2017: 37–43.

42 Bramstedt KA. Family refusals of registered consents: the disruption of organ donation by double-standard surrogate decision-making. Intern Med J 2013;43(2):120–3.

43 Toews M, Caulfield T. Evaluating the “family veto” of consent for organ donation. CMAJ 2016;188(17-18):E436–7.

44 Australian Law Reform Commission. Human tissue transplants report (report no 7), 1977. Available: http://www.austlii.edu.au/au/other/lawreform/ALRC/1977/7.html [Accessed 8 June 2020].

45 Cherry MJ, Fan R, Evans KK. Family-Based consent to organ transplantation: a cross-cultural exploration. J Med Philos 2019;44(5):521–33.