1

End-of-Life Law Reform

Context and Challenges

Ben P. White and Lindy Willmott*

INTRODUCTION

The law that regulates end-of-life decision-making is the subject of ongoing scrutiny and is constantly changing internationally. Although trajectories and timelines may be different in different parts of the world, there is constant pressure to reform in this area. Even if there are not current proposals for change or review of the law initiated by the State (or individual members of parliament), there is persistent agitation for reform from key stakeholders, and the state of end-of-life law is the subject of ongoing public debate.

The most obvious example is whether law should change to allow assisted dying (or to change or repeal current assisted dying laws where they exist). Recent developments around the time of writing include new laws being passed to permit assisted dying in the Australian states of Western Australia¹ and Tasmania;² New Jersey³ and Maine⁴ in the United States; and New Zealand.⁵ There have also been significant judicial decisions that have recently changed the law on assisted dying. One example is the Truchon case,⁶ which successfully challenged limits on access to assisted dying under both the Canadian federal law⁷ and the

---

¹ Voluntary Assisted Dying Act 2019 (WA).
² End-of-Life Choices (Voluntary Assisted Dying) Act 2021 (Tas).
⁵ End of Life Choice Act 2019 (NZ).
⁷ The eligibility requirement in Criminal Code RSC 1985, c. C-46, s. 241.2(2)(d) (introduced by Bill C-14, An Act to Amend the Criminal Code and to Make Related Amendments to Other...
Québec law.\textsuperscript{8} This decision prompted the federal government to pass amendments to that law via Bill C-7.\textsuperscript{9} Other examples are the German constitutional ruling\textsuperscript{10} which struck down laws prohibiting assisted suicide services, and the English case of Newby,\textsuperscript{11} the most recent in a series of such cases arguing that the existing prohibition on assisted dying breaches the European Convention on Human Rights.\textsuperscript{12}

But end-of-life law, as we outline below, is not just about – or even mostly about – assisted dying. There has also been ongoing reform or debates in relation to other areas of law that deal with death and dying. One of the other main legal issues in this field is the law that governs the provision, withholding or withdrawing of potentially life-sustaining treatment. Although perhaps less topical than assisted dying, these laws continue to evolve with ongoing change to the relevant adult guardianship, mental capacity or medical treatment legislation. Hong Kong is consulting on new legislative proposals to recognise advance directives in statute,\textsuperscript{13} and there were recent sweeping changes to adult guardianship and medical treatment legislation in the Australian state of Victoria.\textsuperscript{14} In addition, there were new or updated laws dealing with withholding and withdrawing life-sustaining treatment in Italy\textsuperscript{15} and Taiwan.\textsuperscript{16} There have also been important judicial developments. The Indian Supreme Court declared that withholding and withdrawing life-sustaining treatment may be permissible in certain circumstances.\textsuperscript{17} In the United Kingdom, the Supreme Court recently settled ongoing debate concluding that court approval is

\textsuperscript{8} The eligibility requirement in An Act Respecting End-of-Life Care, RSQ 2014, c. S-32.0001 (Québec), s. 26(3) that the person be at the ‘end of life’ was held to be invalid.
\textsuperscript{9} Bill C-7, An Act to Amend the Criminal Code (Medical Assistance in Dying), SC 2021, c. 2.
\textsuperscript{10} Second Senate of the Federal Constitutional Court, Zum Urteil des Zweiten Senats vom. 26 February 2020, Bundesverfassungsgericht.
\textsuperscript{11} R (Newby) v. Secretary of State for Justice [2019] EWHC 3118.
\textsuperscript{14} Guardianship and Administration Act 2019 (Vic) (in force in 2020); Medical Treatment Planning and Decisions Act 2016 (Vic) (in force in 2018).
\textsuperscript{15} Rules on Informed Consent and Advance Treatment Provisions 2017 (Law N. 210) (Italy).
\textsuperscript{16} Patient Right to Autonomy Act 2019 (Taiwan).
\textsuperscript{17} Common Cause (A Regd. Society) v. Union of India and Another (Unreported, Supreme Court of India, Civil Original Jurisdiction, Writ Petition (Civil) No. 215 of 2005, 9 March 2018).
not required to withdraw or withhold clinically assisted nutrition and hydration from a patient with a ‘prolonged disorder of consciousness’.18

Another area of end-of-life law – that governing palliative care – is also changing albeit less rapidly than the preceding two areas. In 2016, France introduced a law that allowed terminally ill patients to access continuous deep sedation.19 A new Korean law, in addition to dealing with decisions about life-sustaining treatment, specifically established a framework to improve the provision of palliative care in that country.20 Other examples are the recently passed laws in New Jersey,21 Kentucky22 and Ohio23 in the United States which establish advisory councils with the mission of enhancing awareness of and access to palliative care.

Unsurprisingly, much has been written about whether these different areas of end-of-life law should be reformed and, if so, what should be the optimal legal position.24 However, the barriers and facilitators of such changes – law reform perspectives – have been neglected in the literature.25 Yet this topic is vitally important. Many of these changes to the law represent seismic shifts in how society regulates end-of-life decision-making. But we know very little about why some attempts to change the law fail and others succeed. A classic example of this is assisted dying in Australia. There have been four laws in Australia permitting assisted

---

18 An NHS Trust v. Y [2018] UKSC 46. This case, and the reform efforts that preceded it, are examined in Chapter 10. See also the discussion of this case in Chapter 11.


20 Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End of Life, Act No. 14013 (Korea).


25 There are a few notable exceptions, although these books tend to focus on assisted dying and only in the United States: see, for example, Daniel Hilary and John Ombink, Dying Right: The Death with Dignity Movement (New York: Routledge, 2001); Nina Clark, The Politics of Physician Assisted Suicide (New York: Routledge, 1997); Howard Ball, At Liberty to Die: The Battle for Death with Dignity in America (New York: New York University Press, 2012).
dying. The first was the Rights of the Terminally Ill Act 1995 (NT) in the Northern Territory, which was promptly overturned by the federal government nine months later. The other three laws – the Voluntary Assisted Dying Act 2017 (Vic) in Victoria, the Voluntary Assisted Dying Act 2019 (WA) in Western Australia and the End-of-Life Choices (Voluntary Assisted Dying) Act 2021 (Tas) in Tasmania – were passed some twenty years later. Why did these four laws pass, but more than forty other attempts to change the law in Australian Parliaments in the intervening two decades fail? Similar questions arise in Canada. Why did the Canadian Supreme Court decision of Carter permit medical assistance in dying despite a contrary decision of the same court twenty years earlier in Rodriguez? There are other examples across the globe. The question of why end-of-life law changes sometimes but not others is critically important. This is particularly so given the historical trend of changing law in this sensitive area being very difficult to achieve.

WHAT IS END-OF-LIFE LAW?

This book is about reform of end-of-life law so some attempt to define the boundaries of this field is needed. For our purposes, we consider end-of-life law as that which deals with decision-making leading up to death but does not include the law that operates after that time. This latter exclusion means that the law governing organ and tissue donation by a deceased person and the law governing the determination of death fall outside this book. Although important legal issues in their own right, they principally deal with decisions made after a person’s death (or as part of certifying their death), rather than as part of end-of-life decision-making, and so won’t be considered further.

On this approach, end-of-life law is comprised of three main areas alluded to earlier: the law that governs assisted dying, withholding or withdrawing life-sustaining treatment and palliative care. However, as we will see, there are some

---

26 Euthanasia Laws Act 1997 (Cth).
27 As at the end of 2015, fifty-one bills dealing with assisted dying had been introduced into various Australian Parliaments since 1993. Seven of these bills sought to remove the prohibition imposed by the Commonwealth Government on territories (as opposed to states) legislating in this area and five sought to hold a referendum on law reform. The remaining thirty-nine bills proposed a model for law reform permitting some form of assisted dying: Lindy Willmott, Ben White, Christopher Stackpoole, Kelly Purser and Andrew McGee, ‘Failed Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics’ (2016) 39 University of New South Wales Law Journal 1–46 at 10. Since that paper was published, there have been a number of other assisted dying bills considered by Australian Parliaments including the Death with Dignity Bill 2016 (SA), the Voluntary Assisted Dying Bill 2017 (NSW) and the Voluntary Assisted Dying Bill 2016 (Tas), bringing the total number of Australian Bills seeking to legalise assisted dying to over forty: Ben White and Lindy Willmott, ‘Future of Assisted Dying Reform in Australia’ (2018) 42 Australian Health Review 616–20.
types of end-of-life decisions that challenge this categorisation and test boundaries. Below we consider briefly these three areas and provide some commentary about terminology so as to guide consistent discussion of these topics in the chapters that follow. Terminology is important in this area to avoid the disputes that are sometimes caused by the use of different language. We also note that it is, of course, not possible to outline the law internationally on these topics comprehensively, so the discussion that follows is necessarily general.

Assisted Dying

Assisted dying is a term increasingly used to describe collectively the practices of both voluntary euthanasia and assisted suicide. We use the terminology of assisted dying as a global concept but, for reasons of clarity, will briefly define other terms commonly used in this debate.\(^\text{30}\) We consider euthanasia to be when, for the purpose of relieving suffering, a person performs an action with the intention of ending the life of another person. It is voluntary euthanasia when this act is done in response to a request for it to happen from a competent person. An example is when a patient receives an injection that will end their life, at their competent request, from a doctor. Assisted suicide is when a competent person dies after another provides them with the means or knowledge to kill themselves. If it is a doctor or physician providing that assistance, this is often called physician-assisted suicide. An illustration of this is when a doctor provides a person with a prescription to obtain medication that, if taken, will end their life.

A note about terminology for assisted dying also requires an acknowledgement that there are a variety of terms used in different parts of the world. Examples include voluntary assisted dying (often used in Australia), medical assistance in dying (the Canadian term), aid in dying or medical aid in dying (increasingly used in the United States) and euthanasia (the terminology generally adopted in Belgium and the Netherlands). While contributing authors have tended to use local terminology in their chapters, we generally adopt the more generic ‘assisted dying’ in this chapter.

At present, assisted dying is lawful in very few parts of the world. In most places, depending on the circumstances, local law may regard it as the crime of murder, manslaughter or assisting suicide. However, there has been an international trend to reform the law and permit assisted dying. In Europe, assisted dying is lawful under certain circumstances in the Netherlands,\(^\text{31}\) Belgium,\(^\text{32}\)

\(^{30}\) In defining these terms, we draw on Ben White and Lindy Willmott, “How Should Australia Regulate Voluntary Euthanasia and Assisted Suicide?” (2012) 20 Journal of Law and Medicine 40–58.

\(^{31}\) Termination of Life on Request and Assisted Suicide (Review Procedures) Act of 1 April 2002 (Netherlands).

Withholding or Withdrawing Potentially Life-Sustaining Treatment

Withholding or withdrawing potentially life-sustaining treatment occurs where treatment that may be necessary to keep a person alive is not provided or is stopped after initially being provided. An example of withdrawing such treatment is

33 Luxembourg, Switzerland and Germany. In the United States, there are now ten jurisdictions where physician-assisted suicide is legal: Oregon, Washington, Vermont, California, Colorado, the District of Columbia, Hawaii, New Jersey and Maine through legislation, and in Montana by way of court decision.

34 In Canada, in response to Carter, the Canadian Parliament amended its Criminal Code to permit medical assistance in dying in 2016. Assisted dying is also lawful in the Australian state of Victoria (and will be lawful in Western Australia and Tasmania too) and in the South American country of Colombia.

Withholding or withdrawing potentially life-sustaining treatment occurs where treatment that may be necessary to keep a person alive is not provided or is stopped after initially being provided. An example of withdrawing such treatment is
removing a ventilator from a person who has a prolonged disorder of consciousness or is in a state of post-coma unresponsiveness. Withholding treatment could happen when a decision is made not to provide clinically assisted nutrition and hydration (such as through a tube inserted into the stomach) to a person with advanced dementia who is no longer able to take food or hydration orally.

These decisions can be lawful in most Western countries although the law does vary internationally. There are broadly three situations when this is permitted. The first is when a competent person decides to refuse potentially life-sustaining treatment. Legal systems generally respect this right to refuse medical treatment absent any other authorisation to provide it. A person’s decision to not receive treatment must be respected even if that treatment is necessary to stay alive and even if the refusal of treatment is contrary to medical advice.51 Most jurisdictions also recognise advance directives which allow a person to make these decisions when competent, which take effect later after that ability to decide has been lost.52

The second situation is when a person lacks decision-making capacity, and their substitute or surrogate decision-maker refuses treatment. Although not as widely recognised as the first situation, many Western countries facilitate this decision-making through adult guardianship, medical treatment or mental capacity laws.53 In the case of children who lack capacity to decide for themselves, parents are generally recognised as having this power.54

Finally, a doctor can also make the decision to withhold or withdraw potentially life-sustaining treatment. Again, this varies between countries, but the law generally does not require doctors to provide treatment that will not benefit a patient. This is commonly framed as allowing a doctor to not provide potentially life-sustaining treatment if they determine that treatment is not in a patient’s best interests or is ‘futile’ or ‘non-beneficial’.55


Most Western legal systems distinguish between assisted dying (generally unlawful, subject to the above discussion) and withholding and withdrawing life-sustaining treatment (can be lawful). Not providing treatment can be lawful because it involves a failure to treat when there is no duty to provide that treatment. There is no duty because one of the three situations outlined above (refusal by a competent person, substitute or surrogate decision-maker refusal or doctor considers treatment is not beneficial) has arisen. By contrast, assisted dying involves taking active steps to end another’s life (or assisting the person to do that themselves) and so breaches the criminal law.

**Palliative Care**

Law’s role in this area arose because of concerns that otherwise appropriate palliative care could accelerate death. Although contested, some considered that medication such as opioids, when given in sufficient doses needed to manage pain and symptoms, could suppress respiration and cause or hasten a person’s death. This could be seen as ‘active steps’ to end a patient’s life and therefore unlawful.

The law’s response was to draw on the ethical principle of the doctrine of double effect. This reasoning sanctions actions done with a good intention even if they may result in a foreseen bad outcome. Accordingly, the law in most Western countries protects doctors (and potentially others involved in providing the palliative care) when they provide appropriate palliative medication with the intention of relieving pain or symptoms, even if it might hasten death. We note though that some argue that a doctor’s intention is difficult to ascertain or may be mixed in terms of motivations, and so the operation of this law in practice may be unclear.

---


Other End-of-Life Practices

There are also ‘new’ end-of-life practices which challenge the categorisation of end-of-life law into these three areas. Sometimes this is because it may be unclear as to which category a practice belongs. An example of this is voluntary stopping eating and drinking (‘VSED’) by a competent adult with the intention of bringing about their death. For some, this is potentially lawful as it is akin to (if not equal to) withholding and withdrawing life-sustaining treatment.60 Others regard this as a form of suicide, and those involved risk the charge of assisted suicide.61 In addition, this practice may also cross over into the palliative care arena if palliative medication is provided to manage pain and symptoms while the person dies.62

Another end-of-life practice, controversial in some jurisdictions, is what is variously called deep continuous sedation, terminal sedation or palliative sedation. This is sometimes used when existing palliative care cannot manage pain or symptoms effectively and so medication is provided to sedate the person towards the end of their life.63 This may not only involve palliative care but can also include the withholding or withdrawal of medical treatment including artificial nutrition and hydration.64 Some consider it a form of ‘slow euthanasia’ when these two steps are combined.65

It is not necessary to resolve the issue of how to characterise these and other end-of-life practices in legal terms nor is it necessary to resolve the boundaries of their lawfulness. However, we note them here to acknowledge that the contours and categories of end-of-life law are evolving and intersecting.

62 White, Willmott and Savulescu, ‘Voluntary Palliated Starvation’.
63 Nathan Cherny, Lukas Radbruch and the Board of the European Association for Palliative Care, ‘European Association for Palliative Care (EAPC) Recommended Framework for the Use of Sedation in Palliative Care’ (2009) 23 Palliative Medicine 581–93; Beller et al., ‘Palliative Pharmacological Sedation for Terminally Ill Adults’.
Concluding Thoughts on End-of-Life Law

What emerges from even a superficial review of end-of-life law internationally is that there are significant similarities, at least at a macro level, in how Western nations regulate this field of care. This is not surprising as modern medicine and the organisation of health care in these countries, as well as societal trends, for example towards patient consumerism, pose the same sorts of questions for lawmakers. If medical treatment can continue to prolong life for extended periods, when should that stop and who should decide? If pain or other symptoms cannot be treated, should a person have an opportunity to end their life and, if so, in what circumstances?66

While these global issues and policy responses in different countries have many similarities, there is also a divergence of approaches. Each country has its own legal, political and societal culture that inevitably shapes local laws. For example, in his chapter, Orentlicher argues that a US preference for legal certainty by drawing ‘bright lines’ for decision-making can be contrasted with a European approach, at least in some countries, where there appears to be greater tolerance for laws that permit more discretion in decision-making.67 The presence or absence of human rights instruments, and their relative robustness, has also shaped end-of-life law locally.68

We conclude this section by noting that ongoing change in end-of-life law, or at least efforts to change that law, lies ahead. This is one reason why we consider that this book about law reform in this area is important. For example, there is a slow but steady trend internationally to legalise assisted dying. There may also be a trend towards greater regulation of end-of-life care, reflecting a wider trend for more regulation of health matters and human activity generally. Illustrations of this include ongoing changes in adult guardianship, mental capacity and medical treatment legislation, but this trend is also evident in the increased use of the courts as arbiters in end-of-life matters.69

66 These legal similarities identified in Western nations do not persist when compared with some other parts of the world where more pressing health law issues, such as basic access to health care, arise. In other words, dealing with laws about the end of life presupposes a certain standard of medical care, that is, that advanced life-sustaining treatment is available to prolong life and so issues of when to stop or not start it arise. Likewise, analysing laws about palliative care assumes that such care is available to patients.
67 See Chapter 7.
68 For example, see Chapter 2, and the role of the Canadian Charter of Rights and Freedoms in prompting assisted dying reform: Canadian Charter of Rights and Freedoms, Canada Act 1982 (UK) c. 11, sch. B, pt. 1, ss. 7, 15.
69 See, for example, the high-profile cases of Charlie Gard and Alfie Evans. In relation to Charlie Gard, see: Great Ormond Street Hospital v. Yates and Others [2017] EWHC 972; Yates and Another v. Great Ormond Street Hospital for Children NHS Foundation Trust and Another (Rev 1) [2017] EWCA Civ 405; In the Case of Charlie Gard (Unreported decision of Supreme Court of the United Kingdom, 19 June 2017, Lady Hale, Lord Kerr and Lord Wilson); Gard and Another