

## **GUEST EDITORIAL: END OF LIFE LAW, ETHICS, POLICY AND PRACTICE**

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The International Conference on End of Life: Law, Ethics, Policy and Practice was held at Queensland University of Technology, Brisbane, Australia in August 2014. It was co-hosted by the Australian Centre for Health Law Research, the Dalhousie Health Law Institute (Canada) and the Tsinghua Health Law Research Center (China). The conference attracted almost 350 delegates from 26 countries and included representation from over a dozen different disciplines with an interest in end of life care.

This issue contains seven articles which span the four conference themes of:

- i) withholding and withdrawing potentially life-sustaining treatment;
- ii) euthanasia and assisted suicide;
- iii) palliative care and terminal sedation; and
- iv) determination of death and organ donation.

We begin the issue with an article from Michael Ashby on how, from the palliative care perspective, we might or should die. The article, entitled ‘How We Die: A View from Palliative Care’, examines the experience of dying, especially with regard to the how, where and when of dying in Australia. While Australia has been ranked the second best country in the world in which to die,<sup>1</sup> the article notes that much remains to be done. Ashby then examines some of the remaining significant medical, legal, ethical and social barriers to care and decision-making at the end of life, including some legal issues, such as terminal sedation (see also McLean’s article below). Other issues that are canvassed include the difficult social and cultural problems about attitudes towards death and dying, ‘death talk’ or communicating about death and dying, in preparing for death and in respect of death causation. The article advocates a move away from a focus on human agency and death causation towards non-obstruction of the dying process, something which palliative care can enable.

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<sup>1</sup> Economist Intelligence Unit, *The 2015 Quality of Death Index. Ranking Palliative Care Across the World* (2015) <<http://www.economistinsights.com/healthcare/analysis/quality-death-index-2015>>.

The next article then shifts to the topic of withholding and withdrawing life-sustaining treatment and focuses in on a key area of debate in this field: futility. The article, '*Texas Advance Directives Act: Nearly a Model Dispute Resolution Mechanism for Intractable Medical Futility Conflicts*,' by Thaddeus Pope, analyses an early model for resolving futility disputes. Pope first examines the nature of medical futility disputes and why there is a need for a process to resolve them. He then shifts to examine the legislation and undertakes a detailed legal analysis of the conflict resolution process established by the Act. He reviews its purpose and history, and then considers the various procedural steps that form part of the Texan model. He also examines how this framework has operated in practice and the extent to which it has been used by hospitals and families. Pope concludes with a normative critique of the *Texas Advance Directives Act*. He argues that while there are benefits to the dispute resolution process, it fails to take sufficient account of fundamental notions of procedural due process and should be reformed accordingly.

A second futility article is '*Futility and the Law: Knowledge, Practice and Attitudes of Doctors in End of Life Care*' by Lindy Willmott, Ben White, Eliana Close and colleagues. It reports on empirical research undertaken in Queensland into doctors' perceptions about the law that governs futile treatment at the end of life, and the role it plays in medical practice. The article begins by outlining the relevant law which is particularly complex in Queensland when compared with other Australian jurisdictions. The article then shifts to describe the empirical research that was undertaken which involved semi-structured interviews with 96 doctors from a range of specialties involved in end of life care. Key findings are that doctors have poor knowledge of the law in this area and their legal obligations and powers when making decisions about withholding or withdrawing futile treatment at the end of life. The attitudes of doctors interviewed were also largely negative towards the law and some reported that the law affected their clinical practice and either had or would cause them to provide treatment that they regard as futile. The article concludes with recommendations for law reform and education.

The next two articles report on overseas law and/or practice on assisted dying. The first is by Linda Ganzini on '*Legalised Physician-Assisted Death in Oregon*'. Her article draws together the various empirical evidence available on the operation of the Oregon regime and examines demographic information about those who have sought assistance to die. She notes, for example, that 3 in 1000 deaths in Oregon are now from physician-assisted death, and most of those dying have cancer or amyotrophic lateral sclerosis. Access to the regime is mostly by educated people with health insurance, most of whom are receiving comprehensive end of life care through a hospice. Ganzini does note, however, that a small number of persons with depression do access the regime, pointing to the need for improved screening for mental illness. She concludes that concerns that legalisation would undermine palliative care and that the regime would be utilised disproportionately by patients without access to good end of life care have been unfounded.

The second article on assisted dying is Jocelyn Downie's '*Permitting Voluntary Euthanasia and Assisted Suicide: Law Reform Pathways for Common Law Jurisdictions*'. This article offers a unique perspective on what Downie describes to be the 'well-travelled terrain' of the voluntary euthanasia and assisted suicide debate. Rather than rehearsing the arguments in support of and opposing reform and describing the legislative models around the world that permit these practices, Downie's article considers a range of pathways to permissive regimes. By focusing on the experiences in five common law jurisdictions (the United States, the United Kingdom, Australia, New Zealand and Canada), Downie explores prosecutorial charging guidelines, court challenges, jury nullification, the exercise of prosecutorial discretion in the absence of offence-specific charging guidelines, and the exercise of judicial discretion, in

addition to legislative reform, as potential law reform avenues. The article concludes with some lessons that can be learnt from the recent experience in Canada which has witnessed the landmark decision of the Supreme Court of Canada in *Carter's case*<sup>2</sup> where provisions of the *Criminal Code* relating to physician-assisted dying were held to be void in some circumstances, as well as legislative reform in the province of Quebec.

While some practices in Australia are clearly lawful (such as withdrawing treatment which is not in the best interests of a patient) and some are clearly unlawful (such as providing medication to a patient with the sole intention of killing that patient), terminal sedation is a medical practice that cannot neatly be categorised as either lawful or unlawful. Opinions also differ about the ethics of the practice. Sheila McLean's article 'Terminal Sedation – Good Medicine? Good Ethics? Good Law?' explores the legal and ethical implications of terminal sedation including when it is combined with the removal or withholding of artificial nutrition and hydration. Remarkably, the legal and ethical dimensions of this practice have received little scrutiny despite the fact that the death of patients is the certain result.

In this article, McLean considers the kinds of practices that are encompassed by the phrase 'terminal sedation' as well as the circumstances in which it is provided, and how practice in this regard varies across jurisdictions, and even within the same country. McLean explores the various ethical and legal principles upon which terminal sedation could be justified, but concludes that the practice, particularly when it involves the withholding or withdrawing of artificial nutrition and hydration, rests on shaky ethical and legal foundations. The author argues that there is an urgent need for 'clarification, consistency, transparency and accountability' as the use of terminal sedation continues to grow.

This special issue concludes with a discussion of the United Kingdom position on deceased organ donation after the circulatory determination of death, and measures that can increase rates of solid organ donation. This is a timely contribution as this issue has become controversial in Australia in recent times.

Dale Gardiner's article, 'How the UK Overcame the Ethical, Legal and Professional Challenges in Donation after Circulatory Death', charts the return of donation after circulatory death ('DCD') in the United Kingdom after the practice had effectively been abandoned for approximately 25 years, following the rise of donation after brain death. Gardiner points out that, today, DCD accounts for 40 per cent of deceased solid organ donation in the United Kingdom. He attributes part of the success of DCD to the introduction of new measures aimed at increasing the number of families that are approached by intensive care staff with the offer of the opportunity to donate. Gardiner points out that even though the consent rate itself has not changed (the rate of consent has remained virtually the same over the last decade), these reforms have resulted in a staggering 311 per cent increase in the number of families approached, and this has translated into a 170 per cent increase in the number of actual DCD donors since 2007.

Gardiner also attributes the rise of DCD to a better ethical and legal framework for DCD in the United Kingdom, which has allowed organ donation following circulatory death to become a usual rather than unusual event in hospitals. In other words, donation conversation is now, where appropriate, a normal part of end of life care. In his article, Gardiner goes on to outline in detail the main factors which he believes brought these changes about.

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<sup>2</sup> *Carter v Canada (Attorney General)* 2015 SCC 5.

The seven articles in this special issue traverse a breadth of end of life issues including withholding and withdrawing life-sustaining treatment, euthanasia and assisted suicide, palliative care and terminal sedation, and determination of death and organ donation. The articles look at these issues from both national and international perspectives and from legal, medical, bioethical and social science viewpoints. This collection also signals the important work that still needs to be done, and of the need for comparative understanding and interdisciplinary perspectives to advance end of life law, ethics, policy and practice.