INTERNATIONAL PERSPECTIVES ON END-OF-LIFE LAW REFORM

Much has been written about whether end-of-life law should change and what that law should be. However, the barriers and facilitators of such changes – law reform perspectives – have been virtually ignored. Why do so many attempts to change the law fail but others are successful? International Perspectives on End-of-Life Law Reform aims to address this question by drawing on ten case studies of end-of-life law reform from the United Kingdom, the United States, Canada, the Netherlands, Belgium and Australia. Written by leading end-of-life scholars, the book’s chapters blend perspectives from law, medicine, bioethics and sociology to examine sustained reform efforts to permit assisted dying and change the law about withholding and withdrawing life-sustaining treatment. Findings from this book not only shed light on changing end-of-life law but also provide insight more generally into how and why law reform succeeds in complex and controversial social policy areas.

Ben P. White is Professor of End-of-Life Law and Regulation in the Australian Centre for Health Law Research in the Faculty of Business and Law, Queensland University of Technology. His research expertise focuses on end-of-life decision-making, and as a former law reform commissioner, he has had a long-standing involvement in law reform.

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CAMBRIDGE BIOETHICS AND LAW

This series of books – formerly called Cambridge Law, Medicine and Ethics – was founded by Cambridge University Press with Alexander McCall Smith as its first editor in 2003. It focuses on the law’s complex and troubled relationship with medicine across both the developed and the developing world. In the past twenty years, we have seen in many countries increasing resort to the courts by dissatisfied patients and a growing use of the courts to attempt to resolve intractable ethical dilemmas. At the same time, legislatures across the world have struggled to address the questions posed by both the successes and the failures of modern medicine, while international organisations such as the WHO and UNESCO now regularly address issues of medical law. It follows that we would expect ethical and policy questions to be integral to the analysis of the legal issues discussed in this series. The series responds to the high profile of medical law in universities, in legal and medical practice, as well as in public and political affairs. We seek to reflect the evidence that many major health-related policy and bioethics debates in the UK, Europe and the international community over the past two decades have involved a strong medical law dimension. With that in mind, we seek to address how legal analysis might have a trans-jurisdictional and international relevance. Organ retention, embryonic stem cell research, physician-assisted suicide and the allocation of resources to fund health care are but a few examples among many. The emphasis of this series is thus on matters of public concern and/or practical significance. We look for books that could make a difference to the development of medical law and enhance the role of medico-legal debate in policy circles. That is not to say that we lack interest in the important theoretical dimensions of the subject, but we aim to ensure that theoretical debate is grounded in the realities of how the law does and should interact with medicine and health care.

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International Perspectives on End-of-Life Law Reform

POLITICS, PERSUASION AND PERSISTENCE

Edited by

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Preface

The law that regulates end-of-life decision-making is constantly evolving. Public discussion, interest group advocacy, media engagement and inquiries by law reform bodies ensure ongoing public debate about existing law as well as proposals for reform. While much has been written describing the current state of end-of-life law, advocating for what the law should be, and analysing how this law operates in practice, very little has been written about how and why law reform occurs in this area. Yet this issue is critical: some reforms of end-of-life law involve fundamental changes to how society regulates very significant decisions. Further, reform in this area, particularly in relation to assisted dying, has historically been very challenging to achieve.

This collection aims to shed light on why some law reform efforts to change end-of-life law succeed and others fail. The genesis of this collection was informal discussions with colleagues about how to bring about end-of-life law reform. It soon became clear from these discussions that the same question was being asked across the globe and there were lessons to be learnt from international experience.

This prompted a workshop, ‘Law Reform in the End-of-Life Field’, at the 2nd International Conference on End of Life Care: Law, Ethics, Policy and Practice held at Dalhousie University, Canada in September 2017. Members of the authorial teams from all but one of the chapters in this collection attended and presented a paper at that workshop (circulated prior to all workshop participants). Each paper had a nominated commentator and was critically and constructively discussed by the group. Those papers, which evolved into the ten case studies in this collection, provide insights into end-of-life law reform efforts in the United Kingdom, the United States, Canada, Australia, Belgium and the Netherlands.

We are grateful for the collegiality and collaborative spirit of the contributing authors over the course of writing this collection. In addition to the workshop review, a later draft of each chapter was sent to two other authorial groups for critical feedback. This not only strengthened the individual chapters but also
elicited new connections and intersections between chapters, enhancing the overall continuity and focus of the collection.

Further collaboration also occurred in writing the concluding chapter which draws together global themes from the ten reform case studies. The collection’s contributing authors were invited to participate in writing this chapter, and the outcome was a thought-provoking collaboration enriched by international and interdisciplinary perspectives. The opportunity to consider collectively with this group the implications of the ten case studies for law reform more generally was the most enjoyable part of editing this collection. We acknowledge the important contribution that all of the authors made, not just through writing their own chapters but to the collection as a whole.

We hope that this book is of interest to those considering how society regulates end-of-life decision-making. Our primary goal in bringing together these international case studies is to inform those involved in, or contemplating, end-of-life reform, whether from an academic, professional or policy perspective. We also hope that the case studies may be of value to those grappling with reform in other complex social policy areas.

We thank Emily Bartels (Queensland University of Technology), who provided extensive assistance with the preparation of the manuscript including providing research assistance, formatting and referencing chapters, co-ordinating the many versions of chapters with authors, and compiling the index and tables. We also thank Rebecca Meehan (Queensland University of Technology) for her assistance with the book proposal, research assistance for early chapters and initial administrative co-ordination. Our thanks also go to Chrystal Gray (Dalhousie University), who assisted with the organisation and logistics of the initial workshop. We are grateful too for the support of Cambridge University Press in the preparation and completion of the book, particularly that of Finola O’Sullivan and Marianne Nield.

We acknowledge the Australian Centre for Health Law Research in the Faculty of Business and Law, Queensland University of Technology. The Centre provided some support with administrative tasks to prepare the manuscript, but more importantly, we are grateful to work and research with tremendous colleagues in the Centre, particularly in the End-of-Life Research Program. A number of the authors in this collection are either based at the Centre or are adjunct professors with the Centre, and we are fortunate to be part of that generous health law community.

We thank our families for their tireless support through this and other projects. Ben thanks Kylie, Madeleine, Ella, Matilda, Adelaide and Amelia. Lindy acknowledges Jim, Kaley, Robbie, Jessie, Matt, Phoebe, Lachlan, Kelly, Ben, Henry and Oscar.

We conclude this preface as we began: noting that end-of-life law is constantly evolving. As a result, by the time this book is published, there will be new legislation (or existing legislation will be amended) and new cases that change the landscape of end-of-life law in various parts of the world. We have endeavoured to present the law and reform developments as at 30 June 2020, but have taken the opportunity (where possible during the publishing process) to mention some later developments.
About the Editors

Ben P. White is Professor of End-of-Life Law and Regulation in the Australian Centre for Health Law Research in the Faculty of Business and Law, Queensland University of Technology. He was a Foundation Director of the Centre and his research area is end-of-life decision-making with a particular focus on voluntary assisted dying. His programme of research has been funded by a series of Australian Research Council and National Health and Medical Research Council grants examining the law, policy and practice of end-of-life decision-making. He is currently undertaking a four-year Australian Research Council Future Fellowship: *Optimal Regulation of Voluntary Assisted Dying*. White has also had a long-standing interest in law reform, beginning with his doctoral thesis which examined the role of consultation in law reform processes. He has served as both a full-time and part-time commissioner at the Queensland Law Reform Commission, and his academic research and submissions have been extensively used by law reform bodies investigating end-of-life issues.

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