



Introduction

DAVID ALBERT JONES, CHRIS GASTMANS
AND CALUM MACKELLAR

Belgium is one of very few countries in the world where one can assess the impact of legalising euthanasia or assisted suicide.

Attempts to legalise euthanasia or physician-assisted suicide date back at least to the 1930s, with the founding of the Voluntary Euthanasia Legalisation Society in London in 1935. However, it was only in the 1980s that organised forms of these practices were legally tolerated in Switzerland and in the Netherlands and the first statute law to provide for medically assisted death was not passed until the mid-1990s, in Oregon. Twenty years later, the number of jurisdictions with extensive experience of euthanasia or physician-assisted suicide remains very small: only Switzerland, the Netherlands, Belgium, Luxembourg and a handful of States in the United States. There are some other jurisdictions where such practices are now, or have been, legal, but in all other cases their experience is much more limited in time or in extent.

Euthanasia in Belgium is the subject of a large body of empirical research and there is also a set of biennial official reports from 2002. However, until the present volume no study has sought to draw this research together into a coherent narrative and present it to an English-speaking readership. Without prejudice to work that has been done on euthanasia in the Netherlands and physician-assisted suicide in the United States, such evidence is always partial. With so few exemplars it is essential also to consider in depth and in detail the experience of Belgium for what it may have to teach in relation to the impact of medically assisted death. The best guide to what *could* happen is what *has* happened.

It can be useful to compare Belgian law and practice with those of other countries, with the Netherlands or Luxembourg, or with the United Kingdom or the United States. Several of the chapters contain such comparisons. Nevertheless, the focus of interest for this volume remains Belgium. By considering the experience of one country in depth and from different perspectives it is possible to explore the diverse ways in which a

change in law in this area can have an impact on society. The aim is to consider what lessons the Belgian experience may hold for other countries that are contemplating a similar move.

The book begins with an account of the Belgian euthanasia law, comparing the law with similar legislation in the Netherlands and in Luxembourg, and examining amendments and interpretations of the law. The author, Herman Nys, is Professor of Health Law at the University of Leuven and is well known in Belgium for his interpretation of the euthanasia law. In the second chapter, Etienne Montero, Professor in the Faculty of Law at the University of Namur, considers the implementation of this legislation. This chapter draws on official reports and independent research to explore the pattern of euthanasia practice in Belgium.

After two contrasting Belgian perspectives, the third chapter provides a viewpoint from the United States. It focuses on areas of overlap between experience in Oregon and that in Belgium, in relation to psychiatric dimensions of the practice. The author is Daniel Sulmasy, professor at the Pellegrino Center and the Kennedy Institute of Ethics, Georgetown University, USA.

A key concern in relation to euthanasia is the impact of a change in the law on the shape of end-of-life care. A palliative care perspective is set out by Paul Vanden Berghe and Gert Huysmans, who are director and president, respectively, of the Federation of Palliative Care Flanders. Their co-author Marc Desmet is both a Jesuit and a medical doctor working in palliative care. The current volume reprints a paper these authors wrote in 2013 on the experience of euthanasia embedded in palliative care, together with a postscript reflecting on that paper in the light of subsequent developments up to 2016. This contribution is followed by a chapter by Sigrid Sterckx and Kasper Raus on the practice of continuous sedation. Professor Sterckx and Dr Raus of the University of Ghent took part in an international collaborative research project on sedation and have edited a scholarly volume on the topic. They examine the contrast between sedation practice in Belgium and that in the United Kingdom. Another clinical contribution, from Benoit Beuselinck, provides an individual perspective from a clinician with fifteen years of experience in oncology who is very critical of the impact of the law.

The last chapter in the Part II is by Trevor Stammers, a former general practitioner in the United Kingdom and currently editor of a bioethics journal and former programme director of a masters in bioethics. The chapter considers the topic of organ transplantation after

euthanasia. The subject functions as a bridge to other debates in bioethics, not least the ethics of novel forms of organ procurement.

The five subsequent chapters consider groups of patients who, it has been alleged or might be supposed, could be affected adversely by such legislation. Kevin Fitzpatrick, a philosopher and former Disability Rights Commissioner for Wales explores the relationship of disability to the practice of euthanasia as this is performed in Belgium. He died before he could finish writing this chapter and, with his prior agreement, the chapter was completed by David Albert Jones.

Joris Vandenberghe, a psychiatrist at Leuven University Hospitals and Associate Professor in the Faculty of Medicine, considers the highly controversial practice of euthanasia in patients suffering from psychiatric illnesses. Such cases are much less prevalent than euthanasia in terminally ill patients, but the numbers are increasing both in absolute terms and as a proportion of the total. In contrast, the extension of the euthanasia act to children, which generated international controversy when the law was amended in 2014, has yet to be applied in practice. This issue is examined by Stefaan Van Gool, a professor in paediatric neuro-oncology and Jan De Lepeleire, a general practitioner who chaired an ethical forum on euthanasia at the University of Leuven. They ask whether the extension of the law was needed and whether it is workable in practice.

Raphael Cohen-Almagor, Professor of Politics in Hull in the United Kingdom, has written extensively on euthanasia in the Netherlands and in Belgium. His chapter considers the practice of euthanizing people who are 'tired of life'. The last vulnerable group to be considered in this section are people with dementia. Currently the Belgian law does not permit euthanasia of people with dementia on the basis of an advance euthanasia directive. However, this is permitted in the Netherlands and there have been repeated attempts to extend the Belgian law to cover such cases. The difficulties with such proposals are explored by Chris Gastmans, Professor of Medical Ethics at the University of Leuven.

Part IV considers conceptual or philosophical issues. Calum MacKellar, the Director of Research of the Scottish Council on Human Bioethics, explores the phenomenon of 'normalisation' applied to euthanasia in Belgium. David Albert Jones, Director of the Anscombe Bioethics Centre in Oxford and Research Fellow in Bioethics at St Mary's University, Twickenham, considers the difficulty of applying empirical data to ethically contested questions in public policy. The empirical evidence from Belgium is examined from three distinct ethical and

4 DAVID ALBERT JONES, CHRIS GASTMANS & CALUM MACKELLAR

philosophical perspectives and it is argued that this process shows convergence to a common conclusion.

A final paper in this section, by Willem Lemmens, Professor of Modern Philosophy at the University of Antwerp, returns to the example of euthanasia for patients with psychiatric disorders. This example is used to explore the relationship between autonomy and vulnerability. A genealogical reading of this issue is presented which highlights some features of the euthanasia debate as it has unfolded in Belgium. Professor Lemmens' considerations relate first to psychiatric patients. However, these considerations provoke critical observations on the Belgian euthanasia practice more generally, and have application to a much wider category of patients.

These fifteen chapters by nineteen authors include contributions from bioethicists, philosophers, lawyers and clinicians. They provide perspectives from outside as well as inside Belgium. Many are critical of some aspect of end-of-life care in Belgium but not all are opposed to medically assisted death in principle or to the Belgian law in particular. Furthermore, even among those who are opposed in principle, almost all clinicians express a willingness, albeit reluctant, to work within the system for the sake of supporting patients.

The book, therefore, represents a collection of different perspectives which are not only diverse in relation to focus and method but also in relation to the author's ethical stance on euthanasia and assisted suicide. There is no consensus view that would represent appropriately all the contributors.

As editors, we believe the book is stronger because it includes such a diversity of views. Nevertheless, the principal aim of the book is to help readers come to an overall view for themselves about what has happened in Belgium with respect to euthanasia.

The editors' own views are presented at the end as they seek to draw some clear conclusions or lessons from the chapters of the volume taken together. Social and ethical understanding rarely comes from a single argument, or a few isolated pieces of evidence, instead it is a reflective process whereby 'light dawns gradually over the whole'.