
1. An introduction to voluntary assisted dying law, regulation and practice

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INTRODUCTION

The landscape of voluntary assisted dying (VAD) has changed radically over the last few decades. Twenty years ago, VAD was permitted in just a few places. It was lawful in Europe in the Netherlands, Belgium and Switzerland with the practice also being permitted in the US state of Oregon and the country of Colombia. Although highly studied, particularly in Europe, it was regarded by many as a ‘boutique’ issue of limited relevance to healthcare more broadly.

Moving forward to the present, at least some form of VAD is now lawful in some or all parts of 17 countries. Joining the three European countries mentioned above, VAD is permitted in Europe in Luxembourg, Germany, Austria, Spain, Portugal and Italy. VAD in the United States is now available in 11 of its jurisdictions, with Canada, Australia (all states but not yet territories) and New Zealand also passing VAD laws. Colombia is now joined in Latin America by Peru, Ecuador and Cuba. Collectively, VAD is now available in jurisdictions that are home to half a billion people.²

This trend towards international liberalisation is likely to continue.³ Indeed, as this book is being written, there are VAD bills before parliaments in Scotland,⁴ Ireland,⁵ France⁶ and

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² Thaddeus M Pope, ‘Medical Aid in Dying – Available to Half a Billion’ <<https://medicalfutility.blogspot.com/2024/07/medical-aid-in-dying-available-to-half.html>>.

³ Joachim Cohen and Kenneth Chambaere, ‘Increased legalisation of medical assistance in dying: relationship to palliative care’ (2023) 13(2) *BMJ Supportive & Palliative Care* 178–80. See also Chapter 36: Ben P. White, ‘The future of voluntary assisted dying’.

⁴ SP Bill 46 Assisted Dying for Terminally Ill Adults (Scotland) Bill [as introduced] Session 6 (2024) <<https://www.parliament.scot/bills-and-laws/bills/assisted-dying-for-terminally-ill-adults-scotland-bill>>.

⁵ Voluntary Assisted Dying Bill 2024, Dáil Bill (2024) 50 (Ireland). <<https://www.oireachtas.ie/en/bills/bill/2024/50/>>.

⁶ N° 2462 *Projet de loi relatif à l’accompagnement des malades et de la fin de vie* [No 2462 Bill on the Support of the Sick and the End of Life], National Assembly (10 April 2024) (France) <<https://www.legifrance.gouv.fr/dossierlegislatif/JORFDOLE000049401821/>>.

the Isle of Man.⁷ There are a range of reasons for this. One is the increased role of evidence in law reform debates about VAD.⁸ Because there is now a reliable body of evidence about how VAD systems can operate safely and effectively, arguments against reform, such as those which make claims about risks to the vulnerable, are harder to sustain empirically.⁹ This has led to a ‘shrinking battlefield’¹⁰ for opponents to advocate against VAD, making reform more likely. The shift from a rare and boutique activity 20 years ago to a now lawful end-of-life choice for half a billion people can also help shift perspectives for lawmakers about the nature and acceptability of VAD.

Although VAD has always been scrutinised given its contested nature, as the practice becomes more common and is permitted in more jurisdictions, examination of VAD through research becomes even more important. There is an increased number of jurisdictions to examine, there are different models of VAD to analyse (including in relation to variation in eligibility criteria and procedural safeguards) and the steadily growing body of empirical evidence about how VAD operates in practice needs to be critically examined.

This chapter provides an introduction to this book, which aims to respond to that need for systemic research about VAD. The chapter begins by defining VAD and explaining why this term was chosen, given the range of terminology that exists in this field. It then outlines the scope of the book, which involves examining what is meant by law, regulation and practice – the three concepts that form part of the title. The chapter then addresses the objective of the book: to provide a comprehensive examination of the field of VAD internationally and how the various chapters contribute to this goal.

WHAT IS VOLUNTARY ASSISTED DYING?

The Terminology of Voluntary Assisted Dying

Clarity about terminology is important as there is a long history in this field of inconsistent and unclear use of terms, leading to confusion and controversy.¹¹ Terminology has evolved over time, with terms such as voluntary euthanasia and physician-assisted suicide commonly used in the past but less frequently today. Further, there is variation across different jurisdictions in

⁷ Assisted Dying Bill 2023 (Isle of Man) <<https://legislation.gov.im/cms/images/LEGISLATION/BILLS/2023/2023-0005/2023-0005.pdf>>.

⁸ For a discussion of evidence-based law reform, see: Ben White and Lindy Willmott, ‘Evidence-based law making on voluntary assisted dying’ (2020) 44(4) *Australian Health Review* 544–46.

⁹ Ben White and others, ‘International Perspectives on Reforming End-of-Life Law’ in Ben White and Lindy Willmott (eds), *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence* (Cambridge UK, CUP 2021) 250–75.

¹⁰ Ben White and Lindy Willmott, ‘Future of assisted dying reform in Australia’ (2018) 42 *Australian Health Review* 616–20.

¹¹ Sarah Mroz and others, ‘Assisted dying around the world: a status quaestionis’ (2021) 10(3) *Ann Palliat Med* 3540–53; Jocelyn Downie and others, ‘Assistance in dying: A comparative look at legal definitions’ (2022) 46(7) *Death Studies* 1547–56; Samuel Blouin and Murielle Pott, ‘Assistance in dying: Conditions for international comparison’ (2022) 46(7) *Death Studies* 1541–46.

the terms used to describe VAD. For example, medical assistance in dying is generally used in Canada, with aid in dying or medical aid in dying often used in the United States. In Australia, VAD is the usual chosen terminology; New Zealand uses assisted dying, while euthanasia is the term often adopted in places like Belgium and the Netherlands. Responding to observations that authors often fail to explain their terminology,¹² a threshold issue to address is the choice to use the term ‘voluntary assisted dying’ in this chapter and in the book’s title.

Most modern terminology uses words relating to assistance or aid in dying, with the term ‘assisted dying’ being very common.¹³ Such a term has been preferred by some as being more descriptive in nature and has been contrasted with labels that reflect particular political and moral viewpoints, such as terms involving references to ‘suicide’ or ‘dignity’.¹⁴ This approach is supported, but it is proposed that the word ‘voluntary’ be added to ‘assisted dying’ as this better captures the concept being considered for two connected reasons.¹⁵ The first is that specifying that VAD is voluntary makes clear that it is a person’s choice to be assisted to die. The term VAD excludes the possibility of confusion about any non-voluntary nature of decisions and emphasises that this is something requested and chosen by a person.

The second and connected reason is that the term VAD also places emphasis on the person seeking VAD, hence it is more person-centred.¹⁶ By contrast, another common set of terms refer to medical (or physician) assistance or aid in dying, but those terms highlight the role of the health practitioner in providing this service. While some may argue that this is valuable because it situates VAD as part of healthcare, the term VAD is preferred because it emphasises the role of the person choosing an assisted death rather than the role of the practitioner who is providing it. A further advantage of VAD over terms such as medical assistance in dying is that it is more inclusive in capturing jurisdictions where VAD may not be conceived as a medical act or part of healthcare.¹⁷

¹² Sheri M Gerson and others, ‘When is hastened death considered suicide? A systematically conducted literature review about palliative care professionals’ experiences where assisted dying is legal’ (2019) 18 *BMC Palliative Care* (article 75).

¹³ See for example: Ben White and Lindy Willmott, ‘End-of-life Law Reform: Context and Challenges’ in Ben White and Lindy Willmott (eds), *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence* (Cambridge UK, CUP 2021) 1–16; Mroz and others (n 11).

¹⁴ Blouin and Pott (n 11). See also: Mroz and others (n 11); Lydia S Dugdale, Barron H Lerner and Daniel Callahan, ‘Pros and Cons of Physician Aid in Dying’ (2019) 92(4) *Yale Journal of Biology and Medicine* 747.

¹⁵ Victorian Government, Ministerial Advisory Panel on Voluntary Assisted Dying (Final Report, July 2017) 8. The author also acknowledges helpful discussions with Dr Greg Mewett on these definitional issues.

¹⁶ In relation to person-centred care (historically also called patient-centred care) and its role in the provision of healthcare, see for example: Maria J. Santana and others, ‘How to practice person-centred care: A conceptual framework’ (2018) 21(2) *Health Expectations* 429.

¹⁷ Blouin and Pott (n 11). It is acknowledged, however, that some argue that the term VAD ‘veils’ the fact that medical participation is needed for VAD and that health practitioners act as gatekeepers to accessing this choice: Courtney Hempton, ‘The Constitution of “Choice”: Voluntary Assisted Dying in the Australian State of Victoria’ in Daniel J Fleming and David J Carter (eds), *Voluntary Assisted Dying: Law? Health? Justice?* (Australian National University Press, 2022).

Although making the case for VAD as the overarching terminology for this book, it is noted at the outset that the book's chapters use a range of terms. This is intentional. Contributing authors have used the terminology that they prefer and consider best reflects the content and context they are addressing. This is particularly the case in the chapters in Part I, which analyse the law, regulation and practice of VAD in different countries.

This section concludes with a brief definition of VAD. VAD is when a competent person voluntarily requests, and is provided with, medication that they take or have administered to end their life. The concept of VAD covers two practices. The first is 'practitioner administration' of VAD (sometimes called 'voluntary euthanasia'), which is when the medication is administered by a health practitioner to the person requesting to end their life. The second practice covered by the term VAD is 'self-administration' (sometimes called 'physician-assisted dying'), which is when the person requesting to end their life is provided with the medication which they then take themselves.

Whether VAD is practitioner administration or self-administration depends on who undertakes the final act to bring about death. To illustrate, self-administration may occur through a range of methods such as the person drinking the VAD medication themselves or through the person taking steps to initiate the release of medication that they receive intravenously. Both examples are self-administration because it is the person, rather than a health practitioner, who undertakes the final act that leads to their death.

Voluntary Assisted Dying is Different from Other End-of-Life Decisions

Part of understanding VAD includes distinguishing it from other significant end-of-life decisions. One such decision is withholding or withdrawing potentially life-sustaining medical treatment, which leads to a person's death. A key distinction generally recognised in law, although whether this distinction can be sustained is contested,¹⁸ is that such decisions are different from VAD because they do not involve taking active steps to end a person's life. Instead, the person dies because of the omission to provide treatment needed to stay alive. At law, this is generally permitted when there is no legal duty to provide that treatment. This might be because the treatment has been refused, either by a competent person (or a formerly competent person through an advance directive), or by an authorised substitute decision-maker on an incompetent person's behalf.¹⁹ It may also be authorised when treating clinicians determine the treatment will not benefit a patient (sometimes called 'futile' or 'non-beneficial' treatment).²⁰

Another significant end-of-life decision can arise when providing palliative medication. Some suggest that when this medication is given in large doses, it could suppress respiration and cause or hasten a person's death. While others contest that proposition,²¹ such actions

¹⁸ See for example: James Rachels, 'Active and Passive Euthanasia' (1975) 292(2) *The New England Journal of Medicine* 78–80.

¹⁹ White and Willmott, 'End-of-life Law Reform: Context and Challenges' (n 13).

²⁰ *ibid*; Ben White, Lindy Willmott and Eliana Close, 'Futile, non-beneficial, potentially inappropriate or "disputed" treatment' in Nathan Emmerich and others (eds), *Contemporary European Perspectives on the Ethics of End of Life Care* (Cham, Switzerland, Springer 2020) 181–98.

²¹ S A Fohr, 'The Double Effect of Pain Medication: Separating Myth from Reality' (1998) 1 *Journal of Palliative Medicine* 315–28. See also: Elaine M Beller and others, 'Palliative

could be seen as active steps to end a patient's life. However, such palliation is usually legally distinguished from VAD. This is generally on the basis that if death does occur, it is only foreseen and not intended, and the need to relieve pain justifies providing this medication.²²

A linked end-of-life practice is palliative sedation (also sometimes called deep continuous sedation or terminal sedation).²³ This is generally a last resort palliative measure when pain or symptoms cannot be managed effectively, so the person is sedated towards the end of their life. This is sometimes accompanied by withholding or withdrawal of life-sustaining medical treatment, such as artificial nutrition and hydration, which, depending on how close a person is to death, may affect the timing of that death. Another increasingly discussed end-of-life decision is when a competent adult chooses voluntary stopping of eating and drinking ('VSED') with the intention of bringing about their death.²⁴ Again, this may be combined with palliative care to manage the pain or symptoms of not eating and drinking as well as the dying process that follows.²⁵

It is acknowledged that there can be some blurriness in distinctions that are made between these decisions and VAD. For example, when categorising an end-of-life decision (and its lawfulness) depends on intention, challenges can arise because intentions can be mixed or unclear, and it can also be dubious to treat decisions with the same outcomes differently.²⁶ For the purposes of this book, however, it is sufficient to acknowledge this wider range of end-of-life decisions, but with an understanding that the focus will be on examining VAD as defined above.

THE LAW, REGULATION AND PRACTICE OF VOLUNTARY ASSISTED DYING

Part of defining the scope of this book requires considering the concepts of law, regulation and practice and their role in this examination of VAD. *Law* is perhaps the easiest to consider

Pharmacological Sedation for Terminally Ill Adults (Review)' (2015) 1 Cochrane Database of Systematic Reviews CD010206.

²² This reasoning often draws on the doctrine of double effect: White and Willmott, 'End-of-life Law Reform: Context and Challenges' (n 13).

²³ 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 and others (n 21).

²⁴ Timothy E. Quill and others, *Voluntarily Stopping Eating and Drinking: A Compassionate, Widely Available Option for Hastening Death* (Oxford UK, OUP 2012).

²⁵ Ben White, Lindy Willmott and Julian Savulescu, 'Voluntary Palliated Starvation: A Lawful and Ethical Way to Die?' (2014) 22 *Journal of Law and Medicine* 376–86; Jocelyn Downie, 'An Alternative to Medical Assistance in Dying? The Legal Status of Voluntary Stopping Eating and Drinking (VSED)' (2018) 1 *Canadian Journal of Bioethics* 48–58; Thaddeus Mason Pope and Lindsey E. Anderson, 'Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life' (2011) 17 *Widener Law Review* 363–427.

²⁶ See for example: Charles Douglas, Ian Kerridge and Rachel Ankeny, 'Managing Intentions: The End-of-Life Administration of Analgesics and Sedatives, and the Possibility of Slow Euthanasia' (2008) 22 *Bioethics* 388–96; J. Andrew Billings and Susan D. Block, 'Slow Euthanasia' (1996) 12 *Journal of Palliative Care* 21.

because, as a general proposition, law is what controls whether or not VAD is permitted. This is because the criminal law in most jurisdictions internationally prohibits taking steps to intentionally end the life of a person (usually treated as murder or some other form of culpable homicide) and prohibits aiding or assisting another person to take their own life (usually a crime such as aiding or abetting a suicide). Hence, for VAD to be permitted, some form of legal intervention to make it lawful in specified circumstances is required, and it is law that usually prescribes the boundaries of what is lawful and what is not.

There are different ways in which the law can come to permit VAD.²⁷ Historically, as the following chapters that examine VAD in each country demonstrate, this has generally been through the path of legislation passed by parliaments. However, legislation can also come into force through publicly-voted ballot initiatives, and this was the case with the early VAD statutes in the United States.²⁸ Alternatively, VAD has been legalised through court decisions, with Colombia and Canada being two examples of this path to reform. Sometimes, as occurred in Canada, court decisions are then followed by legislation to define the boundaries of permissible VAD practice.²⁹ VAD law is often a standalone legal instrument, such as the VAD Acts in Australia, but the legal provisions permitting VAD can instead be contained in other laws. An example of this is in Canada, where VAD laws are in the federal *Criminal Code*, where VAD is carved out as an exception to the usual criminal law.³⁰

It is not only law, however, that determines what is permitted and how VAD operates. The wider concept of *regulation* is also significant for VAD practice. Regulation is a contested concept³¹ and historically has been seen as focused on regulatory instruments issued by the State, typically the instrument of law.³² However, modern approaches³³ recognise regulation as a wider concept. To illustrate, Black's widely-used definition states: 'regulation is the sustained and focused attempt to alter the behaviour of others according to defined standards or purposes with the intention of producing a broadly identified outcome or outcomes, which may involve mechanisms of standard-setting, information-gathering and behaviour-modification'.³⁴

On this approach, regulating behaviour in the VAD setting occurs through a range of instruments beyond the law, including policies, guidelines, ethical codes, training, and funding programmes. Indeed, one chapter in this book, 'Holistic approaches to regulation of voluntary assisted dying',³⁵ considers this issue and argues that understanding how all of these regulatory instruments function together to guide behaviour is critical for effective evaluations of

²⁷ White and others (n 9).

²⁸ Chapter 10: Thaddeus Mason Pope, 'Assisted dying in the United States'.

²⁹ Jocelyn Downie and Kate Scallion, 'The Path from Rodriguez to Bill C-14 and Beyond: Lessons about MAiD Law Reform from Canada' in Ben White and Lindy Willmott (eds), *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence* (Cambridge UK, CUP 2021) 17–39.

³⁰ See Chapter 11: Eliana Close and Jocelyn Downie, 'Medical assistance in dying in Canada'.

³¹ Julia Black, 'Critical Reflections on Regulation' (2002) 27 *AJLP* 1; Christel Koop and Martin Lodge, 'What Is Regulation? An Interdisciplinary Concept Analysis' (2017) 11 *Regul Gov* 95.

³² Black (n 31).

³³ *ibid*; Koop and Lodge (n 31).

³⁴ Black (n 31) 26.

³⁵ See Chapter 22: Ben P. White, 'Holistic approaches to regulation of voluntary assisted dying'.

VAD regulation. This wider concept of regulation and its role in guiding behaviour beyond the law is featured in a range of chapters throughout the book.

Finally, the book reports on the *practice* of VAD, generally in the form of empirical research or other available public data about how VAD systems are operating. The concept of practice here takes its context from being examined in conjunction with law and regulation. For instance, the book does not purport to deal with practice issues that are primarily clinical in nature such as which VAD medication is used or clinical techniques for its administration. Therefore, the practice reported on in this book focuses on law and regulation and considers evidence on matters such as how often VAD is provided, for which groups of people, and the practical barriers and facilitators for VAD access.

Each chapter reporting on VAD in the various countries where it is lawful has a designated section considering the local practice of VAD. Other chapters are also informed by empirical evidence and practice. To illustrate, reflections on whether VAD should be available for mature minors or in cases where a person's only condition is a mental disorder will be informed by the evidence about what currently happens in practice in jurisdictions that permit this.

AN OUTLINE OF THE BOOK

Comprehensive Examination of Voluntary Assisted Dying Law and Regulation Internationally

The objective of the *Research Handbook* series that this book is a part of is to 'provide a scholarly, state-of-the-art overview of research and the scope of current thinking in the field.' Hence the goal was to create an edited collection that would comprehensively examine the field of VAD law and regulation internationally. This examination aimed to address three domains. The first was to have contributions from all jurisdictions where VAD is lawful so readers would have a complete picture of VAD internationally, at least at the time of writing. The second domain was to examine key and emerging issues so that current and future debates about VAD are considered. The third domain was to include a range of analytical viewpoints on VAD so that it is evaluated from different perspectives. More on this is set out below when outlining the scope of the book. It is acknowledged that developing a project like this involves making judgements, and a book on this topic by another editor could look quite different. However, it is hoped that this volume addresses the objective outlined above.

Key to being able to comprehensively examine the field of VAD has, of course, been the contributing authors. The chapters are written by leading scholars from the countries being analysed and with specific VAD expertise in the subject matter of the chapters. It was also pleasing to have contributions from a cohort of newer and future leading VAD scholars in this book. Contributing authors are from a range of disciplines. Although this is a book about law and regulation, VAD is an interdisciplinary field, and chapters were contributed by authors from the disciplines of law, bioethics, medicine, nursing, sociology, social work and health sciences. These interdisciplinary perspectives enriched the collection as a whole.

Book Overview

In addition to this introductory chapter, the book is organised in four parts. Part I is entitled ‘International perspectives on voluntary assisted dying law, regulation and practice’ and is comprised of 14 chapters reporting on the 17 countries where VAD is lawful. Beginning in Europe, chapters examine the Netherlands, Belgium and Luxembourg (similarities meant these two countries are considered in the same chapter), Switzerland, Germany, Austria, Spain, Portugal and Italy. North America is considered next with chapters on the United States and Canada, and they are followed by Australia and New Zealand. For Latin America, there is a chapter on Colombia as well as a chapter on the three new countries with VAD laws in that region: Peru, Ecuador and Cuba.

Contributing authors for Part I were invited to follow a consistent template so that readers would be able to understand not only the position in a particular country but also compare across those 17 countries. Hence, these chapters address how VAD became lawful and analyse the law across a range of domains such as the method of VAD permitted, eligibility criteria, processes to access VAD, objections to providing VAD by individuals and institutions, and oversight, reporting and compliance. These chapters also consider how the VAD system is working in practice, including perspectives from empirical research and data from oversight bodies, as well as key debates or possible future directions for VAD in the country. Authors were particularly invited to highlight law, regulation or practice that is unique or distinctive to their country.

Part II addresses ‘Frontiers of voluntary assisted dying law, regulation and practice’. These six chapters consider debates about more permissive aspects of VAD: access on the basis of mental disorder, access for minors, advance requests, access for older persons on the basis of being ‘tired of life’, supported decision-making for VAD, and organ donation after VAD. Although described as ‘frontiers’, it is recognised that these practices already occur at least in some countries where VAD is permitted, and these experiences are documented in these chapters. Authors were also invited to express their views on how access to VAD in these contexts should be governed.

Part III considers the ‘Regulation and societal control of voluntary assisted dying’. One chapter makes the case for holistic approaches to understanding VAD regulation (mentioned above) while others consider models of oversight of VAD practice and the role of research and evaluations in regulating VAD. A fourth chapter in this part addresses the debated issue of whether there are slippery slopes in VAD. The purpose of this part as a whole is to reflect on regulatory approaches to VAD and how societal control of the practice is or should be exercised.

Part IV is entitled ‘Rethinking conceptions of voluntary assisted dying’. These ten chapters see authors reflecting on different normative perspectives on VAD law, regulation and practice. They include reflections on the concept of patient choice in VAD as well as chapters on objections to VAD by individuals on the grounds of conscience and by institutions. There are also chapters on the relationship between VAD and palliative care, human rights assessments of VAD, and the social determinants of health and VAD (with a particular focus on access to VAD by prisoners). This part also includes contributions that look at VAD through the perspectives of feminism, disability, First Nations peoples, and populations who are racially, culturally, and linguistically diverse. Authors of these chapters were invited to chart the field in terms of the breadth of arguments raised from these normative perspectives – recognising that

for some there is quite a body of literature (e.g., disability) but very little in others (e.g., First Nations' perspectives) – as well as adding their views about VAD in the particular setting.

The book concludes with Part V, which comprises a final chapter about the future of VAD. It draws on the learnings of the preceding 35 chapters to reflect on local and international trends in VAD and what the future may hold. One conclusion is the need for reliable evidence to inform debates about whether to have VAD laws and the evaluation of existing VAD laws. It is hoped the evidence base provided by this book can help contribute to those debates.