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978-1-107-04320-6 — Euthanasia, Ethics and Public Policy
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EUTHANASIA, ETHICS AND PUBLIC POLICY

SECOND EDITION

Whether the law should permit voluntary euthanasia and/or physician-assisted suicide is one of the most weighty and controversial questions facing modern societies. Internationally, the main obstacle to legalisation has proved to be the argument that, even if these actions were morally acceptable in certain 'hard cases', they could not be effectively controlled and society would slide down a 'slippery slope' to practices that most people would agree to be morally unacceptable. In particular, the argument runs, the law could not prevent the killing of patients who did not make a truly free and properly informed request, or for whom palliative care would have offered a viable alternative, and for an ever-expanding range of reasons. How cogent is this argument?

This book provides the general reader (who need have no expertise in philosophy, law or medicine) with a lucid introduction to this central question in the debate, largely by reviewing the experience of three jurisdictions that have relaxed their laws: the Netherlands, Belgium and the US state of Oregon. The book will interest readers, whatever their views on the ethics of voluntary euthanasia and physician-assisted suicide, who wish to ensure that their opinion about whether they should be legally permitted is better informed.

JOHN KEOWN MA (Cambridge) DPhil (Oxford) PhD (Cambridge) DCL (Oxford) holds the Rose Kennedy Chair in the Kennedy Institute of Ethics at Georgetown University. Formerly, he was Senior Lecturer in the Law and Ethics of Medicine in the Faculty of Law at the University of Cambridge. His previous publications include *Abortion, Doctors and the Law* (1988), *Euthanasia Examined* (1995), *Debating Euthanasia* (with Emily Jackson, 2012), *The Law and Ethics of Medicine* (2012) and *Bioethics and the Human Goods* (with Alfonso Gómez-Lobo, 2015). (His surname is pronounced '*Key* own'.)

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CAMBRIDGE BIOETHICS AND LAW

This series of books 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. Since the early 1990s, 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 and 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 debates in the UK, Europe and the international community involve 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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EUTHANASIA, ETHICS AND PUBLIC POLICY

An Argument against Legalisation

SECOND EDITION

JOHN KEOWN
Georgetown University

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University Printing House, Cambridge CB2 8BS, United Kingdom

One Liberty Plaza, 20th Floor, New York, NY 10006, USA

477 Williamstown Road, Port Melbourne, VIC 3207, Australia

314–321, 3rd Floor, Plot 3, Splendor Forum, Jasola District Centre, New Delhi – 110025, India

79 Anson Road, #06–04/06, Singapore 079906

Cambridge University Press is part of the University of Cambridge.

It furthers the University's mission by disseminating knowledge in the pursuit of
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www.cambridge.org
Information on this title: www.cambridge.org/9781107043206
DOI: 10.1017/9781107337909

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First published 2002
Second edition 2018

Printed and bound in Great Britain by Clays Ltd, Elcograf S.p.A.

A catalogue record for this publication is available from the British Library.

Library of Congress Cataloging-in-Publication Data
Names: Keown, John, author.
Title: Euthanasia, ethics and public policy : an argument against legalisation /
John Keown, Georgetown University, Washington DC.
Description: Second edition. | Cambridge, United Kingdom ; New York, NY, USA :
Cambridge University Press, 2018. | Series: Cambridge bioethics and law |
Includes bibliographical references and index.
Identifiers: LCCN 2018021303 | ISBN 9781107043206 (hardback) |
ISBN 9781107618336 (paperback)
Subjects: LCSH: Euthanasia–Law and legislation. | Terminal care–Law and legislation. |
Euthanasia–Moral and ethical aspects. | Terminal care–Moral and ethical aspects. |
BISAC: LAW / Medical Law – Legislation.
Classification: LCC K3611.E95 K46 2018 | DDC 179.7–dc23
LC record available at https://lccn.loc.gov/2018021303

ISBN 978-1-107-04320-6 Hardback
ISBN 978-1-107-61833-6 Paperback

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To my late friends and colleagues
Dr Edmund Pellegrino
Professor Alfonso Gómez-Lobo
and Professor David Price

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FOREWORD TO THE FIRST EDITION

Forewords do not usually begin with a disclaimer, but there is a reason here, for *Euthanasia, Ethics and Public Policy* uncompromisingly addresses themes that colleagues of the present writer, and occasionally he himself, have tackled in the past and may have to tackle together in the future. Comity and courtesy make it necessary to avoid the implication that the opinions expressed in this valuable work are necessarily shared in full. This being said, it is a pleasure to welcome a contribution to what is, at present, the most intellectually demanding, the most ethically challenging and the most important for its contingent effects as well as for its immediate practical impact, of all the points on the line where law, medicine, belief and reason intersect.

The image of the slippery slope is often called up as a warning to those who take an easy step without looking to see where the next may lead, but it also reminds us that in this area the concepts themselves are slippery, escaping sideways from the effort to grasp them. The overlapping problems of accelerated death demand intellectual honesty rather than unfocussed right-thinking, and an emphasis on duties as well as individual rights.

The steepness of the slope, and its treacherous footing, are often concealed by an emollient vocabulary. Thus, the expression 'best interests' conveys an upbeat meaning, at odds with its more chilling implications. So also, the contemporary watchword 'personal autonomy' distracts attention from the duties of those implicated in the rights-based choice of the principal actor. Indeed, so deceptive is the terminology that these two antithetical concepts, authoritarian and libertarian, are quite frequently deployed at the same time: an important example of the need to know what words mean before employing them in debate. The present work uncompromisingly takes this stance and is right to do so. Equally, it exposes the interchangeable usage of concepts which are not the same: intend/foresee, cause/assist and so on. This is nothing new in itself, but the emphasis in the present context is a valuable corrective.

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Again, the sceptical eye cast on expressions which mean different things to different people, such as 'the sanctity of life', will help to discourage their use as common coin.

On the purely jurisprudential side of the debate there is also much to repay study. The unconvincing shifts and expedients in which the courts have taken refuge are clearly exposed. If this makes uncomfortable reading for the professionals, so much the better, so far as the future is concerned. The book is also an important contribution to the polemic about the feasibility of protection against the abuse of assisted death. Nothing can make up for the paucity of the available data, but the careful analysis of such hard facts as exist will be of value to decision-makers (including the judges) who have to shape policies by reference to pragmatic as well as purely ethical and logical considerations. The debate will continue, but we shall all be better informed.

In sum, we find here a work which displays a consistent and deeply felt ethical purpose, and yet is able to do so in a moderate and scholarly tone. The subject, which requires us to think so deeply about what our lives in society are really about, badly needs contributions of this kind. No doubt it will not persuade everybody, but it is hard to believe that everybody will ever be of the same mind. Rather than try to broker an unattainable unanimity, what we badly need is for our minds to be informed and alert. For this reason, I am glad to welcome the book, and to express the hope that many, outside as well as inside the professions whose preoccupations it treats, will take the trouble to read it carefully, and reflect upon what it has to say.

Lord Mustill

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FOREWORD TO THE SECOND EDITION

Shortly after Magna Carta was sealed in 1215, a long poem telling the life story of the man who saved it from oblivion, William Marshal, 'the greatest knight' who ever lived, was written. The account of his remarkable life took care to address the detailed circumstances of his death. They can be summarised in a few words, 'La bon fin va tout'. A ready translation is that even after a life full of honour and triumph, a good death is worth everything. To this day that philosophy endures, and it is likely to endure for as long as humanity. However blessed we may be in life we pray (if we pray at all) and if we do not pray, we certainly hope that we ourselves and all those we love will have the blessing of a good death: in today's language, perhaps, a death that is peaceful in the widest sense of that word. In truth we wish it for everyone.

In this magisterial work, *Euthanasia, Ethics and Public Policy*, Professor John Keown addresses the most delicate and sensitive moral, legal and societal issues to which the achievement of a peaceful but nonetheless premature self-inflicted death can give rise.

William Marshal himself, a medieval man, would not have thought that death by suicide could ever be a good death. To him and his contemporaries in Western Europe it would have been murder, self-murder. The criminal justice system reflected this belief. In England and Wales the Suicide Act 1961 decriminalised suicide. The legislation largely reflected a sense of deep compassion for those who had attempted unsuccessfully to kill themselves just because their minds were understood to be 'unbalanced'. By contrast decriminalisation has increasingly come to be perceived as belated recognition of a 'right', the properly informed exercise of personal autonomy, to end one's own life. The next, inevitable question was whether those who in good faith and at the behest and with the consent of the intended suicide assisted him or her to exercise this 'right', should continue to be liable to prosecution and conviction.

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This is the great moral and legal problem of our times. Unambiguous, absolute, but mutually contradictory views are held and passionately advanced. Beyond the respect which should, but is not always, showed to views which are not shared, the debate is not clarified by the language and terminology used to inform it. Presumably we always know what we mean by the words we choose to use during the debate, but what do others think that we mean? And what do they mean when they deploy the very same words that we have used? Sometimes phrases are used which obfuscate some of the realities. There is further source for confusion just because answering the main question (whether assisting suicide should be decriminalised, and if so subject to which conditions?) engages further moral and legal questions.

For example, if assisting suicide is to be decriminalised, to what conditions should the process of assistance be subject? What body should be set up to regulate and enforce effective safeguards against malign influences over the mind and will of the intended suicide? With what powers will it safeguard the vulnerable? How can any regulatory process prevent a gradual disapplication, whether by disuse or misuse, of effective safeguards, sometimes described as the 'slippery slope' argument? Should the presence of a 'terminal illness' be an essential requirement of the process? Advances in medical science have enabled life to be preserved where an individual subject to a particular condition, such as steadily deteriorating neurological conditions, or having suffered appalling injuries, would have died long before; if that individual wishes to end his or her life when the condition becomes unbearable, would assisting the individual to commit suicide nevertheless remain criminal? Is the autonomy of that individual circumscribed in a way which does not extend to their terminally ill brother or sister? If the process is to become part of the National Health Service, should members of the medical profession have an absolute entitlement to decline to be involved in any part of the process? Surely no one should ever be compelled to assist anyone to end his or her life. In this country where should constitutional responsibility for decriminalisation rest, with Parliament or the judiciary? Since the first edition of this work in 2002, the courts in the United Kingdom have moved from the decision in *Pretty* via a number of other cases to *Nicklinson*, and further litigation will shortly reach the Supreme Court. On this particular issue I have already expressed myself in unequivocal terms that, as the conscience of the nation, Parliament must accept the responsibility. However, the Supreme Court of Canada, vested with a different constitutional responsibility, appears to have decided the issue in *Carter*.

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Professor Keown addresses these problems with great care and on the basis of close study of the available evidence, in particular in countries or states where assisting suicide has been subject to a measure of decriminalisation. Indeed, perhaps his greatest concern is to identify the emerging evidence and take the discussion beyond broad philosophical contentions and emotional sensitivities and ground it in the realities. He acknowledges the arguments advanced by those who favour decriminalisation. He addresses the trends in countries where decriminalisation has not yet occurred, and where it has. He turns to the evidence – in particular from the Netherlands, Belgium and Oregon – about how decriminalisation has worked in practice. As for the decision in *Carter*, he suggests that it suffers from significant flaws which undermine its weight as an authority. His personal belief is unequivocal and made clear in the subtitle to the book. He is arguing against legislation which would decriminalise assisting suicide.

Whichever side of the argument is embraced, those who share Professor Keown's view will welcome the work and point to his findings to support their position. Those who take the opposite view cannot simply brush aside his conclusions as mere assertion. They need to recognise the force of his argument and where they can, attempt to refute it. And for those like me, who hope to have a peaceful ending of life, and who indeed may be clear on some aspects of the problem, but who are still open-minded about how the fundamental question should be answered, this work provides an invaluable analysis of the sensitive and delicate problems which must be addressed.

Lord Judge

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PREFACE

There are few more momentous and controversial questions facing contemporary societies than whether voluntary, active euthanasia (VAE) and/or physician-assisted suicide (PAS) should be permitted by law. Should the law allow physicians intentionally to hasten the deaths of patients who wish to die, either by administering a lethal injection or by prescribing a lethal drug? When the first edition of this book was published in 2002 the question was already a subject of heated debate. Since then the debate has only intensified. The law in several jurisdictions has been relaxed either by legislatures or by courts to permit VAE and/or PAS, and legalisation is under active consideration elsewhere.

In the United States, Oregon's statute permitting PAS has served as a model for others; a total of seven states and the District of Columbia have now legalised PAS. In 2015, the Supreme Court of Canada upheld a right to VAE and PAS and the following year the Canadian Parliament enacted legislation to accommodate that ruling. In Europe, Belgium and Luxembourg have followed the Netherlands in permitting VAE and PAS and the Dutch have carried out further national surveys. The United Kingdom has witnessed no fewer than four significant developments. First, in 2009, in the *Purdy* case, the Law Lords required the Director of Public Prosecutions to publish guidance indicating the factors which influence the decision whether or not to prosecute the crime of assisting suicide. Second, in 2014, in *Nicklinson*, the Supreme Court (which has replaced the Law Lords) declined to issue a declaration that the law's blanket ban was incompatible with the European Convention on Human Rights. However, several of the judges either dissented or indicated that a future application might succeed, though Parliament should first be given the opportunity to reconsider the ban. Third, in 2015 Parliament did reconsider the ban: an Oregon-style bill (the latest of several Parliament has debated since the first edition) was rejected by a large majority in the House of Commons. Fourth, in 2017, in *Conway*, the Divisional Court rejected another application for a declaration of

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incompatibility, though the case seems destined for the Supreme Court. In Australia, the debate has reignited in several states and in November 2017 the Parliament of Victoria enacted a government bill to permit VAE and PAS. Finally, people from around the world have continued to travel to Switzerland where assisting suicide is not illegal if the motive of the person providing the assistance is not selfish.

Since 2002 we have, then, witnessed an increase in legalisation. However, while more than a trickle, it has not been a flood. Despite the continuing efforts of pressure groups like 'Compassion and Choices' in the United States and 'Dignity in Dying' in the United Kingdom the campaign for legislation has met with less success than might have been expected, given the widespread support it appears to enjoy among the public and undoubtedly enjoys among bioethicists and the mass media. Not only have many more proposals for legalisation been rejected than enacted by legislatures in the United States and United Kingdom, but the Supreme Courts of the United Kingdom, Ireland and South Africa, and the High Court of New Zealand, have all declined to follow their Canadian colleagues in discovering a legal right to VAE or PAS. Opposition to relaxation of the law remains substantial.

Opposition is sometimes based on the view that it is always morally wrong for one person, medically qualified or not, intentionally to kill another innocent person even at their request, but it is often rooted in the concern that, if VAE were legalised, patients who did not really want to die, or who were incapable of making a request, or who were not suffering severely, or whose suffering could be alleviated by palliative or social care, would nevertheless have their lives terminated. There is also the concern that VAE, introduced as an exceptional intervention in hard cases would, sooner or later, become normalised, just another end-of-life option – perhaps even the default option – for many terminally or even chronically ill patients and for the frail elderly, especially for those who feel a burden on their relatives or society. Indeed, concern about such a slippery slope is proving to be *the* major obstacle to legalisation. But is this concern justified? This is the question which occupies centre-stage in the current political debate and it is the question which forms the centrepiece of this book. The book offers the general reader, who need have no expertise in philosophy, law or medicine, a lucid introduction to the question whether, if VAE and/or PAS were legalised in hard cases they could be effectively controlled by the law.

There is no shortage of books and articles by bioethicists and healthcare lawyers arguing for legalisation. There are precious few which, like

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this book, go the other way. The book will be of interest to all readers, whatever their views on the ethics of VAE/PAS, who wish to ensure that their opinion on the question whether these practices should be legalised is better informed. The book offers the reader an opportunity to consider in adequate depth a key argument against legalisation, an argument which is often misrepresented or marginalised in the existing literature.

The book does not attempt to analyse the debates in all those jurisdictions which have considered changing their laws – that would require an even bigger volume. Its focus is the effectiveness, or otherwise, of legal control in the three main jurisdictions which have taken the step of relaxing their laws and whose experience has generated a substantial body of evidence and expert analysis: the Netherlands, Belgium, and the US state of Oregon. In addition, the book analyses the recent legalisation of VAE in Canada and considers whether its legislation is any more capable of ensuring effective control than the legislation in those three jurisdictions. The book ends with some brief observations on the legislation in Victoria.

This second edition is a heavily revised and updated volume, significantly longer than the first edition. Each chapter has been revised, sometimes substantially, and there are nine new chapters, on the Netherlands, Belgium and Canada. To help make room for the new material some parts of the first edition (Parts V, VI and the Afterword), have been sacrificed. Some of the important issues they addressed, not least the withholding, withdrawal and refusal of treatment, especially when accompanied by an intention to end life, are touched on in the second edition, but readers wanting a deeper analysis of the important questions they raise are encouraged to consult the first edition.

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ACKNOWLEDGEMENTS

I remain grateful to the editors and publishers who gave permission to reproduce the following materials. Chapter 3 was first published in Mike Parker and Donna Dickenson (eds.), *The Cambridge Medical Ethics Workbook* (2001) 27 and parts of Chapters 3 and 5 appeared in (1997) 113 *LQR* 481. Much of Chapters 7–12 was published as two chapters in Luke Gormally, *Euthanasia, Clinical Practice and the Law* (1994) and papers in (1992) 108 *LQR* 51, (1994) 6(1) *Bioethics Research Notes* 1 and (1999) 25(1) *J Med Ethics* 16. (I thank the co-author of the last paper, Professor Henk Jochemsen, for permission to reproduce it as Chapter 11). A version of Chapter 23 appeared in Derek Ross (ed.), *Assisted Death: Legal, Social and Ethical Issues after* Carter (2018) 85 *SCLR* (2d.) 1.

In relation to both editions, I thank all those who kindly gave their time to meet with me and/or to read draft chapters. In relation to the second edition, I am especially grateful to Professors Martin Buijsen, Theo Boer, Herman Nys, Etienne Montero, Chris Gastmans, Trudo Lemmens, Dr Marie Nicolini, Edward R. Grant and William Saunders. I remain solely responsible for the book's argument and accuracy.

I am also indebted to two very distinguished judges: Lord Mustill, the former Lord of Appeal, who wrote the foreword to the first edition, and Lord Judge, the former Lord Chief Justice of England and Wales, who has written the foreword to the second.

The first edition thanked the superb staff at the Squire Law Library at Cambridge, especially David Wills and Peter Zawada. The second edition thanks the equally superb staff of the Kennedy Institute of Ethics' Bioethics Research Library, especially Martina Darragh and also Patty Martin.

Finally, I am grateful to Finola O'Sullivan, editorial director, Law, at Cambridge University Press for her friendly encouragement and patience.

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ABBREVIATIONS

ALS	Amyotrophic lateral sclerosis
COP	Dutch euthanasia review committees, *Code of Practice*
EOLC	End-of-Life Clinic
Gormally	Luke Gormally (ed.), *Euthanasia, Clinical Practice and the Law*
Griffiths1	John Griffiths et al., *Euthanasia and Law in the Netherlands*
Griffiths2	John Griffiths et al., *Euthanasia and Law in Europe*
Guidance	KNMG and the Dutch Nurses' Association, *Caring for people who consciously choose not to eat and drink so as to hasten the end of life*
Guidelines	KNMG, 'Guidelines for Euthanasia'
HC	House of Commons
HL	House of Lords
IVAE	Involuntary active euthanasia
Kamisar	'Some Non-Religious Views against Proposed "Mercy Killing" Legislation'
Keown1	John Keown (ed.), *Euthanasia Examined: Ethical, Clinical and Legal Perspectives*
Keown2	*Euthanasia, Ethics and Public Policy: An Argument against Legalisation* (1st ed.)
Keown3	*The Law and Ethics of Medicine: Essays on the Inviolability of Human Life*
Keown4	Emily Jackson and John Keown, *Debating Euthanasia*
KNMG	Royal Dutch Medical Association
LAS	Lay assisted suicide
Lords' Report	*Report of the Select Committee on Medical Ethics*
MND	Motor neurone disease
Montero	'The Belgian Experience of Euthanasia since its Legal Implementation in 2002'
NVAE	Non-voluntary active euthanasia
NVVE	Dutch Association for Voluntary Euthanasia; since 2005 the Dutch Association for the Voluntary End of Life
Parl Deb	Parliamentary Debates
PAS	Physician-assisted suicide

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PASSED	Physician-assisted suicide by stopping eating and drinking
PE	Passive euthanasia
PNAS	Physician or nurse practitioner-assisted suicide
Report (Remmelink)	*Medische beslissingen rond het levenseinde. Rapport van de Commissie onderzoek medische praktijk inzake euthanasie* (1991)

Dutch national surveys:

First Survey/Survey1	P. J. van der Maas et al., *Medische beslissingen rond het levenseinde. Het onderzoek voor de Commissie Onderzoek Medische Praktijk inzake Euthanasie* (1991)
Second Survey/Survey2	G. van der Wal and P. J. van der Maas, *Euthanasie en andere medische beslissingen rond het levenseinde. De praktijk en de medlingsprocedure* (1996)
Third Survey/Survey3	G. van der Wal et al., *Medische besluitvorming aan het einde van het leven: de praktijk en de toetsingsprocedure euthanasie en het Verslag van de begeleidingscommissie van het evaluatieonderzoek naar de medische besluitvorming aan het einde van het leven* (2003)
Fourth Survey/Survey4	B. Onwuteaka-Philipsen et al., *Evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding* (2007)
Fifth Survey/Survey5	Agnes van der Heide et al., *Sterfgevallenonderzoek 2010. Euthanasie en andere medische beslissingen rond het levenseinde* (2012)
Sixth Survey/Survey6	Bregje Onwuteaka-Philipsen et al., *Derde evaluatie Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding* (2017)
Task Force	Report of the New York State Task Force on Life and the Law, *When Death Is Sought: Assisted Suicide and Euthanasia in the Medical Context*
UAE	Unrequested active euthanasia
VAE	Voluntary active euthanasia
WHO	World Health Organization

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