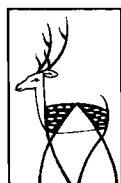


Debating Euthanasia

Emily Jackson
and John Keown

Debating Euthanasia

Emily Jackson
and
John Keown



• HART •
PUBLISHING

OXFORD AND PORTLAND, OREGON

2012

Published in the United Kingdom by Hart Publishing Ltd
16C Worcester Place, Oxford, OX1 2JW
Telephone: +44 (0)1865 517530
Fax: +44 (0)1865 510710
E-mail: mail@hartpub.co.uk
Website: <http://www.hartpub.co.uk>

Published in North America (US and Canada) by
Hart Publishing
c/o International Specialized Book Services
920 NE 58th Avenue, Suite 300
Portland, OR 97213-3786
USA
Tel: +1 503 287 3093 or toll-free: (1) 800 944 6190
Fax: +1 503 280 8832
E-mail: orders@isbs.com
Website: <http://www.isbs.com>

© Emily Jackson and John Keown 2012

Emily Jackson and John Keown have asserted their right under the Copyright, Designs and Patents Act 1988, to be identified as the authors of this work.

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, without the prior permission of Hart Publishing, or as expressly permitted by law or under the terms agreed with the appropriate reprographic rights organisation. Enquiries concerning reproduction which may not be covered by the above should be addressed to Hart Publishing Ltd at the address above.

British Library Cataloguing in Publication Data
Data Available

ISBN: 978-1-84946-178-8

Typeset by Hope Services, Abingdon
Printed and bound in Great Britain by
Page Bros Ltd, Norwich, Norfolk

Series Editor's Preface

This innovative and exciting series was inspired by one of the best-known philosophy books of the latter half of the twentieth century. *Utilitarianism for and against* by JJC Smart and Bernard Williams, published in 1973, is described on its cover as '[t]wo essays . . . written from opposite points of view'. It is one of the classics of the modern literature on utilitarianism. Based on this model, books in the *Debating Law* series will contain two essays of around 30,000 words, each developing a strong and intellectually rigorous argument on a topic of contemporary and ongoing debate. The aim is to stimulate, challenge and inform by bringing contrasting perspectives together in the one volume.

The *Debating Law* series offers a forum for scholarly argument and advocacy. It gives essayists the opportunity to make a fresh and provocative statement of a normative position freed from a tight requirement of 'balance'. Although debaters are encouraged to exchange ideas during the writing process, it is not the intention that the two essays will answer one another but rather that each will provide an independent statement of a point of view. Authors may take different tacks and address different issues within the broad topic, and the starting points or foundations of the case on one side may be different from those of the case on the other side. The confident expectation is that the debate format will sharpen issues, and highlight areas of both agreement and disagreement, in an effective and illuminating way.

The *Debating Law* series is designed for a wide readership. The aim is that each essay should be self-contained, accessibly written and only lightly end-noted. Books in the series will be valuable for those coming to the topic for the first time and also for the experienced reader seeking a stimulating, thought-provoking and concise statement of different points of view. They will provide valuable resources for teaching as well as lively discussions of important issues of wide current interest.

Peter Cane

Acknowledgements – John Keown

I am grateful to Professors John Finnis, Luke Gormally, Christopher Kaczor and Damien Keown, who read and commented on all or part of my contribution to this volume. I remain solely responsible for my contribution's accuracy and argument.

I dedicate my contribution to this book to Alfonso Gómez-Lobo, the Ryan Professor of Metaphysics and Moral Philosophy at Georgetown University, and to Dr Amanda Perreau-Saussine, Fellow of Queens' College, Cambridge.

Acknowledgements – Emily Jackson

I am very grateful to Hugh Collins, Daniel Slater, Robert Phillips and Clive Seale for their comments on an earlier version of my contribution, and to Peter Cane for his invaluable editorial suggestions. I benefited enormously from attending a workshop on prospective legal immunity at Kings College, London, organised by Roger Brownsword, Penney Lewis and Genevra Richardson, so my thanks are also due to them, and to the other participants at that event.

Contents

Series Editor's Preface	v
Acknowledgements – John Keown and Emily Jackson	vi–vii
 In Favour of the Legalisation of Assisted Dying <i>by</i> Emily Jackson	1
I. Introduction	1
II. Why We Should Try	8
III. The Status Quo is Indefensible	13
A. Double Effect	14
B. Terminal Sedation	16
C. 'Do Not Attempt Resuscitation' Orders	18
D. Treatment Withdrawal	19
E. Exporting the 'Problem' of Assisted Suicide	33
F. The Euthanasia/Assisted Suicide 'Underground' and the Benefits of Regulation	34
IV. Why Might Anyone Think We Shouldn't Try?	37
A. The Sanctity and Value of Life	37
B. Effect on Doctor–Patient Relationship	43
C. Regulatory Difficulties	47
V. What Might an Assisted Dying Law Look Like?	62
A. Other Countries' Experience	62
B. Process	66
C. Method: Assisted Suicide or Euthanasia, or Both?	70
D. Substance	73
VI. What are the Consequences of not Trying?	80
 Against Decriminalising Euthanasia; For Improving Care <i>by</i> John Keown	83
I. Introduction	83
II. Definitions	86

III. Ten Arguments For Decriminalisation	87
A. Autonomy	87
B. Compassion	101
C. Legal Hypocrisy	105
D. A Right to Suicide	110
E. Public Opinion	113
F. Legal Failure	114
G. The Netherlands	118
H. Oregon	128
I. Religion	136
J. Economics	138
IV. Professor Jackson's Arguments	139
A. Jackson 1	140
B. Jackson 2	157
V. The Joffe Bill	164
A. The Bill	164
B. Key Committee Recommendations Not Adopted	165
C. Extension and Abuse	166
VI. Conclusions	170
<i>Bibliography</i>	175
<i>Index</i>	179

In Favour of the Legalisation of Assisted Dying

Emily Jackson

I. INTRODUCTION

THE CORE of my argument is that we owe it to people who experience permanent and irreversible suffering, and to those who justifiably worry that this lies ahead of them, to do all that we can to alleviate their distress. In a very small number of cases, this may entail allowing people who cannot be helped in any other way, and who believe that death offers the only possible release from their suffering, to have their lives ended quickly and painlessly.

This might be through *euthanasia*: which derives from the Greek *eu* (good) and *thanatos* (death), but which has acquired a more specific modern usage. The *Oxford English Dictionary*'s definition is 'a gentle and easy death, the bringing about of this, especially in the case of incurable and painful disease'. While the *OED* does not specify exactly how the gentle and easy death is to be brought about, it is generally assumed that euthanasia refers to a third party deliberating ending a person's life. Legalised euthanasia would normally involve a doctor giving a patient a lethal injection. If instead a close relative were to end a person's life in order to

2 *In Favour of Legalisation*

relieve their suffering, that would not generally be described as euthanasia, rather it might be a case of *mercy killing*.

Euthanasia is sometimes referred to more specifically as voluntary active euthanasia (VAE), in order to distinguish it from *involuntary* and *passive* euthanasia. In *involuntary euthanasia*, a person's life would be ended without their request: an example might be giving a lethal injection to someone who is permanently comatose. Causing death through the withdrawal of life-prolonging medical treatment is sometimes described as *passive euthanasia*, but since 'treatment withdrawal' is a less value-laden term, I shall simply refer to treatment withdrawal and I will not use the term passive euthanasia.

In *assisted suicide*, the person who dies ends their own life, but they are helped to do so by a third party. Legalised assisted suicide would be likely to involve a doctor helping a patient to die by prescribing a lethal dose of medication, which the patient then takes him or herself; this is sometimes described more specifically as physician assisted suicide (PAS). The person assisting the suicide need not be a doctor, however, and so I shall simply refer to assisted suicide, rather than PAS.

Later in this essay, I discuss the relative merits of legalising euthanasia and/or assisted suicide. Each has advantages and disadvantages, but the question of which method should be preferred is secondary to the central question of whether it is sometimes acceptable to deliberately do something to help bring about a patient's death. As a result, I will also use the term *assisted dying* to refer to both euthanasia and assisted suicide.

So why might someone ask for an assisted death? In 2009 Robert Baxter, a 75-year-old retired truck driver who had been suffering from lymphocytic leukaemia, posthumously won his claim against the State of Montana that he had a right to die 'with dignity'. According to the Montana Supreme Court, this should have extended to offering protection from liability under the State's homicide laws to a physician who prescribed him lethal medication.¹ After his death, his daughter told the Court that he

¹ *Baxter v Montana* 224 P 3d 1211 (Mont Sup Ct 2009).

had ‘yearned for death’, and in his affidavit he had set out clearly and eloquently why he thought he should have the right to ‘aid in dying’:

As a result of the leukaemia and the treatment I have received to combat it, I have suffered varying symptoms including anaemia, chronic fatigue and weakness, nausea, night sweats, intermittent and persistent infections, massively swollen glands, easy bruising, significant ongoing digestive problems and generalized pain and discomfort. These symptoms, as well as others, are expected to increase in frequency and intensity as the chemotherapy loses its effectiveness and the disease progresses.

Given the nature of my illness, I have no reasonable prospect of cure or recovery. As the cancer takes its toll, I face the progressive erosion of bodily function and integrity, increasing pain and suffering, and the loss of my personal dignity.

I have lived a good and a long life, and have no wish to leave this world prematurely. As death approaches from my disease, however, if my suffering becomes unbearable I want the legal option of being able to die in a peaceful and dignified manner by consuming medication prescribed by my doctor for that purpose. Because it will be my suffering, my life, and my death that will be involved, I seek the right and responsibility to make that critical choice for myself if circumstances lead me to do so. I feel strongly that this intensely personal and private decision should be left to me and my conscience – based on my most deeply held values and beliefs, after consulting with my family and doctor – and that the government should not have the right to prohibit this choice by criminalizing the aid in dying procedure.²

Win Crew, whose husband Reg was one of the first UK citizens to die in a Dignitas clinic in Switzerland, explained why he had chosen an assisted death:

My husband suffered terribly as a result of MND [motor neurone disease]. Only weeks after the diagnosis he was unable to move his arms, depending on family and carers to feed him, wash him, dress him. This progressed to his legs, and in no time at all, he could neither feed himself nor go to the toilet, and he had to sleep and live in

² <http://community.compassionandchoices.org/document.doc?id=20>.

4 *In Favour of Legalisation*

a chair. He was barely able to support his own head, and was told by doctors that he would soon have to be fed from a peg [a feeding tube].

As each day passed, Reg found his life increasingly unbearable – a living hell. Palliative care did little for him. His dignity was stripped away, each time the disease closed down another part of his body, and so was his independence. Reg loved life, but not in the incapacitated shell of his former self.³

Tony Nicklinson, a 54-year-old British man who has suffered from locked-in syndrome since having a stroke in 2006, has explained why he wants to be helped to die:

I need help in almost every aspect of my life. I cannot scratch if I itch, I cannot pick my nose if it is blocked and I can only eat if I am fed like a baby – only I won't grow out of it, unlike the baby. I have no privacy or dignity left. I am washed, dressed and put to bed by carers who are, after all, still strangers. I am fed up with my life and don't want to spend the next 20 years or so like this. Am I grateful that the Athens doctors saved my life? No, I am not. If I had my time again, and knew then what I know now, I would not have called the ambulance but let nature take its course.⁴

My claim in this essay will be that, in the absence of evidence that an effective assisted dying law is actually *infeasible*, we should not abandon patients like Robert Baxter, Reg Crew and Tony Nicklinson. This is not an argument in favour of death. On the contrary, I will argue that a regulated system in which euthanasia and/or assisted suicide was an option could extend and enhance the lives of people facing the prospect of a prolonged and distressing decline. A recent study of patients suffering from advanced cancer found that the option of assisted death operated as a 'hypothetical exit plan', which provided reassurance and enhanced their ability to tolerate the present burdens of

³ Personal story, www.dignityindying.org.uk/personal-stories.

⁴ Robert Booth, "'Locked-in' syndrome man demands right to die" *The Guardian* (19 July 2010).

treatment.⁵ The prospect of being able to maintain control and autonomy at the end of life is therefore of value to many more patients than would ever actually opt for an assisted death.

It is also important to note at the outset that there is a critical difference between my position and that of opponents of assisted dying. Supporters of assisted dying recognise that not everyone shares the view that it is acceptable. I would vigorously support and uphold the right of every person to reject assisted dying for themselves, and the right of every healthcare professional to conscientiously object to playing any part at all in its provision. Both access to and participation in assisted dying must be optional and voluntary, and the personal beliefs of those who would want nothing to do with it must be respected. In contrast, opponents of assisted dying do seek to impose their belief that it is wrong on others whose views are different. In a secular society, where we recognise that our fundamental moral values differ, shouldn't we respect both the beliefs of people like Tony Nicklinson, who feel strongly that they should have access to assisted dying *and* the beliefs of opponents of assisted dying, who would reject it for themselves?

It is also important to recognise that people like Robert Baxter, Reg Crew and Tony Nicklinson do not seek death lightly. Of course, a request for assisted death should prompt us to investigate other ways to alleviate the person's suffering, before steps are taken to end their life. But if someone asks for an assisted death, it would be patronising and heartless to presuppose that their desire for death is just a passing response to temporary discomfort. Decisions about how we die are – as six distinguished American philosophers explained in their joint submission to the US Supreme Court in 1997 – significant and deeply personal issues of conscience:

Certain decisions are momentous in their impact on the character of a person's life – decisions about religious faith, political and moral

⁵ R Nissim, I. Gagliese and G Rodin, 'The Desire for Hastened Death in Individuals with Advanced Cancer: A Longitudinal Qualitative Study' (2009) 69 *Social Science & Medicine* 165–71.

allegiance, marriage, procreation, and death, for example. Such deeply personal decisions pose controversial questions about how and why human life has value. In a free society, individuals must be allowed to make those decisions for themselves, out of their own faith, conscience, and convictions . . . Most of us see death – whatever we think will follow it – as the final act of life's drama, and we want that last act to reflect our own convictions, those we have tried to live by, not the convictions of others forced on us in our most vulnerable moment.⁶

My argument will proceed as follows. First, I will explain in more detail why I believe that we should try to design a law which permits assisted dying in certain limited circumstances. Next, I will consider a range of counter-arguments which my opponents might invoke in order to establish that legalisation would be either wrong ('in principle' objections), or dangerous ('regulatory difficulty' objections).

Those with faith-based objections to assisted dying commonly cite additional secular arguments against legalisation; but if someone believes assisted dying is morally wrong, proving that regulatory objections are not insurmountable will, in practice, make no difference to them. Where the 'in principle' objection to assisted dying is grounded in a person's religious belief, there is almost certainly nothing I or anyone else could do to persuade them that assisted dying is sometimes an acceptable response to unbearable suffering. But it is important to remember that I am not asking someone with a religious objection to assisted dying to change his or her mind. On the contrary, my claim is that people who object to a practice on faith grounds ought to recognise that the law should not insist that others, who do not share their faith, must have their freedom restricted in order to satisfy a religious tenet which makes no sense to them.

There are people who have faith-based objections to homosexuality. Of course, this means that they are free not to engage in

⁶ Ronald Dworkin, Thomas Nagel, Robert Nozick, John Rawls, Thomas Scanlon and Judith Jarvis Thomson presented an *Amici Curiae* Brief for Respondents – referred to as 'The Philosophers' Brief' – to the Supreme Court in two cases heard at the same time (*Washington et al v Glucksberg* 117 S Ct 2258 (1997) and *Lacoe v Quill* 117 S Ct 2293 (1997)).

homosexual behaviour themselves: the legalisation of homosexual sex did not make it compulsory. But it does not give them the right to tell others, who do not share their beliefs, how to live their lives. We are entitled to make choices about our own conduct according to our own religious values, but we are not – in a liberal, secular democracy – entitled to foist those values on others.

In contrast to ‘in principle’ arguments against legalisation, secular regulatory objections to assisted dying are often essentially empirical claims that legalising assisted dying would have a range of undesirable consequences. Relevant here, of course, is the fact that some variation of assisted dying is lawful in a number of jurisdictions: namely the Netherlands, Belgium, Switzerland and Luxembourg, in Europe, and the states of Oregon and Washington in the US. Evidence from these places is clearly relevant and useful when considering regulatory objections to assisted dying and whether they can be effectively overcome, but multiple factors may affect our ability to ‘read across’ from one country’s experience to the likely effects of legalisation in another. For example, the Dutch have very high levels of trust in the medical profession in general, and in their family doctors in particular. In Belgium, there is an exceptionally well funded system of palliative care. As a result, claiming that the Dutch system would function well in a country where doctors are not trusted as much, or that the Belgian system would work when funding for palliative care is patchy, might be problematic.

I am not going to pretend that all of the arguments against assisted dying are groundless. Clearly, since the result will be a person’s death, there are reasons for taking very seriously objections to legalisation, based upon the possibility that we might mistakenly believe someone’s request was voluntary, or that they were competent, or indeed that they were in fact terminally ill. My point will instead be that none of the various objections to legalisation is sufficiently compelling to justify a refusal even to attempt to devise an effective assisted dying law.

Finally, it might be thought that this modest argument – that we should at least try to design an effective assisted dying law –

does not take us very far. But at the end of this essay I will reiterate that a refusal to contemplate legalisation of assisted dying has costs and negative consequences which – when placed in the balance with the challenges that arise from legalisation – should lead us to put as much effort as we can into alleviating the suffering which prompts patients' requests for assisted dying. I am certainly not suggesting that euthanasia should be the first response to such a request. On the contrary, there is often much that can be done to improve patients' quality of life, even when they believe their condition to be hopeless. But if we don't admit that there are some patients whose suffering cannot be relieved by palliative care or social support services, or even by love, we are disbelieving the accounts of people who know more about their own suffering than we ever could. We owe it to them to do all we can to provide the care and support that will help them avoid the 'loss of self' that commonly prompts requests for assisted dying, but when we cannot do any more, I will argue that we also owe it to them to honour and respect their desire for a peaceful death.

II. WHY WE SHOULD TRY

There is, most commonly among a subset of patients suffering from terminal conditions – such as cancer and motor neurone disease – a strong and understandable desire for more control over the dying process which they know lies ahead of them. In the West, most people now die from degenerative diseases, like cancer, which can result in a slow and drawn-out decline. As well as prolonging patients' lives, medicine has also prolonged and medicalised the experience of dying, with more and more of us experiencing protracted, institutional deaths. Life-prolonging technologies not only enable us to live longer, but are also responsible for 'the ever lengthening twilight that divides life from death.'⁷

Of course, all of us will die, and so the choice is not between an assisted death and not dying at all. Rather, and to put it bluntly,

⁷ 'TW' Furlow, 'Euthanasia and the Tyranny of Technology' in M Kohl (ed), *Beneficent Euthanasia* (New York, Buffalo Books, 1975).

the options are dying now or dying later. In choosing an assisted death, a patient is essentially opting for an earlier death, over which they are able to exercise some control, in preference to a later death, where control may be absent, and which may be preceded by a period of extreme dependency.

All of the available evidence suggests that what people fear most towards the end of life is seldom pain, but what I will refer to as ‘loss of self’. Surveys from Oregon and the Netherlands consistently show that the principal motivations for seeking assisted death are loss of autonomy (in Oregon in 2009, this was cited by 96.6 per cent of people who sought access to assisted suicide); loss of dignity (91.5 per cent); decreasing ability to participate in activities that made life enjoyable (86.4 per cent) and losing control of bodily functions (52.5 per cent). Inadequate pain control, or concern about it, was much less commonly cited (10.2 per cent).⁸

In one study of the reasons for people’s interest in assisted suicide, a patient with metastatic lung cancer explained what he meant by his fractured sense of dignity:

And I was on the commode and I had to be wiped and I just about cried my eyes out because of . . . you know, I never felt . . . I said to the nurses, God, who would have ever thought it would ever come down to this. I got these diapers or whatever it is that they call it . . . And that’s presenting a problem. I don’t like to think of myself as that. Things like that. That’s my dignity and it comes down to types of things like that really . . . So I get mad.⁹

And a study of people living with AIDS again found participants used the notion of ‘dignity’ to describe their experiences:

You’ve become a bag of potatoes to be moved from spot to spot, to be rushed back and forth from the hospital, to be carried to your doctors’ appointments or wheeled in a wheelchair, and it really

⁸ Oregon Department of Human Services, *Twelth Annual Report on Oregon’s Death with Dignity Act* (2009) www.oregon.gov/DHS/ph/pas/docs/yr12-tbl-1.pdf.

⁹ HM Chochinov, T Hack, T Hassard, LJ Kristjanson, S McClement and M Harlos, ‘Dignity in the Terminally Ill: A Cross-Sectional, Cohort Study’ (2002) 360 *The Lancet* 2026–30.