1   Introduction

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Death and dying in today's managed care society are messy. I do not
mean messy physically (although that may be the case as well), but
messy emotionally and philosophically. This is particularly true when
considering issues such as physician-assisted suicide and euthanasia. It
is impossible to engage in the debates on these twinned issues without
feeling that any answer reached will not be completely satisfactory. If it
is decided that these practices should be allowed or at least decriminal-
ised, then you have to accept the very real possibility that abuses may
exist. If you take the contrary position – that these practices should not
be allowed – then you have to deal with the fact that medical care at
the end of life is often a painful, debilitating, dehumanising experience,
despite the wonderful advances in palliative care and the care provided
by medical staff.

   I am not convinced, however, that this messiness is necessarily a bad
thing. This should not be an easy issue. We are dealing with lives, both
in a biological and in a narrative sense, which may be in conflict. We
are dealing with fundamental philosophical ideas such as autonomy,
choice, respect, dignity, paternalism, personhood and life, which may
often pull in different directions. We are dealing with complex argu-
ments that span philosophy, ethics, law and medical practice. Finally,
we are dealing with empirical arguments when the information is not
always readily available or easily analysable. These are basic human
questions that do not readily lend themselves to easy answers. Nor
should they.

   In addition, of course, there is a plethora of academic (and non-
academic) work in the area, much of it taking a specific perspective
on, or focusing on a particular aspect within, the debates around the
end of life.[1] Even if it were desirable to read everything that has been

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[1] While the literature on the subject is too vast to list all of the possible academic sources
   on the subject, some of the most important books in the area are: R. Dworkin, *Life's*

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written about the subject, which is doubtful, to do so would be practic-
ally impossible. You may be required to look at materials from a par-
ticular jurisdiction only; alternatively, you may be limited to materials
from a certain perspective (e.g. either legal, ethical or medical). You
may simply read as widely as possible and hope for the best – i.e. to have
read sufficient material to be able to provide a good general assessment
of the issues, even at the risk of ending up staring blankly at someone
who has quoted the latest obscure text about some aspect of the end-
of-life debate.

   If it is already impossible to read everything within this morass of
information, argument and opinion, what can one more work in the
area possibly add? One answer is that it can attempt to be comprehen-
sive. In other words, it can attempt to make it easier for those seeking
to learn about the topic to be able to navigate the large collection of
material and inform themselves about the debates on the end of life.
There are two ways it is possible to accomplish this goal. First, one way
that a book can be comprehensive is to look at the issues surrounding
end-of-life treatment from more than one perspective.

   Second, there is a tendency to focus on only one aspect of end-of-life
decisions. Some academic works will focus, for example, on euthan-
asia and assisted suicide; others on particular aspects of one subject.[2]
End-of-life decisions, however, are a set of possible options available to
doctors and medical staff when patients are dying. They are not isolated
decisions, but part of a range of possibilities that the doctor or other
health-care practitioner might consider. As such, there is an interrela-
tion that can be missed if one only considers different possible actions
(or inactions) in isolation. The simplest way these particular decisions

Dominion (New York: Vintage Books, 1994); J. Keown (ed.), *Euthanasia Examined*
(Cambridge University Press, 1995); J. Griffiths, A. Bood and H. Weyers, *Euthanasia
and Law in the Netherlands* (Amsterdam University Press, 1998); H. Hendin, *Seduced by
Death: Doctors, Patients and Assisted Suicide* (New York: W. W. Norton and Co., 1998);
M. Otlowski, *Voluntary Euthanasia and the Common Law* (Oxford University Press,
2000); J. Keown, *Euthanasia, Ethics and Public Policy: An Argument against Legalisation*
(Cambridge University Press, 2002); R. Magnusson, *Angels of Death: Exploring the
Euthanasia Underground* (New Haven, CT: Yale University Press, 2002); M. P. Battin,
Ending Life: Ethics and the Way We Die (Oxford University Press, 2005); R. Huxtable,
Euthanasia, Ethics and the Law: From Conflict to Compromise (Abingdon: Routledge-
Cavendish, 2007); P. Lewis, *Assisted Dying and Legal Change* (Oxford University Press,
2007); and J. Griffiths, H. Weyers and M. Adams, *Euthanasia and Law in Europe*
(Oxford: Hart Publishing, 2008).

[2] For example, Keown, *Euthanasia, Ethics and Public Policy* and Lewis, *Assisted Dying
and Legal Change*, both focus on euthanasia and assisted suicide generally. Griffiths *et
al*., *Euthanasia and Law in the Netherlands*, focuses on assisted dying practices in the
Netherlands. Magnusson, *Angels of Death*, focuses on a particular empirical study that
he performed.

may interact is if one particular action is removed from the list of pos-
sibilities for legal reasons, then it may become more difficult for the
doctor or health-care worker to act in what he or she might consider to
be the most appropriate manner. The doctor may then feel that another
option must be shoe-horned to fit what is believed to be most appropri-
ate. Treatment options may then begin to resemble other options even
if they did not do so originally. This may cause conflicts legally or eth-
ically when trying to differentiate between certain practices, making it
harder for health-care practitioners, lawyers and ordinary members of
the community to decide which actions are acceptable and which ones
are not. There is, thus, an important reason to consider these types of
treatment decisions as a range of possibilities instead of isolated prac-
tices. It provides us with a greater consistency among practices, helps us
to understand the relations between various practices and allows us to
measure the impact one treatment has on other treatment possibilities.

Comprehensiveness is important, but it is not the only (or even the
main) goal of this book. It is also my intention here to examine end-
of-life issues in a way that reveals and illuminates the role of bioethics
in modern life. Bioethics, like any form of ethics, is a philosophical
pursuit designed to examine issues so as to allow us to live more moral
lives. Its goal, then, is to make our lives better by providing a frame-
work for making better (more moral) decisions. Indeed, some of the
decisions bioethics is particularly concerned with can be some of the
most difficult decisions we could ever face, and we might expect that
advice and input from people more accustomed to thinking through
the various dilemmas and complexities involved in such decisions may
often be very welcome. But that is not always the case with bioethics.
Disability rights groups protest against bioethicists either in person or
online.[3] Peter Singer, one of the world's most famous bioethicists, is all
but barred from speaking in Germany.[4] The Catholic Church has even
recently suggested that some of the most dangerous types of 'new sins'
occur in bioethics.[5] Not medical science, biology or science in general –
but bioethics.

As a result, we have a field of study that is supposed to improve our
moral lives which has been characterised as a malign influence. We have

[3] See, for example, the website of the disability rights group, Not Dead Yet, http://
notdeadyetnewscommentary.blogspot.com/search/label/bioethics (accessed 21 June
2011) or P. Singer, *Practical Ethics* (2nd edn) (Cambridge University Press, 1993),
pp. 337–359, where he discusses protests against him.
[4] Singer, *Practical Ethics*.
[5] D. Willey, 'Fewer Confessions and New Sins', http://news.bbc.co.uk/1/hi/world/
europe/7287071.stm (accessed 21 June 2011).

a field of study designed to help determine what is morally right which
is often criticised for getting it so morally wrong. How then to explain
this disconnect? In some ways, of course, this is not the fault of bioethi-
cists or bioethics. Statements made by bioethicists can often be misin-
terpreted, misquoted or misunderstood. Quotations may be attributed
to bioethicists which might be incomplete expressions of what they said.
They may even be statements which are not representative at all of what
the specific bioethicist has said. Peter Singer, in particular, seems to be
routinely criticised for positions he either does not actually hold or to
positions which are, at best, caricatures of his actual position.[6]

That this occurs so often should not necessarily surprise us.
Bioethicists, like all philosophers, may care more about things such as
the logical foundations of arguments or consistency of ethical positions
than the ordinary member of the moral community.[7] For bioethicists, it
is less a concern of being able to live with the consequences of a decision
than being able to defend that position in a published work – largely
because bioethicists may not be confronting these issues directly (or
at least not directly when they are writing the journal article or book).
Ordinary members of the moral community, who are likely to face these
decisions only when they have a direct impact on their lives, are much
more likely to be concerned about being able to sleep at night or look
loved ones in the eye after making a decision than they are about the
logical consistency or reasonable defensibility of that decision. So, the
risk of making a decision which is contrary (or apparently contrary) to
another, earlier decision probably matters less to an ordinary member
of the moral community than to a bioethicist.

An acceptance that these are two separate projects – resolving ethical
dilemmas in our own lives, and engaging in academic debate about eth-
ics – does not mean that the dichotomy goes away. While some blame
belongs to those who misrepresent, intentionally or otherwise, the posi-
tions or aims of bioethics, there is also fault on the part of bioethicists
themselves. That is because bioethicists do sometimes say some rather
counter-intuitive things. Some bioethicists claim that apes are entitled

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[6] Peter Singer's responses to most of the common misunderstandings of his theory
can be found at his website: www.princeton.edu/~psinger/faq.html (accessed 21 June
2011).

[7] I am going to use the phrase 'ordinary member of the moral community' throughout
this book as a shorthand for those individuals who would not consider themselves or
be considered by others to be an expert on bioethics. So, essentially, someone who
does not spend their professional life researching issues of medical law and ethics.
Another possible term for this might be the oft-quoted UK legal phrase of the 'man on
the Clapham omnibus'. For reasons that will become apparent in the chapter on moral
status, I will avoid that particular phrase.

to more moral status than human infants, especially, but not exclu-
sively, those which could be classified as severely disabled.[8] We may
make the same sorts of claims about those with dementia, or in per-
sistent vegetative states.[9] Alternatively, we may claim that even patients
who have no chance of recovery or improvement should be continued to
be maintained by medical science, despite what doctors advise or what
the family of the patient or indeed anyone else actually connected with
the patient wants.[10] We might argue that all life should be protected and
therefore we are committing mass murder when we brush our teeth.[11]
Add to this a plethora of terms that appear familiar but are used in
highly technical and often confusing ways (for example, 'personhood',
'quality of life', 'autonomy', 'dignity', 'harm' and even – as we will see
in Chapter 3 – 'innocent') and the whole thing can be impossible to
work through.

What we seem to have, then, is a similar problem to the one in legal
theory exposed by H. L. A. Hart in the first few pages of *The Concept of
Law*.[12] We have an ever decreasing circle of people called 'bioethicists'
who talk among themselves about ideas which are not only confusing
to ordinary members of the moral community, but are seen as wrong,
absurd or clearly wrong-headed. Even more importantly, we seem to
have a situation where the ordinary member of the moral commu-
nity appears to be unable to use these particular ethical frameworks.
Nowhere is this starker than in the case of Peter Singer. Singer has long
championed the idea that those who are not persons[13] are not entitled
to full moral consideration, particularly in relation to whether or not

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[8] See, e.g., J. Glover, *Causing Death and Saving Lives* (Penguin Books: London, 1977);
   J. Harris, *The Value of Life* (Routledge: London, 1985); H. Kuhse and P. Singer,
   Should the Baby Live? (Oxford University Press, 1985); and M. Tooley, *Abortion and
   Infanticide* (Oxford: Clarendon Press, 1983).

[9] J. Harris, 'The Philosophical Case against the Philosophical Case against Euthanasia',
   in Keown (ed.), *Euthanasia Examined*, pp. 36–45.

[10] J. Keown, 'Restoring Moral and Intellectual Shape to the Law after *Bland*' (1997) 113
   LQR 482–503. J. Finnis, '*Bland*: Crossing the Rubicon' (1993) 109 *LQR* 329–337. In
   both cases, the argument presented is more complex than the one listed above. Both
   Keown and Finnis argue that intentional killing of a patient because the life of the
   patient is determined to be 'worthless' is unacceptable, but that some withdrawal of
   treatment in cases where it is futile is acceptable. However, it is clear that in the case
   in question, *Airedale NHS Trust* v. *Bland* [1993] 1 All ER 821, the doctors and family
   did intend to kill Anthony Bland and did so precisely because they saw the value of
   his continued existence as being 'worthless'.

[11] M. A. Warren, *Moral Status* (Oxford University Press, 1997), p. 37, discussing the
   viewpoint of Albert Schweitzer.

[12] H. L. A. Hart, *The Concept of Law* (2nd edn) (Oxford University Press, 1994), pp.
   1–2.

[13] A term discussed in greater detail in Chapter 2.

they can be killed.[14] Those who are not persons include patients with dementia. When his own mother was struck with dementia as a result of Alzheimer's disease, Singer admits that he did not treat his mother in the way which his theory recommends.[15] But, if Singer cannot abide by his own theory, why should the rest of us (who have no investment in the theory) be guided by it either if faced with similar circumstances?

The critical concept in bioethics, then, may be about usefulness. Despite its logical cohesiveness or internal consistency, a theory about ethics which is completely impractical may be of no more use than one based upon the teachings of the flying spaghetti monster.[16] What is useful, however, is a theory of ethics that ordinary members of the moral community can put into practice. It is important to remember that ethics is, by and large, a personal thing. What matters is that the ethical system one adopts has to be a useful one for the individual. If an individual cannot see how an ethical system can be put into practice, they are likely to deride it as useless and ignore it. When evaluating an ethical system, then, perhaps we ought not to be focusing on whether it is a universally acceptable system, or one characterised by logical consistency or internal coherence. Rather, perhaps we should, when we evaluate the merits of an ethical system, place more emphasis on how readily it might be used by individuals in real-life situations. This is not to suggest that things like internal coherence and logical consistency are unimportant. It is very important that ethical systems be able to produce consistent results across a number of situations and display internal coherence. Otherwise, moral decisions may well be made on whims or random chance. Nevertheless, if you cannot put a theory into practice, all of its logical consistency and internal coherence count for nothing.

Chapters 2 and 3 of this book provide examples of what this means in practice. Chapter 2 concerns ideas about moral status and about how we determine who matters morally and who does not. This debate has long been dominated by two theories as to how we make these sorts of determinations. One theory holds that species membership is of primary importance. Human beings, quite obviously, are at the top of the chain and therefore are deserving of full moral status. Other species are entitled to less moral status and as such we may do things to them

[14] Singer, *Practical Ethics*, pp. 89–95.
[15] M. Specter, 'The Dangerous Philosopher', *The New Yorker*, 6 September 1999, pp. 46–55.
[16] For those interested, the flying spaghetti monster is a deliberately absurd creation intended to make a point about the difference between scientific evidence and religious belief. For further information about the flying spaghetti monster, see www.venganza.org (accessed 21 June 2011).

which we may not do to human beings. The problem with this is that it
is incredibly difficult to be able to show why human beings are entitled
to this special status without relying on theological or self-serving argu-
ments. But the alternative creates its own problems. The alternative to
regarding species membership as the primary determinant for moral
status is to focus on an entity's possession of specific characteristics.
These can be anything, but are most often things like rationality or
sentience. However, this can mean that not all human beings are enti-
tled to full moral status. Adopting a more easily satisfied characteristic
(life, for example) only seems to create further problems; we may end
up regarding bacteria as being as morally relevant as human beings, for
instance. Consequently, we end up spending time debating these two
different approaches while ordinary members of the moral community
remain as confused as before or conclude that the whole debate is noth-
ing more than some sort of elaborate joke.

Chapter 3 deals with the concept of the value of life and presents
similar problems. Again, the debate in bioethics revolves around two
positions. The first, referred to as the sanctity or inviolability of life,
argues that life has an inherent value. The alternative position, known
as the quality of life position, holds that life does not have an inherent
value but is only valuable because of the things that it allows us to do.
These two positions are said to be mutually exclusive – in other words,
it is necessary to choose between them. Many ordinary members of
the moral community, however, seem to prefer a compromise position
between the two. They may want to insist, for some purposes, that life
is inviolable, but to treat quality of life as being relevant at other times.
Bioethicists, however, indicate that such selectivity is not possible with-
out logical inconsistency.

Under the traditional bioethics formulations above, such issues may
seem irresolvable. But the traditional formulations are not the only
ones. This book will show that a different way is possible by provid-
ing, in Part I, a practical ethical formulation for end-of-life concerns.
In order to do so, it will be necessary to return to the first principles
involved in these particular issues. In other words, we have to start at
the beginning in terms of the basic ethical and legal concepts and the
broad frameworks they inhabit. In the cases of some of the ethical con-
cepts, this will mean a re-examination of key ideas and a clearing out of
some of the intellectual clutter that has arisen. What will remain, how-
ever, will be ethical concepts which are more readily available to and
applicable by ordinary members of the moral community. These will
then be worked together into an overall ethical framework from which
we can make decisions about end-of-life treatment in a way which is

intellectually coherent but still capable of providing practical moral
guidance that it is actually possible to follow in our daily lives. This does
not mean that the resulting ethical framework created in Part I will be
universally acceptable. Not everyone who reads the framework will find
it convincing or right. I make no claims, therefore, that the answers
suggested here are the only valid ones. Instead, I aim only to suggest
a useable, coherent framework which, I believe, offers a helpful way of
negotiating the complexities of decision-making at the end of life.

But ethics is only part of the story when considering end-of-life treat-
ment. It is also essential to ask whether and how the ethical framework
created in Part I can be implemented by legal regulation. It is not a
simple matter of merely taking the ethical conclusion and making that
decision legally acceptable. Ethics is primarily about ideals – what we
think that people ought to do, ideally, in certain circumstances. Often,
the law cannot insist on ideals, but can only deal with the reality of par-
ticular situations. That means that even if we consider a decision to be
ethically acceptable, problems in regulating behaviour may mean that
the practice must be legally sanctioned. Concerns such as the impact on
others unrelated to the action, the prevention of abuses, so-called 'slip-
pery slope' arguments and procedural safeguards may all be stronger
considerations in legal frameworks than in ethical ones. It is therefore
necessary to consider to what extent the ethical answers arrived at in
Part I of the book can be implemented in any legal framework and what
type of legal framework is best suited to address not only the ethical
questions but practical and legal questions as well. This will involve an
examination not only of the legal structures available, but also of the
empirical evidence that is available about these practices.

Part II of the book will therefore focus on the legal regulation of
end-of-life decisions. As with Part I, there is considerable clutter that
should be addressed. First, as with the ethical approaches, there is a
tendency to regulate individual aspects of end-of-life decision-making
in isolation, without regard to their interaction with other issues. So, for
example, attempts may be made to legalise physician-assisted suicide or
voluntary euthanasia or to change the manner in which we make with-
drawal of treatment decisions for incompetent patients without wider
discussion about the overall regulation of death and dying. Considering
the interrelation between these various end-of-life issues, this is a sig-
nificant oversight and one this book will seek to address. As such, the
sections in Part II will not just focus on isolated aspects of end-of-life
decisions, but rather will consider how the conclusions reached about
the regulation of one practice will impact upon the regulation of other

practices at the end of life. It will be possible at the end of Part II, therefore, to envisage a coherent regulatory scheme for all end-of-life decision-making, not just one or two practices.

In addition to the creation of a comprehensive regulation scheme, another focus of Part II of the book will be on clarification about how we should best evaluate the effectiveness of any such scheme. There are two points which are vital to any evaluation. The first thing to keep in mind is the appropriate standard for evaluation. For example, in many cases where people are examining whether to legalise assisted suicide or euthanasia they look at the possibility of breaking the law. Since the number of incidents where the law is broken is clearly not zero, they determine that assisted suicide and euthanasia should not be legalised. But looking for a rate of zero is extremely unhelpful in evaluating whether these practices should be legalised. No statute or legal rule is ever completely effective. Even if we consider the most trivial regulation (say a parking regulation) and couple it with the harshest penalty, we are unlikely to get complete success, presuming that success is compliance with the law. Why then should we expect this to be any different? One argument may be that we are dealing with human lives and therefore the stakes are much higher than in parking regulations or other trivial matters. This is, of course, true. That just means we ought to make sure that we get it right. To do so, we have to make the success rate as close to 100 per cent as we can. We should also try to create a law that is as foolproof as possible and therefore strive for complete success as an ideal. Even with all that, though, we need to keep in mind that despite our best efforts, we will not reach that ideal. So, basing decisions about regulation schemes for end-of-life decisions on whether they reach that ideal is fruitless.

Often, such unrealistic expectations of our regulatory schemes are accompanied by the failure to notice that all jurisdictions currently have a regulatory scheme in relation to end-of-life practices, whether they be statutory-based or based in the common law. The evaluation of any proposed new regulation must therefore include an appraisal of how the existing regulation works. When comparing regulatory schemes, we need to keep in mind the question of metrics. If our biggest concern is the rate of compliance with the law, it does no good to expect the new regulation to achieve a 100 per cent success rate if we are not expecting the same of the current regulation. In other words, we must compare like with like. Otherwise, we risk determining that the current regulation is the most appropriate despite it having a much lower success rate than an alternative.

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Considerations about the slippery slope argument[17] present an example of unrealistic expectations coupled with a failure to recognise the existence of a current regulatory scheme. When evaluating regulations which would legalise or decriminalise voluntary euthanasia or assisted suicide, much is made of the possibility of a slide towards non-voluntary or involuntary euthanasia.[18] In order to show this, commentators often rely on the evidence from the Netherlands which shows that there are instances of non-voluntary/involuntary euthanasia following the legalisation of voluntary euthanasia.[19] This does not prove the point as convincingly as some commentators wish, however. All the Netherlands information proves (at least in isolation) is that the Dutch have not been completely successful in preventing non-voluntary and involuntary euthanasia. In other words, the Dutch system, like every other regulatory system including our own, does not command perfect obedience. As stated already, perfect obedience is an illusory goal anyway, and the lack of it should not be taken as evidence of any fundamental unsuitability of the regulation (or scheme of regulation) in question. Instead, these considerations only serve to underline the need to make comparisons on an equal footing in order that realistic assessments about the value of the various regulatory schemes available can be valid ones.

In summary, then, Part I will provide an examination of the ethical concepts which are relevant in decision-making about medical treatment at the end of life. The purpose of this part of the book is not only to present the current arguments about these ethical concerns but to critically analyse whether they actually provide a useful method for determining how we ought to act. From this, it will be possible to create an ethical framework at the end of Part I which will be able to provide one method for determining how we ought to treat patients at the end of life. Part II will take the conclusions reached in Part I and explore how best to legally regulate end-of-life decisions consistent with those conclusions, taking account not only of proposals for change, but also the currently regulatory system. From this, it will be possible to draw general conclusions about the ethical and the legal frameworks we should adopt to help us determine the acceptability of treatment at the end of life.

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[17] Slippery slope arguments will be explained in greater detail in Chapter 13.
[18] See, e.g., Keown, *Euthanasia, Ethics and Public Policy*.
[19] *Ibid*.