Ethics at the End of Life: New Issues and Arguments
Ethics at the End of Life

The 14 chapters in *Ethics at the End of Life: New Issues and Arguments*, all published here for the first time, focus on recent thinking in this important area, helping initiate issues and lines of argument that have not been explored previously. At the same time, a reader can use this volume to become oriented to the established questions and positions in end-of-life ethics, both because new questions are set in their context, and because most of the chapters—written by a team of experts—survey the field as well as add to it. Each chapter includes initial summaries, final conclusions, and a Related Topics section.

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Ethics at the End of Life
New Issues and Arguments

Edited by John K. Davis
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End-of-life ethics was among the first topics to develop when modern medical ethics got going in the early 1970s. It is well developed. It is not, however, static. This volume is a collection of new articles on various aspects of end-of-life ethics, with a focus on cutting-edge work and new issues. It is meant both to display recent thinking in end-of-life ethics and to initiate new issues and new lines of argument that have not been explored before. At the same time, a reader can use this volume to become oriented to the established questions and positions in end-of-life ethics, both because new questions are set in their context and because most of the chapters survey the field as well as adding to it.

The chapters are organized by topic, and the order of the topics reflects the order in which someone deliberating about the end of life might consider those topics. It is natural to begin with questions about when and whether a patient may be better off dead (or at least has a life that is no longer worth living). Those questions are covered by the chapters in Part I, which develop connections between end-of-life ethics and the now-lively topic of philosophy of death. However, it is inevitable that we will not agree about those questions in all cases, and therefore the next set of issues concerns whose answer is decisive—that is, who gets to decide whether a patient is better off dead. Those issues are addressed by the chapters in Part II, which discuss when a patient with diminished competence may make that decision, how such decisions might be made in advance, and who makes them if the patient cannot. Once a decision has been made that a patient’s life should no longer continue, questions arise about the proper way to end it. Many people believe that letting the patient die is morally permissible, but that killing, suicide (killing oneself), and physician-assisted suicide are not permissible. The two chapters in Part III question those constraints. Parts II and III represent the core of end-of-life ethics as it is usually understood. Part IV groups together three chapters that raise largely new issues. The first two concern the relationship between the patient and other parties, and explore the ethics of grief and solidarity between the patient and others. The final chapter discusses the farthest frontier of all: the
possibility of slowing aging and extending life far beyond its present biological limits.

Most discussions of end-of-life ethics note that patients are sometimes better off dead, or at least do not benefit from continued life. In Chapter 1 Geoffrey Scarre asks whether there is any sense in the idea that a patient could be “better off dead.” After all, if death involves nonexistence (a possibility we should not rule out), it is hard to see how nonexistence is good or bad for someone who no longer exists (how can anything be good or bad for you if there is no you?). Scarre considers what makes a life a “worth living,” whether a life has intrinsic value (and not merely instrumental value) apart from its value for the one living it, whether someone might rationally think that suffering makes his or her life more worth living, and whether such judgments are objective or subjective. Scarre concludes that some patients really are better off dead, but that judgments about this are heavily subjective in nature, and that it’s hard to generalize about which lives are worth living.

Whether a patient can be better off dead can be seen as the flip side of some well-known questions about the harm of death: if death involves nonexistence, how can death be bad for the one who dies? In Chapter 2 Taylor W. Cyr surveys several aspects of that question, including the two main positions on the issue. According to the first view, the deprivation account, death is harmful to the one who dies not because death is bad for that person but because death deprives him or her of further life that would have been good for that person. In short, it is not the state of nonexistence that is bad; it is the absence of a good existence. According to the second view, Epicureanism, death is not harmful to the one who dies. Cyr discusses several arguments for and against each of these views.

The traditional puzzles about the harm of death assume that we cease to exist when we die, but what if that is false? After all, many people claim to have had near-death experiences in which they briefly experienced an afterlife. Does the existence of an afterlife make a difference to questions about whether a patient can be better off dead, or whether death is ever harmful to the one who dies? Benjamin Mitchell-Yellin argues that it does not. In Chapter 3 he discusses the harm of death and the desirability of immortality, and concludes that the existence of an afterlife has less importance for those issues than one might think.

When we ask whether, when, and how a patient might be better off dead, we are also raising questions about how bad death would be for that patient (i.e., the condition of being dead, not the process of dying). We tend to think that death is more tragic the earlier it comes in life, for younger people have more years of potential life to lose. This is a deprivation account of what we might call the severity of death—how bad or tragic a death is. Jens Johansson explores this issue in Chapter 4, points out that a person’s life expectancy at
the time of death is not the only relevant factor in determining how bad death is for that person, and defends the deprivation account of the severity of death against two objections.

When we ask whether a life should end, we must also ask when it does end. Modern medicine can keep patients alive for years in a state of permanent unconsciousness. Such patients are warm, they breathe, and they metabolize, but their consciousness and personality are forever gone. Are they still alive? Is the body alive but the patient dead, or are both dead? How can there be two kinds of death, and if there are, do we die twice? If not, when do we die? In Chapter 5 John Davis surveys and evaluates several criteria and definitions of death, and argues that death occurs when all capacity for experience is forever gone. Patients, in other words, are essentially sentient beings, and they die when they lose the capacity for sentience.

There is no consensus on when life is no longer worth living, and there may never be. We can settle such questions, therefore, only by settling the question of who gets to settle the question—that is, who gets to decide when the patient should no longer be kept alive. Up to the 1960s and 1970s, doctors tended to decide what was best for the patient, sometimes without informing or consulting the patient. By the 1960s and 1970s, a series of court cases established the doctrine of informed consent. Now nothing could be done to the patient without informing the patient and getting the patient’s consent. This was matched by a consensus among medical ethicists that providers should follow a principle of respect for patient autonomy. However, we do not respect the decisions of all patients—just those who are competent and autonomous.

Autonomy means “self-determination,” roughly speaking, but there is more to it than that. We need a concept of autonomy that captures the precise sense in which a patient’s desires are truly her own, and not the result of some interference or irrationality. Competence is a particularly difficult concept to pin down; merely being conscious, adult, and “not crazy” is intuitively plausible but not quite right. We need a definition and criterion of competence that capture cases where we think the patient has made an irrational choice, but do so without requiring us to second-guess whether his or her choice is a good one. In Chapter 6 James Stacey Taylor addresses these challenges, and explains how the concepts of autonomy and competence apply to end-of-life decision-making in general.

Very often patients are deeply and permanently demented or unconscious, and cannot make decisions about whether and when to end their lives. When the patient cannot make that decision, who does? Sometimes patients use a legal document known as a living will to make decisions about their medical care in advance, including decisions to reject further care and to die. However, living wills have been controversial. Some ethicists argue that if the patient is permanently incompetent, or better yet, permanently unconscious, the patient’s
previous intentions and values cannot now be attributed to the patient, and the
patient’s past intentions and values have no moral authority (i.e., we are not
ethically required to honor them). Instead, these critics argue, surrogate decision-
makers should do whatever is in the best interests of the patient as he or she
is now. Eric Vogelstein defends this view in Chapter 7, arguing that we can
respect the autonomy of currently incompetent patients only by respecting the
desires and values the patient currently has, not the ones he used to have. He
also questions the view that what is in a patient’s current best interest depends
partly on the patient’s prior values.

Not all patients who are incompetent near the end of life are unconscious,
and there are degrees of dementia. Some patients are demented or otherwise
incompetent but still capable of having desires or making decisions, at least
on simple matters. It is possible for such patients to have different judgments
and desires than they had earlier, when they were competent and wrote a living
will. However, they may be too demented to comprehend their own advance
directives or reevaluate them in a reasoned way, so they cannot quite rethink
or reconsider their earlier decisions. They cannot be said to have changed their
mind in the sense of consciously forming a new intention for their current med-
ical treatment, but they do have cognitive states that at least resemble a change
of mind. Should we respect their advance directives, or should we treat these
as cases where the patient changed his or her mind, and respect the patient’s
current values? Paul T. Menzel discusses such cases in Chapter 8, and argues
that many of these cases involve a change of mind. Menzel argues for a refined
concept of change of mind and contends that we should respect the patient’s
current values, not the patient’s earlier choices, even if the patient is now too
incompetent to understand and revise his or her earlier decision.

By the 1990s the medical profession had largely come to agree that with-
drawing or withholding life support is often the right decision, at least when the
patient’s quality of life is very low. This produced a new problem: sometimes
the patient’s surrogate decision-makers (typically family members) refuse to
terminate life support, perhaps because they do not believe the prognosis, or
they cannot let go, or they do not want to be responsible for a relative’s death,
or they believe that all human life is sacred, or they think the patient’s quality
of life is better than the providers tell them it is. In response, many medical
professionals and ethicists invoke medical futility to justify refusing to provide
life support in such cases. An intervention is futile in this sense when it will not
achieve the goal of treatment, not because it is difficult or unlikely to succeed,
but because it is simply not going to produce that result under any realistic
circumstances. The idea is that, just as physicians can unilaterally refuse to
provide interventions like antibiotics for a viral infection (antibiotics work on
bacteria, not viruses), they can also unilaterally refuse to provide life support
when it is futile to do so because doing so confers no benefit on the patient.
Some people object that unilaterally refusing to provide an intervention on
grounds of futility does not respect patient autonomy and gives too much power to providers. In Chapter 9 Nancy S. Jecker defends this use of the concept of futility against these objections. She argues that these objections are based on an excessively broad conception of patient autonomy, and that there is a social agreement among physicians and society that supports such refusals.

Most patients who wish to die, or who no longer benefit from continued life, die when the doctors withdraw or withhold whatever is needed to keep the patient alive (life support, cardiopulmonary resuscitation, antibiotics, and so on). This is described as “letting die.” However, there are patients who are in a condition bad enough that they wish to die, but they do not require life support, CPR, antibiotics, or other interventions to stay alive. Letting them die in the usual way is not an option. Their lives can be terminated only by killing them. Many ethicists believe that killing such patients is wrong even in cases where letting die would be morally permissible if they were on life support and otherwise in the same medical condition.

Everyone, however, requires food and water. Some patients receive this by tubes, others by mouth, but both groups can refuse food and water. This is a trend; it is becoming more common for patients to intentionally end their lives by refusing food and water. This need not involve the pangs of starvation and painful dehydration. It can be paced and managed with palliative care so that it is not hard on the patient, yet still leads to death. However, there is some controversy over this practice. Some ethicists oppose it because they believe that only medical treatments are morally permissible to refuse, and they think that delivering food and water, even by intubation, is not a medical treatment. Some object that withholding food and water from the patient is a kind of killing (or suicide, given that the patient requests this), and that killing (and suicide) is morally wrong.

In Chapter 10 Paul T. Menzel argues that currently competent patients have a moral right to refuse food and water (even if we consider it a form of suicide, which Menzel does). However, Menzel also says it is less obvious that this right extends to cases where the decision was made in advance, when the patient was competent, and the patient is now permanently incompetent. Menzel also discusses two problematic features of advance directives that refuse food and water. First, incompetent patients usually retain a desire to eat. Second, providing food and water is basic personal care. Menzel argues that the first objection fails in cases where the advance directive clearly addresses the future patient’s desire to eat, and that the second objection fails on the grounds that if patients have a right to refuse medical care, they also have a right to refuse personal care.

Menzel undermines the prohibition against killing patients by arguing that withdrawing food and water is a form of letting die. However, there are other ways to challenge that prohibition. One well-known work-around concerns patients at the end of life who are in very severe pain. If the pain is severe enough,
the amount of morphine needed to kill the pain may suppress respiration and kill the patient too. Even so, the patient’s pain needs to be addressed, and it seems cruel to prolong the patient’s agony just because he is not on life support. Some ethicists have argued that this practice is morally permissible because the moral rightness of treating pain outweighs the moral wrongness of killing a patient. The most developed version of this argument invokes the doctrine of double effect. According to one formulation, this doctrine says that an action that has a foreseeable effect (killing the patient) is morally justified if that effect is not intended, and that effect is necessary to achieve a proportionately good effect (i.e., good enough to outweigh the wrongness of the unintended effect).

Thomas S. Huddle discusses the doctrine of double effect in Chapter 11. He is skeptical that it can be made to work, primarily because he is skeptical that defenders of the doctrine can overcome the “problem of closeness.” The problem is that it is hard to draw the distinction between intended effects and unintended but foreseen effects in a way that prevents the doctrine from justifying actions that seem clearly immoral. For example, a terrorist who sets off a bomb killing dozens of civilians could argue that he foresaw but did not intend to kill them; his real intention was to weaken the government he considers his enemy and thereby liberate his own people. Even if we assume for discussion that the government he opposes really is tyrannical and unjust, and that his people are oppressed and have the right to rebel, his action seems immoral, yet the doctrine seems to justify it. Defenders of the doctrine must solve the problem of closeness. Huddle is skeptical that they have succeeded.

The doctrine of double effect is supposed to justify some cases of killing without also justifying other forms of killing, such as euthanasia and physician-assisted suicide. However, some ethicists argue that euthanasia and physician-assisted suicide are morally permissible. They reject the claim that there is a morally relevant distinction between killing and letting die, and their view is now coming into the mainstream. At the time I am writing this, euthanasia and physician-assisted suicide are still illegal in most places, but euthanasia is legal in the Netherlands, Belgium, Columbia, and Luxembourg, while physician-assisted suicide is legal in the Netherlands and the American states of Washington, Oregon, Vermont, New Mexico, Montana, and California. Huddle addresses the killing/letting die distinction, and the more general doing/allowing distinction it is drawn from. He surveys a variety of arguments for and against the moral relevance of that distinction, and concludes that the doing/allowing distinction is not a good basis for objecting to physician-assisted suicide.

Most writing on end-of-life ethics focuses on the person whose life is ending, but there are other affected parties to consider, particularly the patient’s family. Providers who engage in moral reasoning in the clinic routinely consider the interests and wishes of family members. Theoreticians, however, have not.
But two of our contributors break new ground by considering parties other than the patient. In Chapter 12 Michael Cholbi explores the ethics of grief in the setting of surrogate decision-making about end-of-life care. He argues that grief makes it much more difficult for surrogate decision-makers (who are usually relatives of the patient) to be rational and make decisions that comply with what the patient wanted, or would have wanted had she considered the situation. He also offers some practical suggestions for dealing with this.

Bruce Jennings approaches end-of-life decision-making from another angle in Chapter 13, where he uses the concept of solidarity to propose an alternative to the individualistic model of end-of-life decision-making, in which the patient makes decisions alone, to a form of shared decision-making based on concern for others and on mutuality and a relational interpretation of autonomy, liberty, dignity, justice, and other more traditional concepts.

The last chapter considers the ultimate end-of-life care: the possibility that we might be able to postpone the end of life far beyond present limits, not by keeping a patient alive in an elderly and senescent condition but by slowing, halting, or reversing aging itself. Until perhaps 15 years ago, this possibility was highly speculative and not widely considered plausible. Over the last few years, however, many well-known geroscientists at major universities have begun making public comments to the effect that slowing aging in humans may well be possible, and might be achieved within the coming century. Not everyone is convinced this is a good idea. Some of those who are opposed argue that extended life would not be a good life, that we might grow bored, or fail to use our time well, or that our lives would lose some of their meaning. Some people are concerned about bad social consequences, such as the possibility that the world will face a Malthusian disaster if everyone extends their life, or that a world where life extension is too expensive for everyone to get it is an intolerably unjust world.

In Chapter 14 Colin Farrelly addresses the justice objection to life extension and the Malthusian concerns. Farrelly argues that justice requires accelerating the development of life extension so we get it sooner, and that failing to develop it when it is possible is an injustice, for that failure condemns billions of people to the chronic diseases of late life. Until now, it was not possible to protect people from the suffering and indignities of senescence, but now it is, so now controlling aging becomes a requirement of justice. He agrees that justice requires making it available to as many people as possible, and that we must be careful not to let it produce excessive population pressure or damage to the environment.

And with Chapter 14 we have gone from asking whether anyone can ever be better off dead to asking what ways of ending life are morally permissible, to asking whether life has to end on any timetable at all, and what ways of failing to extend it are unjust. Perhaps the right to die will be eclipsed by the right not to age.
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1 Is It Possible to Be Better Off Dead?


2 How Does Death Harm the Deceased?


3 The Significance of an Afterlife


4 The Severity of Death


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5 Defining Death


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6 Autonomy, Competence, and End of Life


7 Deciding for the Incompetent


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In re Westchester County Medical Center, 72 N.Y.2d 517 (1988).


8 Change of Mind: An Issue for Advance Directives


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Further Reading

Buchanan, A.E. and D.W. Brock (1990) Deciding for Others:


9 Medical Futility and Respect for Patient Autonomy


10 Refusing Lifesaving Medical Treatment and Food and Water by Mouth


Further Reading


Suicide, Physician-Assisted Suicide, the Doing-Allowing Distinction, and Double Effect


Huddle, T.S. (forthcoming) “What’s a CIED Got to Do with


12 Grief and End-of-Life Surrogate Decision-Making


Further Reading


13 Solidarity Near the End of Life: The Promise of Relational Decision-Making in the Care of the Dying


Aspen Law and Business.


14 Justice and the Aging of the Human Species


