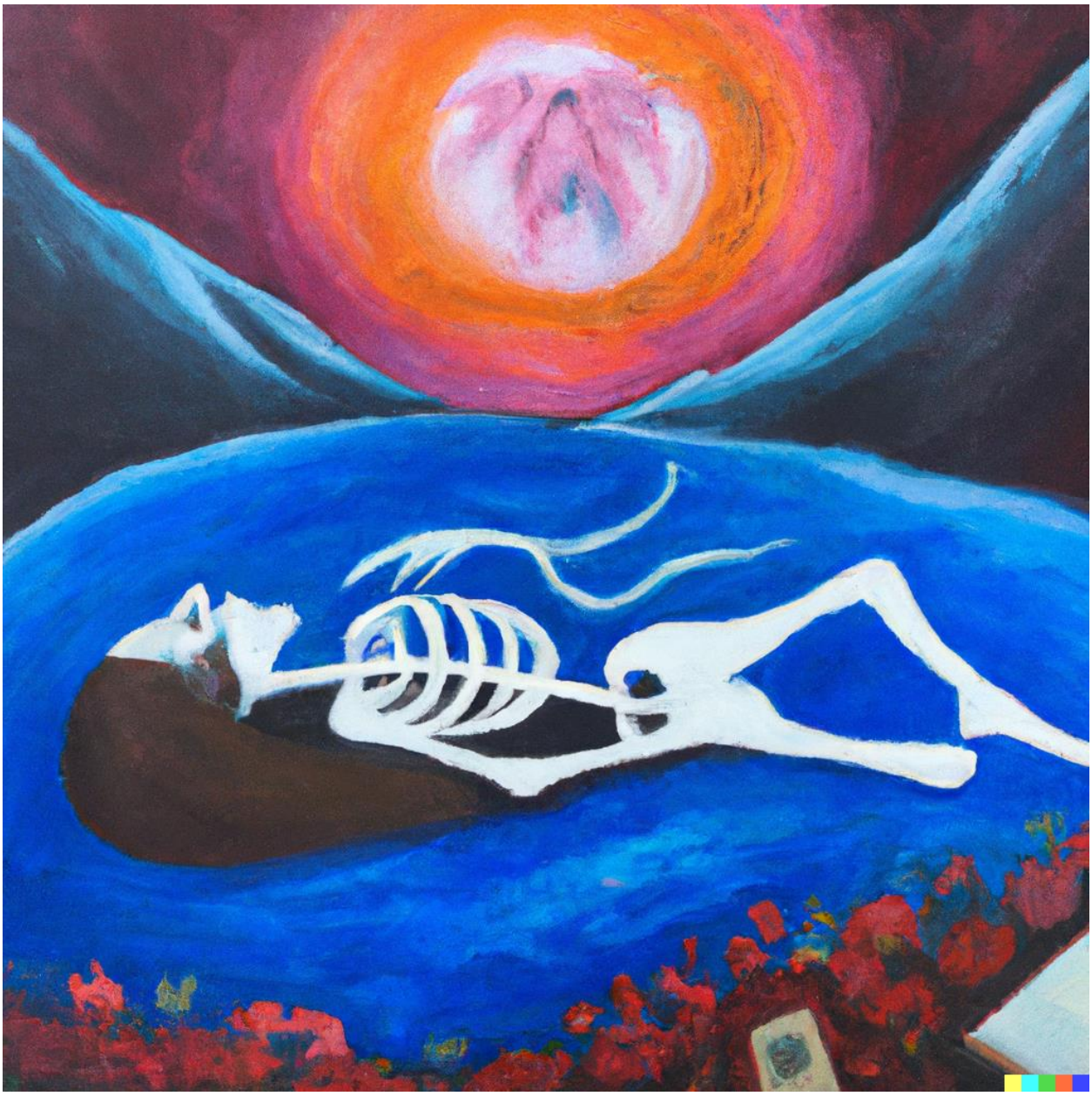
How Should We Think About Death?

Bioethics: Course Notes | Brendan Shea, Ph.D. (Brendan.Shea@rctc.edu)



In this lesson, we'll think through some philosophical puzzles concerning death. In particular, we'll be thinking hard about questions such as the following:

1. What does it mean to die? How can we define death?
2. In what sense, if at all, is dying a bad thing for the person who dies?
3. Would immortality (of whatever sort) be a good thing?

We'll be surveying various philosophical views, both ancient and modern, to understand what's challenging and exciting about these questions and why they resist easy solutions.

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2 SOME PHILOSOPHICAL PUZZLES ABOUT DEATH

> *"Our primary purpose is to define irreversible coma [with no discernable central nervous system activity] as a new criterion for death. There are two reasons why there is a need for a definition: (1) improvements in resuscitative and supportive measures have led to increased efforts to save those who are desperately injured. Sometimes these efforts have only partial success so that the result is an individual whose heart continues to beat but whose brain is irreversibly damaged. The burden is great on patients who suffer permanent loss of intellect, on their families, on the hospitals and on those in need to hospital beds already occupied by these*

comatose patients. (2) Obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation." [1]

Philosophers are famous (or infamous, depending on who you ask) for taking seemingly straightforward ideas or concepts and showing how they are much more complex than they appear. So, let's consider the case of **death**. Humans have been thinking about (and writing about) death for a long, long time. Moreover, it's a topic that most individual *humans* devote considerable time thinking about and preparing for. We have definite feelings about death (we generally don't like it!). In fact, it's tough to think about anything (other than sex or politics) that people think about more. Despite all of this time and effort, when it comes right down to it, its not always clear what we *mean* when we say things like "Death is a bad thing." *Death* here might mean one of any number of things:

1. Death might mean the *state* of being dead (or, "not alive").
2. Death might mean the *process* of our lives ending, through age, disease, injury, etc.
3. Death might mean the *instantaneous threshold* between living and not-living (i.e., "the moment of death").

To make things more complex, being "alive" (the opposite of "being dead") itself admits of various meanings. When I say of someone "that they are still alive", am I making the **"animalist"** claim about their biological body's continued physiological functioning (so, counterintuitively, a "brain-dead" person is still alive, since their heart might still be working) or is instead a "**personist"** claim about their still being the "same person" psychologically speaking (here, counterintuitively, severe dementia might "kill" me even while my body continues to live). Or is it some combination of these things?

Before 1950 or so, these questions were almost exclusively of philosophical (and religious) interest since a person who was "dead" according to one definition would pretty quickly be dead according to the other, as well. However, as our medical technology has improved, these disagreements have increasingly had practical ramifications. So, for example, most modern medical **whole-brain** definitions of "death" equate it with the irreversible loss of all brain activity (see above quote). However, this doesn't fit neatly with either animalist definition of life (according to which "**somatic"** death should be defined in terms of cardiac activity or something similar) or the personist definition (according to which I would have died when my **higher-brain** activity ceased, which might have been quite some time ago)[2].

Questions for Discussion:

1. **When you talk about (or think about) "death", what do you "mean" by this? A state? A process? The moment separating life from death?**
2. **Why do you think the "whole brain" definition of death has been adopted in medicine and law? What would be the problem with adopting "somatic" or "higher-brain" definitions of death?**

2.1 THE EPICUREAN ARGUMENTS: FEARING DEATH IS IRRATIONAL

Accustom yourself to believe that death is nothing to us, for good and evil imply awareness, and death is the privation of all awareness; therefore a right understanding that death is nothing to us makes the mortality of

[1] "A Definition of Irreversible Coma: Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death," *JAMA* 205, no. 6 (August 5, 1968): 337–40, https://doi.org/10.1001/jama.1968.03140320031009.

[2] The discussion and terminology here is adapted from Luper "Death," in *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta, Summer 2016, 2016, http://plato.stanford.edu/archives/sum2016/entries/death/..

> *life enjoyable, not by adding to life an unlimited time, but by taking away the yearning after immortality. For life has no terror; for those who thoroughly apprehend that there are no terrors for them in ceasing to live. Foolish, therefore, is the person who says that he fears death, not because it will pain when it comes, but because it pains in the prospect. Whatever causes no annoyance when it is present, causes only a groundless pain in the expectation. Death, therefore, the most awful of evils, is nothing to us, seeing that, when we are, death is not come, and, when death is come, we are not. It is nothing, then, either to the living or to the dead, for with the living it is not and the dead exist no longer. –Epicurus* [3]

OK, so enough about what death means. On to more important questions: Why are most humans so frightened of death? And should we be? This brings us to some famous arguments given by the Greek philosopher **Epicurus** (c. 340 to 270 BCE) and his later disciple, the Roman philosopher/poet **Lucretius** (c. 99 to 55 BCE)**.** These philosophers purported to show that it was *irrational* to fear death, even assuming there was no afterlife (as both Lucretius and Epicurus felt the truth of their "atomic" philosophy entailed). Along with engendering philosophical discussion, Epicureanism was, for hundreds of years, a philosophical idea with considerable popular appeal, and it competed with Stoicism and Christianity throughout the Hellenistic and Roman periods as an overarching account of how people ought to live their lives and how they could deal with the certainty of their own deaths.

Epicurus's argument (sometimes called the **"Timing Problem"**) is intended to demonstrate it is *literally impossible* for death to harm us. The argument is also supposed to be therapeutic for those who read it, as it helps to relieve a different sort of death-related harm: those caused by *worrying* about our deaths. The argument:

1. An event can *only harm me if it harms me at some specific time.* (For example, I am harmed by the event "Pouring boiling water on my foot" only if there was some particular time that this event actually occurred. In this, it was around my 30th birthday, and I was trying to boil some potatoes!).
2. I can't be harmed by future events, since they haven't happened yet. (So, it might well be that I'll someday be harmed by arthritis, but I'm not harmed *now* since I don't have arthritis right now.).
3. Death can't harm me before I die since that is in the future.
4. Death can't harm me after I die because "I" won't exist to be harmed.
5. So, since death can't harm me at any specific time, it can't harm me. (So, I should stop worrying!)

Epicurus's basic idea is that there is something deeply confused about how we think about death. In particular, it's tempting to think of death as the *worst* possible harm that can happen to us. So, if we made a list of "bad things I don't want to happen to me", death would definitely be on it, and somewhere near the top. So, for example, it's worse than papercuts, getting dumped, losing one's job, or even being sick for a long time. But when we look closer at this list, Epicurus thinks we'll notice that death is NOT like the other things on this list. The other bad things are all things that might happen to ME, at some time and place, and which would cause me to feel something or other. But death isn't like this! I simply won't be around to feel what death feels like. Dying might indeed be unpleasant (Epicurus grants that sickness is bad!), but Epicurus suspects (reasonably) that many of us see death as categorically different (and worse than) mere disease.

Lucretius presents a companion argument, usually called the **Symmetry Argument.** Here's Lucretius:

> *"Life is granted to no one for permanent ownership, to all on lease. Look back now and consider how the bygones of eternity that elapsed before our birth were nothing to us. Here, then is a mirror in which nature*

[3] Robert Drew Hicks, *Stoic and Epicurean* (C. Scribner's sons, 1910).

shows us the time to come after our death. Do you see anything fearful in it? Do you perceive anything grim? Does it not appear more peaceful than the peaceful than the deepest sleep?" Lucretius [4]

This argument might be spelled out as follows:

1. I am NOT "harmed" by not having been born earlier than I was. (That is, given that I was born in 1979, I don't spend much regretting the fact I wasn't born in 1969, or 1879, or 79 BCE).
2. From my point of view, the time after I die is perfectly symmetric to the time before I was born (I don't exist in either time). If I can't be harmed by one, I can't be harmed by the other.
3. So, I can't be harmed by the non-existence after my death.
4. So, I can't be harmed by death, and I shouldn't be worried about it.

Again, this argument is meant to get us to pay attention to some odd aspects of how we think about death. On one level, we *know* that death is inevitable—there will come a time when we don't exist (at least according to Lucretius). But what's so bad about "not existing"? Lucretius notes that there was already a ton of time we didn't exist (the whole history of the universe before we were born). However, we seem to think this is not a big deal. Lucretius suggests we adopt the same attitude toward what happens after we die.

Questions: OK, so what do you think? Have Epicurus and Lucretius convinced you that you should stop worrying about death? Do you think they *could* persuade you if you spent some time rehearsing these sorts of arguments to yourself every day? In short: do you have what it takes to be an Epicurean?

2.2 THOMAS NAGEL: YES, DEATH IS BAD

Observed from without, human beings obviously have a natural lifespan and cannot live much longer than a hundred years. A man's sense of his own experience, on the other hand, does not embody this idea of a natural limit. His existence defines for him an essentially open-ended possible future, containing the usual mixture of goods and evils that he has found so tolerable in the past…Viewed in this way, death, no matter how inevitable, is an abrupt cancellation of indefinitely extensive possible goods…If the normal lifespan were a thousand years, death at 80 would be a tragedy. As things are, it may just be a more widespread tragedy. If there is no limit to the amount of life that it would be good to have, then it may be that a bad end is in store for us all. – Thomas Nagel

In his 1973 article "Death"[5], the American philosopher Thomas Nagel argues that Epicurus and Lucretius got things wrong. More specifically, he argues that death DOES harm us, and it does so by depriving us of the life that we enjoy.

1. Nagel begins by noting that most of value our own lives, even when things aren't going our way. We *prefer* experiencing the world to not experiencing it (e.g., most of us would not want to be put in a permanent coma).
2. So, what is it that bothers us about death? Nagel argues it can't simply be loss of consciousness (most of us don't mind temporary non-dreaming sleep) or even non-existence (he grants Lucretius's point that we don't regret the time before we were born). So, the badness of death isn't a "positive" badness in the way that pain/suffering are. Instead, it is a "negative" badness-it is bad because of what it takes away from us—the joys of being alive.

[4] Lucretius [Titus Lucretius Carus], *On the Nature of Things*, trans. William Ellery Leonard, 1997, https://www.gutenberg.org/ebooks/785.
[5] "Death," *Noûs* 4, no. 1 (1970): 73–80, https://doi.org/10.2307/2214297.

3. Now, the problem: if death IS bad for me, HOW and WHEN is it bad for me? This brings us to the Epicurean argument. Nagel argues, contra Epicurus, that things can be bad for me even if they don't directly "hurt" me (i.e., they don't cause physical or mental pain), and even if the harm doesn't occur at a particular time. He offers several examples:
    a. a person who is betrayed by his friends but never finds out,
    b. a person whose wishes are ignored after her death, and
    c. a person who receives a severe brain injury, which leaves them in an infantile (though happy!) state.

    For Epicureans (who focus on pleasure/pain as the only sources of value), it is hard to see why any of these should count as "harms" or "bad things." However, Nagel thinks we ought to agree that they are, in fact, bad. It's just that their badness is in some way "relational" and depends on something besides our internal states. (That is, you couldn't tell *just by looking at the people in examples a-c* that these things had happened. Instead, we'd need to look at the wider world, history, etc.)

4. Once we recognize we recognize the possibility that things might be bad for me without my necessarily being causally affected by them, we can see how death can harm us. Death is a comparative/relational harm—when I die, I miss out on all the good things that *might have been* had I not died.
5. While Nagel doesn't go so far as to claim that death is *always* bad (e.g., maybe it is better than eternal torment) he does argue it is almost always bad, insofar as most of us enjoy life, even under pretty adverse circumstances. Death is bad, compared to the (good!) life we would rather be living. Nagel grants it might be *worse* to die young (on the grounds that you miss out on more of lie). However, just because someone dies at the "normal time" for humans doesn't magically make the badness of death go away.

Questions for Discussion: Much of the philosophical discussion of Nagel's article has focused on his idea that we can be "harmed" by things that don't affect us (and that we can be harmed by things that happen after we die!). What do you think of his examples? Do they convince you?

2.3 BERNARD WILLIAMS ON DYING AT THE RIGHT TIME

"Suppose, then, that categorical desire does sustain the desire to live. So long as it remains so, I shall want not to die. Yet I also know, if what has gone before is right, that an eternal life would be unliveable. In part, as EM's case originally suggested, that is because categorical desire will go away from it: in those versions, such as hers, in which I am recognisably myself, I would eventually have had altogether too much of myself. There are good reasons, surely, for dying before that happens. But equally, at times earlier than that moment, there is reason for not dying. Necessarily, it tends to be either too early or too late. EM reminds us that it can be too late, and many, as against Lucretius, need no reminding that it can be too early. If that is any sort of dilemma, it can, as things still are and if one is exceptionally lucky, be resolved, not by doing anything, but just by dying shortly before the horrors of not doing so become evident. Technical progress may, in more than one direction, make that piece of luck rarer. But as things are, it is possible to be, in contrast to EM, felix opportunitate mortis - as it can be appropriately mistranslated, lucky in having the chance to die." -Bernard Williams [6]

Bernard Williams begins his article "The Makropulos Case: Reflections on the Tedium of Immortality" by reflecting on the strange (fictional) life of Elina Makropulos (EM from here on out), the lead character in a play by Karl Capek. After taking an immortality potion cooked up by her father long ago, EM is 342 years

[6] "The Makropulos Case: Reflections on the Tedium of Immortality," in *Problems of the Self: Philosophical Papers 1956-1972* (Cambridge, UK: Cambridge University Press, 1973), 82–100.

old. However, after all this time, life has nothing left to offer her—she is bored, indifferent and cold toward life. She chooses not to retake the potion, and dies.

So what do Elina's life and death have to teach us? Bernard Williams argues it shows two different things:

- **Premature Death is Bad.** First, contra the Epicureans, most of our lives are not like EM's. There are things in our lives that are worth doing, and dying prematurely prevents from us from doing those. So, contra Epicurus and Lucretius, Williams argues that death can be (and often is) a bad thing. This agrees with Nagel.
- **Immortality would be Bad, Too.** Second, in contrast to Nagel, Williams argues that the Makropolus case shows that life can be *too long*. Our lives have a particular structure, and this structure simply can't support our living (good, meaningful lives) for indefinite periods. Williams will argue this applies to EM's particular brand of immorality and all possible versions of immortality (from reincarnation to nirvana to heaven, etc.).

While William's argument is a bit more complex than those we've considered so far, the basic are as follows:

1. Categorical desires give our lives meaning**,** since we want these things *even if we are not alive to see or experience them*. So, for example, my desire is that my child has a good life, that my students come to see the value in philosophy, that I solve Zeno's paradoxes, or that I finish some piece of art can provide a *reason* to live. By contrast, I have plenty of non-categorical desires, which are things I want only on the condition I'm still alive ("If I'm still alive in the year 2150, I'll desire to eat food and read science fiction novels."). Williams grants that's there something to the (Nagel-esque) desire to "just keep having experiences", but he contends this isn't enough to sustain most of us.
2. The case of EM shows that categorical desires have a certain "shelf-life." That is, while raising 3 or 4 (or 10 or 20) children can give meaning to life, Williams doubts that we would continue finding it worthwhile if we raised 100,000 children (one after another). The same goes for artistic creation, political activity, research, learning, etc. At some point, these desires simply run out, and can't be replenished/replaced by new desires.
3. So what about immortality of the sort promised by various religions? Williams argues there are only two possible options, and neither one solves the problem. First, the immortal life might be of EM's type, where I get to keep my existing personality and categorical desires. It might well be that I don't succumb as easily as EM does (among other things, I don't have to deal with a sexist society and terrible men. However, in the end, Williams argues that I'll eventually meet her fate (and find life to be not worth the living of it.).
4. On the other hand, there are versions of immortality (such as reincarnation, nirvana, or Aristotle's idea that I become a self-thinking thought) that solve the "boredom" problem, but only by destroying *me* in the process. Finally, some conceptions of the afterlife are a bit more ambiguous ("heaven"). However, once we start looking closer, these present the same dilemma. So, for example, could *I* enjoy an eternity contemplating God's awesomeness? It sure seems like I (and every human I've ever met…) would get bored quickly. So, if this is what immortality amounts to, it sure doesn't seem like it is *me* that is going to live forever.

Williams concludes that there are no easy options when thinking about life and death. He argues against the Epicureans that we have reasons to regret dying early. And against Nagel, he argues that life can, at some point, be too long.

We'll conclude things by considering one more complication. In response to Williams, it can be tempting to argue that "well, all this means is that we should all aim to live as long as we possibly can (e.g., through continuous advances in science). After all, we can choose to die if we get bored of life, just like EM." The

problem here lies in considering *who* is going to makethe choice to live or die when that point comes. After all, when "I" have exhausted all of my categorical desires, I'll cease to be "me" in any meaningful sense. In my place, there will be a person who (if he cares about anything) is entirely devoted to the pleasures of the moment. What might such a being look like? One of Williams's most famous students, Martha Nussbaum [7] once suggested that they might look like the gods of Greek mythology—petty, vicious, squabbling beings with little concern for how their actions affect others). Moreover, this conception of what a too-long life might look like is mirrored in other fictional and mythic accounts of human-like immortals: for example, think of Milton's rebellious angels, Bram Stoker's Dracula, the gods of Norse mythology, etc. This all suggests that we should be very careful before accepting EM's immortality potion, in whatever form it comes in.

2.4 FOR DISCUSSION

1. Suppose that a super-powerful being approaches you and asks which of the following you would prefer. Once made, your choice cannot be taken back. What might be some drawbacks to your choice?
    a. You will get to live out your life, die, and then cease to exist.
    b. You will be granted immortality in (more-or-less) your current form—you won't age, can't be killed, etc. If you'd like, the being will grant this same sort of immortality to your friends and loved ones (provided they agree to it).
    c. You will live out of your lives as normal, and then be reincarnated/reborn as a new human or animal of your choice, with no memories of your previous life.
    d. You will live out your lives as normal, and then go to a heaven in which there is no hunger, pain, thirst, and so on. You will spend your time contemplating God, thinking about mathematics, doing philosophy, or something else of the sort. Your psychology will be altered so that becoming bored with such things will be *unthinkable*.
2. Socrates once claimed that philosophy (the best of all human activities!) was nothing but "preparation for death," and that those who spent their time doing philosophy would find death unthreatening. Many subsequent philosophers in the Western Tradition (including the Epicureans, Stoics, Jewish-Christian-Islamic thinkers) have agreed with him, though they haven't always agreed *which* sort of philosophy is needed! After our (brief) introduction to these issues: what do you think? If you spent *more* time thinking carefully about these issues, would it really make things easier? (Or might it do the opposite?)

2.5 REFERENCES

Part of this lesson here is based on arguments I expand on in Shea [8] and Shea [9]. Feldman [10] provides a detailed examination of the Epicurean view of death, and some puzzles regarding it. A good overview of philosophical

[7] "Mortal Immortals: Lucretius on Death and the Voice of Nature," *Philosophy and Phenomenological Research* 50, no. 2 (1989): 303–51.
[8] "To Bite or Not to Bite: Twilight, Immortality, and the Meaning of Life," in *Twilight and Philosophy: Vampires, Vegetarians, and the Pursuit of Immortality*, ed. Rebecca Housel and J. Jeremy Wisnewski (Wiley Blackwell, 2009), 79–93.
[9] "Leonard Cohen as a Guide to Life," in *Leonard Cohen and Philosophy: Various Positions*, ed. Jason Holt (Open Court, 2014), 3–15.
[10] "Some Puzzles about the Evil of Death," *The Philosophical Review* 100, no. 2 (1991): 205–27.

questions concerning the afterlife in particular (and how it might avoid Williams' dilemma) can be found in [11]. In recent years, Nussbaum [12] has backed off the view that immortals would necessarily be vicious. However, her revised position plausibly depends on the idea that there would be some beings that these immortals could help in meaningful ways.

3 READING: NINE LESSONS A PHYSICIAN LEARNED ABOUT DYING (BY EZRA KLEIN AND ATUL GAWANDE)[13]

When I was a kid, I had an overwhelming fear of death. It was the kind of terror that you can't be talked down from, the kind of terror you can only hope to eventually learn to ignore. I became compulsive about avoiding the subject. I would close books when it came up. I would leave rooms when it was discussed. I developed obsessive mental protocols to manage the fear. When I would hear the word "death," I would automatically think, "no death," as if casting a counterspell. "Dying?" "No dying." "Dead?" "No dead." Death was too big a topic to simply ignore. It had to be banished. It had to be fought.

I have an easier time talking about death now, but I wouldn't call it a favored topic. So I was a bit apprehensive when I sat down to talk with Atul Gawande.

Gawande, a cancer surgeon and New Yorker author, wanted to talk about dying. In fact, he wants everyone to talk about dying. He's even written a book, "**Being Mortal**," to get the conversation going.

The inspiration, Gawande, says, was realizing that he didn't know how to talk about dying — nor did his colleagues. "What I saw over and over again is that mortality is one of the problems that we simply didn't deal well with. I didn't deal well with it. I didn't know how to break bad news to people."

And so Gawande set out to learn how to give people the worst news they would ever get. He interviewed more than 200 people about aging, living with terminal illness, and dying. I asked him to tell me what he learned.

3.1 WHAT IS DEATH?

This might sound like an obvious question, but it isn't. You can define death a lot of ways. It can be the death of consciousness, for instance, which does not always come at the same time that the basic bodily functions shut down.

But we're going to go with the basic scientific definition here. "Death is when oxygen no longer is able to supply your brain," says Gawande. "That's the final common pathway."

[Brendan: Can you think of any other definitions of death? (Perhaps from areas other than medicine?)]

3.2 THE BEST WAY TO TALK ABOUT DYING IS TO TALK ABOUT LIVING

"The reason why I felt like I wasn't doing a very good job as a doctor is it felt like the choices I was giving a patient were, do you want the operation that gives you this tiny chance that you might be able to live longer, or do you want to give up?" Gawande says.

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[11] William Hasker and Charles Taliaferro, "Afterlife," in *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta, Spring 2019 (Metaphysics Research Lab, Stanford University, 2019), https://plato.stanford.edu/archives/spr2019/entries/afterlife/.
[12] "The Damage of Death," in *The Metaphysics and Ethics of Death*, ed. J.S. Taylor (Oxford: Oxford University Press, 2013).
[13] Ezra Klein, "9 Lessons a Physician Learned about Dying," Vox, October 21, 2014, https://www.vox.com/2014/10/21/7023257/atul-gawande-taught-me-dying-being-mortal.

"What I recognized from following different people around who turned out to be really good at these conversations is that they were never giving up. They were fighters, but fighters for a different concept of hope — the hope that you would have as good a life as possible all the way to the very end, no matter what comes. You are often fighting to just have a good day today. And when you do that, if you sometimes ignore how much time there might be, the irony is that people not only don't live shorter, they often live longer."

In a way, Gawande's critique of American medicine is that it's so focused on battling death that it's forgotten to prize life. Doctors focus too much on what a last-ditch operation might achieve, and too little on what it might cost. And even when no further interventions are planned, there's a tendency to view the decision as some kind of surrender, rather than as an effort to give someone the highest quality of life they can have in their remaining days. "The goal is not a good death," he says. "**The goal is how do we have as good a life as possible all the way to the very end while coping with the fact that we are biological creatures, that we are flesh and blood and are going to have limitations as we go along."**

[Brendan: What do you think of this quote?]

3.3 LESS MEDICINE DOESN'T ALWAYS MEAN LESS LIFE

The way American medicine usually frames the question of end-of-life care is, do you want doctors to do absolutely everything they can to extend your life, even if those interventions may be horribly painful, or run the risk of terrible complications, up to and including death? Or do you want to give up on the possibility of extra time in order to avoid the pain, suffering, and possible complications of those interventions?

Gawande doesn't buy it. "There's a study — and now there have been a bunch of these — but the most scientifically-done one randomized people at Mass General hospital with Stage 4 lung cancer to either get the usual oncology care, or get the usual oncology care plus a palliative-care specialist who discussed this thing that we don't want to discuss. The ones who had that discussion ended up stopping chemotherapy sooner. They ended up choosing hospice earlier. They had less suffering at the end of life. And the fascinating thing is they lived 25 percent longer."

That seemed to raise the possibility, I said to Gawande, that there was a win-win here: less aggressive interventions at the end of life might, surprisingly, mean more life, as well as less pain. He agreed. "When we use the $80,000 drug as the fourth line of action, all you get is the harm. You just get the toxicity. And you get none of the benefit. And the result is the average person, when you're taking it at that stage, it ends up sacrificing everything that they were trying to live for, and in fact, sacrificing time. So yes, it's a win-win deal."

3.4 TALKING ABOUT DEATH IS A SKILL. WE SHOULD REWARD IT.

One reason there's more surgery and less discussion is that the health system will pay a doctor a lot for doing a surgery and basically nothing for having a frank, sensitive, hard conversation about end-of-life choices. Of course, doctors have those conversations anyway, every single day. But a side-effect of the economics is that doctors don't have much incentive to learn about how to have those conversations. There's good economic reason to go to fun conventions in beach resorts where you learn about new drugs and new devices and new surgeries. But no one puts on fabulous conventions about end-of-life discussions.

"We really reward me for being a surgeon," says Gawande, "and this debate about whether we are going to make it possible for people to be rewarded for being really good at these human sides of the skills. I think is a really fundamental part of this debate."

[Brendan: Have you been involved in end-of-life care (perhaps for a relative)? How well did medical staff handle these sorts of conversations?]

3.5 THE NEARER YOU THINK YOU ARE TO DEATH, THE MORE YOUR PRIORITIES CHANGE

"I describe the research of a woman named Laura Carstensen at Stanford, who studied people ages 18-94," says Gawande. "Young people basically aspire to achieve, to get, to have. They're willing to delay gratification. When we become aware of the fragility of our life and we get older, we focus on a narrower group of friends and family. We become much more focused on intimacy and deeper relationships with folks and being connected to a few things that make us feel purposeful in the world. And that can change overnight."

What's interesting about Carstensen's research, Gawande continues, is that it really is about mortality, not just age. When young people feel death might be nearer, their priorities shift. "During 9/11, she did some research and found that young people all moved to the older signature. We all wanted to be with family. We wanted to focus on a few people, that we wanted to make a difference for them and not just the broad world. And three months later, we were back to being like, yeah, this is all fine."

At about this point in our discussion, I brought up Ezekiel Emanuel's **essay** explaining why he wants to die at age 75. The argument he makes is really about achievement: once his capacities begin to diminish and he's unlikely to make further major professional contributions, Emanuel's view is that life, at least to him, loses a lot of what makes it worth living.

Gawande counters with Carstensen's studies. "The studies like Laura Carstensen's show that as that [aging] happens, people are not becoming more unhappy. They're actually, in general, less likely to be depressed, more likely to have more complex emotions that you don't have at a younger age. You shift from trying to win that Nobel prize to realizing that that didn't matter so much, and what you really care about is being close and connected to my family and a few friends."

3.6 EVEN THE DEPENDENT WANT TO BE INDEPENDENT

Though priorities in old age might shift toward close friends and family, it's actually not the case that the elderly want to live with their families. This was a bit of a surprise to me: I've read a lot of laments about how, in the West, the elderly don't live with their families, and so end up isolated and unhappy. The data tells a more complex story.

"As we got pensions and Social Security, the very first thing that families did is they moved apart," Gawande says. "The parents did not want to live in the home with their son or daughter and follow their rules, and the son and daughter did not want to keep living with mom and dad telling them what to do. Sociologists call it 'living at an intimate distance.' Near, but not too near, is kind of the idea we aspire towards. This is happening all over the world. People are increasingly likely to live into their old age alone and want to have that preserved. It works great until you can't be independent anymore."

[Brendan: How do your priorities differ from your older family members (such as grandparents)? How do you anticipate your priorities/interests will change when you reach their age?]

3.7 NURSING HOMES ARE SOME OF THE SADDEST, MOST INNOVATIVE PLACES IN THE WORLD

"The people who are changing the way we build nursing homes, I think, are some of the most innovative people in America right now," Gawande says. "You know, we talk about the technology innovators. I mean, these people are doing things that I think will affect us in far more important ways."

Nursing homes, right now, are built to emphasize the word "nursing" rather than the word "home". At the center, typically, is a nursing station. But nursing home reformers are trying to change all that and to build them around kitchens. And that's where it gets tricky.

"In the kitchen," Gawande says of this new breed of nursing homes, "you could go to the refrigerator and get whatever food you want. That is unbelievably controversial, if you can imagine, because people will say, well, you know, a diabetic person might go to the refrigerator and take out a soda and that's not safe. An Alzheimer's patient might go and take something out besides the pureed food they're supposed to be on."

"We make these choices all the time in our home and taking those away from people takes away really fundamental things about who they are, what makes a life worth living. The biggest complaints about patients in nursing homes — by the way you can get a report filed against you in a nursing home — are about violating food rules. So you'll see Alzheimer's patients hoarding cookies. Give them the damn cookie. They might choke on it, but what are we trying to keep them alive for? Let's allow some risk, even in the Alzheimer's patient, to be taken."

3.8 ONE PROBLEM WITH OLD AGE IS THAT NURSING HOMES MARKET THEMSELVES TO THE YOUNG, NOT TO THE OLD

"An expert gave me this quote that has really stuck in my mind," Gawande says. "Safety is what we want for those we love and autonomy is what we want for ourselves."

Nursing homes know that. And they also know that, more often than not, their customer isn't the person moving into the nursing home — it's the younger relative who's managing the move. "Whether it's a home-health agency or an assisted-living facility or a full 24-hour-a-day nursing home, these places market themselves to our desires, not to our parents' desires, because more often than not, we're the decision makers. So we bring the parents around and they will tell us, 'We are incredibly safe,' and that's what we want to hear. But how lonely are people there? How purposeful are their lives?

"People experience these as prisons. As people get older they get lower levels of anxiety, higher levels of happiness, until you put them into these institutions, and then that's when you see the three plagues of loneliness, helplessness, and boredom.

"You know, people don't want to play bingo and be comfortable all the time. They want to know that they have some things that connect them to who they are. But that is not what families are asking about. And so the result is that we get places that end up reconstructed to look like more and more like hospitals, instead of like homes where you can go to the kitchen and get what you like."

[Brendan: I know many students have worked in nursing homes! What do you think works (and doesn't work) about our current way of arranging care for the elderly?]

3.9 WHERE WE DIE IS CHANGING — FAST

"In 1950 in the United States," Gawande says, "the majority of people died in their home. And the reason why is they didn't see that there was much likely benefit of going to a hospital. But we discovered a ton of stuff in the last half-century so that by the end of the 90s, 83% of us died in an institution, most commonly the hospital. And only 17% died in the home. That was out of faith that there was going to be something that could be done.

"But as prosperity continued to rise, we began to expect that we're going to have some control and some quality of life and there's been, in the last 5 years, this countervailing force. We're closing in on 50 percent of people now dying in hospice, either at home or in a hospice center outside a hospital."

4 READING: THE GOOD DEATH (BY MARY TALBOT)[14]

It's a modern dream that we can plan a good and peaceful death but what can we really do to meet the end of all we are?

For as far back as I can remember, I have been preoccupied with what it will be like to die. As a girl, I would often zone out on my bed, or at my desk in school, imagining that I was on the verge of death, and trying on a range of possible reactions: terror, confusion, grief. What I really hoped for in those moments of morbid fantasy was a kind of peaceful, alert confidence. I would be brave and mature enough when I died. I would let go and master whatever might be waiting on the other side. But, mostly, all I could authentically muster was a shiver of panic.

As I moved into adulthood, I began to collect glimpses into the deaths of family members and friends. There were hints at how to be at peace, but some of these deaths were sad and torturous. An elderly friend with pneumonia who expired tethered to ICU machines against her wishes, another who succumbed to cancer, leaving two young daughters behind, and another who died of AIDS, shunned by his family, delirious and heartbroken. Living in a society that offers few lessons on how life should end, and where the moribund are mostly hidden from view, it's hard to find tangible examples of dying well.

A few years ago, I signed up to volunteer with a New York City hospice. I was inspired by a dying friend who described how lonely she was being terminally ill in a death-phobic culture. Maybe I could be of comfort to someone like her. But also, I simply wanted to be near dying people – to get an education in death, to glean some coordinates for the roadmap to my own end.

My tenure as a volunteer began with a six-week training programme, a valiant effort by the volunteer coordinators to prepare us – for the iron grip of medical bureaucracy, paperwork and protocols we would have to endure, as much as for visiting with the dying and their families. The first day, 35 of us sat around a conference table and engaged in a hospice kind of icebreaker, in which we each had to narrate what we wanted our own deaths to be like.

One woman imagined a lovely death arriving as she dozed in a rocking chair on the porch of her childhood home in South Carolina, surrounded by kin. A graduate student described his perfect end in the midst of some exhilarating adventure – skydiving or hiking in the Andes: a sudden accident in the midst of thrill; no lingering pain. A retired nurse with grown children envisioned a serene, solitary demise in her bed, at home in Brooklyn, lulled by the familiar whir and soft wind emanating from the ceiling fan.

Only a handful of us mentioned a death inspired by religious ethos – getting right with God, say, or moving toward a state of enlightenment. I attributed this partly to the fact that we were in the centre of a secular metropolis – had we gathered, say, in Kansas, the group's orientation very likely would have skewed deeply Christian. But part of it was due to the fact that none of us was actually dying. Reams of deathbed chronicles report that when death is imminent, many people, even confirmed atheists, reach down to long-buried religious roots for solace and direction.

No one wanted heroic medical treatment to prolong life if death were imminent or if we were suffering terribly. In essence, we described our desire for control over the circumstances of our deaths, and for the ability to tailor them to our personal preferences, and in so doing we were in tune with our culture. According to sociologist Tony Walter, 'the good death is now the death that we choose'. It is shaped, he writes in *The Revival of Death* (1994), 'not by the dogmas of religion nor the institutional routines of medicine but by the dying, dead or bereaved individuals themselves'.

Indeed, the more deaths you're exposed to, the more diversity of experience you see. Scores of studies by social scientists and articles by death experts, many based on interviews with dying people and their caregivers, point to the vast range of good death concepts and experiences. 'I can't presume to know what anyone else's good death looks

[14] Mary Talbot, "In a Secular Age, What Does It Mean to Die a Good Death?," Aeon, September 25, 2014, https://aeon.co/essays/in-a-secular-age-what-does-it-mean-to-die-a-good-death.

like,' says Barbara Coombs Lee, an intensive care nurse-turned-lawyer who co-authored Oregon's Death with Dignity law in 1994. 'A good death is one that comports with the way we've lived our lives, with our manifest values and beliefs. And that is going to differ for everyone.'

[Brendan: In your view, what would count as a "good" death for yourself?]

My hospice group might not have been a scientifically selected sample, but we formed a robust cross-section of urbanites who wanted to approach death conscientiously and with purpose. In placing so much emphasis on control and self-determination, and faith in the idea that choice would remain within our grasp, were we ignoring the fact that dying is the ultimate loss of control?

Until relatively recently, Western people's expectations about death had little do with personal choice. Cultural prescriptions for how to die have been around for as long as people have organised themselves into societies, and for the most part, they were rooted in belief about how things would go in the afterlife. For the ancient Greeks, the goal was *euthanasia,* referring, literally, to the 'good' or 'noble' death, as of a hero in battle or an upstanding citizen departing this world with absolute moral purity – the better to face the trials that awaited in the underworld. The transcendent value of pleasure in the Graeco-Roman world figured into the good death, too. A second-century astrologer noted that a person born under a particularly propitious constellation would 'die well falling asleep from food, satiety, wine, intercourse or apoplexy'.

By the 15th century in western Europe, how-to guides known as *Ars Moriendi* ('The Art of Dying') provided Christians with very specific deathbed rules of conduct. These manuals reached their apotheosis with a bestselling booklet by the English cleric Jeremy Taylor called *The Rule and Exercise of Holy Dying* (1651), which, thanks to the advent of vernacular printing, proliferated for the next 200 years. Taylor's tome and others like it instructed dying people on 'how to give up one's sould gladlye and willfully', how to resist the devil's temptations at the time of death, how to emulate Christ and what prayers to recite. A priest was to interrogate the dying person about the state of his soul and plans for the afterlife, and the many onlookers were to learn what they could, both about the spiritual condition of the deceased and how to behave when their own time came.

These aspects of the good death dominated in the Judeo-Christian world well into the 19th century. Family had always figured prominently in the *ars moriendi* – to assemble around the bed, perform rituals, encourage the dying person, and imbibe his momentous last words. During the American Civil War, when a tenth of the US population was perishing, away from home, 'soldiers, chaplains, military nurses, and doctors conspired to provide the dying man and his family with as many elements of the conventional Good Death as possible', writes the historian Drew Gilpin Faust in *This Republic of Suffering* (2008), her masterful study of death in that conflict. They struggled 'even in the chaos of war to make it possible for men – and their loved ones – to believe they had died well'. The use of embalming and undertakers – professional death attendants – became widespread, as returning the body to the family, whenever possible, was imperative to the closure of good death.

In some ways, the cultural phenomena surrounding death that emerged during the crisis of war became routine with the more or less permanent upheavals of the industrial revolution. Like soldiers mobilised for battle, huge swaths of the population began moving away from home, rupturing the family and community structures that once oversaw the dying process. The rise of the commercial funeral industry was part of a trend that legislated – and priced – home dying virtually out of existence. Longer life expectancy, combined with life-preserving medical technology, meant that more and more people would eventually die with dementia or bodies that had in other ways outlived their faculties. By the middle of the 20th century, medicalised death was the norm. As Katy Butler describes it in *Knocking on Heaven's Door* (2013), a memoir of her parents' deaths, medical intervention to prolong lives in hospitals reached such a pitch that last words could hardly be uttered – dying people's mouths were too clogged with tubes and respirators to speak.

The modern hospice and palliative care movements emerged in compassionate reaction to the pain, loneliness and grief in which so many medicalised deaths end. Set in motion by Dame Cicely Saunders, an Anglican nurse and

physician who founded the first modern hospice in 1967 in London, and the psychiatrist Elisabeth Kübler-Ross, whose work with the terminally ill inspired her 'five stages of grief' paradigm, these models focus on the psycho-social needs of the dying person and the alleviation of physical symptoms. A good death, from the view of a hospice, includes **'an open awareness of dying, good or open communication, a gradual acceptance of death, and a settling of both practical and interpersonal business',** writes Beverley McNamara, an Australian sociologist who studies the concept of good death in hospitals and nursing homes. 'In order for the social and psychological aspects of death awareness and acceptance to take place,' she adds, 'the dying person's suffering should be reduced and they must be relieved of pain.' Spiritual concerns, too, are taken into account as part of the psychological package, but are not necessarily given more weight than other dimensions of care.

[Brendan: What do you think about this model of thinking about a "good death"?]

This version of how to die – a sort of hospice *ars moriendi* – has become the conventional wisdom about what comprises good death among many of the people who study modern dying, or work in the trenches of end-of-life care. I think back to my volunteer training group and the salient themes that recurred in our disparate fantasies. We wanted a minimum of pain and discomfort, a favourite place (usually home), privacy and a congenial ambience (skydiving notwithstanding), our worldly affairs in order, the chance to say goodbye and sew up loose emotional ends with loved ones. A peaceful and, ideally, lucid mind.

Iwanted all those things too, but the notion that I could guarantee myself any of the external trappings of a good death – comfort, loving bystanders, freedom from pain, a ceiling fan – has always struck me as tenuous. As a teenager wound up in thoughts of mortality, I first found an inkling of relief when I began to meditate, inspired by some instructions I read in a yellowing, 1960s paperback about yoga for weight loss. Those early attempts at quieting the relentless chatter in my mind and feeling the thread of my breath were a revelation – there was something I could access inside that seemed reliable, and softened my worries about dying. I sought out more books on meditation, began to visit a local Zen centre, and in the intervening decades, adopted Theravada Buddhism as my religion.

That same sort of yearning for inner peace has led several generations of Westerners to pick up an Eastern compass. In the 1960s and '70s, as Saunders and Kübler-Ross were railing against the heartless treatment of the dying, and forging new models of care, seekers began filling the spiritual vacuum at home with yoga, Buddhist meditation and such guideposts as the Tibetan Book of the Dead, all of which uphold death as part of a cyclical journey requiring rigorous preparation – not as an awful terminus.

The first Buddhist I knew to die was the poet Allen Ginsberg. He was surrounded by friends, students and his teacher, all chanting and sitting vigil in his East Village apartment, before, during and for three days following his death, according to Tibetan Buddhist custom. It was understood that the people around him could actively assist his passage, and that the final moment of consciousness was paramount, the most important moment of his life.

On my very first outing as a volunteer, I experienced a hospice death. I shall call the patient I was assigned to visit Sonia, a 51-year-old grandmother with nine grown children and many grandkids. She had struggled with a decades-long crack cocaine habit, and was now consumed by breast cancer she had mostly neglected to treat. At the close of an afflicted, sometimes homeless life, Sonia had summoned her waning energies to ask whichever family members visited for forgiveness, to say she loved them, as she was doing with a daughter-in-law when I walked in. Her translucent lips curved into a weak smile when I placed a tiny flowering plant on the table near her bed and then she sank into a deep, interior quiet, absorbed, it seemed, in the work of shutting down.

I was asked to call the hospice hotline, to fetch a chaplain to give Sonia her last rites – the nurses and her daughter-in-law thought it was time. Staff bustled in and out, checking the morphine drip that kept her pain at bay, and glancing at the empty urine bag (Sonia had stopped eating and drinking several days before). Her face was smooth and pale as parchment, her skin refrigerator cool, and her breaths came in short, jagged sips, punctuating wide gullies of profound silence.

For several hours I sat, my hand on her arm, in a state of electrified attention, watching a stranger disengage from life. Sonia released her last breath, almost imperceptibly, in the characterless, air-conditioned room of the run-down Brooklyn nursing home. 'She had a good death,' a hospice social worker told me over the phone the next day, when I described my time with Sonia. 'A good death is good for everyone.' As I left the nursing home and walked out into the stunning heat of the July day, I was struck by the contrast between the acute mystery of dying, and the banal settings and circumstances in which it usually takes place. As my physician friend Liz said to me once, from a clinical standpoint, a good death is usually anticlimactic. 'Whatever is happening for the person internally, spiritually, you're not going to see,' she said. 'But when a death is going badly, you know it.'

Still, in a world as heterogeneous as ours, can there be one *ars moriendi* that fits all? Can we safeguard the common denominators of good care and still accommodate wide-ranging individual choice? **Ironically, hospices and palliative care teams – entities that grew out of a deep desire to mitigate the suffering of dying people – have come under fire for being too rigid and unimaginative in their views and rhetoric. Just because someone is dying in hospice care doesn't mean they want to talk about it. Nor should be expected to articulate how they might hope their deaths to be.**

[Brendan: What do you think of this criticism?]

Some argue that the Western psychological approach to good death leaves out the myriad social, ethnic and religious currents that make up our global civilisation. The anthropologist James Green, whose book *Beyond the Good Death* (2008) has become a primer for the burgeoning number of college courses on death and dying, has no use for Kübler-Ross's stages, which he sees as far too narrow and culture-bound. Since retiring from academia, Green has worked as a hospital chaplain in Seattle, a vocation he says has proved to him that 'a white, middle-class model for dying is not a universal model. Not everyone is looking for some happy contentment and growth. The ending of suffering may not be what they're looking for.'

Certainly, there are plenty of faith traditions in which enduring suffering is seen as an indispensible part of dying, a source of honour and the key to salvation. Take the poet and undertaker Thomas Lynch whose mother, a devout Catholic, was determined to emulate the passion of Christ as she died. 'She refused the morphine and remained lucid and visionary', offering her pain 'up to the suffering souls', writes Lynch in *The Undertaking: Life Studies from the Dismal Trade* (1997). 'I'm not certain it works – only certain that it worked for her.'

Other people, for whom a room full of hovering caregivers or worried relatives would be the antithesis of a good death, might prefer to die alone, undistracted by the pull of the living. At the time I began writing this essay, my 83-year-old uncle died, after breaking two ribs and then contracting the flu in hospital. He had fallen and lain on the floor of his apartment for two days, likely in considerable pain, before anyone found him. It sounded bad, but he had decided he was ready to go, and this was his opportunity for exiting, on his terms. The truth of that was borne out by the affection and goodwill he showed his family at the end, and which infused his joyful memorial service.

Nowhere is the issue of choice in constructing a good death more fraught than in the discourse around the 'aid in dying' movement and the passage of laws, such as one ratified in Oregon in 1997, or another recently debated in the British House of Lords, that allow doctors to prescribe a lethal dose of medicine to a terminally ill person who wants to hasten her own death. Remarkably, less than half of dying people who obtain lethal drugs end up using them. 'That's the palliative effect of choice,' says Coombs Lee. 'People experience improved quality of life when they have the means to avoid their worst nightmare.'

Needless to say, it's extremely hard to maintain control, autonomy and independence when we're approaching the end. The one strategy for getting to a good death that everyone seems to agree on is advance planning – planning now – while we are still alive and cogent. 'One should be ever booted, spurred and ready to depart,' wrote Michel de Montaigne in the 16th century. In arranging temporal things – making wills, assigning health proxies, researching and sharing our wishes for end-of-life care and for the preparation and disposition of our own bodies – we can hedge our

bets for dying as we want and avoid burdening our caretakers with heavy, confusing decisions when we can no longer make them. More than 70 per cent of people in the US, for instance, say they want to die at home, but more than 80 per cent end up dying in hospitals and nursing homes, in part because no advance directive made those wishes known.

Putting our worldly affairs in order can also make it easier to drop the attachments and anxiety that muddle the mind as we approach death. But even the best-laid plans can be torn asunder, or overlooked. Death is unpredictable and prone to disruptions, even when papers are in order, or when a hospice has been brought in. There can be unwanted medical interventions, misunderstood directions. We might be too demented or impaired to know what's happening. We might die suddenly – violently – hit by a car or in cardiac arrest, without what the psychologist Ronna Kabatznick calls, in reference to post-tsunami Thailand, 'the privilege of transition' – a deathbed, a chance to say goodbye, a body to mourn over.

If my experience with hospice care has taught me anything, it's that the only way to ensure some measure of wellbeing at death, given all that can go awry in the time leading up to it, is through developing an inner strength that cannot be shaken by the demise of the body, by the loss of all that is dear to me, or even by pain. Looking back on my enduring childhood obsession with dying well, it's no surprise that I would jibe with this view. Buddhism teaches that we can attain a reliable, *deathless* happiness through the cultivation of discernment, ethics and meditative concentration. **Apprehending the unavoidable truth of impermanence – that we are of the nature to get sick, grow old and die, that all things arise and pass away – might be the ultimate groundwork for dying.**

[Brendan: How would you describe the "meaning" of this quote in your own words? Do you think it is accurate?]

Over the course of several years, I sat with dementia patients receiving hospice care at a down-at-heel nursing home in Manhattan. Few of the dying people I met there seemed to have family or friends who visited regularly, and for the most part, it was impossible to know their plans for death, or if they'd had any. Most seemed lonely and anxious. A man in his seventies, whom I shall call Mr Pollard, appeared to be on a brutal psychic treadmill, reawakening, moment after moment, into panic, not knowing where he was or how he'd gotten there. He would relax a little when I held his hand.

Of course, improving the circumstances and care of the sick, old and dying – doing what we can to ensure people get the good death they want – is critical; a humanitarian revolution that has yet to take place. But most of the circumstances of our deaths are ultimately beyond our control. Any one of us could be Mr Pollard. It could be me sitting in a drenched diaper with the TV blasting. It could be me having food shovelled in my mouth when I don't want to eat. It could be me asking for morphine when I'm wracked with pain and hearing I'll have to wait two hours for the next dose. The only thing that is within our control is inside. To die contentedly like that, in a dingy room with no privacy, filled with indifferent strangers, will take serious inner work. If I can get that 'thing' from the meditation, it will be the most reliable medicine I can have, accessible whenever I need it, when all else fails. As I see it, it's the only hope for the good death I want – unburdened, unafraid, mindful.

5 CASE STUDIES: END OF LIFE CARE (BY ELIZABETH MENKIN)[15]

The following cases are from the Markulla Center for Applied Ethics.

[15] Elizabeth Menkin, "End-of-Life Decision Making," Markulla Center for Applied Ethics, August 25, 2015, https://www.scu.edu/ethics/focus-areas/bioethics/resources/conserved-patient/end-of-life-decision-making-case-1/.

5.1 CASE 1

Mrs. Doe is conserved because of her severe dementia and has been a nursing home patient on Medi-Cal for more than five years. She has no family and left no written instructions about her health care wishes. In the past two years, she has become unable to walk or to follow any simple commands. She has not spoken in months. During the past year, she has required spoon-feeding, and she has been taking progressively longer to eat each meal. Because of episodes of coughing and possibly choking, her diet has been changed to puree with thick liquids. She still seems to prefer some foods, and the staff can tell you which foods she will usually spit out. She has been hospitalized twice for pneumonia in the past year but has recovered without needing ICU treatment.

One Saturday evening, Mrs. Doe is congested. She begins running a fever, and her breathing seems labored. The nursing home staff calls 911 and sends the patient to the hospital. The emergency room physician consults with the internist and the pulmonologist, and the patient goes to the intensive care unit. She is intubated and put on a ventilator. After two days of antibiotics and vigorous suctioning, she seems to be breathing better, but she has required restraints to keep her from pulling out the breathing tube and sedatives so she does not try to hit the ICU staff.

You come to see Mrs. Doe in the ICU on Monday afternoon. On your way to see her, you get a message that the nursing home has just called you to see if Mrs. Doe will have a feeding tube placed while she is in the hospital. They point out that she has been losing weight and takes so long to eat a meal that it is impacting the staff's ability to get other jobs done. When you arrive in the ICU, the patient is still on the ventilator, and each wrist has a binder that secures her to the bed frame. Although she is somewhat sedated, she seems uncomfortable, and there is still an aura of panic that penetrates her drug haze.

5.1.1 Review Questions

The ICU physician is glad to see you because he has lots of questions about what happens next with the patient.

1. Is she is "full code"? Should they "do everything"? - i.e., should she be resuscitated if she suffers a cardiac arrest?
2. Do you give permission for them to continue to restrain her arms so that she does not pull out the tubes?
3. Can the nursing home do IV antibiotics?
4. Will the nursing home accept her back if she overstays her seven-day bed hold?
5. Will she be transferred back to the hospital again for her next bout of pneumonia?

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5.2 CASE 2

The public guardian has just been granted healthcare decision making power for Ms. Long, a 78 year-old woman with severe dementia, diabetes with impaired vision, and poor kidney function, recent recurrent pneumonia, and prior strokes. You are seeing her for the first time in a skilled nursing facility. She was transferred there yesterday following a four-month hospitalization.

When you arrive at the skilled nursing facility to see Ms. Long, she looks very thin, and the nurse tells you that there is a large necrotic pressure sore on her sacrum. The aides are repositioning her so that the speech therapist can do her evaluation. There is an IV running fluids in the patient's left arm, and her right arm lies limp on the bed. Some of the time she seems to look at a face and track movements, but sometimes not. She does not give any answers to simple questions, either verbally or with nods or shaking her head, and does not consistently look at the person who is talking to her. She does not give any social smile in response to the speech therapist's attempts to engage her. You notice that the patient grimaces when she's moved, and cries in apparent pain when she is rolled on her back. She

opens her mouth when offered a straw but does not suck on the straw. She takes a small amount of ice cream that is offered by spoon, but after two more tries by the speech therapist she pushes it away and slaps using her left hand.

5.2.1 Review Questions:

1. Is Ms. Long terminally ill?
2. What are the treatment decisions at this point?
3. Artificial nutrition and hydration?
4. CPR / DNAR?
5. On what basis will these decisions be made?