“I am going to start by stating the obvious: you are going to die.”

The speaker, Barbara Mancini, a sixty-year-old blonde dressed in a conservative suit, paused to let her opening statement sink in. She stood at the front of a large auditorium filled mostly with men and women in their sixties and seventies. They had come to attend a public “Death with Dignity” educational event in Chapel Hill, North Carolina, and Mancini was the plenary speaker.

Mancini, a former nurse, had become an advocate for medical aid in dying after helping her terminally ill ninety-three-year-old father overdose on a bottle of morphine, at his request. In a television interview with Anderson Cooper on 60 Minutes in October 2014, Mancini said, “He asked me to hand him the bottle and I did. I had the dosing syringe in my hand, and he took the cap off, and he drank what was remaining in the bottle.”

What followed was a horrifying sequence of events that rattled Mancini even in retelling them two years later. She told the hospice nurse what she had done, the nurse called 911, and her father was treated for an overdose. Mancini was arrested and charged with abetting an attempted suicide. At the hospital, her father was declared incompetent, and it fell to her mother to decide whether to treat the overdose (which he clearly did
not want), or to let him die, which would have been worse for Mancini’s legal case. Her mother chose the former. Her father was irate, telling the hospital staff not to hurt his daughter. He died four days later of pneumonia. A yearlong prosecution ensued, during which Mancini amassed thousands of dollars in legal fees and was forced to take unpaid leave from her job until a judge finally dismissed the case. In the aftermath, Mancini became a staunch advocate for Compassion & Choices, a national non-profit organization committed to expanding end-of-life choices.

At the end of her account, Mancini offered the audience three takeaway points: (1) end-of-life care should align with the patient’s values, preferences, and wishes; (2) this could happen again; and (3) medical aid in dying should be an option. Her closing line, “Who gets to tell you how you will die?” was met with a standing ovation.

How did American society get to a place where choosing how you will die would seem like an obvious right and a reasonable expectation? How did death become something one does rather than something that happens? And what had prompted this large crowd of seniors to attend this event, even though aid in dying was not a legal option in North Carolina?

Medical aid in dying has expanded rapidly in recent years and has quickly captured the public’s imagination. At the time of this writing, ten jurisdictions permit physicians to prescribe terminally ill adult patients a lethal dose of medication, provided certain preconditions are met, making this end-of-life option legally available to one in five Americans. Similar legislation is under consideration in many additional states, and is expanding to new groups of patients in countries like the Netherlands and Belgium, which have longer histories with assisted death. This growing sociopolitical movement heralds the possibility of a new era of choice in dying, motivated by a desire to control the timing and circumstances of death and avoid dependence on others. Yet social studies of medicine have repeatedly demonstrated that the realities of policies in action often fall short of advocacy visions, raising questions about how much choice and control aid in dying actually affords.

Advocates like Barbara Mancini presume a straightforward path, in which a terminally ill patient desiring to hasten death requests assistance from a trusted physician, who will accede to the patient’s wishes. If only
medical aid in dying had been a legal option in Pennsylvania, Mancini wants us to believe, much of her father's end-of-life suffering could have been avoided. Yet this narrative overlooks the many roadblocks to accessing aid in dying in states where it is legal, including identifying a physician willing to prescribe, paying for the medication, and following a complex bureaucratic protocol to ensure all of the legislative safeguards are met. Mancini's father might have been able to navigate these challenges with the help of his daughter, who, as a nurse, was experienced with the health care system. However, this book treats his ability to do so as a starting point for investigation, rather than a foregone conclusion, as the advocacy narrative suggests.

Until now, very little has been publicly known about how medical aid-in-dying laws affect ordinary citizens once they are put into practice. This book offers an in-depth account of how patients, caregivers, and health care providers navigate aid in dying as a new medical frontier in the aftermath of legalization. It chronicles two years of research I undertook to document the implementation of Vermont's 2013 Patient Choice and Control at End of Life Act. My primary research materials are interviews with 144 Vermont patients, caregivers, health care providers, activists, legislators, and other policy stakeholders, as well as participant observation in advocacy and educational events and professional medical conferences.5

Between May 31, 2013, and June 30, 2017, paperwork for fifty-two individuals using this law was filed with the Vermont Department of Health. Forty-eight of them had a death certificate on file, of which twenty-nine had ingested the lethal prescription as of January 2018. Of the remaining individuals, seventeen died from their underlying disease, one died from other causes, and one had an unknown cause of death.6

The most common diagnoses were cancer (43) and amyotrophic lateral sclerosis (ALS) (7). While these absolute numbers are relatively low, they correspond with utilization rates from a twenty-year report of Oregon's Death with Dignity Act, which found that 64 percent of those who had received a prescription ultimately ingested the medication and assisted deaths accounted for nineteen per ten thousand total deaths.7

These utilization statistics underscore that, although medical aid in dying has captivated the public's imagination over the past twenty years, only a small segment of American society is likely to experience it themselves. This
is a matter not only of personal preference but also of eligibility, including having one of the diagnoses better suited to medical aid in dying. Roughly 25 percent of people in Vermont, and 23 percent in the United States overall, died from cancer between 2009 and 2018; for ALS, the figures were 0.4 percent and 0.2 percent, respectively.  

At the same time, the cultural impact of medical aid in dying stretches much further than these numbers suggest. Studies from the Netherlands and Oregon demonstrate that it is discussed far more than it is performed, and that it can serve as a gateway for conversations about other end-of-life concerns. As I will describe in this book, my own research supports such findings, as many health care providers shared how questions about aid in dying had opened up larger discussions of patients’ hopes, desires, and fears surrounding the dying process, or other ways of hastening death, such as through voluntarily stopping eating and drinking. Therefore, the significance of legalization for the culture of death in America is much greater than the number of reported deaths implies: it changes the conversation about control over dying and invites new ways of thinking about scripting death.

In the pages that follow, I illustrate how medical aid in dying enables some terminally ill people to exercise agency over death against a backdrop of existential uncertainty, bureaucratic regulation, and the biomedicalization of end-of-life care. However, this opportunity to "script" one’s death is not evenly distributed but instead favors individuals from more privileged socioeconomic backgrounds. Two interlocking premises of the book, therefore, are that scripting death distributes agency over the dying process and certain people have more control over dying than others.

Medical aid in dying is known alternatively as physician-assisted suicide, physician aid in dying, and death with dignity. A politics of language underlies these choices: proponents find the language of suicide offensive and inaccurate (because terminally ill proponents very much want to live), while opponents view "aid in dying" as euphemistic and misleading and assert that there are many other ways to die “with dignity.” (“We have death with dignity,” one hospice nurse told me. “It’s called hospice.”) While I was working on this project, proponents in the United States deliberately shifted their terminology from physician-assisted death to aid in dying or medical aid in dying to decenter the role of physicians. To further
complicate matters, outside of the United States, *aid in dying* is an umbrella term that may include physician-administered medication (widely known as euthanasia) and patient-administered medication (widely known as assisted suicide), whereas, in the United States, only the latter is legally permitted and thus denoted by this term. In Vermont, many patients, clinicians, and policy stakeholders avoid the language of death entirely and refer to the Patient Choice and Control at End of Life Act as simply Act 39. One hospice employee told me that advocates chose this language intentionally, to avoid alienating opponents.

This fraught language has presented me with a conundrum in writing this book. The labels used to describe this practice unavoidably signal meaningful social, political, and moral values for advocates on both sides of the debate. I have tried to maintain a neutral stance on the ethics and politics of assisted dying, and I remain quite ambivalent about the practice, as I explain further below. I have chosen to use the term *medical aid in dying* out of deference to proponents, for whom the stakes of avoiding suicide stigma are more consequential, in my view, than the moral stakes of their opponents. I recognize the consequence of this choice: that some readers will see this language as expressing a bias. However, it is a choice increasingly made by professional medical societies, and one that I believe reflects a shifting public conversation about terminal illness and gaining control over death.

**scripting death**

The desire for control over dying is a powerful cultural force in contemporary American society, but it is not universally shared. Brenda Jones, a Vermont hospice and palliative care physician, explained to me that control over death is a bit like control over birth. Just as many expectant mothers today create elaborate birth plans, she said, “There are people who want to script the whole thing as best that they can. And others are kind of like, ‘Well, I’m just going to see what happens.’” Although it would be several years before I realized it, Brenda had handed me the title for my book.

Anthropologists and cultural observers have long recognized that pregnant women in the United States often seek control over the uncertainty
of childbirth through meticulous planning, yet the notion that death may likewise be scripted has been less fully explored. Like birth, whether or not one desires to script death is shaped by a range of social factors, such as religion, race, and class. It may also depend on individual characteristics, such as personality and family background, and circumstances, such as diagnosis, prognosis, and the anticipated mechanism of death. Some who seek to script their deaths follow a nonmedical path. One activist I spoke with was adamant that, if things got to a certain point, she would simply have her daughters push her into a moonlit lake in a leaky canoe. (Drowning, I learned while working on this project, can be a relatively painless way to die. Whether or not her daughters would acquiesce to this plan is another matter.) Similarly, the nonprofit organization Final Exit Network supports “safe, certain, painless and peaceful methods for self-deliverance,” such as self-asphyxiation with helium.

Yet many who seek to script their deaths crave the cultural legitimacy of a legally and medically authorized form of hastened death. In exploring such desires, I use the term aspirational death to signal the aesthetic, affective, and ethical preferences that inform orientations to dying as a matter of personal choice and careful choreography. Aspirational deaths form in relation to culturally specific, idealized notions of what constitutes a “good death.” For example, in many societies, a death that is foreseeable is generally considered to be good. In contrast, a death may be labeled bad if it is traumatic, unexpected, or comes to someone who is too young. The activist who imagined being launched to her death in a leaky canoe was reacting to her father’s death, which was nothing like what he had wanted. “It was tragic, and it was awful, and it disrespected who he was as a human being,” she told me. He had planned everything out, from his funeral arrangements to his intended self-asphyxiation using a garden hose and an exhaust pipe. But in the end, he was diagnosed with a debilitating form of cancer four days before he died and spent his last days bedridden. “Having seen a bad death,” she explained, “you kind of start envisioning what you would like to have happen when you are ready to go.”

Understandings of the good death make use of cultural scripts for dying, mental models, or templates for dying well that vary culturally and historically. In many cases, cultural scripts for dying are shaped by religious frameworks that imbue suffering with meaning and orient the dying
person and mourners toward preparation for the afterlife. In contemporary Western societies, however, the growth of secularization has led medicine to replace religion in assuming institutional control over death.\textsuperscript{18} The term \textit{aspirational} also suggests that the desired form of death may be out of reach or unattainable. In the case of medical aid in dying, this might be a result of living in a state where it is not legally authorized, being unable to find a physician to write the lethal prescription, or failing to meet the statutory requirements (e.g., mental competence, a six-month prognosis, or the ability to self-administer the medication).

By posing scripting as a central analytic concept for understanding human control over death, I play on several distinct meanings of scripts, including norms or expectations for behavior; protocols and procedures that order work processes and institutional practices; and written documents, such as written prescriptions for medication. Scripts, as textual documents, make explicit those practices or routines that might otherwise go unnoticed, and help to outline the possible consequences when processes are laid out in official documents, such as laws or hospital policies. Scripting also encompasses staging or choreographing death to fulfill preferences about how, when, where, and with whom one dies. One ramification of scripting death, therefore, is making tacit the aspects of death and dying that might otherwise go unstated—such as the tendency for bodies to expel fluids as they cross the threshold from life to death. At the same time, because scripts go only so far in determining action and events, the concept also invites questions about how people improvise when things do not proceed as expected.\textsuperscript{19}

\textbf{CONTROL AND AGENCY IN DYING}

Social scientists have traditionally investigated expanding human control over death and dying through the lens of technology and its presumed threat to nature. Technological progress in medicine over the past fifty years has led to increasing societal debates about how people understand the boundaries between life and death and the prolongation of life through biomedical technologies.\textsuperscript{20} The cultural legacy of controversial decisions regarding families’ rights to discontinue mechanical ventilation (such as in
the case of Karen Ann Quinlan) and artificial feeding (such as in the case of Terri Schiavo) is that death has become something that can be controlled through human intervention, and not merely something that happens.

Nowhere has the struggle for human control over death been more culturally and ethically fraught than with the concept of brain death. The concept was adopted in 1968 by a Harvard University committee tasked with considering potential criteria to define the permanent and irreversible cessation of brain function. Two technological developments in medicine precipitated their charge: the development of intensive care medicine and the expanded use of mechanical ventilation, and the advent of organ transplantation. Introducing neurological criteria for death meant patients could be declared dead while a ventilator maintained their lung function, keeping vital organs and tissue "alive" and available for procurement and transfer to people in need. Subsequently, because the patient was effectively dead, mechanical ventilation could be stopped.

The introduction of neurological criteria for death responded to a pressing practical need and the laudable policy goal of increasing the supply of vital organs for transplantation. Yet it also introduced conceptual problems. As the anthropologist Sharon Kaufman has written, “With a ventilator, one could be declared dead while still appearing to be alive. It was a radical stance that gave rise to an unintended, unprecedented question that continues to haunt us: was the body, pronounced brain dead and connected to a breathing machine, actually alive or dead? No longer would dead mean dead. Death was in this sense doubled.” In addition to this crisis of meaning, the scientific logic of brain death has been challenged over time. Patients who meet the criteria for neurological death may retain a range of vital functions (such as sexual maturation and wound healing). This flies in the face of the judgment that they are in any sense dead and makes easy demarcations between person and corpse difficult.

While scientists have grappled with uncertainty regarding the boundaries of biological life, social scientists have recognized that the cessation of biological life may not always coincide with the social death of the person—that is, a loss of one’s identity, social roles and activities, and social connectedness that results in their being treated as less than fully human. In her ethnography of euthanasia in the Netherlands, the anthropologist Frances Norwood suggests that seeking an assisted death
enables people to avoid a situation in which social death precedes the biological death of the person. Because the extended use of life-prolonging technologies may lead to social death, it may be tempting to view medical aid in dying as offering salvation from the modern scourge of technology. Indeed, when asked to described bad deaths, many health care providers invoke technology, such as the nurse who recounted the following:

We had a gentleman who had had a massive stroke and was on a ventilator and really, no hope of him recovering. And his son, for whatever reason, didn’t want to let him go. And who knows why. No idea what the history was there. But we basically chemically coded this gentleman for five days, and because it’s a teaching facility they did a lot of stuff on him. You know, they put chest tubes in, and they drained his abdomen, and I just felt so bad for that man, who had no voice to say if he wanted it or if he didn’t want it.

Owing to stories like these, some sociologists have suggested that the assisted-death movement reflects a crisis of faith in biomedicine as the lynchpin to end-of-life care. From this perspective, medical aid in dying poses an antitechnological solution to redress the problems wrought by technologically mediated hospital deaths.

However, it would be a mistake to view the assisted-death movement as simply a reaction to the growth of medical technologies and their expanded role in controlling death. The historian Shai Lavi has shown that efforts to legalize euthanasia in the United States can be dated to the early twentieth century and preceded the advent of contemporary biomedical technologies. Lavi argues that the growth of life-prolonging technologies and the euthanasia movement were both products of a broader Enlightenment desire to master the dying process. Therefore, as the anthropologists Naomi Richards and Marian Krawcyzk recently argued, life-extending and death-hastening techniques are “two sides of the same coin,” and both “can be understood as manifestations of a Western denial of dying.”

A fundamental proposition of this book is that scripting death through medical aid in dying fundamentally alters dying by permitting people to control its trajectory—for example, by shortening the dying process or sanitizing it to avoid the “dirty,” the bodily decay and deterioration that accompany natural death. Yet it also permits people to control the cultural and personal meanings of death. Staging an aspirational death that includes
being surrounded by loved ones and saying heartfelt goodbyes enables people to imbue death with a sense of continuity and coherence with one’s life as lived, avoiding the sense of painful rupture that often comes with dying. This distinguishes medical aid in dying from other attempts at controlling death, such as writing advance directives for end-of-life care.33

Pairing agency with control as constitutive components of scripting death underscores how pursuing assisted death can be seen as the ultimate enactment of independence and personal choice. If control represents the desired effect, agency is the pathway through which it is realized. Agency is closely related to the bioethical concept of autonomy: the ability to make decisions about one’s body and the freedom to do so. To simplify a lively set of bioethical debates, proponents generally maintain that assisted-dying laws promote autonomy by expanding the range of possible choices that a terminally ill person can make and providing them with control over the timing and circumstances of death. In addition to retaining autonomy, avoiding dependence on others at the end of life is a key motivating factor. This set of reasons for pursuing assisted death contrasts with popular presumptions about the role of pain, sidestepping challenges to legalization that fixate on the inadequacies of palliative care. The growth and expansion of hospice and the hospice Medicare benefit, which pays for hospice services for Americans over the age of sixty-five, has improved pain control at the end of life over the past several decades.

While it is hard to deny the importance of autonomy to the assisted-death movement, while I was working on this book, I became curious about how it dominated the public conversation about medical aid in dying. Consider Compassion & Choice’s slogan: “My life. My death. My choice.” Where, in this formulation, is the physician, who is expected to write a prescription to satisfy the speaker’s autonomous wishes? What about the speaker’s family? Moreover, in an unequal and stratified society, who has the capacity to make such a choice? However powerful the desire for personal control over death may be, it must also be balanced against other values and sociopolitical forces in an interdependent world.34

For anthropologists, agency—which I define broadly as the capacity to act with intention—is always located within larger social relations and systems of power.35 Sherry Ortner suggests that people use agency to pursue cultural projects “that infuse life with meaning and purpose.”36