

ONE

Holding Life and Death in Their Hands

It is 6 A.M. The critical care resident checks on one of his patients before morning rounds and encounters ten angry family members encircling the unresponsive patient's bed, livid that he had been intubated (had a breathing tube inserted into his airway) and attached to a ventilator in the middle of the night. The patient, a seventy-six-year-old white man and former purchasing agent, had been admitted to the hospital for a relatively minor stent (drainage tube) procedure and to explore his eligibility for a liver transplant. He had previously designated his wife power of attorney for health care and documented that he did not want to be resuscitated or intubated.

The previous day, tests had revealed that the patient had liver cancer and would probably not be eligible for a transplant. Late that night the patient experienced breathing difficulties, and the medical team asked for his consent to be intubated and placed on a ventilator. At 3:25 A.M. the patient, alone in his room in the intensive care unit (ICU), had consented.

Two hours after the hostile encounter in the patient's room, the critical care team—an attending physician, fellow, and two residents—arrived for morning rounds. As he examined the patient, the attending physician spoke to the assembled family.

CRITICAL CARE ATTENDING: I'm going to look at his heart and lungs, and then I know you have concerns about the vent [ventilator].

WIFE: Pull the plug.

DAUGHTER-IN-LAW: This is not what he would have wanted.

CRITICAL CARE ATTENDING: Would he feel differently if he was able to potentially get a transplant?

DAUGHTER-IN-LAW: No.

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CRITICAL CARE ATTENDING: If the cancer is confined to his liver, they wouldn't rule him out as a transplant candidate. It's a long shot, I'll be honest. But they haven't ruled him out yet.

WIFE: I thought they found fluid in his abdomen and so he can't get a transplant.

CRITICAL CARE ATTENDING: They haven't told us that he's definitely not a candidate.

WIFE: Just pull the damn plug!

CRITICAL CARE ATTENDING: See, we're in a bit of a bind. He told the nurses last night that he wanted to be intubated, and in effect retracted his living will. But sometimes when people are in distress they'll make decisions differently. You don't think this is what he wanted?

WIFE, DAUGHTER-IN-LAW, DAUGHTER, AND TWO SONS: [In unison] No.

DAUGHTER-IN-LAW: He talked about this at length with me in the last three months. He told me in detail what he wanted. It's not this.

WIFE: I think he was just frightened.

DAUGHTER-IN-LAW: Yes, I think he was scared. He thought he was just coming here for stents for his liver. Now he's on pressors and Levo [life-supportive medications].

CRITICAL CARE ATTENDING: We'll have to consult with our ethics committee to make sure that we're doing the right thing—that we're following his wishes.

DAUGHTER-IN-LAW: Yes, we understand.

CRITICAL CARE ATTENDING: We'll talk to Ethics and the nurses who were here as soon as possible to get their thoughts. Unfortunately, during the night, things sometimes are complicated because the primary team and the family aren't around.

The critical care team then consulted the chair of the hospital ethics committee to determine whether the patient's wife was permitted to reverse the patient's decision made just hours earlier. The physicians and nurses who had cared for the patient overnight and had secured his consent to be intubated were consulted as well. Physicians also reviewed instructions in the patient's power-of-attorney document. At 10:30 A.M. the critical care team removed life support and initiated comfort measures. The patient died around midnight.

It is unusual to hear the expression "pull the plug" in a hospital, let alone observe loved ones demand so quickly and decisively that physicians do so. More often families beg physicians to do everything possible, even when

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all hope is gone. The family of a second ICU patient shows the lengths to which loved ones may go to ensure that the plug remains securely in place. The immediate and unequivocal insistence of the first family to remove life support is matched by the unrelenting and fierce resistance to doing so by this second family. And the justifications for their decision look entirely different from those articulated by members of the first family, who stood in the patient's shoes and reprised his instructions and conversations.

The second patient is a fifty-five-year-old Middle Eastern man from a Christian denomination who immigrated to the United States in his late teens. He works in real estate. While doing pushups at home, he collapsed and had a seizure. He was taken to a small neighborhood hospital, which found that an aneurysm (a weak bulging in the wall of an artery that supplies blood to the brain) had ruptured. Initially talking and moving, the patient suffered another seizure and lost consciousness. He was airlifted to a second hospital, which administered life support and other interventions, but an exam suggested possible brain death. The patient's family transferred him to a third hospital, seeking a second opinion and a lifesaving intervention. Arriving at 1 A.M., the neurosurgeon on call explained to family members that an intervention was not appropriate and that another brain-death exam would be administered in the morning. The next morning the senior neurosurgeon on the case explained to the patient's family that the results were consistent with brain death.

NEUROSURGERY ATTENDING PHYSICIAN: The doctors have done an exam and I have reviewed all the scans. His brain is dead. His heart is only beating because we are giving it medication. He cannot think, cannot talk, cannot see, cannot hear.

SISTER: Give it more time to see if it comes back.

NEUROSURGERY ATTENDING PHYSICIAN: It cannot come back. It is destroyed. There is no blood going into the brain. . . . If there was a one in a million chance, I would do something. . . . Twenty to fifty percent of people with aneurysms do not survive. I do aneurysms, hemorrhages, brain trauma. This is what I do. If there is anything I could do, I would do it. If there was a one in a billion chance, I would do something.

WIFE: I believe in miracles.

NEUROSURGERY ATTENDING PHYSICIAN: I believe in miracles too. But I deal in facts. His brain is completely dead.

WIFE: They said something about a nuclear flow study [a scan that measures the amount of blood flow in the brain].

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NEUROSURGERY ATTENDING PHYSICIAN: If you want that, we can do that.

WIFE: If there is even minimal flow, there is still hope. I was a doctor for four years. I know that things can happen. You don't always know what will happen.

About a half hour after the meeting ended, a senior neurologist arrived to perform a different kind of brain-death exam in the presence of the family. As he performed each step, he told the witnesses what he was doing. He shined a flashlight in the patient's eye and explained that he didn't see any reaction to light. He asked for permission to turn the patient's head to see if his eyes move. He explained that they didn't. He said that he will pinch the patient's fingers to see if he responds to pain. He noted that the patient didn't. He explained that he will put some cold water in the patient's ear to see if his eyes move. The neurologist inserted the water and said that it can take as long as a minute. Everyone in the room was riveted, staring at the patient's eyes, but they don't move. The patient's mother began shaking her head no. The neurologist put cold water in the other ear, again with no response. He then sat down beside the patient's wife and explained that, once again, the exam indicates brain death.

As they await the results from the nuclear flow study, fifteen family members begin filing in and out of the patient's room. Many are in tears. Others are screaming at the patient to wake up and commanding, "Don't do this to us!" As the hours tick away, visitors continue to implore the patient to wake up and open his eyes. "C'mon, it's time to wake up!"

The results from the flow study finally come back. The critical care attending physician escorts the family to a conference room. He hands a copy of the report to the patient's sister, who passes it to her brother and then to the patient's wife. They each slowly read the report. The physician explains that the report is absolutely clear; you can see it for yourself. "The scan shows that there is no flow to the brain. It is unequivocal. This confirms what we have known all day from the various tests that we have done—that he is brain-dead. Brain dead means that we can no longer treat him." Family members begin to protest that they need more time, and the patient's brother explains that they believe everything the physician said, but they need to be sure. They need to know that they have done everything that they can for him. As the resistance continues, the neurosurgery attending enters the room and declares, "I have just reviewed the last set of scans. The brain is entirely dead and the blood vessels in the brain are all empty." As the family files out of the room, the critical care attending tries negotiating with the patient's wife: the team will continue to treat the patient, but there

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will be no escalation of treatment, including resuscitating the patient if his heart should stop. The wife agrees.

The next morning the patient's sister arrives to rescind the do-not-resuscitate agreement, request that physicians give the patient Ambien (a sleeping pill touted on the Internet to reverse brain damage), ask for the name of the hospital's lawyer, and explain that the family hopes to transfer the patient to another facility and a better neurosurgeon. The nurse manager of the ICU responds that he will arrange a family meeting.

SISTER: We did that yesterday and we weren't happy with it.

NURSE: The patient is brain-dead. That means he is dead. Because he is dead.

We cannot in good conscience send a dead patient to another facility. He is dead. He has passed. There is no blood flow to the brain.

AUNT: We don't believe it.

SISTER: People come back.

NURSE: But he has no blood flow to the brain.

SISTER: We know of another situation exactly. No blood flow and the guy comes back.

Some family members tell the hospital chaplain that the patient's fate is in God's hands and that they wish to give God every opportunity to restore the patient to health. God will decide. Others continue to argue with various members of the health care team that they do not believe the diagnosis. They cite anecdotal stories of individuals written off as brain-dead who are now alive and fully functional. Their goal is to keep the patient alive while they locate another specialist or institution that can perform a lifesaving intervention, a miracle. They will not give up until they find someone—whether at the Mayo Clinic or in London—able to do the intervention of which physicians in this hospital are incapable. They bring a lawyer to the hospital to ensure that physicians do not remove the patient's life support before they have an opportunity to transfer the patient elsewhere. Dubious that the family can arrange a transfer, the medical team nonetheless agrees to give them time to try to do so, although nurses and other physicians privately complain to one another about their discomfort and moral distress in treating a dead patient.

The next day, to the amazement of the health care team, an outside neurosurgeon agrees to treat the patient, and a local facility agrees to a transfer. (Just hours earlier an ICU nurse had confidently declared to his colleagues that, if any facility agreed to take a dead patient, he would quit his job.) ICU doctors prepare the brain-dead patient, his organs rapidly failing, for

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the risky ambulance ride to the new facility. A few days later, a death notice for the patient appears in the local newspaper.

Many of you probably cannot imagine yourself standing in the shoes of a member of either of these two families—deciding as they decided, as quickly or resolutely, or for the reasons they expressed. Some of you may not even realize how very likely it is that someday you too will stand at the bedside of a loved one facing wrenching life-and-death decisions on his or her behalf. And perhaps others of you are horrified to think that what happened to one or both of these patients could happen to you.

You are in good company. This book shares the very different stories of roughly two hundred other intensive care unit patients and how their families and friends negotiated medical decisions on their behalf. Like the first patient, many had preexisting medical problems, some of very long standing. Some patients were in the ICU for an elective procedure or second opinion; a few flew across the country when local physicians offered little hope. Others experienced complications—*infections, respiratory problems, cardiac arrests, strokes*—from unrelated medical procedures performed elsewhere in this or another hospital. And, like the second patient, for many the symptoms came out of the blue. They were at home, at work, in a public place, or engaged in sports when they collapsed, suffered a seizure or the worst headache of their life, or exhibited slurred speech, weakness on one side, or confusion. And others were transported to the ICU after a fall, accident, or assault.

The unfortunate patients in these stories are current or former doctors, nurses, lawyers, teachers, bus drivers, farmers, bookkeepers, construction workers, factory workers, business owners, musicians, performers, security guards, architects, salespersons, homemakers, honor students, and likely drug dealers. They are celebrities and street people. They are young and old, male, female, and transgendered, rich and poor, gay and straight, someone's parent and another's child. They are black and white, Hispanic and Middle Eastern, East and South Asian, Protestant and Catholic, Jewish and Muslim, Jehovah's Witness and Hmong, evangelicals and agnostics. Some live blocks and others thousands of miles away. Some are attended by round-the-clock vigils of family and friends; others languish alone in their room, day after day, without a single visitor.

The patients are as diverse—literally—as the American census.¹ Yet what they have in common is so much more fundamental than mere demographics or the circumstances of their visit. Whether comatose, nonrespon-

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sive, unconscious, sedated, or suffering cognitive deficits or dementia, they cannot speak for themselves. Denizens of intensive care units offering the highest-tech interventions that modern medicine has invented, they lack the capacity to direct their care—to embrace or refuse surgeries, procedures, medical devices, medications, or life-sustaining treatments that might cure their disease or relieve their symptoms, extend their lives or their suffering, restore their quality of life or destroy it, cheat death or sentence them to a fate worse than death. The biggest life-and-death decisions of their lives—literally—had to be made by someone else.

Hospital records will tell you that more than half didn't make it out of the hospital alive—nine in ten of them, because someone directed physicians to stop aggressive measures. They will document what procedures were performed or tally the many millions of dollars collectively paid for that care. This book will tell a different story. I look beyond the hospital bed and gaggle of white coats administering to unresponsive bodies secured with a tangle of lines, tubes, and monitors—activities methodically documented in the medical record and in many other books and articles—to the anxious faces of loved ones hovering nearby, and to waiting rooms and conference rooms and hallways. I tell the stories of these others, without the white coats, who also hold life and death in their hands, however reluctantly. It is easy to forget, in the drama of saving lives, that their stories are often the most decisive. After all, for every patient who died despite their doctors' best efforts, nine others did so at the behest of their loved ones.

Loved ones hold life and death in their hands because Americans' constitutional rights of autonomy and self-determination to make decisions regarding medical treatment are so sacred that they are extended by law to proxies or surrogates authorized to decide on patients' behalf when the latter cannot.² Intensive care units represent ground zero for surrogate medical decision making because of the gravity of the illnesses and injuries they attract and the aggressive interventions they offer. Two studies found, for example, that because so few ICU patients have decision-making capacity, 96–97 percent of decisions to withhold or withdraw life support were made by someone else.³ Although impaired capacity may be commonplace in intensive care units, it is not uncommon elsewhere, especially near life's end. One study found that 70 percent of Americans aged sixty or over requiring decisions about care and treatment in the "final days of life" lack capacity to make these decisions.⁴ Because these numbers are so large, most of us will someday be called on to act as a health care surrogate on behalf of another and perhaps need one ourselves.

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These surrogates who make treatment decisions on patients' behalf often determine the trajectories of life's end: whether patients go to a health care institution at all and what kind; the level of risk or suffering to assume in the hope of a cure; the appropriate tipping point between length of life and quality of life; whether they receive routine treatment, cutting-edge interventions, aggressive care, life support, or hospice care, and for how long; whether they receive comfort care or heroic measures in their last hours; whether they die at home or in a hospital; the disposition of their bodies (organ donation, autopsy, cremation, etc.); and whether their wishes (if they ever expressed any) are honored, forgotten, or betrayed. And they choose between fidelity to patient interests and what is best for themselves or others. Surrogates also control many of the expenditures on health care near the end of life,⁵ much of it, studies find, for unwanted treatment.⁶

Yet despite their critical role for so many near life's end, we know remarkably little about these surrogates, the decision-making process they follow, the choices they make, and the challenges they face. Other researchers have employed various methods to answer some of these questions. Many have presented hypothetical scenarios to healthy would-be patients and would-be surrogate decision makers. Some have abstracted data from medical records. Others have conducted retrospective interviews or surveys of varied informants—decision makers, family members, physicians, and others. And a few have collected snapshots of a meeting or a final decision. Some of the most powerful work has been done by journalists and documentary filmmakers who eschew the scientific method altogether. Typically cherry-picking a handful of compelling stories, too often about white middle- or upper-middle-class families, their accounts necessarily ignore the experience of many. In appendix A, I elaborate on these varied approaches and describe their blinders, limitations, and biases, which led me to look elsewhere to understand how surrogates navigate what could be the end of another's life.

This book offers a very different window on how these end-of-life trajectories take shape and change course—by systematically observing them, day after day, for more than two years. Early each morning, a medical social worker and/or I rushed off to a neurological or medical intensive care unit in a large urban Illinois teaching hospital serving a very diverse population of patients.⁷ Like flies on the wall, we went along on critical care rounds and then hung out in the ICUs throughout the day to observe spontaneous encounters as well as formal meetings between health care providers and families and friends of patients who lacked decision-making capacity. After the meetings ended, we reconstructed (from memory) transcripts of

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what was said and documented characteristics of the meetings and participants, social dynamics, and emotional tone. We also examined patient medical records. Appendix A provides greater detail on our method and on its strengths and limitations.

More than 2500 patients passed through the two ICUs during the research period, some of whom lacked the capacity to make medical decisions throughout their ICU admission. We observed those who spoke on their behalf. These surrogate decision makers faced a host of medical decisions, ranging from whether to undertake surgery or other medical procedures to whether to withhold or withdraw life support or donate the patient's organs. We observed not just the big final decisions documented by so many of the other researchers and storytellers, but also the ongoing conversations and smaller incremental decisions that shaped and constrained the bigger choices surrogates ultimately faced. In all, we observed more than a thousand encounters regarding 205 patients, involving more than 700 of their family and friends and almost 300 different health care providers.

These observations yield rich, detailed accounts of the dialogue between health care providers, families, and others, day after day, as diagnoses and prognoses change; treatments succeed and fail; new interventions become necessary or are exhausted; new medical teams rotate on and off the service; significant others appear and disappear; and families' understandings, goals, and expectations change. We observed how participants make and remake treatment decisions on behalf of patients: the questions they ask, the stories they tell, their statements about the patient, the rationale or justifications they offer, the conflicting understandings or priorities they negotiate, how they make sense of technical or incomplete information and mixed messages they receive, how they balance their obligations to the patient with their own self-interest and the interests of others, how financial considerations or religious and other values come into play, how conflicts erupt and are managed, the role of advance directives and of law in the deliberative process, and how health care providers instigate, frame, and shape the decision-making process. In short, what and how did participants decide? And why do some decision makers authorize one aggressive intervention after the next while others do not—even on behalf of patients with similar problems and prospects?

In this book I tell their stories, drawing on the most extensive observational study of surrogate decision making undertaken to date. The transcripts that I will share throughout the book take you to the private bedside, hallways, and conference rooms to hear, in their own words, pulsing

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with raw emotion, how physicians really talk to families and how loved ones respond, inquire, ignore, regale, justify, plead, or disagree. Their words will often be more instructive than my own, and I encourage you to spend time with them. Still, however exhaustive the portrait I share, this book does not—and cannot—report on all of the many sites and settings in which end-of-life decision making unfolds. But it does open an expansive window on that private world and exposes an extremely diverse collection of participants.

The window opens on the ICU itself, where you will become familiar with the rooms, technology, actors, sights, sounds, rhythms, and routines. Looking behind the privacy curtains, you will meet health care personnel, patients, and especially their significant others. Drawing on examples from the experience of hundreds of patients and families, you will learn of the misfortunes that brought patients to the ICU and the worlds from which they traveled. You will see the arrangements, if any, that they made in advance to prepare for medical decision making on their behalf. You will get to know the friends and family who visit or maintain the occasional vigil at the bedside, the complex tangled family trees from which some travel, the sometimes challenging or contentious struggles to determine who gets to speak on behalf of the patient, and how decision makers come to understand their role and responsibilities.

Now familiar with the setting and the actors, the book turns to the medical decisions themselves that physicians and significant others negotiate. You will hear physicians describe in their own words the varied medical interventions appropriate near life's end; the risks, benefits, uncertainties, and other considerations they disclose as they discourage or seek consent to these procedures; and how loved ones respond and the ways the dialogues unfold—with emotions, misunderstandings, and conflicts on display. Considerations of prognosis—the likelihood that the patient will recover, become disabled, or die—course through these conversations and often play a significant role in how surrogates respond. The book explores prognosis—how it is avoided, framed, conveyed, even negotiated with loved ones—and reveals the silences, accuracy, consistency, and biases to which prognosis is often subject.

The central question of the book can now be addressed. How do loved ones and others make decisions on the patient's behalf? I present the legal and bioethical norms about surrogate decision making and the difficulties of following these norms in the real world, even as so many participants don't even know that they exist. One of those difficulties results from the impossibility of truly knowing another's wishes, another from the conflicts

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of interest that arise at the bedside and are inevitable when loved ones, who have the most to gain or lose, are entrusted with life-and-death decisions. Yet another reflects the cognitive biases that compromise the judgments of physicians and decision makers alike.

Given that decision-making norms are often unknown or difficult to follow, I reveal how surrogates and other friends and family improvise and the decision-making criteria they fashion, sometimes in collaboration with health care providers, sometimes in opposition to them. Again in their own words, I show how loved ones struggle with and justify the excruciating medical decisions they are called on to make on behalf of the patient—from standing in the patient’s shoes or maximizing what’s best for the decision maker (as did the two families who opened this chapter) to avoiding decisions altogether (whether because they are in denial or because they are waiting for the patient to regain the ability to decide or for God to do so), and much more. I uncover the characteristics of patients and families that gravitate to one decision-making strategy or another and what difference choice of strategy makes in the likelihood the patient will survive, the length of hospitalization and likely suffering, or the emotional distress experienced by loved ones. I also provide systematic evidence that advance directives—living wills and health care proxies—touted to enhance patients’ autonomy and to empower their decision makers and ease their burden make almost no difference in the two ICUs.

So what does or could make a difference? The book concludes with lessons learned and proposes steps that readers—whether would-be patients, would-be surrogates or family members, health care providers, health care institutions, legal professionals, or policy makers—might undertake before it is “too late” and even after.

Is This for Me?

If you are still reading this, you may be questioning its relevance. After all, like a significant majority of Americans, you hope to die at home—not in an intensive care unit or even a hospital. But, if you are like more than two-thirds of Americans, your life will not end at home.⁸ Most Americans will spend time in a hospital near life’s end. Almost three-quarters of Medicare enrollees are hospitalized at least once (on average, for eight days) in the last six months of life, 40 percent of enrollees in an intensive care unit. One in five Americans will die in a hospital and one in seven in an ICU.⁹

Intensive care units are not only places to die, of course. Misfortunes

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throughout the life course often require critical care. Many ICU patients are neither elderly nor chronically sick. Half of all the patients admitted to the two ICUs were fifty-seven years old or younger (with average life expectancies of another twenty-five years).¹⁰ For 43 percent of the patients observed, their visit to the ICU came out of the blue. Like many of you, these unlucky patients did not foresee themselves confined to an ICU either.

Moreover, even if you are determined or fortunate enough to escape intensive care throughout your life, this may not be true of those you love. Many of you will spend time in ICUs, not on beds or gurneys, but in waiting rooms and at bedsides, charged with excruciating life-and-death decisions on behalf of another or supporting, challenging, or bearing witness to those who are. Given the prevalence of visits to intensive care units, it is almost inevitable that each of us will eventually find ourselves at the ICU bedside of a loved one. That day may not be too far off, given the relatively young ICU population. Research has consistently found that choosing life or death for another is one of the most difficult decisions of a lifetime and the source of guilt or remorse that can haunt families decades later. This book foreshadows what some of you may encounter at those bedsides as patient, surrogate, or witness and offers an opportunity to question, reflect, and converse with your friends and family before it is too late. Perhaps the most generous final gift one can leave to a loved one is that of information, reassurance, and trust that may help avoid the helplessness, paralysis, guilt, or self-doubt that plague so many families after the patient loses the ability to speak.

Lessons from the ICUs are especially relevant to those of you who serve, counsel, or care for people as they near life's end and their families—physicians, nurses, chaplains, social workers—as well as those training to do so. Some of you may feel that you already know what happens at the ICU bedside. But this knowledge comes from the idiosyncratic prism of your own experience: the kinds of patients or clients you serve and the length and depth of these relationships; the medical problems, prognoses, and treatment decisions unique to your specialty; your own bedside manner; your personal values; and the ways that you interact with patients and their families, present information, offer options or support, and provide or avoid advice. You may not realize just how different these prisms are for some of your colleagues, especially those who serve a highly diverse population of patients—differences that may shape the understandings (and misunderstandings), priorities, challenges, crises, and options faced by the patients, families, and clients that you inherit from or share with them. Drawing on observations of almost three hundred health care providers,

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this book takes you along on their rounds and into their offices and conference rooms as they negotiate life-and-death decisions with those who speak for their patients or clients. Helping families negotiate the end of life is rarely the favorite part of a health care provider's job description. This book shows how others undertake these responsibilities and provides new insight into what families are going through.

For those of you who provide legal counsel, helping clients anticipate the challenges of infirmity or death, drafting documents to protect their interests, or responding at times of crisis, this book will provide a cautionary tale about the efficacy of legal solutions to the challenges near life's end and some suggestions about how you might play a more supportive role.

Finally, scholars, bioethicists, and those who work on health care policy are well aware that surrogates represent a critical black box in understanding outcomes at the end of life and efforts to change the American way of death. If seven in ten Americans who need medical decisions in the final days of life lack the capacity to make these decisions, surrogates play an enormous role in controlling the trajectories of life's end—decisions made; the alignment or misalignment of patient preferences and treatment;¹¹ resources expended, conserved, or squandered; and pain and suffering mitigated or exacerbated. This book shares rich new data from an extremely diverse population that help shine a light into that black box.

In short, whether providing, receiving, directing, bearing witness, or seeking to improve intensive care, this book is or will someday be about you.

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