Introduction

The vast majority of Americans will die in hospitals or nursing homes, and most will pass through a state of incompetence before they die—a condition that will render them unable to make decisions about life-sustaining medical treatment. Some will be incompetent for only a few hours or days; others will spend their last months or years in a state ranging from profound confusion to complete unconsciousness. Inevitably, other individuals will be called on to make difficult decisions about prolonging the dying process and about the medical technology that will be used.

Making end-of-life decisions is a relatively recent phenomenon. In earlier times, life-sustaining treatment decisions never had to be made because medical treatment, such as it was, could do very little to prolong life when illness struck. Indeed, before the twentieth century, hospitals and doctors were just as likely to be responsible for precipitating one’s demise as they were for prolonging one’s life. In those days, infection was the primary cause of death, and pneumonia, influenza, and related disorders normally took their toll with some dispatch.

Today, instead of dying days or weeks after infection sets in, Americans typically die months or years after a chronic, degenerative illness is diagnosed. Thanks to modern medical technology, victims of some of the leading killers in the United States (e.g., heart disease, cancer, and stroke) may enjoy an extended period of time after illness is diagnosed, with symptoms managed so that a reasonable quality of life is maintained. Often, medical technology can stall or even reverse the disease process so that health is completely restored in a patient who would surely have died just a few decades ago.

As Mark Twain reminds us, however, there is nothing quite so sure in life as death and taxes. Though death can be forestalled, it always wins in the end, and therein lies the problem. Although medical technology often can provide patients with a good quality of life as they begin to die, it can also extend biological life even at the edge of death, when the quality of conscious life is quite low. The fact is that an aggressive use of antibiotics, tube
feeding, artificial respiration, and cardiopulmonary resuscitation can extend life long after the patient's conscious appreciation of it has ebbed. The situation can be summed up in a single question, one that never had to be asked in the past: At what point do we say enough is enough and allow the patient to slip from this world into the next?

The American Hospital Association estimates that as many as three out of four hospital deaths occur after decisions are made to forgo life-sustaining medical treatments that have the potential, by definition, to prolong the patients' lives. But though these decisions are made thousands of times each day across the nation, the individuals who are called on to make the decisions often find themselves facing life-and-death choices for the very first time. Physicians have more experience in these matters than members of the lay public, but they, too, often find themselves responding without a full understanding of all the considerations and options involved. As likely as not, the physicians who counsel the patient and family have received little if any training in such matters during a medical education that focused on sustaining life rather than managing death. Most professional associations—the American Medical Association, the American College of Physicians, and the American Nurses Association, for example—have issued statements of guiding principles that address end-of-life decision making. But for any number of reasons, knowledge of these guiding principles often does not reach the hospitals and nursing homes where rank-and-file caregivers practice.

Even if these guidelines were communicated more systematically, caregivers might continue to harbor concerns about legal liability, moral culpability, and ethical responsibility. Personal, ideological belief systems that contradict the positions of professional associations also may make it difficult for some caregivers to act according to standards and guidelines promulgated by others.

This book is written with both groups—family members and caregivers—in mind. Its purpose is to clarify the medical, legal, ethical, and clinical issues associated with end-of-life decision making on behalf of those who have become irreversibly incompetent before an inevitable (if not imminent) death.

The book opens with a discussion of the legal travails of Rosemarie Sherman, the mother of a man who had been persistently vegetative for nearly two decades. Throughout those years, Sherman had cared for her son, Joey Fiori, both at home and later in a nursing home, and she had long held out hope that Joey would regain consciousness. After seventeen years, however, she began to believe the doctors, all of whom agreed that her son's condition would never improve. Ultimately, Mrs. Sherman decided, as thousands of others do every day, that the family member she was responsible for would not want to continue existing in biological limbo, so she asked that life-sustaining medical procedures be withdrawn from her son.
But unlike thousands of other family members who are allowed to make such decisions quietly and privately at the patient’s bedside, Sherman was forced to go to court for permission to withdraw treatment. Once there, she was opposed by the attorney general of Pennsylvania, whose legal team argued that she had no right to, as they put it, “starve” her son to death.

The case of Joey Fiori is not typical in a strict sense because it was heard before a state supreme court and because Fiori survived in a persistent vegetative state (PVS) for a much longer period of time than most severely demented patients. Fiori’s case is typical, however, in the sense that there are approximately 25,000 PVS patients and hundreds of thousands of severely demented patients in the United States today whose conditions approach the “vegetative” category. Arguments made on both sides in the Fiori case are also entirely typical of arguments made regarding end-of-life decision making in cases that fit this general class of patients.

Chapter 2 covers the key points of consensus on end-of-life decision making, a consensus that has been evolving in the medical, legal, and ethics communities since the mid-1980s. Chapter 3 broadens the consensus debate to include the positions of mainstream religious groups in the United States, the opinions of the general public, and the role that clinical practitioners play regarding the provision of life-sustaining medical treatment for hopelessly ill patients. This consensus supports the right of a patient’s surrogate to withhold or withdraw any life-sustaining medical treatment, including tube feeding, when the patient has irreversibly lost the capacity to understand or interact with his or her environment. Chapter 3 closes with a review of some of the sticking points of the consensus position, discussing various reasons why the position does not always inform the decision-making process that actually takes place at the bedside.

Chapter 4 broadens the discussion to address the plight of individuals who are severely demented. There are approximately 25,000 patients who would qualify as persistently vegetative in the United States today, but there are nearly 2 million patients who are severely demented. These individuals, typically victims of strokes or patients in the end stages of Alzheimer’s, Pick’s, or Parkinson’s disease, are sustained at the end of life for weeks, months, or perhaps even years through the use of artificial nutrition and hydration (ANH) and the aggressive use of antibiotic therapy. Do the arguments regarding end-of-life decision making for persistently vegetative patients apply equally well to the millions who are suffering from advanced dementia? Chapter 4 attempts to answer this question.

This leads to a detailed discussion of artificial nutrition and hydration in Chapter 5. Advances in tube-feeding techniques, equipment, and solutions since the 1970s have made ANH one of the most common medical procedures employed today. Because the ability to swallow is either lost or seriously compromised in all persistently vegetative patients and most severely
demented patients, the provision of ANH is often a requirement for sustaining life. Is artificial feeding a medical treatment like any other, or is feeding, even through tubes, a basic requirement of life that must always be provided? When ANH is withheld or withdrawn, is much suffering involved, and do patients really “starve” to death as a result?

These kinds of unanswered questions lead family members to worry that deciding to forgo food and fluids for another may cause pain or at least discomfort (even though it would not). They also worry that a decision to forgo food and fluids would fly in the face of standard medical practices and accepted ethical principles (even though it does not). No changes in the American psyche can take place overnight. But perhaps, if armed with knowledge about the reality of dehydration at the end of life as laid out in Chapter 5, Americans could think more clearly about the subject as we proceed toward the cultural change that can and must ultimately take place.

Chapter 6 summarizes some of the key findings of the first five chapters. Recommendations for improving a decision-making policy that has, to this point, lurched forward, sideward, and sometimes even backward are also proposed here. Every day, caregivers and family members find themselves grappling with end-of-life decisions that challenge us to rediscover the meaning of caring and the essence of humanity. It is hoped that Chapter 6 will lead us toward a more enlightened understanding in these areas.

The days of allowing nature to take its course because nothing more could be done for the patient are over. Now, there is almost always something that can be done to sustain—or at least attempt to sustain—life for the hopelessly ill. If the patient is competent, there is very little controversy about his or her options: An adult can accept or reject any medical treatment. The only real controversy arises with regard to patients who are not competent to make decisions for themselves. In such cases, the question facing caregivers and family members is: How far should we go to sustain the life of one who is hopelessly ill and irreversibly and severely demented (at best) before we choose to allow nature to take its course?

The question inevitably has a complex answer: It depends. Conclusions about forgoing life-sustaining treatment may depend on how severely demented and how hopelessly ill the patient is. They may depend on what the patient would have wanted, if able to decide. They may depend on the degree of bodily invasion and violation of dignity involved in continued treatment. And they may depend on how burdensome continued treatment would be to the patient, to the family, and to society as a whole.

Although life is indeed a sacred trust that we should not toy with lightly, the sanctity of life does not automatically trump all other interests and considerations when it comes to end-of-life decision making. The simplistic “never give up” answer to the life-sustaining treatment dilemmas may be suitable for some, but there must be room for other answers to the question.
in a pluralistic society that puts so much emphasis on individual rights and human dignity.

"It depends" is really the only route out of the thicket. But this, of course, only begs another question: "It depends on what?" It is hoped that the text that follows will help decisionmakers (caregivers, family members, and policymakers alike) find answers to this question, a question that promises to come into play when, with the "help" of medical technology, we are caught between two worlds—this one and the next—at the end of conscious life.

By all accounts, Daniel Joseph "Joey" Fiori was an ideal guest and vigorous young man with a promising future. He played drums in his high school band in suburban Philadelphia and possessed a variety of talents, including football at school and tennis at the beach where he spent much time during the summer as a teenager. After graduating, Joey was looking forward to furthering his education by studying medicine, physics, and math, two areas he tested well within his reach given his By of 14.

The Vietnam War intervened, however, and in 1968, rather than be drafted by the army, Joey enlisted in the navy. He served with distinction in Vietnam and was going home on leave in 1971 to marry his childhood sweetheart when tragedy struck, just six days before the wedding. Fiori was involved in a motorcycle accident that caused him severe brain damage (Hinds 1994).

Fiori was still severely impaired when he passed consciousness after more than a year as a coma. His vocabulary consisted of only two words—rich and why—and his ability to interact with people around him was extremely limited. He was also wheelchair-bound. Raymond Sherman, Joey's mother, took her son home and cared for him with the help of home health care aides.

Joey Fiori's medical problems were compounded in 1976 when he fell while attempting to get out of his wheelchair and walk. The fall caused a break in his leg that was serious enough to require a stay at the local veterans hospital. While he was convalescing there, hospital personnel failed to provide the required antibiotic medication Fiori had taken for years. As a result, he suffered a grand mal seizure that left him in a persistent vegetative state (IVS) (see Fig. 4.1). Mrs. Sherman brought legal action against the hospital, and the Veteran Administration ultimately agreed to continue care her fully for the cost of her son's health care in the county hospital and her own health care for the duration of her life.

As with most veterans in an IVS, the continued existence of Fiori's former home, where his mother, relatives, and his wife's extended family resided, was an issue.