

# Making Faithful Decisions at the End of Life

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# 1

## *Resisting and Accepting Death*

The theological foundation of this book, which is developed in chapter 2, rests on the assertion that the Bible provides two seemingly opposing views of death, both of which need to be embraced by Christians. On the one hand, the Bible says that we are to fight against death as the enemy. On the other hand, it says that we must accept death as an undeniable part of what it means to be mortal human beings and not God. This book rests on the assumption that Christians must hold to both these claims. Hence, when faced with a life-threatening condition, we cannot rely on an absolute principle to preserve life. Rather, we must discern whether it is a situation where death should be fought against or one in which we must accept that this person's time to die has arrived—however untimely that person's death may be.

The medical profession tends to understand death almost exclusively as the enemy to be fought against, even when the fight has reached the point of futility. Bodily life is prolonged as patients are put on what the physician Jessica Zitter calls the “end-of-life conveyor belt.” Dying patients are often not told how near death they may be, and treatments are frequently offered that result in prolonged dying rather than a good life in the days, weeks, or months prior to death. And while patients

believe that these treatments have some chance at success (and for them, success means cure), health-care providers know otherwise, as Zitter became aware when she was a resident:

Often in these cases, everyone in that room knew that the patient would never make it out; we may have known it for days prior. And yet we plowed on inserting lines and shouting commands until our higher-ups gave us permission to stop. The assumption was always that more was better.<sup>1</sup>

Of course, we *want* physicians to fight to save our lives. Physicians who readily or casually embraced death would pose a real threat to their patients. But having physicians who continue to treat our bodies or parts of our bodies without looking at the whole person and without acknowledging when further treatment cannot stave off death for any significant amount of time creates unnecessary suffering and robs patients of the possibility of leading a meaningful life as they face death.

The first part of this chapter describes the problems that have arisen from the prevalent collective inability of both physicians and patients to address end-of-life issues in any other way than through relentless and sometimes unreasonable efforts to stave off death as long as possible. The second section describes key court cases regarding patients' rights that initially challenged the prevailing emphasis on cure and allowed patients or their families to discontinue treatment even against the physicians' wishes. It also presents court cases that represent a different dynamic, one in which patients are allowed to demand that all efforts at cure be continued even when physicians believe additional treatments are futile. All these cases focus on the issue of who decides (the physician, the patient and family, or the state) as well as whether there is an absolute moral obligation to preserve life. Finally, the chapter briefly introduces the ethics of resisting and accepting death by describing the often-cited Georgetown principles (autonomy, nonmaleficence, beneficence, and justice). A Christian contextual ethic will be presented in chapter 2.

## WHEN CURE IS THE ONLY GOAL

Prior to advances in medicine in the twentieth century, people who were dying were treated like people who were dying. That may seem a simplistic observation, but when the twentieth century saw the introduction of technologies such as mechanical ventilators and CPR (cardiopulmonary resuscitation) and medicine began to cure once-intractable diseases, the goal of medicine and the role of the patient changed dramatically. Now patients with life-threatening illnesses tend to be identified as sick, which of course they are, *rather than* dying, which they may indeed be, and the almost singular goal of care has become cure, *even when cure is no longer possible*. Once given the role of a sick person, a dying patient is expected to comply with every effort of the medical team to fight the disease.<sup>2</sup> Furthermore, fighting the disease means that even talking about death must be avoided by the medical team, the patient, and family members. A good death or, better still, a good life up to the point of death become unattainable because the person with a terminal illness is never recognized (and, therefore, never respected) as someone for whom death is near.

Focusing almost entirely on preserving bodily life can lead to neglecting a person's spiritual, social, and emotional needs. Rather than being surrounded by loved ones and being presented with the opportunity "to make amends, to explain, to bequeath or to apologize,"<sup>3</sup> the dying person is isolated from family and friends—often in ICU (Intensive Care Unit)—unable to take advantage of final opportunities to say things that need to be said. Calling this "the tyranny of survival," Allen Verhey observes that for all the effort to defy death, the opposite of what is intended occurs, for death is allowed an early victory as treatments create as much suffering as the disease itself.<sup>4</sup>

It can be difficult for patients with life-threatening illnesses and their families to determine when to say, "No more." Patients wait until doctors say that they've done all they can, but in reality there is almost always more doctors can do. There

are always more drugs, more operations, more radiation treatments or chemotherapy, and then, of course, a feeding tube and a respirator to extend life, or perhaps to extend dying. Jessica Zitter describes this reality in her early days as a physician in ICU:

And there was always something more to do, something else to try. The protocols that I crammed into my exhausted brain were always about escalating care, designed to guide me through increasing the levels of pharmacologic and technical support. I never even considered that a dying patient might choose comfort as his priority and thus require a protocol to de-escalate the life-prolonging treatments that we steadily heaped on.<sup>5</sup>

Without clear indication from a physician that life-saving treatment has become futile, patients and their families feel caught between *fear* that further treatment will do more harm than good and *hope*, however thin, that the next round of treatment will produce the miracle they are waiting for. Too often they get no clear indication from doctors that further treatment cannot stave off death for long or extend life in any meaningful way. Most physicians say that *they* will not choose medical intervention when they are close to death. Studies have shown that the vast majority of doctors in the United States (almost 90 percent) say that they will avoid aggressive treatment if diagnosed with a terminal illness. But those same doctors are often unable to advise patients to do the same—or even to give them a choice.

The compulsion to treat, of course, is deeply ingrained in doctors' medical training. Jessica Zitter knows that this relentless focus on cure defies that part of the Hippocratic oath recited by medical students that says, "I acknowledge that there is art to medicine as well as science, and warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug." But having been taught the intricacies of treatment, she says, doctors are never taught how to talk to a patient about dying or to family members when news is bad:

It felt almost cruel to say that the end was approaching, that I thought it unlikely they would survive another hospitalization, that I was concerned they would die on a breathing machine. I didn't have the time nor did I know the words. I didn't have any alternative options to offer besides more treatment.<sup>6</sup>

But sometimes alternative options are what a patient needs. As the physician Atul Gawande claims, "People with serious illness have priorities besides simply prolonging their lives," priorities that include minimizing suffering, interacting with family and friends, being mentally alert, avoiding an overwhelming sense of being a burden, and all the while seeking to achieve "a sense that their life is complete."<sup>7</sup>

Zitter believes her training led her to objectify her patients by using her skills to treat only the body while overlooking the individual human being in front of her. She fears that learning to focus solely on cure—even when cure was no longer possible—diminished the compassion that motivated her to become a doctor to begin with. It was only when a family support team (a precursor to palliative care) inserted itself onto the ICU unit where she worked that Zitter began to change her mind, but even then, it required a monumental effort to overcome her well-ingrained beliefs and turn her attention to more patient-focused care.

Zitter is not, however, suggesting that she or her colleagues in medicine lack compassion. Most of the doctors she knows are compassionate and have the best intentions in caring for their patients. Medicine itself, one might say, fell victim to its own successes, and practitioners have been caught up in an ethos that views death as a disease that can be cured rather than an inevitable event that needs to be acknowledged and discussed, often fought against, but in some circumstances accepted. When the prevailing ethos dictates that further life-saving treatment be pursued even when death is most certainly imminent, the dying patient's physical pain, emotional distress, and other forms of suffering can be ignored. However much compassion may be intended by physicians in their

uncompromising fight against death, Zitter knows that this “collective tendency” of doctors (and sometimes patients, as we will see below) to ignore death and focus almost solely on cure “fuels a tremendous amount of suffering.”<sup>8</sup>

Nevertheless, even as we criticize medicine, medical training, and doctors themselves for being unable to face the reality of death, we must resist the temptation to demonize medicine. Writing as someone who had benefited from medical treatment for a life-threatening disease, the Christian ethicist Allen Verhey reminds us to be grateful for medicine’s ability to resist death:

We may and should be grateful, of course, for the great advances of medical care in the last century. None of us wants to return to bloodletting and snake oil. We must not neglect the fact that there was a time, not so long ago, when physicians were relatively powerless against the diseases that threaten death and when their ministrations were as likely to kill you as to cure you. The desire for medicine to heal motivated those advances.<sup>9</sup>

Consider the toll in lives lost to cholera, TB, polio, and more recently AIDS when medicine had no effective tools to fight these diseases. Advances in treating heart disease, childhood leukemia, and other forms of cancer are also to be lauded and celebrated.

Unfortunately, in some parts of the world and even in certain parts of our own country, people still die of diseases that now have vaccines, cures, or at least the likelihood of being reduced to chronic conditions for people who have access to medical treatment. Rather than simply rail against medicine for its inability to treat dying patients with honest compassion, we should be grateful and promote access to life-sustaining medical care to every U.S. citizen and every country around the world. But we can also be critical. Being grateful for advances in medicine that can genuinely stave off death and being critical of medicine’s tendency to make cure its singular goal even when death is imminent are not mutually exclusive. Despite

medicine's great successes, the "failures of those successes," as Verhey says, need to be addressed as well.<sup>10</sup>

It would indeed be wrong to place responsibility for the inability to face death on doctors alone. There is a noticeable movement in the opposite direction involving an increasing number of cases in the United States where doctors *are* ready to stop life-extending treatment while patients, or more often their families, insist that everything be done. Some patients and family members choose to "rage against the dying of the light"<sup>11</sup> against all odds and sometimes against all reason. In one case, even though the patient's body was deteriorating to the point that the odor of death filled the hospital room, the patient's wife insisted that medical treatment continue—until the moment the patient died. This kind of situation puts enormous stress on the medical team, making nurses feel like they are assaulting a human body and being disrespectful of the person who is dying.

Also, doctors often report that when they are able to be honest about a patient's poor prognosis and admit to the patient or family that the next possible treatment will not, in fact, bring the desired results, patients and family members sometimes complain that the doctor has taken away their hope. When Atul Gawande tried to help a patient understand that surgery to remove a tumor could lead to stroke, paralysis, or even death, the patient defiantly replied, "Don't you give up on me. You give me every chance I've got." Gawande describes his own reaction:

I believed then that Mr. Lazaroff had chosen badly and I still believe this. He chose badly not because of all the dangers but because the operation didn't stand a chance of giving him what he really wanted: his continence, his strength, the life he had previously known. He was pursuing little more than a fantasy at the risk of a prolonged and terrible death—which was precisely what he got.<sup>12</sup>

These Promethean efforts at cure, whether fed by physicians' or patients' inability to face the reality of death, focus too

exclusively on death as the enemy and express a tragic idolatry that refuses to accept human mortality.

There are landmark legal cases that reflect this inability of doctors, on the one hand, and patients and their families, on the other, to admit that death is imminent and continued life-sustaining treatments inappropriate. These cases demonstrate that in the arena of both end-of-life care and patients' rights, we have traveled in the proverbial manner of two steps forward and one step back and that in our personal lives, in the world of medicine, in the field of law, and in society as a whole we need to think more carefully and talk more openly about medical treatment at the end of life. Two particular questions will be addressed throughout the summary of these cases: (1) Who decides: physicians, the patient and family members, or the courts? (2) Does human life have absolute value so that medicine and the state have an absolute obligation to preserve life in every case?

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