Chapter Six

Conclusion and Recommendations

Death is not extinguishing the light. It is putting out the lamp because the dawn has come.
—Rabindranath Tagore (cited in Bertman 1991)

If dying patients want to retain some control over their dying process, they must get out of the hospital if they are in, and stay out of the hospital if they are out.
—George Annas (1995)

An eight-year study of death in the United States, involving nearly 5,000 seriously ill patients and published in the Journal of the American Medical Association (SUPPORT 1995), found that despite the emergence of the right-to-die movement and the increased sensitivity to end-of-life decision making that was expected to follow implementation of the Patient Self-Determination Act, patients are still reluctant to make their treatment preferences known. Even when patients execute advance directives or discuss preferences about limiting treatments with family members, doctors are often oblivious to those preferences and proceed with aggressive treatments anyway.

"The system," according to Dr. William A. Knaus, one of the study’s codirectors, "doesn’t know when or how to stop. . . . Physicians are acknowledging that patients are dying, but only at the last minute" (Knaus 1995). He concluded that "we’re going to have to develop a better vision for living well while dying."2

A number of things can be done to bring that vision into clearer focus, including (1) developing a set of standards within the medical profession that would apply to the care of mortally ill patients, (2) making better use of hospice care, (3) developing a better, more widely shared sense of the
concept of “medical futility,” (4) providing better education about death and end-of-life decision making for caregivers and the general public alike, (5) modifying the old “slippery slope” theory of ethics to take account of changing, more complicated realities, and (6) making better use of advance directives.

Standards of Care

Developing standards of care is one way to begin resolving some of the troubling and contentious issues regarding end-of-life decision making that now are handled either behind closed doors at the bedside or publicly and confrontationally in the courts. Standards of care are panned by some as nothing more than “cookbook medicine.” But standard protocols are really only models or patterns of clinical practice that serve as a baseline from which variations in treatment can be adapted, given the specific clinical circumstances and the stated or implied preferences of the decisionmakers involved.

The federal Agency for Health Care Policy and Research (AHCPR) has already moved decisively in this direction by developing a number of standard care protocols as part of its Medical Treatment Effectiveness Program (MEDTEP). Specific MEDTEP guidelines for seventeen clinical diagnoses have been issued to date (e.g., treatment for backaches, cancer pain management, and the management of breech births). A number of other standards are being developed.

AHCPR does not require or expect that physicians will act strictly according to protocol in every case. The standards do, however, put physicians in touch with the very latest consensus regarding the treatment of illness and may help shield them (to a degree) from legal liability if things go badly after standard protocols were followed. Treatment standards are also becoming popular with third-party payers and managed care systems that require physicians to document—and in many cases, get approval for—deviations from established standard practices. Standards of care are clearly the wave of the future in health care, and there is no reason why they should not encompass life-sustaining medical treatment as well.

Standards of Care at the End of Life

Medical ethicists and clinicians have been formulating and experimenting with end-of-life treatment standards since the mid-1980s. As Table 6.1 reveals, the standards promoted to date are really no more than menus of treatment approaches from which patients or their surrogates can choose, in consultation with their physician(s). “Aggressive treatment”—the application of any and all medically reasonable treatments to save the patient’s life—typically lies at one end of a continuum of care. “Comfort care
<table>
<thead>
<tr>
<th>Authors of Standard Care Protocols</th>
<th>Wanger et al. 1984</th>
<th>Volicer et al. 1986</th>
<th>Mott and Barker 1988</th>
<th>Luchins and Hanrahan 1993</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Population</td>
<td>“Hopelessly Ill”</td>
<td>Advanced Alzheimer’s and Dementia</td>
<td>Nursing Home Residents</td>
<td>End-Stage Dementia</td>
</tr>
<tr>
<td>Aggressive treatment</td>
<td>All treatments provided, including emergency resuscitation</td>
<td>Diagnostic workups, CPR tube feeding, hospitalization</td>
<td>Maximum care, including hospitalization for surgery and intensive care</td>
<td>Do everything; use respirators, CPR, tube feeding, and electric shock for heart attacks</td>
</tr>
<tr>
<td>“High-end” level of intermediate care</td>
<td>Intensive care and advanced life support provided but no CPR</td>
<td>Aggressive treatment but no CPR; patient has a DNR order</td>
<td>Hospitalization but avoid surgery and intensive care if possible</td>
<td>Aggressive treatment but avoid electric shock in case of heart attack</td>
</tr>
<tr>
<td>Intermediate level of care</td>
<td>General medical care: surgery, chemotherapy, antibiotics, and other drugs, ANH</td>
<td>No CPR, artificial respiration, or hospitalization for intercurrent illnesses</td>
<td>Avoid hospitalization but use antibiotics, as needed, for infection</td>
<td>Aggressive treatment but avoid using respirators and electric shock</td>
</tr>
<tr>
<td>“Low-end” level of intermediate care</td>
<td>General nursing (comfort care), no vital sign checks, diagnostics, or antibiotics</td>
<td>No CPR, hospitalization, diagnostic work-ups, or antibiotics</td>
<td>a</td>
<td>Avoid using respirators, electric shock, or drugs to treat acute illness</td>
</tr>
<tr>
<td>Comfort care only</td>
<td>General nursing care, food and fluids only as needed for comfort</td>
<td>Supportive care, no CPR, no diagnostics, no antibiotics, no tube feeding</td>
<td>Avoid hospitalization; no antibiotics or IV fluids, except for comfort</td>
<td>Avoid using tube feeding; avoid antibiotics, CPR, and respirators</td>
</tr>
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*aMott and Barker describe only two intermediate care levels: “high-end” intermediate and intermediate.*
only”—an alternative associated with the hospice approach and with the emphasis on treating symptoms (holistically and in their entirety) rather than trying to arrest or reverse the patient’s underlying pathology—lies at the other end of the spectrum.

Currently, there are no standard, widely accepted treatment protocols apart from the essentially illegitimate default response: aggressive treatment. Doctors will occasionally act unilaterally or in consultation with the patients or members of the patient’s family and move across the treatment continuum in the direction of the comfort care only option. But that decision is usually made only toward the very end of a chronically degenerating illness, long after the patient and family have endured a substantial amount of preventable suffering. “On a day to day basis,” writes Ellen Goodman (1995), summarizing the results of the SUPPORT study, “neither doctors nor patients were talking about what the patients wanted. They were both following the cultural script, talking about the next chemotherapy, the next procedure. They were patching, fixing, going from crisis to crisis without ever asking, ‘How can I live well while dying?’” A standard of care that required physicians to present patients with an array of treatment approaches might go a long way toward reversing this less than ideal, largely illegitimate status quo.

If some variation of this menu was adopted, a patient or a surrogate could be apprised of the full range of acceptable treatment options available. All decisionmakers need not elect the comfort care only option, but all should be informed that this is a perfectly acceptable treatment level (from both a medical and a legal perspective). And why should it not be? Most people believe the comfort care level is desirable (see Tables 3.1, 3.2, 3.3, and 3.4), and it is an option that many ultimately choose for themselves or for their loved ones, even if they wait (too long) to do so.

Introducing a treatment grid into the bedside decision-making process would remove the often erroneous assumption that all possible medical treatments are desired and should be provided, and it would replace the “aggressive treatment reflex” with a deliberative choice process that emphasizes the autonomy and dignity of the patient. Erring on the side of life has been the standard of care ever since the technology required to prolong life by artificial means was developed. Given the evidence regarding preferences of the public, however, it may be time to question this presumption openly in order to give patients and surrogates the option of doing only what makes sense for them, from their own informed perspective.

The AMA’s Council on Ethical and Judicial Affairs has already begun to back away from the aggressive treatment presumption in considering the plight of the permanently unconscious. In its report on forgoing life-sustaining treatment for incompetent patients, this group (Council 1991: 67, 69) notes:
In the situation of a permanently unconscious patient, prolonging life may not be in the best interests of the patient. An existence that is severely degraded and causes constant suffering of loved ones who must stand by to watch the patient linger on the edge of life may not be worth prolonging from the patient's perspective. In addition, there may be a patient interest in the kind of memories left behind.

Some would argue caution here, for there is always the hope for a miraculous recovery. Regarding this notion, Dr. Sherwin Nuland (1994: 233-234) writes that

in this high-tech biomedical era, when the tantalizing possibility of miraculous new cures is daily dangled before our eyes, the temptation to see therapeutic hope is great, even in those situations when common sense would demand otherwise. To hold out this kind of hope is too frequently a deception, which in the long run proves far more often to be a disservice than the promised victory it seems at first.

Aggressive treatment is the norm, continues Nuland, but “usually, [patients] suffer for it, they lay waste their last months for it, and they die anyway, having magnified the burdens they and those who love them must carry to the final moments.” If Nuland’s account is accurate, then the default rule, which presumes the desirability of aggressive treatment to the end, deserves to be thoroughly rethought; indeed, perhaps it should be replaced by a treatment protocol that emphasizes patient autonomy and dignity and provides more palliative-oriented treatment options from the earliest days of mortal illness, when selecting them can still do some good.

A Duty to Die?

Does providing treatment options for patients start us on a road that will lead, inevitably, to a belief that the infirm and the elderly have a duty to select comfort care only when they become sick or frail? Does this standards-of-care proposal create a “duty to die” mentality?

Richard D. Lamm, formerly the governor of Colorado, irritated many when he suggested, in a speech delivered in 1984, that elderly, terminally ill persons have “a duty to die and get out of the way. Let the other society, our kids, build a reasonable life” (cited in Worsnop 1992: 149). It may have been a grating sentiment, but it was not an original one. Thomas Jefferson himself penned a very similar thought near the end of his life: “There is a ripeness of time for death, regarding others as well as ourselves, when it is reasonable we should drop off, and make room for another growth. When we have lived our generation out, we should not wish to encroach on another” (cited in Nuland 1994: 73).
Sherwin Nuland (1994: 86-87) is among the authors who made this poignant point most recently:

Far from being irreplaceable, we should be replaced. Fantasies of staying the hand of mortality are incompatible with the best interests of our species and ... the best interests of our very own children. ... [To] die and leave this stage is the way of nature—old age is the preparation for departure, the gradual easing out of life that makes its ending more palatable not only for the elderly, but for those also to whom they leave the world in trust. ... Persistence can only break the hearts of those we love and of ourselves as well, not to mention the purse of society that should be spent for the care of others who have not yet lived their allotted time.

One need not accept the musings of Jefferson, Lamm, or Nuland as determinative, however, for patient self-determination and palliative care that saves money, decreases suffering, and enriches the dying time can be advocated without concluding that anyone has a duty to die. One of the larger points of this book is that if patients were fully empowered with the knowledge and autonomy needed to make truly informed treatment decisions for themselves or their loved ones, the vast majority would likely choose comfort care only when illness progresses beyond the point at which life can be consciously enjoyed. This would, in large part, obviate the need to force palliative care on those who would prefer a more aggressive approach, which could and should remain an appropriate, acceptable (and reimbursable) treatment option.

The Hospice Alternative

One major problem with the comfort care only option is that many health care institutions do not consider comfort care a legitimate treatment alternative (e.g., see Tables 3.7 and 3.8). This was certainly the case with the nursing home that forced Rosemarie Sherman into court when she requested that the tube feeding of her son be stopped. Consequently, it may do little good for physicians to offer the comfort care only option if the institutions in which they practice do not recognize this as a legitimate treatment modality. Hospices will have to take up the slack in the interim, until the hospice approach is more widely and generally accepted (and paid for by third-party payers).

The hospice alternative replaces the aggressive "curing-based" approach to extending life at all costs with a "caring-based" approach to living well while dying. Those using the hospice philosophy work in interdisciplinary teams to address the full range of physical symptoms and psychosocial problems that the patient and family endure as a disease runs its course to-
ward death. Simply put, caring and symptom management are emphasized while cure is accepted as beyond reach (Wheeler 1993: 756).

Hospice care, covered by Medicare since 1982, has become more popular over the years; in 1992, 154,000 Medicare decedents (about 10 percent of all recipients who died that year) made use of hospice services. This group of hospice patients consumed less than 1 percent of the Medicare budget in 1992 (approximately $700 million, or about $5,000 per decedent) (Scitovsky 1994: 581). The remaining 90 percent of Medicare recipients who died that year consumed approximately 27 percent of the Medicare budget, with over $19 billion in medical bills, or about $14,000 per decedent—nearly three times as much per capita as the hospice patients. (See Chapter 4 for more on medical costs at the end of life.)

Currently, there are about 1,800 hospice programs in the United States. Most are home care programs in which hospice nurses, social workers, and physicians travel to the homes of dying patients to provide medical and psychosocial support and guidance.

Decreased suffering and increased quality of what life remains are both associated with this palliative-oriented approach. Suffering decreases quantitatively because the dying process is no longer protracted indefinitely. At the same time, the quality of life is increased because efforts are focused on managing the symptoms of the disease (e.g., controlling pain and discomfort) rather than attempting to reverse or arrest the underlying pathology and perhaps exacerbating the symptoms in the process.

Dr. Nuland's observations regarding common practices at the end of life today are hardly reassuring (Nuland 1994: 142–143):

By and large, dying is a messy business . . . even for those who do achieve a measure of serenity during separation. The period of days or weeks preceding the decline of full awareness is frequently glutted with mental suffering and physical distress. Too often, patients and their families cherish expectations that cannot be met, with the result that death is made all the more difficult by frustration and disappointment with the performance of a medical community [that] continues to fight long after defeat has become inevitable. . . . Treatment decisions are sometimes made near the end of life that propel a dying person willy-nilly into a series of worsening miseries from which there is no extraction.

Palliative care can be emotionally enriching for patient and caregivers alike, especially when family and friends assume (or reassume) roles as primary caregivers in the process. In fact, palliative care is much more conducive to family participation in the dying process (Wanzer et al. 1989: 845–846). Tubes and machinery often serve as barriers to hands-on, personal contact. But when technology is de-emphasized, backrubs, spoon-feeding, and hand-holding become more important and more possible. When the dying time is interminable, those close to the patient may slowly
withdraw, visiting less often and providing less in the way of personal care over time. Alternately, when the decision to forgo life-sustaining treatment is made and the dying time is delimited (those using hospice care typically die in a matter of days or weeks at most), those close to the patient can be present and provide support every step of the way.

When hopelessly ill patients are tube fed, for example, they may live on for years, and there is very little that a family member can do to help out with care. But when tube feeding is forgone, relatives can rearrange work and family schedules to devote increased time and attention to the patient's last days, knowing that the end is near. With tubes and feeding apparatus removed, friends and family members can be invited to participate in the terminal care of the patient—moistening the lips of the dying loved one and providing chips of ice on the tongue to slake any sensations of thirst that might develop. This can be a richly emotional and satisfying time for both patient and loved ones, a time when troubles are resolved, peace is made, and final good-byes are shared. How much better it would be to come to terms with the death in this manner, rather than merely receiving an impersonal call from the nursing home: "Your ______ has died."

Survey data suggest that the vast majority of family members and professionals believe that hospice care is particularly appropriate for persons suffering through end-stage dementia. And reports of pilot programs that provide hospice care to patients suffering from advanced dementia indicate that the approach is feasible on a larger scale (Hanrahan and Luchins 1995: 56). Increased use of hospice services for patients in end-stage dementia would save resources, as well. The latest and most comprehensive evaluation of the small number of patients covered for hospice care under Medicare shows that $1.26 is saved for every dollar spent (Kidder 1992, cited by Scitovsky 1994: 582). Another study showed that Alzheimer's patients getting palliative care had annual expenses of $6,000 less than Alzheimer's patients cared for in a traditional, long-term care facility (B. Volicer et al. 1993: 539).

Hospice placements for such patients are not easy to arrange, however. The problem is that Medicare enrollment criteria require the attending physician and the director of the hospice to certify that the patient is within six months of death before the institution can qualify for reimbursement. As Beverly Volicer and her colleagues point out, hospice-like care may be appropriate for patients with advanced dementia, but "the variable rate of deterioration makes an informed judgment about anticipated survival time for individual patients difficult" (B. Volicer et al. 1993: 535). Consequently, even though 90 percent of responding family members in one study indicated that hospice care would be appropriate for a loved one with end-stage dementia, only about 30,000 of the approximately 2 million patients suffering from severe dementia nationwide ever get into a hospice program (Hanrahan and Luchins 1995: 57). So patients and their families are
caught in a vicious circle: The patient cannot get into a hospice program unless he or she can be declared terminally ill, and the patient cannot be declared terminally ill unless he or she can get into a hospice program—a classic catch-22 of grave proportions.

This poses an interesting dilemma: Although caregivers advocate the use of hospice, the lay population desires access to hospice, and resources can be saved through greater use of hospice, current federal regulations stand in the way. One way out of this bind, short of changing the Medicare guidelines, would be to create a statistical model that would predict, within acceptable limits, the six-month survival rate of patients with end-stage dementia. Factors such as age, severity of dementia, management strategy (the agreed-upon level of care, chosen from the standard care menu discussed earlier), and time since admission to a long-term care facility might be statistically weighted and combined to determine if the expected mortality will likely occur within the six-month period required by current rules.

A second alternative would involve modifying Medicare’s current six-month rule so that those who could not reliably be said to be within six months of death could still be accepted into hospice (where they would in all likelihood die within six months). A third alternative would be to insert the term mortal illness in place of the term terminal illness as the qualifying prognosis for hospice care reimbursement (Sachs et al. 1995: 553). Mortally ill would be used to refer to “dying patients who have a progressive illness that is expected to eventuate in death and for which there is no treatment expected to alter the course substantially” (Sachs et al. 1995: 553).

Even if the six-month prognosis problem could be overcome at some point, however, funding for hospice care is likely to be problematic. Funding for hospice and home health care has been increasing in recent years, but any significant shifts in the direction of palliative care will require government, third-party payers, and health care alliances to pour more resources into these two areas. Although palliative care may be less expensive than aggressive care in the long run, it is not free. And the fact that more hospital beds (some of them in intensive care wards) would be abandoned by those seeking a more palliative approach will not, in itself, save the institutions providing high-tech care any money. Indeed, moving toward palliative care will lead to a net decrease in revenue for high-tech institutions and a net decrease in income for some specialists, even though health care dollars will surely be saved overall.

**Medical Futility**

It is important to provide patients and their surrogates with a sense that a range of acceptable options might be open to them—from aggressive care to the hospice alternative. However, there are times when offering the full range of options does not make sense from either a medical or an ethical
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perspective. At one end of the scale, for example, physicians might reason­ably decline to offer surrogate decisionmakers the comfort care only option for an incompetent, seriously ill patient if there was some medically sound reason to believe the patient might regain competence and enjoy a conscious and acceptable quality of life. But because aggressive care is the default position adopted by most physicians and family members, there is little danger that the comfort care only option will be inappropriately applied or overused today.

Actually, the need for limiting options at the aggressive care end of the scale has proven to be more problematic. When physicians argue that a patient is so hopelessly ill and irreversibly vegetative that further aggressive medical treatments would be futile and need not be offered, they run the risk of being charged with “giving up too soon” by patients, family members, colleagues, and maybe even the courts. Many caregivers still shrink from making the call to halt treatment on the grounds that to do so violates the “do no harm” tenet of the Hippocratic oath. But some quote another relevant principle in Corpus Hippocratum that implores physicians to “refuse to treat those who are overmastered by their disease, realizing that in such cases medicine is powerless” (cited in President’s Commission 1983: 15–16). Recent studies of physician behaviors suggest that this latter principle guides a significant number of caregivers today.

For example, David Asch, John Hansen-Flaschen, and Paul Lanken (1995: 288) found that an overwhelming majority of the 1,050 critical care physicians in their study had unilaterally withheld (83 percent) or withdrawn (82 percent) patients’ treatments on grounds of futility. Furthermore, nearly one-quarter of the respondents (23 percent) indicated that they had withdrawn life-sustaining treatment on the basis of medical futility even though they did not have the oral or written consent of the patient or family, and 12 percent of those respondents claimed to have proceeded in this way without the knowledge of the patient or family. Fully one-third of the respondents reported withdrawing life-sustaining treatment from at least one patient who was not capable of making such a decision and was unrepresented by a surrogate decisionmaker. And a small but significant proportion of respondents (3 percent) reported withdrawing treatment despite the objections of the patient or family.

At one time in the not-too-distant past, a decision to withhold treatment despite the objections of the family might have been considered an ethical breach of the first order. Today, however, a stream of literature supports such decisions in cases of persistently vegetative patients and others who are irreversibly, terminally ill once the diagnosis has been established with virtual certainty. Lawrence Schneiderman, Nancy Jecker, and Albert Jonsen (1990: 952) leave no doubt on this score, arguing that “the patient has no right to be sustained in a state in which he or she has no purpose other than mere vegetative survival; the physician has no obligation to offer this option or services
to achieve it." Jecker and Schneiderman (1993: 151) contend that offering medically futile treatment only raises false hopes, is emotionally damaging, and extends and maybe even adds to the suffering a patient endures.

Although these liberal interpretations of futility are accepted by many clinicians, acceptance is far from universal. Still, two recent court cases brought by physicians and hospital administrators suggest that some caregivers are beginning to feel more comfortable about discussing the issue of futility in public, which is an important and necessary step in the process of building a general consensus position on what is still a very contentious issue.

**Helga Wanglie**

In 1990, eighty-six-year-old Helga Wanglie suffered a heart attack. Although she was successfully resuscitated, the interruption of the oxygen supply to her brain during the attack left her with extremely severe and irreversible brain damage. After several months of observation and treatment at the Hennepin County Medical Center (HCMC) in Minneapolis, Minnesota, the diagnosis of persistent vegetative state was confirmed. Wanglie was being sustained by artificial respiration, artificially provided food and fluids, and antibiotics for recurrent pneumonia. Given Wanglie's deteriorating condition and poor prognosis, the medical staff at HCMC urged the family to forgo her life-sustaining medical treatments.

Members of the family—Oliver, Mrs. Wanglie's husband of fifty-three years, and two children—disagreed with the withdrawing of treatment on religious and personal grounds. Oliver Wanglie claimed he fully understood the dismal prognosis but was "hoping for a miracle." He also noted that his wife had told him many times what her preferences would be: "If anything happened to her," he relayed, "she didn't want anybody or anything to shorten her life. I intend to keep that promise" ("Doctors Want to Pull Plug" 1990).

After a series of attempts to persuade the Wanglie family of the hospital's position, Dr. Michael Belzer, the HCMC medical director, wrote a letter to Oliver Wanglie: "All medical consultants agree with [the attending physician's] conclusion that continued use of mechanical ventilation and other forms of life-sustaining treatment are no longer serving the patient's personal medical interest. We do not believe that the hospital is obliged to provide inappropriate medical treatment that cannot advance the patient's personal interest" (Cranford 1991b: 23–24).

When this letter had no effect on the family's decision, the medical center, with the concurrence of its ethics committee and its board of directors, went to court to seek the appointment of an independent conservator with the power to recommend that Mrs. Wanglie's life-sustaining medical treatment be withdrawn. It was the first court proceeding in which an institution (in this case, a public entity) sought to end life-sustaining treatment for an incompetent adult patient against the wishes of family members.
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After a hearing, Hennepin County Probate Judge Patricia L. Belois ruled in favor of the family and appointed Oliver Wanglie as conservator of his wife, stating: "He [Mr. Wanglie] is in the best position to investigate and act upon Helga Wanglie's conscientious, religious, and moral beliefs" ("Judge Rejects Request" 1991). Three days later, on July 4, 1990, Helga Wanglie died of sepsis (a poisoning of the blood and tissues) with all life-sustaining equipment connected and operating. The family's medical bill for services provided during her last hospitalization approached $1 million.

Subsequently, Dr. Stephen Miles (1991: 513–514), a medical ethicist at HCMC, criticized the judge's ruling in an article published in the New England Journal of Medicine:

A patient's request for a treatment does not necessarily oblige a provider or a health care system. Patients may not demand that physicians injure them (for example, by mutilation), or provide plausible but inappropriate therapies (for example, amphetamines for weight reduction), or therapies that have no value (such as laetrile for cancer). . . . Patients can refuse any prescribed treatment or choose among any medical alternatives that physicians are willing to prescribe. Respect for autonomy does not empower patients to oblige physicians to prescribe treatments in ways that are fruitless or inappropriate. . . . Disputes between physicians and patients about treatment plans are often handled by transferring patients to the care of other providers. In this case, every provider contacted by the hospital or the family refused to treat this patient with a respirator. These refusals occurred both before and after this case became a matter of public controversy and despite the availability of third-party reimbursement. We believe they represent a medical consensus that respirator support is inappropriate in such a case.

Later in the year, the Minneapolis Star Tribune published an editorial that came to a similar conclusion ("Helga Wanglie's Life" 1991): "The hospital's plea is born of realism, not hubris. . . . It advances the claim that physicians should not be slaves to technology—any more than patients should be its prisoners. They should be free to deliver, and act on, an honest and time-honored message: 'Sorry, there's nothing more we can do.'"

Catherine Gilgunn

Catherine F. Gilgunn was not in good medical condition in 1989 when, at the age of seventy-one, she was admitted to the hospital for surgery to repair a fractured hip. She suffered from diabetes, heart disease, chronic urinary tract infections, and Parkinson's disease. One breast had been removed because of cancer the year before, and she had also suffered a stroke. One of her hips had been replaced once, the other twice.

Before Gilgunn's surgery could begin, she suffered a series of uncontrollable seizures that left her comatose, with irreversible brain damage. After six years in this condition, physicians at Massachusetts General Hospital
decided to enter a DNR order on Mrs. Gilgunn’s chart and began trying to wean her off a ventilator. They did this after consulting with the hospital’s optimum care committee and Gilgunn’s daughter, Joan.

The hospital committee agreed with the decision, as did John J. Paris, a Jesuit priest and ethicist at Boston College who described the hospital’s decision as entirely defensible. Doctors were not obliged, explained Paris, to resuscitate a patient who was so ill that such efforts, even if successful, would accomplish no purposeful medical goals (beyond the sustaining of organic life). The daughter disagreed, however, saying her mother had always wanted everything done for her (Kolata 1995). Mrs. Gilgunn subsequently died, and no attempt was made to resuscitate her.

Joan Gilgunn sued the two doctors directly involved with the decision to write the DNR order, and a jury was impaneled to hear evidence and arguments on both sides of the case. After the case had been presented, Suffolk County Superior Court Judge David Roseman instructed the jury on its responsibilities with regard to the state’s interests in the case: “The state’s interest in pursuing life is high when human life can be saved and where afflictions are curable, but wanes when the afflictions are incurable.” After two hours of deliberation, the jury cleared the two physicians of wrongly ignoring the daughter’s demands to keep Catherine Gilgunn alive on life support. Members of the jury agreed that Gilgunn would have wanted her life to be sustained, as the daughter claimed, but also found that continued treatment would be futile and of no medical benefit (Ellement 1995).

Informed Consensus

Evidently, the realm of medical futility is an unsettled area of law, ethics, and medicine. As one observer noted: “Our medical inventions have invited our own dilemma ... sometimes the machines are a blessing. And sometimes they are a curse. But we haven’t invented laws or rules yet to tell the difference” (“To Suffer” 1984). In the meantime, physicians will have to find their own way, with occasional help from judges and juries. All indications are that physicians are moving in the direction of unilaterally withholding or withdrawing treatment when the patient is hopelessly ill and nothing more can be done to restore even a minimal quality of life. For the most part, they are doing this quietly (as reported in the Asch, Hansen-Flaschen, and Lanken study [1995]), but occasionally, the process becomes public (as in the cases of Helga Wanglie and Catherine Gilgunn).

Professional organizations have already begun to codify rules that legitimize physician behavior along these lines (especially with regard to the unilateral writing of DNR orders).17 And with trial court cases beginning to be heard, appellate-level court decisions—the ones that carry weight as case law—will not be too far behind. Increased economic pressures—manifested as managed care, capitated payment plans (e.g., health maintenance organi-
zations and preferred provider organizations), and cuts in reimbursement rates for Medicare and Medicaid—will, rightly or wrongly, encourage the process of building a consensus on medical futility.

The task of developing a concept of medical futility should not be taken lightly, however. Rather, the process must be deliberate, informed, broad-based, and participative (e.g., involving representative cross sections of the lay public). Polling data already suggest that the public is very much opposed to the current presumption in favor of aggressive therapy for the hopelessly ill. But these polls, like all polls, have some basic flaws that affect the weight that can be attributed to them. Most significantly, the scenarios and treatment options posed in public opinion polls often are simplistically worded, and rarely is any effort made to determine how well the respondents understand the questions or how deeply they have thought about their responses.

Some medical researchers have attempted to solve this problem (at least partially) by educating respondents about the conditions and treatments under consideration. Questions are then posed in the context of detailed vignettes rather than in overly simplistic statements of one or two sentences (e.g., see Emanuel et al. 1991: 881; Lo, McLeod, and Saika 1986: 1613). More of these kinds of vignette-based studies would provide a better idea of where informed opinion (as opposed to mass opinion) is on the issue of medical futility.

A few years ago, the state of Oregon launched an initiative that led to a massive restructuring of its Medicaid program. To fashion the new policy, state officials created a consensus-building process that, in addition to mail and telephone surveys and extensive consultation with medical experts, included focus group research and town meetings to explain and discuss various proposals and solicit public input. The consensus that resulted was not universally embraced within the state. But it was more informed and more legitimate than any consensus based on surveys or expert opinion alone. Perhaps a similar effort, oriented toward developing a concept of "medical futility" that could be generally accepted across the nation, would be worth attempting.

The kind of information gleaned would be very useful to family members and caregivers who currently must bury their feelings of fear, guilt, and anxiety over whether life-sustaining medical treatment is medically futile. The participatory development of a shared sense for what medical futility means would go a long way toward relieving some of the concerns people have, while at the same time diminishing patient (and family) suffering, restoring patient dignity, and conserving resources associated with the dying.

There should be room for a plurality of positions when it comes to end-of-life treatment preferences. However, plurality cannot extend to every patient in every condition regarding every treatment. Rather, this plurality should operate within limits, with boundaries set up at the aggressive care end of the spectrum to prevent patients from demanding medically futile
treatment, just as there are boundaries set up at the other end of the spectrum today, when surrogates are prevented from giving up too hastily if serious illness is not yet considered irreversible.

In sum, we need a national dialogue on the issue of medical futility. We now have only anecdotal evidence, limited survey data, and a smattering of qualitative research studies to go on. A systematic effort should be made to collect data on the informed views of Americans so that an informed consensus can be established. This project should be a high priority, since enormous costs, resource allocation issues, emotional burdens, and patient autonomy and dignity all hang in the balance. As Handler (In re Jobes 1987: 460) notes, just as constitutional norms of personal privacy must be shaped "by the traditions and collective conscience of the people, so the common law of handling dying patients will be shaped by shared notions of how 'we' citizens want to be treated at that critical juncture. That is, shared notions of human dignity will ultimately govern decision making on behalf of incompetent moribund patients." These shared notions can govern, however, only to the degree that they are known, and they will govern well only to the degree that they flow from a process that is both informed and broadly participatory.

Education

One of the most straightforward solutions to the end-of-life decision-making dilemmas Americans face today involves education. As pointed out in Chapters 2 and 3, there is a great deal of agreement on many of the most troubling issues that caregivers and decisionmakers face when life hangs in the balance. The problem is that many caregivers are not aware of this consensus. And though there are no data to indicate the public's level of understanding about the consensus position itself, it seems fair to assume that the level of awareness is low here, as well.

Caregivers and the lay public may generally agree with the consensus position, but since their awareness of its existence is highly variable, they tend to fall back on the safe, culturally scripted position that leads to the decision to treat illness aggressively, every step of the way to the very end. All too often, we act the way we think we are supposed to act.

Public Misinformation

The response to a letter in the syndicated Ann Landers column (1995) is symptomatic of just how much education is required. The letter dealt with the plight of a seventy-two-year-old woman, a victim of Parkinson's disease who had been tube fed for eight years because of an inability to swallow. "The poor woman was flat on her back and unable to move for the entire eight years," wrote the patient's daughter-in-law. In the process, the woman
had wasted away to a weight of 65 pounds. The daughter-in-law went on to say that even though all family members agreed that continued feeding was “cruel and inhumane,” doctors refused to even consider withdrawing ANH from the patient because doing so, they said, would mean the patient “would starve to death.” Eventually, the tube came out by accident, and the patient, coherent at the time, chose not to have it reinserted. She died shortly thereafter and “was kept comfortable the entire time,” according to the daughter-in-law, who ended her letter with this: “We need to keep our loved ones who are terminally ill comfortable, but they should be permitted to go when their time comes.”

In reply, Ann Landers wrote: “The doctors’ refusal to remove your mother-in-law’s feeding tube was totally appropriate—not only from a medical viewpoint, but also legally. Had they removed the tube, they could have been charged with murder. When the tube accidentally fell out and your mother-in-law chose not to have it reinserted, the physicians on the case were no longer responsible for what happened.”

In her brief reply, Ann Landers managed to completely contradict at least three fundamental principles of the consensus position. First, patients (if they are competent) or their surrogates, acting in good faith, do have the right to make end-of-life decisions in cases of hopeless illness, and doctors should either accede to those decisions or transfer the patient to a caregiver who will. The preponderance of medical opinions, legal precedent, and, for that matter, ethical principles all point in this direction, Ann Landers’s statement notwithstanding. The doctors’ refusal to respect the family’s wishes may have been predictable and understandable, but it was not appropriate.

The fact is that the consensus position deems it appropriate for families to make end-of-life decisions on any number of bases, including the weighing of benefits and burdens a treatment imposes. The invasiveness of ANH or any other treatment is certainly one aspect to consider. Other relevant issues might include helplessness, immobility, incontinence, subjection of bodily processes to public exposure, extent of mental dysfunction, prolonged physical or chemical restraints, disfigurement (e.g., amputation for gangrenous limbs), and so on (Cantor 1989: 420). These are all quality of life factors that both the President’s Commission (1983: 134–135) and the Catholic Health Association have accepted as legitimate criteria to consider.

Third-party concerns associated with treatment have also been considered to be entirely legitimate criteria on which to base life-sustaining treatment decisions. How emotionally troubling is a treatment for the patient’s loved ones? How long can treatment be prolonged before the emotional and financial drain on family members begins to outweigh whatever marginal benefit accrues to the patient? And what resources devoted to the hopelessly ill might better be diverted to those who have reason to hope for a return to a good quality of life if treatment is provided? Both the President’s Commission report and the Vatican’s statement on euthanasia
agree that these are legitimate issues to assess when making life-sustaining treatment decisions. It also seems perfectly reasonable to assume what a number of courts have suggested: The emotional and financial impact on the patient’s family and friends would generally be an important concern of the dying individual.

Second, the doctors’ actions and Landers’s comments seem to imply that it was perfectly appropriate to withhold feeding once the tube fell out, although withdrawing feeding would surely invite criminal prosecution. Once again, nearly every significant piece of legal, medical, and ethical writing on this subject has rejected the distinction between withholding and withdrawing treatment. Simply put, any treatment that can be withheld can be withdrawn.

It is true that psychological barriers to withdrawing treatment exist. Psychologically, withdrawing treatment is quite different and much more troubling than withholding it (Solomon et al. 1993: 20). There may be no morally important difference between the two, but there is a huge difference for clinicians who have to carry out orders by clamping the feeding tubes or switching off the respirators that sustain the patient, especially when death does not occur immediately or in the expected time frame: Withdrawing just does not “feel the same” as withholding (Printz 1988: 85). At the same time, it is clear that whatever disquieting feelings withdrawal of treatment creates, these feelings should not be determinative, even according to the conservative state courts of New York and Missouri.

Third, caregivers who withdraw treatment are not accessories to a “murder.” The consensus position clearly states that forgoing treatment, even ANH, at the behest of legitimate surrogates who are acting in good faith does not constitute murder, suicide, assisted suicide, or euthanasia. Today, even though tube feeding of the hopelessly ill is widespread, the decision to forgo feeding and allow hopelessly ill patients to die of dehydration is made regularly by patients and surrogates, in hospices and elsewhere, all around the country.

As Ann Landers’s flawed response suggests, those who would hope to educate caregivers and the general public about what is legally, medically, and morally acceptable at the end of life have their work cut out for them, for they will not be writing on a blank slate. Rather, they will have to erase from the slate the misconceptions that exist both in the general public and in the medical community. Only then can they move ahead with the process of educating Americans about the consensus position and the range of options that should be available to the dying patient.

**Denial and Unrealistic Expectations**

In addition to the proliferation of public misinformation about end-of-life decision making, there is a great deal of private misunderstanding about
the indignity and suffering that accompany modern death. Today, the art of
dying seems to have been replaced by the science of living. The sophistica-
tion of rescue medicine, the wonder of high-tech interventions, and the
seemingly miraculous cures that are reported almost daily in the popular
media have fueled a sense of cultural scientism—a faith that medicine can
ultimately deliver us from any affliction (Hoefler 1994: 32–35). Scientism
also reinforces the ever present denial of mortality that makes end-of-life
decision making hard to think about prospectively and even harder to deal
with in real time (Hoefler 1994: 21–32).

Perhaps part of this denial of mortality stems from the fact that modern
Americans do not see death as often or as intimately as they did in eras past,
when death within the immediate family struck, on average, every seven
years. The typical American can now expect an average of eighteen years—
one full generation—between the deaths of close family members. And when
death does occur, it more often than not takes place in an institution of high-
tech medicine—out of touch, out of sight, and, in may ways, out of mind.

At the beginning of the twentieth century, 80 percent of all deaths oc-
curred in the home, where the body was prepared by family members,
waked in the family’s parlor, and buried in a grave dug in the family plot
out back by relatives and close friends. Today, more than 80 percent of all
deaths occur in institutions, after which the body is prepared by a stranger
(a licensed mortician) and waked in that stranger’s place of business (the fu-
neral home). The grave is dug by another stranger’s backhoe, after which
the mound of excavated dirt is covered with grass-green carpet lest grave-
side mourners dwell on the meaning of that pile of earth. Together, these
sanitized, third-person experiences with death lead us to think of death as
something that only happens to someone else, not to us.

If we move past the denial phase, we enter another phase in which we ei-
ther believe (or at least hope) that our passing will be marked by little in the
way of pain and much in the way of dignity. Nothing could be further from
the truth, according to Sherwin Nuland (1994: 265–268).27 Dr. Nuland ex-
plains that death is often marked by indignities of all descriptions, includ-
ing the inability to care for oneself, the loss of mental faculties (especially
with AIDS and Alzheimer’s), and a loss of control that is as frightening for
the patient as it is for members of the family. Death is made even more dif-
ficult by vain attempts to stave off the inevitable decline at the end of life. A
dignified death is something that only a few will have but that more could
experience if they faced the reality of death squarely and recaptured the
spirit of *ars moriendi* (Latin, meaning “the art of dying”), in which peace is
made and the humility of one’s own life in the big picture is more fully ap-
preciated. Death should be a celebration of the years that have preceded it,
not a process consumed with the suffering and indignities that mark most
passings. Squarely facing death and making decisions not to prolong it un-
necessarily should be the capstones of a worthy life. Futile attempts to res-
cue life from the jaws of death when the chances of doing so are remote and marked by further suffering only diminish and desanctify life, blowing the importance of the dying time out of all proportion. The sanctity of life is best honored by leading a good life, not in futile or even wasteful attempts to deny nature and, for those who believe, God what will be theirs, regardless of what we do on earth to forestall the inevitable.

The data on death and dying in the United States are as sobering as Nuland’s anecdotal reflections:

- Less than one in four Americans will enjoy a quick and unexpected passing from this life (Nuland 1984: 18). The rest of us will be left to cope with a managed death that can drag on for years or even decades.
- Half the population dies of a chronic condition that had been diagnosed, on average, nearly two and a half years earlier (President’s Commission 1983: 18).
- Seven percent of the elderly population become severely demented from Alzheimer’s or some other chronic degenerative disease before they die, a process that takes, on average, six to seven years to run its fatal course.
- The vast majority of patients and family members will, at some point, decide to withhold or withdraw life-sustaining treatment and allow a terminal pathology to run its course at the end of life. More often than not, however, this decision is made in the last days of life, after long bouts of suffering and emotional trauma have already been endured.
- Half of all patients who die will be in moderate to severe pain in the last few days of life, and a third or more will spend at least ten of their last days in an intensive care unit (Winslow 1995).

In the end, death in the United States is still considered a taboo subject, and it is not discussed in private or in public. As a result, our unrealistic expectations and our denials are never challenged, which is why so many of us have no idea what dying is like or what the consensus position permits. This was one of the clear messages of the massive SUPPORT study: Essentially, all of the efforts at patient education and empowerment on right-to-die issues failed. “What we learned,” said Dr. Joanne Lynn (1995), one of the study’s codirectors, “was that the conspiracy of silence about death was stronger than we expected and the force of habit was also stronger than we expected.”

Family members are not aware of the latest medical and ethical thinking on the subject of dying. The rituals of denial, the distance that has grown between Americans and death, the emergence of scientism, and the rise of unrealistic expectations together have conspired to shape the modern American culture of death, thwarting efforts at education or introspection.
To educate ourselves about death, we would be wise to volunteer in a nursing home, a hospice, or a hospital. We might decide to care for a dying relative at home or at least give a careful reading to Sherwin Nuland’s *How We Die*. In the process, we might then begin to frame realistic goals and expectations about how we wish to die and how aggressively we wish to stave off our inevitable passing.

**The Slippery Slope**

One of the most enduring of all barriers to enlightened decision making about hopelessly ill individuals is erected by ethicists and others who bandy about the phrase *slippery slope*. The *slippery slope* refers to a continuum of ethical actions; one end of the continuum, the high point of a slanted line, is defined by actions that are ethically acceptable. The further one moves down and away from this point, the more ethically suspect an action becomes. And the more steps one takes down the slope and away from the moral high ground, the easier it supposedly becomes to slide uncontrollably until entirely unethical actions at the lower end of the slope are practiced and accepted as the norm. The moral high ground for slippery slope theorists is often defined by the “never give up” ethic of care, in which everything possible is done to save and extend the patient’s life without taking any other concerns into consideration. At the bottom of the slope, the infirm are coerced into thinking they have a duty to die. Ultimately, the specter of active, nonvoluntary euthanasia for the mentally and physically disabled in society, à la Nazi Germany, is raised.28

The problem here is that, too often, these slippery slope theorists talk in terms of an overly simplistic world in which options are arrayed along a single inclined line; in this world, anyone who deviates from the moral high ground occupied by never give up ethics risks sliding uncontrollably toward dehumanizing atrocities of the first order. This is an unrealistic and, in some cases, a morally inappropriate position to take because the underlying ethic itself is flawed: Doing everything possible is *not* always the best or most morally appropriate course to take.

A better and more realistically grounded view would envision three ethical inclines instead of one, each with its own moral high ground and each with its own potential to become a slippery slope that, if followed too far for too long and with too little thought, could lead to serious ethical wrongs. The proposed slopes are based on three central themes: futility, autonomy, and dignity.

**Futility**

The first new incline for ethical analysis is based on the notion of medical futility. The moral high ground here is defined by the judicious use of med-
ical resources; at the bottom of the incline, patients or surrogates demand and get treatments that are so “inappropriate” that providing them constitutes a misuse of resources (see the section on medical futility earlier in this chapter).\textsuperscript{29} Medical resources (e.g., space, expertise, machinery, organs, and funding) are scarce, and devoting these resources to hopelessly ill patients when the chances of achieving a worthwhile medical goal approach the vanishing point constitutes an ethical transgression, especially when others who stand a much better chance of achieving a good medical result do not receive the care they need as a result.

When a patient’s situation is medically futile, only comfort care should be provided. And when we provide more than that, we begin to slide down the slippery slope, moving toward a point where some have access to care that they cannot put to good use while others suffer and die for lack of care they need but cannot get.\textsuperscript{30} This is not to suggest that there will be no controversy regarding what constitutes futile medical treatments. As Nuland (1994: 221) notes: “The boundaries of medical futility . . . have never been clear, and it may be too much to expect that they ever will be.” The best we can do is depend on a deliberative process and develop an informed consensus on the meaning and consequences of medical futility, understanding that, at the margins, there will always be some degree of error and even abuse—both in overtreating when treatment really is futile and undertreating when it is not. The expectation here is that using medical futility as one criterion will diminish poor decision making, not eliminate it.

**Autonomy**

The second of the three ethical inclines is based on autonomy. In this scenario, the patient has made clear, either personally or through a legitimate surrogate, what he or she wants done toward the end of life. If there is a reasonable hope that medical intervention will help the patient achieve a worthwhile goal (i.e., if the proposed treatment is not futile) and if the patient or surrogate desires that the treatment be provided, then treatment should be provided. By the same token, the patient or surrogate may reject any treatment, regardless of how good or bad the prognosis is, as long as the decision is informed, uncoerced, and (in the case of surrogate decision-makers) made in good faith.

The autonomy incline actually has not one but two slippery slopes. One leads in the direction of rationed care for the patient who wants a potentially helpful treatment but cannot afford it. The other involves aggressively providing care when it is not desired by the patient or surrogate. There is no controversy whatsoever in the courts regarding a person’s right to make decisions for him- or herself. And there is no controversy over the right of surrogates to make those same decisions in the name of an incompetent patient. The only controversy involves who will be the surrogate (does he or
she know the patient best, and is he or she acting in good faith?) and what level of evidence will be required to make a decision to forgo life-sustaining treatment. Even in states such as New York and Missouri, where clear and convincing evidence is required, a surrogate need not produce anything in writing; specific oral statements are enough to qualify.

The autonomy incline emphasizes the rights of the individual—rights that are protected as a matter of common law, constitutional law, and, in an increasing number of states, by case and statutory law as well. Here, a decision to forgo life-sustaining treatment, on the moral high ground of this incline, is celebrated as a perfectly ethical (and legal) choice rather than as a morally inferior act (as it might well be using the never give up ethics of the traditional, simplistic slippery slope).

**Dignity**

The third incline in the triad is based on the notion of dignity—that is, the belief that the decision that affords the patient the most dignity controls. This concept comes into play when (1) the proposed treatment has the potential to provide at least some minimal benefit, at a reasonable cost (rendering the futility slope irrelevant), and (2) it is entirely unclear what the patient would have wanted (rendering the autonomy slope irrelevant). In this scenario, the patient might be a lifelong incompetent or a loner without living family members or close friends. The patient might also be just a typical individual who, like most Americans, happened to keep personal views on end-of-life decision making to him- or herself.

Although no one can say with any certainty what these patients would have wanted, it would be a mistake to return to never give up ethics in such cases. The never give up philosophy leaves no room for a balancing of interests, and it penalizes those who did not or could not make their end-of-life medical preferences known by sentencing them to interminable treatment. When a patient’s desires cannot reliably be determined, the patient’s “dignity interest” should control, where dignified treatment is defined as the treatment most people would choose for themselves under similar circumstances.

Norman Cantor (1989: 415, emphasis in original) has argued persuasively that humane and dignified treatment is probably the touchstone of modern medical ethics and the general movement in the direction of patients’ rights that has been ongoing since the middle of the 1960s. Perhaps the key to defining humane treatment for the permanently unconscious being is broad societal consensus. The patient’s humanity is promoted by medical decisions which reflect a course which the vast majority of competent persons would choose for themselves in the same circumstance.

Those who subscribe to never give up ethics would probably agree with the Pennsylvania attorney general’s contention that Joey Fiori should have
been kept alive because he “was incapable of suffering pain or humiliation. . . . Fiori’s continued life could present no increased loss of dignity or intrusion on privacy” (Unger and Knorr 1995: 30). Those who believe the dignity interest should prevail would take issue with this position, however. The passage of time in an undignified state certainly increases the total indignity, even if the individual is unaware of that indignity—indeed, even if the individual is dead. In fact, the bodies of the dead must be treated with dignity as a matter of law. Can we stand to do any less for those who are living?

Some would also argue that when the patient’s desires cannot reasonably be determined, then it is best to continue aggressive treatment, based on the (false) assumption that it is preferable to keep alive all those who would rather have died than it is to let die all those who would have wanted to live. These critics would require—as the courts in New York and Missouri have—that surrogates produce clear and convincing evidence of a desire to forgo life-sustaining treatment in a particular case before honoring such a request. This is yet another manifestation of never give up ethics that, as Lindgren argues (1993: 186), makes no sense: “If most people would not want to be kept alive with high technology, why do we require proof that they want what most people want?”

Annas (1988) makes the same point by suggesting that it makes no sense to require exacting evidence of the patient’s desire to refuse treatment while accepting unquestioningly the mere possibility that the patient would want treatment, especially when the overwhelming majority of Americans say they would not want to be kept alive in a hopelessly ill state of irreversible unconsciousness. Further, he argues, forcing an irreversibly ill and demented patient to endure what many agree to be a humiliating existence is at least as troubling as withholding treatment from such a patient when it may have been desired.

The central problem of requiring clear and convincing evidence boils down to the fact that all indications suggest that the vast majority of Americans would not want to be kept alive in a vegetative state. If this is true, then many more will be harmed by acting on the never give up presumption than would be harmed using a patient’s dignity interest as a guide. This may be even more true for the severely demented, a class of patients who may retain some residual ability to sense the pain, discomfort, and frustration of continued life in a seriously degraded and hopelessly ill state.

In the end, decisions to give up on life-sustaining treatment and focus on comfort care can legitimately be made on any one of three bases—futility, autonomy, or dignity—depending on the circumstances of the case. Each of these inclines has its own slippery slope. And all three inclines must be considered together in any holistic view of end-of-life decision making (see the flowchart in Table 6.2). By contrast, never give up ethics provide us with an overly simplistic moral framework that does not respect the constitutionally protected autonomy interest, takes little account of resource
<table>
<thead>
<tr>
<th>Slope</th>
<th>Situation</th>
<th>Implementation</th>
<th>Harms avoided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sanctity of life</td>
<td>All situations</td>
<td>Do everything possible to save the life of the patient.</td>
<td>Allowing death to take place when life could have been extended.</td>
</tr>
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**A New Series of Ethical Inclines**

<table>
<thead>
<tr>
<th>Slope</th>
<th>Situation</th>
<th>Implementation</th>
<th>Harms avoided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical futility</td>
<td>Does the proposed treatment have a &quot;reasonable chance&quot; of achieving a worthwhile goal?</td>
<td>NO Treatment may be provided in the short term if the patient or the members of the patient’s family need time to become reconciled to the situation. Long-term treatment is morally optional, and may be morally problematic.</td>
<td>Denying treatment to those who may benefit because scarce resources are devoted to the provision of medically futile treatment to patients at the end of life.</td>
</tr>
</tbody>
</table>
Is patient competent to make decisions?

Has the patient left an advance directive or otherwise made his or her wishes known?

Is there someone close enough to the patient to know what the patient would want?

Any "YES" response

Any treatment may be accepted or refused by the patient or appropriate surrogate decision maker, in accordance with the patient's liberty interest.

Denying treatments to a patient who wanted them, or providing treatments to a patient who did not.

All "NO" responses

An individual, preferably a close friend or family member, is designated to "stand in the patient's shoes" and use knowledge of the patient's values to decide what is reasonable to assume about what the patient would want done.

Any treatment may be accepted or refused by a surrogate decision maker based on knowledge of the patient's views and in light of the balance of benefits and burdens of continued life and treatment, as most members of society would weigh them (the "best interests" standard).

Forcing incompetent, mortally ill patients to accept continued life-sustaining treatment when the vast majority of Americans view continued treatment to be undesirable and inhumane, and there is no evidence to suggest that the patient would think otherwise.
scarcity issues, and discounts as ethically suspect the balancing of interests that leads the vast majority of Americans to favor a less aggressive course of care at the end of life. In short, the never give up philosophy sanctifies the state’s common law interest in preserving life without full consideration of patient autonomy, medical futility, or the patient’s best interests. It is a dated and paternalistic ethic with little to offer us in the way of guidance in the modern debate about end-of-life decision making. And it should be retired as a relic whose utility has long since passed.

Advance Directives

Currently, living wills are completed by very few individuals. Moreover, even when living wills are completed, most clinicians agree that these documents have a minimal effect on the way they practice medicine (Ely et al. 1992: 473). Indeed, William Knaus (1995) found that advance directives had almost no effect at all on end-of-life decision-making scenarios. Many clinicians reject living wills as too vague to be operative; others simply disagree with the sentiments stated and decide to act on the basis of their own hunches and instincts instead.

One reason living wills are vague is that most patients who fill them out do so with little input from their physicians; providing such input takes time that physicians often do not have (and cannot bill for). There are approximately 115,000 general practitioners in the United States to care for 265 million people, or approximately 1 physician for every 2,300 individuals. If each general practitioner spent just five minutes a year discussing advance directives with every patient, it would take twenty-four eight-hour days; put another way, a whole month would be devoted annually to end-of-life treatment consultations. One way to begin addressing this problem may be to make advance directive consults a reimbursable expense under Medicare and Medicaid. Ethically, this is the right thing to do, and it may well save money and limit suffering in the long run. It would certainly enhance the degree to which patient preferences are identified and honored.

Most hospices address the advance directive problem by creating their own statements of philosophy and protocols regarding end-of-life treatment decisions. According to the President’s Commission (1983: 113–114), since the palliative ethos of hospice care is very much at variance with the curative ethos of both the hospital and society at large, most hospices take pains to explain their approach to prospective patients and their families. Many have lengthy admission procedures, wherein the prospective patient is informed of the hospice philosophy and consents to it prior to being accepted into the program. This consent serves the same purpose as an advance directive.

Nursing homes might do well to adopt a similar approach (and no doubt, some already do), although the range of treatment options would
Conclusions and Recommendations

surely be broader than it is with hospice. Admission is a good time to estab-
lish at least a baseline set of values and expectations about the degree of ag-
gressiveness that patients or their surrogates desire as illness progresses.
Admission is also an opportune time to discuss the various kinds of scenar-
ios that come up in nursing homes, scenarios that many patients and surro-
gates have not considered. Then, regular or “as needed” follow-up confer-
ences should be scheduled to ensure that decisionmakers remain abreast of
the patient’s evolving clinical situation and that the caregivers remain
abreast of the decisionmakers’ evolving preferences.

A key part of any protocol along these lines would have to involve patient
and surrogate education. As noted earlier, education is vital in making in-
formed decisions about life-sustaining medical treatment. When the patient
loses the will or the ability to take in food and fluids orally, for example, a
discussion about what it means to forgo ANH should be held (see Box 6.1).
Some caregivers may answer questions about forgoing food and fluids if
asked, and a few may even initiate a discussion on this subject. But rarely do
dthey document having had such a talk, given the sensitive nature of the sub-
ject. Ultimately, if these issues are not brought into the light of day, decision-
makers will forever be making judgments based on flawed assumptions.

There is so much misinformation about how one dies when food and flu-
ids are waived and the provision of sustenance plays such a large role in our
culture to begin with that in many cases, surrogates and patients may not
even think that forgoing ANH is an option. Therefore, caregivers have
some responsibility to initiate discussions on this topic if surrogates are to
make decisions that are truly and fully informed. All this consulting will re-
quire increases in staff, no doubt, but again, from an ethical as well as a
financial point of view, moving in this direction would probably be well
worth the effort (and well worth reimbursing).

Summary

We have concluded that the cases that involve true ethical difficulties are many
fewer than commonly believed and that the perception of difficulties occurs
primarily because of misunderstandings about the dictates of law and ethics.
Neither criminal nor civil law precludes health care practitioners or their pa-
tients and relatives from reaching ethically and medically appropriate deci-
sions about when to engage in or forego efforts to sustain the lives of dying pa-
tients (President’s Commission 1983: 184).

Today, thanks to a dizzying array of advanced medical technologies and
procedures, the day of death can be forestalled for months, years, and even
decades in some cases. But these advances have proved to be a mixed bless-
ing. Although the quantity of the average life has increased dramatically
since the beginning of the twentieth century, the quality of those last years
Conclusion and Recommendations

BOX 6.1 Forgoing ANH—A Primer

The following points regarding the forgoing of ANH might be discussed (for more on ANH, see Chapter 5).

- ANH is uncomfortable and irritating at best; it is often physically painful and mentally distressing, almost always requiring continuous restraints when the patient suffers from dementia.
- Starting ANH does not mean it cannot be stopped.
- Forgoing ANH is a perfectly acceptable course of action to take from a medical, legal, and ethical standpoint; it does not constitute abandonment.
- If fluid intake is halted, death comes relatively quickly (almost always within fifteen days, often much sooner)—the way it had for years prior to the popularization of ANH.
- Dehydration leads to a relatively comfortable passing that is usually accompanied by less pain and perhaps even a sense of euphoria. Symptoms are easily managed.
- Terminal dehydration puts the patient (or surrogate) in control; death from dehydration occurs without the need for assistance from others (except for the provision of comfort care and emotional support). No expertise is required; one simply stops taking in fluids, and nature does the rest.

If Americans only knew these things, they might feel sufficiently empowered to choose the dehydration alternative—calmly, confidently, and maybe even proudly—when the prospects of returning to a relatively good quality of life are dim. The old cliche “information is power” could not be more appropriate to this dimension of end-of-life decision making. In the not-too-distant future, perhaps Americans, armed with information about ANH and the dehydration alternative, will begin asking for a DNI (do not intubate) order as often as they ask for the now commonplace DNR order in the twilight of life.

of life—as perceived by the patient or, if he or she is incompetent, by the patient’s family—leaves a good deal to be desired. Life can be and has been extended in years, but many people have come to ask if the quality of life that results is worth the cost, both in financial terms and in the coin of false hope and prolonged suffering.

The problem is that increases in our qualitative health expectancy have not kept pace with increases in our biological life expectancy. As David Crippen (1994) notes: “An unintended side effect of modern technological advances has been the plausibility of maintaining moribund patients in a state of suspended animation for prolonged and sometimes indefinite periods.” We can attribute this situation, in large part, to the never give up ethic of medical care, a moral frame of reference that dictates (to caregivers and patients alike) that life is sacred and should be preserved at any cost.
Conclusion and Recommendations

It is time we made a conscious effort to revisit this basic and misguided presumption, a point the authors of the President’s Commission report made in the early 1980s: “There is a legitimate moral and legal presumption in favor of preserving life and providing beneficial medical care with the patient’s informed consent. Clearly, however, avoiding death should not always be the preeminent goal; not all technologically possible means of prolonging life need be or should be used in every case” (President’s Commission 1983: IV).

The status quo on end-of-life decision making is largely the product of cultural myth and misunderstanding. The myth is that we should always err on the side of life. Only a small percentage of Americans actually support this myth, but because so few recognize it as myth, most continue to go along with it, thinking that they are acting as the culture expects. Consequently, it becomes incumbent upon those who assist families in decision-making situations to inform themselves and then their patients and their patients’ surrogates about the emerging standards and clinical realities of medical care. If caregivers and decisionmakers were fully aware of the modern consensus in this regard, it would lessen the confusion, anxiety, and guilt associated with making the weighty life-and-death decisions that must be made in most cases.

In sum, though perfecting end-of-life decision making is beyond the reach of this or any text, it is hoped that the words laid down here will help move us in the right direction—away from the never give up ethics of the status quo and toward a more reasoned and thoughtful approach to death and dying. That approach would be advanced through (1) establishing medical standards for the care of mortally ill patients, (2) making better use of hospice care, (3) developing a more useful and widely shared concept of medical futility, (4) improving education about death and end-of-life decision making for caregivers and the general public alike, (5) modifying the old slippery slope theory of ethics to encompass changing, more complicated realities, and (6) making better use of advance directives. Then, perhaps, autonomy and dignity will (re)assume their rightful places as the goals of health care in life, in death, and especially in that hazy area that many of us pass through in the twilight of life—when we find ourselves in the moribund limbo Rosemarie Sherman called “between two worlds.”