Hard Decisions in Hard Times: Helping Families Make Ethical Choices During Prolonged Illness

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This chapter focuses upon the kinds of health care decisions that face patients and their loved ones at the end of life. The intention is to show how health professionals and other support persons often make these decisions more difficult than they need to be and to identify a few basic ideas for how to facilitate responsible health care decision making by those who are experiencing major loss in the context of prolonged and progressive illness.

Every medical treatment decision is an ethical decision. That is to say, every such decision is an answer to a *should* question:

- Should I undergo another round of chemotherapy?
- Should we bring Grandma home to die?
- Should we begin dialysis?
- What should we do about this low blood count?

A sound answer to each question depends on technical information or expert advice. But none can be answered by
reference to technical knowledge alone. Each decision has a value component. Each turns, in significant part, upon some notion of what is worth what; that is why every medical decision is an ethical decision.

In the course of a prolonged illness, the patient and (usually) her close family members or friends will make many such ethical decisions. They will make them in conjunction with health care professionals who bring to the decision-making process relevant knowledge and experience and, one hopes, skillful, empathic support.

Patients and caregivers will need such support, not only because these decisions tend to be difficult and couched in unfamiliar terms, but because the decisions must be made in the context of grief. A prolonged illness, even if it is not perceived as necessarily ending in death, nonetheless entails prolonged grief. A long, often progressive illness typically includes loss of well-being, vigor, function, social status, and self-image. Responses to such losses are profound, whether they are losses in one’s self or in a partner, parent, child, or sibling.

Sudden death or death after a brief illness compresses grief. There are relatively few health care decisions to make and they tend to seem largely apart from real life. In a brief, fatal illness, survivors are actually excused from making some decisions. Other decisions and major pursuits are postponed. Life seems to stand still. One takes time out for a brief illness and for acute grief. By contrast, in prolonged illness, life must go on and health care decisions that must be made are made in the midst of life and in the midst of grief. Moreover, these decisions tend to be more complicated in terms of their impact on ongoing family patterns and interests:

- Should we put Mother in a nursing home?
- Should Peter be taken off the ventilator?
- Is it right to let Dad make this decision about amputation?
• Should we feed her by mouth even though we know she could get pneumonia?

As these questions or ethical dilemmas illustrate, many health care decisions are choices among ‘least worst’ alternatives. Accordingly, the guilt that is a familiar component of grief can easily find a focus. Guilt, whether real or imagined, is no friend of sound and timely decision making. It is easy to see how the interaction of grief and ethical decision making cuts both ways: the nature of the decisions prompts grief responses, while aspects of grieving tend to complicate decision making.

**Shared Decision Making**

Important health care decisions tend to be shared decisions; more than one person is usually involved in the process. This appears to be true both in the sense that it is proper that it be so, and in the sense that that is what generally happens.

Decisions are shared in two dimensions: First, the clinician (the physician or other health professional) and the patient (or surrogate for the patient, if the patient is incapacitated) share decision making in a process known as ‘informed consent.’ The clinician lays out options, provides explanations and predictions and, perhaps, offers advice. The patient or surrogate assimilates, analyzes, and evaluates. The process is properly and, indeed, necessarily a dialogue. It ends with a decision to which both parties agree, and a plan of care that they then implement cooperatively. Though this process is often flawed and occasionally is so flawed as to support a judgment that there was no informed consent at all, this shared decision making is the ethical (and legal) ideal. Most of the time, clinicians, patients, and families manage a rough approximation of the ideal.

The second dimension of shared decision making is what happens between the patient (or surrogate) and his significant support people. Patients and principal family caregivers rarely act
alone, despite the fact that they might be fully within their rights
to do so. Even when one member of a family is clearly authorized
to make decisions, it almost invariably happens that others are
informed, involved, and consulted. Dying mothers and fathers
frequently reshape their decisions to accommodate the sensibilities
and preferences of their grown children. Spouses typically take each
other into account and do not act on their individual preferences
alone. Even deeply estranged family members commonly make
room for each other in family councils. The sole signature on a
consent form belies the typical array of stakeholders and the fact
that, as hard as it may be to do so, they do tend to acknowledge
and include each other when there are important health care deci-
sions to make on behalf of a common loved one.

In two senses, then, health care decisions at the end of life ordi-
narily come out of a process of shared decision making. Not only
do patients or their surrogates decide in conjunction with profes-
sional advisors, but those who are bound by familial duty or affec-
tion generally consult broadly as important end-of-life decisions are
made. They do so for a variety of reasons. The one most often is
articulated is, “I want this to be something they can all live with.”
It would not be too far off to rephrase this sentiment as, “I want
to decide in such a way as to not unduly complicate their grieving.”

Responsibility

People faced with difficult health care decisions are often most
impressive, even inspiring, in their bravery and selfless devotion to
duty. The young parents of a child with devastating congenital
problems who, despite the fact that nothing in their short lives
has prepared them for this responsibility, learn what they have to
know, master their urge to flee, and face into an ordeal that one
might expect would overwhelm them. A daughter manages to
put aside her own deeply held preferences in order to honor
her father’s wishes. A husband who is very nervous about
bringing his dying wife home does it anyway. The neighbor of a
woman who has no family volunteers to become the legal guardian in order to authorize her friend’s removal from life support. To work with such people as they make these decisions is a great and humbling privilege.

A few families are seriously dysfunctional and some patient surrogates are thoroughly irresponsible. Occasionally, decision makers or whole families manage to evade responsibility in ways that defy the conscientious efforts to assist and support. There are passive-aggressive personalities who make a pretense of responsibility, while the patient languishes and clinician frustration mounts. Fortunately, these are relatively rare.

All of what follows in this discussion of ethical decision making as it impacts upon grieving persons presumes that most patients and most family members are basically responsible, and that, with proper assistance, they will engage in good faith efforts to discern the right thing to do.

**Sound Decision Making**

It is possible to identify certain features of a good decision-making process without requiring subscription to any particular methodology or ethical theory. In general, the marks of sound decision making include:

**Adequate information.** Good decisions require good information. The very first step in any sound decision-making process is to assess whether the relevant information is reliable and complete. *Information* includes both fact and interpretation, both description and judgment. The perceived adequacy of the information may depend in significant measure on the reputation of those who have gathered the facts and made the interpretations.

**Appropriate identification of alternatives.** A frequent and serious mistake in decision making is to proceed to make a choice between two or three perceived options when, in fact, more care or imagination would have revealed additional alternatives. Sometimes the choice is framed in a way that distorts or obscures
the nature of the real options. It is possible to do everything else flawlessly and still miss the best alternative because it was never identified or adequately articulated.

Identification of decision makers. It may not be obvious who should make certain decisions. This uncertainty can derail an otherwise good process. Shared decision making as discussed above entails an often delicate apportionment of decision-making power or complementary aspects of a complex decision.

Identification of stakeholders. For many decisions, persons or organizations who would not be identified as rightful decision makers nonetheless have a discernable interest in the outcome. Interests may include money, prestige, ego, ideological stance, or expected courtesies. Full understanding of the social, political, organizational, and economic context within which the decision process unfolds requires attention to interested parties as well as to those who have direct decision-making roles.

Tolerance as affirmative respect. Those who share responsibility for a joint decision may or may not come from the same place ethically. If they approach the decision in basically the same way (for example, from the perspective of ‘rights’ and centrality of the principles of personal liberty), then decision making is apt to go smoothly. However, it commonly happens that those who share decision making proceed from different starting points or along divergent paths. In such cases, sound and efficient decision making depends upon a common commitment to tolerance and respectful listening.

We seem to be becoming a more tolerant people, despite signs of a worldwide resurgence of religious fanaticism and ethnic jingoism. Most of us seem to be more aware of pluralism and less certain that our cultural perspective is the only one worth notice. One hopes that this modern awareness does not lead to a moral relativism in which one opinion is thought to be as good as any and morality is equated with mere preference. Tolerance is a much more robust and demanding virtue. It respects persons, especially
as they attempt to make principled decisions. True tolerance succeeds not by devaluing the issues or traditions that divide us, but by affirmatively respecting those who differ in good faith.

**Clarity about key terms and concepts.** Good decision making is marked by precision of language, especially with respect to those words that are central to moral reasoning, emotionally loaded or heavy with obscure authority. In short, good decision making is careful to either avoid or to define exactly those kinds of evocative terms and allusions that are deliberately used by advertising writers and campaigning politicians. In the language of morals, as in political speech, there is a time and place for rhetorical flourish and emotional appeals. But when there are important decisions to make in difficult circumstances, sound decisions depend in part upon a good-faith effort to be as clear as possible about what is meant by key words and important ideas.

The above six marks of good decision making are all the more important when some of the parties are simultaneously coping with significant loss. If prolonged illness means ‘living with grief,’ it means deciding with grief. This realization underscores the importance of optimizing the decision-making process along the lines just suggested.

**Common Decision Points in Prolonged Illness**

The balance of this chapter is devoted to some of the common decisions faced by or on behalf of patients with prolonged and ultimately fatal illnesses. Against the background of earlier discussions of the shared nature of health care decision making and the characteristics of good decision-making process, we now proceed to examine some practices that militate against good decision making, entailing added stress and, perhaps, longer term complications for grieving patients and their loved ones.

We will also consider alternative strategies consistent with the foregoing marks of good decision making. These are potential interventions by which professionals and caregivers can make hard
choices not easy but more satisfying and more healing. Assuring sound and confident health care decisions is a way of facilitating, rather than complicating, the adaptive process known as grief.

**Foregoing Cure-Oriented Treatment.** At some point in many prolonged and progressing illnesses, there comes a point (or points) when those who share responsibility for the treatment plan will ask, “Should we stop our efforts to ‘beat’ the disease in favor of efforts to promote quality of life?” This development begins with an acknowledgment that the likelihood of cure or remission is fading and that the patient and the therapies are being overwhelmed by the disease. In the terms of grief dynamics, denial and bargaining give way to acceptance. This is not a happy moment, though it is often accompanied by a sense of relief or release.

Of greatest importance to these decisions is the availability of adequate information and accurate identification of alternatives. Physician judgment and physician communications are key to good decision making, though other parties to the process, including other health professionals and loved ones, can be either helpful or hindering.

Prognosis, a judgment about what the future is likely to hold both with continued treatment and without it, is the sort of judgment that physicians are uniquely trained to make. Patients, family members, and even other health professionals are dependent upon physicians to make these judgments and to communicate them. Failure to do so is not uncommon and is the proximate cause of much disordered decision making and much unnecessary suffering.

When Elisabeth Kübler-Ross began her ground-breaking research a generation ago, the first thing she learned was that few of her physician colleagues at a large public hospital acknowledged having any dying patients. Thanks to Dr. Kübler-Ross and many others, the incidence of professional denial is surely lower today. However, it is still common to find patients whose acknowledgment that they have come to the end of their lives is achieved
without any direct help from their medical advisor. In every hospital there are nurses and senior residents who can identify a handful of attending physicians who seem never to recognize impending death until it is unmistakable to even untrained observers. Here, the failure to provide adequate information is not a matter of factual inaccuracy, but flawed judgment.

It is also not uncommon for physicians and other professionals to acknowledge among themselves that a patient is irretrievably dying, but not to communicate that effectively to the patient or family. Few of us like to be bearers of bad news; but if that is part of one’s job, then a failure to effectively communicate it is a failure of duty and a subtle form of the ancient ‘physicianly’ sin of abandonment. Other members of the health care team may be slow to compensate for the physician’s failure. Nurses, consulting physicians, social workers, respiratory therapists, and other professionals are often reluctant to assume a function often thought to be, and sometimes jealously guarded as, the exclusive province of the attending physician.

Put most plainly, many patients and families cannot and do not make good and timely decisions in large part because they are not told the truth and are either given, or allowed to persist in, false hopes for recovery or survival. Whether because of ignorance, a lack of nerve or a powerful need to avoid, some physicians all of the time and many physicians some of the time seem unable to effectively communicate to their patients or their patients’ families that death is near. The consequences for sound health care decisions are serious. Appropriate choices about when to switch from curative care to comfort care depend absolutely upon medical judgments about what is reasonable to expect.

More common than the failure to make or communicate the medical determination that a patient is entering the final stages of his disease process is the failure to appropriately identify alternatives. The main culprits here are attitudes and habits of thought—the modern notion of the physician as one who ‘fights’ disease and
our liberal faith that there is a potential technological solution for
every problem.

Acknowledgment that cure-oriented treatment may no longer
be appropriate is often presented as though it means the end of
therapy. ‘There’s nothing more we can do’ is a familiar refrain. The
alternative to more chemotherapy or other life-prolonging inter-
vention is seen as ‘giving up.’ This defeatist language both reflects
and creates negativity and hopelessness. It suggests abandonment
and, because of relentless specialization, may indeed signal a
change to a completely new set of professional caregivers.

Dr. Patricia Murphy, a nurse specializing in bereavement
and clinical ethics, has proposed a more positive and accurate way
to frame the ethical question about foregoing cure-oriented
treatment. The core idea is to characterize the choice as between
two vigorous and ongoing forms of therapy, rather than seeing
one choice as doing nothing or giving up. To counter the passivity
and defeatism of the common perception, Dr. Murphy has coined
the acronym ACT, or Aggressive Comfort Treatment, as a way to
characterize the alternative to aggressive efforts to reverse or arrest
the disease process.

ACT is not merely a way to put a positive spin on an otherwise
depressing decision point. It actually helps correct a false impres-
sion that palliative care is ‘nothing’ and the misleading notion that
medicine has no concern for the alleviation of pain or enhanced
quality of life.

It is true that palliative care has been overshadowed by curative
medicine for the past fifty years. Most physicians and nurses do a
notoriously poor job of pain control at the end of life, according to
many observers and several important national studies. The nega-
tive language typically used to characterize the option of shifting
treatment to comfort-oriented goals has affected the attitudes and
shriveled the competencies of health care professionals. It has
undoubtedly influenced patients, families, and professionals to
pursue life-prolonging treatment long after they might otherwise have switched to therapies that maximize quality of life.

Language is powerful. It shapes perceptions and conditions choices. Perhaps ACT will prove to be a semantic force for the rehabilitation of palliative care as an essential medical competency. In the meantime, it suggests a way to help patients, families, and professionals to avoid guilt-driven and misbegotten pursuit of elusive goals because they did not want to ‘give up.’

**Do-Not-Resuscitate and Do-Not-Hospitalize Orders.**

In hospitals, decisions to forego cardiopulmonary resuscitation (CPR) are the most frequently made decisions with regard to withholding potentially life-sustaining treatment. Outside hospitals, the most frequent such decision is probably the decision not to send a dying patient to the hospital when that patient shows signs of impending cardiopulmonary failure. Such decisions are properly recorded in medical orders entered into the patient’s record after agreement by the patient or patient surrogate that CPR and its usual intensive-care aftermath would not be of net benefit.

Do-Not-Resuscitate (DNR) orders and Do-Not-Hospitalize (DNH) orders are appropriate for patients who are dying, permanently unconscious or seriously demented, in a condition that is both very burdensome and irreversible, or unlikely to survive in other than an intensive-care environment. It should be obvious that sound decisions about DNR or DNH orders are dependent upon the sort of prognostic judgments discussed at length in the preceding section. Patients or patient surrogates depend upon physicians to make and communicate these prognostic judgments upon which they can then form an opinion about whether CPR and its aftermath is ‘worth it.’

Patients and caregivers need to know about the probabilities of success for CPR relative to the patient’s condition. Lay people are commonly shocked to learn that the success rate (measured in survival to discharge) of many of the hospitalized patients most likely to receive CPR is as low as one percent. Physicians who
simply ask, “Do you want us to try to restart her heart if it stops?” are likely to get an answer that is unsound by virtue of its being grossly uninformed or misinformed. The remedy is clear. Patients (and, more often, families) need to be told about the probability of success.

Physicians or other professionals who engage in these decision-making dialogues can (and arguably should) also recommend or advise, rather than merely dispassionately ask. There is something ironic about a physician who has always offered recommendations at each treatment decision point until death is in view, and then suddenly has only questions and no more advice. This not-so-subtle behavioral shift suggests that the physician is disengaging at precisely the point at which a grieving patient or family most needs the constancy of a trusted and familiar medical advisor.

The choice about DNR is often presented as though it were a choice between life and death. It is ordinarily not really that at all. DNR should be more accurately and realistically seen as a choice between two kinds of death. Health professionals (or perceptive nonprofessionals) should frame the DNR decision for grieving family members in terms like this:

Your dad has come close to the end of his life. While it is impossible to predict how long he might manage to live, we can say with considerable confidence that he will not get significantly better and that his heart will fail—probably sooner than later. You all understand that, do you not?

OK, since we are agreed that your dad’s death is close, I think the goal of care from this point forward should be to do everything we can to assure his comfort and to enhance his chances to enjoy whatever life remains. I think we’re all committed to that goal. Right?

Now, when his heart does finally give out, it would be technically feasible to try CPR. I don’t think we should do that. The chances of it working are practically nil and
I’d rather see you all gathered at his bedside, speaking soothing words to him and each other and putting a cool washcloth on his forehead and telling him you love him. That’s good care for him when his poor old heart finally gives out. CPR won’t really help and doing it will mean that you can’t do what we know will help. What do you think about this?

This kind of decisional guidance is notable, not only for its accurate information about the probabilities of successful CPR and for the helpful advice offered by the physician, but also for the way in which the alternatives are framed. The choice is not between doing something and doing nothing, but between two differing interventions, one aimed at life extension and one aimed at life enhancement. If the reframing were motivated by a desire to sugarcoat and obscure, it would not be a worthy suggestion. Rather, it is justified on the basis of giving this family a more realistic and accurate understanding of the nature and consequences of the decision at hand. Finally, this approach is much more apt to afford the survivors the comfort, support, and confidence of a caring, fully engaged professional who shares in the decision with them.

**Tube Feeding**

The provision of hydration and nutrition through plastic tubing is a technological intervention frequently considered when patients cannot take food or drink by mouth. Tube feeding can be accomplished by way of tubes inserted through the nose and into the stomach (nasogastric or NG tube), or surgically implanted through the abdominal wall into the stomach (C tube or PEG) or (less commonly) into the small intestine (J tube). Also, for shorter periods, nutrients can be delivered through small-bore tubes directly into the bloodstream (hyperalimentation or HAL).

There is rarely any question about the appropriateness of artificially delivered hydration and nutrition when the intervention is employed as a bridging maneuver to support the patient over a
critical period until relative health is restored. However, questions may and often do arise when the incapacity to take oral feedings is a feature of a condition from which the patient is not expected to recover. Examples include:

- a 60-year-old woman who has suffered a massive stroke from which recovery is thought to be remote;
- a 75-year-old man with far-advanced Alzheimer’s disease who does not eat enough to maintain good nutrition;
- an 88-year-old woman with congestive heart failure which confines her to her bed and bedside chair and who, despite ‘having her full mental faculties,’ has little appetite and wishes that her daughter would just stop constantly pressing her to eat.

In each of these cases someone among the professional or family caretakers will suggest—and perhaps passionately insist upon—artificial hydration and nutrition. In each case, someone else will almost surely wonder aloud whether tube feeding is appropriate or vigorously argue that it is not. The symbolism of food and drink and the emotionally loaded associations of food with caring, nurturing, comfort, and family duties will almost surely play a role in decision making about the care of these patients.

Very careful attention to the way key words and concepts are employed would be required as the family members of each of these patients think and talk about whether to institute, withhold, or withdraw tube feeding. They will almost surely be vulnerable to emotional and intellectual manipulation. Someone—perhaps, regrettably, a nurse or physician or clergy person—may say to them, “you wouldn’t want your mother to starve, would you?” Sound decisions in such cases require that great care be taken to preserve important distinctions and remain clear-headed. For example, while ‘starvation’ may describe what would happen in the body of an unconscious patient, there would be no subjective
experience of deprivation in that patient. An emotionally laden statement such as “your mother will starve” conjures up images of concentration camp victims whose experience is totally unlike that of a profoundly brain-damaged, permanently vegetative stroke victim.

Dying patients who are alert, like the 88-year-old woman with end-stage heart disease, typically lose interest in food, a kind of anorexia of the dying. There is no evidence that they suffer. In any case, if such patients become hungry or thirsty, they can simply ask for or accept food and drink.

In all these instances, allusions to starvation are misleading. Such language by well-meaning people turns out to arise from ideological agendas or careless assumptions. It is not helpful for emotionally vulnerable family members trying to discern the right thing to do in confusing circumstances.

Careful attempts to distinguish between ‘feeding’ and mechanically mediated nutritional support are important to clear thinking. There is a world of difference between patiently offering Grandma a few spoonfuls of applesauce or Ensure pudding and pumping a pharmaceutically-prepared preparation directly into her stomach through a length of plastic tubing. A whole lot more than calories and minerals is being conveyed through spoon-feeding. Offering that spoonful is what we have been doing for our young, our old and our sick since time began. That, not tube feeding, is what is always obligatory.

One of the often overlooked consequences of resorting to tube feeding is that we stop or reduce the symbolically and interpersonally rich ‘nourishment’ that accompanies assisted feeding. To speak carelessly, or rhetorically, of tube feeding as if it were the same thing as a daughter lovingly helping her dying mother sip some broth or ginger ale is inaccurate and unhelpful. It does not lead to sound decision making, especially by those who are making choices in the context of anticipatory grief.
Summary

Family members, friends and health care professionals who share responsibility for health care decisions with or on behalf of persons during a prolonged illness make those decisions in the midst of their grieving. Grief can complicate the decision making; less-than-optimal decision making can complicate the grieving.

Both as a way to assure sounder decisions and as a way to avoid unnecessary complications of grief, those who would support others through such hard times would do well to pay attention to the characteristics of sound decision making. In this chapter we have identified some marks of good ethical thinking:

- adequate information
- appropriate identification of alternatives
- identification of decision makers
- identification of stakeholders
- tolerance as affirmative respect
- clarity about key terms and concepts.

Finally, we have looked at several specific decisions or ethical dilemmas commonly faced in the course of prolonged illnesses. In the context of these situations, we have identified some unhelpful behaviors and suggested strategies that support quality decision making.

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The original version of this article appeared in Living With Grief: When Illness is Prolonged, Kenneth J. Doka and Joyce Davidson, Eds., Hospice Foundation of America, 1997.