DEAR DR. JEFF
Jeffrey Nichols, MD, CMD

The Path to Doing the Right Thing

Dear Dr. Jeff:
Our nursing home ethics committee is occasionally faced with difficult decisions regarding end-of-life decisions for residents who lack the capacity to make decisions for themselves. Family and friends disagree, at times quite bitterly. The staff caring for the resident accepts the committee decisions, but often not very happily. Although we try to make each decision in accordance with our best understanding of the resident’s wishes in order to respect patient autonomy, the process leaves many disgruntled or unsatisfied. What do you suggest?

Dr. Jeff responds:
Last month I approached this question through a discussion of the limitations of a medical ethics process that treats autonomy as the sole ethical principle to be honored. Certainly, the rights of individuals who retain decision-making capacity must be a paramount consideration, as adults of any age should make their own decisions regarding their lives and their bodies. However, the numerous problems regarding advance directives — including the inevitable difficulty of identifying in advance how medical decisions might present and how preferences might change over time — make a blind obedience to these directives problematic at best.

The notion that designated proxies will make decisions when patients lack the ability to make them for themselves frequently falls short ethically, particularly in the typical situation when the designated proxies have no direct knowledge of how patients would, in fact, have made choices in their altered condition. Unfortunately for geriatricians, very few families discuss “Would you want to be on dialysis if you are already demented?” at the dinner table between “What’s for dessert?” and “What’s on TV tonight?”

Although the designation of health care proxies or agents definitely simplifies problems for the providers and provides a legal framework for decision making without resorting to the courts, the actual ethical basis for this process is rather doubtful. State laws typically authorize certain documents, such as durable powers of attorney for health care, or create a formal hierarchy of decision makers authorized to give or refuse consent on the patient’s behalf. But we should not confuse what is legal with what is ethical.

Using the theory that health care decisions made in accordance with a resident’s prior values demonstrate respect for the personhood of the resident, many ethics committees make serious efforts to explore what a resident’s actual values were to attempt to clarify the resident’s probable decision-making process. Often the designated proxy and other friends and relatives can be useful sources for information regarding a value structure that may be complex and nuanced.

For example, simply identifying the religious denomination with which an individual identified does not necessarily mean that the resident accepted all the teachings of that religion regarding health care and end-of-life decisions, or even knew what they are. The world’s major religions — Islam, Christianity, Buddhism, Hinduism, Judaism — are all divided into different denominations and movements with significant differences in practice. Even when a comparatively unified set of theological teachings is widely accepted — such as the Roman Catholic Church’s Ethical and Religious Directives for Catholic Health Care Services, a work that is widely disseminated and periodically updated — the interpretation of the circumstances creating an obligation to accept a feeding tube has varied from diocese to diocese.

A Life of Conflicts
Most of us simultaneously embrace contradictory values. We prize our independence and also our relationships with friends and family. We are concerned with preserving our lives and health but make frequent exceptions as needed for our pleasure or convenience. We try to minimize stress yet celebrate holidays with our families — including those relatives we can’t abide. We want to share our bounty with the less fortunate while still protecting our assets. We seek less clutter and more simplicity in our lives, but buy lottery tickets. Values frequently manifest most clearly when in conflict, as individuals demonstrate their priorities. Unfortunately, this often makes decision making based on respect for a resident’s values difficult, if not impossible.

Both the principle of substituted judgment, which underlies the use of proxy decision makers, and the attempt to derive current choices through the creation of a retrospective values history are attempts to extend the ethical principle of autonomy into regions where individual autonomous decisions are no longer possible. However, autonomy is not the sole basic ethical principle.

Beneficence, the obligation to do good to others, is an underlying principle of ethics for professionals, and it is a key concept in medical and nursing ethics. Financial and pension advisors may have no obligation to provide advice designed exclusively for their client’s best interest, but for health care professionals beneficence is not a choice; it is an obligation.

Beneficence is often portrayed as a bland instruction to do the right thing and is often regarded as simply the equivalent of non-maleficence (“above all do no harm”). However, this principle also extends to avoidance of actions that neither help nor hurt a patient — particularly when an act is done primarily to benefit the professional. For instance, nurses ethically should not advise a patient to choose a wound dressing that is less likely to promote healing merely because it is easier for the nurse to apply.

And the presence of health insurance is not an indication for a surgical procedure. Increasingly, pay-for-performance guidelines have attacked the principle of beneficence by rewarding practitioners for testing that is not medically indicated for particular patients.

Caring the Root of Treatment
The great Walsh McDermott, one of the original editors of the Cecil-Loeb Textbook of Medicine and a pioneer in population health, argued that the concept of beneficence should be expanded to “Samaritanism” — the professional expectation to actually care for the patient. We should not define ourselves as health care providers, as though we are owners of a medical store that sells medical services based on the patient’s preferences (even if we are honest salespeople of quality goods). If that is all we are, a corner drug pusher could be considered a “provider” of medications as well. Rather, we are suppliers of medications and caregivers, as indicated by our professional judgment.

The New Testament parable of the Good Samaritan is the foundational story of Samaritanism, and hundreds of hospitals and medical awards have been named in its honor. In this story, a man has been beaten by robbers and left half-dead beside the road from Jericho to Jerusalem. Several travelers of rank pass him by, but a Samaritan (then a despised ethnic group) stops to help; he then washes and binds the man’s wounds. If the tale stopped here, it would encourage simply an obligation to provide emergency assistance to the injured — as enshrined in the Good Samaritan laws that protect practitioners from lawsuits when they help in emergencies. But many forget that the story does not stop here. The Samaritan places the injured man on his donkey, transports him to a nearby inn, pays the innkeeper to provide care for the man, and promises to return later to pay any additional expenses required for his care.

Aspects of this tale are particularly salient for those of us involved in long-term care. The parable suggests to us an obligation to go beyond immediate medical care, to concern ourselves with the lives of our residents in an active way. This obligation may require much more than providing care in accordance with advance directives. Rather, it means participating in the formation of those directives, relieving suffering where we can, and helping to guide our patients and their families away from options that will only increase suffering, whether physical or existential.

Martin Luther King Jr. took this a step further: “On the one hand we are called to play the Good Samaritan on life’s roadside; but that will only be an initial act. One day we must come to see that the whole Jericho road must be transformed so that men and women will not be constantly beaten and robbed as they make their journey on life’s highway.” This is a Christian formulation of the foundational Jewish ethical imperative tikhun olam — to heal the world. For those of us in long-term care, this process should begin where we work.

Any discussion regarding end-of-life choices is in part a discussion of the risks and benefits of various alternatives. One of the stressful aspects of ethics committees is the participants’ awareness that none of the choices is likely to produce a good outcome — and with the extraordinary risk of choices that can produce significant suffering. Although the nature of disease and modern technology may control the benefits that the alternatives offer, we must find ways to minimize the risks.

The goal of our Quality Assurance Performance Improvement (QAPI) projects should go beyond improved statistics. The decision for continued survival in a long-term care facility despite an impaired condition and additional medical procedures should still be a decision for the highest attainable quality of life. The decision to forgo interventions should be a choice for a final period marked by comfort and respect, and for a painless death with dignity, surrounded by those who love and care for you, whether they are family, facility staff, or both.

Dr. Nichols is past president of the New York Medical Directors Association and a member of the Caring for the Ages Editorial Advisory Board.