Dear Dr. Jeff:

Our nursing home ethics committee is occasionally faced with difficult situations 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:

Ethics processes in the long-term care setting should not be a zero-sum game — that is, not a process that requires whatever is gained by one side must be lost by another. The goal of the committee should not be to decide who is being ethical, with the presumption that an alternative viewpoint is rejected as unethical, wrong-headed, or downright evil. Arguments may have winners and losers, but real-world clinical ethics often have only losers. When faced with end-of-life decisions, usually the only real decision to be made is how the process will play out, and perhaps whether it can be slightly delayed and how much the patient will suffer during the dying process. Making these decisions should not be an additional source of family strife, sibling competition, or grief. The experience of a dying loved one is difficult enough without conflicts and additional drama.

The template for long-term care ethics committees since at least the 1980s has been relatively simple. First, determine whether the resident has the capacity to make his or her own decisions. If yes, the resident makes the decision, and no further thought is required. If no (the resident lacks decision-making capacity), the resident has identified a proxy decision maker or provided a written advance directive addressing the needed decision. If yes, the proxy or the advance directive makes the decision.

Proxy decisions are honored using the principle of substituted judgment (the proxy speaks with the voice of the patient) unless there is convincing evidence that the proxy is acting purely from self-interest. Proxies may overrule prior written instructions, as their decision may be considered the same as the resident’s wishes, but even best-guess decisions may be honored when there is no other authorized decision maker.

So what is going wrong? Why are you, the family, and the facility staff left unsatisfied by the process? Perhaps the problem comes from the entire process being based on an insuffi cient single principle, spun out beyond any logical support.

Autonomy Is Elusive

The entire template I have described was created around the ethical principle of autonomy. Autonomy has come to be the central principle in medical ethics. (As a famous medical ethicist is reported to have jocularly said, “There are many important principles in ethics of which the first is autonomy and I forget the rest.”) The roots of the word are the Greek auto for self and nomos for custom or law, and the meaning of “the ability to make one’s own laws or decisions” is most commonly used in reference to political decisions and self-government. The opposite of autonomy is control by others.

Clearly, autonomy is not a typical feature of most of our lives. In the political sense, most humans do not live in countries where they possess even nominal control over their government. In the United States, a country originally founded to allow white men with property to participate in their own government (a principle gradually extended after considerable struggle to other groups), most Americans increasingly lack a belief that they have control over their government, which they perceive as dominated by corporate elites and lobbyists. Certainly, the spectacle of a government nearly passing health care “reform” legislation that was opposed by an overwhelming majority of Americans and essentially everyone in the medical community has reinforced the perception that the average American lacks political autonomy.

Beyond notions of political autonomy, few of us exercise autonomy over most areas in our lives. As Rousseau put it in the opening of The Social Contract, “Man is born free and everywhere he is in chains.” Economic realities, family obligations, and environmental constraints hem us in on every side. In the medical field, the conditions that create the need for long-term care are beyond the control of nearly all our residents, and even the most cooperative of patients can rarely reverse these conditions or even control the progression of their illness. (Job 9:3–35 speaks to our powerlessness against such misfortunes.) “Bad genes, bad behavior, and bad luck are among the primary predictors of nursing home placement.

So why, among the endless and depressing list of constraints, should autonomy be the sole ethical principle? Eric Cassell, MD, in his wonderful and enlightening work The Nature of Suffering and the Goals of Medicine (Oxford University Press, 1991), discusses this issue. Legal awards are allowed for “pain and suffering,” in recognition that suffering — emotional distress — is a concept different from pain. The relief produced by kissing a boo-boo, for example, does not come from alleviating the pain of a scraped knee but from reassuring us of our place in an essentially safe universe where we are loved. One aspect of the suffering induced by illness is the powerlessness and loss of control it produces.

Often, having sufficient information about the diagnosis and course of a disease can provide comfort beyond that of any particular treatment. Patients’ choices regarding treatment options help to restore a sense (illusion?) of control, which may relieve their suffering. This is all consistent with the choices we offer to residents regarding meal times, bathing schedules, bedtimes, and daily outfits — all attempts to restore some dignity and power to individuals who are essentially powerless and totally dependent, even for their activities of daily living.

Respect for the personhood and dignity of the individual underlies the expanding list of “resident rights” embodied in federal regulations, which attempt to redress the power imbalance inherent in institutional medical care of the weak and frail.

Acknowledging Reality

Clearly, the single-minded concentration on resident rights and autonomy becomes less useful when a resident lacks the capacity to make decisions. I doubt that many patients derive much comfort from the promise that their wishes will be respected should they become too cognitively impaired to decide for themselves — and even less from being able to designate who will make these decisions after they lose decisional capacity. Health care proxies and legislation designating priorities among family and friends are certainly useful for clarifying the medical decision-making process, but they are minimally useful for the residents themselves. As multiple studies have confirmed, potential proxies make decisions with no statistical correlation above chance when compared with the decisions the residents would make for themselves. “Substituted judgment” is a convenient myth.

One of the forgotten ethical principles is “peace in the family.” This is a well-established value in the Judeo-Christian heritage, and probably in other religions as well. End-of-life decisional struggles may have a subtext: family members trying to prove either that the dying patient loved them more (“She made me the proxy, so I am the winner”) or that they loved the patient more (“I want her to live, and you want her to starve to death”). It is unlikely that most residents want the process of their dying to be an additional cause of suffering for their family (including their new nursing home family) or a new chapter in ongoing sibling rivalries. Indeed, I have had many residents elect to undergo chemotherapy, with all its attendant discomforts, though they believed it would be ineffective because it satisfied the needs of their spouse or children.

Human beings exist in family and society. It diminishes the humanity of our residents to describe them as simply selfish consumers of health care, whose decisions are based only on their own needs and preferences.

I have never seen an advance directive specifying that an individual wishes to be kept alive at all costs, even if it bankrupts the family and causes them extreme emotional suffering. Similarly, I have never seen an advance directive that rejects all life-prolonging interventions even if the likely date of death coincides with a beloved granddaughter’s wedding. An ethics committee process that works out a compromise among the affected parties might ultimately provide a more valid demonstration of the resident’s genuine desire, compared with a committee ruling on the validity of a decision by a legally designated proxy.

Long-term care facilities should work to enhance the autonomy of our residents, but a single-minded fixation on this goal oversimplifies the complexity of truly caring for them. In the process of attempting to respect the individual we need to recognize when “rules” are in fact guidelines, not instructions, and that one size rarely fits all.

Jeffrey Nichols, MD, CMD