Dear Dr. Jeff:
The staff at our facility are frustrated by a small number of families pressuring us for what seem like unreasonable intervent ons for their relatives, especially when the relative is not only extremely elderly but severely demented with multiple medical problems. Legally, they are the decision-makers and have the right to direct hospital transfers and drug their “loved one” to multiple consultants who, in turn, recommend multiple expensive tests and invasive procedures. The dying process for these residents is prolonged and painful, usually leading to a final hospital transfer where the inevitable attempt at CPR is unsuccessful. Is there anything we could do to protect our residents against what feels like elder abuse?

Dr. Jeff responds:
I, too, suffer from the recurrent delusion that I know what is best for everyone. Having children and grandchildren is an excellent reminder that we can try to guide and direct but can’t really control other people’s lives no matter how much we love them. Our patients or residents may come to us for advice, but in the end they may choose to eat the diet they prefer rather than the diet proposed by their dietitian; they can take or reject their medicines regardless of how clearly their nurse explains them; they can refuse the completely appropriate blood tests that we order and subsequently go to another practitioner and accept an entire battery of lab work that is inappropriate for their age and medical status. In short, residents have the right to be pig-headed and foolish — the right to be wrong. Sometimes everything turns out as well for them as it would have if they’d followed our advice.

In the practice of long-term care, we are more comfortable with residents who reject treatments that might benefit them than we are with those who request interventions that, in the judgment of the interdisciplinary team, seem hazardous or futile. Although there is an absolute right to refuse, there is no right to demand that practitioners order medications or tests that aren’t indicated or are potentially dangerous. Patients have a right to seek advice from their practitioner of choice, but not the right to have those recommendations followed by the facility or the attending physician. Similarly, there is no obligation to make the appointment for them or to arrange transportation or an escort. However, it is always worth exploring why a patient is making these requests; they may be evidence of underlying worries about their medical condition that deserve to be addressed and, if possible, resolved.

Sometimes the mental comfort of the patient is a sufficient indication for a test or procedure. For example, our facility recently updated our policy regarding indwelling Foley catheters to changing them as needed rather than monthly, following the recommendations of many within nursing leadership. One resident asked that his catheter continue to be changed monthly because every extra day that it was in place he worried that it was becoming infected or would cause bleeding. Reasonable requests like this should be accommodated. Another resident asked to be referred to a urologist for a cystoscopy because of one episode of blood in her urine in the context of a documented infection. She was very worried that she had cancer; a discussion about hemorrhagic cystitis and a urine cytology examination relieved her anxiety.

Non-Resident Decision Makers
Conflicts become more difficult when the decision maker is not the resident but a designated proxy or next of kin. They are presumed to be speaking with the “voice of the resident,” but members of the interdisciplinary team sometimes doubt that this is true. Multiple studies comparing the hypothetical care decisions made by a proxy with the choices the patient would actually make have suggested that the concordance is not much better than pure chance. Actual discussions regarding goals of care between patients and their proxies are uncommon and frequently tend to be quite vague. What might seem like a straightforward request — not to be kept alive with tubes, for example — may be hard to translate into a decision regarding a time-limited trial of intubation, much less a hospitalization or Do Not Resuscitate order.

We may understand these conflicts better if we had to address them ourselves. How many health care professionals who have designated a formal proxy have discussed with that proxy what our preferences would be with a 6-month course of chemotherapy? Now say we are already somewhat demented but still recognize our family members and enjoy meals and activities. What if that chemotherapy offers us an 80% chance of extending our life by 4 years? What if it were a 20% chance of cure with no life prolongation for non-responders? Or a 100% chance of cure preceded by 6 difficult months?

Would the knowledge that the resident highly values family involvement, does not particularly object to going to doctors, loves Judge Judy, and does not actively practice any religion provide enough information about their values to help guide these decisions? Would the likelihood of scheduling oncology visits so they don’t conflict with a favorite television program change the balance between risks and benefits? How about the fact that the resident already routinely wears a wig? Often it simply isn’t possible to know what the patient would have chosen under a particular set of circumstances that may arise.

Do Everything
When the family or the health care proxy chooses the invasive course, they may well be reflecting the choice of the resident. The preference for heroic procedures, hospital care over community care, multiple specialist opinions, tests of minimal or no utility, overmedication, and death-denial are all characteristics of modern American medical care. Regrettably as the decisions many family members make may seem, they are hardly outside of the range of the deplorable community standard of care. When our warm handoff to the emergency department elicits the angry question “Why isn’t this dehydrated, dehvenilized 90-year-old with urosepsis a DNR?” our answer might be “The family watched too many episodes of ER and House, and is expecting a miracle cure. And it wouldn’t make any difference anyway since as of now, she is breathing and has a pulse.”

Long-term care physicians are frequently at a disadvantage recommending aggressive comfort care measures when the hospital experts are still recommending aggressive medical interventions. One major New York teaching hospital has for years run advertisements with the tagline “Amazing Things Are Happening Here.” In several of the patient testimonial videos, the patients refer to the “miracles” that were performed for them or their surprise that they were returned to 100% health after years of illness. In another ad, a nurse states that she chose her job because she wanted to be a part of making miracles happen! This is, in fact, an excellent hospital, but none of my nursing home residents have ever experienced a miracle there — one branch of the “miracle” hospital does not even have a palliative care consultant. Of course, decisions to “do everything,” like decisions to have a feeding tube placed, often come from a misplaced expression of love for the resident. Lacking clear instructions from the resident, proxies have difficulty separating what they want and need from what the patient might desire. Sometimes the proxy is operating on a futile internal drive to demonstrate their love by showing themselves and the world by leaving no stone unturned in their attempt to save the loved one — thus avoiding any guilt associated with opting for less aggressive treatment. At other times, the drive may come from panic at the prospect of impending loss. When they are challenged to consider the values of their parent, many children would argue that their parent’s love for them was so great that they would have happily undergone any suffering to simply be alive and present with the family. And there is often some truth to this perception.

A fifth or sixth hospitalization for the same condition might suggest to some that further repetitions of this pattern would be unreasonable. But others might conclude that survival with congestive heart failure or chronic lung disease or recurrent infections can be prolonged forever with “modern medicine.” The presence of vital signs in patients who have spent much of their last years of life in hospitals or radiology suites is seen as proof that the course of treatment is successful, even as the downward spiral continues.

Many of the seemingly burdensome treatments inflicted on our residents are the recommendations or suggestions of “specialists” who treat one organ or system. These practitioners are not treating the patient as a whole, so they often cannot recognize the limitations of these treatments in a patient who is experiencing functional decline and suffering near the end of life. When health care proxies follow a physician’s suggestions — whether for screening colonoscopies or an eleventh MRI — they may be painfully prolonging the dying process, while still following the historic choices of the patient. This may be untrue but it is certainly not elder abuse in the classic sense.

Discussions regarding risks and benefits can be awkward when the risks appear very large and the benefits very small. Still, the point of such discussions is to consider the alternatives after providing sufficient evidence for an informed choice, with the resident’s values providing the relative weights. In weighing the burdens and benefits of various interventions, many seniors regard the prospect of being an ongoing personal or financial burden to others as a significant factor in their decision making.

For example, my 90-year-old grandfather had been in relatively good health barring mild congestive heart failure and severe hearing loss (caused by 65 years working in a metal shop) when recognition of anemia and the subsequent...
work-up led to a diagnosis of gastric cancer. Faced with the choice of high-risk surgery or hospice, he unhesitatingly chose surgery — as he saw it, either he would be cured or he would die on the table. He regarded either as preferable to surviving for months as a burden to others, even if he was reasonably comfortable and pain-free. As it happened, he enjoyed another 10 years of active life.

Understanding Motivations

If this seems like a defense of the over-invasive family, perhaps it is. Just as we need to explore and respond to the concerns of our residents when they request seemingly irrational or unnecessary treatments, we should also explore the understanding and motivations of the decision maker. We do not have to be passive observers in this process — but first, we need to spend more time making sure that the decision-makers have been meaningfully informed of the clinical situation. Families may have been informed that a disease is “treatable” without hearing the qualifying “for a time.” Newspaper stories of impending new cures for Alzheimer’s disease or surgeries for Parkinson’s disease may confuse families with a belief that these are just around the corner if only they hold out or find the right doctors. Sometimes the simple act of reviewing the problem list — and all the comorbidities and failing organ systems — is a valuable corrective to an excessive attempt to “cure” the primary diagnosis.

Rather than simply blaming the outside specialists, we should try to reach out to them and create a mutual plan that respects the resident’s overall condition. They may need to be freed from the expectations of an anxious family who is constantly asking whether there isn’t anything more that can be done so they can actually recommend drawing limits. Sometimes the family will accept from them the truths that they cannot hear from us. Losing a spouse or parent is always painful. Watching their physical and cognitive decline may be equally or even more painful. We should sympathize with the frantic efforts that many proxies make to fight off the inevitable even as we are saddened to see the adverse effects of the choices they make. Demonizing the family is not a useful approach to denial and emotional distress. Until “aggressive” palliative care becomes a more viable option, we need to find compromises that support the family while struggling to protect the resident.

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

Louisiana Nursing Home Residents Escape Mass Evictions

A divided Louisiana Senate voted 27-10 to back a state operating budget of more than $28 billion that would make steep cuts across state government to protect health programs for the elderly and disabled. The budget approved on May 15 will protect nursing home residents from evictions and keep Louisiana’s safety-net hospitals from closure.

Before the budget approval, the Louisiana Department of Health recently sent out letters to about 37,000 post-acute and long-term care facility residents, informing them that they could lose their Medicaid coverage and be evicted later this summer. This was the result of deep cuts to health care in the current state budget due to an approximately $550-$650 million shortfall, created by the expiration of temporary taxes.

The vote helped stave off a “devastating ripple effect,” said Mark Berger, executive director of the Louisiana Health Care Association, by avoiding a logjam at emergency departments and home and community-based agencies, as record numbers of older people and their families sought to obtain these services.