Advance Care Planning Discussions Help Physicians Walk the Talk

Dear Dr. Jeff:

When we have obtained advance directives such as do-not-resuscitate orders and helped a resident to identify a health care proxy, the major decisions regarding invasive and extraordinary health care procedures remain troubled and conflicted. Our residents still wind up dying in the hospital, often in the intensive care unit. What are we doing wrong?

Dr. Jeff responds:

DNR orders are the beginning and end of many facilities’ discussions with residents regarding their goals of care. The Patient Self Determination Act of 1990 required health care providers, including nursing homes and home care agencies, to notify patients of their right to execute advance directives concerning their care. At far too many institutions, this requirement is taken literally. That is, patients being admitted to the hospital have an informational handout placed under their pillow as they are wheeled to their rooms. Uncommonly, at PA institutions, this farce is continued by adding the information sheet into the giant packets of materials that patients or their designated representatives have received on admission as part of the admissions agreement.

You have truly exceeded expectations in trying to help your patients identify individual proxies to make decisions for them should they be physically or cognitively unable to make health care decisions themselves. Unfortunately, as you have discovered, neither of these two documents ensure a desired and planned outcome as advanced illness evolves.

Naming a health care proxy is an important first step because it allows someone designated by the resident to make decisions. Health care proxies rarely know what the resident would have actually wanted (in some concordance studies in which residents and their proxies are presented with scenarios about potential health problems, there is no correlation between them beyond chance). The proxy may well be no better prepared than the resident for complex medical decisions.

Discuss CPR, Then Transfer

Discussions about CPR are not futile even though the procedure often is. First, they offer an opportunity to discuss the nature and complexity of a resident’s underlying disease, its progression, and the likely outcomes. Just as tests are frequently organized with a few easy questions at the beginning, a discussion about advance planning and goals of care can begin here as every patient and family is aware that death will certainly come sometime, if only in the far off future. Even though the health care system seems to treat “full code” vs. DNR as a key issue, the decision is made regardless of whether the patient will die with or without a few broken ribs, at least in the LTC nursing home population.

Hospital transfer, not CPR, is often the key decision. Hospitalization itself is frequently another step in a painful downward spiral of recurrent infections, weight loss, mental and physical frailty, and skin breakdown. Most residents survive their first few hospital transfers, often returning physiologically stabilized but functionally worse. In long-term care, do-not-hospitalize orders have significant consequences; DNR orders do not. The failure to address the important questions, regardless of whether it is with the patient or the proxy, is the process failure that leads to the frustrating results you cite.

Prognosis Matters

Patients have a right to know their diagnosis and prognosis. Prognosis is not the same as life expectancy, which is notoriously hard to predict. It is, rather, the probable course of disease. It is also the rational basis on which to consider and finalize health care decisions before the development of an acute, life-threatening change of condition. Residents and families frequently have little knowledge of the natural history of specific conditions, much less the implications for a particular case. Although in many facilities issues regarding advance directives are left to social workers, prognostic information and specifics about medical treatment options are topics that only a medical practitioner should be expected to provide. It is, uniquely, the role of the physician (or nurse practitioner or physician assistant) to discuss these important matters with a patient and/or family, in sufficient detail that they can make informed decisions.

For example, a new resident may be admitted with amyotrophic lateral sclerosis (ALS, or Lou Gehrig’s disease). This is an incurable disease associated with inevitable functional decline, progressive weakness and muscular atrophy. Typical life expectancy is 3 to 5 years from onset of symptoms; however, 10% of patients are still alive at 10 years. While there is certainly vital information to share with a patient, it is worth listening to the patient’s and family’s accounts of how rapidly the disease has progressed to discern whether this particular patient is likely to survive 3 years or 10 years.

More important than the life expectancy, however, is the usual course of the disease. Patients with amyotrophic lateral sclerosis will typically develop difficulties with speech and swallowing, and ultimately die of respiratory failure. When the diaphragm and chest wall muscles become sufficiently weak, labored breathing and shortness of breath are expected consequences. Decisions regarding intubation, particularly since it likely to be permanent, should be made before the critical stage has arrived, because the resident is likely to be cognitively intact but have limited ability to speak and ask questions about the risks and benefits of prolonged mechanical ventilation.

Similarly, decisions regarding feeding tubes should be addressed before dysphagia becomes critical and recurrent aspiration provokes respiratory complications. All the familiar literature debunking feeding tubes is directed at their use in end-stage dementia, a totally different clinical scenario. The practitioner who has failed to initiate these discussions has guaranteed that when the critical decision time occurs, the resident and family will be unprepared. Whether the resident chooses an implantable electric stimulator for the diaphragm, some period of extended life dependent on a ventilator, or hospice care, that should be the patient’s own decision, not one made in the face of a crisis with pneumonia and its resultant dyspnea and cyanosis.

Similarly, patients with longstanding diabetes complicated by significant peripheral vascular disease or diabetic nephropathy should be provided with good information about their likely prognosis. Diabetics with small vessel disease do poorly with multiple surgical attempts to bypass vessels or limit tissue loss. Similarly, frail diabetics with end stage renal disease typically experience repeated hospitalizations with a severely impaired quality of life, while international data suggest that those who are dependent on transfers actually live longer without dialysis. Many would benefit from directly addressing their problem when significant impairment is identified, allowing them to use this period near the end of their lives productively. Just as oncologists too frequently believe that their role is to treat the cancer rather than treat the patient, vascular surgeons are often entranced with “limb-sparing” procedures that are not patient-sparing, and too many nephrologists are simply dialysis providers. Whose responsibility is it to discuss the probable prognosis with a patient who is failing to heal an amputated toe? Certainly not the social worker’s.

Many families predict a much more rapid death than is typical for moderate or even advanced stage dementia patients. Families frequently press for hospice care when death is still several years away. The progression from symptoms difficult to manage in the community (wandering and incontinence) may result in a nursing home stay of a decade or longer. This is important information for a family, emotionally and financially. Those who attempt a bedside vigil are likely to exhaust themselves long before this kind of attention is actually appropriate. Nevertheless, a discussion of the risks of hospitalization should be initiated at this point. Residents who may blossom in the nursing home when familiar caregivers assist them in their activities of daily living are at particular risk of physical and chemical restraints or functional decline when hospitalized. These residents’ proxies should be informed about the services that your facility can provide to a resident who declines medically. They might consider a DNH directive, to be revisited if a condition develops that they and the team conclude might tilt the risk/benefit ratio for hospitalization in favor of a transfer.

And as residents progress toward the final stages of the disease, consideration should be given to a deliberate decision to forgo artificial fluids and feedings, long before aspiration pneumonia or significant weight loss forces the decision.

Discussion Incentive

Doctors have avoided these discussions because they falsely believe they are being asked to predict life expectancy, a challenging task still required for hospice referral. Fortunately, Medicare has recognized the need for these advance care planning discussions and developed billing codes to reimburse for them. And, since there is recognition in the billing codes that these discussions are a gradual process requiring revisiting as conditions change, there are available codes for extending and reviewing these questions. Genuine informed discussions about prognosis should, in turn, produce the advance directives that truly enhance patient autonomy and collaborative care.

Dr. Nichols is president of the New York Medical Directors Association and a member of the Caring for the Ages Editorial Advisory Board. Read this and other columns at www.caringfortheages.com under “Columns.”

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