Dear Dr. Jeff:

After receiving a recent survey deficiency, our facility completed an exhaustive plan of correction regarding DNR orders. Although more than 90% of our residents have DNR orders that are clearly documented and communicated and the follow-up survey confirmed we are now code compliant, there has been no impact on our hospitalization rates. Several residents continue in a revolving door pattern between here and the hospital, distressing patients and families. What are we missing?

Dr. Jeff responds: There is a longstanding confusion between documenting preferences regarding cardiopulmonary resuscitation (CPR) and effective advance care planning. Far too many health care professionals and family members believe that an order not to perform CPR extends, by inference, to many other health care choices. Naming a health care proxy and decisions regarding hospital transfer and invasive procedures are different but much more likely to have a significant impact on a resident’s quality of life.

The process for obtaining decisions regarding do not resuscitate (DNR) preferences and ensuring that these have been properly documented and communicated to all shifts of staff can be difficult. In the end, DNR orders in the long-term care setting are meaningful but rarely critical. After all, the rate of successful resuscitation in hospitals for all cardiopulmonary arrests is less than 20%, whereas statistics for 30-day survival after CPR in the community are approximately 2%. Advanced age and poor underlying medical status predict an even lower probability of survival. Time between the arrest and the initiation of external electronic defibrillation also correlates with poor outcome. One large study from an excellent Canadian facility, which shared a code team with the hospital next door, did not record a single nursing home resident who survived 30 days after cardiopulmonary arrest.

In the end, a decision to not attempt resuscitation is largely about respect for the body of the deceased resident rather than a meaningful health care decision. Unfortunately, the extraordinary rate of success demonstrated on television medical programs, in which as many as two-thirds of resuscitated patients walk out of the hospital, has contributed to making these discussions difficult.

That said, in younger and less functionally impaired nursing home residents, particularly those admitted for post-acute care, CPR might offer at least some minimal prospect for success. Units for these patients who wish an attempt at resuscitation should have trained staff and readily accessible defibrillators.

In July 2014, the Journal of the American Medical Directors Association (JAMDA) published an excellent review and meta-analysis of the efficacy of advance care planning with an accompanying commentary by Dr. Karl Steinberg, the editor in chief of Caring for the Ages. Interventions using videos, brochures, individual and group conferences, scripts, and chart reminders serve to encourage the completion of advanced directives in a variety of patient populations. With no good evidence to support one technique over another, facilities should follow the leadership of local champions, regardless of discipline, and use the most appropriate mechanisms for their patient population.

Goals of DNR

The real goal is not that DNR forms are signed, but rather that resident care preferences are identified and respected. Advance directives should reflect the wishes of the patient not of the facility or the attending physician. Advanced age alone should not be a reason to deny patients a chance to prolong their lives should they choose, nor should frail seniors be subjected to painful interventions and die alone in a hospital simply because of a facility’s reflex responses to deteriorating medical status. The quality of a facility’s program that encourages advance directives should not be measured by the number of DNR orders alone, although they often reflect the outcome of an honest discussion of the resident’s medical condition and the relationship between the likely result of an attempt at CPR and the resident’s goals of care.

Since the terrible failure of the 1995 SUPPORT trial (JAMA 1995;274[20]:1591-8), it has been clear that identifying patient preferences and goals of care may not necessarily alter medical practice. The SUPPORT trial involved more than 9,000 patients at five teaching hospitals. Specially trained nurses initiated extensive conversations with patients and their families, encouraged conversations with their physicians, and provided all parties with prognostic information, including the probability of death or significant disability. Yet no improvement was observed in the concurrence of patient preferences and the number of days spent in intensive care units or on mechanical ventilation, in the level of reported pain, or in patients who were comatose prior to death. Nearly 20 years later, as hospital care gradually transitions from the primary physician to the newer hospitalist model, it seems even less likely that a hospital physician would be familiar with an individual patient’s wishes.

Three Avenues to Better Care

Fortunately, three other advance directive mechanisms offer significant hope that residents’ wishes will be respected. These are: the formal designation of a health care proxy or agent (also known as a Durable Power of Attorney for Health Care); Do Not Hospitalize (DNH) or Do Not Intubate orders (DNI); and the POLST (e.g., Physician or Medical or Clinician Orders for Life-Sustaining Treatments) paradigm forms. They are not mutually exclusive, and a resident may have any combination or all three.

They represent attempts to identify, create, and document enforceable orders regarding the plan of care.

Often the most useful document is the designation of a health care proxy. Most states have enacted legislation to allow families to make medical decisions regarding the care of other family members when they are unable to make decisions for themselves. These mechanisms are often cumbersome and ineffective, particularly as they attempt to create order out of chaotic family relationships. Should the long-separated wife of an elderly man make medical decisions for him because they are still legally married? Or perhaps the partner he lived with for the past 2 years before institutionalization? The adult child who pays his bills using a standard power of attorney, but who rarely visits? Or the one with medical knowledge, or perhaps the child who lives nearest or yells the loudest? With rapidly changing marriage laws, couples may be married in one state and not in another, which may affect a spouse’s ability to make medical decisions for his or her loved one. An ethically valid proxy should represent the voice of the resident based not on blood or certificates but on knowledge of the resident’s values and preferences.

Even residents with significant dementia can decide who should make decisions for them when they are unable to do so for themselves. A resident who is still able to identify family members and friends has the capacity to name a proxy. Because the designation of a health care proxy is relatively simple, it is entirely possible to ask a resident who should make a decision and then turn immediately to that proxy to present the risks and benefits of a course of treatment. Unlike the “Do Not” format of many advance directives, proxies allow for complex decisions under confusing or uncertain circumstances. Proxies are appropriate for all residents, including those who are cognitively intact, as the probability of delirium accompanying any severe illness in long-term care typically leads to the need for an additional informed decision maker.

DNH and DNI orders protect residents from unwanted interventions that might arise in an emergency. Without a clear directive (a DNR order is silent in these situations), the facility appropriately calls for an emergency hospital transfer. This is the typical scenario that shuttles residents with advanced disease into a pattern of emergency department visits and multiple hospitalizations. It is best to discuss when hospitalization would be desired or rejected long before the actual crisis. Such discussions are particularly appropriate for patients with amyotrophic lateral sclerosis (ALS) or severe chronic lung disease, for whom hospitalization and mechanical ventilation are likely future outcomes, absent clear advance directives.

The POLST paradigm is a format for comprehensive advance care planning, incorporating complex patient preferences into a set of orders that are portable across care transitions. They allow patients to choose interventions they want and to specify those they don’t. AMDA’s House of Delegates endorsed the use of the POLST paradigm at its 2014 meeting as a mechanism to enhance advanced care planning. Subsequently, a multi-author study published in the July 2014 issue of the Journal of the American Geriatrics Society evaluated more than 50,000 deaths in Oregon that determined the approximately 18,000 individuals with POLST forms in place were almost four times more likely to have their wishes respected regarding terminal care (J Am Geriatr Soc 2014;62[7]:1246-51). In hospitals with palliative care programs, the POLST process helps create instructions for the post-acute facility or home care, thus avoiding repetitive discussions and unwanted rehospitalizations.

Too many facilities only document that they distributed the information required by the Patient Self-Determination Act; they do not have serious advance care discussions. Your facility should be congratulated on the work you have already done to accurately document and respect patient treatment preferences. Having already started the conversation, it should be easier to continue.

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