Revisiting Comfort Care

Dear Dr. Jeff:

Multiple articles tell us that if we only had quality palliative care services in nursing homes, we would not need (fill in the blank, from physician-assisted suicide to rebushipsizations to statutes to hospice referrals). Our facility has been trying to create a program and a policy for comfort care while still complying with regulations from the Centers for Medicare & Medicaid Services. We reached out to the palliative care specialist at the local hospital for advice, but she stated that she had no experience with nursing home care and no suggestions except obtaining advance directives and referring patients to hospice. Can you help?

Dr. Jeff responds:

Confusion regarding the differences between comfort care, palliative care, and hospice care continue throughout organized medicine. This confusion may be worse in long-term care, where the acceptability of the general notion of enhancing patient comfort and forgoing invasive procedures has wide acceptance, but only limited application. Financial pressures to avoid hospital transfers and managed care penetration into long-term care have stimulated further interest in programs seen as reducing expensive interventions, increasingly costly medications, and futile hospitalizations. Even mandatory antibiotic stewardship programs, featured as preventing the development of resistant organisms and antibiotic-related complications, have a simultaneous intention of cost reduction. Indeed, some facilities use their pharmacy antibiotic bills as a measure of program success.

Regardless of motivation, these trends have empowered many practitioners and medical directors in long-term care to develop practices and policies that the many knowledgeable and compassionate professionals in our field have sought for years. Ironically, the dreaded “reg” that are sometimes cited as a barrier actually support many of the care enhancements that good programs would introduce. Some of these regulatory elements date back to the original Federal Nursing Home Reform Act (OBRA 87) reforms, which attempted to endish geriatric best practices into nursing home care. Although the intentions from CMS leadership have not always penetrated to local survey agencies or individual surveyors, most will recognize and support good care, which requires appropriately documented resident choices and resident autonomy.

What Is Comfort Care?

Comfort care is a vague term that suggests many different possibilities. Although some have used comfort care as a synonym for palliative care, the National Cancer Institute defines it as “care given to improve the quality of life of patients who have a serious or life-threatening disease.” Because nearly all residents of nursing homes, and many in assisted living facilities, have serious diseases that have produced significant functional deficits, this definition would apply to them. The National Institute on Aging website suggests that comfort care has four key elements: attention to physical comfort, mental and emotional needs, spiritual issues, and practical support. These are all mandatory elements of the Minimum Data Set and care planning process in the nursing home. Every long-stay resident and most post-acute residents by this definition should receive comfort care (attention to some needs might need to be arranged after discharge for very short stays).

Indeed, what resident or family would reject comfort care? Who would voluntarily opt for rough handling, an uncomfortable mattress, nasty food, or unattended pain and discomfort while consuming unnecessary or harmful medications, with emotional and spiritual distress ignored or dismissed as a behavioral complication of dementia or a natural consequence of aging? Who would ask to be awakened from a sound sleep at 6 a.m. because morning care is the responsibility of the night shift and must be completed before the next shift arrives at 7 a.m.? Who would want to be denied access to religious activities required by their faith? Or be forced into incontinence because of a lack of assistance getting to the toilets? Some of these deficient practices still occur in a few facilities, but every facility should already be working to completely eliminate them. They are indeed violations of the Requirements of Participation in Medicare and Medicaid.

Again, nursing home admission should put everyone on comfort care. and by the way, I prefer no one break my ribs and stick a tube down my throat prior to embalming.” Advance directives like these may remove the need for time-consuming and strenuous activities by the staff, but they do not really help guide the care of the living. Similarly, designation of a health care proxy simplifies decision-making, but it does not necessarily clarify the decisions to be made or even prevent needless interventions or expensive futile care processes.

The POLST (Physician Orders for Life Sustaining Treatment) Paradigm form — the name varies from state to state (e.g., MOLST, POST, COLST) — is a more significant step toward palliative care. This medical order allows a resident or health care proxy to make advance decisions on a number of common pre-terminal interventions, such as intubation with mechanical ventilation, feeding tubes, hemodialysis, and antibiotics. The form can be adapted to cover a variety of potential interventions that might require transfer outside the facility customized to the specific individual, such as cancer chemotherapy or blood transfusions, and it allows authorization of time-limited trials of interventions that might prove to be temporary. Thus, a resident might authorize a trial of dialysis to determine whether a decline is related to acute renal failure or another underlying disease, while specifying that if no significant improvement in functional or cognitive status occurs, the dialysis should be terminated.

Because POLST is a medical order, it would require a specific override by the decision-maker and the physician, which dramatically improves the likelihood of compliance with the resident’s wishes and decreases the rate of inappropriate hospital transfers. Most of the interventions that might be rejected would require hospital transfer and often occur with an urgency that prevents careful thought and discussion. These forms require physician signature and generally require medical explanation regarding their nature and relevance for the particular patient, so they require physician and team input.

This is the sort of advance care planning that is reimbursable under the Medicare billing codes and it should be encouraged. POLST is not palliative care per se, particularly as patients and proxies may still choose a variety of uncomfortable interventions with minimal probability of benefit, but it does help seriously ill people get the kinds of treatment they want and avoid getting treatments they don’t want.

Unfortunately, formal palliative care training often excludes significant exposure to nursing home residents, except when they are transferred back into acute care. I was on the faculty of one otherwise excellent program where the total exposure was one half-day at our facility.

Palliative Care Essential

There is a national shortage of specialists certified in palliative care. They are highly sought-after in acute care settings where the need is critical and their services can be liberating and transformative. The palliative care needs for nursing home residents are real, but could and should be adequately addressed in high-quality long-term care. Although there are many excellent practitioners certified in palliative care who work in nursing homes, they are predominantly nursing home physicians who have been grandfathered into the field. Although insufficient for board eligibility in palliative care, many geriatric fellowships now include significant palliative care components in their curriculum and rotations; in fact, there are combined palliative and geriatric fellowships.
With the tremendous growth of the hospice industry (more than two-thirds of American hospices are for-profit), the likelihood is that any hospice physician who might consult in your building has little or no formal training in palliative care or expertise in the management of nursing home residents. Although hospice does offer many potential benefits to your residents, and particularly to their families, do not expect that a hospice contract will necessarily provide much assistance to your proposed program.

Knowledge Gap
Twenty-five years ago, when I was asked to be the acting medical director for the hospice that was affiliated with the hospital and nursing home where I worked at that time, I decided to seek board certification from what was then the American Board of Hospice and Palliative Medicine. As I read the review materials for the examination, I was astounded to discover that they sought to teach these presumed specialists a variety of topics that are probably already quite familiar to most of the readers of this article: basic medical ethics, the need to treat pain, the principles of team-based care, listening to the patient and the family, basic pressure ulcer management, the concept of delirium, and the use of laxatives, particularly for patients also receiving narcotics. What was new largely concerned hospice eligibility, certification, and mandatory minimum services.

After two recertifications from the American Board of Internal Medicine, I have learned more about pain relief through aggressive invasive procedures and about the needs of dying children and their families, but the additional knowledge and insight I have gained regarding nursing home palliative care has come from my colleagues, JAMDA and other geriatrics journals, and presentations at the Society national conferences. The Core Curriculum materials and Clinical Practice Guideline are an excellent place to begin.

Palliative care is care provided to manage symptoms, rather than cure illness or prolong life. Residents are “on palliative care” when they or their proxy determine the goals of care and prioritize symptom management over other possible goals. And palliative care can be given in conjunction with what is often considered traditional “curative” care. Aligning the plan of care with the goals of care is much more than simply creating a list of interventions that might or might not be done. It requires a comprehensive review of the medication list, but also all the elements of the care plan. Does a floor ambulation program enhance the resident’s independence or simply aggravate sore knees and hips? Does a low-salt diet decrease the enjoyment of meals or help to limit the symptoms of congestive heart failure? Could more be done for a resident who has apathy or mild depression that isn’t sufficient to “trigger” on the Major Depression Rating Scale?

Most of the functional deficits and nursing needs that necessitate long-term placement are aspects of diseases that can’t be cured and whose natural history is largely beyond the control of modern medicine. Whether the underlying diseases are cognitive, neurologic, cardiac, pulmonary, or endocrine, good palliative care is often the best care that an excellent geriatric team can provide. A palliative care program helps to focus on the residents’ goals, and our own — both what we do and why we do it.

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