Dear Dr. Jeff:

Our nursing home has a contract with a nearby hospice to help us provide care to terminally ill residents. But it seems that our staff and theirs are constantly squabbling. I planned to switch to another hospice that is slightly farther away, but friends tell me that it is no better. Why should professionals who give compassionate care to the dying be so difficult to work with? Do you have any suggestions on how we can all get along? Or should we just cancel the contract and provide quality end-of-life care ourselves?

Dr. Jeff responds: Conflicts between nursing homes and hospices are depressingly common, so common that they are obviously not the result of individual bad apples. There are structural, institutional reasons for this friction, and they need to be examined and addressed.

Despite the need to provide coordinated care, hospices and nursing homes come from dramatically different traditions and cultures, operate within conflicting regulatory environments, experience different financial concerns and constraints, and bring differing areas of expertise to patient care.

When you add the bizarre contradictory regulations that require each organization to be responsible for the coordination of care and responsible for care deficiencies in the other party, it is amazing that collaborations exist at all. However, as nursing homes are increasingly the site of care for dying seniors, with an estimated 25% of deaths in the United States occurring in nursing homes, the need to get all this right is already large and likely to grow even more.

In this column last year (Caring For The A ges, June 2010, p. 6), I described the potential benefits to a nursing home and its residents of a relationship with a hospice program. These include enhanced access to expensive medications for symptom control (provided as a hospice benefit), the experience of hospice nurses in enhancing resident comfort, the availability of social work and bereavement counseling to the families of the dying patients, the potential for individualized comfort services such as one-on-one music therapy or reminiscence therapy, and the clarity that the hospice declaration provides to state and federal surveyors when they review the charts of nursing home residents who have experienced negative outcomes such as weight loss or skin breakdown. These advantages have not changed.

From Different Places

The hospice benefit was not an original component of Medicare. It was added in 1983 after demonstration programs around the country confirmed that hospice programs offering a defined set of benefits could provide care that both satisfied patients and their families and saved dollars and time. An arbitrary number of 6 months’ life expectancy was selected as a qualification, and regulations decided to capitate payments to maximize hospices’ flexibility in delivering needed care.

These demonstration projects grew out of an international hospice movement that sought to transform end-of-life care from what was perceived as a cold, painful, frightening, medicalized process, with death usually coming to a person alone in a hospital surrounded by machines. Instead, death was to be a dignified, comfortable process, preferably coming at home, with the patient surrounded by friends and family. Of course, these supposed opposite poles were both exaggerated, but they did reflect some truth.

The hospice movement’s historic roots were in religious facilities founded to care for the dying. The modern hospice movement traces back to Dame Cicely Saunders in England and her founding of St. Christopher’s Hospice in the 1960s. Dr. Saunders had originally trained as a social worker.

The movement placed itself in opposition to the medical establishment, and early hospices were located in homelike settings far from hospitals and nursing homes. Hospices in the United States frequently continue to identify with the counterculture and alternative medicine, even when operated by giant for-profit corporations or large teaching hospitals.

It is not surprising that a movement that was originally designed to take control of the dying process from the doctors (sometimes explicitly to put it back in the hands of spiritual figures) should frequently find itself in opposition to formal medicine.

Many hospices assume that physicians will wish to withdraw from the care of the patient when he or she chooses the hospice alternative – and they are often right. Even when the referring physician wishes to continue to be involved with the patient, hospice nurses often expect function with great independence. In a home setting, nurses usually see a patient much more frequently than the physician does and generally request approval for a long list of as-needed medications. This allows the hospice nurse to adjust medications rapidly in response to evolving symptoms rather than track down the primary physician to receive verbal orders as the patient declines.

Hospice social workers and pastoral staff are also accustomed to a community environment where they operate without much need to coordinate with a primary physician or other nonhospice professionals. Hospices hold interdiscipli- nary team meetings and develop care plans in collaboration with their hospice medical directors, but these chart entries aren’t necessarily communicated to the primary physician.

At the same time, nursing homes are also required to create interdisciplinary care teams that review them with the attending physician. Nursing home physicians must continue to make all the federally mandated visits and are expected to continue to provide all needed primary care to their residents. Most nursing homes’ attending physicians are present in the facility routinely and may be physically present more frequently than the hospice nurse.

There is, for the nursing home, no expectation that care decisions at the end of life will be ceded to the hospice team, or that the nursing home physician will cease to provide care, even if the goals of that care have changed from curative to palliative.

When the hospice staff operates independently, the nursing home staff may feel disrespected or even at risk of regulatory deficiencies. That said, nursing homes and nursing home physicians do need to learn more about the provision of care that addresses symptoms while eliminating unnecessary testing and inappropriate medications. The nursing home medical director and the hospice medical director should help with this process.

No Wrong Answer? Hospices legitimately claim expertise in the care of the dying. Nursing homes legitimately claim expertise in the care of the elderly. Who is the expert in the care of patients who are both elderly and dying? Before turf wars break out, both staffs have to be open to the knowledge and experience of the other. Nurses who have provided loving care of a resident for many years must be open to advice from “outsiders” when that resident reaches the last 6 months of life.

At the same time, hospice nurses need to respect the geriatric expertise of the nursing home staff and their knowledge of the resident and the family that has developed over years of providing care. AMDA’s 2007 “White Paper on Palliative Care and Hospice in Long Term Care” (www.amda.com/governance/whitepapers/palliative_care.cfm) recommends a formal process to coordinate the two plans of care. I would suggest going beyond this to a shared plan created in a meeting of the teams. Coordinated care of the resident requires that everyone be literally on the same page.

Many hospices assign their care teams by geographic areas. The staff visiting your nursing home may also be seeing terminally ill patients living in neighborhoods near your facility. While this saves travel time, it often means that the hospice team has little familiarity with nursing home care, its regulations, or the resources available there. This, in turn, may lead to care proposals that are unnecessary or inappropriate. For example, many hospices routinely request that physicians order their standard list of as-needed medications, including many powerful anticholinergics and sedatives that are generally inappropriate for the elderly and might represent dangerous polypharmacy.

In my experience, hospices with a team that specializes in the care of nursing home residents, regardless of which home they may be in, are much more effective in communicating patient needs to the nursing facility staff. If the hospice’s typical patient roster doesn’t afford that possibility, the hospice should consider more formal training, – at least, of the staff assigned to your facility – on issues of nursing home care and geriatrics.

When I was a hospice medical director, I was shocked by how little training our staff had in dementia care, the identification and management of delirium, and pharmacologic issues in the elderly. At the same time, many nursing homes are reluctant to administer appropriate doses of analesics to patients with pain or to accept administration schedules that don’t acknowledge the known half-lives of the pain medications being administered.

The process that you describe as “squabbling” may be minor in details, but the underlying conflicts represent a potential threat to your residents. If your staff is ignoring suggestions that might make residents more comfortable simply because they distrust the messenger, everyone loses. You should encourage your medical staff to report problems to you and allow you to resolve them with the hospice medical director. The two clinical staffs need to meet regularly. We all need to share our expertise and learn from each other for the good of our residents.

By Jeffrey Nichols, MD

Dr. Nichols is the vice president for medical services of the Cabrini ElderCare Consortium in New York City, which includes two skilled nursing facilities, three home care programs, and a senior housing complex. He invites your questions for possible discussion in this column. Please submit them by e-mail to caring@elsevier.com.