Ashes to Ashes, Dust to Dust

Dear Dr. Jeff:

Yesterday morning I found an experienced CNA standing outside a resident’s room crying. Attempting to console her, I asked if I could help. She replied, “Pappy’s dead and I didn’t even know.” Other than to confirm that a long-time resident had died over the weekend, I had little to offer by way of consolation. Do you have any suggestions?

Dr. Jeff responds: There is an inherent contradiction in asking long-term care (LTC) staff to care about people for money. I don’t mean assessing their functional abilities and care planning, or assisting them with activities of daily living, or providing a variety of professional services designed to meet their physical, intellectual, nutritional, and spiritual needs, but to genuinely care. Caring implies feeling concerned and affection. The Oxford English Dictionary derives “care” from the Old Norse word for sickbed and the Old German word for grief. The underlying focus of the person-centered care movement is to try to establish some sort of caring relationship between institutional staff and the residents under their care.

Surveyors notwithstanding, the point of honoring resident preferences is to see each resident as a worthwhile human being with desires and needs and to wish to respect them.

In a recent article in the Journal of the American Geriatrics Society, a geriatrician recounted his journey from viewing his patients as a sad and frightening collection of cognitively and physically impaired individuals, whose lives lacked meaning or purpose, to the point where he eventually recognized them as human beings with innate dignity and worth. As sad as this account was, there are many professionals in long-term care who discharge their responsibilities competently, but without any emotional involvement with the individuals under their charge. But for many front-line employees, including not only nursing, but housekeeping, dietary, and recreation staff, residents become like family.

Most facility mission statements encourage these relationships, but I am always amazed how often they are genuine.

Staff members often know the details of residents’ lives, including family secrets, and take pride in “their” resident’s physical appearance. Particularly for those residents who lack highly involved families, aides often bring in special toiletries from home, hair decorations or small items purchased with their own money to brighten their lives. In facilities where linens are scarce, aides will hide extra towels or sheets to ensure that their residents’ needs are met.

In facilities with regular staffing assignments, personal involvement is often intense, as a single aide might spend 40 hours weekly with a small group of chronically ill residents over several years. Facilities have encouraged the concept of “neighborhoods,” but we are truly talking about relationships that go much deeper than that of neighbors. Of course, these relationships often develop among residents, including not only roommates and those who share recreational interests from music to bingo but also table mates. (Who eats three meals every day with a neighbor?) Home health aides and aides in assisted living facilities (ALFs) often spend equally long hours with even smaller numbers of frail seniors and may easily become involved with their lives, as they enter their homes and are surrounded by their personal mementoes.

Dealing With the Inevitable

Death is also a regular visitor to LTC facilities. Our patients come to us because of their physical and cognitive frailty, which we know as a marker for shortened life expectancy. The hospice mantra, “Would you be surprised if this patient died within 6 months?” is inappropriate for long-term care. We shouldn’t be surprised when any resident dies. After all, average life expectancy for a long-stay nursing home resident (according to the 2004 Nursing Home Survey) is 835 days—or slightly more than 2 years—from admission. Some studies suggest that one-third of nursing home residents die within 6 months of admission and nearly a half within a year. A facility with 100 beds should anticipate 40 deaths per year.

In a recent newspaper article discussing a district attorney’s decision to investigate the suspicious death of a 71-year-old, ventilator-dependent nursing home resident, the family was quoted as saying they had no warning that she was seriously ill. Either this was massive family denial or a failure to adequately communicate the extent of this resident’s disease and overall prognosis, or, most likely, both. Because ALFs now accept severely functionally impaired admissions, their statistics are not very different. Average length of stay for those admitted to assisted living cognitive units is 17 months, with half progressing to nursing homes and half dying within the ALFs. Regardless of whether our patients meet technical hospice criteria, or whether they choose to embrace or forgo invasive treatments, they are all at the end of life. This includes younger residents with severe functional impairments. As nursing homes increasingly avoid futile terminal hospital admissions and embrace hospice care, death in these facilities will become more common. In fact, at least a quarter of all deaths in the United States now occur in nursing homes.

How can we embrace both a philosophy of loving kindness and the reality of death? The practice of long-term care has made significant progress in the recognition of death by encouraging advance directives and collaborating with hospice programs. Hospice provides a bereavement benefit for families, and some facility social workers direct families to other local resources, such as AARP or senior center bereavement programs.

But for our employees and residents, life is simply supposed to go on as usual. The room is cleaned and a new resident replaces the old with as little time lost as possible. The demands of census always trump the needs of grief. When my grandfather died at age 100, after spending nearly 18 years progressing through levels of care in the same facility, his belongings were promptly boxed and brought to the basement while his room—a single he inherited off the waiting list—was immediately reassigned. The facility made no effort to recognize his death, although the activities director who had invited him to her wedding took the day off to attend his funeral.

Many facilities try to hide the reality of death. Declarations of death and death certificates become an emergency, as bodies are rushed out through service elevators to back entrances and waiting hearses. The departed resident is treated as though he or she miraculously disappeared. HIPAA regulations are falsely asserted to justify refusal to acknowledge that the missing resident has died. Staff and residents are denied their basic human need to grieve. Hospice programs know their staff will experience grief and potential burnout, and they design programs to address this. But LTC facilities, regardless of their association with community hospice programs, do not.

Rituals of Death

One excellent exception to these behaviors has been modeled by several Veterans Affairs nursing homes. When a resident dies, an honor guard of employees marches with the flag-draped body, accompanying the deceased to the hearse. This recognition of at least one aspect of their life’s value contrasts dramatically with most common practices. Are the lives of all our residents not worthy of some gestures of respect and remembrance?

Grief and burial practices vary significantly among religions. Many Americans are nominal observers of religions that believe in an afterlife that offers hope for some happier future. Some follow religions that espouse belief in reincarnation, again with hope for a future life less troubled than the life just passed. Others doubt the existence of any divine beings or of any life beyond the grave. Regardless of whether the deceased, their family, or our staff anticipate a future with harps and wings or simply a return to the dust, I know of no set of beliefs that suggests that the dead should be ignored and forgotten.

Nursing homes and ALFs should design rituals that afford those who have lived among us some appropriate recognition. These rituals would allow our employees and residents an opportunity to express their grief and honor the departed. Some facilities have a monthly event to honor those who have died, and although certainly a step in the right direction, this does not fully meet the need. Since we are 7-day multiple-shift institutions, these rituals should in some way offer opportunities for day, night, and weekend participation. Ideally, they would allow some time for those who knew the deceased resident to talk, perhaps tell stories, or share special memories.

Facilities offering person-centered care should have collected details of the individual’s past life and work, so these may be shared as appropriate. Even mentioning the deceased resident’s name with a moment of silence at each change of shift for a week would be a welcome ritual. Obviously, the timing and nature of these observances would need to be adjusted to the facility. And they need not be overly religious, because our residents and staff are diverse in their formal religious practices.

Although families certainly go through their own grieving process, they would be comforted knowing that the institution where their loved one has died is remembering them. If we embrace the reality that long-term care is where old people go to die, and work to create a reality where they are cared for as individuals during that process, we also must provide them the respect and dignity that death at the end of a full life should afford.

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By Jeffrey Nichols, MD