



## DEAR DR. JEFF

Jeffrey Nichols, MD, CMD

### What It Means When a Resident Wants to Die at Home

#### Dear Dr. Jeff:

*We are fortunate to share a palliative care specialist nurse practitioner with our local hospital. She is careful to document goals of care. Unfortunately, she nearly always documents that patients wish to die at home. As a skilled nursing facility committed to respecting resident choices, I am not sure where that leaves us. Do you have any suggestions?*

#### Dr. Jeff responds:

You are indeed lucky to have access to a palliative care specialist. American medical care faces an overall shortage in all aspects of palliative care. This is particularly true in long-term care where residents with advanced disease are frequently transferred with their palliative care needs unaddressed.

Identification of the goals of care is an essential component of a comprehensive palliative care evaluation, and should be part of what any of us who serve as attending practitioners to nursing home residents should do. It is wonderful that this professional feels comfortable beginning the discussion. But the discussion has just begun, it is not completed. Not only do goals of care change over time, but general statements of goals need to be explored further to fully understand what is desired. As providers of care, we want to respect a patient's actual wishes, not simply accept a few common phrases as a full explanation, or check off a few boxes on a form.

One common example is the patient whose goals do not include prolonging life, but who now discovers that a beloved granddaughter will be married or produce a great-grandchild within a few months. That same patient might choose some reasonable measures to prolong life until that particular life event has been completed — whether to be present for the occasion or simply to avoid having their death complicate an otherwise joyous family event. One of the screensavers on my computer is a picture of my father holding his great-grandson in his arms 2 weeks before his death.

Words and their nuances are important and complex. Patients who “don't want to die connected to tubes” may not be thinking of the latex tubing of a condom catheter when they are no longer able to reach a commode or use a plastic urinal. They may or may not be referring to tubing delivering intravenous or subcutaneous narcotics for enhanced pain control. The patient who does not want “any more needles” might or might not be referring to a paracentesis to relieve a painfully distended abdomen or a pleural catheter to relieve recurrent

pleural effusions producing uncomfortable shortness of breath. Certainly “no machines” is unlikely to mean refusing an electric bed that offers patients some control over their own positioning.

The goal of being made “comfortable” is particularly unhelpful. Even the patient who chooses full CPR or life on mechanical ventilation still wishes to be as comfortable as possible. No one asks for a lumpy mattress, a nasty diet of their least favorite foods, or an ignored call bell when they need repositioning or toileting. Every resident deserves our best effort to make them comfortable. The point is really how best to resolve issues when the goals of care cannot all be achieved or are frankly contradictory. This requires a process of ongoing discussion, including clarification of both the actual medical situation as it evolves and digging deeper into the meaning of various expressed wishes to reach their underlying meaning. The wish to die at home is a common example of a goal that requires further exploration.

#### Prepping for Discharge

A short-term, post-acute admission to a skilled nursing facility might be a significant component of a plan focused on eventual death at home. For many patients, the enhanced functional independence provided by a course of skilled rehabilitation contributes a significant component to a safe discharge home, particularly given the limited hours of support offered by hospice programs. Even for those with very severe or advanced disease, functional enhancements or modifications of aspects of a medication regimen may be key factors in their path to returning home.

For example, a patient with a massive stroke requiring two people to transfer and a feeding tube might still be safely discharged home to a caring family if the resident could achieve single-person transfer status, and if several family members are trained in safe transfers and the management of tube feedings. The ability to transfer independently from bed to a bedside commode frequently removes the need for 24-hour care when the patient lives alone, or when the spouse or other caregiver is also too frail to provide significant assistance. Achieving marginally adequate diabetic control on oral agents while removing the need for insulin injections, or transferring a patient to a once per day medication schedule, may allow a safe discharge home when there is no one available to assist with injections or when assistance with medication administration is only possible once daily. There is certainly nothing inappropriate or

fraudulent about a rehabilitation-oriented skilled nursing facility admission followed by a discharge to the community, to a lower level of care such as an assisted living center, or to a hospice.

#### Where Is Home?

On the other hand, for most long-stay nursing home residents, their room at the facility is their home. From the viewpoint of a hospice, care provided to these residents is categorized as home hospice care. Most such residents have no other home as their houses have been sold or their apartment leases lapsed when there was no reasonable expectation for them to return. Not only is the nursing home where they live, but the regular nurses and certified nurse assistants they see many times per week and the roommates or table-mates with whom they share all their meals and most of their daily activities are functionally their family.

Good nursing homes strive to be as homelike as possible; admittedly they are institutions, but they are ones where you are surrounded by people you know or recognize, and who know you as an individual. Even when there are family members who live nearby who might consider taking in a dying resident for terminal care, that is not dying at home for most residents. An institution with around-the-clock staffing and specialized equipment is more likely to be able to meet the care needs of the dying individual than an overburdened and unprepared individual in the community, no matter how well-intentioned they might be.

Even a familiar residential possibility in the community may not represent what patients mean when they refer to dying at home. Not everyone lives in a comfortable cottage with a white picket fence, where they can spend their day in a rocking chair near the fireplace with a comforter around their legs while puppies and grandchildren frolic at their feet. This message was brought home to me many years ago when a case that I had regarded as a major success proved to be an abject failure.

A patient in her late 70s with multiple chronic medical problems was admitted to our facility for a short-term stay after an exploratory laparotomy for bowel obstruction identified an obstructing colon cancer with extensive liver metastases. The surgeon was able to remove the tumor, but the wound opened up entirely and required a partial reclosure with retention sutures and packing. She came to the nursing home with a transfer note stating that she had refused any consideration of chemotherapy; she wished to have wound care until the incision closed

and restorative rehabilitation to allow her to return home with hospice care. The social history stated that she was a widow living in a one bedroom basement apartment in the same building as her adult son, where the two of them had shared superintendent responsibilities.

After 8 weeks and successful management of multiple complications, the wound was nearly closed, requiring only a simple protective dressing that she was able to apply herself. She could transfer in and out of bed independently and walk more than 50 feet with a walker, which she stated was the distance from her bed to the bathroom or the kitchen. We had, we thought, addressed her anxiety and depression regarding this new terminal diagnosis and her ability to meet her own care needs. Because she and I had developed some rapport — whereas her prior care had been provided by residents in the hospital outpatient clinic — she asked me if I would continue to care for her in the community. I obliged.

On my first visit, I quickly understood her situation. Her basement apartment was a series of tiny rooms with only two small ceiling-height slits in the wall serving as windows facing a rubbish-strewn back courtyard. Her building had no front door lock, and her son and some companions were on the first-floor landing smoking crack when I entered — fortunately too stoned to be a threat. Her refrigerator did not work, and she was eating canned foods that she heated on the stove. She was obviously miserable. It quickly became clear that her original wish to die at home had simply meant the opposite of dying in the hospital, uncomfortable and surrounded by strangers. I hadn't helped her; I had facilitated a plan that would have resulted in a death frightened and alone. Fortunately, readmission to the nursing home was possible.

Maya Angelou wrote, “The ache for home lives in all of us. The safe place where we can go as we are and not be questioned.” Home is where there is security and warmth, food and comfort, someone who will care that we are alive and be with us when we die. That may be back in the community; or it may be with friends or family; or it may be in an assisted living facility or a nursing home. We must absolutely respect our patient's goals of care, but we shouldn't settle for slogans or empty phrases about their wishes. Take the time to get it right. ✎

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