

Marla Fern Gold

Comfort, Compassion, Dignity

Mark End Of Life Care

In the year before 83-year-old Jack Klein succumbed to congestive heart failure, he was hospitalized at least six times.

After each hospitalization, he became more frail and dependent. Yet just days before he died, Klein underwent brain surgery following a stroke, an operation his daughter now says was a “big mistake,” and one the doctor never should have suggested. “He never should have had surgery,” says Faith

Yoblon, who oversaw his care.

In fact, Klein’s doctor was so focused on extending his life that he never mentioned that Klein was dying, a fact that still rattles

Yoblon. “I knew he wasn’t going to live a long time, but I didn’t know death was imminent,” she says. If she had known, she says she definitely would have opposed the last-minute surgery.

When Klein’s wife, Gertrude, was diagnosed with an inoperable brain tumor just months after his death, Mrs. Klein and Yoblon took the opposite route: no surgery, no life-prolonging treatment. Instead, Mrs. Klein spent her last months receiving palliative—or comfort—care, dying under the watchful eyes of her daughter as well as a hospice caregiver and a personal care assistant.

“Surgery may have prolonged her life by a couple of years, but they wouldn’t have been good years. She decided to trade one-and-a-half bad years for six good months,” says Yoblon. “We let her go peacefully.”

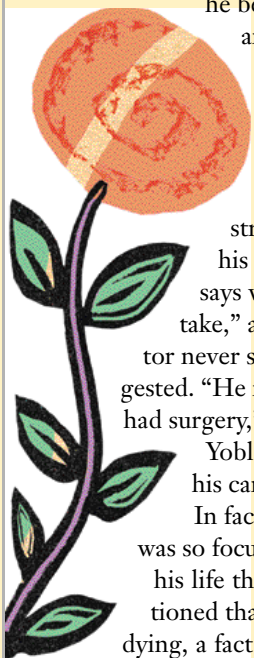
Outlook On Dying Must Change

As the U.S. population continues to age and baby boomers become care-

givers—or in some cases the cared for—the standard of care at the end of life is undergoing rampant discussion and change. Nowhere is this change more obvious than in long term care.

“Twenty-five percent of all deaths in the United States occur in a nursing home,” says Davina Porock, an associate professor of nursing at the University of Missouri-Columbia. Most of those deaths are not the definitive terminal death associated with cancer, adds June Lunney, MD, adjunct investigator, Laboratory of Epidemiology, Demography, and Biometry, National Institute on Aging. “In many cases, these deaths are not a surprise, but they are not predicted,” says Lunney, also a nurse consultant with the National Institute of Nursing Research. This unpredictability often leaves many patients on a trajectory of

MARLA FERN GOLD is a freelance writer specializing in long term care and the elderly. She is based in Annandale, Va.



cure when comfort measures might be more appropriate.

How then can caregivers determine when a patient is near the end of life, and what type of care should be provided when an individual reaches that benchmark? One standard of care gaining momentum nationwide is palliative care, which focuses on pain management and comfort care and offers psychosocial, spiritual, and physical care at the end of life. However, before palliative end-of-life care can be

provided, the search for a cure must be abandoned, a troubling decision for many. Judy Peres, deputy director, New York City-based Last Acts Partnership, says, "We continue to be a death-denying culture, and that's where we need to make some changes. Living while dying embraces the natural life cycle, and we need to be better at recognizing where the lines are crossed and where cure is futile."

Perhaps the greatest barrier to appropriate end-of-life care is the

inability of caregivers to know when a patient reaches the end of curative options. "Our ability to prognosticate death is very poor," confirms John Carter, MD, co-director of the Palliative Care Center at the 1,600-bed Jewish Home and Hospital in New York.

According to Lunney, most deaths fall into four distinct categories. One is sudden death. Another is expected death in the short term from cancer. People with this diagnosis are most



What Is Palliative Care?

“Palliative care is comprehensive, specialized care provided by an interdisciplinary team to patients and families living with a life-threatening or severe advanced illness expected to progress toward dying and where care is particularly focused on alleviating suffering and promoting quality of life. Major concerns are pain and symptom management, information sharing and advance care planning, psychosocial and spiritual support, and coordination of care.”

—American Academy of Hospice and Palliative Medicine

likely to receive end-of-life care, according to Lunney. Next is entry-re-entry deaths, where people slowly get worse but go home between hospital stays. These people have a serious chronic illness that presents an ongoing threat of sudden exacerbation and death caused by organ failure.

The fourth type, lingering expected deaths, are associated with frailty in old age. These people have no reserve defenses and either die when an unpredicted medical challenge occurs—such as influenza—or decline so gradually that signs of the end cannot be clearly identified. These people often reside in nursing facilities, Lunney says.

“There are variable types of decline,” she says. “In many cases, the death was preceded by a cycle of decline, improvement, then more decline. That’s the issue in long term care facilities: We recognize that most people are functionally dependent, and while that in itself is a negative prognostic factor, it is not a terminal prognostic factor.”

The missing link, according to providers, is recognizing when a patient has crossed the line from treatable illness and decline to the terminal stage. “Especially in the elderly past age 80, they begin to develop limitations and medical problems, and it is very unclear when these people can be patched back together and when they cannot,” says Lunney. “All too often we do not have a good set of criteria to say, ‘Now they are dying.’”

Criteria To Check

Cherry Meier, long term care manager for the National Hospice and Palliative Care Organization, has developed a set

of questions that could guide caregivers toward that discovery. Her criteria have been submitted to the Centers for Medicare & Medicaid Services for review, and they may be included in a future version of the minimum data set (MDS). Meier’s questions include:

- Is the patient experiencing irreversible decline or decline unresponsive to treatment?
- Does the patient have an advance directive indicating that he or she does not desire life-prolonging measures?
- Has the patient’s responsible decision maker indicated a desire for comfort rather than curative care?
- Has the patient been diagnosed with a terminal or life-limiting illness?

“The idea would be if the answer to any of these questions is affirmative, then perhaps a palliative care plan would be appropriate for this patient,” says Meier.

In the meantime, triggers for providers include steady decline in areas such as weight, hydration, and range of motion and patients exhibiting late-loss activities of daily living (ADLs) or little or no activity or becoming bedfast, says Meier. “These changes occur in just about every patient at the end of life,” she says. Other triggers may include pressure ulcers, bladder or bowel incontinence, or use of an indwelling catheter.

At Lakeview Village Health Center, in Lenexa, Kan., staff review a trigger form that includes things staff would see when someone is entering into the end-of-life stage, says Administrator Barbara Frank. The trigger form includes observable markers of deterioration such as patient is less active, patient is using more as-needed med-

ications, patient is retaining more fluid, family is noticing decline, and patient is talking more about death.

However, Howard Tuch, MD, director of long term care programs at Hospice of Southwest Florida and director of palliative care services for Menorah Manor in St. Petersburg, Fla., cautions that these changes do not automatically mean that a patient is dying. “You must have assessments in place that rule out common and remediable reasons for [the decline],” says Tuch. For instance, a patient dying of lung cancer will lose weight, but the facility must make sure that the weight loss is unavoidable and not the result of a mouth sore, depression, constipation, or another remediable problem.

Further complicating the identification process are patients with Alzheimer’s disease or other dementias who may be unable to articulate pain and can no longer perform ADLs, but with good palliative care can live for one to two years at the end stage.

Benefits Of Palliative Care

Ladislav Volicer, MD, a professor of pharmacology and psychiatry at Boston University School of Medicine, has developed a nationally recognized palliative care program for individuals with advanced dementia. His philosophy: “Advanced dementia is a terminal illness like terminal cancer because there is no treatment that would stop progression or treat it.” As a result, he says, treatment goals for patients with advanced dementia should always be “comfort, dignity, and quality of life.”

Those treatment goals are the cornerstone of palliative care, which champions comfort care for people



The Hospice Connection

While some facilities go it alone, others turn to hospice providers for help. However, long term care providers as a group are divided regarding the use of outside hospice services. While most praise the pain management and grief counseling hospice offers, some providers object to the notion that long term care providers cannot help patients die well.

“I think in long term care we should be experts in dying. Our goal should be to help people die comfortably and with dignity,” says Jean Hyde Grubman, director of dementia services at The Wilshire, in Lincolnshire, Ill.

“A significant number of people die each year in nursing facilities, and die often enough that we should be skilled in management of the dying patient. If your facility feels like it is not good at this, you should do inservices or get outside help to train your staff, because this is a doable task,” says David Brechtelsbauer, MD, a medical director with the Evangelical Lutheran Good Samaritan Society.

On the other hand, some providers laud hospice services for their ability to provide an extra set of eyes and hands for dying patients.

“I believe that nursing facilities are better off having hospice providers. First of all, in looking at the way the system is currently structured, having another interdisciplinary team helping

to document and provide a rationale why treatment is going the way it is helps,” says Cherry Meier, long term care manager for the National Hospice and Palliative Care Organization.

Further, Meier says, when someone signs up for hospice benefits, the patient has an informed consent switching from curative to palliative care, a DNR, and a physician’s written orders that the person has less than six months to live, “and that documentation supports this person’s palliative care plan,” she says.

Hospice sees for itself a strong role in end-of-life caregiving in long term care. “I hope facilities recognize that they can’t be all things to all people,” says Ursula Robinson, director of clinical services, compliancy, and privacy with Hospice and Palliative Care of Greensboro, N.C. “They have their expertise in rehabilitation and chronic care, and hospice can bring the expertise in end-of-life care to that picture and make a good team.”

To enroll in the Medicare hospice benefit, a physician must sign an order that the Medicare-eligible patient is reasonably expected to live no more than six months. However, there are no penalties if the person outlives the six-month benchmark.

Patients can be re-enrolled repeatedly, says Lance Danko, director of oper-

ations with United Hospice, a subsidiary of United Health Services-Pruitt Corp., in Toccoa, Ga.

Once enrolled, the patient is no longer eligible for Medicare skilled care services. He or she must pay room and board out of pocket, or through Medicaid, if eligible. However, a patient can disenroll from hospice at any time and revert back to Medicare skilled care, if applicable.

The Medicare hospice benefit covers everything related to the terminal illness, such as equipment, medications, ADL care, and skilled care, according to Danko.

Basic hospice services also include pain management.

In addition, hospice services include grief counseling for the patient, the family, and facility staff for up to 13 months following the death.

Caring for the certified nurse assistants (CNAs) who care for a facility’s dying patients is paramount to good care, say providers. “Staff need a tremendous amount of support when they work in an area like this,” says Grubman. “They come to love the residents, and one after another they have to say goodbye to them.”

Many providers offer grief counseling to CNAs through facility chaplains or through contracts with hospice organizations.

who are actively dying as well as for people with debilitating medical conditions. “In nursing facilities, the majority of people are near the end of life,” says Carter of the Jewish Home and Hospital. “Two-thirds of patients who are referred to us die within three months of referral. Life-threatening illnesses are very common here.”

In fact, says Tuch, “With many patients in long term care, with the degree of disability they have, we should be doing palliative care on 80

percent of our residents.” A pillar of palliative care is its focus on pain management. “Because pain is one of those things people don’t want to have at any time,” narcotic medication is one resource available to help manage pain, says David Brechtelsbauer, MD, a medical director with the Evangelical Lutheran Good Samaritan Society, headquartered in Sioux Falls, S.D.

A survey released by Last Acts Partnership this spring found that nearly half of the 1.6 million

Americans living in nursing facilities have persistent pain that is not noticed and not adequately treated. In some cases, state laws on the use of controlled substances create barriers to pain management, the report said.

According to National Hospice and Palliative Care’s Meier, another barrier to adequate pain control is lack of education. “There are lots of myths around narcotic medications in general, and when a caregiver sees a person’s condition as fragile, it becomes a little



Pastor Charles Arndt leads a bedside memorial service in the Dove Room at the St. Croix Valley Good Samaritan Center, St. Croix Falls, Wis.

scary to give them narcotics,” says Meier. In addition, some of the drugs that are helpful at the end of life, such as Elavil for nerve pain, are psychotropic, so that triggers extra scrutiny from surveyors.

“It takes expertise to know which type of medication is needed and when to give it,” says Meier, who adds that recent research shows that giving narcotic medications on a regular schedule helps to control pain better than on an as-needed basis—with the patient receiving less medication.

Mercy Retirement and Care Center in Oakland, Calif., is taking part in a study to reduce pain and improve quality care in long term care. As a result, the facility is providing a lot of staff education in pain assessment and management.

To assess the pain of patients with cognitive impairments, the facility uses PAIN AD, a pain assessment tool developed by the Veteran’s Administration, which helps staff look at facial expressions, movement or fidgeting, calling out, and other observable signs to assess pain. In addition, nurses are instructed to reevaluate patients following administration of pain medication. “We’re really using these scales to document where the pain is and to make sure we’re treating it,” says Sister Melanie O’Brien, Mercy Retirement’s director of nursing (DON).

Since patients in late-stage Alzheimer’s may be unable to communicate, Jean Hyde Grubman, director of dementia services at The Wilshire, an Alzheimer’s campus in Lincolnshire, Ill., also teaches her staff that a patient who is calling out or who cannot sleep may be in pain. “We have to get to know the residents really well” to do this, she says. “We try to do that through having regular caregivers who can ‘read’ them without words.”

Other Kinds Of Support

In addition to pharmacologic pain management, palliative care offers a laundry list of nonpharmacologic interventions. At the Jewish Home, palliative care services include aromatherapy, massage, soothing music, gentle touch, biofeedback techniques, and breathing exercises.

Many facilities also utilize the calming effects of animals to help relieve pain and anxiety in dying patients. O’Brien says Mercy Retirement’s dog, Captain, “has a sense for those who are dying. He sleeps in the room of people who are dying. It is very comforting to them, as well as to their loved ones.” Mercy is part of a California-based study evaluating nonpharmacologic pain management techniques such as massage and whirlpool baths. “Those seem to make residents really comfortable. We also use music, the rosary on

tape, lots of handholding, distraction, and aromatherapy,” says O’Brien.

In addition, emotional and spiritual concerns are a strong focus of palliative care. To that end, perhaps the most needed, yet most difficult, aspect of palliative end-of-life care is simply having someone with the dying patient at all times and providing whatever support the individual wants or needs.

Sitting with dying patients is a hallmark of the Dove Program at St. Croix Valley Good Samaritan Center. “There’s no structure to our end-of-life program,” says Wade Reddy, administrator. “We just encourage people to not stay away, to be present.”

When patients at the St. Croix Falls, Wis., facility are critically ill or near death, staff display a white dove at the nurses’ station to remind staff and visitors to “remember these people in prayer and offer to visit them.”

The Dove Program is initiated by the DON when a patient is dying. Suggestions for “sharing” with the patient at that time include visits, touching or caressing the person’s arm, offering a cool wash rag for a warm forehead, prayer, reading to the patient, sharing personal experiences, or singing to the patient.

In 1997, staff created a “Dove Room” by converting a large room into a special area for dying patients and their families. The comfortably furnished room, which includes such amenities as a TV and a microwave, is available to families regardless of whether the patient is moved. “It allows people to grieve in privacy, or to have the whole family stand around Mother’s bedside without crowding out a roommate,” says Reddy.

At Mercy Retirement, the Compassionate Care of the Dying program is initiated when a patient’s condition reaches the terminal stage. “Our program came out of a general need in the facility to help our elderly die well,” says O’Brien. “We have a lot of elderly residents who live here and choose to die here and don’t want



Angels Passing By

In 1999, Debbie Afasano, then director of nursing at Bon Secours Maria Manor Nursing and Rehabilitation Center, in St. Petersburg, Fla., was at a crossroads. For years, she had studied the writings of death and dying expert Elisabeth Kubler-Ross and knew that the typical pathway of death in long term care was not right.

“We had people die alone, and that was just not acceptable, unless that was someone’s preference. We had cultural barriers where people were afraid of death, or not even wanting to go into the room of a dying person.”

Around that time, Bon Secours’ corporate office wrote a position paper on care of the dying. The plan was for each facility to look at medical futility, advance directives, caring for the caregivers as well as for the patients and their families, making sure staff understood and were vested in ensuring each individual’s wishes,

extraordinary measures, but want to be comfortable.”

Right now Mercy is raising funds and providing staff education for Compassionate Care Carts, which will include CD players with soothing music, rosary tapes, pamphlets on the dying process, scented lotions, snacks for family members, and other tools to help the patient and family during the dying process.

Ironically, the closeness that develops between caregivers and patient may hinder a move toward palliative treatment. In many cases, both families and caregivers are reticent to suggest that a loved one is dying. “There is denial,” says Yoblon. “If you hire hospice, for example, you are admitting that this person is at the end, and you’re telling them they are at the end.”

and the various dimensions of pain. Each facility was responsible for putting together a care-of-dying committee that would look at how the facility managed pain and end-of-life care, as



Angel Carts contain comfort items, including lotions.

well as “how do we make sure we are upholding our moral and ethical needs?” says Afasano, who now is assistant director of quality assurance and policy with the Florida Health Care Association. “This plan challenged us to be present in care, being a constant loving presence at a resi-

In addition, advance care planning with advance directives (AD), a vehicle that providers say should be a living document that tracks patients’ wishes and needs, and changes when a patient’s condition changes, is often lacking. Oftentimes when AD talks begin, the patient is too ill or confused to be a part of the decision-making process, say providers. In other cases, the AD is simply a “do not resuscitate” (DNR) order and does not discuss hospitalization, the use of antibiotics, artificial feeding and hydration, pain management, comfort care, and the myriad other issues that come into play near the end of life.

“The foundational element is the advance directive and discussion about goals of care and preferences of care,” says Brechtelsbauer. “Caregivers need to remember that this is a process, not

dent’s bedside. This really inspired us to look at how can death be meaningful.”

Soon, the corporate philosophy and committee work became a living, breathing entity, as a long-term beloved facility patient began dying.

Explains Afasano, “We had a resident who had lived in our facility for several years and she was dying, and our challenge became: How do we make sure that she doesn’t die alone? That was really the initial cry that came through the facility.

“She had touched people on three different units, her husband had been a real presence to people on staff, he stroked us and loved us and told us we were doing a great job most of the time, and we were concerned for both of them. His daily role was to be there as her advocate, so we wanted to care for him as much as we wanted to care for her.”

To do this, Afasano sent out a chal-

an event. Conditions change, dementia changes, so it is reasonable to expect that most families and residents will realistically change their goals of care.” Part of the AD discussion should include code status, do-not-hospitalize orders, no-antibiotic orders, and codes of care, he says.

“Many nursing facilities struggle with ethical issues at the end of life, particularly over the issue of feeding tubes,” says Ethel Mitty, an adjunct clinical professor of nursing, Division of Nursing, New York University. “In some cases, an impartial mediator such as a hospice nurse may be needed to work through a discussion of the benefits and burdens of feeding tubes.” In addition, Mitty says, since certified nurse assistants (CNAs) often have a lot of influence with families, they too need to understand the downsides of

lenge to staff. “I said, ‘We cannot let her die alone, and we need to let her husband know that if he cannot be with her, we will be.’”

The first emblem of the program was an angel ripped from an old Christmas card, which Afasano glued to the front of a notebook and asked staff to sign each time they visited the patient. “It was a simple concept. Little did I know where it was going to take us,” says Afasano.

Within three days, she says, the book became filled with the story of the patient, “incredible writing of the heart. Staff transformed this end-of-life situation into this life story. It became a testimony to their relationship, his role in inspiring staff in sickness and in health, and a testimony to her,” Afasano says.

“They told her story, and what was so remarkable was that they could see her and all her beauty despite the fact that illness had taken her voice, her abilities. Her husband ended up with this volume of memories, and the book made it up to the altar next to

artificial nutrition and hydration. Volicer says tube feedings can cause diarrhea, bloating, nausea, and infection of the stomach. “We explain to families that tube feedings won’t stop progression of the illness, but will provide more discomfort for the dying patient,” he says.

In the area of resuscitation, most providers encourage patients to sign DNRs at admission. “We explain that resuscitation would not be successful in most cases, and when it might be, it also probably would result in lots of discomfort for the patient, such as rib fractures,” says Volicer, noting that patients often “don’t survive the acute care hospitalization that follows.” In fact, he says, “mortality is higher for those who go to the acute care hospital than those who just stay in the nursing facility.”

the minister at her funeral.” After that experience, “Angels Passing By” became a formalized program that now includes Angel Carts filled with lotions, oral care items, scented pillow spray, music, angel pins, an angel notebook with a logo drawn by someone at the facility, shampoo, and soap that can be warmed in a microwave. The carts are delivered to a room whenever a patient is dying.

Staff also spend time dressing and grooming the patient. “We learned through our bedside vigils that if the resident liked to wear makeup and her beads everyday, the resident should continue to still be herself,” says Afasano.

For families, the facility makes sure carts are sent up for lunch and dinner and that snacks are available throughout the vigil. Quilts, pillows, comfortable chairs, and portable telephones are also provided for family members.

In addition, volunteers crochet bedcovers and provide quilts and angel dolls, which go home with families.

Mitty is conducting research to determine whether protocols she has written help staff make appropriate hospitalization decisions. “It is surprising the number of residents who are clearly dying—they have erratic vital signs, strange breathing patterns, their skin is ashy looking—who are being sent to the hospital,” she says. “Is it that providers just don’t want someone dying in the nursing facility, or is it that they really do not recognize that the person is dying?”

Tuch sums up the need for advance-care planning, including a well-thought-out palliative care plan. “You can start with the sense that a person is in the terminal stage and we expect them to die in our facility,” he says. “So what can we do to ensure that good standards of care are met, and how are we going to attend to physical

pain issues; psychosocial issues; plus acute care admission, DNRs, and food and hydration expectations?”

Comfort And Joy

Visitors walking into the Comfort Care Unit at St. John’s Home, in Rochester, N.Y., last year were confronted by a mouth-watering smell. A trip to the dining room would find patients, all nearing the end of life, dining on seafood prepared by a Red Lobster chef. Most of the food was pureed, but that was beside the point. “One resident had wanted lobster, and that’s not on our menu cycle,” says Carol DuMond, nurse manager of the comfort care unit. “That [event] started something,” she says.

Since that time, patients on the unit have been treated to “spa day,” a day of pampering with massages, champagne, whirlpool baths, and strawberries dipped in chocolate. Another day brought a Mexican food feast, and other days have brought patients to the zoo, a local farmer’s market, even a boat ride on the Erie Canal, says DuMond. “We are always striving to do special things and really serve these ladies and gentlemen,” she says.

Underlying the facade of joy, however, are detailed policies and procedures to ensure that end-of-life care meets each patient’s physical, psychosocial, and spiritual needs. Every week, staff meet for comfort-care rounds, where they discuss each patient and assess any areas where care could be improved. “For residents who are able to participate, we have symptom-management cards that we review with them before rounds,” says DuMond, noting that the cards cover pain, nausea, depression, and general feelings.

At Mercy Retirement, staff developed policies on preferred preference of treatment, a no-CPR policy, an informed-consent policy to be completed by physicians, and a policy regarding surrogate decision making, as well as policies on withholding or withdrawing nutrition, pain assessment

and treatment, and staff education. These policies are discussed with staff and with each of the campus' assisted living residents.

"We try to get an advance directive completed when residents are in assisted living, when the resident can do better decision making," says O'Brien.

At Lakeview, Frank wanted to ensure that advance directives would be followed during a crisis. As a result, the facility developed a trigger on blue cardstock that sits in the front of the chart and summarizes the AD.

"It is very clear if the person is 'full code,' if the person is a DNR, and who the power of attorney for health care is. In addition, we highlight anything unusual about this AD," says Frank. "This system is in place to let the nursing staff know exactly what this person wants when something happens."

Meeting Individual Needs

Knowing what each individual wants is a hallmark of care at Evergreen Retirement Community, in Oshkosh, Wis. The Eden Alternative facility includes three types of independent living, three types of assisted living, and three units of skilled care.

Each skilled care unit is a 36-person community, says Chief Executive Officer David Green. "We have no director of nursing, no nursing department, no social services department, no programming department," he says.

"Instead, we put all staff responsible for that community of residents under one manager," a structure that creates a "household neighborhood design," says Green. "In the same way a village creates a social support system, the household neighborhood design creates a small environment that is essential if you want to create a home."

Within this structure, the same caregivers work with the same residents over time, creating meaningful relationships. "High quality of life means meaningful relationships, meaningful activities, family involvement, personalized care that is resident-directed."



An Evergreen Retirement Community resident reads a story to preschool children.

Even with the best of intentions, a facility's end-of-life caregiving plan must pass muster with regulatory inspectors. In some cases, many of the triggers on the MDS form come into play as a patient is dying, such as weight loss, loss of mobility, and late-stage ADL loss. "When those are triggered, they are supposed to alert surveyors to potential problems, but all too often, surveyors look at them as actual problems," says Meier.

"Then we get into issues where surveyors are second guessing whether staff did everything to prevent the outcome. These people have chronic illnesses, and the course of these illnesses is a trajectory when care should gradually change from curative to palliative," Meier says.

To avoid problems with surveyors, says Meier, it is paramount for providers to document every step of the decision-making process that led to a palliative care plan. Tuch adds that the documentation must include physician orders declaring that the patient is in a terminal stage.

Another thing that hangs up palliative care in nursing facilities is looking at the issue of "highest practicable functioning." "How do you apply that statement to someone who is dying?" asks Brechtelsbauer. "Some people worry that they will be criticized for not trying to aggressively rehabilitate the resident."

Meier says it is important to under-

stand that the highest practicable level in the dying process is significantly different than in curative care. "For instance," she says, "is the resident not nauseated and vomiting, not having seizures, not having skin breakdown, is the resident's mouth moist, and is the resident free from pain. The highest practicable standard when someone cannot be cured is how can that person be kept comfortable. That, to me, is what palliative care is all about." ■

For More Information

Online resources for end-of-life caregiving include:

- Partnership for Caregiving: www.partnershipforcaring.org.
- "Best practices" for end-of-life caregiving for long term care providers: www.lastacts.org (Part of Partnership for Caring site).
- Robert Wood Johnson Foundation's "Means to a Better End": www.rwjf.org/special/betterend.
- American Academy of Hospice and Palliative Medicine: www.aahpm.org.
- National Hospice and Palliative Care Organization: www.nhpc.org.
- Hospice and Palliative Nurses Association: www.hpna.org.
- Pioneer Network: www.pioneernetwork.net.
- Supportive Care of the Dying: www.careofdying.org.