A Daily Bourbon and a Few Laughs

Hospice care gets personal.

by Heide Aungst

Eileen Reeve tells the story about when her daughter and son-in-law came to pick up her husband, Jim, at Hospice House to bring him back to the family home in Madison for Thanksgiving dinner.

Hospice House, built in 1995, right on Lake Erie at the end of East 185th Street, is the residential unit of Hospice of the Western Reserve — and was the first residential facility to open in Northeast Ohio.

"How has everyone here been to you?" his son-in-law asked.

Jim can no longer speak or move most of his body because of amyotrophic lateral sclerosis (ALS), more commonly known as Lou Gehrig's disease, which destroys the neurons that make muscles work. He painstakingly types with one finger, one letter at a time. When the sentence is complete, he punches a button and the computer speaks for him.

"Good. But everyone just keeps dying around here," he finally replied.

When Eileen finishes telling the story, Jim laughs. He moves his head back and makes deep, guttural sounds. His weakened facial muscles make eating difficult and speaking impossible, but still allow him to smile.

It's a radiant smile that makes visitors quickly forget that they're in the presence of a dying man. It makes them wish they'd known Jim Reeve back when he was a proud Navy man on the battleship U.S.S. *New Jersey* during the Korean War or a claims adjuster raising his family in Chesterland, east of Cleveland.

In his room, Jim displays a flag that flew over the *New Jersey* on Oct. 20, 2003 — 53 years to the day after his discharge. He keeps an album of his Navy days in the room. Eileen also arranged a special recognition at Hospice House to honor his years of service.

At Hospice House, Eileen and Jim Reeve recall many happy moments from their 42-year marriage.

Looking at the spectacular lake view out the window of Jim's hospice room, Eileen recalls building a sailboat in their basement by hand with Jim and their daughters, Ann and Nellie, and the hours the family spent sailing together.

Those are the memories that Jim and Eileen recall of happier times during their 42-year marriage. Eileen tells the stories, but Jim fills in the details she has forgotten. He still knows all the dates and names in their mutual history. His body no longer functions, but his mind is as sharp as can be.

Eileen often finishes the sentences Jim begins typing and expands on the story. What's striking is how often and freely they laugh together as they remember anecdotes, such

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as their wedding photographer forgetting to remove his camera's lens cap and not realizing it until almost everyone had left.

On their 40th wedding anniversary, their daughter Ann wrote the couple a special card, citing their sense of humor during this trying time as one of the things she loves best about them.

How does Jim maintain his sense of humor?

With one finger he types: "Life is a cruel joke."

Hospice and the Aging Population

At 72, Jim is among a growing number of senior adults and their families who benefit from hospice care in the weeks or months preceding their death. Hospice use overall is growing in the United States, up from 158,000 in 1985 to 885,000 in 2002.

The word "hospice" derives from the Latin word *hospitium*, meaning guest house. The first hospice opened near London in the 1960s, using the team approach to caregiving and pain management for terminally ill patients. The first hospice in the United States opened in 1974, in New Haven, Conn.

Hospice provides comfort and support to patients with terminal illnesses that no longer respond to curative treatments.

Since older adults get more diseases, it only makes sense that they are good candidates for hospice care. In 2002, about 81 percent of hospice patients were 65 or older, according to the National Hospice and Palliative Care Organization.

David Simpson, CEO of Hospice of the Western Reserve, the largest hospice organization in Northeast Ohio, says that in 1990, they welcomed their first patient over the age of 100. Last year, they had served 33 individuals over the age of 100 just through September.

"The trend is to live older and older, and we see some pretty perky 95-year-olds who we can really help," says Stephanie Romine, director of alternative home care for Hospice of the Western Reserve. "Often, they are the ones in assisted living who we can help stay there at the end of their life."

That trend to live longer means that hospice is moving into nursing homes and assisted-living facilities, too. In Northeast Ohio, the Montefiore Home in Beachwood may be the only facility with its own hospice staff.

The benefit of that, says director Michele Petruccelli, is that the nursing home's medical director is also the hospice medical director. That makes it easy to transition patients into hospice care. Receiving hospice services requires physician approval.

Other nursing homes and facilities contract with hospice providers. Hospice of the Western Reserve, for example, contracts with 160 nursing homes and as well as going into additional assisted-living facilities.

The Hospice Philosophy

The fact that more and more people in nursing homes benefit from hospice care confuses people who don't fully understand the hospice philosophy. Why would different nurses need to come to a nursing home where there already are nurses — or into the home of an older adult who is receiving home care?

One of the key philosophies of hospice is

Common Myths About Hospice

There's no point in calling hospice until the person is within days of dying. In fact, if there's one message hospice workers would like to get across, it's that people don't call soon enough. Hospice workers like to have time to get to know the patient and family and work through life issues. One of the criteria for Medicare payment for hospice services is expected death within six months, but benefits can be renewed. Jim Reeve, for example, received hospice services for more than a year.

Hospice is only for cancer patients. Hospice is available to anyone with a life-limiting illness that no longer responds to treatments aimed at a cure. Besides cancer, hospice accepts individuals with numerous diseases including heart failure, pulmonary disease, kidney failure, dementia and Parkinson's disease.

Hospice is only for the young. Hospice of the Western Reserve once had a patient who was 103. It's the disease process, not the patient's age, that qualifies someone for hospice care.

It's only a natural progression for the elderly to get diseases like dementia or Alzheimer's, so there's no point to calling hospice. Even though those diseases affect memory, there are other physical signs that a person is nearing death. A person might stop eating, lose weight or experience more frequent illnesses. Most hospices are willing to perform assessments on a patient to see if he or she would be a candidate.

My grandmother is in a nursing home that has its own nurses. My father has home health-care nurses at his home. Isn't that enough? Hospice uses a team approach that includes nurses, physicians, social workers and spiritual counselors. Unlike nurses from other areas, hospice works with both the patient and the family. Hospice nurses and physicians are experts in comfort care and pain management. Other nurses and physicians — whether they provide care in the home or in a nursing home — often welcome a hospice team.

I'll have to give up all medications and treatments if I call hospice. You do have to give up any active attempts to cure the disease for which hospice is admitting you, such as chemotherapy for cancer. But you don't have to give up other treatments. For example, if you're a cancer patient with high blood pressure, you still get your high blood pressure medication. While extremely rare, hospice workers do tell stories of patients who have actually gotten better in hospice. Robert Phillips-Plona, director of residential services for Hospice of the Western Reserve, tells of a man who came into Hospice House in an ambulance, seemingly within days of dying, but walked out on his own a few months later. The man had AIDS, but, with the care and nurturing of the staff, his symptoms were brought under control and he regained his health.

I'll become addicted to pain medications in hospice. Patients can develop tolerances to pain medications, but they don't get addicted. "There are all different kinds of medications for pain and combinations of medicines that can be used," says Arlene McNamara, manager of the Seasons of Life Hospice associated with Parma Hospital. It's most important that pain is controlled and the patient remains comfortable.

I'm not religious — and I certainly don't want to be converted while I'm so ill and vulnerable. Hospice serves people with all belief systems. Spiritual counselors are not religious counselors and don't convert patients into any belief system. Instead, they meet the patient wherever that patient is in coming to terms with death.

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that it "neither prolongs life nor hastens death." Instead, hospice deals with every aspect of a person in the final stages of life: physical, social, emotional and spiritual.

"Many people are really, really fearful when they hear the word 'hospice' because they think it's a program for the dying," explains Rev. Theodore Bell, the chaplain of the Seasons of Life Hospital and director of pastoral care at Parma Community General Hospital. "Really, it's a program that helps a person live life to its fullest, however that might be lived until death occurs."

Simpson calls it "what you do in the meantime." The "meantime" being that period between doctors saying there's no hope for a cure and the occurrence of death.

"We're about comfort, about caring, about life opportunity, fulfillment, about development," he says.

While words such as "fulfillment" and "development" may sound odd in relationship to death and dying, Simpson says that the hospice team of nurses, physicians, social workers and spiritual counselors often helps patients achieve life goals before dying. Several patients have had art shows at Hospice House. One woman with Lou Gehrig's disease, who, like Jim Reeve, could not speak or move, composed music that was published in four songbooks before her death.

Sometimes, it's a simple request that can be easily fulfilled.

"It's asking, 'What can I as a human being do for you as a human being to make your wish come true?' " explains Arlene McNamara, a nurse and manager of the Seasons of Life Hospice, a service of Parma Community General Hospital.

McNamara gives the example of one elderly Italian man at Seasons of Life who couldn't stand the pasta they served. She went home, dug out her Italian grandmother's recipe and brought him homemade spaghetti and meatballs. She even made enough to freeze so he could have it any time he wanted it.

The nurse comes into Jim Reeve's room every day at 4 p.m., not to give him medicine, but to pour him a bourbon. He has had that bourbon every afternoon of his adult life and, in the hospice philosophy, that shouldn't change now because he is *living* at Hospice House.

Finding Hospice Sooner

Besides understanding the philosophy of hospice, workers in the field hope that people

Grieving for a Grandparent

Tensie Holland, bereavement coordinator at Hospice of the Western Reserve, likes to quote a line from a poem: "Whose grief is worse?"

When someone dies suddenly in an accident, Holland observes, people often say that they wish they'd had time to say goodbye. But when someone dies of a terminal illness, some say they wish they hadn't watched their loved one suffer.

The truth is that everyone handles grief differently.

"Their loved one may be 99 years old," Holland says, "and they don't like it any more than losing someone who's 20. It's the relationship that they had with the person that makes the difference."

While it's expected that a grandparent will die before a grandchild, Holland cautions that it's important for parents not to just shrug off the death and expect the child to simply go on as if nothing happened. Losing a cherished grandparent can be as hard for a 5-year-old as it is for a 35-year-old.

Holland offers these tips to help your child — and you — cope when a grandparent or beloved older adult dies:

• **Be open with children during a grandparent's illness.** Holland says adults often ask, "Should we tell the children?" But if you hide the grandparent away from the child as protection, you may be doing more harm than good. After death, it's as if the grandparent "disappeared."

• **Allow children to express their feelings to the grandparent while they're ill.** If Grandma doesn't look like herself because she's lost lots of weight, allow the child to draw cards or talk on the phone. Theresa Giersz, a hospice nurse at the Seasons of Life Hospice in Parma, says she recalls a family whose grandmother had taught each grandchild piano. The woman's room was close to the piano in the lobby, so each grandchild played a song for the woman before she died.

• **Tell the child when the grandparent dies.** Don't couch it in language such as "sleeping" or "lost." That is too confusing to children.

• **Reassure children that they are safe.** Children often become scared that others they love — or even they themselves — will die soon, too. Sometimes, if a parent even has a common cold following a death, children think this means the parent will die, too.

• **Tell children exactly what to expect at an open casket or funeral.** This will take away fears.

• **Involve children in the funeral service.** They can write something to their grandparent and put it in the casket or even read it at the funeral. The children may want to help make photo collages to be displayed at the funeral home during visitation.

• **Listen to the child, not to "society."** Don't force children to do anything they don't want to. If they don't want to go to the visitation or funeral, respect that. Don't tell them that their cousins will be there, so they have to go, too. Respect their thoughts in the coming months, as well. Just as with adults, everyone grieves differently. "Some people are comforted by having pictures around, and some people put them away," Holland notes.

• **Answer children's questions to the best of your ability or within your own belief system.**

• **Validate children's thoughts and feelings.** Hospice nurses and bereavement counselors often hear children say that they "see" a person after death. Ask them questions about what they see. Don't tell them they're crazy or just imagining it, even if that's what you believe. (Likewise, a dying person will often experience "visioning" — that is, seeing angels, Jesus or someone who has preceded them in death. Family members should validate and discuss this, not ignore it or tell the person that "No one's here; you're imagining it.")

• **Don't hide your own feelings from your children.** Grieve as a family.

• **Talk about the person who died.** Look at photo albums. Remember good times together. Don't forget about the person and the impact he or she had on you and your children.

• **Take advantage of bereavement support.** If you've just lost your parent, go to support groups yourself. If your child is having trouble adjusting, allow him or her to go to a group, as well. Most people don't hesitate to put children into a grief support group if a parent, sibling or best friend dies. Too often, parents think children don't need this because losing a grandparent is "the natural order" But children can benefit immensely from opening up to other children in their age group who have lost someone they love. Bereavement support for children usually involves expressive therapies, such as art and music.

• **Be patient** with yourself and with your child. "There is no timetable for grief. There are no magical numbers," Holland says. "It's learning to adjust to a life without that person, rather than 'getting over it.'"

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— and physicians — understand other aspects, as well.

For example, less than 54 percent of the patients served by hospice nationally are dying of cancer, meaning it's common to have another disease, as Jim Reeve does. About 10 percent of patients have end-stage heart disease and seven percent suffer from dementia, something that used to be just accepted as a part of getting older.

But Jim is unlike the hospice "stereo-type" in another significant way. He has had hospice care for more than a year, beginning with in-home care and then, when Eileen could no longer care for him, he moved to Hospice House in March 2003.

Medicare benefits usually cover the cost of hospice for patients 65 and older for only six months. But what many people don't know is that the benefit is renewable, so as long as a physician says that a patient will not be cured.

"We, as doctors, are really bad at that guess," says Dr. Susan LeGrand, director of education for palliative medicine at The Cleveland Clinic Foundation. The Clinic provides in-home care, as well as residential care at a wing of The Renaissance, an assisted-living facility in Olmsted Township. "So, now the suggestion is to ask, 'Would you be surprised if this person died in six months?' rather than 'Would you predict that?'"

Despite that new definition, LeGrand says that physicians usually refer patients — and patients ask about hospice — too late.

"The length of stay in hospice has shrunk significantly," she says. "One-third of patients are in for less than two weeks. One is not doing hospice care then; you're doing crisis intervention."

Ideally, LeGrand says, the team would like a minimum of 90 days to work with a patient and family. Family is defined by whoever the patient names. Besides immediate family, family can include a best friend or nursing-home roommate. Family members are followed for a year with grief support following the patient's death.

Hospice and Spirituality

Another key part of hospice is the spiritual component. There are a lot of misconceptions surrounding what that involves.

For one, hospice is not a Christian philosophy, otherwise it wouldn't work in the Jewish Montefiore Home. Spiritual counselors try to meet patients at whatever level they are on spiritually, not religiously. That means everything from atheist to fundamentalist.

Petruccelli says the rabbi at Montefiore sees recognition in even nonverbal patients' faces when they hear music and Hebrew prayers from their youth.

Besides patients being assigned a spiritual adviser, hospice nurses are trained in spiritual care. At Seasons of Life, for example, nurses are trained in "therapeutic touch." That involves lightly touching the patient while soft music plays.

McNamara finds that patients are sometimes fearful of death and hold back from their minister or priest, but talk with a nurse later.

"Our nurses have a spiritual aspect to them, too," says McNamara. "If our patients are ready to talk — about end of life, afterlife, guilt — our nurses are there to listen. That's one of the best things we can do is to let the patient talk and listen in a very nonjudgmental way."

Eileen Reeve admits she didn't want anyone coming into Jim's room and preaching to him. She is Catholic and raised their daughters that way. But Jim has always been agnostic. Eileen wanted that respected, especially at this time in his life.

Jim was assigned a spiritual counselor, a man he describes as "a Jewish Buddhist." They talk, says Eileen, but no one has tried to convert Jim.

"I can't believe in a God who allows millions of kids 2 die in every hideous way," Jim types.

"He has always said that," Eileen points out.

"If God made man in own image..." he begins typing. You can feel tension in the room, tears beginning to well up in his visitors' eyes as Jim gets philosophical about his impending death. Those present try to finish the sentence as Eileen does:

"He wouldn't have done this to you? There wouldn't be diseases like ALS?"

Jim turns his head once to indicate "no" and continues to type.

"He's into clones," he types.

Jim knows he just got everyone in the room and laughs heartily.

Eileen feels sure that it's hospice care that allows them both to keep laughing, even in this most challenging of times. ■

Palliative Care vs. Hospice

The words "palliative care" and "hospice" are often used together, confusing people as to what they are.

While both forms of care treat the person physically, emotionally, socially and spiritually, palliative care can treat people who are still actively trying to cure their disease.

Palliative-medicine physicians are experts at managing pain and other complex symptoms. They work with cancer patients, as well as patients with other involved diseases such as congestive heart failure. Hospice programs provide palliative care to patients at the end of life, but palliative-care medicine is a broader field than just hospice.

"One of the objectives of modern palliative care is to not just focus on the dying patient, but to be involved with earlier-stage disease, and that can include patients who have just been diagnosed," explains Dr. Declan Walsh, chairman of the post-acute medicine division at The Cleveland Clinic Foundation. "Philosophically, we believe that these issues of palliation are very much a partnership with attempts to cure the illness."

That means that, unlike hospice, palliative medicine can use technology or treatments to relieve symptoms while the patient is still trying for a cure.

Walsh says that The Cleveland Clinic is one of only about 20 centers in the United States that have comprehensive palliative-medicine units. The Clinic's program started in 1987. In 1991, the World Health Organization named it "a demonstration project" so that similar programs could be started around the world. The Clinic's 23-bed inpatient palliative-medicine unit will celebrate its 10th anniversary this year.

Cleveland is also unique in that the first graduate program in palliative-care nursing in the U.S. was started in 1998 at the Breen School of Nursing at Ursuline College in Pepper Pike. In 1993, Ursuline nursing professor Denice Sheehan co-wrote the first nursing textbook on palliative care.

"Most people, including health-care professionals, do not understand the concept of palliative care," says Sheehan, coordinator of Ursuline's palliative-care program. "I'd like to debunk the myth that you have to be actively dying to be eligible for palliative care. A patient should seek expertise in palliative care just as you would from a cardiologist if you have heart disease." — *HA*