

Los Angeles Times

Taking Life's Final Exit

By Valerie Reitman Times Staff Writer
Mon Jun 14, 7:55 AM ET

PHILADELPHIA — My brother took more trains, planes and automobiles in the last week of his life than he had taken in months, perhaps years. Those journeys were all the more surprising because they occurred in an intensive-care unit at the end of his three-year battle with bone marrow cancer.

Bedridden after being rushed to the hospital for what would be the final eight days of his life, Kenny casually mentioned that he was visiting Detroit. It was a rather odd place for him to be traveling — even if only in his imagination — because the hospital was near home in suburban Philadelphia and he didn't have any ties to the Motor City.

But it was near a border, a border he seemed intent on crossing, be it real or metaphoric.

"How far is it to Canada?" he wanted to know. "Where's the map?"

Though very weak, Kenny, 45, intermittently recognized and chatted lucidly with family gathered by his bedside. But he would drop in news of his varied travels: He had gone skiing one afternoon in Australia, he told us, stopped by North Carolina another day, and more than once had been "stuck in passport control."

At first, our family dismissed these journeys as confusion; we would laugh through our tears about the various places and modes of transport he had been taking. It must be the painkillers, we thought. Or maybe hypoxia, the oxygen deprivation in the blood that often contributes to delirium in sick people. Or that the cancer now was destroying his mind, just as it had racked his body.

But then our cousin Lynne mentioned that her parents had done a lot of similar traveling in the last days of their cancer battles. Uncle Larry (Lynne's father) had insisted that his passport and fanny pack be kept by his bedside; he was intent on keeping an imaginary 3 p.m. appointment with the emperor of Japan, where I was living then and where he had hoped to visit. He too had asked for a map — of Japan. Aunt Lois, who had died four years before, had talked about needing to catch a train, asking Lynne to buy her a ticket.

There seemed to be a pattern. A nearby bookstore turned up a 1992 title that offered some clues: "Final Gifts: Understanding the Special Awareness, Needs and Communications of the Dying."

Its chapter titles were uncanny: "Where's the Map?" and "I'm Getting Ready To Leave." Authors Patricia Kelley and Maggie Callanan, longtime Washington, D.C.-area hospice nurses, had heard similar talk so often from their dying patients — conveying this sense of moving from one place to another, of being in transition — that they concluded it must be a special language the dying have to communicate what is happening to them.

"It would be easy to say it's just coincidence, but when you see it over and over, there has to be something there," Kelley said in a telephone interview. "I do think people experience something we can't describe."

The authors termed the phenomenon "nearing death awareness" — a state they think reveals what dying might be like and what a person needs to die peacefully.

It has some similarities with the more widely known near-death experiences reported by some patients who are resuscitated on operating tables or at the scenes of accidents. They report seeing a bright light at the end of a tunnel, with people and events of their lives flashing as if in a kaleidoscope.

In contrast, however, those dying slowly often talk of preparing for a trip or of trying to finish something, Kelley and Callanan found, perhaps using language pertaining to their professions or hobbies. One dying man who liked to sail, for instance, talked about the ebbing of the tides; a watchmaker mentioned that the clock was not ticking fast enough; a carpenter described details of completing an imaginary house.

The observations built on an earlier four-year study by physicians Karlis Osis and Erlendur Haraldsson, in which hundreds of physicians and nurses observed 50,000 dying patients from India and the U.S. In both cultures, patients commonly reported deathbed visions of movement toward something and of being greeted by deceased loved ones who were helping them to "cross over" in their last moments.

Several healthcare workers and bereaved families interviewed for this article also witnessed similar phenomena. A few days before Jennifer Lee Foster, 26, of Millbrook, N.Y., died of leukemia, she told her relatives she had seen a young neighborhood boy who had been killed years earlier in an auto accident. The boy said, "How you doing, Jen? I was waiting to say hi to you," recalls her mother, Jean DiMarco, of Millbrook.

Kathy Pollard, educational director at Hospice of the Valley in Phoenix, said that she had seen dying patients countless times shaking their heads "yes" or "no" and making motions with their hands as they talk with deceased people.

Loved ones shouldn't argue, but simply affirm what the person is saying or inquire about what they're seeing or doing, Pollard says. One sweet old lady put her hand up and touched Pollard's cheek one day, and said, "Oh, my dear — isn't the train we're on beautiful?"

"Are you on a train?" Pollard asked.

"Yes, I am," the woman replied.

"Oh, where are you going?" Pollard asked.

The old woman's eyes closed. "I'm on the way to South Dakota."

"And what will happen when you get there?" Pollard replied.

"Well, my dear," the old lady answered, "then the journey will be over."

Just before Pollard's own father died two years ago after a stroke and a fall in a nursing home, he kept saying, "Ma, Ma, open the door." Pollard leaned in close and whispered, "You can open the door, Dad."

Says Pollard, "We believe the patient is on the journey and they are going to make the decision when the train stops or when to open the door [and die]. We reassure the patient that he or she's going to be OK, and say things like, 'Dad, you've been a great father — I'll miss you like crazy, but you're going to be OK.' "

As Kenny did, the dying frequently mention being "stuck" or "held up" — which Kelley and Callanan say may indicate something is keeping them from letting go — such as concern about how a spouse or children will cope or the need to take care of something undone or to see a loved one. A young man dying of AIDS (news - web sites) told Kelley about his father being "in the way." They had long been estranged, and the young man was hoping (for naught) that his dad might visit.

The phenomenon isn't universal. Some are too sick; others can't talk. Moreover, a person's behavior in death will typically be much like it was in life — a very private person isn't likely to become talkative on his deathbed. And not everyone who speaks of wanting to go home or take a journey is talking about death.

An elderly woman in her 80s pleaded with Sara Perry, a social worker at Montgomery Hospice inpatient program in Maryland, to take her home. Perry told her soothingly that "sometimes when people are as sick as you and they talk about going home, they are really talking about going to heaven." The woman shot back, "Listen, honey, I'm talking about going home to my apartment."

Why dying people speak of taking journeys is anyone's guess. Drugs don't seem to play much of a role, hospice workers say, because the phenomenon occurs both in those who are taking painkillers and those who aren't. If anything, they say, the more drugs one takes, the less likely any conversations.

Others speculate that the dying may be experiencing visions similar to those in a dream. "The

mind has its own set of analgesics," said sociologist Robert Fulton, a University of Minnesota professor emeritus and a pioneer in the study of death and bereavement in the 1960s. "The mind is well capable of drugging itself. In a dream, there might be the euphoria of meeting a dead friend and having a conversation.... The brain is kind of cleaning itself up, like a computer downloading."

The dreams are reinforced by images of immortality, and of heaven and hell or reincarnation, embraced throughout history as well as in modern life. Kelley speculates that the dying recognize "that they're going from one world to another one" or the feeling that they're "going somewhere."

Perhaps the travels are due to a "freeing up" of the spirit once the dying person has accepted that death is imminent, said Dr. William Lamers, who set up the second hospice in the U.S., in Marin County in the 1970s. This brings about a phenomenon he has witnessed again and again: The dying person, if in a comfortable setting and in little pain, is at peace with his or her condition and takes interest in the well-being of the survivors, who often aren't nearly as comfortable with the imminent death.

That can be particularly true with dying children, says Betty Ferrell, a nurse and research scientist at City of Hope National Medical Center in Duarte, who has worked with the dying for 25 years. The child might say that angels came to visit and beckoned him to come. But rather than finding it comforting that the child isn't afraid, parents get upset, and say, "'Oh no, you're staying right here with me,'" Ferrell says. (Ferrell directs a new national program to help nurses better understand and care for dying patients, using "Final Gifts" as a text.)

Then there are those who believe that maybe — just maybe — the dying really are going on journeys or being visited by their deceased loved ones. Author-hospice nurse Callanan sees no harm, and maybe some consolation, in such credence.

For my family, just knowing that so many others had taken such "journeys" on their deathbeds gave us comfort, as we passed around "Final Gifts" during long hours at the hospital. We came to believe that Kenny had reconciled himself to dying. A strapping 6-foot-3 electrical engineer who hadn't taken a sick day in more than 20 years at the steel mill he helped run, Kenny had vowed that he had "no doubt he'd beat this thing," even though multiple myeloma is virtually incurable and most patients live three to five years at most.

The most promising treatment — a stem-cell transplant followed by a bone marrow transplant from our brother Bob, an exact match — didn't work, and our hopes for a long remission faded. Drug after drug failed, and tumors on his spine threatened paralysis. A month before his death, his local oncologist — handing his wife, Cyndie, and son, Zach, a box of tissues as he matter-of-factly delivered the news — advised that the most humane thing would be to stop treatment.

Still, Kenny wouldn't give up and asked his main oncologist in Philadelphia to try something else, telling him that he knew he was going to die eventually, but intended to live a few more years rather than a few more weeks. The doctor complied with another experimental drug. Kenny grew weaker, however, until he could barely walk and couldn't climb the stairs to bed.

Once settled into the ICU with oxygen, he was more comfortable — and began to accept the reality. "It seems like my body's telling me something.... Everything seems to be shutting down."

The death-related imagery soon started popping up, what Callanan termed "previews of coming

attractions." Kenny thought he had seen towels labeled "hospice" as he came into the hospital. One day, he told his teenage children there were buzzards in the hospital room corner. When they told him that wasn't true, he replied calmly, "It's only natural," indicating to us that he didn't find this image of death at all macabre.

He mentioned being visited by "John," but couldn't tell us who John was except to deny it was anyone we suggested. Only weeks after his funeral did we figure out that he probably meant our brother Chris' father-in-law, whom he didn't know well, but whose wake he had attended months earlier.

Three nights before he died, he told daughter Jessica, 16, to "get my shoes, Jess. We need to get on the boat." Did he mean the small catamaran he sometimes sailed with our father, we asked. "No, it's a big boat," he retorted, seeming indignant that we couldn't see what he could. "Where's my green duffel?" he said. "I need to pack."

When a nurse popped in later, he inquired in earnest, "Do we change buses here?"

I stayed with him through that night, and he asked out of the blue, "Is the viewing today?" Do you want a viewing, I asked, knowing how much he hated them and preferred cremation. "Well, you don't know whether to have one or not," he replied. "I guess you could have one and I don't have to be there."

I reread aloud to him the beautiful letters Zach, Louise and Jess had written, thanking him for being such a wonderful father and telling him how much they loved him. More than likely, it was concern for them that was keeping him from letting go.

"Losing you is going to be really hard, but you need to stop suffering" Jessica wrote. "And don't feel bad that you're going to be leaving us, OK? I love you so much, Daddy. I will miss you so much. You will always live on in spirit. Goodbye, Daddy. Your daughter forever with love, Jessica." And she drew five stick figures, with a caption, "We will always be a happy family."

He started to cry. "Oh Val, what am I going to do?" But a half-minute later, it was as if, mercifully, he was somewhere well beyond the gravity of it all. He stopped crying and asked quizzically, "Val, where are we?"

Is there anything he wanted me to tell his wife and kids for him, I asked, a redundant question because he had often told them how much he loved them.

"No," he replied, "I'll write on the plane."

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