

The Mystery of End-of-Life Rallies

Palliative care experts say it is not uncommon for people in hospice care to perk up briefly before they die, sometimes speaking clearly or asking for food.

Susan Linnee had not eaten for weeks by the time she entered hospice. A 75-year-old editor, she was dying of a brain tumor and as her body weakened, she grew confused and stuporous. But suddenly, 17 days later, she perked up and asked for what her brother, Paul, called “odd food”: dill pickles, liverwurst and seed bread. Relatives fetched the delicacies and she nibbled a few bites. More animated than in previous days, she engaged in lucid conversation. Soon thereafter, she slipped into a barely responsive state and died two weeks later.

In speaking with the medical team, her brother learned that the brief rebound his sister experienced was called an “end-of-life rally.” Palliative care experts say revivals are common, although no one knows exactly why.

“There’s great mystery around this,” said John Mastrojohn, the executive vice president of the National Hospice and Palliative Care Organization. “But everyone who works in the sector has a story.”

Anecdotally, doctors and nurses interviewed for this article said that a striking number of their dying patients had experienced a rally, also known as terminal lucidity. Bounce-backs generally last only a couple hours, but some go on for so long that the patients can take a break from a hospice for a few months.

Dr. Craig Blinderman, the director of adult palliative medicine at the Columbia University Medical Center, hears lots of accounts. Yet evidence-based data is elusive, if nonexistent, he said. Aside from the challenges of catching dying people at the moment of springing back, it’d be tough to get the medical ethics board to determine that the research would benefit the patient. This type of study would require constant drawing of blood and monitoring of patients, which runs counter to the quiet fade away that is a signature element of palliative care.

Dr. Blinderman has theories about causes, however. He postulated that as organs shut down, they can release a steroid-like compound that briefly rouses the body. In the specific case of brain tumors, swelling occurs in the confined space of the skull. The edema shrinks as hospice patients are weaned off food and drink, waking up the brain a bit.

These windows of energy can startle family members sitting at the bedside. Those who hold out hope that their loved ones may somehow recover may see the comebacks as encouraging. Some find the little flickers disturbing or even heartbreaking.

“I always provide a lot of anticipatory guidance, that you should not be surprised or alarmed or that it means that your loved one is healing,” Dr. Blinderman said. “Obviously you don’t want to dash hopes, but you have to make clear that Dad is not rising like Jesus Christ.”

Dr. Janet Bull dispenses the same advice, as chief medical officer at the Four Seasons Compassion for Life, a non-profit hospice care organization in North Carolina. During her 18 years in the field, Dr. Bull has seen many rallies, but one in particular stands out.

“I had this one patient, he was demented for years, and then he said things near the end that blew away his mom,” she recalled with wonder. “He hadn’t had a meaningful conversation with her for 10 years.”

Physiologically, experts believe that the mind becomes more responsive when a hospice patient is taken off the extensive fluids and medications such as chemotherapy that have toxic effects. Stopping the overload restores the body to more of its natural balance, and the dying briefly become more like their old selves.

Mr. Mastrojohn speculates that the social support at a hospice can give the chronically ill more pep than in a sterile hospital where they’re hooked up to machines.

Then there’s a spiritual or psychological component, which defies scientific explanation. Hospice professionals note a compelling desire to say goodbye or bond with loved ones in those last moments. There’s no way to test this hypothesis, but there’s no way to falsify it, either.

“People know when they are dying. They have this internal gut feeling that tends to expand at the end of life, and they seek a strong final connection,” said Dr. Bull.

Other doctors nodded their heads when told about Ms. Linnee’s request for a last meal. They said that often ralliers will ask for a particular food associated with childhood or comfort. The request is generally explicit, say, a Diet Sprite rather than any old beverage.

Dr. Martha Twaddle cited the case of an Illinois woman in her 50s who was reaching end-stage heart failure. She had been barely reactive, but then sat up and asked for a hamburger famous in Skokie.

“It’s some enormous hamburger, the size of your face with all this stuff on it. She took two bites and then fell back asleep,” said Dr. Twaddle, a physician associated with the Northwestern Medical Group in Lake Forest, Ill., who has worked in palliative care since 1989.

She has had nonreactive patients jolt up to ask for a relative or share final wishes before they die. “Sometimes they want to give instructions to the family, like, ‘Don’t forget to take care of the car.’ Something mundane but important to them.”

Palliative care experts suggest accommodating a loved one's request, no matter how odd it may appear.

Dr. Charles Wellman, the long-time chief medical officer at the Hospice of the Western Reserve in Cleveland, has had patients who become alert only for the doctor. They will not talk for days, and then their eyes open when Dr. Wellman walks into the room. "I think they get tired and withdrawn," he speculated. "They're transitioning to another existence, and they have work to do on that. Maybe they get annoyed with family, but they might make an effort to respond to the doctor."

But rallies frequently revolve around a relationship, particularly if the patient is waiting for a child to come from out of town to pay last respects.

"We had one patient whose son was in the military," Dr. Twaddle said. "There was no way the son could get to her for a month. The woman was out of it during that time. He finally came. She responded, and then passed 15 minutes later."

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