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Democracy Dies in Darkness

Hospice workers find peace in helping patients find comfort at the end of life

By **Michael Ollove**

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CLEVELAND — It is 7:30 on a summer morning in a room overlooking the slate-gray, lapping waters of Lake Erie. Ten or so people, some just arriving at work, some finishing a night shift, sit silently on benches and in armchairs below stained-glass windows. A plump golden retriever named Linus, a therapy dog, wanders from one person to another, gratefully accepting their caresses.

Kevin Dieter, a hospice-care physician with graying mustache and goatee, gently suggests they get started. A nurse sitting opposite him begins reading names. In the pause after she pronounces each, Dieter strikes together two palm-size Buddhist meditation chimes, producing a tinkling that quickly evaporates. The names go on and on. Evonne and Molly and Andre and Jerry. Twelve in all.

Twelve patients who were alive in this hospice house three days ago when this ceremony was last held. Twelve who have died since, each in one of the bedrooms lining the quiet hallways, each having hoped for a death free of pain or distress and, for the lucky ones, bitterness or resentment.

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Providing the possibility of that wished-for death is the professional mission of all in this room, of all the 935 employees and 3,000 volunteers who work for the 40-year-old nonprofit Hospice of the Western Reserve. Each day they serve 1,200 hospice patients, most of them in hospitals, nursing homes or their homes, and as many as 88 in one of three hospice houses in the Cleveland area, including this one off Lakeshore Boulevard.

By Medicare's criteria, to receive hospice services, each of those patients is deemed to have six months or less to live. In most cases, they also must agree to forgo curative treatments.

All the employees will say they've gotten used to hearing The Questions — from family and friends, even from the loved ones of patients they care for. “We get asked that all the time,” said Tammy Wright, 43, a nurse’s assistant with hospice certification, now in her ninth year doing hospice work. “Why did you ever choose to work there? Why would anyone elect to spend their workdays so entwined with death and grief? And how can you possibly get up the next morning to do it all over again?”

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It is hard to think of another profession with such constant exposure to dying. Yet, as intense and exhausting as hospice care is, you seldom hear any of the Western Reserve’s doctors, nurses, aides, social workers and bereavement counselors describe the job as grim, sad or dispiriting. Instead, they tend to portray the work as deeply fulfilling, gratifying and, perhaps most counterintuitively, life-affirming. And in working in the presence of imminent death, they all say they have witnessed sights that defy expectation or explanation.

“We see God working here all the time,” said Dee Metzger, 68, a hospice nurse in the Medina Inpatient Hospice Care Center southwest of Cleveland. “All the time.”

The annual turnover rate among employees at Western Reserve is a surprisingly low 12 percent, according to Judy Bartel, the organization’s chief clinical officer. To retain employees, the hospice offers them many outlets to combat burnout and what is called “compassion fatigue.”

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As more Americans opt for hospice care, keeping the required workers dedicated, replenished and content is a growing concern. The number of hospice patients grew 167 percent between 2000 and 2016, to more than 1.4 million, according to a report from the Medicare Payment Advisory Commission. Nearly half of Medicare beneficiaries who died in 2015 had received hospice services.

At Western Reserve, those who quit the job are the ones who can't leave the work behind when they head home.

"It's sacred work," says Lisa Scotese Gallagher, one of whose tasks is to help the staff deal with the stress and emotional intensity of their jobs. "But the expectation that we can be immersed in suffering and loss and not be touched by it is unrealistic."

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'My soul and my role aligned'

Every week, Dieter loses 10 to 20 patients. Even those who survive the week aren't likely to see many more sunrises.

By the conventional measures of medicine, Dieter would be considered a failure. But he and his colleagues at Western Reserve do not evaluate themselves by the binary formula of life or death. In their professional lives, death is the inevitable, the constant, the unavoidable.

“At the end of life, there’s not a lot of fixing you can do,” Dieter says.

The hospice caregivers gauge their performance by how they usher their patients to their end. “The most we can do is provide opportunity for our patients to have the best deaths possible for them,” said Dieter, 62, medical director of Western Reserve’s David Simpson Hospice House. “While everyone else is running away from it, we in end-of-life are rushing forward, saying, ‘We know what you’re going through. We want to help.’”

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There is a shortage of hospice care in the nation, with not enough hospice doctors and nurses to keep up with an aging population, particularly in rural areas. Many hospices are understaffed, especially for those needing home care. Western Reserve relies on extensive fundraising to supplement Medicare and provide extra services for patients, such as art and music therapy.

The easier part is relieving physical symptoms, most often pain and agitation, which Dieter controls through medication. “Most of death isn’t medical, it’s spiritual and psychological,” he says. Hospice workers know they can’t erase all hurts and resentments. But often they facilitate conversations that can lead to deathbed reconciliations.

Shortly after the ceremony in the meditation room, Dieter slips into the room of a 75-year-old woman with advanced pancreatic cancer.

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She had been readmitted two days earlier, with swelling, edema, agitation and restlessness. Dieter had administered medications to try to get the symptoms under control, although in his estimation she was now actively dying with kidney and liver failure.

Dieter is heartened when he finds the tiny, white-haired woman sitting up in her bed, her eyes open and with no signs of the jerking he had observed earlier.

“I had a surprise this morning,” her husband says from an armchair at her bedside. “She’s going to hang around a little longer.” Turning to her, he says, “You’re like a cat. You have nine lives.” She doesn’t seem to follow.

Dieter pulls up a folding chair and speaks quietly to her, occasionally reaching over to pat her leg.

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“I know you’re confused,” Dieter tells her. “Part of that is the medicine, part is your illness. But you’re doing better.” She smiles wanly.

Outside the room, Dieter says she could be staging a rally, a brief improvement that could buy her a little more time. Or it could be just a pause before she resumes her march to the end.

An erudite man who quotes poetry and Latin ruminations about death, Dieter has been doing this work for nearly 30 years. “Most of us will tell you that we get more from our work than we give,” he said. “For me, it’s a way of having my soul and my role aligned.” Hospice care, he said, has taught him not to hold on to resentments and to try to find joy in the everyday.

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The work, Dieter says, does not sadden him. “If I felt helpless to impact how people experience the end of their lives, it would be awful. The fact that I and our team can do something about it, that’s what carries you through. You lean into it, knowing that your skills and presence are making a difference.”

'God's waiting room'

Others speak of how the work enriches their lives. “I was the biggest chicken in the world about death before I came here,” said Audrey Boylan, 51, a nursing assistant in the Simpson hospice. “Now, thanks to [the patients], I’m not afraid at all. It’s an honor to sit there and hold their hands. To help them find peace and comfort. I consider this God’s waiting room.”

Linda Cotoam, 69, a United Methodist pastor for 26 years and spiritual care coordinator at the Western Reserve hospice house in Westlake for the past six, said that her hospice work has broadened her faith in a way her previous 20 years in the church had not. “I got a wider view of who God’s people are, a wider view of God as much more accepting.”

Although Western Reserve is in no way religiously associated, virtually everyone interviewed for this story described themselves as spiritually inclined even though some are not religiously observant.

“This job will confirm any faith you have, but it will also challenge those beliefs when you see the suffering some go through,” said Misty Durbin, 42, a social worker in the Westlake hospice. “To do this work, you need something, whether it is prayer or nature or meditation.”

With Gallagher’s prodding, the staff is quite intentional about what she calls self-care, ways to replenish themselves so they can remain mentally engaged in the work. It is vital, she says, that workers not suppress their feelings, but find ways to process and share them with others.

One of the primary dangers is compassion fatigue, a numbing to the suffering of others that is frequently experienced by caregivers. The signs are increased irritability, a dread of going to work, an inability to experience joy and often an increased use of alcohol or drugs. Another sign, Gallagher says:

“Depersonalized language, like referring to a patient by diagnosis rather than using their name.”

Western Reserve offers programs to help the staff cope, including yoga and reiki sessions. Employees are encouraged to find peers they can confide in. And workers develop their own activities to acknowledge the meaning of their jobs, such as the ceremonies in the meditation room, which Dieter inaugurated when he came to Western Reserve three years ago. “In honoring their lives, it brings us closure,” says nurse Jill Rossman, 55, who had attended that morning’s ceremony.

Many workers say they intentionally wall off their home lives from their professional roles. Durbin says she has selected a spot halfway on her drive home, a Key Bank branch. Before she gets there, “I go through the day, grieve, feel angry, do whatever I have to do. But the rest of the way, I don’t allow any more of that. It’s ‘What are we going to have for dinner? What are we going to do tonight?’ ”

'Visioning'

What is hard to put aside, hard to dismiss, is the remarkable moments they experience with patients as death approaches. They’ve all seen patients wait for a loved one to arrive before dying, or hold off death until family members leave. To Dieter, it is an indication of something that startles outsiders.

“Patients seem to have control over the moment they die.”

Not long ago, Lindsay Turk, a 32-year-old social worker, had an elderly patient, a devoted father with a large family, who for a week had been “actively dying,” meaning that his internal organs were failing. Each time she visited, he was surrounded by family members. She gently suggested that they take a break so as not to exhaust themselves. But, she also had a hunch.

“Sure enough, he died soon after they’d left. He just couldn’t burden them with having to watch him die.”

Dying patients often speak of an impending journey. “They’ll say they’re waiting for the train or boat or bus,” Durbin says. “They’ll say they’re going home, although they don’t mean their actual home. One patient we had wanted to put his shoes on, because he knew he was leaving. Another wanted to pack his things.”

One phenomenon familiar to any experienced hospice worker is visioning. Usually a day or two before dying, some patients “see” deceased loved ones hovering nearby. Sometimes they gesture or speak to their visitors, and recall the meetings later. Dieter insists these are patients who are not suffering from dementia or hallucinations.

Boylan, the nurse’s assistant, recalled being in a room with a dying patient not long ago when he motioned toward something in the room. “Doesn’t your mother look beautiful in that dress?” the elderly man said to his adult daughter. His wife had died years before.

The man asked Boylan for a tie. “He wanted to look good for his wife,” she says.

On her break, Boylan drove to a nearby thrift shop and picked out a purple-and-black tie. Upon her return, she bathed the man, combed his hair and shaved him. She grasped his hand and put it to his face so he could feel how smooth his skin was. Then she dressed him in a hospital gown and tied the tie as best she could. He beamed.

“I said to him, ‘I’ll be right back, I just have to take the linen out.’”

She returned a few moments later, to find him lying back on his pillow, his eyes closed, his face relaxed.

Boylan had lost another patient. She left the hospice house that day with a smile. She had helped another on his way.

Ollove is a reporter for Stateline, an initiative of the Pew Charitable Trusts.

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**amhmc** 1 year ago *(Edited)*

Wow how do I get through the article and be able to type without the tears blocking my vision? What a beautiful, kind, real, compassionate story. Bless everyone involved including the therapy dog who no doubt has an understanding of how he is needed. I appreciated the thoughts of separating their lives from their work. I need to do more to help. Thank you.

Like 👍 Link ↗ Report 🚩

**Willreadalmostanything** 1 year ago

My aunt was recently in hospice. The hospice doctor came by just after midnight the day before she died. He was very compassionate and prayed with her - although she was not conscious to experience it. Yet I am sure she felt the caring, as she relaxed shortly afterward.

The nurses were very good, too. In the few days before her passing, three RN/RN supervisors stopped in to discuss concerns that had been expressed - a great relief to those of us who were with her and which led to 24 hour LPN medication coverage, also a relief as one of her caregivers had been reluctant to give pain and anti-anxiety medications as needed and ordered. I might add that this was due to a mistrust of the medications, fearing that they might lead to an earlier death.

Everyone associated with the hospice was a blend of practicality,

professionalism and compassion. It IS very much appreciated.
I very much hope that hospice is not a social support service that gets cut in the current administration.

Like  Link  Report 



ChicagoChuck 1 year ago

I worked as a hospice chaplain in Chicago for many years. This article is spot-on in its description of how the work is a constant blessing and inspiration to those who do it. How fortunate we are to be able to join in this part of a person's journey.

Like  5 Link  Report 



MuyCricket 1 year ago

What a beautiful and tender article! A friend in Memphis who has done hospice work said this is the best article on the subject she has seen. Thank you....

Like  5 Link  Report 



AnnabellLeigh 1 year ago

Hospice workers are amazing. Thank you, thank you, thank you!

Like  6 Link  Report 



Corydoras 1 year ago

Makes me hope I can find such good care when it's my time.

Like  3 Link  Report 



A-bling 1 year ago



Had experience with hospice when both of my parents died. They were the ones who told me that they were about to die. Because of them, I was there when they died. They told me they were about to die.

Like 2 Link Report



Gray Owl 1 year ago

What a beautiful, thoughtful article. Thank you for writing this. And what amazing people they are, the ones who choose to work in hospice care. They have my admiration and my gratitude for the compassion, smiles and comfort they bring to those who are dying, and to their relatives and friends.

Like 5 Link Report