Demystifying the Process of Dying

What do physicians and hospice nurses know about dying that we don’t? Much that would make the impending death of a loved one easier to understand and endure.

For many, witnessing the process creates a miasma of conflicting emotions. Fear. Helplessness. Uncertainty.

Hospice and palliative, or comfort, care for patients nearing the end of life smoothes the Way for patients and their loved ones.

“My mantra is, dying is all about spirituality,” said Dr. Kevin F. Dieter, associate medical director of Summa palliative care and hospice services in Akron. “The first thing we have to acknowledge is that patients are near the end of life. We need to validate to them what’s going on. They are waiting for us to tell them because they need to get things wrapped up.

“The end of life can be a time of healing, reconciliation and closure. But unless you know you’re dying, those things can’t happen.”

Prognosticating when a patient will die, said Dieter, a Jackson Township resident, is more art than science.

“The No. 1 thing is losing functional status, spending the majority of time in bed. They’re so tired, fatigued,” he explained, “When you step back, it begins to makes sense. Their lives are winding down.”

It wasn’t always that way.

A century ago, most people died at home. Families were not strangers to the process.

“Because of medical technology, we’ve had 100 years of forgetting,” Dieter said. “The majority of people died fairly quickly. Only 10 percent lived long.”

“In the Middle Ages in Europe, all three religious traditions had this wisdom about dying. This was all before the Inquisition,” he explained.
“As death approaches, the spiritual and nonphysical stuff becomes important. This knowledge helped people make the transition with prayer, music and ritual.

“When we became technologically more focused, there were lots of benefits. But when it comes to dying, medical technology can get in the way and prolong the dying process.”

**A Life-Changing Loss**

The death of his wife 10 years ago precipitated Dr. Steven D. Grossman’s shift from family medicine to palliative care.

“I said I’m going to take this and do more with it,” he recalled. “It was devastating to the entire family in many respects. We still had two children to be concerned about.”

Grossman, medical director of Aultman hospice and palliative care services, has seen too many of the same scenarios play out to dismiss them as coincidence.

“The experience is so powerful,” he said. “Maybe family members have held off coming, but now we’re down to hours. Maybe there are estranged members. Or relatives in prison. Or an elderly sibling in California who can’t be there.

“We have to provide an environment to try to address those things, the final conversations and final goodbyes.”

Often, the patient will hold on until a wayward adult child arrives to make amends.

While medical care focuses on science, Grossman said, the last days of life call for “non-science.”

The sequence of events is familiar.

“When the patient comes to us on Day 1, the family is hysterical. By Day 2, they’re a little more comfortable. By Day 3, they’re feeling guilty but praying that they go. They have become more comfortable with the situation. Those days help prepare families for the loss.

“The granting of permission by the loved one that it’s OK to do what you need to do now is important,” Grossman said. “They need to hear, ‘Don’t worry about me.’ Without it, they can’t let go. They need to know that you will be all right when they’re gone.”

**Unfinished Business**

Patients with terminal illnesses often wrestle silently with concerns about the futures of those they leave behind. Perhaps there is a disabled child. They may worry about the cost of medical care wiping out what they hoped to leave for their heirs.

Some are at odds with their religion. Maybe a decades-long feud nags at their conscience. There may be regrets about missed opportunities and career shortcomings. Mending fences often becomes a priority.

This is the time when palliative care doctors, hospice nurses and family members can contribute most by listening. Could a lost friend be located? Leaving a written legacy of their lives is important to some. Families can help by recording as the patient reminisces.
Often, patients will voice their private fears and concerns to a hospice nurse who then can make family members aware.

Kathy Lombardi, a Mercy hospice nurse, said patients often lose interest in current events, television and pastimes they once enjoyed.

“They become more focused on the family and things that are really important to them,” she said. “They may call out for their mother even in the weeks before death. They may not be very lucid and at times seem to be talking to people who have passed.”

Lombardi, a hospice nurse for 17 years, considers her work a privilege, connecting with families during difficult times. “It is very sacred time to be a part of helping them on that journey,” she said.

**Someone to Lean On**

When Marilyn Valentine’s mother drew her last breath two years ago, hospice nurse Sherry Buehler was on call. It was 2 a.m., but Buehler arrived within minutes at the woman’s Dover home.

“She bathed my mother and stayed with her until the people came to take her to the funeral home,” recalled Valentine, who like Buehler is a registered nurse.

Even though Valentine’s nursing career made her no stranger to death, she remains steadfastly grateful for a hospice program that stepped in before her mother passed.

“When she came through the door, it was the emotional support she provided our family. Just the knowledge that she was there was comforting,” Valentine said.

But everything comes with a cost.

Eighteen months ago, Buehler, who has worked as a hospice nurse on and off for 19 years, felt her emotional resources ebbing. She needed a break, acknowledging that the intensity of the profession had given her what she termed “a flat affect.”

For now, Buehler is working in a Dover surgical facility. She also volunteers her services on medical missions. But she does not rule out more hospice work in the future.

“That’s my calling. Dying people are such a gift. They’re very, very honest,” Buehler said. “You don’t get a lie from somebody dying. What they have done is really taught me how to live.”

**Death and Dying**

As a loved one nears death, here are some factors to consider:

- What family members mistake for delirium actually is part of the patient’s last journey. The patient may be restless, agitated, talking about packing their bags or missing a train. Calling out to a loved one who has passed or carrying on a seemingly one-sided conversation indicates the patient is making the transition, perhaps talking to someone on the other side.
• Skin color changes and sometimes becomes mottled. Often, the change begins at the feet.

• Those who have been present as a loved one neared death often mention a breathing change known as a death rattle. Often, they mistakenly identify the change as lungs filling with fluid. Usually, that is not the case. Dr. Kevin F. Dieter, associate medical director of Summa palliative care and hospice services in Akron, said the patient no longer is clearing his throat or swallowing hard as healthy people do several times a day. “Phlegm drains down the back of the throat and lays there,” he said. “When you breathe, air is moving through the voice box and causing those secretions to move. It can sound very disturbing, but we can treat that.”

• Family members often feel hurt when the patient begins withdrawing emotionally. Food and drink no longer appeal. “Now and then, they might want their mouth moistened. Our bodies have had a long time to adapt to the natural dying process. The body knows how to do that. But it is hard for families because eating and drinking are part of being alive,” Dieter said.

• A dying person’s behavior may change, confounding his loved ones and caregivers. If a pain pill is proffered, the patient may reject it. “They are telling you, ‘I can say no to this but I can’t say no to the disease,’” Dr. Steven D. Grossman said. “They need to hold onto control in any way possible.”

• Temperature fluctuations are not uncommon. Hands and feet may grow cold.

• Urine output decreases as the body begins to shut down.

• It is not uncommon for a dying patient to rally, however briefly. Family members, feeling blind-sided when their loved one dies soon after, fail to recognize the rally as a final gift. “(Patients) often know before we do,” Buehler said. “They will start giving their heart to family members. They could be alert when they were not a day earlier.”

• Palliative care professionals say people die as they lived. “Someone for whom micromanagement is important may experience a difficult death because they do not have control,” Dieter said.

• Remember that the last sense to fail is hearing, Dieter advised. “Dying is not 100 percent alive and the next moment 100 percent dead,” he said. “It’s a process. But even if they are unresponsive, they still can hear. We still think they can feel, so holding their hand and telling them you love them is important. Ask forgiveness and give forgiveness.”

• World War II veterans sometimes experience greater struggles as death approaches, Dieter said. “They can have really agitated deaths with a lot of struggling. What we think happens is actually post-traumatic stress kicks in. Grandchildren will say, ‘Grandpa doesn’t talk about the war.’ But at the end of life, you have to deal with that stuff. It was different then than it is now with today’s soldiers. You can say, ‘I can imagine bad things happened in the war. It’s OK, it’s forgiven.’ Sometimes you can feel the difference in the room when they finally let go of that.”

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Please answer the following questions prior to attending Session 1 of the Hospice Volunteer Orientation. Write whatever you feel necessary. Please feel free to jot down questions/concerns/comments regarding this topic and we will address them during Session 1.

1. After reading the article, has it changed your thoughts about hospice?

2. What have you learned about Hospice care that you were previously unaware of?

3. What struggles, if any, do you think you will face as a Hospice Volunteer?

4. Has a close family member, friend or someone you know received hospice care? If so, what were your experiences with hospice? What did you like/dislike understand/not understand? Was the hospice team helpful to you and your family during that difficult time?