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DEALING WITH DEATH AT HOME

The price of not talking about death

Death is a topic few want to discuss. But ignorance makes caregiving harder.

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In the movies, people often die in some quick, dramatic way. There are bullets, train wrecks, serial killers, monsters, or, at least, exotic illnesses. If they die quietly, they almost always leave with a memorably pithy comment.

Many of us don't know much more than that about death until it comes to live in our own house. Friends may lose family members, but they rarely talk about the uglier aspects of dying. We all conspire to protect one another - and perhaps our loved ones' dignity - from the smells, sounds, and suffering that accompany the slow shutdown of vital organs. Why think about that until you absolutely have to?

But our reluctance to talk about the mechanics of decline and caregiving comes at a price. Ignorance can make first-time caregiving more frightening and disturbing.

"It would be a lot easier if we didn't hide death, if we didn't medicalize death, if there was a general acceptance and recognition of mortality," said Lydia Dugdale, a Yale University doctor who wrote an [essay on the "art of dying well"](#) for The Hastings Center Report in December. She says bioethicists should "create a framework for teaching an aging population to prepare for death and to support one another through the dying process."

"Many families kind of share a common charade" as the dying begins, said Joseph Straton, a doctor who is medical director for Southeastern Pennsylvania for VITAS Innovative Hospice Care. "Everybody knows, but everybody's keeping a secret from each other."

Hospice workers can be wonderful guides, but health-care experts agree that hospice often starts too late. Lynn O'Brien, director of hospice at Abington Memorial Hospital, said half of her patients join hospice less than seven days before they die. By then, many are well into the dying process.

The American ideal death, Dugdale said, is to die of a silent heart attack in your own bed while you sleep.

That's not what most of us get. "The reality is we die of serious illnesses that have a time trajectory where we know death is coming," O'Brien said.

Many cancer patients do well until the last month or two, when caregiving takes a "dramatic uptick," Straton said. "People with cancer have a much more rapid decline as they're approaching death."

Cancer cells proliferate wildly, ultimately crowding out normal cells, causing pain and making organs malfunction. Cancer hurts more than many other killer diseases, though the pain can be controlled, Straton said.



TOM GRALISH / Staff Photographer
At the Warminster Campus of Abington Health Center, hospice director Lynn O'Brien (left) talks with Allen Fellows, 90, a patient with congestive heart failure, and his daughter, Ruth Mason.

"Dying is not easy," Straton said. "Especially dying from cancer is not easy because there's so much that goes wrong in the body."

Patients with cancer in their lungs are more likely to feel short of breath than people with cancer elsewhere. Abdominal cancers are more likely to cause pain, nausea, or abdominal obstructions. Cancer in the brain causes more neurological symptoms.

While death is a highly individual process, O'Brien and Straton said many people go through predictable steps.

First, people begin sleeping more than usual, because of less oxygen in the blood or pain medicines.

It's hard to watch. "It feels like they're giving up or that the disease is winning," Straton said. Instead of trying to keep patients awake, he suggests making the best possible use of the few hours a day when they are alert.

Early on, people may also begin withdrawing from activities and other people.

Oxygen deprivation and pain meds can also lead to increasing confusion, which is common among the dying. It is the most frequent reason that families call hospice nurses, O'Brien said.

Toward the last two weeks, patients' appetites may decline even before it's obvious that they're dying. This is another tough symptom for families.

"I'm Italian," Straton said. "Food is love."

But eating less is part of the process. Forcing dying people to eat can make them nauseated.

When the dying do eat, some are drawn to junk food, which may upset caregivers who see good nutrition as a way to fight disease. Straton said people who are tired and short of breath are attracted to high-energy food. "It takes energy to chew," he said.

Eventually, many people have swallowing problems. Families will need to puree foods or offer smoothies, baby food, or yogurt.

Incontinence is also common.

Many dying cancer patients have trouble breathing. Morphine and antianxiety drugs can help, but they can also cause more sleeping. Patients may begin snoring more loudly as they lose muscle coordination.

At the end of life, people frequently become anxious and agitated. Some patients pick at their sheets and clothing and thrash in bed. It's called terminal restlessness, and Jane Feinman, senior vice president of hospice for Hospice of Philadelphia, said: "It's really hard to watch and manage at home."

People in the last week of life often dream of a loved one who has died. "They have a sense of someone in the room," O'Brien said. She gives them permission to talk about it by saying, " 'Tell me who's been here to see you,' and they can take that any way they want."

Some people also begin using "journey language," a symbolic way of discussing death. "A lot of people will wake up and say, 'I need to go home or . . . what time is the train coming? Do I have my ticket?' " O'Brien said.

She suggests playing along. Ask, "Are you ready to get on the train . . . when it comes?"

As the heart slows, it pumps less effectively. This means that hands and feet will feel cooler. Not long before the death, patients may begin to turn purple or blue. They may also feel feverish.

Because cancer may affect younger people who are otherwise healthy, the dying process can take a surprisingly long time. "What would take hours in a much older sicker person could take days in an otherwise healthier person," Straton said. People seem to be declining and then rally.

The body typically stops making urine 24 to 48 hours before death.

As the brain slows down, swallowing gets harder. This can make saliva build up in the throat, causing the gurgling death rattle so closely associated with death. It is heard within hours or a couple days of death. O'Brien said it can be managed with drops that dry secretions.

In the final hours, breathing becomes fast and shallow, punctuated with breaths that may be seconds apart. Eventually, they stop, often without the telltale signs of death you'll see in movies. Straton remembers a young man asking how he would know when his father had taken his last breath. All Straton could say was, "There's no breath that follows it."

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