

# *The Atlantic*

## What It Feels Like to Die

Science is just beginning to understand the experience of life's end.



Ted S. Warren / AP

**JENNIE DEAR**

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“Do you want to know what will happen as your body starts shutting down?”

My mother and I sat across from the hospice nurse in my parents' Colorado home. It was 2005, and my mother had reached the end of treatments for metastatic breast cancer. A month or two earlier, she'd been able to take the dog for daily walks in the mountains and travel to Australia with my father. Now, she was weak, exhausted from the disease and chemotherapy and pain medication.

My mother had been the one to decide, with her doctor's blessing, to stop pursuing the dwindling chemo options, and she had been the one to ask her doctor to call hospice. Still, we weren't prepared for the nurse's question. My mother and I exchanged glances, a little shocked. But what we felt most was a sense of relief.

During six-and-a-half years of treatment, although my mother saw two general practitioners, six oncologists, a cardiologist, several radiation technicians, nurses at two chemotherapy facilities, and surgeons at three different clinics—not once, to my knowledge, had anyone talked to her about what would happen as she died.

There's good reason. "Roughly from the last two weeks until the last breath, somewhere in that interval, people become too sick, or too drowsy, or too unconscious, to tell us what they're experiencing," says Margaret Campbell, a professor of nursing at Wayne State University who has worked in palliative care for decades. The way death is talked about tends to be based on what family, friends, and medical professionals see, rather than accounts of what dying actually feels like.

James Hallenbeck, a palliative-care specialist at Stanford University, often compares dying to black holes. "We can see the effect of black holes, but it is extremely difficult, if not impossible, to look inside them. They exert an increasingly strong gravitational pull the closer one gets to them. As one passes the 'event horizon,' apparently the laws of physics begin to change."

What *does* dying feel like? Despite a growing body of research about death, the actual, physical experience of dying—the last few days or moments—remains shrouded in mystery. Medicine is just beginning to peek beyond the horizon.

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Until about 100 years ago, almost all dying happened quickly. But modern medicine has radically changed how long the end of life can be stretched. Now, Americans who have access to medical care often die gradually, of lingering diseases like most terminal cancers or complications from diabetes or dementia, rather than quickly from, say, a farm accident or the flu. According to the Centers for Disease Control's [most recent figures](#), Americans are most likely to die of heart disease, cancer, or chronic pulmonary lung disease.

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**“Pre-death dreams were frequently so intense that the dream carried into wakefulness.”**

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For those who do die gradually, there's often a final, rapid slide that happens in roughly the last few days of life—a phase known as “active dying.” During this time, Hallenbeck writes in *Palliative Care Perspectives*, his guide to palliative care for physicians, people tend to lose their senses and desires in a certain order. “First hunger and then thirst are lost. Speech is lost next, followed by vision. The last senses to go are usually hearing and touch.”

Whether dying is physically painful, or how painful it is, appears to vary. “There are some kinds of conditions where pain is inevitable,” Campbell says. “There are some patients that just get really, really old and just fade away, and there's no distress.” Having a disease associated with pain doesn't mean you'll necessarily endure a difficult death, either. Most people dying of

cancer need pain medication to keep them comfortable, Campbell notes—and the medicine usually works. “If they’re getting a good, comprehensive pain regimen, they can die peacefully,” she says.

When people become too weak to cough or swallow, some start to make a noise in the backs of their throats. The sound can be deeply disturbing, as if the patient is suffering. But that’s not what it feels like to the person dying, as far as doctors can tell. In fact, medical researchers believe that the phenomenon—which is commonly called a death rattle—probably doesn’t hurt.

Ultimately, because most people lose awareness or consciousness in their last few hours or days, it’s hard to know for certain how much patients are suffering. “We generally believe that if your brain is really in a comatose kind of situation, or you’re not really responsive, that your perception—how you feel about things—may also be significantly decreased,” says David Hui, an oncologist and palliative-care specialist who researches the signs of approaching death. “You may or may not even be aware of what’s happening.”

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A week or two after we spoke to the nurse, my mother sank into a state where she was rarely conscious. When she was awake, it was only the most basic part of her that was there: the part that told her legs to move to get her to the bathroom, the automated steps in brushing her teeth and then wiping the sink afterward. Her mind turned away from her children and husband for the first time.

I wanted to know what she was thinking about. I wanted to know where her mind was. Being at the bedside of an unresponsive dying person can feel like trying to find out whether someone is home by looking through thick-

curtained windows. Is the person sleeping, dreaming, experiencing something supernatural? Is her mind gone?

For many dying people, “the brain does the same thing that the body does in that it starts to sacrifice areas which are less critical to survival,” says David Hovda, director of the UCLA Brain Injury Research Center. He compares the breakdown to what happens in aging: People tend to lose their abilities for complex or executive planning, learning motor skills—and, in what turns out to be a very important function, inhibition.

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**“The waves get higher and higher, and eventually, they carry the person out to sea.”**

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“As the brain begins to change and start to die, different parts become excited, and one of the parts that becomes excited is the visual system,” Hovda explains. “And so that’s where people begin to see light.”

Recent research points to evidence that the sharpening of the senses some people report also seems to match what we know about the brain’s response to dying. Jimo Borjigin, a neuroscientist at the University of Michigan, first became intrigued by this subject when she noticed something strange in the brains of animals in another experiment: Just before the animals died, neurochemicals in the brain suddenly surged. While scientists had known that brain neurons continued to fire after a person died, this was different. The neurons were secreting new chemicals, and in large amounts.

“A lot of cardiac-arrest survivors describe that during their unconscious period, they have this amazing experience in their brain,” she says. “They see lights and then they describe the experience as ‘realer than real.’” She realized the sudden release of neurochemicals might help to explain this feeling.

Borjigin and her research team tried an experiment. They anesthetized eight rats, and then stopped their hearts. “Suddenly, all the different regions of the brain became synchronized,” she says. The rats’ brains showed higher power in different frequency waves, and also what is known as coherence—the electrical activity from different parts of the brain working together.

“If you’re focusing attention, doing something, trying to figure out a word or trying to remember a face—when you’re doing high-level cognitive activity, these features go up,” Borjigin says. “These are well-used parameters in studying human consciousness in awake humans. So, we thought, if you’re alert or aroused, similar parameters should also go up in the dying brain. In fact, that was the case.”

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In her last couple of weeks, when my mother’s mind seemed to be floating off somewhere else most of the time, she would sometimes lift her arms into the air, plucking at invisible objects with her fingers. Once, I captured her hands in mine and asked what she’d been doing. “Putting things away,” she answered, smiling dreamily.

This half-dreaming, half-waking state is common in dying people. In fact, researchers led by Christopher Kerr at a hospice center outside Buffalo, New York, conducted a [study](#) of dying people’s dreams. Most of the patients interviewed, 88 percent, had at least one dream or vision. And those dreams usually felt different to them from normal dreams. For one thing, the dreams seemed clearer, more real. The “patients’ pre-death dreams were frequently so intense that the dream carried into wakefulness and the dying often experienced them as waking reality,” the researchers write in the *Journal of Palliative Medicine*.

Seventy-two percent of the patients dreamed about reuniting with people who

had already died. Fifty-nine percent said they dreamed about getting ready to travel somewhere. Twenty-eight percent dreamed about meaningful experiences in the past. (Patients were interviewed every day, so the same people often reported dreams about multiple subjects.)

For most of the patients, the dreams were comforting and positive. The researchers say the dreams often helped decrease the fear of death. “The predominant quality of pre-death dreams/visions was a sense of personal meaning, which frequently carried emotional significance for the patient,” they report.

In patients’ final hours, after they’ve stopped eating and drinking, after they’ve lost their vision, “most dying people then close their eyes and appear to be asleep,” says Hallenbeck, the Stanford palliative-care specialist. “From this point on ... we can only infer what is actually happening. My impression is that this is not a coma, a state of unconsciousness, as many families and clinicians think, but something like a dream state.”

The exact moment at which this happens—when a person enters a dream state, or even when a person starts dying—is hard to pinpoint.

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That was true in my mother’s case. In the early hours one morning after it snowed, I was keeping watch with two of my mother’s friends in her library, the room where we’d moved her to accommodate a hospital bed. She seemed peaceful, and in the dim light of the morning, we stood at different points around the bed, listening to her raspy breathing.

She made no dramatic moves or indications that she was about to leave us.

She didn't open her eyes or sit up suddenly. She took a last, slightly louder breath, and died.

"It's like a storm coming in," Hallenbeck says. "The waves started coming up. But you can never say, well, when did the waves start coming up? ... The waves get higher and higher, and eventually, they carry the person out to sea."

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