

DALE ROBERTS

Here and Gone, 2016
Encaustic on panel, 45 x 45 in



COURTESY THE ARTIST

JOHN MOIR

A Kindness While Dying

Embracing Compassion at the End of Life

At age ninety-seven my wife's mother suffered a major stroke that left her bedridden and in the care of a nursing home. Her condition was heart wrenching, and our doctors advised us that she had no hope of recovery. All we could do was to help her live out her final days as peacefully as possible. But we soon encountered an all-too-common challenge: a medical system that leaves many people at the end of life suffering needlessly and dying in ways they would not choose.

Despite her stroke, my mother-in-law's mental faculties were still intact, and she understood that the end was near. "I've had enough," she told us several times. "I'm done."

It wasn't long before she lost interest in eating, which for her was nothing short of extraordinary. My mother-in-law cherished food and cooked scrumptious meals. Throughout her life, eating comforted her and safeguarded her days. Her fixation with food was hard earned. Born in Brooklyn at the end of World War I to immigrant parents, her family struggled financially and the source of their next meal was sometimes uncertain. Her parents gave her a popular name of that era—Shirley—and did their best to adapt to a new culture, but it was not an easy life.

By the time I met her, Shirley was securely middle-class. Nevertheless, she always kept a well-stocked refrigerator and a kitchen drawer filled with Hershey's bars. I soon learned that food was the currency of her affection. When she heaped your dinner plate with brisket and mashed potatoes and coleslaw and insisted on bringing you second and third helpings, she was serving up love.

But all that changed as Shirley's life drew to a close. The hospice doctor told us that her loss of appetite was a normal part of the dying process and estimated that she had perhaps two weeks left. The nursing home, however, had other ideas. They persisted in bringing her meals and encouraging her to eat. Three times a day an aide bustled into her room with a full tray. Shirley was usually asleep.

"Wake up, Shirley, it's time to eat." The aide raised her hospital bed and tied a bib around her neck.

"Come on, Shirley, just a few bites. The custard is delicious." The aide put the food to her mouth. Shirley shook her head and clamped her lips tight. But if the aide persevered long enough, Shirley gave in. The aides meant well, but every bite she ate prolonged her misery. Food became her nemesis.

Two weeks passed, a month, two months. Our frequent visits to the nursing home grew increasingly difficult. Because of Shirley's immobility and poor circulation, infections covered her feet and back. She required powerful medications for comfort. When she was awake, she sometimes cried out for help and repeated her mantra that she was "done." We did everything we could think of to make her comfortable, to soothe her torment, to make this nightmare more tolerable.

It was never enough.

We began wondering why she was lingering. At last a sympathetic nurse showed us the record of her food intake. With the aides cajoling her to eat, she was consuming just enough calories to keep her alive.

Shirley faced a predicament common in the final stages of life: when do we stop fighting and accept death's inexorable arrival?

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While advances in science and technology have brought medical miracles, these same breakthroughs have complicated how we die. Modern medicine's plethora of possibilities means that even in a person's waning days, it is easy—and often tempting—to order another test, another treatment, another intervention. It is much harder to know when to stop.

When the end draws near, there are questions to be considered: How do we respect a patient's wishes? When do we cease prolonging an intolerable dying process? What is a good death?

There is growing momentum for embracing a more compassionate way of dying. As the baby boomers enter old age, increasing numbers of them are pressing the medical and palliative care communities to reform end-of-life care. Six states and the District of Columbia have already enacted death with dignity laws, allowing terminally ill patients to end their suffering.

Fundamental to improving how we die is training doctors to facilitate skillful discussions with dying patients and their families, providing a clear-eyed assessment of the options available including stopping treatment. Atul Gawande, a surgeon and a professor at Harvard Medical School, writes in his book *Being Mortal*: "I learned about a lot of things in medical school, but mortality wasn't one

of them. . . . Our textbooks had almost nothing on aging or frailty or dying. How the process unfolds, how people experience the end of their lives, and how it affects those around them seemed beside the point. . . . [T]he purpose of medical schooling was to teach how to save lives, not how to tend to their demise."

Without training, doctors can be reluctant to be the bearers of bad news. They also may feel that a patient's death represents a failure. Moreover, patients and their families often have their own aversion to receiving a poor prognosis. For example, a study at the Center for Research on End-of-Life Care at Weill Cornell Medical College showed that nearly 40 percent of terminally ill cancer patients had not discussed their life expectancy with their oncologists.

The words left unsaid in these situations often lead to increasingly futile treatments that bring unnecessary suffering. Gawande says that as death approaches, it's time to ask dying persons about *their* goals. "We don't recognize that people have priorities besides just living longer," he said in an interview with *Science of Us*.

There comes a time when it is a kindness to let death take its natural course.

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At last, my wife and I met with the nursing home's director to request that Shirley be fed only if she wanted to eat. The director was sympathetic. Clearly we were not the first family that had raised this issue. But all she could tell us was, "It's the policy." A large corporation owned the nursing home, and their rule was immutable: three times a day a full tray was to be delivered to every patient.

At last the director said quietly, "You could take her home. Then the feeding would be up to you."

My wife began to cry. Her mother needed complicated round-the-clock nursing care, which we could not provide. Eventually, we settled on a compromise. Aides would continue bringing Shirley three meals a day but with instructions not to wake her and to feed her only if she wanted to eat.

It did not work.

With different aides arriving at each meal, many did not get the word and the feeding continued. We turned to our doctor and to hospice for advice, and we talked

with friends who had faced similar dilemmas with elderly parents. We heard stories of loved ones drifting through twilight days on just enough calories to keep them alive. A friend's mother existed for months in an assisted living facility, subsisting largely on a calorie-dense pudding the institution fed her. Our friend told us, "We had to take control of the feeding to end her suffering."

And that is what we decided to do.

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Long before we reach life's final stage, it is beneficial to fill out an advance directive making clear how we want to end our days. Not only does this provide guidance for family members and medical personnel, but the process itself is an opportunity to reflect on what we will want and to discuss our wishes with our loved ones. Some directives, such as Five Wishes, cover not only medical interventions and legal matters but personal and spiritual choices as well.

Nowadays, there is good reason for having an advance directive. Until the mid-twentieth century, the majority of Americans died at home. But now, dying is primarily an institutionalized experience. While studies show that most of us would prefer to die in our own beds, 80 percent of people now end their lives in hospitals and nursing facilities. And as in Shirley's case, these institutions tend to default to mandated interventions and aggressive end-of-life measures.

Family members, with whom the decision making often rests, can find themselves having to choose between sanctioning useless interventions and rejecting their natural instincts to treat and to feed. For many of us—as it was for Shirley most of her life—food equals love. How can we not want our loved ones to eat, even if they resist?

For a dying person, losing interest in food is generally not painful. In fact, eating at this stage can actually create discomfort. Fortunately, Shirley avoided a feeding tube, an intervention often used when an elderly person can't or won't eat any longer.

Shirley was dying not because she had stopped eating. She had stopped eating because she was dying.

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In order to take control of Shirley's feeding, three times a day one of us drove to the nursing home and sat with

her during mealtime. Usually she was asleep when the food arrived, and we advised the aide that the director had left instructions not to wake her. But if Shirley's eyes were open, we asked her if she wanted to eat. She always shook her head no. Within a few days she fell into a coma. Her breathing slowed. Still the trays of food kept coming.

Early on the last day of her life, two members of Threshold Choir, a group that sings for the sick and dying, came to visit. Shirley was sleeping peacefully. Sunlight brightened the room, and in the garden outside the window, a towhee foraged through the undergrowth.

It was a moment—the final hours of nearly a century of living. At the same time, it all seemed so ordinary, so perfectly natural.

The singers sat by Shirley's side and held her hands and softly harmonized:

Oh what a beautiful morning

Oh what a beautiful day . . .

By now, she was breathing only four or five times a minute. Morphine kept her tranquil. We told her that she was safe, that we were with her, that she was loved. At last she was free of the feedings that had prolonged her suffering. She could let go.

I hope she heard the singing. I hope she was dreaming of a bountiful dinner table with a brisket roasting in the oven and filling the house with the aroma of love.

John Moir is a journalist whose work has appeared in the *New York Times*, *Smithsonian*, the *Washington Post*, the *Christian Science Monitor*, and numerous other publications. He is the author of two nonfiction books, has contributed to three anthologies, and has received more than two dozen writing awards.