

IDEAS HEALTHCARE

# End-of-Life Care Needs an Overhaul

Jennifer Brokaw | Robert Kane | Sept. 29, 2016

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**Even experienced physicians struggle to navigate it**

By the end of the first term of the next person elected President in 2016, there will be [about 13 million more people over age 65](#) in the United States than when President Obama was last elected in 2012. In their lives, [70 percent of people over 65 will require long-term care](#)—the range of services, both medical and social, that are designed to meet the personal care needs of the elderly or disabled but are [not covered](#) by traditional health insurance or Medicare (though it is covered by Medicaid for the poor or disabled).

We are two experienced physicians who were responsible for our loved ones in long-term care facilities. Both of our experiences left us deeply concerned about the ability of ordinary, non-medical people to receive quality, dignified care at the ends of their lives in these facilities.



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**Dr. Robert Kane:**

You would have thought that I would be able to obtain the care I wanted for my mother—I’ve been studying long-term care for over 40 years, and I hold an endowed chair at the University of Minnesota on the topic. But I was not able to. In 2000, my mother had a stroke. I discovered that although she had one of the country’s best case managers (me) and a devoted caregiver (my sister), and even a reasonable amount of money, it was impossible to direct her care according to her wishes.

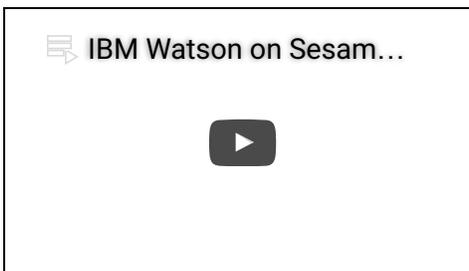
We were frustrated at every level. In the acute hospital setting, they put her in a noisy, brightly lit intensive care unit where she was over-stimulated and raving. Nurses gave her medications to sedate her that had the opposite effect and precipitated episodes of delirium. Even after we pointed out the perverse effect and got them to record that fact in the chart, the next shift did it again.

In assisted living, we observed that when her congestive heart failure got worse, my mother’s behavior deteriorated. When I proposed a simple system of weighing her each time and adjusting her diuretic medications on the basis of a simple calculation, I was told that was against the rules.

She fell often. Each fall led to the EMTs being called and her being taken to the emergency room, where she lay unattended on a gurney for hours. Each time, she became disoriented and delirious. We talked with the assisted-living staff to explain why these frequent trips to the ER did more harm than good. We even proposed signing a waiver of liability and having them call the



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EMTs only when there was evidence of serious injury, but they said that was beyond their capacity.

Finally, in a nursing home, they evaluated her frequent choking episodes and determined that she had a problem with aspirating food into her lungs. The treatment was puréed food and thickened liquids. This regimen ended one of the few pleasures she had left—eating food she enjoyed. Once again we offered to sign a waiver of liability, and once again we were told that it would not protect the staff from the regulators. She died several months later of the condition the thickened liquid was supposed to prevent: aspiration pneumonia. While we were relieved her suffering had ended, I had lingering feelings that I had let her down.

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**Dr. Jennifer Brokaw:** I took over Power of Attorney for my uncle, Bill Brokaw, who lived 2,000 miles away from me, when it was apparent that he was in the throes of dementia. He had no spouse or children of his own to take charge. As an emergency physician and professional patient advocate, I was surprisingly unprepared to anticipate the intricacies of managing his life with rapidly progressing Alzheimer's. When I came into the situation and gained a small amount of his trust, I immediately asked him about his wishes regarding health care if he were unable to speak for himself. Although he was already in the moderately advanced stage of Alzheimer's, he told me unequivocally that he did not want to live with dementia, and that he was not afraid to die. I pledged to myself that I would do everything in my power to make sure he had a dignified end and that nothing be done to prolong his life.

Unfortunately, Bill's disease was always a step ahead. Independent living in the apartment became untenable when he stopped eating or bathing. "Aging in place" just wasn't feasible.

Luckily, I found Mary, a geriatric care manager and an expert in this area. She had become a care manager because of her own experience advocating for her father-in-law. We undertook a painstaking look at every option, including Alzheimer's only facilities, board-and-cares in private homes and the more luxurious assisted-living, memory-care facilities. Unfortunately, we were about to find out that signing a contract with a facility meant playing by their rules.

Although the manager of the facility went out of her way to accommodate our concerns and Bill's dignity, she too quickly learned that his disease was progressing faster than we could anticipate. Behavior problems for him were persistent as he refused help with bathing and toileting. He sometimes struck staff who were attempting to help him. Soon, the private physician who covered the facility approached me about using a sedative medication. I knew that sedatives in Alzheimer's patients was a no-no. It puts them at risk for falls, delirium and worse behavior. I was reluctant to consent, but I believed that not medicating Bill would put him at more risk as his agitation worsened.

Within days, Mary, who was there almost every day to check on him, noticed Bill was sleeping often and drooling. While he may have been a little more compliant with staff, his overall behavior hadn't changed—he just became sleepy and unsteady on his feet.

Furthermore, he was not able to participate in the one aspect of assisted living he really enjoyed: Day trips on the bus.

As the months passed, we experimented with several different medical regimens. Then I insisted that he be taken off all behavior-altering medicines. They just weren't working. His mind became more addled in day-to-day tasks, and the intrusion of other impaired residents into his personal space led to more behavior outbursts and a physical confrontation with another resident.

In the final months of his life, we battled with the facility to keep him in the facility he had come to see as home. The administration threatened to transfer him to a place with more "safety measures" in place, but we knew that would mean physical and medical restraints. The thought of him being tied to a bed, and further sedated, enraged me. As a physician and a loving niece, I felt helpless.

Thankfully, the state Ombudsman for Long Term Care was brought in. She took our side wholeheartedly and asked the facility to look at their staffing and training more carefully. The company responded that he could stay if we hired a 24-hour-a-day private attendant. His monthly costs of care skyrocketed to \$12,000.

Thankfully, his body shut down rapidly. He died on hospice care only a few months later. Ironically, the extra attention of hospice volunteers, including pet therapy and music therapy, produced a calm in him we hadn't seen for two years.

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If not even people like us—with all our resources and personal connections—could not get the acute medical and long-term care that honors the wishes of patients and families to have a gentle and dignified end, the system is broken. If the most skilled people in the country have serious problems getting high-quality, long-term care for their loved ones, what chance do lay-people have? We spend a great deal of time and effort looking for ways to pay for this care and to make it cheaper. We need to invest in making it better.



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