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A parting lesson from my parents

By Andrew Dreyfus DECEMBER 16, 2015

WE OFTEN TRY to keep our personal and professional lives separate, but sometimes they collide unexpectedly. That happened to me over the complex and delicate issue of end-of-life care, where our health system still struggles to honor patient choices and values.

Five years ago, my father, Carl Dreyfus, died at the age of 92. He had been a local businessman, community activist, and loving husband and father. He lived with a pacemaker for three years but then showed increasing signs of congestive heart failure. Though his mind remained strong, he was less and less able to do the things that gave him pleasure — playing Cole Porter on the piano, reading biographies, tending the garden. His appetite suffered, and he slept for much of the day. Life was closing in on him in ways that he dreaded for himself and his family. When it became clear the end was approaching, he agreed to begin hospice care in his home.

My father and stepmother had once read an article about deactivating a pacemaker at the end of life, and now my father asked one of his cardiologists about that possibility. Unfamiliar with such a question, the doctor resisted. But after consulting with colleagues and attending a family meeting where my father again asked quietly if there was any way “to speed this along,” the answer was yes. The pacemaker could be turned off. Although still uncommon, such an action is consistent with national clinical and ethical guidelines, akin to withdrawing other treatments that prolong life.

A few days later — after careful planning with the hospice team — that is exactly what happened. On his last morning, my father walked downstairs as usual, ate a small breakfast, glanced at the newspaper, and returned to bed. When the cardiologist arrived, he wirelessly turned off the pacemaker that had been keeping my father’s heart beating at a normal rate. As his heartbeat slowed, he gradually lost consciousness. Throughout the day, his grandchildren sang to him to keep him company, and his children said goodbye. In the middle of the night, he died painlessly, his wife close by his side, just as he had hoped.

My father was following a path similar to that taken a few months earlier by my brother Nick. Nick had worked in radio and TV broadcasting and later in sales, but kidney failure stopped his career and imposed decades of illness, complications, and disability. He faced the rigors of dialysis, two failed kidney transplants, and many hospitalizations with courage and a tough independence. He retained his rich “radio voice” and boyish smile, but his body became frail. After suffering liver failure, he faced the likelihood that he would eventually require a transplant and also lose one of his legs. Nick decided instead to discontinue dialysis, knowing that it would lead quickly to his death. He entered a residential hospice program and died in less than a week, surrounded by his family.

Then, two years ago, my mother, Rosalind Dreyfus, died of cancer at her home, also supported by hospice care. She was private but adventurous and even after being diagnosed with an incurable lung cancer in her early 80s, she continued to lead a full life. Once, in her last few months, my mother vanished after a visit to the beauty parlor, much to the distress of her family. It turned out she was at a restaurant with some young friends, indulging in fried clams.



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When her cancer spread and her health rapidly declined, my mother received limited radiation treatment but made it clear that she didn't want to be hospitalized. And she wasn't — not for a single day. Instead, she spent her final weeks at home, visited by a steady stream of friends and kindly supported with palliative treatment by hospice caregivers. At the moment my mother died, her three sons, her daughters-in-law, and her grandchildren encircled her in a final, familial embrace.

Each of these losses was excruciating, but my grief was softened because my parents and brother made decisions about their care and died gently, free from invasive medical treatment and touched by loved ones until the very end. Unfortunately, their experiences are not typical.

A 2014 REPORT by the Institute of Medicine called “Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life” found that, despite some progress over the past 20 years, a wide gap still exists between the kind of end-of-life care we want and what we usually receive. Many of the report's recommendations for improvement focus on two broad areas — communication among patients, loved ones, and clinicians, and the care patients get during advanced illness and at the end of life.

Research finds cascading benefits from talking early about our end-of-life care wishes. Conversations about goals and preferences are the first step to formal advance care planning — the process of thinking about and documenting priorities and wishes for end-of-life care. These conversations, in turn, allow patients and families to begin to prepare emotionally for serious illness and can alleviate patient concerns about whether they will be involved in decisions about their care. What's more, people who have created advance care plans are more likely to choose palliative and hospice care focused on relieving pain and discomfort near the end of life.

Despite all the benefits, these conversations are far too rare. A recent survey found that while most Americans want to discuss end-of-life care wishes with their physicians, only 17 percent say they have had that conversation. Communication within families is no better — there is a wide gap between what we want and what we do. Ninety percent of Americans think it is important to talk with our loved ones about our wishes for end-of-life care, but only a small fraction has actually done so. Talking about end-of-life care is hard to do and easy to avoid.

Clear, regular conversations and carefully documented plans become even more important when an advanced illness progresses. That is when medical decisions about care become more nuanced and complex, and patients' priorities and wishes may change. If a patient becomes incapable of making decisions, the burden may shift to family members with different opinions about the best course of action. Sometimes collaborating physicians may also disagree about the benefits and risks of a therapy or intervention.

The absence of clear communication and regular advance care planning increases the odds that patients will receive care that does not reflect their values, preferences, and needs. While critics of the US health care system often express concerns that people “want more and get less,” the end of life is a time when many people want less care but get more than they want, often in the form of high-tech interventions and futile acute care. The vast majority of Americans say they want to die at home, but most still die in institutions. While the use of hospice is up among seniors, so too is the percentage of people enrolled for three days or less — often too short a time to gain its great benefits. ICU use in the last month of life is also on the rise. And an increasing number of elderly patients move between different sites of care — home, hospital, nursing home — in the very last days of life. These transitions are stressful at any time, and even more so close to the end.

Changing the status quo will require hard work on multiple fronts: broader training of clinicians on how to talk to patients and families about end-of-life care; electronic medical records that document our care preferences and make them available to any clinician we encounter during a medical crisis; public education about the value of advance care planning; and broader availability of the medical, emotional, and spiritual support that palliative care can offer.

Massachusetts has long been a health care pioneer — from improving public health to expanding coverage to changing how we pay for care — and we can be a national model for end-of-life care as well. We begin at a strong starting point: Our state is home to several organizations that are breaking new ground in this area. It has been through my association with one of them that I found my personal and professional concerns with end-of-life care merging.

THREE YEARS AGO, I joined the advisory board of Ariadne Labs, a joint center of Brigham and Women's Hospital and the Harvard T.H. Chan School of Public Health. Ariadne is led by surgeon and author Atul Gawande, whose most recent book, "Being Mortal: Medicine and What Matters in the End," explores aging and end-of-life care with extraordinary insight. Among many initiatives, Ariadne has developed a new approach to improving communication among patients with advanced illness, their families, and clinicians. Its Serious Illness Care Program includes training and coaching for clinicians; a system for documenting personal goals and priorities in a patient's electronic record; and a conversation guide that addresses patients' understanding of their illness, their preferences for information and family involvement, their personal life goals, fears, and anxieties, and the trade-offs they are willing to accept.

Several months after my mother's death in October 2013, I found myself at Ariadne Labs listening to the early findings from a trial of its new program at the Dana-Farber Cancer Institute. The results were striking. For patients under the care of physicians trained on Ariadne's program, conversations happened earlier, more frequently, and with a greater focus on patient values, goals, and priorities. Doctors embraced the approach, as did patients, who also reported feeling less depression and anxiety after their conversations. It was here that I heard the echo of my personal experiences, for these were the same kinds of conversations that had allowed my father, mother, and brother some peace at the end of life. And here was an approach — based on evidence — that could give this opportunity to others.

I returned from the meeting with two questions. How could Blue Cross Blue Shield help spread Ariadne's success to more physicians? What else could we do — as a health insurance plan — to improve care for our members with advanced illness?

We started by offering to sponsor clinicians from across Massachusetts to attend Ariadne's three-day course last June. If a hospital or physician group sent one person, we'd pay for the second. Our ultimate goal was to create champions inspired to set up the Serious Illness Care Program within their health systems, a process that we would support financially. And to help spread Ariadne's innovations, we are collaborating on a short, online version of the training that will be available to Massachusetts clinicians through the Blue Cross website.

As our work with Ariadne deepened, we also learned from local and national experts in hospice and palliative care and studied best practices from other pioneering health plans. As a result, Blue Cross will make a number of changes in our approach to advanced illness care, communication, and coverage for 2016. We will: expand member benefits to allow the earlier use of the kind of hospice care that was such a blessing for my family; change payments for advance care planning to include mental health clinicians in recognition of the important role that they play in these critical conversations; develop a new program to help individuals with advanced illness receive more care at home; and add advance care planning to the wellness program we offer to our own employees. This last work is in partnership with two local organizations — the Conversation Project, which prepares people to think and talk about their end-of-life care values and preferences, and Honoring Choices Massachusetts, which helps people collaborate with their care providers to set goals, plan for the future, create health planning documents, and ensure that their choices are honored throughout their lives.

ON MY OFFICE bookshelf, I have a bound copy of a 1927 article from the Journal of the American Medical Association entitled "The Care of the Patient." The author was a noted Boston physician, Francis Weld Peabody, and his article became a pillar of medical training. In it, he wrote, "The secret of the care of the patient is in caring for the patient."

My grandfather trained under Peabody and quoted him to me frequently, especially when he found himself in the unfamiliar role of patient. Eighty-eight years later, we have not fully embraced Peabody's simple but holistic view of clinical care. As Atul Gawande writes in "Being Mortal," "We've been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being."

As I have become more involved with this work, I have wondered whether the CEO of a large health plan is the right person to talk about end-of-life care. But I only have to remember how important this issue was to my brother and my parents to realize that — in this case at least — my personal experience should inform my professional actions. Everyone, regardless of economic, cultural, racial, or geographic differences, must have their choices and values heard and respected. Everyone deserves the chance to live the best life possible, to the very end.

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