

NARRATIVE MATTERS



DOI: 10.1377/HLTHAFF.2011.0197

Hospice And The ‘End Game’

After her husband’s death from cancer, a veteran reporter concludes that hospice “should be front and center in the debate over the kind of health care future that we want.”

BY ELEANOR CLIFT

My late husband, Tom Brazaitis, had trouble handling a sinus infection, but when he got the diagnosis of stage 4 cancer several years before his death, he responded with grace and gallantry.

He drew on an inner strength that I think surprised him as much as it did me. He endured treatments that mimicked the flu, inducing a fever of 105 degrees and then cooling him down to the point where he lay shivering under an electric blanket turned to high. He called

the regimen “shake and bake.”

After the cancer that had begun with a tumor in his kidney eventually metastasized to his brain, he had surgery at the Cleveland Clinic in 2003 to remove the largest of the lesions, followed by several sessions under the gamma ray knife for targeted radiation of the brain. When they screwed the metal frame into his head for the procedure, he had me take his picture. It wasn’t an image I wanted to remember, but he got a kick out of the photo, sending it around to family and friends. You’d think he was posing in the stocks at Colonial Williamsburg as op-

posed to prepping to have his brain radiated.

Cancer, Then Metastatic Cancer

The cancer had first been found in Tom’s left kidney in the summer of 1999, and at the time, Tom didn’t believe the news. After all, he’d run five miles that morning. He was at the top of his game professionally and personally, writing a column and running the Washington bureau of his hometown newspaper, the *Cleveland Plain Dealer*. He indulged his lifelong love of musical theater as the music chairman for the Gridiron Club in its annual roast of politicians.

Before Tom could be cleared for surgery to remove the affected kidney, he had a battery of tests to see if the cancer had spread. When he got the all-clear sign, he called me and exulted, “I don’t have cancer—my kidney does,” a play on the formulation that President Ronald Reagan had used after undergoing surgery to remove a cancerous polyp in 1985. Reagan had declared that he didn’t have cancer, his colon did—prompting the White House press secretary to urge reporters not to challenge the president, saying it was important for Reagan’s recovery to maintain his signature optimism.

Tom sailed through the operation and had no worries about losing a kidney; one is enough to live a healthy life. The assurances from the surgeon that he “got it all” fooled us into thinking we had cancer in the rear-view mirror. Tom’s six-month checkup indicated he was cancer-free. But at the one-year mark, a spot on his lung was biopsied and proved to be kidney-cancer cells that had metastasized. The surgeon might have gotten all that he could see, but microscopic cancer cells had escaped his knife and set up residence elsewhere.

The world of metastatic cancer care is a world unto its own, and anyone who has stepped into it as a patient, or as the loved one of someone undergoing treatment, knows that it is at once a horror show and a place filled with compassion-

ate and caring people. Tom's oncology nurse at the Cleveland Clinic, Laura Wood, was his lifeline. She could jolly him into eating when he didn't feel like it, and rally his spirits when he was down. She gave me the confidence to care for him, counseling me on the phone when I was near hysteria, assuring me that his high temperature would come down, that the spike was normal.

Tom continued to write his weekly column throughout his illness, focusing mostly on politics but also sharing with readers the highs and lows of his ongoing battle. Tom was a newspaper guy, and when a deadline loomed, he sprang into action, cancer be damned. I, too, found solace in my work life as a reporter and writer for *Newsweek*, and as a panelist on the weekly talk show, *The McLaughlin Group*.

Finding a new normal is the challenge for people living with cancer. Tom's treatments required him to inject himself with a combination of drugs that would arrive at our home via FedEx in a refrigerated container. Between the two of us, we got so adept at the injections, along with timing when the side effects would kick in, that we could carry the drugs with us, even ducking into the woods in the middle of a round of golf, joking about how he was going to shoot up. That was our new normal.

We were grateful for it as long as it lasted, knowing that the course of the disease would surely take us down another notch, and we'd have to adjust all over again. Tom marked the beginning of his final decline with the August day in 2004 when he had to walk off the golf course without completing the round. This was a man who'd play thirty-six holes of golf the day before reporting to the Cleveland Clinic for brain radiation, as though he were bargaining with the gods of golf to keep him going.

A Different Philosophy Of Care

The day finally arrived when Tom's oncologist gently suggested that he might want to take a break from the regimen of drugs that didn't seem to be doing much good anyway. It was just after Thanksgiving in 2004, some four years after Tom had been diagnosed with metastatic cancer—a pretty good

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run, given the relentless nature of the disease. The doctor made it sound as though Tom had earned this reprieve, which he certainly had, but tucked in among the well-wishing was the word *hospice*.

I didn't know much about hospice care then, but I did know it was meant for people who had six months or less to live. I don't think Tom even heard the word, because he looked puzzled when he saw me crying.

They say hospice is the best medical care that no one wants because it signals the end of life, and American culture is all about fighting until your last breath. But hospice is far more than a waiting room for death; it's a different philosophy of care for both the patient and the family. Entering hospice generally involves an end to harsh treatments and a focus instead on palliative care to provide the best quality of life in the time remaining. I remember when the nurse doing the hospice intake visited us at home to enroll Tom, and the odd sense of relief I felt now that the day I had been dreading for so long had arrived. Tom had a phrase for it, "the end game," and he seemed okay with that.

The biggest surprise for me was the realization that much of the time I'd be on my own managing Tom's care. For him, there'd be no more doctor visits and hours spent receiving a chemo infusion. Tom at first missed those outings; he enjoyed chatting with the nurses and filling his pockets with the candy that was always available.

The way hospice works is that the services increase according to the patient's need, and at the beginning of the months Tom spent in hospice, he was still ambulatory and didn't require daily attention. That would, of course, change. The hospital bed that was brought into our living room initially served as a convenient place to pile newspapers, and a cozy place for our

two cats to sleep. But then another one of those markers occurred, the day in mid-January when Tom couldn't make it down the stairs from our bedroom to the living room.

Suddenly the hospital bed seemed like an oasis in the world of the living, when the alternative meant being confined to the bedroom. A hospice aide who'd once played football asked Tom how he'd feel about being carried downstairs. "Not good," Tom replied. So the aide got a wheelchair. Strapping Tom in, and with the help of one of his football-playing buddies, he transported Tom down the stairs in what turned out to be a joy ride. Tom was laughing as the two men eased him into the bed that he wouldn't get out of until he died.

I tell that story because I think it's reflective of the holistic care that hospice strives to deliver. It gave my husband the closest thing to a "good death" that I could imagine once death was inevitable and imminent.

End-Of-Life Options And Planning

Hospice care is especially well suited to late-stage cancer, yet more than half of patients with advanced cancer who say they want to die at home end up dying in a hospital, often against their wishes. This was among the findings reported in the *Dartmouth Atlas of Health Care's* end-of-life study released in November 2010.

It's not that physicians are ignoring what patients want and overriding their wishes with aggressive medical care, although that does happen. The problem is more attributable to the widespread ignorance and denial about the cascade of events that occur when death is imminent. "The well-documented failure in counseling patients about their prognosis and the full range of care options, including early palliative care, leads many patients to acquiesce to more aggressive care without fully understanding its impact on the length and quality of life," says physician David C. Goodman, the lead author and co-principal investigator for the *Dartmouth Atlas* study and director of the Center for Health Policy Research at the Dartmouth Institute for Health Policy and Clinical Practice.

Aggressive care during the last sixty days of life accounts for a disproportionate share of the nation's medical costs. Although no one wants to deny care to extend life, if patients and their families were made aware of the limited health benefits to be gained from further intervention, they might opt instead for palliative care with the goal of maximizing quality of life.

In 2009, when a provision was inserted in proposed national health reform legislation that would have allowed Medicare to pay physicians and certain other health care providers to discuss end-of-life choices with beneficiaries, former Republican vice-presidential contender Sarah Palin characterized the proposal as leading to “death panels.” The phrase took hold, putting Democrats and President Barack Obama on the defensive, even though it was a Republican, Sen. Johnny Isakson of Georgia, who'd introduced the provision. “How someone could take an end-of-life directive or a living will as that is nuts,” he told the *Washington Post*. “You're putting the authority in the individual rather than the government. I don't know how that got so mixed up.”

My first reaction, too, was disbelief. I thought surely the facts would catch up with the distorted interpretation that Palin and others were touting. Boy, was I wrong.

Critics of health care reform were able to twist a benign provision into something diabolical, igniting primal fears that, in a time of scarcity, old people and people seen as defective would be denied care. I realized the damage that had been done when, at a town meeting in July 2009, a woman named Mary stood up to confront President Obama. She said she'd been told that a clause in the health care plan says that everyone of Medicare age will be visited and told to decide how they wish to die.

Obama at first tried to make light of her concern, saying there aren't enough government workers to carry out such a task. Then he explained that the intent of the clause was to encourage people to fill out a living will, so their wishes would be respected. He noted that he and his wife, Michelle, have such documents, and that if the provision became law, Medicare would cover the cost of a



consultation about end-of-life care every five years.

The provision didn't become law, and although the Centers for Medicare and Medicaid Services later proposed a similar arrangement through regulation, the agency ultimately withdrew that proposal as well. So in a political environment of heightened suspicion of government, the perception still lingers that end-of-life planning is code language for the government's wanting to force people to prematurely end their lives.

The Need For Critical Conversations

The way the debate over bogus “death panels” flared up shows how difficult these conversations are, even as the need for them becomes more critical. The hospice industry, too, is changing, adjusting its services to meet the needs for care of an aging population and the fragile elderly with debilitating illnesses and dementia.

Historically, since the founding of the first American hospice in 1974, the majority of hospice patients suffered from cancer. But in 2003 there was a tipping point, and for the first time the majority of the patients did not have cancer. Instead they had heart disease, lung disease, or neurological disorders, especially Alzheimer's. At any point in the trajectory of these diseases, people may be dying, but not necessarily on a six-month timetable. Under the Affordable Care Act, hospices must have a physician or nurse practitioner certify after a face-to-face encounter that a patient is still terminally ill after 180 days

(the end of a six-month period). It's an attempt by Medicare to control costs, and to make sure there's no fraud.

Art Buchwald, the noted humorist who died in 2006, wrote a column while he was in hospice care about what he jokingly called “the hospice scam.” He'd refused dialysis and thought he'd die within a few weeks. Thanks in part to the excellent care he received at an inpatient hospice in Washington, D.C., his kidneys started functioning well enough that he was able to check out of the hospice and enjoy another year of life that he hadn't expected to have.

Buchwald was fortunate in that he was financially independent and could pick up the cost of any additional hospice care once Medicare declared him “better” and stopped paying the bills. He told me when I visited him that it was the equivalent of the cost of a suite at the high-end Four Seasons hotel chain. Ironically, if he'd resumed dialysis, Medicare would have paid for it.

My husband, Tom, was sixty-four when he died, so he wasn't eligible for Medicare. We used employer-provided insurance—first his, then mine. He was atypical of the hospice population, both in terms of his relatively young age and in the length of time that he received hospice services, which was four months.

One-third of patients admitted to hospice die within seven to ten days, and that number has stayed steady, says Donald Schumacher, president and chief executive officer of the National Hospice and Palliative Care Organization. “What is it that's keeping patients from getting timely referral, and when is it the responsibility of the medical profession, or even the government” to make that information available, he asks, so that people won't have to spend their last days in a hospital intensive care unit?

A lot of it has to do with the difficulty of having what doctors refer to as “the conversation,” regardless of who initiates it. A profession dedicated to saving and extending life is reluctant to embrace death and dying as an integral part of life. It wasn't until 2006 that hospice and palliative care was recognized as a board-certified subspecialty. There are now more than 2,500 doctors schooled and trained in hospice and

end-of-life care, which is enormous progress. But the number still amounts to less than 1 percent of the nation's doctors.

For too many physicians, that conversation is hard to have, and families, too, are reluctant to initiate a discussion about what Mom or Dad might want until they're in a crisis, which isn't the best time to make these kinds of decisions. Ideally, that conversation should begin at the kitchen table with family members, rather than in a doctor's office.

A Clear-Eyed Look At Reality

Hospice care not only offers people a better quality of life in their final days, but it's also less expensive than traditional hospital care. A 2007 Duke University study found that Medicare saves about \$2,800 per beneficiary when hospice is brought in at the end of life.

With the nation facing an unsustainable deficit that is at least partially the result of escalating health care costs, hospice should be front and center in the debate over the kind of health care future that we want. But for now the public is so sensitive about saving money on health care that if policy makers talk about cost savings, it's received as code for rationing.

It's been my experience that regardless of politics, anyone who's experienced hospice with a family member or friend generally comes away as a supporter.

The Affordable Care Act has a pilot project on what's called concurrent care, which the hospice community has sought for years. It allows Medicare patients to continue conventional therapy while accessing hospice services, so people aren't confronted with what many see as a terrible choice: giving up all treatment in order to get the benefits of hospice care. This change in the law is already in effect for children enrolled in Medicaid and the Children's Health Insurance Program. The thinking is that most people, given the time to make the transition away from futile conventional therapy, will shift to palliative care and hospice, with the resulting benefits to themselves and society at large.

It's been my experience that regardless of politics, anyone who's experienced hospice with a family member

or friend generally comes away as a supporter. Elizabeth Edwards, who died in December 2010 after battling breast cancer for six years, had long championed the holistic care that hospice offers. Clear-eyed and courageous about facing the relentless illness that she knew would claim her life in the end, she embraced the decisions that she had control over. Central to that was her wish to die at home, and hospice was able to give her that gift.

We remember Edwards's story, and those of countless others who lived their remaining time with grace and dignity and joy that we don't usually associate with people who are staring death in the face. There are those who every day—like my husband, Tom—receive terminal diagnoses and display great courage, surprising their family and friends, and perhaps even themselves. It's not unique to the human experience, and as people enter this last stage of life, they deserve the knowledge to make the choices that are right for them. ■

Eleanor Clift (Eleanor.Clift@newsweekdailybeast.com) is a contributor to *Newsweek* and *Daily Beast*; a panelist on the public affairs show, *The McLaughlin Group*; and the author of *Two Weeks of Life: A Memoir of Love, Death, and Politics* (Basic Books, 2008). She joined the National Hospice Foundation board as an advocate in 2006.