

Dying Shouldn't Be So Brutal

By Ira Byock, [nytimes.com](https://www.nytimes.com), February 1st, 2015

"Travel safe!" It has become a nearly reflexive wish I give to friends who are coming or going. This fall, I noticed myself holding back from saying it to Michael, a dear friend who was wrestling with incurable cancer. The journey metaphor was too poignant.

I also avoided "Stay safe." After all, dying is inherently precarious.

Instead I said: "Be well. I'll be thinking about you." That was true. I could have added, "and worrying about you." That was true, too. Michael was receiving state-of-the-art treatments at a renowned cancer center in New York City. As he became sicker, the treatments got more intense. Each decision came with more difficult trade-offs and uncertainties. Each step to stay alive risked making things worse.

He knew it. We'd talked openly about it. His life was precious and worth fighting for, so every option was worth carefully considering. But modern medicine has yet to make even one person immortal. Therefore, at some point, more treatment does not equal better care.

When Michael was out of standard options, they offered him a Phase I clinical trial — essentially an experiment. But his increasing pain and breathing problems were being poorly managed, sapping his strength and will to live. By phone I suggested to the nurse practitioner overseeing the study that Michael and his family would benefit from hospice services, starting with ensuring that he was correctly taking both long-acting and "as needed" pain relievers (and adjusting laxatives to counteract the pain relievers' constipating effects). Hospice providers could also have responded to his wife and children's questions about the details of caring for him at home.

"It's his choice," the nurse said, referring to Medicare rules that require patients to choose between cancer treatment and hospice care.

It was, but what a terrible choice to have to make.

Michael, who has since died, was suffering needlessly. Hospice care could have vastly improved the quality of his waning life, and eventually it did. But those rules mean that dying patients enrolled in Phase I studies, which aren't intended to be treatments, are routinely denied access to hospice services. Caveat mortalibus — let the die-er beware!

Our health care system is well honed to fight disease, but poorly designed to meet the basic safety needs of seriously ill patients and their families. We can do both. We must.

People who are approaching the end of life deserve the security of confident, skillful attention to their physical comfort, emotional well-being and sense of personal dignity. Their families deserve respect, communication and support. Exemplary health systems and healthy communities deliver all of this today. But they are few and far between.

Since 1997, the [Institute of Medicine](https://www.nationalacademies.org/pubs/institute-of-medicine/) has produced a shelf of scholarly reports detailing the systemic dysfunctions, deficiencies and cultural blinders that make dying in America treacherous. Most people want to drift gently from life, optimally at home, surrounded by people they love. Epidemiological and health service studies paint an alarmingly different picture.

An American living with cancer has a roughly [one in four chance of dying in a hospital](#) and a similar chance of spending a portion of his or her [last month in intensive care](#). The chances are higher with chronic lung or heart disease. An American with Alzheimer's disease will very likely spend most of his or her last months in a nursing home, yet many long-term care facilities are woefully understaffed and ill equipped to care for demented people.

Less than 45 percent of dying Americans receive hospice care at home, and nearly half of those are [referred to hospice](#) within just two weeks of death. Hospice was designed to provide end-of-life care, but this is brink-of-death care.

DYING is not easy, but it needn't be this hard.

Most Americans don't want to think about dying. There's an assumption that dramatically improving how we die would be too complicated or costly.

Thankfully, the opposite is true. Over the past two decades the fields of geriatrics, hospice and palliative medicine have demonstrated that much better care is both feasible and affordable. Successful approaches share core attributes: meticulous attention to alleviating people's symptoms and maximizing their independence, continuing communication and coordination of services, crisis prevention and early crisis management, and decision making rooted in patients' and families' values, preferences and priorities. Together these steps reliably improve sick people's quality of life, modestly extend survival and save money.

Those of us who have been on a quest to transform care have been standing on a two-legged stool. We've demonstrated higher quality and lower costs. Missing is the visible, vocal citizen-consumer demand. Without it, large-scale change will not happen.

As a baby boomer, I wonder when we became inured to bad care. We're the generation that transformed childbirth, creating the natural birthing movement over resistance from the medical establishment. As health outcomes when women were prepared for childbirth proved consistently higher than the status quo, the medical community gradually climbed onboard.

In the 1970s we supported hospice as a countercultural movement in response to people dying badly, mostly in hospitals, often in pain, often alone. Hospice proved effective and was eventually embraced by mainstream health care. It has become an industry with over 4,000 programs nationally, and the quality of care has become uneven. Still invaluable, hospice is no panacea.

It's high time we boomers shook off our post-menopausal and "low T" malaise and reclaimed our mojo. Remember Howard Beale, the fictional news anchor brilliantly portrayed by Peter Finch in the 1976 film "Network"? Fed up with the inequities of modern life, one night Beale exhorts viewers to go to their windows and yell, "[I'm as mad as hell and I'm not going to take this anymore!](#)" We'll figure out the details later, he says; right now it's time to yell. And, across the country, they do.

The persistently unsafe state of dying in America should provoke a Howard Beale moment. We'll find solutions in various white papers and Institute of Medicine reports. First, we need outrage.

With a citizen-consumer leg to stand on, we could write a Safe Dying Act. Let's start by requiring medical schools to adequately train young doctors to assess and treat pain, listen to patients' concerns and collaborate with patients and families in making treatment decisions — and test for those skills before awarding medical degrees. Let's require nursing home companies to double staffing of nurses and aides, and the hours of care accorded each resident. Let's set minimum standards for palliative care teams within every hospital. Let's routinely publish meaningful quality ratings for hospitals, nursing homes, assisted living, home health and hospice programs for people to use in choosing care. And let's repeal the Medicare statute that forces incurably ill people to forgo disease treatments in order to receive hospice care.

Medical school deans and corporate chief executives will vigorously testify against our bill, and opponents will try politicizing the matter as a means of paralyzing Congress. They will fail. When public safety is threatened and we become engaged as a national community, political action follows.

As the end of life approaches, whether death is welcomed or feared, there is a lot we can do to make the process of dying safer.