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THE END

## Dying Shouldn't Be So Brutal

By IRA BYOCK



“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](#) 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.

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# We Must – and We Can – Do Better

By IRA BYOCK, MD

**D**espite more than three decades of earnest efforts to improve end-of-life care, a crisis persists in the way we die.<sup>1</sup> It is a man-made crisis, although no one is to blame. Perhaps, in a sense, we are all at fault for wanting to bring every ounce of science and technology and every dime to bear to protect and preserve life.

Surely we can be forgiven for that. Still, we must craft a better way forward. We live in unprecedented times and face social and ethical predicaments that no other nation or society has encountered.

■ For the first time in the history of humankind, there soon will be more people older than 60 on our planet than there are people who are 20 or younger.

■ Thanks to advances in medicine, millions of people now survive many cancers, heart damage, kidney failure and other conditions that would have rapidly ended their lives even a few decades ago.

■ People are now sicker before they die than at any time in human history.

We are fortunate to have ever-more effective treatments available for late-stage diseases — from biological cancer agents and stem cell therapies to left-ventricular assistance devices to kidney, heart and liver transplants. Yet these life-prolonging therapies often make it difficult to know when it is time to let life go.

A better way forward is possible. In effect, we have been approaching serious illness and dying from the wrong direction. As a result, all of our good intentions and substantial investments of time, energy and money inadvertently have perpetuated patterns of excessive treatments and inattention to people's personal needs.

## SHIFTING THE FOCUS TO PERSONS

Contemporary America's health care system is actually a disease detection and treatment system. We are rightly thankful for the prowess that science has given us to diagnose and treat disease. But while diagnoses and treatments are medical, illness and dying are personal — profoundly so. In seeing only the medical aspects of illness, we keep missing the obvious and bring the wrong tools to the job of caring well for dying people. Filtered through billing codes and criteria for “medically necessary” services, people's personal needs remain largely unseen. The inattention is not malicious, but it is

negligent.

Better care is not esoteric. People who are facing the end of life want competent treatment for their symptoms, and they want

to be assured that they will not suffer horribly as they die. They want to know that their families will be supported in care giving and in grieving. Beyond these basics, many patients have asked me, “How do I do this? I've never died before.” They want guidance in the work of completing their affairs and relationships and in closing their lives gracefully.

Since the mid-20th century, we have been training doctors to be technicians more than clinicians. While technical skills and tools are valuable, they are insufficient.

Despite modest improvements in the past decade, American medical education is failing its trainees, who go on to fail their patients. It is not the fault of individual physicians. Still, it is fair to say that when it comes to end-of-life care, society is not being well served by the doctors it educates, licenses, certifies and compensates.

Doctoring that responds to the personal experience of illness and dying can be taught, and the results are satis-

fyng for patients and physicians alike. However, adequate training requires more than a day or two of curriculum time.

### SYSTEM-BASED SUFFERING

The business of American medicine contributes to making dying harder than it has to be. An extensive exposé in *Time* magazine by journalist Steven Brill in March 2013<sup>2</sup> and a subsequent *New York Times* series reveal how a medical-insurance-industrial complex inflates prices, CEO compensation and shareholder profits.<sup>3, 4, 5</sup> The “more is better” business model of American medicine sees the detection and treatment of diseases as income opportunities, but it views caring for people with serious illness as a chore and added expense.

It’s an expense that insurance and health care

systems often shift to sick people and their families through co-pays, uncovered prescriptions, deductibles, lifetime caps and out-of-pocket costs. Even reasonably well-to-do individuals and couples routinely are impoverished during a lengthy illness.

The resulting financial and social hardships have warped the ethical landscape of caring. As a student and young physician, I assumed that dignity was a settled matter of clinical ethics. In 1948, the United Nations’ “Universal Declaration of Human Rights” had recognized the inherent dignity of all members of the human family. Yet I soon learned that people in hospitals and long-term care facilities can be made to feel undignified when there is no one to relieve their pain, or when they need help in getting to the bathroom and nurses or aides are unavailable to answer their call.

## THE SPIRITUAL CORE OF HUMAN EXPERIENCE

Excerpt from *The Best Care Possible: A Physician’s Quest to Transform Care Through the End of Life*, by Ira Byock, MD

**A** heightened awareness of the essential mystery of life and the potential to evoke terror and awe affects anyone who ventures close to a person’s dying. Confronted with the mystery of life — and death — we reflexively try to make some meaning of our experience in the world, strengthen our relationships with others, and feel part of something larger and more enduring than ourselves.

Throughout time and across cultures, people have conveyed wisdom for dealing with life’s mysteries through religions. Anthropologists and archaeologists have found evidence of spiritual practices throughout human history. Religious teachings, customs, rituals, traditions, stories, and songs have guided individuals and families through births and deaths, celebrations and grief. Not surprisingly, people who have a deep religious faith often feel it is a source of strength and comfort in dealing with illness, caregiving, death, and grief.

Spirituality is rightly considered the province of religion, but it is not an exclusive province. Accompanying people who

are dying has taught me that human life is inherently spiritual, whether or not a person practices a religion.

One afternoon in clinic, I asked Mr. Grady, a gruff, wizened farmer from Thetford, Vermont, if he considered himself a spiritual person. It is a question I ask every patient, unless the person has already volunteered information about his or her beliefs. I ask, because I can’t count the number of times I would have surmised wrongly.

“Nah, not me,” Mr. Grady said with a wry, tight smile. Congestive heart failure and lung disease gave him the habit of delivering short, considered bursts of words, all spoken in a thick New England brogue.

I probed a bit. “Do you have a sense of where we go after we leave this life?”

“Yup,” he replied with a chuckle, his smile giving way to a broad, toothless grin. “The worms go in; the worms go out,” he replied, his hand and wrist mimicking an undulate in motion.

I was curious about where he was planning to be buried. “Where will the worms go in and out of your bones, Mr. Grady?”

“Oh, we have a family cemetery on a hill in Thetford,” his tone now earnest

between pauses to breathe. “We Gradys have been buried there since the early 1800s.” Another breath. “I suspect my grandchildren and their grandchildren will be there, too.”

Mr. Grady didn’t pray, attend church, or believe in God. However, his strongly felt connection to the land and his family, including generations of ancestors that preceded him and generations that would follow, seemed authentically spiritual to me.

Our team members — and increasingly, clinicians in our field — sometimes use poetry to explore spiritual aspects of people’s experience.

Alice Fehling was a forty-seven-year old woman with advanced intraperitoneal cancer and ascites who was admitted to the hospital when her leg suddenly turned cold and blue. After the successful removal of an arterial clot restored circulation to the limb, she developed kidney failure. During rounds one Sunday morning, I visited Alice in her hospital room. Following the requisite pain and bowel update, we indulged in musings about illness, healing, God, and love. The conversation began when I asked about the collection of Rumi’s poems on her bedside table. We read a few and then I



### WRONG WORDS, WRONG ACTIONS

Because a social and cultural dystopia clouds individual decision-making and the national conversation about how we die, the public is disheartened and angry. People have seen loved ones suffer or languish in ICUs, hospitals and nursing homes, and many fear the prospect of caring for aging parents in the years ahead. Their trust in the medical profession is low. In this muddled morass, the so-called “Right to Die” or “Death with Dignity” movement has emerged as the most prominent outlet for people’s fear and frustration.

“Right to Die” is an effective slogan, but little more. No civil right to suicide exists in any social compact. Euphemisms such as “aid in dying,” “self-deliverance” or “hastenings” disguise a primitive response to basic human needs. The phrase “Death with Dignity” sends a message to

elderly or ill people that in order to remain dignified, they need to die before becoming senile or physically dependent.

One need not accuse the assisted suicide movement of being maleficent to acknowledge that the results are pernicious.

Sanctioning suicide or euthanasia is not the solution to the crisis that surrounds how people die. Oregon-style “Death with Dignity” Acts do not make physicians better at treating pain, or communicating well, or skillfully guiding people through the inevitable challenges of being mortal. Such laws do not improve staffing in nursing homes or fix the injustice of requiring sick people to give up treatment for disease in order to receive hospice care for their comfort and well-being and their families’ support. While cloaked in the progressive language of rights, in the midst

shared a favorite poem and asked her to guess who wrote it.

*You do not need to leave your room,  
Remain sitting at your table and listen.  
Do not even listen, simply wait.  
Do not even wait, be quiet, still and  
solitary.  
The world will freely offer itself to you  
to be unmasked.  
It has no choice.  
It will roll in ecstasy at your feet.*

“That’s wonderful, but I have no idea who the poet is.” Alice said.

“Franz Kafka,” I replied.

Alice was surprised that Kafka, the quintessential existentialist whose writing typically portrayed the universe as cold and impersonal, leaving each individual exposed to circumstance and happenstance, would offer a vision of an ecstatic world. This led Alice and me to talk about chaos theory, fractals, and patterns within randomness. She spoke about healing and well-being in the face of loss and her sense of God within us all and all that is. She knew she was dying and hated to leave her husband with whom she felt ever more deeply in love. Alice said that except for her physical

ailments, she had felt “well” and alive in these last few months.

The spiritual impact of death’s approach is often felt by those who know and care for a person who is ill. Birth, illness, and death, even with the financial strain, time pressures, and turmoil in health care, imbue clinical care with a spiritual dimension.

Doctors and nurses only rarely talk to one another about these things. However, over the years many colleagues have spoken to me about accompanying patients in their final days, hours, and moments before death. Again and again, the words, “privilege” and “sacred,” are part of their descriptions. “There was something sacred about being there when Mrs. Jones passed.” Or, “It was a sacred moment for the family,” adding, “for me, too.” Along with, “It was a privilege to help care for Mrs. Jones. I feel fortunate to have been there as she died.” Or simply, “What a privilege!”

My unscientific sample suggests that the experience of sacredness and privilege in the presence of these events is shared by people of all religions, politics, and temperaments. I have exchanged nods of silent recognition of the indefatigable quality of people’s deaths with

unsentimental surgeons and tightly wrapped intensivists. It is not just the end of life, but somehow a culmination of human experience. To those who have had the experience, no explanation is necessary; to those who have not, no explanation will be sufficient.

None of this suggests that modern clinicians harbor a religious agenda. My sense is that “sacred” is merely the word that most closely fits what many of us experience. “Sacred” is experienced—physically and emotionally—as complete rightness in the moment. The sacred is not reasoned or abstracted, but felt. It is phenomenological or anthropological, rather than theological or medical. Within the sacred, the mystery of life is miraculous. There is no terror, only awe. All paradox and conflict are resolved, or more precisely, dissolve. ...

This is not intoxication in any sense. In fact, it is a deep awareness of the true nature of reality, a sense of being fully, firmly grounded.

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of serious deficiencies in medical and long-term care, the legalizing of assisted suicide represents acquiescence to failed social policies, clinical practices and woeful deficiencies in personal care and social support.

We can do better than that. A wealth of studies demonstrates that much better end-of-life care is achievable and affordable. In the hands of skilled, highly developed teams, people's comfort and sense of well-being can often be preserved, even in dire circumstances.

### SCALING UP MODELS THAT WORK

The deeper solution to this crisis requires seeding the collective imagination of the public with reliable, humane and dignified alternatives to suicide and euthanasia. The public is hungry for hopeful narratives and images of real people in the most difficult situations being cared for in skilled, respectful and loving ways. The evidence that such caring can happen is plentiful, but so far it has failed to capture the public attention.

Enlightened assisted living and continuing care programs, such as PACE (Program of All-

Inclusive Care of the Elderly)<sup>6,7,8</sup> have shown that by integrating health care, social services, nutrition and transportation, it is possible to affordably meet the needs of frail elders who would otherwise be relegated to woefully understaffed nursing homes. Eden Alternative, Greenhouse, Pioneer Network and similar programs have reinvented long-term care, infusing community values, pets, plants, children, laughter and joy into the lives of institutionalized elders. Innovative clinical services, such as "open access" hospice and palliative care, enable people to receive comprehensive attention to their comfort and quality of life, while also receiving state-of-the-art disease treatments. Evidence-based counseling modalities are available to enhance an ill person's sense of dignity, completion and well-being.

Programs that are pushing the envelope in the most creative and heartening of ways exist within many of our own institutions and communities, but at present they are reaching a small fraction of those who would benefit. The swelling numbers of frail elders and chronically ill people in our communities make it clear that the time for small-scale change has passed. The work before us entails swiftly bringing to scale best practices and innovative programmatic models and proudly telling the stories of our programs, teams and the people we serve.

Enlightened and reliably effective approaches to care must be publicized, opened to journalistic inspection and debated, thereby becoming part of the national psyche, expanding our collective imagination and raising expectations of what is achievable. A noteworthy example is a *New Yorker* magazine article about Beatitudes, a dementia care facility in Arizona that is at once remarkable and intuitive.<sup>9</sup> The stories of the people who live or work at Beatitudes allow readers not merely to understand, but to imagine and feel how good care and a frail person's quality of life can be in circumstances that many now believe are worse than death.

This is a propitious time to foster radically positive change. Value-based payment reforms in which providers of health care services share financial risk with payers are transforming the business model of health care from volume of services — "more is better" — to measured quality of services — "better is better."<sup>10,11</sup>

This change is particularly hopeful for improving care for people with advanced illness because characteristics of patient-centeredness are now embedded within the definitions of quality<sup>12</sup> and

## RESOURCES

Corrections for our cultural tunnel vision about illness and dying are plentiful, if we pay close attention. Stories of people's lived experience with dying reveal that many can achieve a sense of well-being during the last months, weeks and days of life. Within the literature of the field of hospice and palliative care, such stories are familiar, but only a few publications and media portrayals have entered the mainstream. Worthy examples of memoirs and biographies include:

*Refuge: An Unnatural History of Family and Place*, by Terry Tempest Williams

*Tuesdays with Morrie: An Old Man, a Young Man, and Life's Greatest Lesson*, by Mitch Albom

*Learning to Fall: The Blessings of an Imperfect Life*, by Philip Simmons

*About Alice*, by Calvin Trillin

*Too Soon to Say Goodbye*, by Art Buchwald

*The Last Lecture*, by Randy Pausch with Jeffrey Zaslow

*The End of Your Life Book Club*, by Will Schwalbe

"The Long Goodbye," columnist Joe Klein's account of his father's illness and dying, published in the June 11, 2012, edition of *Time* magazine

"StoryCorps," the independent national oral history project, <http://storycorps.org/>



reported measures of quality.<sup>13,14</sup>

Furthermore, research clearly demonstrates that comprehensive patient-centered and family-centered models of care that involve shared decision-making, coordination and crisis prevention and crisis management plans are significantly less expensive than the current, solely disease-focused approach.<sup>15,16,17,18,19</sup>

### THE CULTURE IS WATCHING

As individual professionals and moral agents, this crisis is unfolding on our watch. Those of us in health care must accept nothing less than excellence. Pressures of finances, regulations and workload — and the seemingly ever-present tyranny of the urgent — can limit our sights to just getting by.

In the midst of these pressures, we can be generous and joyful in our clinical practices, as well as in our management of institutions, programs and personnel, while being uncompromising about quality. Each of our programs carries opportunities to innovate and elevate quality — first and foremost, for the sake of the people we serve, but also to enable colleagues to examine, learn from and, if deemed worthy, emulate our programmatic experiences.

We have a historic opportunity to contribute to a healthy maturation of Western culture by reasserting basic human values and the right of each person we serve to feel wanted, worthy and dignified through the very end of life. By melding clinical excellence and ethical clarity with authentic respect for each person's dignity, feelings, well-being, as well as their families' well-being, we can advance life-affirming values and vision within our society and culture.

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# The American crisis around dying persists

By Ira Byock

Describing the way frail elders and dying people were cared for in post-World War II Britain, Dr. John Hinton wrote in his 1967 book, *Dying* (London: Viking Press), “The dissatisfied dead cannot noise abroad the negligence they have experienced.” Half a century later, and an ocean away, Hinton’s statement is sadly resonant.

A crisis exists in the way we support one another and experience the last phases of life. Contributing causes are delineated in *Dying In America* (<http://goo.gl/XrCKIY>), and in six other Institute of Medicine reports since 1997 that address the way our nation cares for seriously ill people and their families.

## Why the Crisis Continues

Three decades of progress in geriatrics, hospice and palliative medicine have proven that much better care is feasible and affordable. So why does this crisis persist? The reasons are part demographic, part economic and, most of all, cultural.

**Demographics:** Twin tidal waves of aging and chronic illness have already begun creating unprecedented floods of unmet need. Many states and local communities are overwhelmed by the demand for medical and social services, including housing, nutrition, homecare and transportation support. Things are only going to get more challenging in the decades ahead.

**Economics:** Innovative approaches to whole-person and family care reliably demonstrate lower total healthcare costs, but in so doing, shift revenue from

doctors, hospitals, pharmacies and related industries to long-term care, home health and hospice, care coordinators, and preventive health and aide-level personnel. When revenue streams are threatened, the status quo wields enormous heft. Current corporate efforts to maximize profits keep staffing short, patient loads high and the emphasis on productivity. A daily tyranny of the urgent hobbles innovation, collaboration and redesign within healthcare.

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**Culture:** Americans possess an admirable zeal for protecting and preserving life, but our culture is immature when it comes to facing infirmity and dying. Our generation has been given hitherto unimaginably powerful abilities to fight disease and forestall death, but not the wisdom to use them. Because science hasn’t made a single human being immortal, at some point, saving life must share priority with other goals.

## Change Means More Communication

Operationally, we know what success looks like. It’s not rationing. Rather, it is through meticulous communication and decision making. When one has conversations with patients, very few want to die in an ICU during maximal efforts to prolong their lives. Most want to fight their disease only as long as their quality of life is worth living and there are good

treatments for their condition. Then, when it becomes their time to leave this life, the large majority would like to be at home, with attention to their comfort and their dignity, surrounded by people they know and love and who love them.

Enlightened approaches to caring for and supporting frail and physically or cognitively dependent elders include PACE, Eden Alternative, the Green House Project, Comfort Matters and Planetree models. In multiple studies, concurrent palliative care and earlier use of hospice is associated with improved outcomes for incurably ill patients with heart failure, cancer and dementia, including fewer crisis ambulance transfers, and less time spent in hospitals and ICUs. Enhanced quality of care, higher patient and family satisfaction, and lower total costs all are achievable. Caregivers benefit, too. Whenever it is measured, clinical staff satisfaction goes up and levels of moral distress plummet.

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**‘Culturally, we have to grow the rest of the way up.’**

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The secret sauce common to all these models is a mature recognition of the precious value and fragile nature of mortal life. It’s reflected in unwavering commitment and meticulous attention to people’s comfort and well-being that includes regular conversations to ensure medical treatments are consistent with each person’s values, preferences and priorities.

There still is time to realize the transformative potential of clinical advances and enlightened models of medical care



Photo: iStockphoto/antrombierfringe

and social support. Bold action in realms of policy, system reform and cultural maturation are needed. The stakes are too high to fail. How people are cared for during these inevitable times of decline and vulnerability powerfully affects every one of us, not merely as professionals, but also as sons, daughters, spouses, mothers and fathers, friends and neighbors.

Culturally, we have to grow the rest of the way up. We are all going to die. It makes sense to live as fully, well and joyfully as possible, for as long as possible. In a healthy society, people are born into the welcoming arms of community and die from the reluctant arms of community. By knitting together physiologic, social and personal aspects of care, we can enhance the quality of people’s lives, their inherent dignity and honor each person through the very end of life.

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# Spirituality & Health

## 5 Questions for Ira Byock

A dialogue on end-of-life care  
By Sam Mowe

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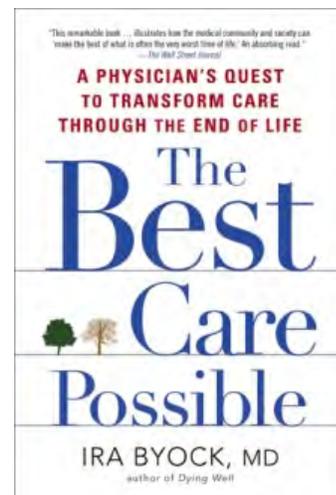


*This is the third in a series of short interviews on end-of-life care that I'm conducting for Spirituality & Health. This week I'm speaking with Ira Byock, MD, a leading palliative care physician, author, and public advocate for improving care through the end of life. Byock is Professor of Medicine at the Geisel School of Medicine at Dartmouth. His latest book is *The Best Care Possible: A Physician's Quest to Transform Care Through the End of Life*. —Sam Mowe*

### **What's it like to be the doctor of a patient who is going through the dying process?**

Well, it's a lot like doctoring a patient who is living. Dying is a part of living. The threshold from living to dying is a mirage. If it's far enough in the distance you can sort of identify when dying begins to happen. But when you get close, it's just a continuum of living.

People often have treatment goals for themselves that are, from my perspective, unrealistic or otherwise really not in their best interest. But one of the things that I live by is the notion that *this is not about me*. This is about them and I'm there to give them the best care I can. So I can lay things out in front of patients and families and try to help them make decisions that use the best of medical science consistent with their values, preferences, and priorities. We offer to help them through any treatment, walking each step with them. But, at the end of the day, it's their life, not mine. I'm just here to serve. Palliative care teams are just here to serve. It's not about us.



### **In your opinion, how does one know when it's time to refuse more treatment?**

Through an iterative process called shared decision-making. It's the center of the bulls-eye of quality care for people who are seriously ill. In practice it means the physician comes to the decision-making as experts in the diagnostics and therapeutics. Patients are already experts in their

personhood—in their values, preferences and priorities. Together, in partnership, physicians and patients determine what the best plan of care is at this point in time—and repeat the process as time passes or circumstances change.

Because life is finite, because we're all mortal, in treating diseases like cancer or heart failure or liver failure or kidney failure or brain failure—which is what Alzheimer's is—it is essential that we talk about what's achievable physiologically. I love treating disease and saving people's lives, but it's just being honest that at some point one has to balance the potential benefits against the known burdens of a treatment and the risks of a treatment.

We talk about personalized medicine in terms of genomics but this process of applying treatments consistent with individuals' particular values, preferences, and priorities is essential to providing the best person-centered care.

### **Are there any legal concerns that would discourage the doctor from saying I think it is time to let this patient die?**

There are no legal concerns that keep a physician from gently being honest with a patient that this disease can no longer be held at bay, that more treatments will just bring more burdens and that, unfortunately, this is in a time of life in which you are facing the end of life. You are dying. Even using the D-word. Sometimes plain speak is just what's needed. I don't like doing this, but it's part of a doctor's job. You know, despite the miracles of modern medicine, we have yet to make a single human immortal. So I'm not apologetic for it, either. It's just part of giving people the best care I possibly can, honestly, authentically.

### **Is changing how we approach death in America more of a financial-policy question or a spiritual-cultural question?**

It's a cultural question. It's how we conceptualize health. The next big thing in American culture should be the realization that wellbeing is possible during serious illness, dying, family caregiving and even grieving. Illness, dying, caregiving and grieving certainly are stressors—and certainly carry huge burdens and risks—but it is anthropologically irrefutable that wellbeing is concomitantly possible during these times. Themes that emerge from people's stories provide a sense of the developmental tasks of completing one's life and architecture of personal wellbeing during these difficult times of life.

I often tell the story of Steve, a quintessential Montana cowboy, whose heavy smoking had ravaged his lungs with end-stage emphysema. Years of feeling lousy and communicating badly had ravaged his relationships with his wife and family. In exploring his anxiety, I suggested he might consider saying four things to the people he cared about: Please forgive me. I forgive you. Thank you. I love you. Steve thought it was a great idea. The next Sunday he literally read the statements before a family dinner. The result not only improved Steve's mood, but it transformed his family. They grew closer and the history of the family shifted. A story that ends well, transforms all that has occurred.

### **What would you like people to say about you after you die?**

I'd want my stone to read he was a good grandson and son, brother, husband and father and grandfather. And I'd like people to say, "Boy, he had a good run."

**Sam Mowe** is a writer living in Brooklyn, New York

See more at: <http://spiritualityhealth.com/articles/5-questions-ira-byock - sthash.ZZ0nCfam.dpuf>

## Dying with Dignity

BY IRA BYOCK

**O**n the last day of 2009, a divided Montana Supreme Court ruled that physicians in the Big Sky state can legally prescribe medications for terminally ill patients to use in ending their lives. Right-to-die activists would have preferred that the court find a constitutional right to assisted suicide. Still, they applauded the narrow decision, which merely exempted physicians from prosecution, as advancing death with dignity. In a separate opinion, Justice James C. Nelson wrote, “This right to physician aid in dying quintessentially involves the inviolable right to human dignity—our most fragile right.”

The ruling will inevitably fuel overheated rhetoric on both sides of the physician-assisted suicide debate. But I believe the rhetoric of the debate misappropriates the word “dignity.” As used by those who want to legalize assisted suicide, “death with dignity” implies that people who are dying are not already dignified. They are. And that is not merely my assertion or some New Age platitude. The preamble to the United Nation’s 1948 Universal Declaration of Human Rights states that “recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world.” This language formalizes an anthropological fact: the impulse to honor and care for our most vulnerable members—infants, elderly, injured, and ill—is part of our humanity.

It is easy to see how this unfortunate choice of terms came about. In contemporary Western society, independence and prowess have become the hallmarks of dignity. Being frail or dependent on others can then feel undignified. The feeling is compounded if a person is pauperized by medical bills, warehoused in an understaffed nursing home, and treated as if she were a nuisance and a burden. The suggestion that an incurably ill person may need to end her life to preserve her dignity seems to add insult to injury.

I am a palliative care physician who regularly cares for terminally ill people. What I really know about dignity did

not come from text or formal training; instead I learned about dignity from the care my parents gave my maternal grandmother. I was eight years old when Grandma Leah had her stroke. Months of therapy left her barely able to communicate and in need of help to eat and use the toilet. Nursing home placement was advised, but out of the question. My parents took her home.

Even as a boy, I was struck by my father’s unabashed tenderness toward my grandmother. After a year, she improved enough to return home with my grandfather. We visited weekends to take her shopping and do household chores. Twice a month for the next twenty years, Dad had Leah soak her feet so he could cut her toenails. All the while, he

relayed gossip and bawdy stories until she feigned shock or giggled. She saw her dignity reflected in his eyes.

Decades later, while serving as medical director for a hospice program in Missoula, Montana, I met a fellow I will call John. He was a handful, to put it mildly—a “management problem.” Although mostly jovial, he was prone to fits of rage.

He required constant attention. He needed to wear diapers but preferred being naked and had occasionally been found urinating behind furniture. But John’s family never considered him undignified. The reason was simple: John was the three-year-old son of a hospice nurse colleague.

Many decades further on, if John develops dementia and acts in similar ways, will his wife and children consider him undignified? If so, why? We do not consider infants and toddlers undignified because they are at a stage of life in which they need physical care, nurturing, and patient, loving attention; why are we less tolerant at the end of life?

Our society is aging, and soaring numbers of chronically ill people live among us—the result of decades of medical progress. They do not have to be social problems. They are family members, neighbors, and friends. We have the collective responsibility to care for them with skill and deep respect. We have the opportunity to care for them with tenderness and love. Most of us will be physically dependent and intimately cared for by others before we die. This fact does not destine us to become undignified. It simply confirms that we are human.

■  
*The need for care is  
not undignified;  
it’s just human.*  
■

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*Ira Byock directs the Palliative Care Service at Dartmouth-Hitchcock Medical Center and is a professor at Dartmouth Medical School. He is the author of Dying Well (Riverhead, 1997).*