We Must – and We Can – Do Better

By IRA BYOCK, MD

Despite more than three decades of earnest efforts to improve end-of-life care, a crisis persists in the way we die.1 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 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.

Doctoring that responds to the personal experience of illness and dying can be taught, and the results are satis-
fying 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 and a subsequent *New York Times* series reveal how a medical-insurance-industrial complex inflates prices, CEO compensation and shareholder profits.\(^2\) 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
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.


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 an ecstatic world. This led Alice and me to happenstance, would offer a vision of an individual exposed to circumstance and who the poet is.” Alice said.

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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)\(^6\) 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.\(^9\) 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.”\(^10,11\)

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\(^12\) and

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**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 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.

IRA BYOCK is a palliative medicine physician and a professor at Dartmouth College’s Geisel School of Medicine, Hanover, N.H. Among his writings are the books Dying Well: The Prospect for Growth at the End of Life (Riverhead, 1997) and The Best Care Possible: A Physician’s Quest to Transform Care through the End of Life (Avery, 2012).

Notes
16. R. Sean Morrison et al., “Palliative Care Consultation Teams Cut Hospital Costs for Medicaid Beneficiaries,” Health Affairs 30, no. 3 (March 2011): 454-463.
17. R. Sean Morrison et al., “Cost Savings Associated with U.S. Hospital Palliative Care Consultation Programs,” Archives of Internal Medicine 168, no. 16 (Sept. 8, 2008):1783-90.