

# 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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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



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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.

*Ira Byock, M.D., is executive director/ chief medical officer of the Institute for Human Caring of Providence Health & Services in Los Angeles, Calif. He is a professor of medicine at Dartmouth’s Geisel School of Medicine in Hanover, N.H., and author of The Best Care Possible (New York: Avery Trade, 2013). ■*