

# expert voices

Essays on Trends,  
Innovative Ideas and  
Cutting-Edge Research  
in Health Care

## Health Care at the End of Life

The health system fails us in our final days; there's a better way.

By Joanne Lynn, MD, Director, The Washington Home Center for Palliative Care Studies; Senior Researcher, RAND Health; and President, Americans for Better Care of the Dying

Americans now face a substantial period — a few months to a decade — of being very sick, frail, or cognitively impaired at the end of life. Four-fifths of us die covered by Medicare, with 90% having cancer, strokes, chronic heart disease, chronic lung disease, or dementia in their last year. The last few years of life rack up the highest health care bills (Figure 1), and all too many older Americans discover that the care “system” — for all it costs — fails to provide reliable support and comfort.

The problem? People coming to the end of life mostly get the leftovers from a medical culture that prioritizes wondrous but often costly high-tech treatments and services. At the edges, the health care system grudgingly dishes up some long-term care, symptom and chronic disease management, and family support. Elderly people are often embarrassed to need “custodial services” like spoon-feeding, assisted transfers, or pain relief, so they do not demand such services. While researchers and policy

makers proudly announce new discoveries that forestall death, no one honors those who patiently give bed baths, prepare meals, read to, hold the hands of and otherwise attend to the frail or seriously-ill elderly.

The time has come to radically rethink our nation's approach to caring for one another in our last years of life.

Initiatives that would truly modernize Medicare have to restructure health care to meet these challenges. One hundred years ago, the average age at death was under 50 years old. The usual causes were injuries and infectious diseases. Persons afflicted with common serious chronic illnesses — mostly tuberculosis and mental illness — were housed away from the community. In contrast, now the average age at death is nearly 80, and those living with serious chronic illnesses are very much a part of our communities.

Whether due to a specific disease or to the aging process itself, long-term fragile health has become the usual course at the end of life. For many, their last years are a halting walk on a tightrope, with death following some small stumble. The typical person now needs someone's help with

basic functions every day for the last two years of life. Our new demographics require new social arrangements.

### Organizing for Better Care

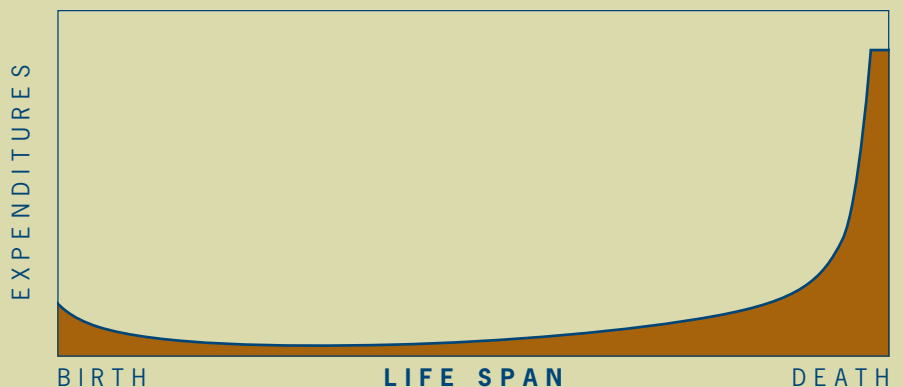
First, it is useful to divide the U.S. population by health status and health care needs:

- (1) Healthy people who need routine preventive care and short-term treatment for illnesses or injuries;
- (2) People with troublesome but manageable chronic illnesses (such as diabetes, high blood pressure or arthritis) who need ongoing coordinated care to prevent worsening, but who then function fairly well; and
- (3) People with serious, eventually fatal, chronic conditions who need continuous care, advance care planning, pain and symptom management, assistance with activities

FIGURE 1

### Health Care Costs Soar at the End of Life

(ESTIMATED DISTRIBUTION)



SOURCE: Lynn and Adamson, RAND, 2003.



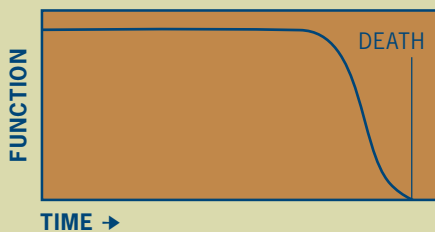
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1225 19th Street, NW  
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Washington, DC 20036  
TEL 202.296.4426  
FAX 202.296.4319  
WEB www.nihcm.org

FIGURE 2  
**The Ways We Die**

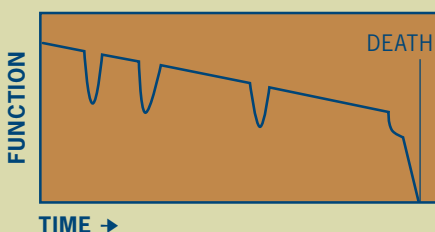
**MOSTLY CANCER**

SHORT PERIOD OF EVIDENT DECLINE



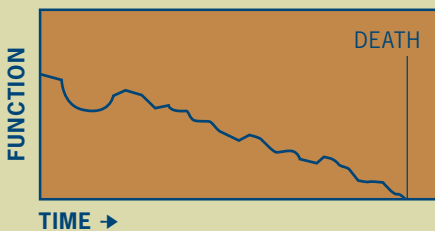
**MOSTLY HEART AND LUNG FAILURE**

LONG-TERM LIMITATIONS WITH INTERMITTENT SERIOUS EPISODES



**MOSTLY FRAILTY AND DEMENTIA**

PROLONGED DWINDLING



SOURCE: Lynn and Adamson, RAND, 2003.

# The federal government should lead the way towards improved care at the end of life.

only a quarter of people who die use hospice, and most for less than a month.

Health care services for the third group, in their last phase of life, should be tailored to three typical trajectories of decline and need. (Figure 2) The first trajectory includes patients who maintain relatively good functioning until eventually being overwhelmed by illness and dying within a few weeks or months. People with cancer typically live out the end of life in this way, and it is a pattern that fits well with the design of hospice programs.

People in the second trajectory experience a slower progressive decline in function, with intermittent bouts of serious problems, which usually require hospitalization and may cause death. People with major organ system failures like congestive heart failure, chronic obstructive pulmonary disease, cirrhosis, or kidney failure often follow this pattern. Good care would include aggressive early treatment of exacerbations, support for self-care, consistent availability of medications, and advance care planning.

People in the third trajectory typically live past age 85 without having one overwhelming illness; they gradually become more and more frail. About half have significant and progressive cognitive disabilities. These patients ordinarily die from a relatively minor complication, such as pneumonia. Mostly, people in this trajectory need help with daily life, symptom relief, and behavior management. Elder services like Meals on Wheels and home aides are critically important, as are comprehensive advance care planning, continuity of medication, mobilizing medical care to the home, and providing support to family caregivers.

## Medicare's Challenge

Unfortunately, Medicare pays for very few of the most important services for people at the end of life. Instead, Medicare covers the hospitalizations that often evidence shortcomings in care. Likewise, Medicare covers a little nursing and rehabilitation after hospitalization, but no ongoing support services.

The one end-of-life service that Medicare does cover — hospice care — is unavailable to most Americans for whom the timing

of death will be uncertain until their very last days. That is because under Medicare the hospice benefit is limited to those with a prognosis of six months or less to live. Moreover, many patients near death still benefit from medical treatments that hospice programs don't provide.

The federal government should lead the way towards improved care at the end of life, by tailoring Medicare, Medicaid, and Veterans' benefits to put better services in place. Expanding hospice eligibility and making transfers into hospice smoother is the place to start. A better-designed and integrated home care program is also vital. Incentives for continuity of care and care planning would also catalyze rapid improvements. The evidence shows that current care is so costly that good care can almost certainly be had at the same cost per person (although the rising number of people coming to the end of life will raise costs overall).

Demonstration projects show dramatically better care. Kaiser Permanente at Bellflower, CA, for example, has integrated hospice and disease management and saved money doing so. The Program of All-Inclusive Care of the Elderly (PACE) provides comprehensive care at home to over 10,000 people in about two dozen cities nationwide, people who would otherwise be in nursing homes. The Veterans Health Care System's initiatives in pain management and advance care planning have rapidly improved the quality of care in recent years.

The forces of inertia are substantial. But the models for change are emerging and pointing the way. If we can learn to live well with serious chronic illness in the last part of life, we will have redeemed the blessings of long life and effective health care. If we do not, otherwise avoidable suffering awaits many of us. A commitment to improve practices now could deliver on the promise of living out life comfortably and meaningfully within this decade.

For more information see: Joanne Lynn and David M. Adamson, *Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age*. RAND Corp., 2003. [www.rand.org/publications/WP/WP137](http://www.rand.org/publications/WP/WP137); See also: [www.medicaring.org](http://www.medicaring.org)

of daily living, suitable housing, and support for family caregivers.

The first two groups account for most Americans on any given day, but almost all of us will spend substantial time at the end of life in that third group, with the prevalence going up sharply with age. Under 65 years of age, probably only a few percent are this sick; but above 65, the rate is around 20%; and above 85, it's nearly 50%.

Our health system today is organized primarily to serve the first two groups, with prevention, emergency and acute care, curative treatments, and hospital-based services. Even "disease management" addresses mostly people of employable age with mild to moderate chronic illness, not those of advanced years with serious illness and progressive disability. Hospice is the one widely available service focused on the very ill, but