I

JUST THE FACTS

Serious Chronic Disease in the Last Phase of Life

Just a few generations ago, serious illness, like hazardous weather, arrived with little warning, and people either recovered or worsened and died within days or weeks. People had a great deal of trouble from illnesses that are now nearly eradicated—such things as childbirth complications, improperly healed fractures, broken teeth, and parasites. Nevertheless, the calamity that caused death was rarely apparent even a week or two ahead of death. Had they not encountered the specific illness or injury that overtook them, most of those who died could have lived for many years. A working man would die of his first heart attack or a young mother of childbirth fever. Our images of health and disease and our health-care system arose in that setting—where people reasonably thought that death had a single cause and that preventing it was the obvious yardstick of successful health care. The usual life story has changed a great deal, but our outdated health-care system is not equipped to handle its new challenges.

Health care for individuals, along with public health, now prevents or cures many of the illnesses and injuries that abbreviated the lives of our ancestors, effectively allowing most Americans to live into old age. Indeed, most of the burden of illness and use of health-care services now fall in the last phase of life, when people generally deal with established, serious, eventually fatal chronic illnesses for a few years. In their younger years, people have two dominant priorities for health care: prevention
and cure of illness. But as people come to the end of a long life today, prevention of serious illness is no longer possible, and neither is cure. Instead, that part of life generates very different priorities, including symptom prevention and relief, support of family members, plans for future care, enhancement of dignity, and completion of life projects.

Most Americans today have long lives; more than 75 percent live past age sixty-five (Hogan et al. 2000). In fact, 83 percent of Americans now die while covered by Medicare (people who are older than sixty-five and also younger people with certain long-term disabilities or renal failure) (Hogan et al. 2000). During the last century, the life span of Americans nearly doubled. In 2000, the average life expectancy was eighty years for American women and seventy-four years for American men, compared to an average of just forty-nine years in 1900 (National Center for Health Statistics 2002, 33). By 2050, life expectancy for women and men will likely increase to eighty-four and eighty, respectively (Institute for the Future 2000).

Back in 1900, only a very few people lingered for years with a disability arising from eventually fatal chronic illness. Most died from infections and accidents, and the time from onset of serious disability to death was measured in hours or weeks, not years. Two serious chronic illnesses caused most long-term, life-shortening disability: tuberculosis and mental illness. Many persons with either condition were segregated into sanatoriums and no longer participated in the life of the wider community. In contrast, Americans today can expect to spend a few years living with serious disability at the end of life, and disability and death will again become a part of everyday life. From the start of the twentieth century to its final decade, the top ten causes of death shifted remarkably, as illustrated in table 1.

Improved public health interventions and medical treatments have meant that very few now die from childbirth, workplace accidents, epidemic infections, or their first heart attack. Instead, Americans live with serious progressive disease for years, and 70 percent of us die from chronic cardiovascular disease, cancers, diabetes, or strokes (Centers for Disease Control and Prevention 1999).
Table 1. *Top ten causes of death, 1900 and 2000*

<table>
<thead>
<tr>
<th>Rank</th>
<th>1900</th>
<th>2000</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Pneumonia</td>
<td>Heart disease</td>
</tr>
<tr>
<td>2</td>
<td>Tuberculosis</td>
<td>Cancer</td>
</tr>
<tr>
<td>3</td>
<td>Diarrhea and enteritis</td>
<td>Stroke</td>
</tr>
<tr>
<td>4</td>
<td>Heart disease</td>
<td>Emphysema and chronic bronchitis</td>
</tr>
<tr>
<td>5</td>
<td>Liver disease</td>
<td>Unintentional injuries</td>
</tr>
<tr>
<td>6</td>
<td>Injuries</td>
<td>Diabetes</td>
</tr>
<tr>
<td>7</td>
<td>Stroke</td>
<td>Pneumonia and influenza</td>
</tr>
<tr>
<td>8</td>
<td>Cancer</td>
<td>Alzheimer’s disease</td>
</tr>
<tr>
<td>9</td>
<td>Senility</td>
<td>Kidney failure</td>
</tr>
<tr>
<td>10</td>
<td>Diphtheria</td>
<td>Septicemia</td>
</tr>
</tbody>
</table>


In addition to changes in life span and duration of illness before death, caregiving and treatment too have changed, as reflected in the following comparison (National Center for Health Statistics 2002):

<table>
<thead>
<tr>
<th>1900</th>
<th>2000</th>
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</thead>
<tbody>
<tr>
<td>Age at death</td>
<td>Forty-seven years</td>
</tr>
<tr>
<td></td>
<td>Seventy-five years</td>
</tr>
<tr>
<td>Usual place of death</td>
<td>Home</td>
</tr>
<tr>
<td></td>
<td>Hospital</td>
</tr>
<tr>
<td>Coverage for most</td>
<td>Family</td>
</tr>
<tr>
<td>medical expenses</td>
<td>Medicare</td>
</tr>
<tr>
<td>Disability before</td>
<td>Usually not much</td>
</tr>
<tr>
<td>death</td>
<td>Two years, on average</td>
</tr>
</tbody>
</table>

Compared to a century ago, not only are people today less likely to die from acute causes early in life, but they are also less likely to get all their care from family members and more likely to require care outside the home. Some of these changes originated in the broader social commit-
ment to Medicare and the potential for more treatments in the hospital. In addition, long-term disability has generated greater needs than many families can handle on their own. Especially as the age of serious illness and death has come later, the spouses and children who provide care have also become older and often are disabled themselves.

Living with Chronic Conditions

A medical school professor, aiming to orient my class to the medical profession thirty years ago, claimed, “Office practice is mainly cuts, sore throats, and the worried well.” He may have been overstating the case even then, but he certainly would be wrong now. Most of medical care has become the care of chronic conditions. Nearly half of all Americans have one or more chronic conditions, which generally require some accommodations in order to get through the day and some ongoing upkeep to prevent or delay worsening or disability (Anderson, Horvath, and Anderson 2002). Currently, about forty million people, or 15 percent of the adult U.S. population, are limited in activities as a result of a chronic health condition (Kaye et al. 1996). Of these, almost 5 percent have difficulty walking (Freedman and Martin 1998); 7–8 percent have severe cognitive impairments (Freedman, Aykan, and Martin 2001); and 20 percent have impaired vision (Desai et al. 2001). With advancing age, the likelihood of disability gets much higher (Fried and Guralnik 1997). After age eighty-five, only one person in twenty is still fully mobile (Sharma et al. 2001). Age and disability are the strongest factors in predicting further declines in functioning, recurrent hospitalization, institutionalization, and death, even after taking into account other personal characteristics such as smoking, obesity, and several specific chronic diseases (Corti et al. 1994; Manton, Corder, and Stallard 1993).

Of those living with any chronic condition, most are suffering from more than one (Wolff, Starfield, and Anderson 2002). In the Medicare population, the average beneficiary sees seven different physicians and fills upwards of twenty prescriptions per year (Anderson, Horvath, and
Anderson 2002). Having multiple chronic conditions puts people at greater risk of disability, activity limitations, and high costs. The healthcare cost for a person older than sixty-five averages three to five times greater than the cost for an average younger person.

Even so, for Medicare populations with various levels of serious chronic conditions at age seventy, the costs of medical care for the rest of life are remarkably similar (Lubitz et al. 2003). A seventy-year-old healthy person with no functional limitations will spend about $136,000 in Medicare-covered services (hospitals, physicians, rehabilitation, durable equipment) during a life expectancy of fourteen more years, living with a functional limitation for six of those additional years. A seventy-year-old who is limited in at least one activity of daily living (such as mobility, toileting, feeding) will spend an average of about $145,000 in Medicare coverage during a life expectancy of twelve more years, having a functional limitation for nearly eight years of that time. Most Americans do not yet recognize the impact of these figures: even the healthy person at age seventy is in for many years of living with a disability, and length of life does not make much difference in the costs per person in Medicare. Yet since the use of institutional long-term care increases steeply with advancing age, the costs that Medicare does not cover will increase sharply with longer survival.

Most elderly people have accumulated some combination of arthritis, hearing or vision problems, dental decay or malfunction, painful feet, sluggish bowels, and urinary difficulties. Most people live for many years with such conditions, which worsen only gradually. Chronic conditions like these incur substantial costs, as well as symptoms and functional challenges; but they don’t generally cause serious dependency or death.

An important group of chronic conditions, in contrast, regularly worsen and eventually cause death. Overwhelmingly, these are cancer, organ system failure (heart, lung, liver, or kidney, mostly), dementia, and stroke. Nine out of ten elderly who die covered by Medicare have one or more of these conditions in the year preceding death (Hogan et al. 2000). Most of us eventually get one or more of these conditions; however, at
any one time, only a small proportion of people have these serious conditions, probably about one-quarter to one-third of the elderly (Lynn and Adamson 2003). Thus, both of these statements are true: most elderly are healthy, and virtually all Americans will have a substantial period of serious illness and disability before death.

Cognitive disability and frailty are rapidly becoming dominant elements of dying in old age, even though they are hard to track because these conditions are not reliably identified and recorded. Already, half of Americans who die past age eighty-five (and one-third of us live that long) have major memory loss as part of their final phase of life (Cornoni-Huntley et al. 1985). The proportion is lower at younger ages, though still commonplace. This cognitive loss can arise from Alzheimer’s dementia, strokes, Parkinson’s disease, and other syndromes. The course early on usually allows the person to be active, but lapses in judgment, memory, and self-control require constant supervision. Later on, the person often becomes unable to move about, use the toilet, or otherwise provide for self-care. From that time to the end of life, someone else must assist with every bodily function. The course usually lasts for years. Since cognitive loss is strongly correlated with age, as more of the population lives to old age, more will have cognitive deficits as part of the challenges posed.

Frailty is, in effect, the fragility of multiple body systems as their customary reserves diminish with age and disease. Instability when walking, problems with vision and hearing, loss of muscle strength, and lack of reserve in critical organ systems (heart and lung, especially) are typical elements (Fried et al. 2001; Gillick 2001). While people with substantial frailty may stay mentally capable, they still need help with daily activities and are at constant risk of major calamities like hip fractures, pneumonia, falls, strokes, and infections. Partly from outliving peers but also from incurring deficits in hearing and mobility, frail persons often become socially isolated and unhappy, especially if they have to leave familiar surroundings to move into nursing homes. Their spouses are often as old and frail, or already deceased, and their children are themselves
getting old, so no family helper may be available or sufficient. Frailty is probably already a major pathway through the last part of life, but the standard classifications of illness do not provide for it and hence often misleadingly count persons with this general state of decline as having “heart failure” or some other specific manifestation.

Indeed, our coding and classifications are generally misleading for those with serious chronic conditions at the last phase of life. Most Americans have a number of years of good health in old age, but usually the accumulation of chronic conditions gradually causes progressive disabilities and limits the person’s ability to overcome setbacks. Younger people have substantial reserves and can often overcome major illnesses, but old and frail people with chronic illnesses exist in a very fragile balance with the demands of their environment and often cannot withstand even small threats to that balance. Living with serious illness or frailty in old age is like walking on a high wire, and the cause of the final stumble and fall is mischaracterized when it is termed the “cause of death,” since being out on the high wire itself is what makes the stumble lethal. Less metaphorically, being in a fragile state of health for a long time at the end of life is what makes colds, flu, pneumonia, falls, and other modest setbacks into common causes of death. We misunderstand the situation when we count the incidental cause as being lethal, when it is really the underlying frailty that allowed such a small setback to lead to death.

The high-wire metaphor illuminates the new importance of multiple coexisting serious illnesses and multiple competing causes of death. Some people will succumb to medical complications within a short time; others in a generally stable but fragile condition will evade fatal complications for a long time. Care that meets the needs of persons with serious, progressive chronic illness in the last phase of life will often have to be available to these individuals for many years. Some will use it that long, while others, who are no more seriously ill, will encounter their final complication and die much earlier. We cannot tell how long most people will have to live once they are living in a delicate balance with a fatal chronic condition.
Shortcomings in Current Care

Surgery, pacemakers, and intravenous antibiotics are readily available in the United States to most patients who need them while living with fatal chronic illness. Those in need generally have adequate insurance because they are old enough for Medicare, have private insurance through employment, or are poor enough for Medicaid. But few patients facing old age and eventually fatal chronic illnesses can count on some other essential elements of good care: for example, relief of symptoms, continuity of services and providers, a safe and functional environment, and help with planning for the future (Institute of Medicine 1997; Wenger et al. 2003).

The health-care system regularly fails to provide sufficient prevention and relief of pain. Among people living in nursing homes, one-fourth of those with pain every day received no pain medication at all, and another half had orders only for trivial kinds and amounts of medication (Bernabei et al. 1998). Another study showed that, among out-patients with pain from metastatic cancer, 42 percent did not receive adequate pain medication (Cleeland et al. 1994). Medications have proven effective in treating and managing pain, making it unnecessary—and even outrageous—for anyone to suffer from overwhelming pain or discomfort (National Cancer Policy Board 2001; Doyle, Hanks, and MacDonald 1998).

If a person’s heart stops, a set of procedures called cardiopulmonary resuscitation (CPR) can sometimes get it started and the person’s life can go on. A person with a sudden heart attack or injury ordinarily wants CPR tried, even though surviving it will usually mean living through a period of critical illness. However, a person with serious illness, disability, and short life expectancy may well prefer to forego attempts at CPR, accepting death when the heart stops rather than endure more travail for a small chance of a short, and even more disabled, survival. Good practice requires giving the patient (or a surrogate if the patient is too sick or otherwise unable to make decisions) the opportunity to consider the merits in advance and to decide whether CPR should be attempted. This
seems obvious, yet a study of ten thousand patients hospitalized for at
least a week with very advanced stages of serious illnesses found that doc-
tors addressed this issue in less than half the cases (SUPPORT Principal
Investigators 1995).

What each of us wants when close to the end of life is confidence that
care will be there when we need it, that the people providing care will be
competent and kind, and that we will have comfort and respect, right up
to the end. But physicians now cannot promise patients with lung cancer
or emphysema and facing a long course to death that every health-care
provider in the area—every emergency room, nursing home, home-care
agency, and hospice—is reliably competent to provide relief of pain and
shortness of breath (National Cancer Policy Board 2001; Lynn and Gold-
stein 2003). Americans who face serious, eventually fatal, chronic illness
must navigate a care system—really, a patchwork of uncoordinated serv-
ices—that does not meet their needs and can even cause them harm (In-
stitute of Medicine 2001). Furthermore, the costs of that care have in-
creased substantially; for example, more than half of personal bankruptcy
cases arise from health-care costs (Jacoby, Sullivan, and Warren 2001).

The Baby Boom Grows Old

The current population of thirty-five million Americans age sixty-five
and older will more than double within the next thirty years (Federal In-
teragency Forum on Aging 2000). Indeed, the population’s average age
is increasing because women are having fewer babies and people are liv-
ing twenty years longer than they did in 1950 (United Nations 2002).
Additionally, the years after World War II saw a surge in births, and those
babies are now aging (Kinsella and Velkoff 2001). The last century’s baby
boomers will be old enough to start having high rates of late-life disabil-
ity between 2020 and 2030.

In the 1960s, when Medicare started, only 9 percent (seventeen mil-
lion) of the population was sixty-five or older, and only 0.5 percent (one
million) of the population was older than age eighty-five. In 2000, 12
percent (thirty-five million) of the population was sixty-five and older, and 1.5 percent (four million) was older than eighty-five. While the numbers of elderly persons will continue to rise, the major increase in serious disability will come when the baby-boom generation starts turning eighty-five in about 2030, when 22 percent of Americans (eighty million) will be over sixty-five, and 2.5 percent (nine million) will be over eighty-five (U.S. Census Bureau 2000).

The effects of the changing demographics will be stunning. Housing will need to accommodate wheelchairs and walkers, income support for retirement will have to last longer, and family and community organizations will have to make room for large numbers of persons with problems in mobility, hearing, vision, communication, and cognition. The services needed during the last few years of life are expensive. In fiscal year 2000, Medicaid paid for 45 percent of the $137 billion annual cost of institutional long-term care (U.S. Congress 2002). The Congressional Budget Office forecasts that the cost of long-term care will reach $207 billion in 2020 and $346 billion in 2040 (Congressional Budget Office 1999). These extraordinary costs risk bankrupting state budgets, which currently devote 20 percent of expenditures to Medicaid, while spending on all of health care constitutes about 30 percent of state spending (National Association of State Budget Officers 2003).

According to U.S. Senator John Breaux (D-LA, ranking member of the Senate Special Committee on Aging), “[Medicaid] has become our country’s ‘de facto’ payer of long-term care for the elderly and disabled. Most people do not know Medicaid expenditures are now outpacing Medicare nor do they realize that Medicaid is the second largest expenditure for state budgets. The unsettling notion here is that we have no real, comprehensive long-term-care system in this country and yet we are spending billions of dollars for a system that was not designed—it just evolved. Unfortunately, the system we have is inefficient, outdated, incomplete and unable to meet the needs of current or future recipients” (Breaux 2002).

People worry that living longer will mean more disability and greater
burdens on society. The jury is still out as to the actual aggregate effects. Several recent studies have documented an apparent reduction in the rate of serious disability in old age (Liao et al. 2000; Crimmins, Saito, and Reynolds 1997; Manton and Gu 2001). The studies are methodologically complex and the rate’s reduction, if any, is slight (Lynn 2000; Freedman, Martin, and Schoeni 2002). Of course, some conditions, like arthritis, hearing and vision deficits, and dental decay, can often be prevented or delayed. However, if general frailty remains as the path to death in advanced old age, most people who live into advanced old age will inevitably endure substantial periods of serious disability before dying.

Fifty years ago, the United States had to build new schools, houses, hospitals, and sports facilities to accommodate a dramatic increase in the number of births: the baby boomers were here. As those boomers reach retirement, they present a similar problem: we do not have the facilities or resources to care for these aging people, especially when they are sick and dying. Five decades ago, we invested in schools and housing to meet the needs of a growing generation; today, we must invest in services to ensure appropriate and high-quality care for that generation as its members grow old and die.

Who Will Provide Care?

Living out the last years of life with serious chronic illness poses challenges that simply did not arise when people died quickly from heart attacks, pneumonias, childbirth infections, or influenza epidemics. Most people living with serious, progressive chronic illness need some other person’s help just to get through the day, often every day, and sometimes constantly.

Unfortunately, our health-care and social systems have not yet fully recognized or begun to prepare for the upcoming frequency and extent of caregiving that the aged boomers will require. Indeed, most Americans have not absorbed the eventuality of needing to provide care for
loved ones, and then needing it for themselves. Few people make plans to anticipate that sequence.

Foremost is the challenge of meeting the needs for hands-on personal care. Since most older people prefer to live in their own home or with family for as long as possible, both family and paid in-home caregivers are essential (McCorkle and Pasacreta 2001; Abel 1990; Koffman and Snow 2001; Ferrell 1998). Unpaid family caregiving has always been the backbone of long-term care. In a national random survey of adults in 2000, more than one-quarter stated that they had provided care for a chronically ill, disabled, or aged family member or friend in the past year. That translates into more than 50 million volunteer caregivers (National Family Caregivers Association 2000a). The federal Administration on Aging estimated that at any one time 22.4 million persons are providing family care (Administration on Aging 2003).

For married elders, the first one to develop an eventually fatal chronic illness can usually rely on the spouse for most of the direct care needed. In a study of all caregivers assisting people age sixty-five and older, spouses accounted for 24 percent, daughters for 20 percent, and sons for 6 percent, meaning that immediate family members are 50 percent of all caregivers (Kassner and Bectel 1998). The onset of illness in the caregiving spouse or in a widowed or unmarried elder often precipitates a crisis for the rest of the family, especially for the daughters and daughters-in-law, who most often assume the role of caregiver (Kassner and Bechtel 1998). Greater opportunities for women today in education and the workforce leave fewer unpaid workers for family care. Smaller family size and higher divorce rates also leave a smaller group of potential family caregivers (Noelker 2001). Single elderly people, whether widows, widowers, or unmarried, often must rely upon paid services (Tennstedt 1999). Even when children can pitch in to help with care, the need for paid help remains substantial (National Family Caregivers Association 2000a).

While most people who provide care to a family member do so out of loyalty and love, and most find it meaningful, the challenges of family