Five hundred years ago, the Spanish explorer Ponce de León embarked on a journey to the New World in search of the fountain of youth. He never found it. Instead, he discovered what is today Florida, the state with the largest percentage of elderly people. Ponce de León might have smiled at the irony of how his discovery turned out. But discoveries often have a way of turning out differently from what we expect. When we think about medical advances in our time, these also have turned out unexpectedly. For instance, people are living longer today, but is the prolongation of life into old age always a benefit? Or have recent gains in human life expectancy instead been a prolongation of decrepitude and frailty? Will further medical advances only make matters worse? This question was raised nearly three centuries ago by Jonathan Swift in his satirical novel *Gulliver’s Travels*.

**The Challenge of Longevity**

*The Case of the Struldbruggs*

Swift described a voyage to the fictional country of Luggnagg, where his hero, Lemuel Gulliver, meets a strange group of beings, the “Struldbruggs,” who are a race condemned to immortality. It turns out that for the Struldbruggs, unlimited life span has not proved the blessing it promised to be. Longevity has come but without good health. Their existence is a dismal prolongation of senescence and decay, a nightmare like unlimited existence in a nursing home, as Swift describes them:

They were the most mortifying sight I ever beheld. . . . Besides the usual deformities in extreme old age, they acquired an additional ghastliness in proportion to their number of years, which is not to be described.

The diseases they were subject to still continue without increasing or diminishing. In talking they forget the common appellation of things, and the
names of persons, even of those who are their nearest friends and relations. . . .

The least miserable among them appear to be those who turn to dotage, and
entirely lose their memories.

In describing the Struldbruggs, Swift raised a question that is still of comp-
pelling interest:

The question therefore [is] not whether a man would choose to be always in
the prime of youth, attended with prosperity and health, but how he would pass
a perpetual life under all the usual disadvantages which old age brings along
with it.

No doubt Swift exaggerated to make his point. To speak of the usual dis-
advantages of old age misses the positive aspects of aging. Today, we see
countless examples of older people who are not debilitated or dependent, but
who rather maintain health and vigor into their later years. Yet Swift’s vision
does raise profound questions about our values: Are the old less valued than
the young? Where will we find the resources to take care of the frail elderly?
Could medical breakthroughs have unforeseen consequences for society,
either for good or for ill? These questions have no easy answers. Indeed, they
are at the center of the controversies examined in this book.

As a beginning, however, we examine several major challenges that peo-
ple face as they grow older. The first is the challenge of coping with an aging
body. Medical advances that help people live longer may seem beneficial,
but a longer period of physical and mental decline has implications for indi-
viduals and for society. The second challenge is that of maintaining a valued
place in society while aging. Older people are often stereotyped as marginal
members of society. However, as the average age in the United States
steadily increases, we are beginning to confront questions of when people
cross from capable old age to dependency. Finally, as individuals grow older,
they do so in the wider context of an entire society that is undergoing a shift
to population aging.

Biomedical advances. There are those who believe that biology will save
us from the problem. They argue that biomedical researchers can meet the
challenge of longevity by developing techniques for delaying the onset of
debilitating conditions in old age. In effect, they hope to postpone sickness
until a final, brief period of life and so eliminate prolonged dependency.
Other biologists believe that we can make good on Ponce de León’s dream
and discover a fountain of youth by altering the fundamental biological
mechanism that makes us grow old. Whether by delaying illness or by actu-
ally preventing biological aging, the scientific optimists believe the “Struld-
brugg” problem can eventually be solved.

Rationing health care. Their optimism is not shared by all. Others believe
that hard choices are called for, and they doubt that biology will save us from
making those choices. We do better, it is said, to acknowledge the biological
limits rather than hope for a technological fix for the problems that often
come with aging. In this spirit, ethicist Daniel Callahan wants to reject high-tech medical care used to prolong life for the very old. Instead, he believes, we do better to ration health care on the basis of age. He recommends forgoing life-extending treatment once elderly people have lived out a full and natural life span.

Providing long-term care. If more and more members of the population live into advanced old age, we will see growing numbers of frail, chronically ill elderly in need of long-term care, at home or in institutions. The term long-term care covers health care and social services needed by those who have lost capacity to care for themselves because of a chronic illness or condition. It is expected that growing numbers of older people will suffer from chronic disorders that keep them from living independently. In that case, long-term care will loom even larger in the future than it does today. Opinions differ about who should bear the cost of that care, but paying the bill for longevity is already a serious challenge to society.

Self-determined death. Neither prolonged debilitation nor rationing of health care is popular with most Americans. But growing numbers today do feel that decline and a diminished quality of life might be sufficient reasons for ending one’s own life. Those who hold this view usually reject the idea of society setting limits but would instead leave the choice about dying up to the individual. Advocates of this idea believe that deliberate termination of treatment must be more openly recognized by law and should be actively supported by health care services.

So here we have four answers to the Struldburg dilemma: hoping for a medical breakthrough, making tough cost-cutting decisions, providing long-term care, or permitting individuals to end life. All are ways of coping with the prospect of a prolonged period of frailty and dependency at the end of life. The options considered here are not mutually exclusive. But each raises profound questions about our values: Are the old less valued than the young? Where will we find the resources to take care of the frail elderly? Could scientific breakthroughs in the biology of aging have unforeseen consequences for society, either for good or for ill?

These questions have no easy answers. Indeed, they are at the center of the major debates examined in this book. The biology of longevity, the economics of health care, and the right to die are all related. By appreciating some key facts about biology, economics, and death and dying, we can better approach the debates surrounding these critical issues.

A difficulty arises from the fact that contemporary medical practice in the United States is based on a strategy of curing disease, not promoting health. This familiar strategy has led to the conquest of many killer diseases, such as smallpox and polio, thus permitting a greater portion of the population to reach old age. Since the 1960s, death rates from cardiovascular disease, on an age-adjusted basis, have dropped by 50% (National Center for Health Statistics, 1995). The net effect of all these interventions has been to raise
average life expectancy in the United States from 47 years in 1900 to 76 years today.

But gains in life expectancy are not the same as raising maximum life span. Life expectancy, or expected years of life from birth, has risen; but life span, which is defined as the maximum possible length of life, has evidently not changed at all. The causes of maximum life span and of aging itself still remain unknown. Biological evidence suggests that maximum life span is genetically determined, and therefore fixed, for each species.

Normal Aging

In a broad sense, one might say that aging begins at birth, but we normally identify aging with changes that come after maturity. Gerontologists often use the term normal aging to describe this underlying irreversible process that is characteristic of each species. Aging can be defined as a time-dependent series of cumulative, progressive, intrinsic, and harmful changes that begin to manifest themselves at reproductive maturity and eventually end in death (Arking, 1998). Primary aging would describe those changes that occur over time independent of any specific disease or trauma to the body, whereas secondary aging would describe disabilities resulting from forces such as disease.

Normal aging is not a disease but eventually leads to functional declines and involves increased susceptibility to death from specific diseases. For example, decline in short-term memory, wrinkled skin, and gray hair are signs of normal aging, but they are not symptoms of disease and need not result in greater susceptibility to death. On the other hand, a weakening of the immune system does increase susceptibility to death.

The idea of normal aging is important because health care professionals see mainly sick people; as a result it is easy to develop negative stereotypes about older people. One common stereotype depicts older people as frail and sick. But in fact, the vast majority of people over age 65 are healthy enough to engage in most activities of daily living, such as bathing, dressing, or preparing meals. More than four out of five report no limitations on such everyday activities of life.

Longevity and Disease

Steps toward health promotion, such as improved diet or increased exercise, can reduce the likelihood of illness and thus increase life expectancy. These steps may also reduce morbidity in later life, but not invariably so. It is clear that declines in the mortality rate need not be matched by decline in morbidity or sickness. Data drawn from the National Health Interview Survey between 1969 and 1986 indicated that there was little significant improvement in self-reported health among the U.S. population. Whether
morbidity will be diminished remains an open question (Crimmins and Ingegneri, 1993). For instance, a patient with a strong cardiovascular system with dementia could live for many years in a dismal state resembling the Struldbruggs. Hopes for delaying disease by health promotion alone may not be convincing. Moreover, a rising curve of survival into old age does nothing to alter maximum life span, the “natural death” that the Struldbruggs longed for.

Scientists have pursued basic research on the biology of aging in the hope of avoiding the Struldbrugg problem, namely, having enormous numbers of frail, sick, and dependent elderly people whose lives are prolonged in a desperate condition. But do we really need to understand the biology of aging itself? Couldn’t we simply concentrate research attention on eliminating the big “killer diseases” that prevent people from living out a full life span? For example, if the most prevalent diseases of later life, the big killers such as stroke, heart disease, and cancer, were eliminated, wouldn’t we all live to be over 100? Unfortunately, the answer is no. Curing all these diseases would give us, on average, only a decade or so more years before some other disease would kill us.

And what if we could eliminate all diseases? Would immortality then be at hand? Alas, the answer is no. Time and chance take their toll in the form of accidents. Unless we turn our attention to the underlying vulnerability, we may change life expectancy but not maximum life span. Still worse, we might succeed in creating more and more long-living “Struldbruggs.” It is quite possible that future declines in death rates will actually have a small effect on average life expectancy but create much larger numbers of very sick old people. The fear, then, according to critics, would be a Struldbrugg scenario: an expansion of morbidity.

This trend will take place, pessimists believe, because medical technology is improving survival prospects for patients with disabling conditions associated with fatal disease—Alzheimer’s would be a good example. But the basic progression of the disease itself remains unchanged. The length of life lived with disability for this part of the population would increase. A second reason for expansion of morbidity is the increasing role of nonfatal diseases of aging, such as arthritis and some forms of stroke (Olshansky et al., 1991). But optimists take a different view. Analysis of data from the National Long Term Care Survey by Kenneth Manton and colleagues showed a significant decline in chronic disability in the elderly population between 1984 and 1989. The proportion of elderly persons who were disabled actually became lower in this period, reflecting improved treatments and lifestyle modifications. For instance, the number of those over age 65 with high blood pressure dropped from 46% in 1982 to 39% in 1989; the percentage of Americans with emphysema went down from 8.9% to 6.4%. The research team concluded that there is reason to expect further progress in the future as successive generations of older people show gains in income and education. On the negative side, they pointed to conditions requiring special attention, such as musculoskeletal problems (e.g., arthritis) and dementia (Manton et al., 1997).
Basic research may find answers to the common diseases of old age. But beyond curing specific diseases, researchers are also looking at interventions that could delay or actually reverse the process of aging. Here we confront far-reaching questions about the impact of research on the biology of aging. Are we talking about moving the average life expectancy closer to the upper limit of the maximum life span—say, closer to age 120? Or are we talking about pushing that upper limit itself—say, up to age 150 or 200? In either event, successful anti-aging interventions would have large consequences for human society. But until such research yields practical results, society will have to cope with the consequences of having more long-living individuals, and one of those consequences is vulnerability to disability and disease.

**Epidemiology of Aging**

Although aging is not in itself a disease, it tends to increase susceptibility to disease. The diseases of later life are the subject of geriatrics, or the medical specialty of old age. Much has been learned about the major diseases of later life, and this subject is important for debates about aging, health care, and society (Blumenthal, 1983).

The discipline of epidemiology originally acquired its name from the scientific study of epidemics. Today, epidemiology is more broadly understood as the use of statistical techniques to study the distribution of diseases in human populations. A basic goal for the epidemiology of aging is to understand what diseases are most common among older people and to assess their impact (White et al., 1986). An example of how epidemiological data are organized is given in Exhibit 4, indicating the 10 leading causes of death among older people.

**Major Diseases in Old Age**

Today, three quarters of all deaths among persons over age 65 come from just three diseases: heart disease, cancer, and stroke. Death rates for heart disease and stroke have declined in recent decades, but they still remain the leading causes of death. If heart disease were completely eliminated as a cause of death, the average life expectancy for someone 65 years old would increase 7 years, ignoring the likelihood of death from one of the other leading causes. Although often not listed separately as a cause of death in vital statistics, Alzheimer’s disease is probably the fourth leading cause of death, chiefly afflicting people over age 65.

Along with diseases causing death, we also need to consider chronic conditions that persist for a long period, whether or not they cause death. Chronic illness is much more common among the old than among the young. Rates of chronic illness are 46% for those over age 65 compared with only 12% for those younger than that age. Exhibit 5 shows the top 10 chronic conditions for people over age 65. It is important to note that some conditions,
such as cataracts and hearing impairment, can be limiting but not life threatening. Other conditions, such as hypertension (high blood pressure) and heart disease, can lead to fatal disorders.

**Arthritis.** Arthritis is the most familiar and most prevalent chronic disease of later life; it afflicts nearly half of all persons over age 65. Arthritis is basically an inflammation of the joints, also commonly known as rheumatism, and it is the most important cause of physical disability in the United States. Symptoms include pain and red, swollen joints and muscles. Like cancer, arthritis is actually the name of a group of as many as 100 syndromes, all slightly different. Rheumatoid arthritis can occur at any age, but osteoarthritis is distinctly related to old age and is aggravated by degeneration caused by wear and tear of the joints.

Degenerative joint disease in some variety is almost certain to occur in people over the age of 70, but the effect of such disease on activities of daily living varies tremendously, and most people live full and active lives with it. The cause of arthritis is not known and there is no cure, but treatment of the disease to reduce symptoms can be effective. Painkilling drugs are not costly, but, for the very serious cases, joint surgery—for example, hip replacement—can be expensive (Moskowitz and Haug, 1985).

**Osteoporosis.** Osteoporosis is a condition involving deterioration or disappearance of bone tissue leading to loss of strength and, often, to fracture. The
disease is most prevalent in women (4 times more common than in men), especially beyond the age of menopause. About one in four White women over the age of 65 will develop osteoporosis. When weakened by osteoporosis, bones are more likely to break, with serious consequences. It is estimated that 1.5 million fractures occur each year as a result of osteoporosis. A hip fracture, often related to a fall, is one of the most common events precipitating admission to a nursing home. About half of those who survive fractures will require some form of long-term care. It is estimated that more than 12 million people in the United States have osteoporosis, and the annual cost of fractures resulting from the disorder is in the range of $7 to $10 billion.

Parkinson’s disease. Parkinson’s disease is a degenerative neurological disorder characterized by a loss of control over bodily movement. It affects about half a million people in the United States, chiefly older people. Symptoms include tremors or shaking of the head and hands, leading to progres-
loss of muscle control and of the ability to walk unaided. Parkinson’s disease is an age-related syndrome, and its incidence increases steadily after middle life. For reasons not clear, dementia is quite prevalent among persons with Parkinson’s, and depression is common as well. Parkinson’s appears to be caused by lack of dopamine production in brain cells, but there is no treatment that slows the progression of the disorder. Drug treatment, such as L-Dopa, however, can relieve symptoms of the disease (McGoon, 1990).

**Cancer.** Recent research has focused on aging and changes in the immune system of the body. The strength of the immune function begins to decline after puberty, and with advanced age comes a propensity to develop autoimmune disorders, such as arthritis, as well as higher rates of cancer. In fact, cancer is overwhelmingly a disease of old age, with half of all cancers occurring in people over age 65. The incidence of malignant disease rises progressively with age, so that cancer today is the second leading cause of death for Americans over age 65, accounting for 21% of deaths among older people (London and Morgan, 1995).

Different forms of cancer seem related to age but actually may be the result of longer exposure to cancer-causing chemical substances known as carcinogens, for example, asbestos or tobacco. Because of successful medical interventions, older people who have cancer are living much longer than in the past, so that cancer can often become a chronic disease. A person diagnosed with slow-growing or controllable forms of cancer may live many years, thus increasing the cost of medical care over a longer period of time. But it is also possible to prolong the period of dying for those with incurable cancer, raising questions not only about the ethics of termination of treatment but also about the cost of life prolongation.

**Cardiovascular disease.** The leading cause of death for people over age 65 remains cardiovascular disease, which includes stroke and heart disease (Kaiser, Morley, and Coe, 1997). Heart disease alone accounts for 43% of all deaths, whereas stroke accounts for another 9% of those deaths. In the past two decades, there has been a decline of almost 30% in deaths from heart disease, and the cardiovascular condition of older people shows wide variations. According to physiological studies, the heart of a healthy 80-year-old man performs as well as that of someone in his 20s within the normal range of everyday activities. But, unfortunately, about two thirds of men in their 70s have clear evidence of coronary heart disease, so death rates remain high. The economic cost of heart disease is staggering: more than $120 billion a year, according to figures from the American Heart Association.

Stroke refers to a neurological deficit in the brain arising from a sudden disturbance in the blood supply. A stroke often results in some degree of paralysis, often on one side of the body, or loss of other functions, such as speech, and it can result in coma or death. Although one stroke in three leads to immediate death, another one in three causes permanent disability. It is
estimated that there are 3 million stroke survivors and 150,000 deaths from stroke each year in the United States (Gorelick, 1994). The costs of caring for impaired stroke victims are estimated at $30 billion, and the loss of quality of life can be substantial for the patient and family (Locke, 1983).

**Dementia and Alzheimer’s disease.** Dementia is an organic mental disorder involving progressive loss of the capacity to think and remember. It is not characteristic of normal aging but is the result of a specific disease process. Dementia is characterized by confusion and memory impairment and may manifest itself in a wide range of symptoms, such as wandering or losing things. Dementia can have various causes, but Alzheimer’s disease is an important one (Katzman and Bick, 2000). Patients with Alzheimer’s may retain social skills and conceal their impairment to some degree. Alzheimer’s disease is often hard to diagnose and separate from other cognitive impairments, such as multi-infarct dementia, a condition caused by a series of small strokes affecting the brain.

Senile dementia of the Alzheimer’s type (SDAT), or Alzheimer’s disease, is the most common cause of irreversible dementia of old age, accounting for two thirds of all dementing conditions. The proportion of people with Alzheimer’s disease rises dramatically with each decade of age over 65, doubling every 5 years. It strikes 1 out of 12 persons older than age 65, but the figure rises to 1 out of 3 among those over age 80. Between 2 and 4 million Americans may now be afflicted with the disease. About half the residents of nursing homes have some form of dementia, usually Alzheimer’s but sometimes multi-infarct dementia that comes from accumulated damage to blood vessels in the brain.

Alzheimer’s is a disease caused by deterioration of brain cells with characteristic plaques and tangles. The disorder typically progresses through stages from mild memory loss, through significant cognitive impairment, to very serious confusion and the loss of ability to handle dressing, bathing, or other activities of daily living (Reisberg, 1983). By the end stage of the disease, there may be incontinence, loss of speech, and inability to walk. A definitive diagnosis of Alzheimer’s is difficult, and confirmation usually can be made only upon autopsy. But a mental status examination, such as the Folstein Mini-Mental Status Exam, can assess functional cognitive losses produced by the disease (Folstein, Folstein, and McHugh, 1975).

Alzheimer’s disease is irreversible and generally foreseeable in its course. In advanced stages, taking care of patients at home usually becomes impossible. The result is often placement in a skilled nursing home, sometimes lasting many years. Even when a patient’s quality of life has severely declined, it is feasible to use modern medical techniques to cure physical illness, such as pneumonia or kidney failure, and thus prolong the lives of demented patients, resulting in great expense.

In terms of the health care rationing debate, it is worth noting that acute care medical intervention can actually be less costly than long-term care over a period of many years for Alzheimer’s patients (Cassel, Rudberg, and Olshansky, 1992). The National Institute on Aging projects that, unless a
A cure for Alzheimer’s is found, by the middle of the next century there could be 14 million people with the disorder, costing billions of dollars a year to maintain.

Alzheimer’s appears to be one of the most common diseases of late adulthood, and genetic factors clearly contribute to Alzheimer’s disease with early onset. One indication of genetic influence is the association between Down’s syndrome and Alzheimer’s. Genes found on chromosomes 21 and 14 are known to cause early-onset Alzheimer’s, whereas another gene on chromosome 19 seems linked to late onset. The lifetime incidence among relatives of patients with Alzheimer’s is estimated at around 20%, or 3 to 4 times the risk among comparable groups. If Alzheimer’s were purely a genetic disease, however, then it would be expected that identical twins would always come down with the disease. But they do not, thus proving that environmental factors must also play a role in expression of Alzheimer’s disease.

Although Alzheimer’s disease is a major problem, its prevalence among older people should not be exaggerated. Most people over age 65 do not suffer from memory defects or dementia. Among all those over 65, there are a significant number—perhaps one in five—who have a mild or moderate mental impairment. This means the overwhelming majority of older people have no mental impairment at all. Memory defects are quite limited among the large majority of normal older people, and the capacity for learning and growth in later life remains impressive.

Responses to the Geriatric Diseases

Interventions to eliminate specific diseases, such as cancer or stroke, can increase life expectancy, but they do not raise the maximum life span of individuals. Furthermore, curing a life-threatening illness does not prevent other nonfatal diseases that may bring chronic disability. One of the big questions about aging, health, and society is whether our health care system is capable of dealing with a growing elderly population. Many critics charge that it is not. Medicine in the United States has often neglected the dimensions of caring for and coping with people who have illnesses that cannot be cured, such as Parkinson’s or Alzheimer’s. That neglect is a matter of special concern for geriatric medicine.

The approach of clinical medicine in most advanced countries, and certainly in the United States, focuses almost entirely on discrete causes of disease and their cures. Intrinsic causes within the organism—in other words, vulnerabilities of aging—are not well understood and are not the focus of attention. The paradox here is that, because survivorship has been increasing, the aged have become an increasing proportion of society and the remaining fatal diseases, whether cancer or Alzheimer’s, are themselves linked to the process of aging itself.

Will a breakthrough in understanding the biology of aging solve this problem? There are reasons for doubt. For example, there is a whole class of
age-related changes not likely to be affected by improved DNA repair, a favored mechanism for explaining biological aging. Many physical changes of old age are in the wear-and-tear category and include the decalcification of bones, uric acid encrustation in cartilage of joints, and cholesterol accumulation in blood vessels. It might be possible for geriatric medicine to develop strategies to control causes at the tissue level and to introduce rehabilitative methods that improve the clinical picture. The problem is that many of today’s dramatic medical techniques—such as kidney transplants or bypass surgery—do nothing to affect the underlying process of aging. We can keep patients alive but can do little to improve their quality of life.

An overview of geriatric epidemiology gives a concrete picture of what the “Struldbrugg” problem might look like in the future. Success in curing some forms of cancer or heart disease could raise life expectancy but leave larger numbers of people living with the burden of chronic diseases such as stroke, arthritis, or osteoporosis. A pragmatic approach to geriatric medicine might favor interventions designed to reduce the burden of age-related diseases on individuals as well as society.

Advances in medical technology and adoption of health promotion measures could bring average life expectancy closer to the theoretical upper limit of the maximum life span. But would we then be inadvertently multiplying the Struldbrugg problem? Those in favor of age-based health care rationing would cut funding from expensive life-sustaining interventions for the very old and redirect those resources toward quality-of-life interventions for age-related diseases. But there are serious questions about whether paying for extended long-term care is actually cheaper than any alternative we can imagine. Those questions involve the economics of health care.

**Economics of Health Care**

The emergence of the Struldbrugg problem in America has had an important public consequence, namely, rising health care expenditures for the very old. The elderly, comprising 12% of the population, consume more than 36% of total health care expenditures—more than 4 times what is spent on younger people. This increase has taken place against a background of escalating costs for health care in general. The proportion of the gross national product for health care today is twice what it was in 1965 when Medicare was first enacted, and Medicare remains at the center of the economics of health care for aging.

As a nation, the United States has gone from spending approximately 9% of the gross national product on health care in 1980 to spending 14% today, which is more than a trillion dollars a year. Health care is now the second-largest item in the federal budget, consuming 20 cents of every dollar spent. Health care spending is growing faster than the general rate of overall inflation, and it remains a concern for the future.
Reimbursement Systems

Medicare is the chief federal government program that pays for health care for 34 million Americans over age 65 and another 5 million disabled people of all ages. Medicare has serious limitations: It doesn’t pay for the first day of hospitalization; it doesn’t cover hearing aids, prescription drugs, eyeglasses, or dental care. It excludes long-term care coverage, except for limited periods after hospital discharge. Like most insurance plans, Medicare has deductibles and co-payments and covers only 80% of physician expenses. Medicare is available primarily on the basis of age, in contrast to Medicaid, a health program funded by both the states and the federal government, which is available to those below the poverty line and pays for a substantial portion of nursing home care.

Medicare was created in 1965 as part of the Social Security Act. Before its inception, half of people over age 65 were without health insurance, whereas today almost all are covered. Much has changed in the Medicare population in more than three decades. Since 1965, life expectancy has risen from 70 to 76 and the 65+ population grew from 9% to 13% of the total U.S. population. Medicare has had a major impact on the health of the elderly population: Since 1965, half as many Americans die of heart attacks and a third as many die of strokes, and this is a tremendous accomplishment.

Like Social Security, Medicare is funded from payroll taxes with additional funding from general revenues and premiums from beneficiaries. But unlike Social Security, the problems of which will surface decades into the future, Medicare faces short-term financing problems. Overall, Medicare spending has risen much faster than the cost of living, and thus it presents government policymakers with a serious problem of cost control.

Medicare actually comprises two distinct programs: Part A, or hospital insurance, and Part B, supplementary medical insurance, covering non-hospital care, which primarily includes physicians’ services along with limited home and outpatient services. Medicare Part A is financed by a compulsory payroll tax administered as part of the Social Security tax levied on all wages up to a specified limit. Part B covers 80% of doctors’ bills as long as Medicare beneficiaries pay a $50 monthly premium, deducted from their Social Security checks. Exhibit 6 shows where money from Medicare goes.

In 1965, when it was first enacted, Medicare spent just over $3 billion. Today it spends more than $200 billion each year. Nearly two thirds of that total goes to hospitals, where acute care and often high-technology care are provided. If health care rationing on the grounds of age were ever to be introduced, it would probably take place in the Medicare program and would show up in the large sector of Medicare concentrated on hospitals.

Although Medicare expenditures have climbed dramatically, Medicare still covers only about half of the out-of-pocket medical expenses of older people. These amount to approximately $1,500 per beneficiary per year—roughly the same percentage as when the Medicare program was first enacted in 1965. Part of the reason is that Medicare Part B reimburses 80% of physicians’ “reasonable charges.” In fact, the amount reimbursed may or
may not reflect actual charges in a specific geographic area. In practice, many physicians in the past have charged much more than the officially allowed Medicare rate, with the patient paying the difference. But that practice has now begun to change. Since 1993, physicians participating in Medicare are limited by law to charging no more than 15% above the rate set for Medicare reimbursement. That law was passed because fewer than half of physicians were willing to accept the official Medicare reimbursement as full payment because the rate was too low. Because of limits on what Medicare will pay, around 30% of Medicare beneficiaries also have private Medigap policies to cover the remainder of their medical bills.

Our experience so far with both the Medicare and the Medicaid programs gives cause for concern about what might happen if cost-containment measures cut down on physician reimbursement from government insurance programs. Officials of the American Medical Association have rejected the idea of the government setting limits on the fees of doctors, and they have argued that such fee limits will inevitably bring about de facto “rationing” of health care.

Similar fears erupted after 1983 when Congress passed a law limiting payments to hospitals under Medicare. In 1983, Congress responded to the high hospital costs of Medicare Part A by introducing a prospective payment system: a new way of reimbursing hospitals for the cost of treating Medicare patients. Under Prospective Payment, hospitals receive a fixed amount for a specific diagnosis given to a patient, no matter how long the hospital stay or the type of service required. Over the past decade, the new prospective payment system has held down hospital costs below what they


NOTE: Total exceeds 100% because of rounding.
would have been without these cost controls. But critics charge that the system resulted in higher outpatient costs and in displacing costs onto families of patients who were discharged “quicker and sicker.”

The system created hundreds of diagnostic categories, or Diagnosis Related Groups (DRGs), that determined how much a hospital would be reimbursed for patient care. The system in effect gives an incentive to hospitals to keep their costs down and discharge patients as early as medically feasible. Despite protests and concerns about the new reimbursement system, DRGs have become an accepted fact of life in American hospitals.

In the 1980s, it was widely feared, and sometimes charged, that these cost-containment measures would lead to “patient dumping” by hospitals along with widespread deterioration of patient care. Such widespread deterioration did not occur, but the 1983 law did have its intended effect in holding down Medicare Part A spending from where it would have been otherwise. Cost containment for hospital spending proved effective, but during the 1980s Medicare Part B spending for physicians tripled in size, and outpatient costs—for example, home health care spending—has increased dramatically in recent years.

In part because of the success of DRGs, Congress acted to try to control costs under Medicare Part B. In 1989, Congress passed another law revising the Medicare reimbursement formula for physicians in different medical specialties. The new legislation introduced a so-called Resource Based Relative Value Scale in the national Medicare program. The new Relative Value Scale means that primary care health providers, such as internists, geriatricians, and family practitioners, will be paid more for their services, whereas other specialists, such as some surgeons, will be paid less than they were before.

This reimbursement scheme is an effort to give more incentive to medical specialties involving prevention, health promotion, and quality of life, in contrast to the expensive technologies of life prolongation. Doctors who spend more time with patients but do not use “high-tech” procedures are to be paid more than they were paid previously. The aim of the new measures is to provide a more equitable system of payments reflecting skill, time, and intensity of work.

Despite the ongoing debate about the particulars of Medicare, it commands strong public support as a universal public insurance program for physical illness. By contrast, no consensus has been mobilized to make Medicare a universal public program for long-term care, mental health treatment, or early detection of illness, which might be beneficial in the long run. Medicare will not pay for regular physical examinations or for dental care. The elderly make use of mental health services at only about half the rate of younger people, partly because of lower rates of mental illness but also because today’s older generation is likely to be more resistant to using formal services.

Despite recent changes in Medicare, preventive care and health promotion remain low priorities. Critics of this bias note that a great deal of money is spent on acute conditions such as heart disease or cataracts. An expensive
procedure such as coronary bypass surgery remains fully covered by Medi-
care, but a physical exam to detect hypertension or recommend preventive
diet or medication is not. Medicare reflects the same priorities favored by the
health care system for the nonaging population. The emphasis on technology
is in some ways perplexing. Contrary to popular belief, it was not medical
technology but largely social interventions—such as improved sanitation,
diet, and public health measures—that accounted for the large drop in mor-
tality in the 20th century. Perhaps further efforts to make lifestyles healthier
could help control health care expenditures for our aging population.

The federal government has subsidized some research into the health
effects of lifestyle improvements. It has also subsidized research and develop-
ment in medical technology; in fact, expenditures for biomedical science
have increased from $3 million after World War II to more than $11 billion
today. Yet in contrast to private industry, in which investment in research and
development leads to lower costs, advances in medical technology have
actually led to higher costs for health care. With each new technique for life
prolongation, we increase the numbers of those who are very old and very
sick.

Prospects for the Future

The escalating cost of health care has become a major problem for the
elderly and for other groups in society. Will biomedical technology help
solve the problem or only make it worse?

In the future, this picture seems likely to grow worse, for two reasons.
First, health care costs, even after adjusting for inflation, have continued to
rise faster than inflation. Second, the aging of the U.S. population will add to
these expenses because incidence of illness and disability is higher among
the old. Those over age 65 spend about 4 times as much money on health
care as people below that age. In terms of overall spending for health care,
expenditures for those above 65 now amount to a third of all health care
spending, while comprising only about 12% of the total population.

It is difficult to predict future levels of use of health care by an aging pop-
ulation. In the past, there were gross underestimates of expenses. In 1965,
planners projected the cost of supplemental medical insurance under
Medicare. But in 1970, only 5 years later, there had been a fivefold increase
in the cost of that program. Between 1967 and 1975, the rate of use in both
parts of Medicare had gone up from 367 per 1,000 enrollees to 528 per
1,000. Recently, Medicare has been growing at a rate 3 times the rate of
inflation.

In light of these huge and rising costs, it is not surprising that there is
widespread concern about the prospect of an aging population in the future.
Based on U.S. Census Bureau middle-range population forecasts, it is esti-
mated that the Medicare costs for the oldest-old (85+) could increase sixfold
by the year 2040 (Schneider and Guralnik, 1990).
Long-Term Care

Dramatic end-of-life decisions often attract public attention in debates about the economics of health care. But a far more widespread phenomenon is taking place away from the hospital intensive care ward, for those needing long-term care. People in need of long-term care may live in many different environments, ranging from a nursing home or assisted living facilities to a single-family residence. Whether in the community or in an institution, people with severe chronic conditions often need help with activities of daily living, and supportive services can be costly.

How will we provide these needed services? The problem cannot be left for the future. Growing numbers of frail, chronically ill elderly are already in need of long-term care, at home or in institutions. Instead of expecting old people to die early or hoping to find the biomedical fountain of youth, we face the practical problem of how to pay for long-term care, whether furnished by families or in institutions. Opinions differ about who should bear the cost of that care.

Consider the hypothetical case of George and Martha Walton. They never expected to live into their 80s, but they’re glad to be alive and glad still to be in their own home in Middletown, USA. Maintaining their home, however, has gotten more difficult since George had his first stroke. Martha finds herself exhausted, and her arthritis prevents her from getting around the way she used to. They can’t afford to hire help to come into their home. They’ve looked into alternative housing arrangements, but the thing George fears most of all is that his condition will deteriorate and he’ll end up in a nursing home. They wonder, where will they turn next?

Housing for the Elderly

George and Martha Walton are struggling with long-term care issues, whether or not they even use or recognize the term long-term care. George and Martha like living in their own home and don’t want to go into a separate residential facility. Their situation, which is typical, shows why the distinction between long-term care services and housing for the aging is not clear-cut. Housing for the elderly was long conceived as a bricks-and-mortar affair; that is, it was mainly a matter of financing or subsidizing shelter dedicated to the aged. But increasingly it is recognized that social as well as physical concerns must be taken into account in planning for housing for the aging population (Newcomer, Lawton, and Byerts, 1986).

Today, around 90% of the older population in the United States live in conventional housing, mostly single-family houses or apartments. Only 5% of the population over age 65 are in nursing homes, whereas another 5% reside in some form of housing that provides congregate facilities or services. Even among the oldest-old (85+), only about a quarter of the population lives in specialized or supportive housing. But health care for an aging population inevitably brings consideration of housing needs as well.
Housing in the early 21st century of an aging U.S. population may produce greater demand for low-cost housing and coordination of services. Building affordable housing for an aging population is a challenge as funding from the federal government for senior housing continues to shrink. Community-based services, such as home health and adult day care, are likely to be important in the future as cost-containment pushes providers to look for alternatives to expensive, medicalized facilities like the nursing home. At the same time, interest in new approaches to senior housing is also growing (Gamzon, 1995).

Today, many public and private sector strategies for planned senior housing strategies are being discussed, including a wide range of options: naturally occurring retirement communities, leisure-oriented, and continuing-care retirement communities; board and care homes; adult day care and respite services; and homesharing, assisted living, and medical care in residential settings.

What are the “alternative housing arrangements” that George and Martha Walton might want to consider? In the past, a home for the aged might have been an option. A home for the aged is a facility typically sponsored by a church or fraternal organization and dedicated to helping the impoverished or dependent elderly. These residential facilities are less common today, but commercially developed retirement communities have been attractive to the more affluent elderly (Hunt et al., 1983).

Also to be noted is a newer type of facility that has recently seen rapid growth: the continuing care retirement community (CCRC; Sherwood et al., 1997). These offer a combination of housing and health care and typically provide a level of social support for those who find it difficult to live on their own. Originally known as “life care communities,” CCRCs promise residents the opportunity to “age in place” by combining different levels of health care with housing, nutrition, social supports, and physical security. CCRCs integrate these services under a comprehensive insurance contract that may involve a form of managed care.

Some analysts believe that, at their best, CCRCs can offer a nearly ideal model of health care for the elderly because of the guaranteed commitment and integrated approach to housing and long-term care needs (Somers and Spears, 1992). But there are drawbacks. CCRCs are often expensive. George and Martha probably would not qualify. A distinguishing feature of the life care community is that residents are committed to remain there for the rest of their lives: they pay a large entry fee, which can be above $100,000, in return for guaranteed support as they grow older and more frail.

If CCRCs represent the high-income end of the housing continuum, it is important to note the prevalence of domiciliary care facilities and board-and-care homes at the lower end (Morgan, Eckert, and Lyon, 1995). These are homes that provide mainly custodial or personal care for elderly and disabled people who don’t need the intensive medical supervision of a nursing home but who do need help with activities of daily living.

Another approach is shown by assisted living facilities that offer residents and their families a homelike environment with personal but very
limited supportive care (Fisher, 1995). The atmosphere of assisted living promotes a maximum degree of autonomy, independence, and privacy. But assisted living complexes can also cover the entire continuum of care: from those that provide only minimal help with activities of daily living to those allowing residents complete nursing care. Assisted living is much more attractive than a nursing home. As hospitals have been pressured to discharge patients earlier and as nursing homes have become facilities for very sick people, assisted living has grown rapidly.

A great advantage of assisted living is that, in contrast to separate retirement communities, assisted living providers expect to integrate themselves into a surrounding service network, including adult day care, meals on wheels, or other social services. Payment for assisted living today is mostly private out-of-pocket, but insurance and public financing seems likely to grow in the future. Already, 800,000 people are living in 33,000 such facilities around the United States, and it a fast-growing industry. Still, some questions about assisted living remain unanswered: What happens when residents begin to get sick or seriously impaired? In contrast to skilled nursing facilities, state regulation of assisted living is not consistent (Mollica, 2000).

The federal government subsidizes rental housing through the **Section 202** and **Section 8 housing programs** for low-income elderly (Lawton, 1980). But housing programs have often looked only at “bricks and mortar” and failed to take into account the social support needs of older people, which tend to increase with advancing age. Those needs are better taken into account through **congregate housing**: a residential facility providing nutrition, housekeeping, and supportive services for the marginally independent elderly (Chellis et al., 1982). Along the same lines, there has been interest in **shared housing**, an alternative housing arrangement involving either group residence with shared common areas or a homeowner who rents out unused rooms (McConnell and Usher, 1980; Streib, Folts, and Hilker, 1984). These options, including subsidized housing, have mostly been targeted at low-income elderly.

On the other hand, for those who can afford it, middle-class and more affluent groups will want to consider leisure-oriented retirement communities, which are different from continuing care retirement communities and other supportive living arrangements because they lack a formalized network of social support services. Residents are mostly “on their own” and are expected to live quite independently. Leisure-oriented communities have a prominent focus on recreational activities: by both image and reality, they cater to a healthy, young-old population who aim at enjoying the positive lifestyle offered by such communities.

A question for the future is whether these leisure communities can maintain their recreational identity as the population begins “aging in” and a demand for increasingly intensive support services develops (Folts and Streib, 1994). Still another question, discussed in later chapters of this book, is whether it is socially desirable for housing for the elderly to be segregated from younger generations.
All of these options are important, but they probably won’t help George and Martha Walton, who just want to remain in their own home. Much of the effort at improved housing for the aging has been planned housing initiated either by government or by the private marketplace. But the overwhelming majority of older Americans live in unplanned housing, typically in the same home and neighborhood they had lived in before, just like George and Martha.

Chronic Care in Old Age

An explosion in demand for long-term care is found in all advanced industrialized countries as a larger and larger proportion of the population survives into old age (Feder, Komisar, and Niefeld, 2000). Compared with the general population, older people on average show twice as many days in which activities are restricted because of chronic conditions. The most important of these conditions are arthritis, rheumatism, and heart conditions. But there are sharp differences in the impact of such conditions among the population over age 65. Apart from people in nursing homes, the young-old group (age 65 to 74) have only a very small proportion—5.7%—who say they need help with everyday tasks such as household chores, dressing, or going shopping. By contrast, among the oldest-old (over age 85), the percentage of those needing help jumps to 40%.

Long-term care is fundamentally different than acute health care. Acute care is appropriate for conditions that result from a single cause that can be treated by medical intervention. By contrast, the chronic conditions requiring long-term care last a long time and may have varied causes. Examples of such disorders are Alzheimer’s disease or other dementias and stroke leading to permanent disability. The result is an inability to perform activities of daily living (Katz et al., 1963).

What does this mean in concrete terms? Consider the case of George Walton, who has reached this point. A series of small strokes have affected him profoundly. His condition has deteriorated to the point where he needs help getting to the bathroom and even feeding himself. Martha has done the best she can, but their children, Carol and Robert, have now convinced them that the only alternative is for George to go into the local Middletown nursing home, where he can get the round-the-clock care he needs. George and Martha are afraid to do it; they don’t like the idea at all.

Nursing home can refer to any residential facility giving some degree of nursing care (Johnson and Grant, 1986). In the United States, about 80% of these facilities are proprietary, that is, operated as commercial, for-profit organizations. Most of the rest are voluntary or nonprofit, with a few run by municipal governments. Among these facilities, it is useful to identify the skilled nursing facility, which is an institution offering medical care, such as a hospital, as well as everyday personal care services to elderly or disabled people. An intermediate care facility, on the other hand, gives health-related care to patients needing a lower level of support. An extended care facility
offers short-term convalescent help to patients coming from hospitals for an extended period of time.

In light of George Walton’s deterioration, he will probably enter a skilled nursing facility. As shown in Exhibit 7, 1.7 million older Americans live in nursing homes, more than all those in hospitals at any one time but still less than 5% of the elderly population. The growth of today’s nursing home population is partly a tribute to medical technology and the success of the longevity revolution. But it may also reflect the fact that American society has failed to provide accessible alternatives to living in a nursing home, namely, long-term care based in the home or community. A sizable number of people in nursing homes don’t need to be there and could probably live in community settings, if appropriate services were available. Estimates of the proportion of the nursing home population in this situation range from 10% to as high as 40%.

Why are George and Martha so fearful about entering a nursing home? Are they right to be afraid? The nursing home has been called a total institution, a term used to describe organizations such as prisons, mental hospitals, or boarding schools, that is, facilities that treat people like “inmates” rather than as individuals (Goffman, 1961). In a nursing home, the daily regimen is carefully organized and scheduled, so residents may lose any sense of control over their environment and easily become depressed.

A lot of criticism of nursing homes finds support in careful observational studies of life in these facilities (Gubrium, 1975), and there have been devas-
tating journalistic stories that expose poor conditions in some institutions. Responsible studies have shown how the poor quality of nursing homes arose out of repeated failures in public policy to guarantee good quality long-term care (Vladeck, 1980). In light of these facts, it is understandable that so many older people today fear institutionalization.

On the other hand, it is important to remember that, just like schools or hospitals, the quality of nursing homes varies widely. The stereotyped view that “all nursing homes are bad” is mistaken and does a disservice to elderly people who actually need skilled nursing care, not to mention to the untold numbers of devoted nursing home employees. Government monitoring and regulation have meant that nursing homes today are much better than in the past, and improvements continue (Kane and Kane, 1987). Moreover, there is a common misconception that, once someone is admitted to a nursing home, residence there is inevitably a life sentence. In fact, 32% of those in nursing homes stay less than a month; many return home.

How likely is it for older people to anticipate entering a nursing home? Among all people over 65, only about 5% (1.6 million people) are in nursing homes at any given time. In other words, it is a mistake to imagine that most or even many older people are in nursing homes. But this low 5% figure may underestimate the importance of nursing homes in the lives of the very old. It turns out that the percentage of those who will spend some time in a nursing home before they die is much larger: up to 40% of people aged 65. The lower 5% figure that comes from citing the percentage of people in a nursing home only at a single point in time is called the five percent fallacy (Kastenbaum and Candy, 1973). Note that this difference between these two figures—5% in a nursing home at a single point in time versus 40% over the course of a lifetime—shows the dramatic difference in how statistics can be presented. These two figures correspond to a cross-sectional versus a longitudinal view of nursing home residence.

The need for chronic care varies significantly among subgroups of the elderly. For those between the ages of 65 and 74, the chance of entering a nursing home is small—only 1 in 100. But for those over age 85, the chance goes up to nearly 1 in 5. Specific risk factors that increase the chances for nursing home placement include mental impairment, chronic disability, advanced age, and spending time in a hospital or other health facility.

Functional Assessment

A key step in determining what kind of help people need is professional long-term care assessment. This determination often serves a “gatekeeping” role in deciding what services will be provided. A multidimensional functional assessment takes place when a geriatric professional, such as a doctor or nurse, conducts a full examination of an elderly person’s physical, mental, and social condition. This test is more than a physical examination because it covers activities of daily living as well as physical and mental health. Among the most important of these activities are feeding, toileting, transferring out
of a bed or chair, dressing, and bathing (Katz and Akpom, 1976). A comprehensive functional assessment also looks at social and economic resources as well as elements such as the physical environment and even strain on caregivers. All these elements play a part in determining the kind of service an elderly person may need.

Does a failing score on an assessment test mean that it’s time to enter a nursing home? Not necessarily: The key to interpreting an assessment lies in the functional emphasis, that is, asking how an impairment actually affects performance of daily tasks such as shopping, doing housework, handling personal finances, or preparing meals. A comprehensive approach to functional assessment is important because someone with, for instance, mild memory impairment or limited physical mobility may be able to live quite satisfactorily alone in an apartment as long as the environment remains safe and a neighbor or relative comes by regularly to help out. For the same reason, a physical assessment looks not only at biological organ systems, but at medications being taken and at the impact of sensory impairment on activities of everyday life.

Gerontologists have developed specialized instruments or questionnaires designed to carry out functional assessments (Kane and Kane, 1981; Gresham and Labi, 1984). A classic example is the Older American Resources and Services, known by its initials OARS, one of several widely used assessment instruments in the United States today (Duke University, 1978). The OARS questionnaire gathers information on topics such as mental status, self-assessed well-being, social contact, and help from family. A second part of the instrument looks at the use of services ranging from physical therapy and meal preparation to employment training or transportation. By carefully assessing activities of daily living in this way, professionals can identify the exact type of help a client needs, for example, a walker device for people at risk of falling, a homemaker–home health aide for someone who can’t prepare meals, and other kinds of help that might enable people to remain safely in their own homes.

The Continuum of Care

A 65-year-old today can expect to live, on average, for 12 more years. During those years, it is likely that health status and service needs for any individual will change, so provision for long-term care will have to reflect changes over time. Why shouldn’t long-term care services take into account those changes? The idea of a continuum of care is based on the goal of offering a range of options responsive to changing individual needs, whether from less intense to more intense, whether at home or in an institution (Brickner et al., 1987).

The ideal of a continuum of care expresses the aim of keeping elderly people as long as possible out of nursing homes—the most expensive and service-intensive setting. The aim instead is to maintain people in the home, in independent living, or in the least restrictive alternative. If we were to take
### Exhibit 8. Support Systems Across the Continuum of Care

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Senior centers and congregate housing</strong></td>
<td>Senior citizens centers offer social and recreational opportunities. Lunches provided for elderly at neighborhood sites, such as senior centers and churches.</td>
</tr>
<tr>
<td><strong>Telephone reassurance</strong></td>
<td>Usually performed by peer volunteers. Daily phone calls, typically shortly after wake-up time, to provide support and monitor status. If telephone is not answered, someone goes to the home to check on the client.</td>
</tr>
<tr>
<td><strong>Friendly visitor</strong></td>
<td>Volunteer visits, talks with or reads to a frail homebound elder.</td>
</tr>
<tr>
<td><strong>Chore service or handyman</strong></td>
<td>Visiting person performs outdoor tasks, such as lawn care or snow removal, for the elder; also may make small repairs and perform minor maintenance.</td>
</tr>
<tr>
<td><strong>Homemaker</strong></td>
<td>Visiting person performs light housekeeping (cleaning, washing dishes, vacuuming, laundry, meal preparation, etc.) and food shopping. Services are performed in the home, but do not include services that involve touching the client.</td>
</tr>
<tr>
<td><strong>Meals-on-wheels</strong></td>
<td>Home delivery of meals supported under the Older Americans Act.</td>
</tr>
<tr>
<td><strong>Personal care</strong></td>
<td>Visiting person performs trained but not professional work for the elder, such as bathing, dressing, assistance with grooming. Services include touching the client but not health care services.</td>
</tr>
<tr>
<td><strong>Home health care</strong></td>
<td>Performed by a trained professional, such as a registered nurse or licensed practical nurse. Administration of medications, measurement of blood pressure, changing of dressings, and so on.</td>
</tr>
<tr>
<td><strong>Mental health services</strong></td>
<td>Provision of counseling, psychotherapy, and psychological support services. Practitioners may be psychiatrists, psychologists, nurses, and social workers.</td>
</tr>
<tr>
<td><strong>Outpatient medical care</strong></td>
<td>Provision of a range of services, from checkups and diagnostic monitoring through therapeutic procedures short of hospital admission.</td>
</tr>
<tr>
<td><strong>Adult day care</strong></td>
<td>Supervision of dependent elderly by professionals or paraprofessionals, offering respite to family caregivers.</td>
</tr>
<tr>
<td><strong>Board and care</strong></td>
<td>Residential placement. Meals are provided, housekeeping is performed, and medication reminders are available.</td>
</tr>
<tr>
<td><strong>Intermediate care nursing home</strong></td>
<td>Placement in a facility with (less than 24-hour) supervision and nursing care provided.</td>
</tr>
<tr>
<td><strong>Skilled nursing facility</strong></td>
<td>Placement in a nursing home with 24-hour services provided by registered nurses.</td>
</tr>
<tr>
<td><strong>Inpatient hospital care</strong></td>
<td>Admission as an inpatient to an acute care facility.</td>
</tr>
</tbody>
</table>

**SOURCE:** Krain (1995).
seriously the ideal of a continuum of care, it would mean spending more money to enlarge the availability of community-based long-term care services. Such a goal, however, would serve the purpose of promoting maximum independence and personal control and might also help minimize public expense (Koff, 1982; Eustis, Grenberg, and Patten, 1984). The reasons for promoting a continuum of care include both choice and economics, but it is rare to find a full continuum of care in most communities in America. There are many gaps, and the long-term care service system remains fragmented and confusing.

Health care is important, but we should not forget the importance of social care and social contact for people like George and Martha. What happens to Martha when she is left all alone after George has entered the nursing home? Who will watch out for her and her needs? If George and Martha were lucky, Middletown, USA, would have a full range of services to help them out, as a few communities already do. The kinds of formal support services delivered to the home that are shown in Exhibit 8 can play a key role in enabling frail elderly to remain in their homes as long as possible (Quinn et al., 1982).

All these formal support systems provide a degree of companionship, monitoring, and concrete services for frail, isolated elderly. They also can shore up the social network of family, friends, and neighbors, that is, the totality of informal helping relationships that maintain integrity and well-being. Gerontologists have documented the crucial role that these natural support systems play in providing social care and their enormous role in the lives of the elderly (Cantor, 1980).

If George Walton had not needed round-the-clock care, there might have been alternatives for him other than going into a nursing home. For instance, why not provide some nursing home services on a daytime basis while he remains at home? That, in essence, is the strategy of adult day care, which is usually offered five days a week. Patients are transported to a health facility, where they are given needed services as a group during the day and then returned to their homes at the end of the day.

Another alternative is home health care in which home care aides provide health-related tasks such as rehabilitation exercises or toileting and transferring patients who are bed-bound (Ginzberg, Balinsky, and Ostow, 1984; Portnow, 1987). Visiting nurses who can dispense medication and perform skilled nursing functions also play a critical role. Home health services have expanded dramatically in recent years, as an alternative to institutionalization and as a means of ensuring speedier discharge from hospitals.

These forms of community-based long-term care can sometimes be more cost-effective than a residential nursing home because housing costs are not involved. Most important, they offer an opportunity for those who can to remain relatively independent. The experience of other countries, such as Canada and Great Britain, suggests that adult day care, along with other varieties of community-based long-term care, will have to play a larger role in the United States than it has in the past (Kane and Kane, 1985).
Exhibit 9. Projected Nursing Home Expenditures for People Age 65+ by Source of Payment: 1990-2020

Paying for Long-Term Care: An American Dilemma

The costs of long-term care are going up fast (see Exhibit 9). In the past 10 years, the annual growth rate for nursing home care has been more than 12%. Expenditures now stand at more than $40 billion and are still climbing. Few individuals can afford to pay the complete cost of long-term care in a nursing home. Usually, Medicaid pays part of the bill. Future projections of long-term care expenditures suggest that private (out-of-pocket) and Medicaid sources will continue to be the biggest source of payment for nursing homes.

Advocates for home care or other community-based care believe that staying at home costs less than entering a nursing home, just as George and Martha want. But home care is not always cheaper than institutional care. Cost estimates for home care typically fail to include the real value of housing or the value of unpaid family caregiving. Moreover, there is sharp debate about whether we ought to pay family caregivers to do what is normally done by family members for one another.

The experience of Medicaid payment for nursing home care suggests that some frail elderly people may end up being placed in nursing homes because institutional care, not community care, is the only form of long-term care paid for under the American system. When advocates for the elderly propose large increases in long-term care, the question arises of who will pay for the expansion (Rivlin and Wiener, 1988).

Should families provide for their own or should the cost of expanded long-term care be covered by government? Paying for long-term care remains an American dilemma.
Self-Determined Death

Our society so far has not been prepared to explicitly ration health care on the grounds of age. Nor do we seem willing to face up to the public policy problem of paying for long-term care. But at some point, decisions become unavoidable, and therefore we turn to our last option: self-determined death. Modern biomedical technology not only enables larger numbers of people to survive into old age, it has also forced care providers to make explicit decisions about the end of life. The result has been a continuing debate about the so-called right to die, which involves choices from forgoing life-sustaining treatment all the way to assisted suicide (Glick, 1992). In this debate, the elderly occupy a central place.

Today, this debate is taking new forms as the cost of health care rises and the oldest-old population increases in numbers. In the future, termination of treatment decisions may unavoidably become intertwined with cost-containment pressures. Instead of individuals claiming a “right to die,” we may even see health care providers or policymakers suggesting that some people have a “duty to die” to stop “futile” medical treatment that uses up scarce resources.

This prospect is not just hypothetical. A case in point is the story of Helga Wanglie, who at age 86 broke her hip and was admitted to a nursing home. As a result of complications, Mrs. Wanglie ended up on a respirator and suffered brain damage. The hospital staff felt that, due to her medical condition and advanced age, Mrs. Wanglie should not receive further life support. Her family, however, insisted that treatment be maintained, so the case wound up in court, which agreed with the family. In many other cases, providers have taken a different view and insisted on treating patients, while the family asked to end medical treatment.

Another case in which financial considerations became mixed up with termination of treatment was the 1989 case of Grace Plaza of Great Neck, Inc. v. Elbaum (1993). In this instance, Mrs. Jean Elbaum was in a persistent vegetative state (coma) and was being kept alive by tube feeding. Mrs. Elbaum had made it clear that she would not want to be kept alive under such circumstances, but the nursing home refused to honor the family’s wishes. Instead, the facility provided treatment and then sued the family for payment of care provided against their wishes.

Over the past 20 years in the United States, discussion about the right to die has developed along legal and ethical lines focused entirely on individual rights and decisions; it has not focused on resource allocation issues. But both the Elbaum and the Wanglie cases, in different ways, show how end-of-life decisions may now become entangled in considerations about who will pay the bill and whether institutions should expend resources on care that is “medically futile.”

The question of medical futility will involve values and will depend on the different treatments involved. A 1987 study looked at several different kinds of treatment that might be withheld from the elderly and explored the
differences among them (U.S. Office of Technology Assessment, 1987). Antibiotics, respirators, cardiopulmonary resuscitation, and kidney dialysis are all very different forms of medical technology. A patient’s personal decision about one kind of intervention may not hold for another kind. Similarly, a decision may be made in one way at home and differently in a nursing home or in a hospital. The setting could make a significant difference in how health care personnel act and what families can expect. Perhaps the most important new developments in the right-to-die debate will center on the question of whether the American health care system can devise practices and forms of treatment that are both respectful of patients’ wishes and atten
tive to the uncertainties involved in end-of-life decisions.

The question arises of whether it is actually in the best interest of de-
pressed or debilitated patients to have life-sustaining care terminated be-
cause of poor quality of life. The topic is controversial because the patient’s best interest may or may not coincide with the interest of the family or of
health care providers. When subjective well-being declines and patients
want to end their lives, should geriatric health care professionals treat this as
a matter of self-determination or as a case of suicide prevention?

Most people are uncomfortable when economic considerations become
involved with end-of-life decisions. But increasing pressure for cost contain-
ment in health care may make it difficult to keep the two matters separate. In
1990, Congress passed the Patient Self-Determination Act to uphold
patients rights. But analysts quickly noted that the law is expected to de-
crease costs for health care by ending unwanted care. As financial concerns
become intertwined with right-to-die considerations, we may wonder
whether backdoor rationing of health care could make it more difficult for
elderly patients to assert their rights. It is always cheaper to say no to treat-
ment than to say yes.

Debates about costs and self-determination take place against a back-
ground of hopes and fears centered on end-of-life decisions. Our hopes are
symbolized by the wonderful one-horse shay, or carriage, which lasted a
hundred years and a day and then fell apart all at once (see Controversy 8).
Our common hope, in other words, is to live a long life and fall apart all at
once without decay. But our fears are symbolized by the horrifying image of
Gulliver’s Struldbruggs, the same people who today might be wandering in
dementia or hooked up to feeding tubes. For increasing numbers of older
Americans, self-determined death seems a way to resolve this struggle be-
tween hope and fear at the end of life.

**Late-Life Suicide**

Self-determined death can mean many things, ranging from termination of
treatment to active euthanasia or assisted suicide. Those who favor self-
determination for end-of-life decisions generally assume that it is possible to
make a rational decision to end one’s life, for example, to refuse further
treatment and simply permit death to occur. That, at least, is the premise involved in the court decisions that uphold the right to self-determination.

But are these decisions always rational? And if they aren’t, does that fact mean that end-of-life decisions cannot be left to individual choice? The question is a difficult one. It is not possible to consider the arguments about end-of-life decisions for older people without taking into account mental health issues: specifically, depression, which is a primary cause of old-age suicide. Suicide is now one of the leading causes of death among the old. The suicide rate for the general population is 12 per 100,000, whereas the suicide rate for those over age 65 is 17 per 100,000: nearly 50% higher.

How can we understand old-age suicide and its causes? The first great sociological investigator of suicide, Émile Durkheim, distinguished several types of suicide. He described altruistic suicide, or self-sacrifice for the sake of the group or society (Durkheim, 1897/1951). A soldier giving up his life on the battlefield to save comrades would be an example of such self-sacrifice. This pattern could describe the voluntary death of some elderly persons in preindustrial societies facing conditions of economic scarcity. The same pattern might also apply to end-of-life decisions among elderly people today who fear becoming a burden on their families.

Durkheim also described a form he called anomic suicide, derived from his sociological concept of anomie, or a condition in which individuals feel hopeless and cut off from any sense of meaning in life. This condition is relevant to thinking about the position of old age in contemporary society. Today, elderly people commonly experience role loss when they give up previous roles upon retirement, the death of a spouse, or the loss of other social positions. Rosow described old age itself in contemporary society as a roleless role, that is, a status with no clearly defined purpose or rules of behavior (Rosow, 1974; Blau, 1981). A final type of suicide described by Durkheim is egoistic suicide, where an individual may not be closely integrated into wider society—for example, among the oldest-old, who have outlived most close relatives. In such cases, it might seem perfectly rational for people to end their lives.

As a general rule, the rate of suicide tends to go up with age and to hit a peak after age 65 in America as in other advanced industrialized countries. Estimates of suicide remain uncertain because there are 100 suicide attempts for every completed suicide. Among the elderly, however, 80% who threaten suicide actually follow through. Furthermore, among the ill elderly, there is no way to estimate those who end their lives by noncompliance with medical treatment or other forms of self-neglect.

There are pronounced differences in suicide rates among subgroups of the elderly, as Exhibit 10 indicates. Among ethnic groups, Blacks have a suicide rate only about 60% of the average for Whites, and unlike Whites, the rate does not increase in old age. For all age groups, men are much more likely to commit suicide than women, and the difference between the sexes widens with advancing age. For example, according to 1980 data, there were 66 completed suicides per 100,000 White males above the age of
85 in comparison to a rate of only 5 for White females. In fact, the highest rate of suicide in the United States occurs among older White men.

Characteristic conditions preceding late-life suicides include loneliness, social isolation, diminished economic resources, the presence of illness or disability, and above all, depression (McIntosh et al., 1994). Depression is an important public health problem for the elderly and must therefore be taken seriously by clinicians and others who work with older people. Early identification and treatment for depression remain a key measure for suicide prevention.

In considering depression and suicide in old age, it is important to maintain a balanced perspective. Most older people in fact enjoy good mental health and a positive attitude. A 1987 Louis Harris survey found that 72% of those over age 65 reported feeling satisfied with their lives. Even when exposed to stress, older people often show a remarkable capacity for adaptation, for instance, in coping positively with bereavement or chronic illness in later life. Adaptation reflects the capacity of the individual to cope with environmental demands and maintain subjective well-being. But when stress exceeds the capacity for coping, psychotherapy and other mental health interventions may play an important role in maintaining the capacity of those in the last stage of life to make rational decisions about the end of life (Butler and Lewis, 1982).

End-of-life choices must also take into consideration what has been learned about the process of death and dying itself. Glaser and Strauss (1965) described the dying trajectory by which a person passes from good health to progressively worse health to the point of death. In her popular book *On Death and Dying*, Elisabeth Kubler-Ross (1969) developed a stage

![Exhibit 10. Suicide Rates for People Age 65+](image-url)
theory of dying in which the terminally ill individual moves through stages from denial to acceptance. With respect to end-of-life decisions, it seems clear that elderly people who are experiencing a stage of denial or a condition of depression might make different kinds of “rational” decisions about terminating treatment. It would therefore be unwise simply to accept a patient’s “spoken choice” at face value. On the other side, clinicians might well have a less positive view of initiating aggressive medical treatment if they were aware that an elderly patient was in a period of terminal decline and facing imminent death.

Conclusion

The overall picture of aging and health care today is a mixed one. On the one hand, some optimists hope for a “compression of morbidity” in which disease is postponed and good health continues until late in life. On the other hand, larger numbers of elderly with physical or mental frailties are now surviving into old age. The need to make choices about treatment and life prolongation is becoming unavoidable.

The root cause of the problem is that contemporary geriatric medicine is largely symptomatic: Health care responds only after people are sick. Responding to symptoms this way is expensive and frustrating. It proceeds the same way that treatment of polio might have gone if specialists had worked to create ever more complex and refined versions of the iron lung instead of finding a vaccine to prevent the disease in the first place. In the same way, the “iron lung” approach to geriatric care is bound to be expensive and frustrating.

The American health care system, including geriatric care, spends a great deal of money on acute care conditions such as heart disease and cataracts. In that respect, Medicare simply reflects the same priorities that are favored in health care for the broader population. An expensive procedure, such as a coronary bypass operation, is fully covered by Medicare, but a physical exam to detect hypertension or recommend preventive diet change is not. Such unbalanced emphasis on technology is in some ways perplexing. Contrary to popular belief, it was not medical technology, but largely social interventions—such as sanitation, improved diet, and public health measures—that accounted for the big drop in mortality in infancy and before middle age that occurred at the beginning of the 20th century.

As a universal public insurance program for physical illness, Medicare commands strong public support. By contrast, it has not proved possible to mobilize a consensus behind a universal public program for long-term care, for mental health treatment, or for such activities as early detection that might be beneficial in the long run. Medicare will not pay for regular physical examinations or for dental care. Preventive care and health promotion also remain low priorities.

Changing these priorities will be difficult, and solutions to the problems of health care and aging remain elusive. Research on the basic biology of
aging will continue, and no one can exclude a dramatic breakthrough that might reshape the conditions of health and sickness in later life. As costs continue to rise, there will be pressure for tough decisions, perhaps even for rationing (Mechanic, 1985). It is unlikely that overt age-based rationing will be adopted in this country, but some form of “backdoor rationing” could come as a result of cost-containment efforts. It seems likely that efforts to liberalize end-of-life decisions will also continue, but we have no way of knowing how many older people or families will decide deliberately to terminate life or where such decisions may lead us as a society. Debates about aging, health care, and society are sure to continue throughout the 21st century.