

Chronic Care in America: A 21st Century Challenge

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Prepared by
The Institute for Health
& Aging, University of
California, San Francisco

for The
Robert Wood Johnson
Foundation, Princeton,
New Jersey

November 1996

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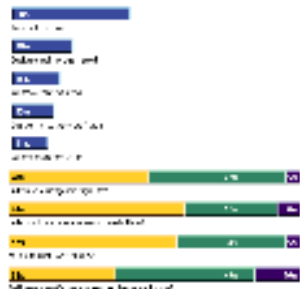
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» The Chronic Care Perspective

Click on small chart to see in full size.



The Number of Americans with Chronic Conditions Are Increasing. . . As Are the Costs of Their Care



People with Chronic Conditions Often Cannot Get the Care They Need

fact sheet

The Chronic Care Perspective

■ What Is the Chronic Care Perspective?

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fact sheet

What Is the Chronic Care Perspective?

It is a way of viewing problems and solutions in the American health care system based on an understanding that:

- Chronic conditions are the leading cause of illness, disability, and death in the United States today.
- Almost 100 million people in the U.S. have one or more chronic conditions
- Over 40 million people are limited in their daily activities by chronic conditions -- and the numbers of people so affected are expected to increase dramatically in the coming decades.
- People are living longer with chronic conditions than ever before.
- Chronic conditions cost the economy \$470 billion (in 1990 dollars) in direct medical costs in 1995, and more than \$230 billion in lost productivity.

INTRODUCTION

The Chronic Care Perspective

Chronic health conditions surround us. We may not recognize the similarities among different conditions that make each "chronic," yet each of us knows someone whose life has been shaped by a chronic condition: an overweight friend who has developed hypertension and may be at risk of heart disease; an aged relative with Alzheimer's disease or confined to a wheelchair after suffering a stroke; a family with a child who is developmentally or physically challenged. People with chronic conditions are not all wasting away, or confined to nursing homes. They are among us. They are us.

In 1995, an estimated 99 million people in the United States had chronic conditions characterized by persistent and recurring health consequences lasting for periods of years. Of these, 41 million were limited in their daily activities by their chronic conditions. Twelve million of those were unable to go to school, to work, or to live independently. And, for most persons with a disabling chronic condition, there are family members and others whose lives are influenced by the additional responsibilities of caregiving.

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fact sheet

**What Is
the Chronic Care
Perspective?**

- The financial incentives inherent in the traditional fee-for-service health care system do not necessarily encourage appropriate types of care for people with chronic conditions.
- There is no effective system to care for those with chronic conditions in the United States; as a result, much of the care that is available is fragmented, inappropriate, and difficult to obtain.
- In comparison with acute conditions, chronic conditions call for a different kind of care: an integrated network of professional expertise, and a far greater reliance on nonprofessional and informal caregiving -- that is, on family, friends, and community-level organizations.
- Managed care has the potential to provide a range of integrated services required by people with chronic conditions, although the managed care industry is just beginning to realize and respond to chronic care needs.

- Chronic conditions do not always get worse; the health status of a person with a chronic condition can improve, deteriorate, or shift in either direction.
- The goal of chronic care is not to cure; rather, it should help individuals with chronic conditions maintain independence and a high level of functioning.

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The Chronic Care Perspective

As America ages, the population of people with chronic conditions will increase dramatically. By 2030, nearly 150 million Americans are projected to have a chronic condition; 42 million of those will be limited in their ability to go to school, to work, or to live independently.



*People with
chronic conditions
are not all wasting
away, or confined to
nursing homes.
They are among us.
They are us.*

The question of how to provide adequately for people with chronic conditions has significant implications for national health care expenditures. The U.S. is currently spending a staggering \$470 billion (in 1990 dollars) annually on the direct costs of medical services for persons with chronic conditions, including nursing homes and other institutional care. Traditionally, the public debate over containing the rate of growth in national health care expenditures is framed in terms of medical services. But treatment and care for people with chronic conditions require a host of non-medical services, from installing bathtub railings to finding supportive housing. The best ways to provide these services often are not by medical specialists or in medical institutions. In fact, the services that keep people with chronic conditions independent for as long as possible are frequently those that emphasize assistance and caring, not curing.

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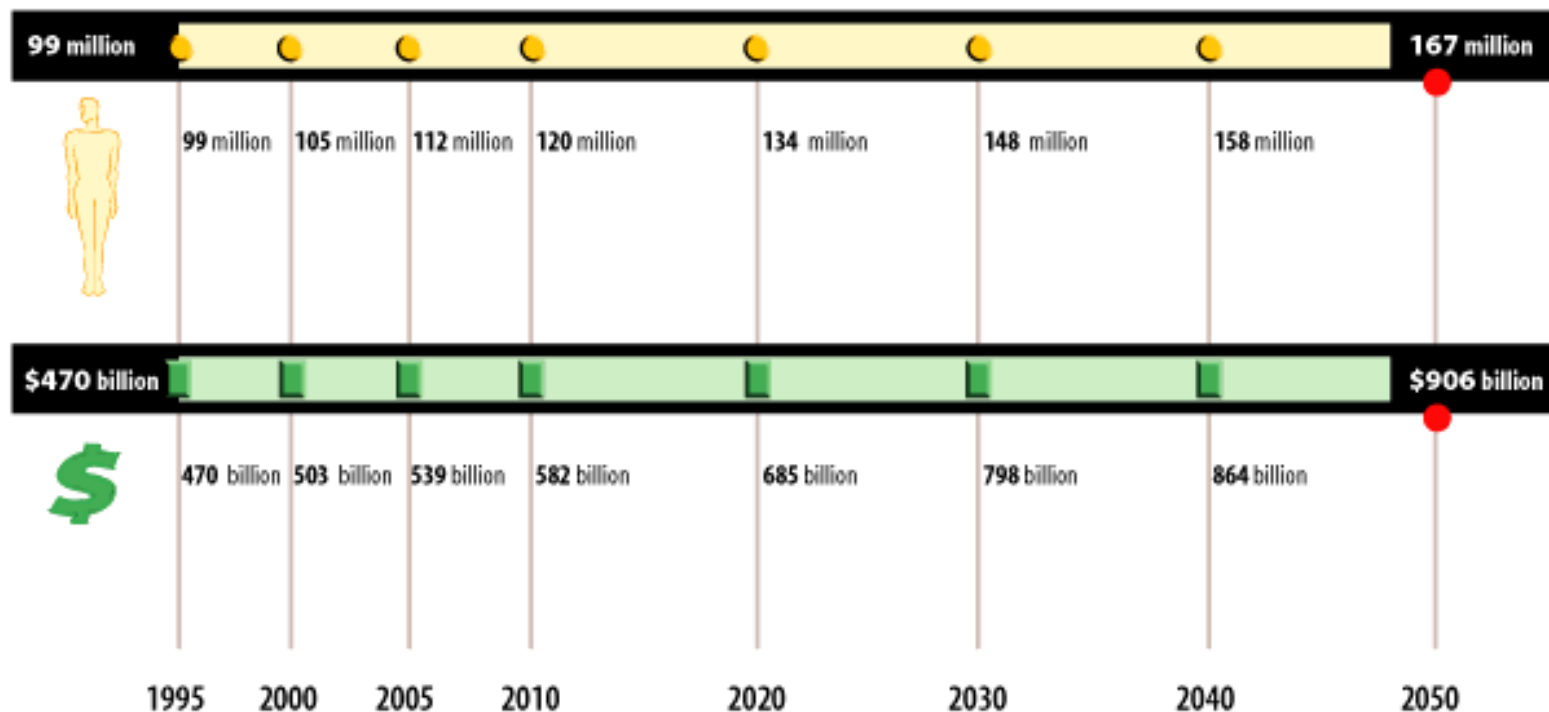
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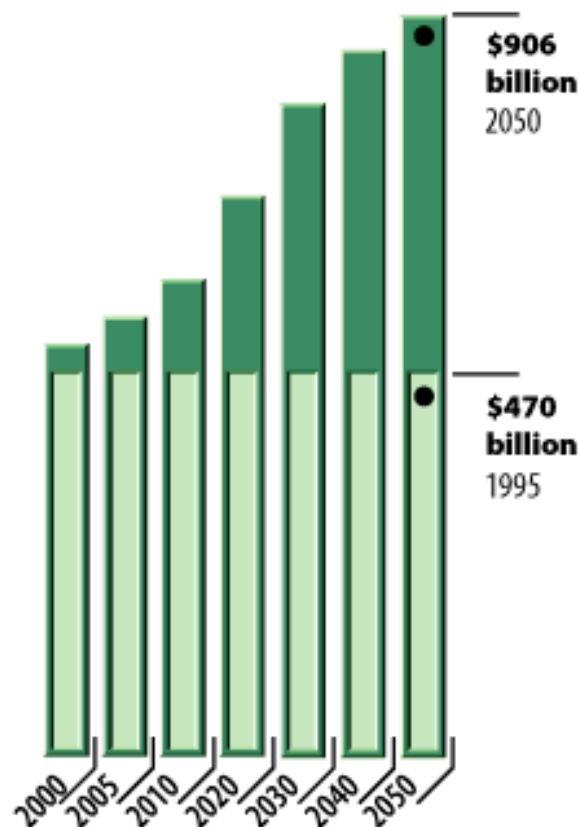
» [The Chronic Care Perspective](#)

The Numbers of Americans with Chronic Conditions Are Increasing. . . As Are the Costs of Their Care

Estimated Number of Persons with Chronic Conditions and Direct Medical Costs for Persons with Chronic Conditions, Selected Years, 1995-2050



Direct medical costs for persons with chronic conditions will nearly double by the year 2050



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NOTES:

Chronic conditions is a general term that includes chronic illnesses and impairments. Chronic illness: The presence of long-term disease or symptoms. (A common definition of "long-term" in population surveys is a duration of three or more months.)


Impairment: A physiological, psychological, or anatomical abnormality of bodily structure or function; includes all losses or abnormalities, not just those attributable to active pathology.

This estimate is of persons in the United States with chronic conditions characterized by persistent and recurring health consequences lasting for periods of years.

Costs are in 1990 dollars, estimated by applying the rates of chronic conditions and the per capita costs in 1990 dollars to the estimated projected population with chronic conditions by gender and age.

SOURCE:

Hoffman, Catherine, and Rice, Dorothy P. Estimates based on the 1987 National Medical Expenditure Survey. University of California, San Francisco -- Institute for Health & Aging, 1995.



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[The Numbers of Americans with Chronic Conditions Are Increasing...As Are the Costs of Their Care - CMYK](#) Size:278K

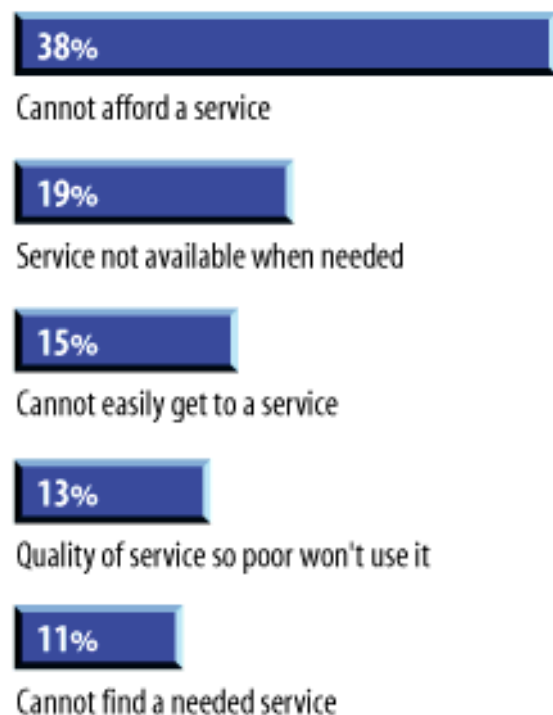
[The Numbers of Americans with Chronic Conditions Are Increasing...As Are the Costs of Their Care - Grayscale](#) Size:94K

» [The Chronic Care Perspective](#)

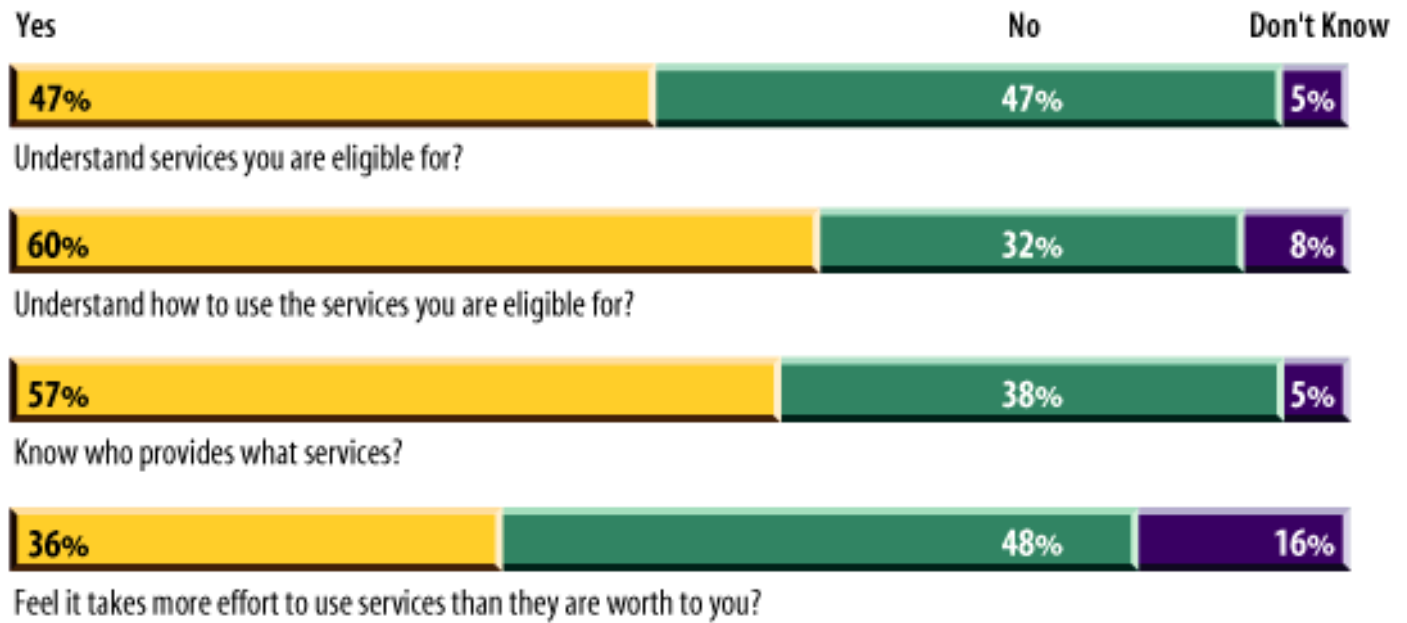
People with Chronic Conditions Often Cannot Get the Care They Need

People with Chronic Conditions Often Cannot Get the Care They Need

Problems Encountered by People with Chronic Conditions



Consumer Attitudes Toward Chronic Care Services



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Among people who have chronic conditions, at least one in three does not understand what services they are eligible for, how to use them, or who provides them. A combination of financial issues, eligibility requirements, and specific factors of individual conditions cause a significant number of chronically-ill people to feel frustrated with the system designed to help them.


NOTES:

Percentages do not total precisely due to rounding.

SOURCE:

Kabcenell, Andrea I., et al. *People with Disabling Chronic Conditions Report on Their Service System*. Unpublished data from the Poll of People with Chronic Illness by The Gallup Organization, 1992.

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[People with Chronic Conditions Often Cannot Get the Care They Need - CMYK](#) Size:374K

[People with Chronic Conditions Often Cannot Get the Care They Need - Grayscale](#) Size: 120K

The Chronic Care Perspective


Chronic Care in America: A 21st Century Challenge asks readers to consider a new perspective on health care in America: the chronic care perspective. To do so will require adjusting the lens through which most policymakers, providers, and people with chronic conditions perceive the current health care and supportive services system.

Chronic care is an unfamiliar term because the health care system in the United States is geared first and foremost to acute medical care -- more specifically, to curing disease. By definition, chronic conditions cannot be cured. And many of the services essential to caring for the chronically ill or disabled person -- including supportive care, rehabilitation, and prevention of secondary conditions such as bedsores or depression -- may be non-medical in nature, provided at home, and require health care workers other than physicians and little or low technology. The focus on acute medical care has obscured some of the simpler, but nevertheless urgent needs of the millions of people with disabling chronic conditions for essential services such as transportation, homemaking assistance, and home health care.

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The Chronic Care Perspective



*The U.S. health
care system is geared
to curing disease.
Chronic conditions
cannot be cured.*

From the chronic care perspective, key elements of our current "system" of care -- its priorities, allocation of resources, training of professionals, and the incentives inherent in its financing -- appear out of kilter and sometimes simply dysfunctional. Technological advances have enabled increasing numbers of Americans to live longer and to survive life-threatening occurrences such as premature birth, heart disease, and traumatic brain injury. However, these technological improvements have not been matched by improvements in the overall organization of our health care and services system. The U.S. does not have a coherent approach to caring for people with disabling chronic conditions. As a result, increasing numbers of people live with deteriorated health; others find that the services they need do exist, but are not accessible. Individuals suffer, and society at large pays a toll in lost productivity and avoidable health care expenditures.

Despite this widespread impact and vast expenditure, there is a profound mismatch between the chronic care services we need and the way financial and other health care resources are allocated. Unless the system changes, the needs of America's aging and increasingly disabled population cannot be met by the available resources.

Health care experts, policymakers, practitioners, and citizens must begin to develop a system of interrelated health care and social services -- a continuum of care -- to better meet the challenge of caring for a growing U.S. population with disabling chronic conditions.

» [Continue](#)

PART I Chronic Conditions: The Major Cause of Illness, Disability, and Death

Chronic conditions are the major cause of illness, disability, and death in the United States today. In fact, in spite of broad public awareness of specific life-threatening diseases such as cancer and heart disease, most people are not aware that, collectively, chronic conditions account for three out of every four deaths in the U.S.

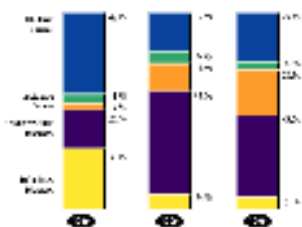
The prevalence of chronic conditions in the late 20th century is due to several factors, notably the changing nature of illness and increasing longevity. Americans are no longer dying from the same diseases as they did in previous generations. Infectious diseases were common causes of death until this century. With the important exceptions of AIDS, tuberculosis, and pneumonia, contemporary Americans rarely die from infectious diseases.

Advancing medical knowledge -- in screening, treatment, surgical interventions, and pharmaceuticals, among other areas -- has prolonged the lives of many people with disabling chronic conditions, and increased the number of survivors of traumatic injury.

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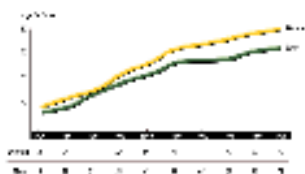
» Chronic Conditions: The Major Cause of Illness, Disability, and Death

Click on small chart to see in full size.



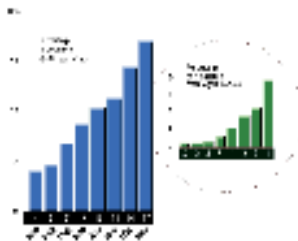
The Changing Nature of Illness and Death Contributes to Increased Numbers of Chronic Health Conditions

Given the limits of medical and public health knowledge at the beginning of this century, Americans frequently died at young ages from infectious and parasitic diseases. As sanitation, nutrition, and living conditions improved and medical technology advanced, deaths from infectious diseases declined steadily and children and young adults survived longer. While deaths from infectious diseases have decreased, deaths from chronic conditions have increased. The people who die from a chronic condition, especially cancer and cardiovascular diseases, often have survived with that condition for a long period of time following diagnosis.



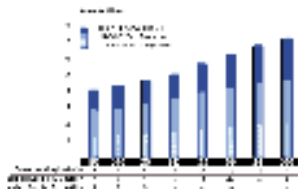
Americans Are Living Longer

A growing number of people are living into their 80s, 90s, even past 100 years of age. While gains in life expectancy in the first half of this century came largely from decreased mortality rates for infectious diseases among children and young adults, the additional gains in life expectancy since then have resulted from lower mortality rates of chronic diseases in older adults. In other words, older Americans with chronic conditions are living longer than ever before. For some time, increases in life expectancy at age 65 have outpaced gains in life expectancy at birth. Between 1950 and 1990, life expectancy at age 65 rose more than twice as rapidly as the increase in life expectancy at birth.



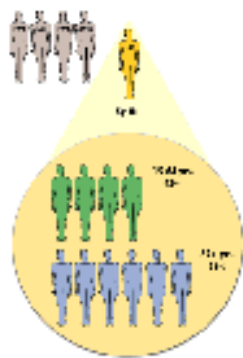
Elderly Population Is Increasing. . . And the Average Age Will Be Older

Growth in the elderly population in the United States has outpaced the non-elderly since 1900, and is projected to continue through the middle of the next century. Most remarkable is the growth in the numbers of people age 85 years and older. By 2000, 13 percent of the population will be 65 or older and one in eight elderly will be over 84 years old. By 2040, 21 percent — one in every five Americans — will be 65 years or older, and there will be almost four times as many very old people, over 85, as there are today.



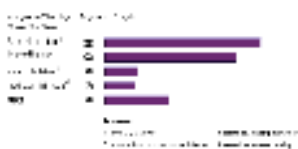
Greater Numbers of People Will Be Limited by Chronic Conditions

The number of people who will be unable to go to school, to work, or to live independently due to a chronic condition is projected to reach 20 million by the year 2050.



One in Five Disabled Persons Needs Help with Basic Daily Activities

One in five of the nearly 50 million disabled persons in America needs help with basic daily activities (such as bathing, walking, taking medications, preparing meals). A large percentage (42 percent) of these people are under age 65.



Chronic Conditions Include a Broad Spectrum of Disabilities

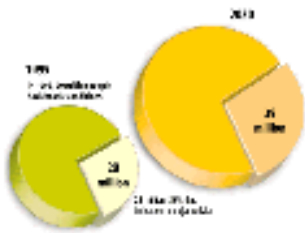


Five Most Disabling Chronic Conditions

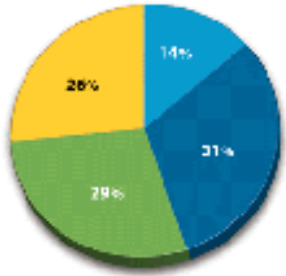
» Who is At Risk for Chronic Conditions?

The Number of Americans with Chronic Conditions Is Expected to Rise

In the span of 25 years, the number of people with chronic conditions will increase by approximately 35 million.



Only 1 in 4 Living in the Community with a Chronic Condition Is Elderly



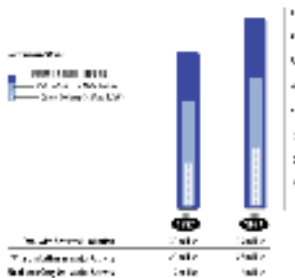
Selected Chronic Conditions by Age Group

Some chronic conditions, such as arthritis, affect the elderly predominantly. Others, such as asthma, affect persons of all ages.

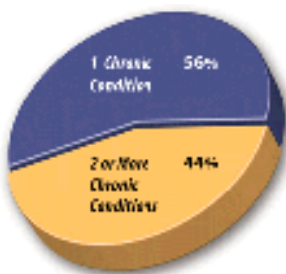


Growing Numbers Report Activity Limitations Due to Chronic Conditions

Between 1987 and 1993, there was an increase of over 20 percent in the number of Americans identified as having chronic conditions that limit their activity, and an increase of at least 33 percent in those identified as being unable to carry on their major activity because of a chronic condition.



Nearly 40 Million Americans Have More Than One Chronic Condition

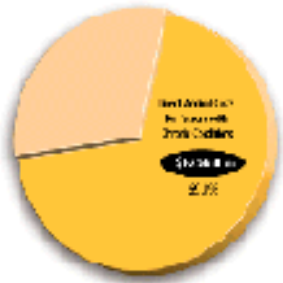


Majority of People with More Than One Chronic Condition Are Middle-Aged or Older

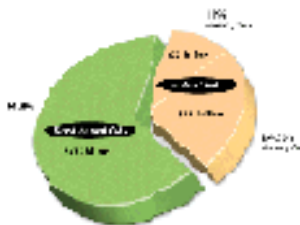


» How Much Do Chronic Conditions Cost the U.S.?

Direct Medical Costs for Persons with Chronic Conditions Represent Nearly 70 percent of National Expenditures on Personal Health Care



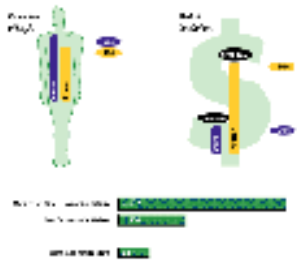
Adding Indirect Costs Brings the Costs of Chronic Conditions to \$659 Billion



Almost Two-Thirds of Chronic Health Care Dollars Are Spent on Hospital Care and Physician Services

Almost 65 percent of the direct medical costs for persons with chronic conditions are for hospital care and physician services. Yet in spite of these expenditures, most hospital and physician care remains episodic. That is, services are concentrated on periods when the person with a chronic condition needs acute care, rather than in non-acute phases when care that is preventive or rehabilitative in nature is beneficial. Little investment is made in prevention — either efforts to prevent the condition from occurring initially, or to prevent disabilities caused by an existing condition.





Medical Care Costs More for People with Chronic Conditions

Medical care costs are disproportionately high for persons with chronic conditions. In 1987, while 46 percent of persons with health problems reported one or more chronic conditions, they accounted for 76 percent of the direct medical care costs.

Having one or more chronic conditions increases the costs of care. In 1987, annual medical costs per person were over twice as high for persons with one chronic condition compared to persons with acute conditions only (\$1,829 vs. \$817 in 1987 dollars). Having more than one chronic condition dramatically raises the total costs of care to \$4,672 per year — nearly sixfold the per capita costs of persons with acute conditions only

» Chronic Conditions: The Major Cause of Illness, Disability, and Death

fact sheet

What Are Chronic Conditions?

Chronic conditions is a general term that includes chronic illnesses and impairments.

Chronic illness: The presence of long-term disease or symptoms. (A common definition of "long-term" in population surveys is a duration of three or more months.)

EXAMPLES: AIDS; arthritis; cancer; heart disease; diabetes; Alzheimer's disease; emphysema; cystic fibrosis

Impairment: A physiological, psychological, or anatomical abnormality of bodily structure or function; includes all losses or abnormalities, not just those attributable to active pathology.

EXAMPLES: blindness; hearing impairment; mental retardation; paralysis

- *Developmental disabilities:* A broad range of conditions evident at birth or in early childhood that can result in lifelong deficits in mental, psychosocial, and physical functioning.

EXAMPLES: cerebral palsy; seizure disorders; autism; structural birth defects, such as spina bifida

- *Impairments caused by injuries:* Severe injury can cause extensive physical and neurological damage, is extremely costly to treat in both acute and chronic phases, and can have a devastating

impact on an individual's social and psychological status.

EXAMPLES: head injuries; spinal cord injuries

Secondary conditions: Conditions related to the main illness or impairment that further diminish the person's quality of life, threaten his or her health, or increase vulnerability to further disability.

EXAMPLES: depression; pressure sores; circulatory problems

» [Continue](#) for part 2 of this fact sheet

Chronic Conditions: The Major Cause of Illness, Disability, and Death

Similarly, improvements in diet, sanitation, and medical care have resulted in significantly extended life expectancy for Americans. The fastest growing group of elderly people in the U.S. is those over 85 years of age -- the population that is most vulnerable to chronic conditions. In addition, the "baby boom" generation, now entering its fifties, will soon swell the over-65 population to record levels, with a corresponding increase in the prevalence of chronic conditions.

Does increased longevity mean less disability?

Often it is said that Americans are living longer – and healthier – lives. Does this mean that chronic disability might become less of a problem in the future? Unfortunately not.

Chronic conditions increase in both number and severity as people age. The high prevalence of chronic conditions among the elderly, combined with a rapidly growing population of elderly people, is expected to dramatically increase the absolute numbers of people with chronic care needs in the 21st century. Even if disability rates decline or disability becomes less severe, this will not completely compensate for the continued growth in absolute numbers of the elderly. In an absolute sense, greater numbers of the elderly are likely to require health services for chronic conditions.

fact sheets

Chronic Conditions: The Major Cause of Illness, Disability, and Death

- What Are Chronic Conditions?
- How Are Chronic Conditions That Cause Limitation Classified?

Who is at Risk for Chronic Conditions?

- Estimated Prevalence of Chronic Conditions, 1995

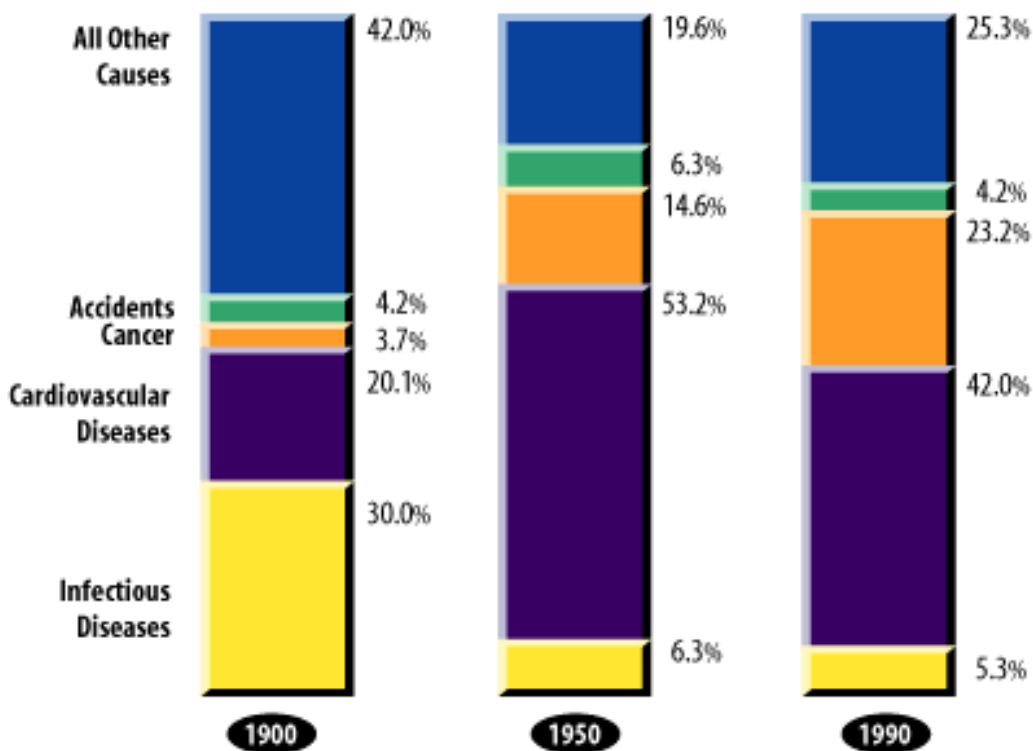
How Much Do Chronic Conditions Cost the U.S.?

- How Much Do Chronic Conditions Cost the U.S.?

» Chronic Conditions: The Major Cause of Illness, Disability, and Death

The Changing Nature of Illness and Death Contributes to Increased Numbers of Chronic Health Conditions

Changes in the Leading Causes of Death, 1900-1950-1990



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Given the limits of medical and public health knowledge at the beginning of this century, Americans frequently died at young ages from infectious and parasitic diseases. As sanitation, nutrition, and living conditions improved and medical technology advanced, deaths from infectious diseases declined steadily and children and young adults survived longer. While deaths from infectious diseases have decreased, deaths from chronic conditions have increased. The people who die from a chronic condition, especially cancer and cardiovascular diseases, often have survived with that condition for a long period of time following diagnosis

SOURCES:

1) U.S. Bureau of the Census. *Statistical Abstract of the United States: 1993* (113th edition). Washington, D.C., 1993 (1980-1990)

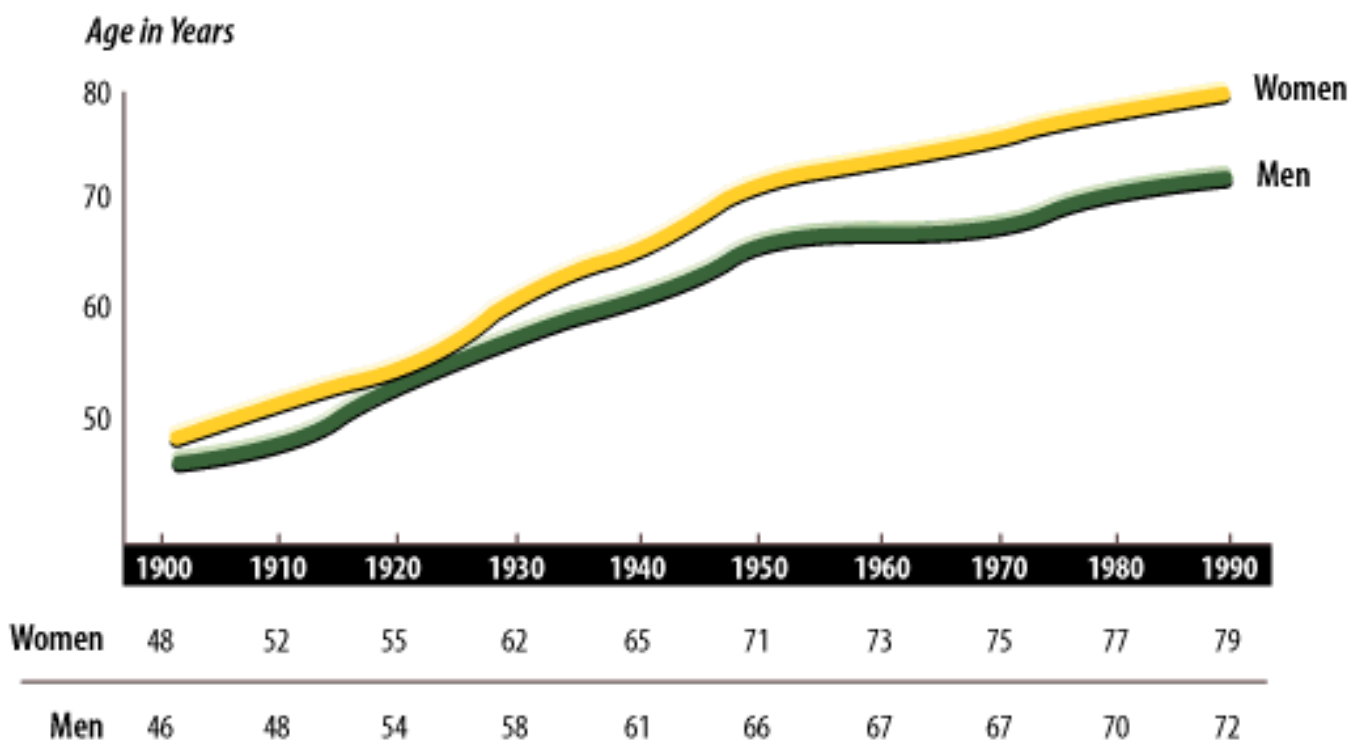
2) U.S. Bureau of the Census. *Historical Statistics of the United States, Colonial Times to 1970, Bicentennial Edition, Part 1*. Washington, D.C., 1993 (1980-1990)

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» Chronic Conditions: The Major Cause of Illness, Disability, and Death

Americans Are Living Longer

Life Expectancy at Birth by Gender, 1900-1990



Increases in Life Expectancy



From 1900 to 1990, life expectancy at birth for women has increased 31 years.

1900  48 yrs.

1990  79 yrs.



From 1900 to 1990, life expectancy at birth for men has increased 26 years.

1900  46 yrs.

1990  72 yrs.

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A growing number of people are living into their 80s, 90s, even past 100 years of age. While gains in life expectancy in the first half of this century came largely from decreased mortality rates for infectious diseases among children and young adults, the additional gains in life expectancy since then have resulted from lower mortality rates of chronic diseases in older adults. In other words, older Americans with chronic conditions are living longer than ever before. For some time, increases in life expectancy at age 65 have outpaced gains in life expectancy at birth. Between 1950 and 1990, life expectancy at age 65 rose more than twice as rapidly as the increase in life expectancy at birth.

NOTES:

1900-1930 data are for death registration areas only. Prior to 1970, deaths of nonresidents of the U.S. were included in these figures.

SOURCES:

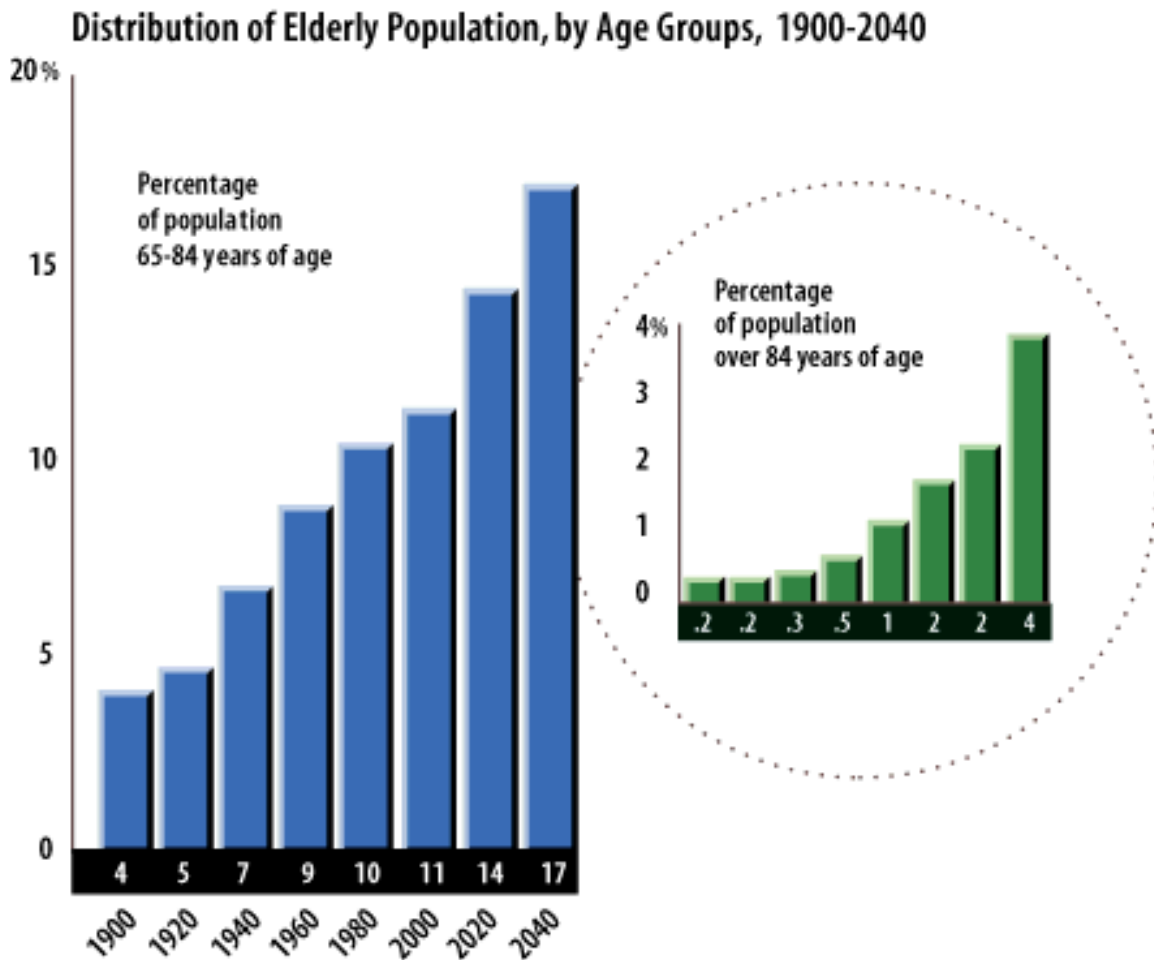
1) National Center for Health Statistics. *Health, United States, 1993*. Hyattsville, MD: Public Health Service, 1994 (1975-1990).

2) U.S. Bureau of the Census. *Historical Statistics of the United States, Colonial Times to 1970, Bicentennial Edition, Part I*. Washington, D.C., 1975 (1900-1970).

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» Chronic Conditions: The Major Cause of Illness, Disability, and Death

Elderly Population Is Increasing. . . And the Average Age Will Be Older



Elderly Population Is Increasing... And the Average Age Will Be Older

By the year 2000, 13 percent of our population will be over 65.

By 2040, the percentage over 65 will have grown to 21 percent.



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Growth in the elderly population in the United States has outpaced the non-elderly since 1900, and is projected to continue through the middle of the next century. Most remarkable is the growth in the numbers of people age 85 years and older. By 2000, 13 percent of the population will be 65 or older and one in eight elderly will be over 84 years old. By 2040, 21 percent -- one in every five Americans -- will be 65 years or older, and there will be almost four times as many very old people, over 85, as there are today.

SOURCES:

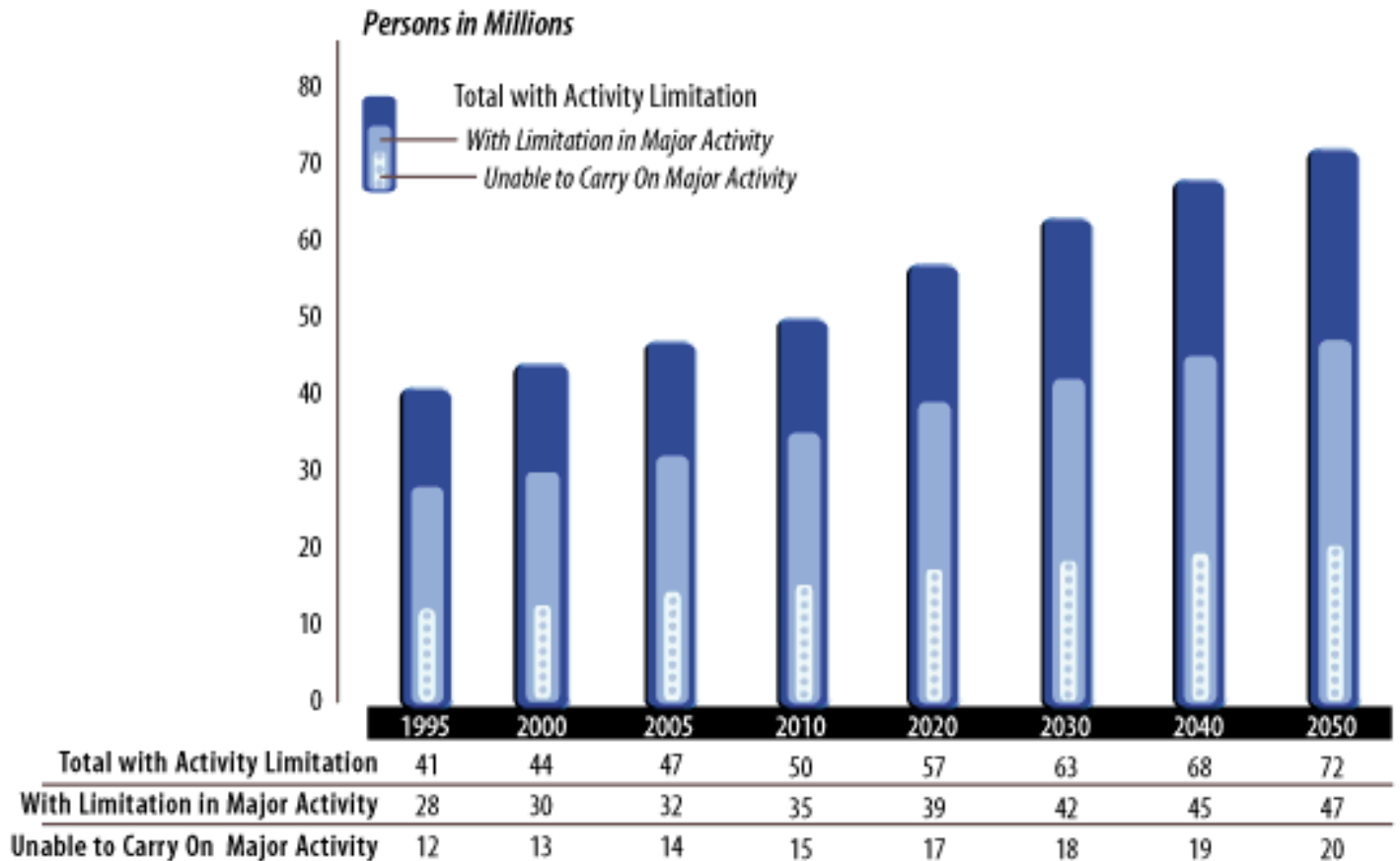
1) Day, Jennifer Cheeseman. *U.S. Bureau of the Census, Current Population Reports, P 25-1104, Population Projections of the U.S. by Age, Sex, Race & Hispanic Origin-1993 to 2050*. Washington, D.C.: U.S. Government Printing Office, 1993 (Years 2000-2050).

2) U.S. Bureau of the Census. *Current Population Reports, Series P 23, No. 128 (Years 1900-1980)*.

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» Chronic Conditions: The Major Cause of Illness, Disability, and Death

Greater Numbers of People Will Be Limited by Chronic Conditions



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The number of people who will be unable to go to school, to work, or to live independently due to a chronic condition is projected to reach 20 million by the year 2050.

NOTE:

Numbers of persons are estimated by applying the rates of activity limitation by gender and age from the 1993 National Health Interview Survey to the U.S. Bureau of the Census projected populations for the selected years.

SOURCE:

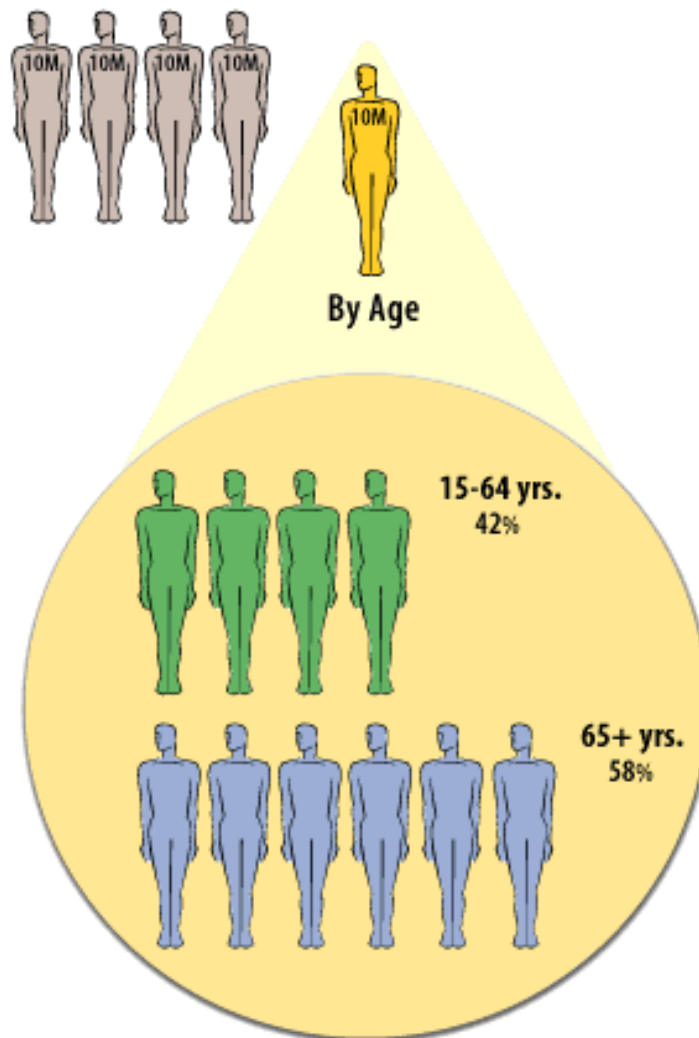
Estimate by Hoffman, Catherine, and Rice, Dorothy P. University of California, San Francisco - Institute for Health & Aging, 1995.

Limitation of activity refers to a long-term reduction in a person's capacity to perform the average kind or amount of activities associated with his or her age group. Persons are classified in terms of the *major activity* usually associated with their particular age group: ordinary play for children under 5 years of age, attending school for those 5-17 years of age, working or keeping house for persons 18-69 years of age, and capacity for independent living (e.g., the ability to bathe, shop, dress, eat, and so forth, without needing the help of another person) for those 70 years of age and over. In regard to these activities, each person is classified into one of four categories: (1) unable to perform the major activity, (2) able to perform the major activity but limited in the kind or amount of this activity, (3) not limited in the major activity but limited in the kind or amount of other activities, and (4) not limited in any way.

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» [Chronic Conditions: The Major Cause of Illness, Disability, and Death](#)

One in Five Disabled Persons Needs Help with Basic Daily Activities



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One in five of the nearly 50 million disabled persons in America needs help with basic daily activities (such as bathing, walking, taking medications, preparing meals). A large percentage (42 percent) of these people are under age 65.

NOTE:

Population consists of 15+ year olds living in the community.

This estimate of the number of disabled persons includes both those with activity limitations and those needing help with Activities of Daily Living or Instrumental Activities of Daily Living:

Activity limitation: A long-term reduction in a person's capacity to perform the average kind or amount of activities appropriate to the person's age group, such as going to school, going to work, living independently.

Activities of Daily Living (ADLs): include bathing, dressing, eating, walking, and other personal care activities.

Instrumental Activities of Daily Living (IADLs): include preparing meals, shopping, using the telephone, managing money, taking medications, doing light housework, and other measures of living independently.

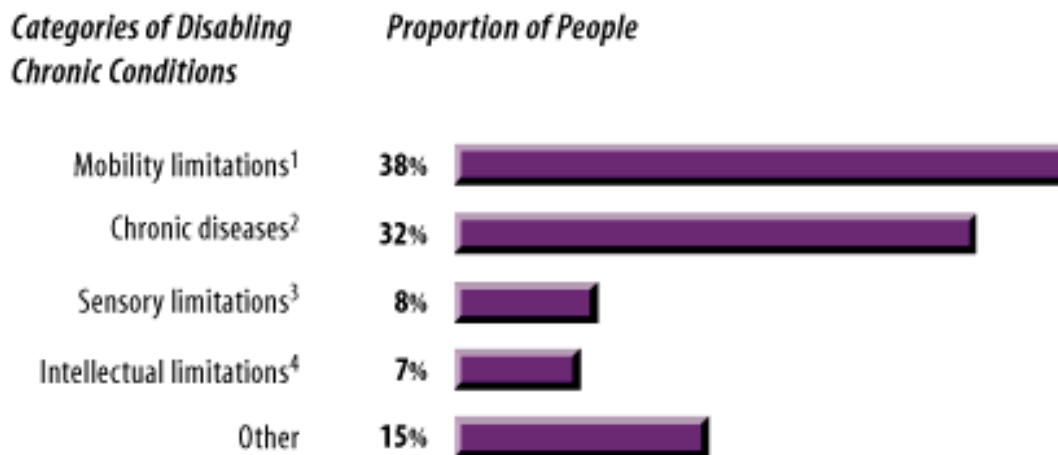
SOURCE:

McNeil, JM. *Americans with Disabilities: 1991-92*. Data from the Survey of Income and Program Participation, P 70-33. U.S. Bureau of the Census, p. 9.

[» Continue](#)

» Chronic Conditions: The Major Cause of Illness, Disability, and Death

Chronic Conditions Include a Broad Spectrum of Disabilities

**Examples:**

1. arthritis, paralysis
2. asthma, heart disease, cancer, diabetes
3. blindness, hearing impairment
4. mental retardation, senility

[Download](#)**SOURCE:**

Institute of Medicine. *Disability in America: Toward a National Agenda for Prevention*, edited by Andrew Pope and Alvin Tarlov. Washington, D.C.: National Academy Press, 1991.

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» Chronic Conditions: The Major Cause of Illness, Disability, and Death

Five Most Disabling Chronic Conditions

<i>Condition</i>	<i>Millions of People with Condition</i>	<i>People Disabled by Condition</i>
Mental Retardation	1.5	84% (1.3 million)
Respiratory Cancers	.2	75% (150,000)
Multiple Sclerosis	.2	70% (140,000)
Blindness (both eyes)	.6	61% (370,000)
Paralysis of Extremities	1.4	57% (800,000)

[Download](#)

SOURCE:

Collins, JG. *Prevalence of Selected Chronic Conditions, United States, 1986-88*. National Center for Health Statistics -- Vital Health Statistics 10 (182), 1993.

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Who Is At Risk for Chronic Conditions?

Chronic conditions affect people of all ages and all strata of society, from newborns to octogenarians, and from the very wealthy to the impoverished. And, contrary to popular misconception, the elderly are not the only ones with chronic and debilitating conditions. Men and women of all ages, ethnicities, education and income levels, and states of health have chronic conditions.

Almost 100 million people in the United States have some form of chronic condition, from minor ailments to severely disabling illnesses and impairments. While the most prevalent conditions, such as sinusitis or hay fever, are usually not disabling, many chronic conditions impose significant activity limitations that change the way people live.

- In 1995, one in six Americans -- 41 million people -- had a chronic condition that inhibited their lives to some degree.
- In 1993, eight million working-age adults were prevented from working due to a disability caused by a chronic condition.
- At least nine million people with disabilities need help with either personal care or home management. Of these, over 40 percent are under age 65.

» Who Is At Risk for Chronic Conditions?

The Number of Americans with Chronic Conditions is Expected to Rise

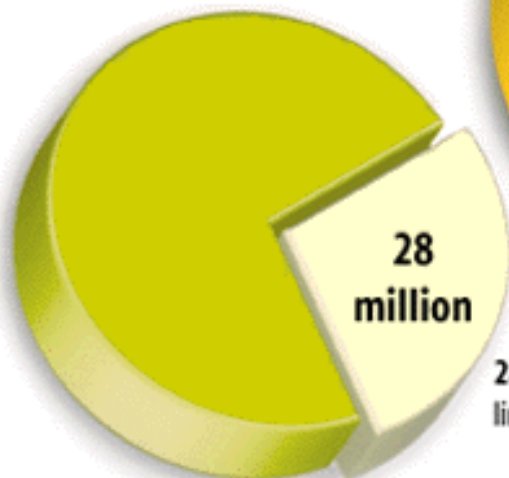
In the span of 25 years, the number of people with chronic conditions will increase by approximately 35 million.

2020

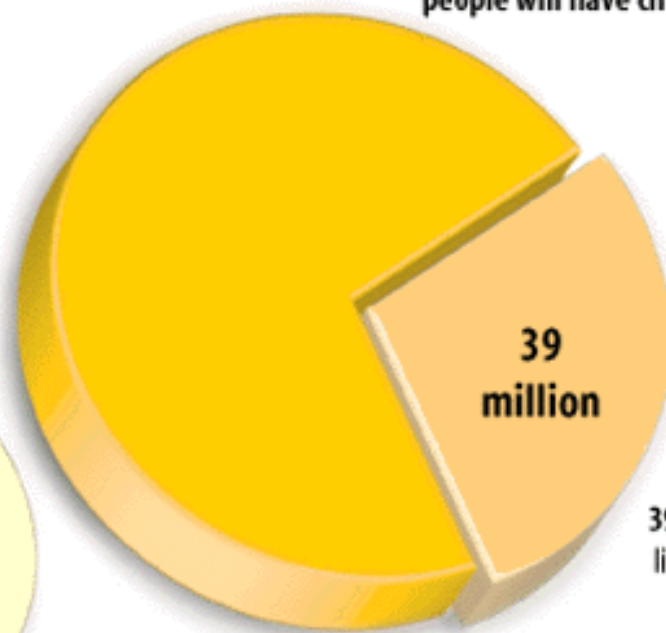
It is projected that in 2020, 134 million people will have chronic conditions

1995

In 1995, 99 million people had chronic conditions



28 million (28%) had limitation in major activity



39 million (29%) will have limitation in major activity

[Download](#)

SOURCE:

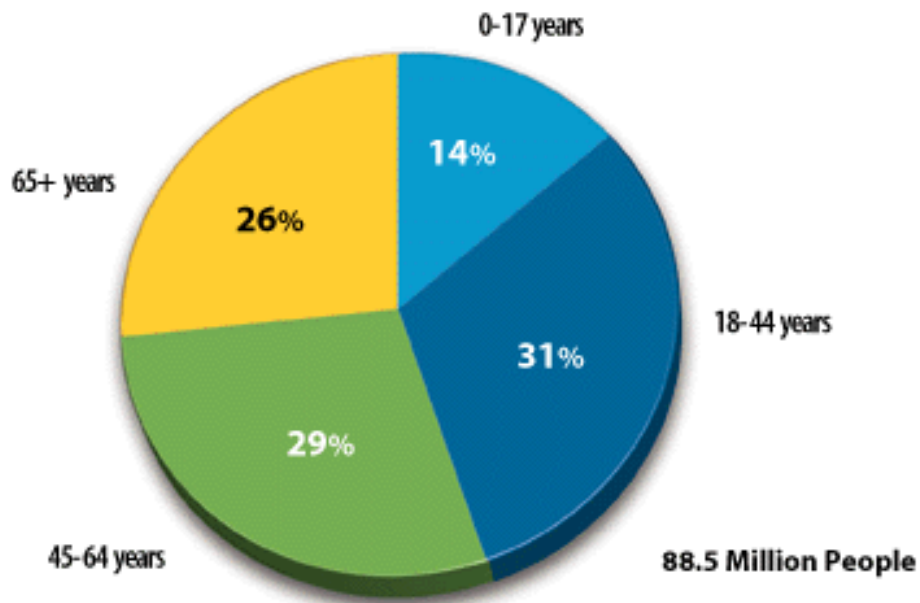
Hoffman, Catherine, and Rice, Dorothy P. Estimates based in part on the 1987 National Medical Expenditure Survey. University of California, San Francisco -- Institute for Health & Aging, 1995.

» [Continue](#)

» Who Is At Risk for Chronic Conditions?

Only 1 in 4 Living in the Community with a Chronic Condition Is Elderly

Percentage of Noninstitutionalized Persons with Chronic Conditions, by Age Group, 1987



[Download](#)

SOURCE:

1) Hoffman, Catherine, and Rice, Dorothy P. Estimates based on the 1987 National Medical Expenditure Survey. University of California, San Francisco -- Institute for Health & Aging, 1995.

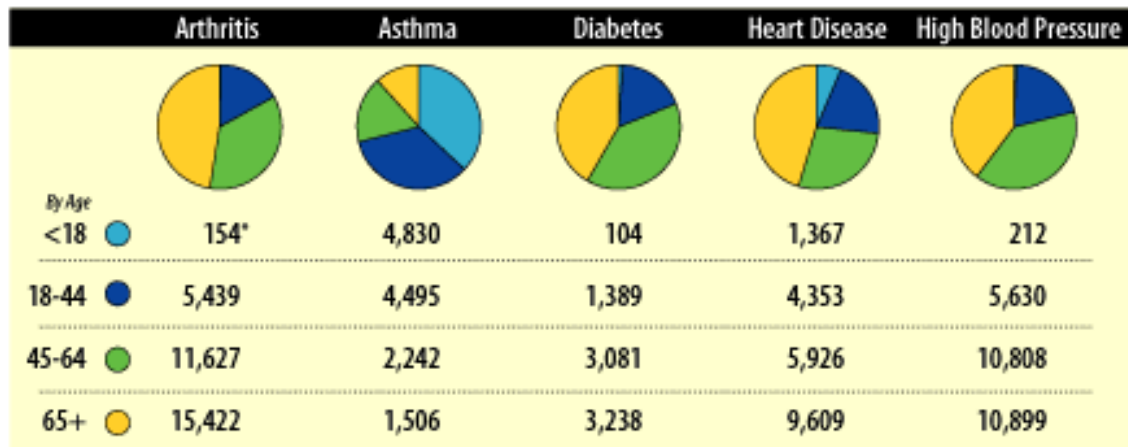
2) National Center for Health Statistics. *Current Estimates from the National Health Interview Survey, 1993*. Vital & Health Statistics, Series 10 (No. 190), Table 62. December 1994.

» [Continue](#)

» Who Is At Risk for Chronic Conditions?

Selected Chronic Conditions by Age Group

Number of Selected Reported Chronic Conditions by Age Group, 1993
(Noninstitutionalized Population, Numbers in Thousands)



*proportionally, this number is too small to chart

[Download](#)

Some chronic conditions, such as arthritis, affect the elderly predominantly. Others, such as asthma, affect persons of all ages.

SOURCE:

1) Hoffman, Catherine, and Rice, Dorothy P. Estimates based on the 1987 National Medical Expenditure Survey. University of California, San Francisco -- Institute for Health & Aging, 1995.

2) National Center for Health Statistics. *Current Estimates from the National Health Interview Survey, 1993*. Vital & Health Statistics, Series 10 (No. 190), Table 62. December 1994.

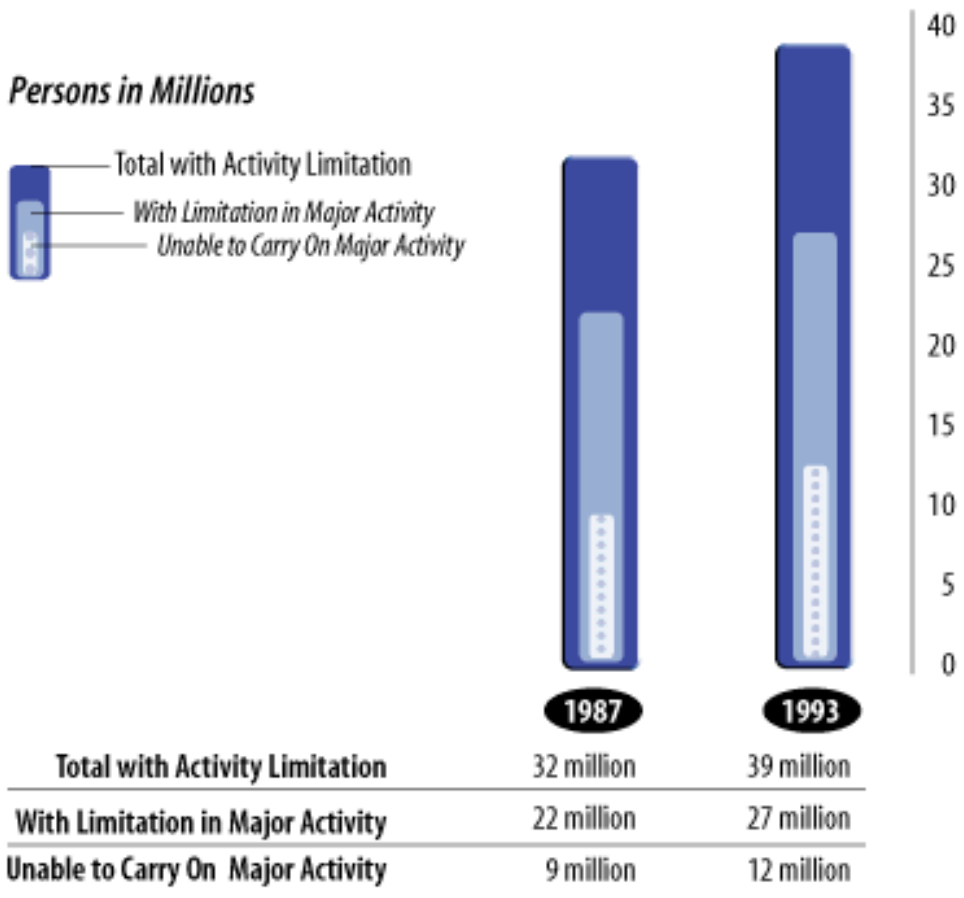
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» **Who Is At Risk for Chronic Conditions?**

Growing Numbers Report Activity Limitations Due to Chronic Conditions

Number of Noninstitutionalized Persons by Degree of Activity Limitation Due to Chronic Conditions, by Age Group, 1987 and 1993



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Between 1987 and 1993, there was an increase of over 20 percent in the number of Americans identified as having chronic conditions that limit their activity, and an increase of at least 33 percent in those identified as being unable to carry on their major activity because of a chronic condition.

SOURCES:

1) 1987, National Center for Health Statistics. *Current Estimates from the National Health Interview Survey, 1987*. Vital & Health Statistics, Series 10 (No. 166), Tables 67 and 68. December 1988.

2) 1993, National Center for Health Statistics. *Current Estimates from the National Health Interview Survey, 1993*. Vital & Health Statistics, Series 10 (No. 190), Tables 67 and 68. December 1994.

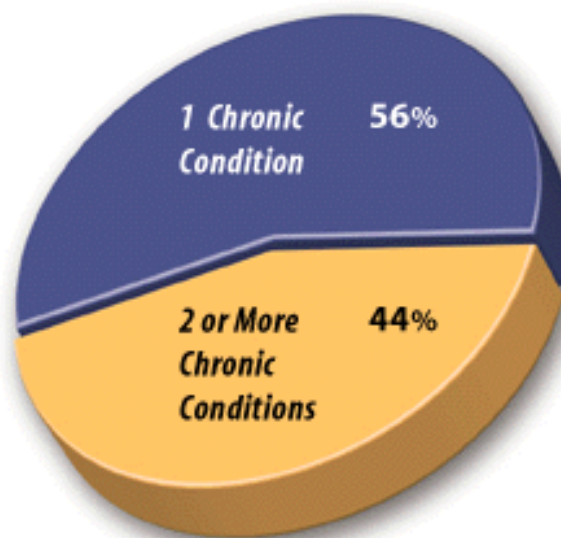
Limitation of activity refers to a long-term reduction in a person's capacity to perform the average kind or amount of activities associated with his or her age group. Persons are classified in terms of the **major activity** usually associated with their particular age group: ordinary play for children under 5 years of age, attending school for those 5-17 years of age, working or keeping house for persons 18-69 years of age, and capacity for independent living (e.g., the ability to bathe, shop, dress, eat, and so forth, without needing the help of another person) for those 70 years of age and over. In regard to these activities, each person is classified into one of four categories: (1) unable to perform the major activity, (2) able to perform the major activity but limited in the kind or amount of this activity, (3) not limited in the major activity but limited in the kind or amount of other activities, and (4) not limited in any way.

» [Continue](#)

» Who Is At Risk for Chronic Conditions?

Nearly 40 Million Americans Have More Than One Chronic Condition

Rates of Comorbidity by Age Group, 1987 (Noninstitutionalized Population)



All Ages

88.5 Million People
with Chronic Conditions

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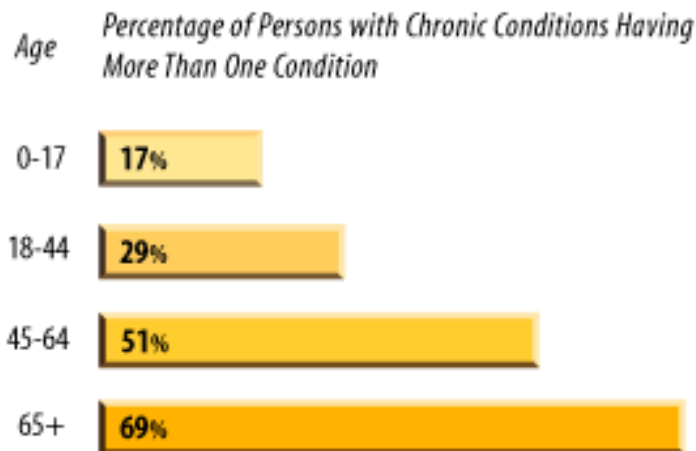
SOURCES:

Hoffman, Catherine, and Rice, Dorothy P. Estimates based on the 1987 National Medical Expenditure Survey. University of California, San Francisco -- Institute for Health & Aging, 1995.

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» [Who Is At Risk for Chronic Conditions?](#)

Majority of People with More Than One Chronic Condition Are Middle-Aged or Older



[Download](#)

SOURCES:

Hoffman, Catherine, and Rice, Dorothy P. Estimates based on the 1987 National Medical Expenditure Survey. University of California, San Francisco -- Institute for Health & Aging, 1995.

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How Much Do Chronic Conditions Cost the U.S.?

The economic costs of chronic conditions are staggering. Chronic care costs make up the largest share of health care dollars spent in the United States. Almost 70 percent of the \$612 billion spent on personal health care in 1990, an estimated \$425 billion, can be attributed to persons with chronic health conditions.

- **The direct medical costs for persons with chronic conditions were \$425 billion in 1990.** (Contrast this with the \$124 billion Americans spent on new and used cars or the \$73 billion spent on education and research in 1990.)
- **The indirect costs for persons with chronic conditions -- in terms of lost productivity -- added \$234 billion to the costs.** \$161 billion in indirect costs were due to premature death and another \$73 billion can be attributed to lost productivity due to people being unable to work or to perform their usual activities. (When a person is unable to work or dies prematurely, the value of his or her productivity to society is lost.) These indirect costs do not include the lost productivity of people who were unable to work

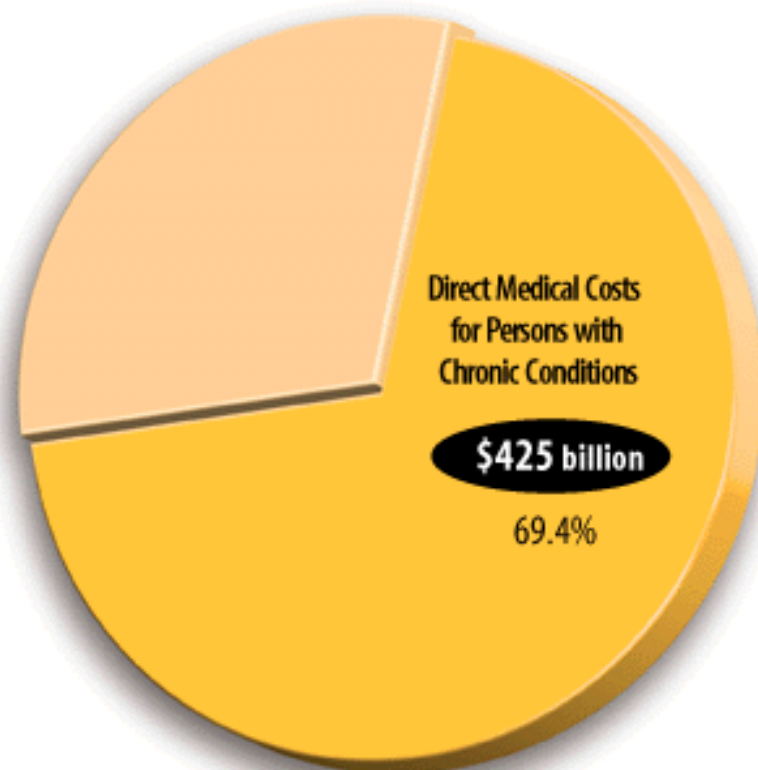
because of their caregiving responsibilities.

» [Continue](#)

» [How Much Do Chronic Conditions Cost the U.S?](#)

Direct Medical Costs for Persons with Chronic Conditions Represent Nearly 70 percent of National Expenditures on Personal Health Care

Personal Health Care Expenditures, 1990
\$612 billion



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NOTES:

1) Personal Health Care Expenditures (as defined by the U.S. Health Care Financing Administration) consist of the following: hospital care, physician services, dental services, other professional services, home health care, drugs and other medical non-durables, vision products and other medical durables, nursing home care, and other personal health care. They do not include the following: program administration and net cost of private health insurance, government public health activities, and research and construction.

2) Direct Medical Costs (as defined by Principal Investigators Hoffman and Rice of the University of California, San Francisco) consist of the following: hospital care, physician services, dental services, other professional services, home health care, prescriptions, medical equipment, emergency services, and nursing home care.

SOURCES:

1) *Health Care Financing Review*, Fall 1994, Vol. 16 (1), Table 13, p. 283.

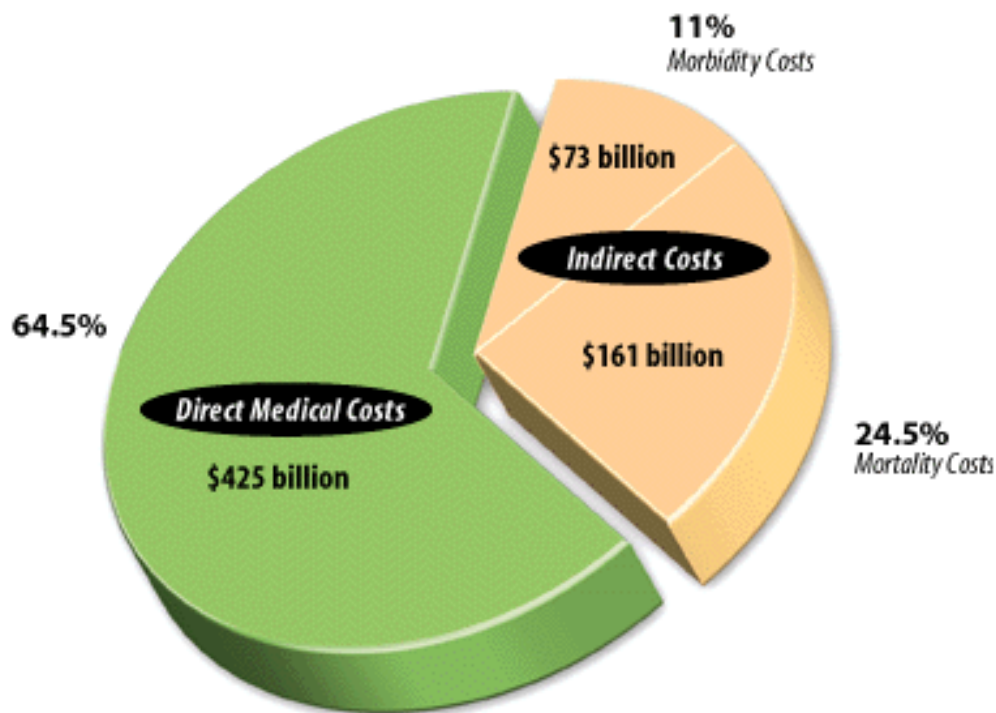
2) Hoffman, Catherine, and Rice, Dorothy P. Estimates based on the 1987 National Medical Expenditure Survey. University of California, San Francisco - Institute for Health & Aging, 1995.

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» How Much Do Chronic Conditions Cost the U.S?

Adding Indirect Costs Brings the Costs of Chronic Conditions to \$659 Billion

Estimated Distribution of Direct and Indirect Costs of Chronic Conditions, 1990
Total Costs in 1990: \$659 billion



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NOTE:

Refer to Technical Appendix for methodology for projecting costs.

SOURCE:

Hoffman, Catherine, and Rice, Dorothy P. Estimates based on the 1987 National Medical Expenditure Survey. University of California, San Francisco -- Institute for Health & Aging, 1995.

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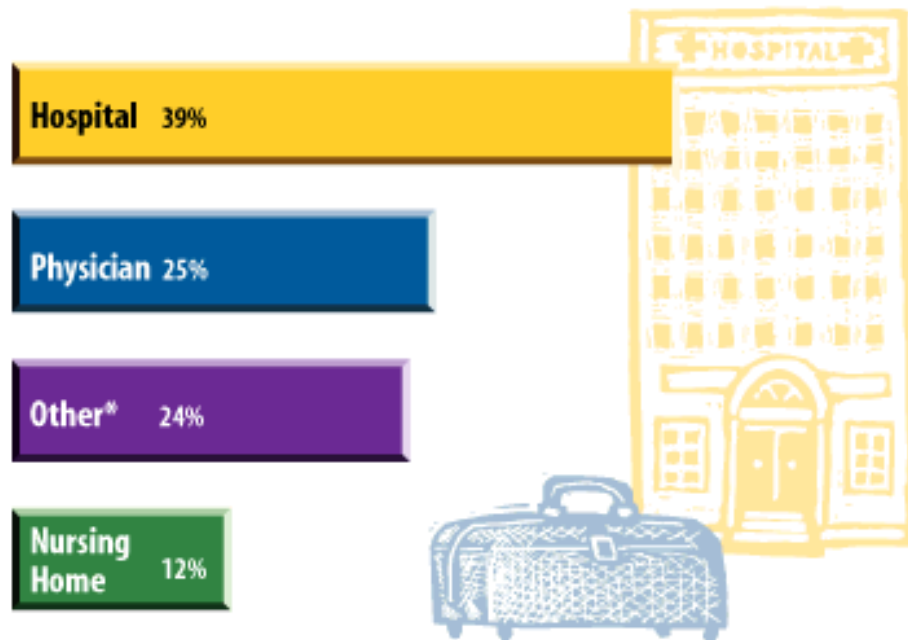
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» [How Much Do Chronic Conditions Cost the U.S?](#)

Almost Two-Thirds of Chronic Health Care Dollars Are Spent on Hospital Care and Physician Services

1990 Direct Medical Costs for Persons with Chronic Conditions
\$425 billion



**including prescriptions, dental care, nonphysician practitioners, home health care, medical equipment, emergency care*

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Almost 65 percent of the direct medical costs for persons with chronic conditions are for hospital care and physician services. Yet in spite of these expenditures, most hospital and physician care remains episodic. That is, services are concentrated on periods when the person with a chronic condition needs acute care, rather than in non-acute phases when care that is preventive or rehabilitative in nature is beneficial. Little investment is made in prevention -- either efforts to prevent the condition from occurring initially, or to prevent disabilities caused by an existing condition.

SOURCE:

Hoffman, Catherine, and Rice, Dorothy P. Estimates based on the 1987 National Medical Expenditure Survey. University of California, San Francisco -- Institute for Health & Aging, 1995.

Source for nursing home costs: Letsch, SW, Lazenby, HC, Levit, KR, Cowan, CA. "National health expenditures, 1991". *Health Care Financing Review*, Winter 1992, 14(2):1-30, table 14.

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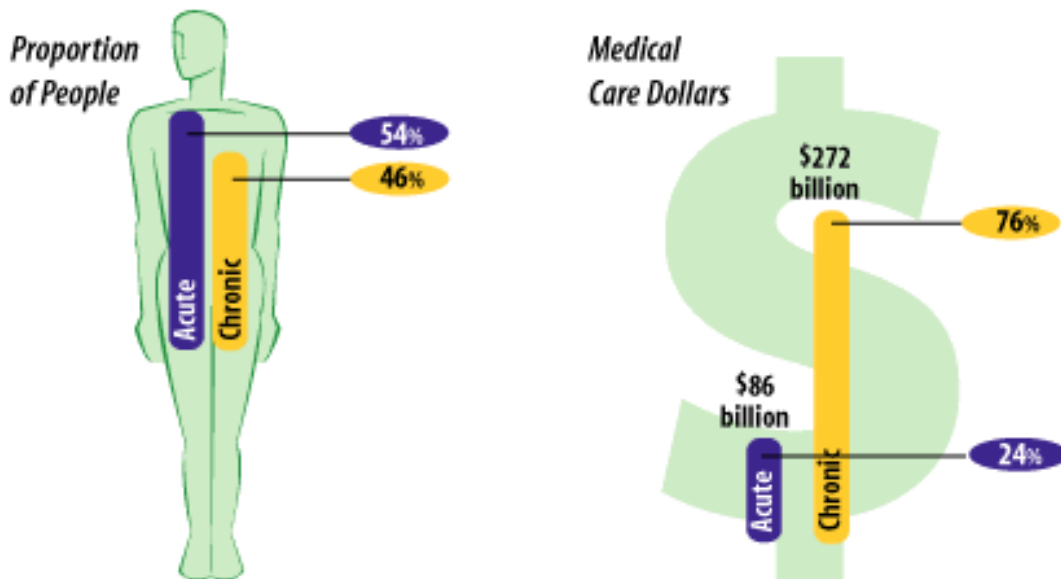
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» How Much Do Chronic Conditions Cost the U.S.?

Medical Care Costs More for People with Chronic Conditions

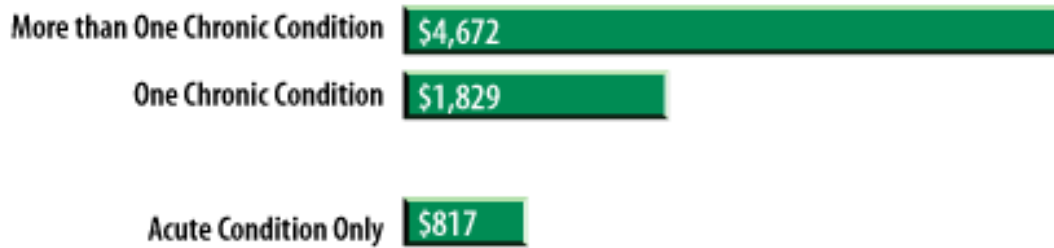
Proportion of Persons vs. Medical Care Dollars, by Condition, 1987



Medical care costs are disproportionately high for persons with chronic conditions. In 1987, while 46 percent of persons with health problems reported one or more chronic conditions, they accounted for 76 percent of the direct medical care costs.

Medical Care Costs More for People with Chronic Conditions

Per Capita Costs, by Conditions, 1987



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Having one or more chronic conditions increases the costs of care. In 1987, annual medical costs per person were over twice as high for persons with one chronic condition compared to persons with acute conditions only (\$1,829 vs. \$817 in 1987 dollars). Having more than one chronic condition dramatically raises the total costs of care to \$4,672 per year -- nearly sixfold the per capita costs of persons with acute conditions only.

NOTE:

Total health care expenditures do not include institutional services.

SOURCE:

Hoffman, Catherine, and Rice, Dorothy P. Estimates based on the 1987 National Medical Expenditure Survey. University of California, San Francisco -- Institute for Health & Aging, 1995.

» [Continue](#)

[» Chronic Conditions: The Major Cause of Illness, Disability, and Death](#)

fact sheet

How Are Chronic Conditions That Cause Limitation Classified?

Experts have different approaches to defining and measuring chronic conditions. Different data sources use different definitions. Experts classify the limitations caused by chronic conditions using the following descriptors:

Activity limitation: A long-term reduction in a person's capacity to perform the average kind or amount of activities appropriate to the person's age group, such as going to school, going to work, living independently.

Functional limitation: Results from impairment or chronic illness and is a restriction or lack of ability to perform an action or activity in the manner or within the range considered normal.

Disability: A limitation or inability (resulting from impairment or chronic illness) to perform socially defined activities and roles expected of individuals in the manner considered normal.

An individual's level of disability is frequently categorized based on the amount of assistance required in both basic and instrumental activities of daily living.

Activities of Daily Living (ADLs): include bathing, dressing, eating, walking, and other personal care activities.

Instrumental Activities of Daily Living (IADLs):

include preparing meals, shopping, using the telephone, managing money, taking medications, doing light housework, and other measures of living independently.

» [Continue](#)

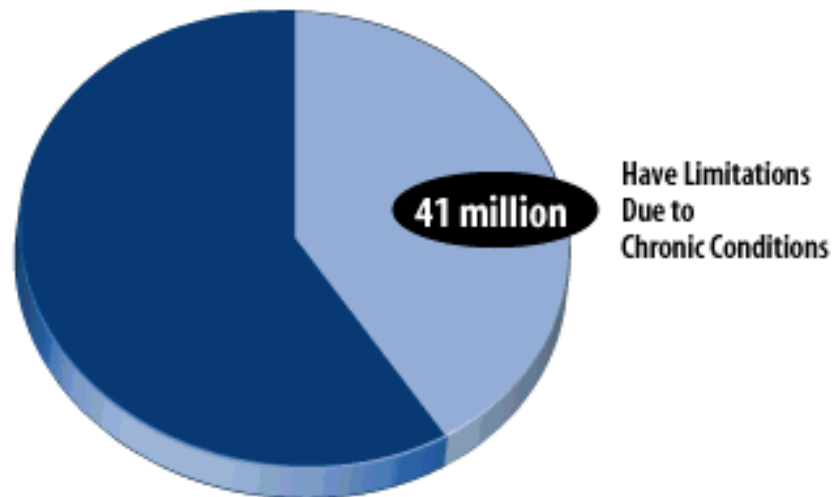
» Who Is At Risk for Chronic Conditions?

fact sheet

Estimated Prevalence of Chronic Conditions, 1995

Persons with Chronic Conditions

99 million living in the community



SOURCES:

Hoffman, Catherine, and Rice, Dorothy P. Estimates based on the 1987 National Medical Expenditure Survey. University of California, San Francisco -- Institute for Health & Aging, 1995.

- Almost 100 million persons living in the community have one or more chronic conditions.
- Every day, one in six Americans is limited in some way due to a chronic condition.

- More than one in every three Americans is at risk of having their chronic condition limit their daily activities.

» [Continue](#) for part 2 of this fact sheet

» Who Is At Risk for Chronic Conditions?

fact sheet

Estimated Prevalence
of Chronic
Conditions, 1995

- Contrary to popular perceptions, the elderly represent fewer than one-third of those who have chronic conditions that cause limitations and disabilities.
- In 1993, the number of American adults age 18-64 who could not work because of a chronic condition could populate a state the size of Massachusetts or Virginia.
- From 1987 to 1993, the number of Americans who were identified as having chronic conditions that limit their activity grew by 22 percent; the number who were unable to work because of a chronic condition grew by 33 percent.
- At least nine million people with disabilities need help with either personal care or home management. Of these, over 40 percent are under age 65.

» [Continue](#)

Who Is At Risk for Chronic Conditions?

- Some chronic conditions are disabling only some of the time; they require episodic care. Chronic conditions do not always get worse; the health status of a person with a chronic condition can improve, deteriorate, or shift in either direction.
- Certain segments of society are more likely to have and be disabled by a chronic condition than others, notably the old, the poor, and those who have more than one chronic condition.

What does it mean to have a chronic condition?

There is no simple answer to the question, "What does it mean to have a chronic condition?"

Chronic conditions affect people's physical and mental health, their social life and employment status in radically different ways. Some chronic conditions are highly disabling, others less so. Some chronic conditions, especially diabetes, may not disable a person currently, but may lead to severely disabling effects if not treated early and effectively. Some people return to former levels of daily activity after recovering from a heart attack, stroke, trauma, or other acute episode; others don't. Some individuals with chronic conditions live full, productive, and rewarding lives; for others, isolation, depression, and physical pain are the consequences of severe chronic illness.

» How Much Do Chronic Conditions Cost the U.S.?

fact sheet


How Much Do Chronic Conditions Cost the U.S.?

The High Cost of Chronic Care

- In 1990, the estimated direct costs of medical services and nursing home and other institutional care for persons with chronic conditions were \$425 billion. This represents 70 percent of the nation's total annual personal health care expenditures.
- The vast majority of the dollars spent in U.S. hospitals are spent on people who have a chronic condition. In 1990, hospital care accounted for the largest share (about 40 percent) of direct medical costs for persons with chronic conditions, at \$167 billion; physician services cost \$105 billion, and nursing home care accounted for \$53 billion.
- In comparison to persons with acute conditions only, medical care costs are disproportionately high for persons with chronic conditions. In 1987, while 46 percent of persons with health problems reported one or more chronic conditions, they accounted for 76 percent of the direct medical care costs.

- In 1987, taxpayers paid 40 percent of the direct medical costs of chronic care, excluding nursing home care, through public financing of Medicare, Medicaid, and other health programs; in contrast, public funds paid only 20 percent of the cost of acute conditions. Private insurance paid about one-third of the expenditures for chronic conditions, and individuals paid about one-fifth of these expenses out-of-pocket.

» [Continue to Part II](#)



Chronic Care in America: A 21st Century Challenge

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The following images are large, high-res tiff files. To download them to your system, click on the title. When it finishes loading the data into your browser window (it will look like random text characters), select the "Save As" option and save it with the .tif extension.

[Direct Medical Costs for Persons with Chronic Conditions Represent Nearly 70 percent of National Expenditures on Personal Health Care - CMYK](#) Size:499K

[Direct Medical Costs for Persons with Chronic Conditions Represent Nearly 70 percent of National Expenditures on Personal Health Care - Grayscale](#) Size:138K

PART II

What Is Chronic Care?

Chronic care differs substantially from what most people associate with medical care. Medical care uses intensive, hospital-based, often high-technology medical services to cure acute manifestations of a disease or injury. Chronic care seeks to enable people with functional limitations to regain or maintain the highest level of independence and functioning possible. Chronic care typically provides both medical care and non-medical assistance from a wide range of caregivers in a variety of settings. Because chronic conditions by definition cannot be fully cured, chronic care also emphasizes long-term assistance and compassionate care.

Chronic care consists of several different types of care, predominantly:

- **Medical Care:**

A wide range of medical services provided in a hospital (such as surgery) or on an outpatient basis (such as chemotherapy treatments), or in the home. It may be in response to an acute phase of a chronic condition (for instance, severe pneumonia resulting from AIDS), complications resulting from one or more chronic conditions, or as part of the ongoing management of a long-term condition

● **Rehabilitative Care:**

Usually prescribed following hospitalization, rehabilitative care includes physical, occupational, and speech therapies. It uses various social, educational, vocational, and sometimes medical services to train or retrain individuals disabled by disease or injury. It is administered in a variety of settings, including hospitals, skilled nursing and other subacute facilities, and in the home.

» [Continue](#)

» How Is Chronic Care Financed?

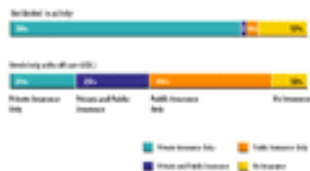
Click on small chart to see in full size.



Public Funds Pay the Largest Share of Direct Chronic Care Costs

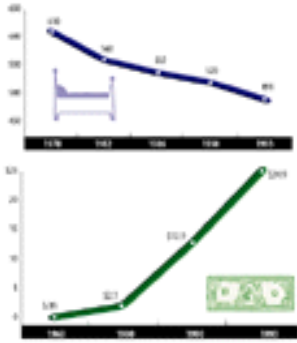


Long-Term Care Costs Drain Both Public and Individual Resources

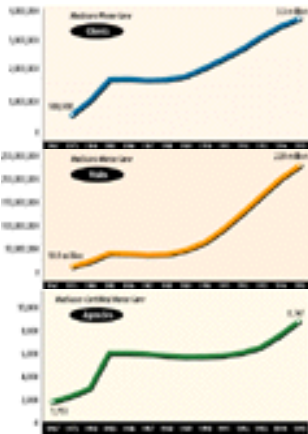


Chronic Conditions Limit Access to Private Insurance, Force Reliance on Public Insurance

» Trends in Chronic Care



Nursing Home Beds Down, Home Care Expenditures Up



Increasing Numbers of Persons with Chronic Conditions Receiving Care at Home

fact sheet

What Is Chronic Care?

■ **Chronic Care Is Different from Acute Care**

Sources of Chronic Care

Informal caregivers -- family, friends, and community unpaid volunteers -- provide the majority of care and assistance to vast chronically-ill and disabled people. Although hospitals have traditionally provided the medical care needed by people with chronic conditions, technological advances increasingly allow medical care to be delivered in non-hospital settings as well. However, because chronic care includes many types of assistance, not only medical care, the "system" of chronic care includes many institutions and sources of care. Some major sources of chronic care other than in hospitals are outlined below.

Home Care

Home care today includes a variety of services, based on the level of assistance required by the person with a disability or chronic illness. Home care services range from high-intensity home health care to lower-intensity, lower-skilled personal assistance services (such as assistance in bathing, eating, shopping, or housecleaning). Services may be delivered in a variety of settings, ranging from an individual's freestanding home to an assisted living apartment or board-and-care home. Since some disabled individuals require help but are not homebound, personal assistance services also may be provided in a work or recreational setting, while the

person is carrying out his or her daily activities.

There are over 15,700 home care agencies, including approximately 8,700 that are Medicare-certified. Each of these may offer any number of the services described above. The staff that provides home health care and personal assistance services range from registered nurses, to licensed practical nurses, to lesser-trained home health aides. Services are also provided by voluntary community agencies which provide meals, transportation, respite care, and other assistance.

» [Continue](#)

How Is Chronic Care Financed?

The vast majority of chronic care is provided as informal care, by unpaid caregivers, usually a person's family and friends. The enormous value of informal care has not been calculated, but this type of care provides an important part of the chronic care continuum.

Formal, paid chronic care includes hospital and physician services, nursing home care, home care, as well as prescriptions, dental care, non-physician care, medical equipment, and emergency care. Excluding nursing home care, Federal and state governments paid 41 percent of the costs of chronic care in 1987; private insurance paid 33 percent, and individuals paid 22 percent out-of-pocket. This can be contrasted with the costs of acute conditions, where Federal and state governments paid only 19 percent, private insurance paid 45 percent, and individuals paid 29 percent.

Nursing homes are a particularly costly segment of the chronic care continuum, a primary reason most reforms in the chronic care system include methods to help people remain independent and out of institutions for as long as possible. Recent data indicate that Americans pay 33 percent of the total costs of nursing home care out-of-pocket (\$23 billion). The public sector pays an even greater share: Medicaid's 52 percent represented an expense of \$36 billion. One

small but growing source of financing for nursing homes and home care is private long-term care insurance.

» [Continue](#)

Trends in Chronic Care

The chronic care delivery system is in a state of flux. Traditional definitions and boundaries of home and institutional care, and the personnel who deliver chronic care services in these various settings, are blurring. New mechanisms for the delivery of care are emerging. Among the trends that have developed in recent years:

● Deinstitutionalization

National policy over the past three decades has sought to minimize the number of people who must rely on institutions for personal assistance. This policy, known as deinstitutionalization, has created several important ripple effects. For one, many deinstitutionalized people with mental illness have encountered a community-based care system lacking in funding and coordination. Another significant effect is a change in the population living in nursing homes. Nursing home residents used to comprise a broad range of persons in various stages of illness and disability. Today, nursing homes care primarily for the frailest people, particularly those with significant mental impairments, strokes, or Alzheimer's disease. People in nursing homes tend to have few financial resources and some have no one looking out for their interests. The vulnerability of the deinstitutionalized population has raised concerns about ensuring that their well-being is adequately protected.

» [Continue](#)

» Widespread Unmet Need

Click on small chart to see in full size.



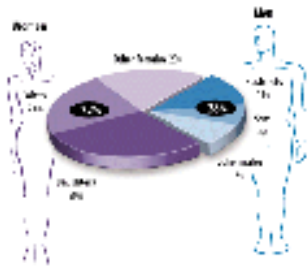
Without Assistance, Adverse Consequences Occur

» Extensive Use of Health Services

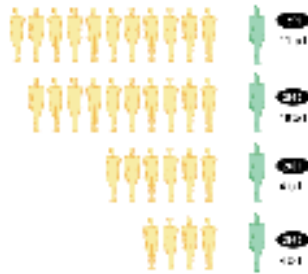


People with Chronic Conditions Use More Hospital-Based Services

» Crisis in Caregiving



Most Caregivers are Middle-Aged Women



The Shrinking Pool of Potential Caregivers



Caregiving: More Than a Part-time Job

PART III Widespread Unmet Need

Health care is one of the nation's largest industries, employing approximately 10 percent of the nation's work force. Yet despite the enormous financial, intellectual, technological, and personal investment in this mega-industry, recent research indicates that people with chronic conditions want something the market is not supplying: affordable, accessible services, and products to help maintain an independent lifestyle as long as possible. Ironically, in a resource-rich nation, millions of people have legitimate health and social service needs that are unfulfilled.

Case History: Springfield, Massachusetts

In the most comprehensive investigation of its kind, persons with disabilities in Springfield, Massachusetts, were studied to assess the extent of their unmet needs. The Springfield Study of Populations with Disabilities investigated the "match" between services and needs among a population of people with chronic conditions, and found that:

- Unmet needs lead to adverse health consequences: half of the people with unmet need for help with transferring out of a bed or chair fell because no one was there to help; over 40 percent with unmet need for transportation missed a medical appointment in the past month, and nearly a third of people with unmet need for help with shopping were unable to get their medications or supplies.
- Over half of all people with disabilities reported having unmet need for at least one formal service, such as physical therapy, mental health services, visiting nurses, transportation, home health aides, and homemakers.
- A substantial proportion (56 percent) of both young and old people who needed help with activities of daily living (ADLs) did not have all of their needs met.
- Younger persons were just as likely to have unmet ADL needs as the elderly and were more likely than the elderly to have unmet need with transferring out of a bed or chair. Younger persons were also more likely than elderly persons to have unmet need for help with light and heavy housekeeping, shopping, and transportation.

» [Continue](#)

Extensive Use of Health Services

People who are chronically ill and disabled use a large percentage of all health services, including the most costly kind -- inpatient acute care services and, in particular, emergency room services.

- Over half of all emergency room visits (55 percent) are made by people with chronic conditions.
- People with chronic conditions account for nearly seven in every ten hospital admissions (69 percent), and 80 percent of hospital days; their average length of hospital stay is 7.8 days compared to 4.3 days for people with acute health conditions.
- They account for virtually all home care visits (96 percent) and over 70 percent of visits to health professionals other than physicians.
- People who are severely disabled (that is, those needing help with self care) make nearly seven times as many physician visits as the non-disabled.

- People with chronic conditions sometimes receive care that is more intensive, more specialized, and more expensive than the care they need or want. While certainly a good portion of services are necessary, there is some evidence of avoidable hospitalizations and emergency room visits, unnecessarily long lengths of stay in hospitals, and unnecessary admissions to nursing homes due to a lack of preventive and primary care. Not only are these expenditures of financial and professional resources potentially avoidable; they are a source of discomfort and distress for patients as well. Improved chronic care may help people avoid the need for hospitalization and emergency room services.

» [Continue](#)

Crisis in Caregiving

One person's disability affects many other people. For the many millions of Americans who require help with everyday activities, family and friends are the first line of support. Indeed, one in four Americans currently provides some kind of care for a person who has a chronic condition. In 1990 nearly 83 percent of persons under age 65 with chronic disabilities, and 73 percent of disabled persons over 65 relied exclusively on these informal caregivers.

Overall, the demand and supply trends in caregiving are pulling in opposite directions.

Demand for caregivers is increasing:

The chances of becoming a caregiver to someone with a chronic condition are much higher today than ever before -- and the likelihood will increase over the coming decade. The demand for caregiving will increase as the elderly population increases, particularly among those 85 years and older, who are most likely to be disabled by chronic conditions.

[» Continue](#)

2000

and Beyond

By all measures, there will be ever-greater numbers of people affected by chronic conditions in the 21st century -- and more people in need of chronic care.

- In 2020, there will be 12 million people age 65 and over with a limitation in a major activity due to a chronic condition.
- By 2020, there will be 39 million people with a chronic condition that causes limitation in their ability to go to school, to work, or to live independently.
- Based on current trends, by 2020 up to 14 million elderly will need long-term care -- double the seven million who need long-term care today.

- In 1970, there were 21 "potential caregivers" (defined here as people age 50-64) for each very elderly person (age 85 or older); by 2030, there will be only six such potential caregivers for each very elderly person.
- By 2030, unless new systems of care are created, chronic care alone is projected to cost the U.S. \$798 billion (in 1990 dollars) in direct medical and nursing home costs.

» [Continue to Part IV](#)

PART IV Conclusion

PART IV Challenges for the 21st Century

The 21st century will confront us more directly than ever before with the need for an effective system of chronic care. This is a society-wide challenge. There is no single solution, no one sector that by itself can improve the system. Multiple sectors of society must work toward an integrated solution to the dilemmas laid out in this Chartbook.

From the chronic care perspective, the most important and salient issues to be addressed in order to improve care for the chronically ill are:

Creating correct financial and other incentives to rebalance resources,

so that the right people receive the right mix of services. On the financing side, for instance, the Medicare and Medicaid programs must adapt their acute care-oriented financing system toward systems that recognize the increasing prevalence and high costs of chronic care. The role of privately purchased insurance and out-of-pocket payment for chronic care services needs further public discussion and debate.

Creating the right mix of medical services.

In the future, we will need not just surgery and other

medical services provided in hospitals, but home care and skilled nursing for patients who are able to leave acute care hospitals but do not require the services of conventional nursing care facilities. This is already a trend: rapid growth in the number of home health agencies has been paralleled by a 167 percent increase in home health care expenditures from 1989 to 1993 (from \$9 billion to \$24 billion). Moreover, home health care grew faster than any other health spending category in four out of the past five years.

» [Continue](#)

APPENDIXES

Profiles: Confronting the Chronic Care Challenge Today

Supportive
Housing

AIDS Housing of Washington
2025 First Avenue
Suite 420
Seattle, WA 98121
(206) 448-5242

Who:

- People with AIDS and HIV.

Goal:

- To provide a wide range of housing options from independent living arrangements to 24-hour nursing care.

Description:

- Developed under the auspices of the Seattle-King County Department of Public Health.
- Minimizes hospitalization through out-of-hospital service approach matching clients' financial resources and medical needs.

- Among the options are: conventional housing using the federal rent subsidy program offered through the Seattle Housing Authority; church-sponsored program to help assist individuals pay mortgage or rent; emergency housing; residential housing providing living assistance with intermittent nursing care; and a nursing residence and adult day health program.

» [Continue](#)

APPENDIXES

Technical Appendix on the Costs of Chronic Care

Methodology for Projecting the Direct Costs of Chronic Care

To project the costs of chronic care in 1990 dollars, the estimated per capita costs in 1990 were applied to the projected future population with chronic conditions by gender and age. The final results show only the effect of the aging of the population on the cost of chronic care; inflation in medical care and in the general economy is not taken into consideration. Following is a more detailed methodology:

- The 1987 chronic per capita health expenditures were updated to 1990 by applying the percentage increase from 1987 to 1990 [Levit, Katherine R., Helen C. Lazenby, Cathy A. Cowan, and Suzanne W. Letsch. 1991. "National Health Expenditures, 1990," *Health Care Financing Review*, 13(1): 29-54] in health expenditures by type of expenditure to the 1987 National Medical Expenditure Survey (NMES) per capita medical expenditures for persons with expenditures for chronic conditions by gender and age (1-14 years, 15-17 years, 18-19 years, 20-44 years, 45-64 years, and 65 years and over).

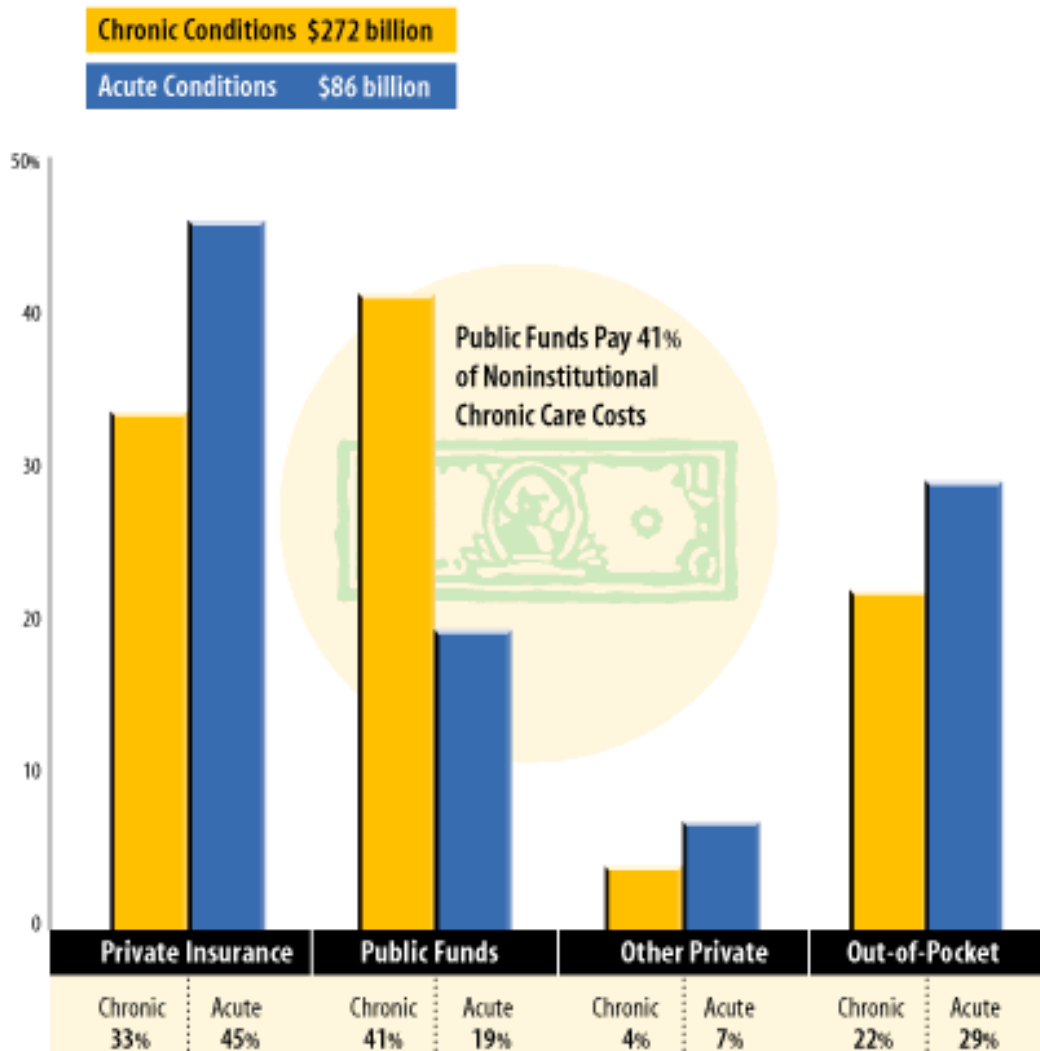
- To obtain the estimated number and proportion of persons in 1990 with chronic conditions, the proportions of the total population with chronic health expenditures in 1987 by gender and age were applied to the total resident population projected by the Bureau of the Census (middle projections) for selected years [Current Population Reports: Series P-25, No. 1040-RD-1, table 2].

» [Continue](#)

» How Is Chronic Care Financed?

Public Funds Pay the Largest Share of Direct Chronic Care Costs

Proportion of Health Care Dollars for Acute vs. Chronic Conditions, by Payer, Excluding Institutional Care, 1987



[Download](#)

SOURCE:

Hoffman, Catherine, and Rice, Dorothy P. Estimates based on the 1987 National Medical Expenditure Survey. University of California, San Francisco -- Institute for Health & Aging, 1995.

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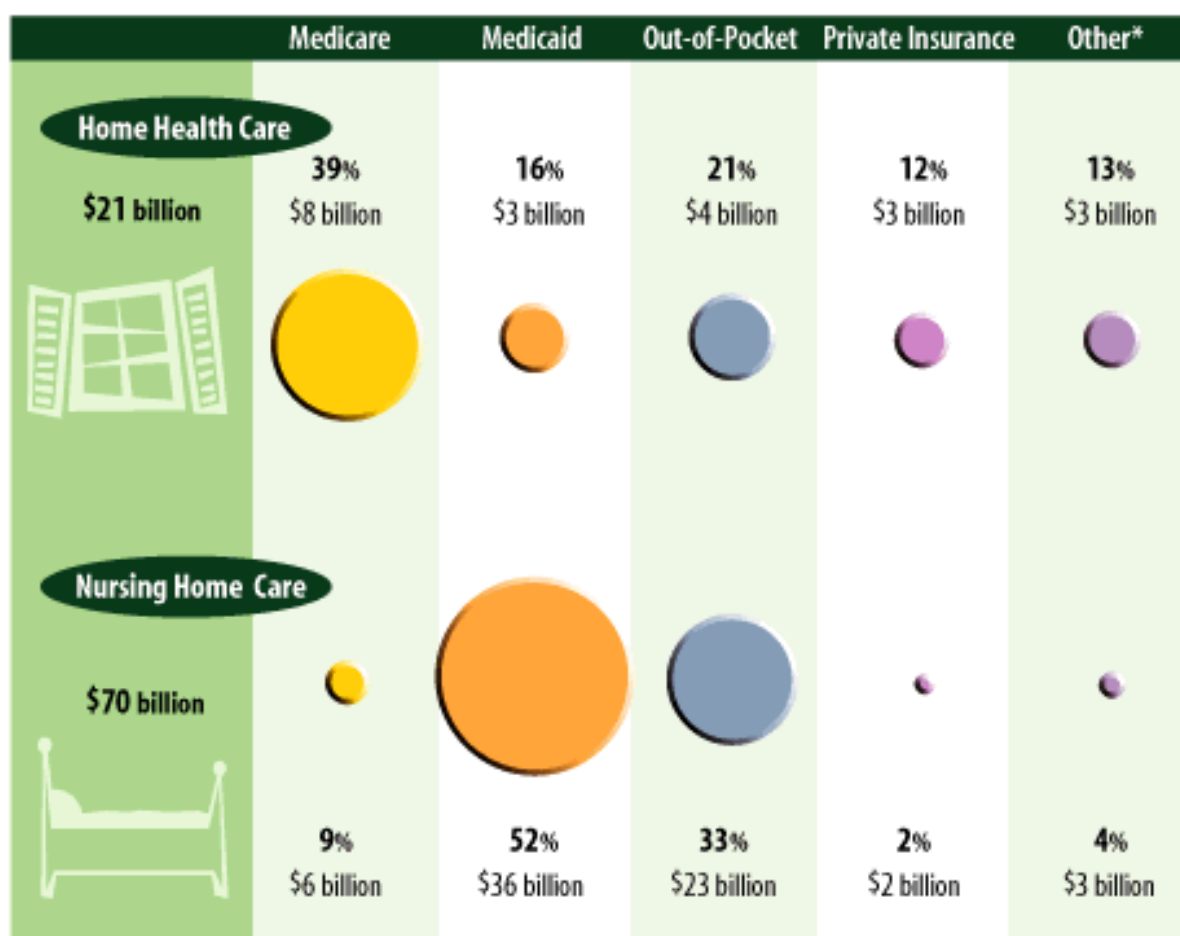
[Contents](#)[RWJF Home Page](#)

PART II The Chronic Care "System"

[Charts](#)[Fact Sheet](#)[» How Is Chronic Care Financed?](#)

Long-Term Care Costs Drain Both Public and Individual Resources

National Health Expenditures for Long-Term Care by Type of Service and Payer, 1993



*includes public and private sources

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NOTE:

Excludes facility-based home care agencies.

SOURCE:

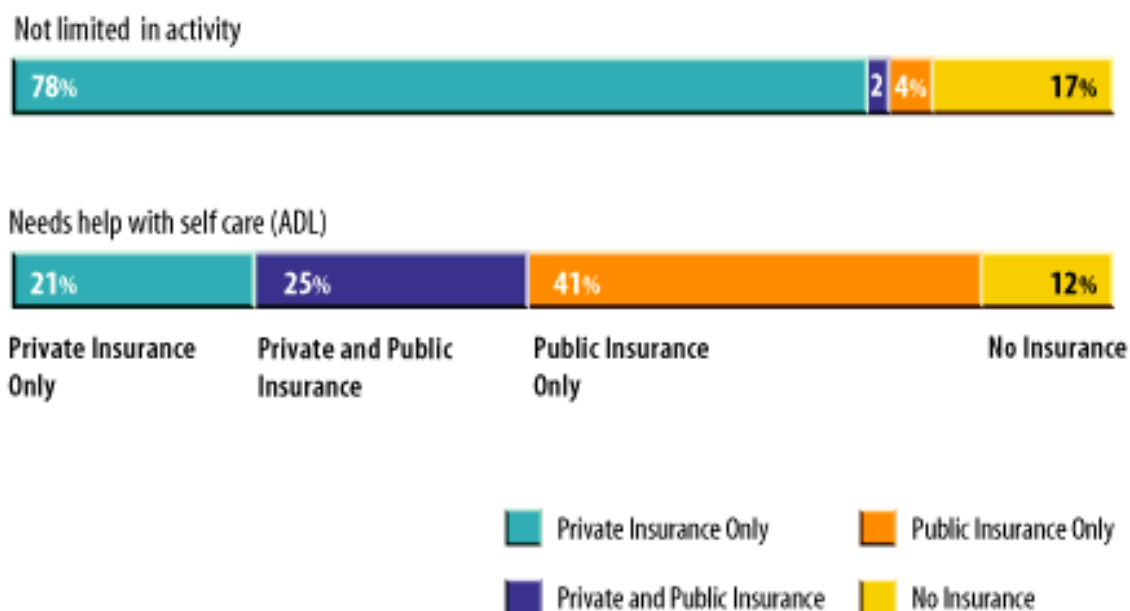
Health Care Financing Review, Fall 1994, 16(1): 291.

» [Continue](#)

» [How Is Chronic Care Financed?](#)

Chronic Conditions Limit Access to Private Insurance, Force Reliance on Public Insurance

Health Insurance Distribution of Working-Age Adults, by Disability Status, 1989



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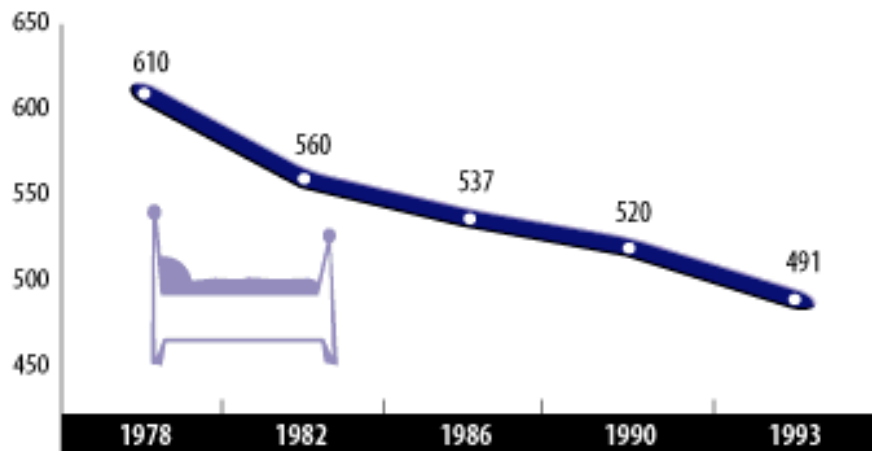
SOURCE:

LaPlante, M.P. *Disability, Health Insurance Coverage, and Utilization of Acute Health Services in the United States*. Disability Statistics Report (4). Washington, D.C.: National Institute on Disability and Rehabilitation Research. Table D, p. 18, 1993.

» Trends in Chronic Care

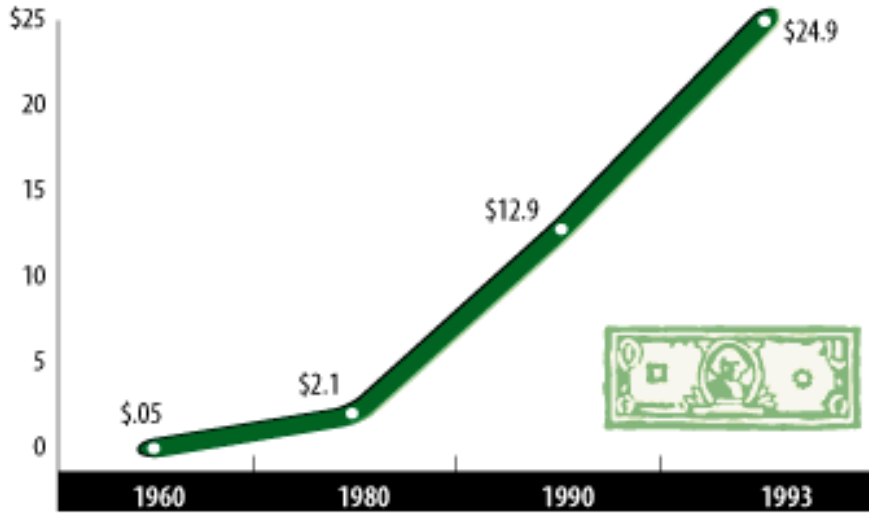
Nursing Home Beds Down, Home Care Expenditures Up

Licensed Nursing Home Beds per 1,000 Population Aged 85 and Over

**SOURCE:**

DuNah, R., Harrington, C., Bedney, B., Carrillo, H. "Variations and trends in state nursing facility capacity: 1978-1993." *Health Care Financing Review* 16(5): 1-17, Table 2, 1995.

National Health Expenditures, for Home Health Care, Facility-Based and Non-Facility-Based, Selected Years 1960-93 (in billions)



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NOTE:

Expenditures include facility-based home health care providers.

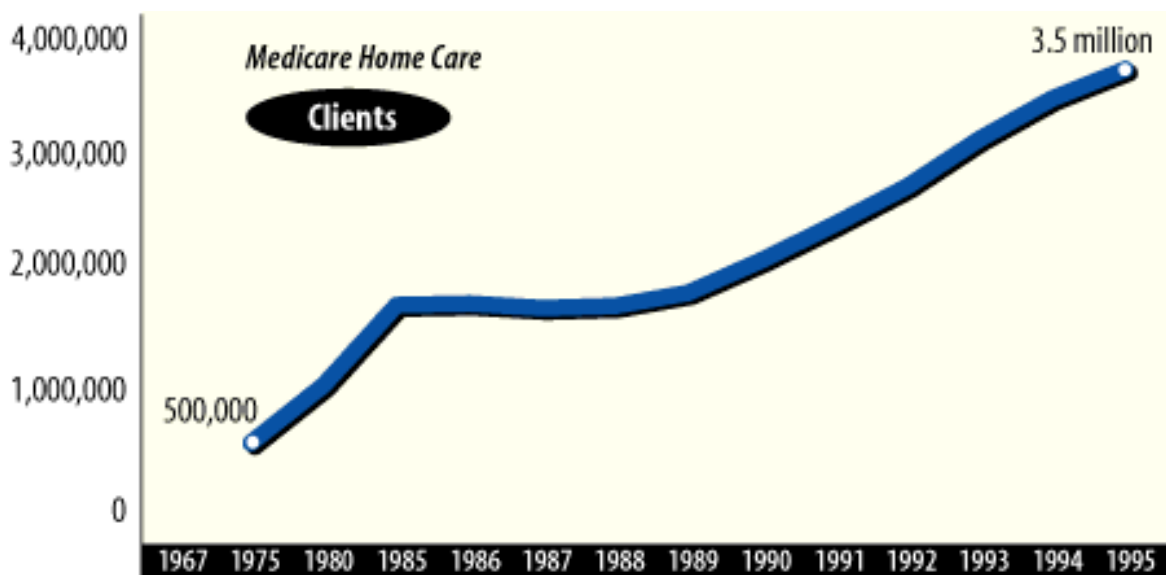
SOURCE:

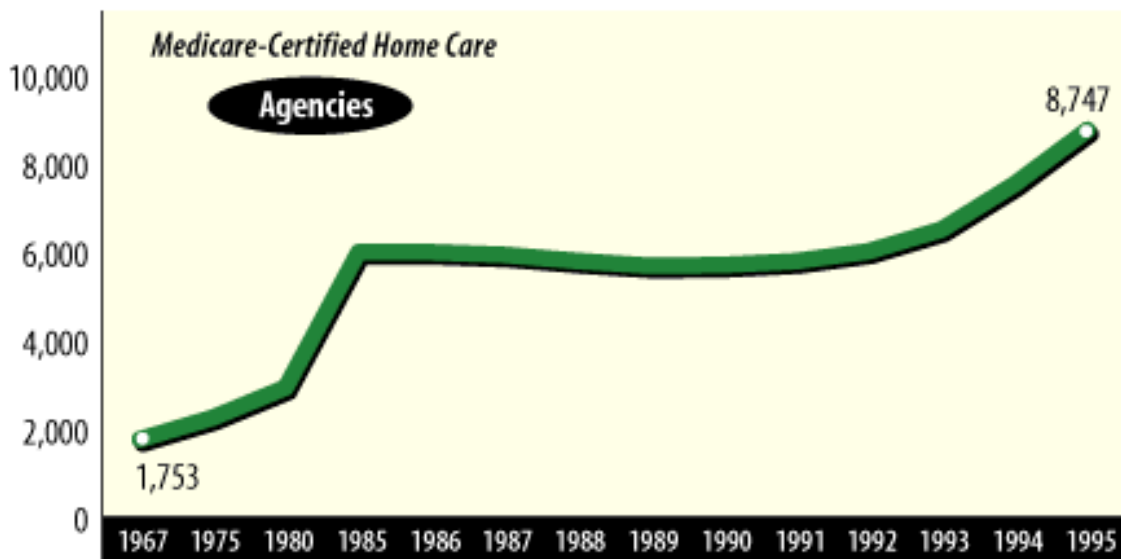
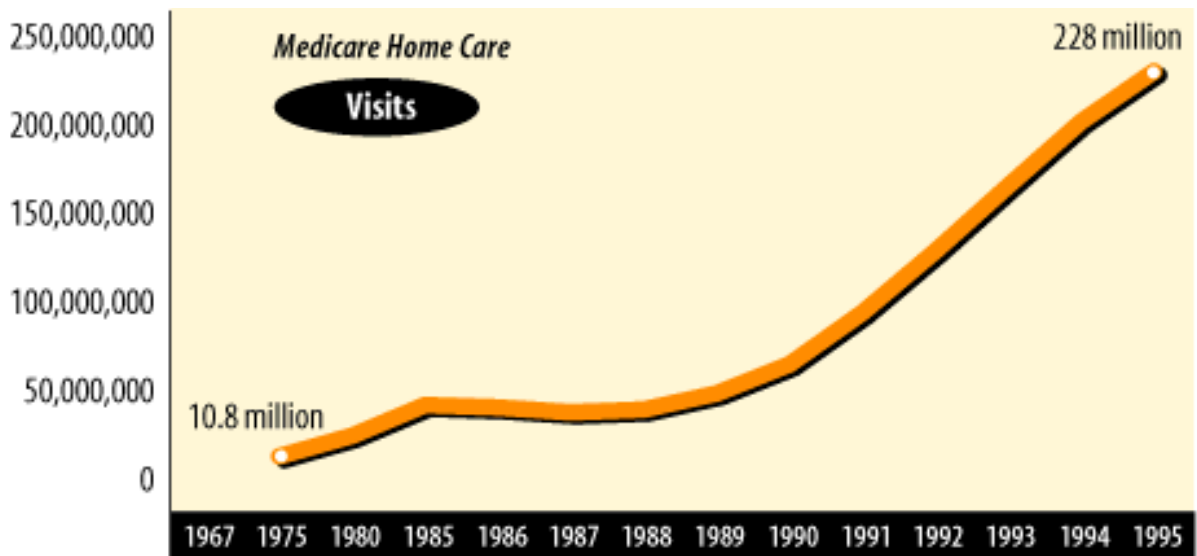
Health Care Financing Review, Fall 1994, 16(1): 257.

[» Continue](#)

» Trends in Chronic Care

Increasing Numbers of Persons with Chronic Conditions Receiving Care at Home





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SOURCE:

National Association for Home Care. "Basic Statistics About Home Care." September 1995. From data by the Health Care Financing Administration, Office of Survey and Certification (number of agencies), and the Health Care Financing Administration, Office of the Actuary (numbers of clients and visits).

» [Continue](#)

» What Is Chronic Care?

fact sheet

Chronic Care Is Different from Acute Care

Goals of Care

acute: To restore a person to previous level of functioning, if possible.

chronic: To maintain independent living, if possible, facilitate successful personal and social adjustment, and minimize further deterioration of physical and mental health. By definition, does not aim to "fix" or "cure."

Providers of Care

acute: Specially trained providers in institutions set up precisely for acute care purposes.

chronic: Multiple sources, including an often unorganized network of relatives, friends, and community services along with hospitals, home health care, and social service agencies. Chronically-ill people and caregivers find that few experts know how to organize a full regimen of chronic care.

Scope of Care

acute: Medical care primarily.

chronic: Broad scope of social, community, and personal services, as well as medical and rehabilitative care.

Quality of Care

acute: Significant government investment in outcome measures and quality of care standards for most hospital-based acute conditions.

chronic: Relatively few measures to date to assess the quality of care provided by home health agencies, community-based agencies, ambulatory care clinics.

» [Continue](#) for part 2 of this fact sheet

» What Is Chronic Care?

fact sheet

Chronic Care Is
Different from
Acute Care

Organizations Involved in Care

acute: Typically occurs within one institution.

chronic: Requires interorganizational collaboration. At its most complex, integrates person's primary care, acute care, and long-term care needs. Might involve local health centers, hospitals, and community service agencies. Caregiver "team" might include primary care physician, specialists, social workers, nurse practitioners, home aides, and family members.

Private Insurance for Noninstitutional Care

acute: Finances about 45 percent of the direct medical costs of acute conditions.

chronic: Finances 33 percent of the direct medical costs of chronic conditions.

[Note: expenditures do not include institutional services, primarily nursing homes] Public Financing for Noninstitutional Care (primarily Medicare and Medicaid)

Public Financing for Noninstitutional Care (primarily Medicare and Medicaid)

acute: Finances about 20 percent of the direct medical costs of acute conditions.

chronic: Finances over 40 percent of the direct medical costs of chronic conditions. However, public financing of community-based services is patchy and complex, which discourages many people from using them.

[Note: expenditures do not include institutional services, primarily nursing homes]

» [Continue](#)

What Is Chronic Care?

● **Personal Assistance:**


This care is generally not medical in nature. Instead it focuses on helping people perform basic activities of daily living (ADLs), such as getting out of bed, using the bathroom, dressing, and eating, and can involve friendly visiting, or help with work or leisure activities. It is typically provided in a home or community setting by relatively low-skilled workers. Personal assistance is required by both those who most likely will not regain former levels of independence and functioning, and those who temporarily have less function. The amount of personal assistance services provided in the community is growing at a very fast rate, largely funded by the chronically ill themselves (out-of-pocket) or by Medicaid. Personal assistance also is provided in nursing homes or other residential settings.

Chronic Care Services

- inpatient and outpatient medical and nursing care
- home health care

- homemaker services
- adult day care
- nursing home care
- help with activities of daily living such as dressing, bathing, and eating
- rehabilitative therapies
- housing with supportive services

» [Continue](#)

A banner image featuring a collage of diverse human faces in various colors (purple, green, yellow, blue).

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[The Changing Nature of Illness and Death Contributes to Increased Numbers of Chronic Health Conditions - CMYK](#) Size:202K

[The Changing Nature of Illness and Death Contributes to Increased Numbers of Chronic Health Conditions - Grayscale](#) Size:80K



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[Americans Are Living Longer - CMYK](#) Size:418K

[Americans Are Living Longer - CMYK](#) Size:135K



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[Elderly Population Is Increasing... And the Average Age Will Be Older - CMYK](#) Size:469K

[Elderly Population Is Increasing... And the Average Age Will Be Older - Grayscale](#) Size:149K



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[Greater Numbers of People Will Be Limited by Chronic Conditions - CMYK](#) Size:379K

[Greater Numbers of People Will Be Limited by Chronic Conditions - Grayscale](#) Size:125K



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[One in Five Disabled Persons Needs Help with Basic Daily Activities - CMYK](#) Size:334K


[One in Five Disabled Persons Needs Help with Basic Daily Activities - Grayscale](#) Size:120K



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[Chronic Conditions Include a Broad Spectrum of Disabilities - CMYK](#) Size:144K

[Chronic Conditions Include a Broad Spectrum of Disabilities - Grayscale](#) Size:59K



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[Five Most Disabling Chronic Contions - CMYK](#) Size:165K

[Five Most Disabling Chronic Contions - Grayscale](#) Size:58K



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[The Numbers of Americans with Chronic Conditions Is Expected to Rise - CMYK](#) Size:676K


[The Numbers of Americans with Chronic Conditions Is Expected to Rise - Grayscale](#) Size:194K



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[Only 1 in 4 Living in the Community with a Chronic Condition Is Elderly - CMYK](#) Size:272K

[Only 1 in 4 Living in the Community with a Chronic Condition Is Elderly - Grayscale](#) Size:86K



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[Selected Chronic Conditions by Age Group - CMYK](#) Size:156K

[Selected Chronic Conditions by Age Group - CMYK](#) Size:67K



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[Growing Numbers Report Activity Limitations Due to Chronic Condition - CMYK](#) Size:255K

[Growing Numbers Report Activity Limitations Due to Chronic Condition - Grayscale](#) Size:99K

» [Who Is At Risk for Chronic Conditions?](#)

Chronic Conditions Affect All Ages

Infants and Children (under 18)

In 1994, almost five million children (6.7 percent of all children, or about one in every 15) had activity-limiting chronic conditions. The proportion of children with activity-limiting chronic conditions has tripled since 1960, although this dramatic increase may be due partly to new methods of collecting and analyzing the data. Chronic illnesses including cerebral palsy, spina bifida, and autism account for a quarter of the chronic conditions in infants and children.

Contrary to common belief, the large majority of children with even the most severe impairments neither die early in life, nor depend on major medical technologies to live at home.

The impact of chronic conditions on the child and his or her family varies by impairment or illness. Nevertheless, families of children with chronic conditions share a common set of challenges: high health care costs, greater caretaking responsibilities, obstacles to adequate education, and the additional stress these issues create for the entire family.

» [Who Is At Risk for Chronic Conditions?](#)

Chronic Conditions Affect All Ages

Diabetes is the leading cause of new blindness and nontraumatic amputations in working-age adults.

40 percent of the 3.3 million Americans with serious mental illness are working-age adults who are limited in ability or unable to work.

Over six million middle-aged adults have heart disease, the number one cause of death in the U.S.

Working-Age Adults (18-64)

One in seven working-age adults -- 23 million men and women -- were limited in their activities by a chronic condition in 1994.

One in ten (11 million) young adults (18-44) had an activity-limiting chronic condition. Nearly a quarter of the activity-limiting conditions in young adults involve problems of the spine and back. Degenerative chronic illnesses begin to surface in young adulthood: high blood pressure and arthritis are among the ten most prevalent chronic conditions in this age group, each affecting nearly six million young adults.

Almost a quarter of all middle-aged adults (45-64) were limited by a chronic condition in 1994, and more than 40 percent of these persons were unable to carry on their major activity, be it a paying job or housework. Middle-aged adults are more than twice as likely to be limited by their chronic conditions as young adults.

» [Continue](#)

» [Who Is At Risk for Chronic Conditions?](#)

Chronic Conditions Affect All Ages

The health problems of elderly adults are not all alike. Among seniors age 65-84, chronic diseases such as arthritis, high blood pressure, and heart disease are the most prevalent and are the leading causes of disability as well. Among people 85 and older, chronic diseases continue to disable, but the combination of intellectual and sensory impairments (particularly visual impairments) cause as much disability as chronic disease.

Senior Citizens (65 and over)

In 1994, nearly 40 percent of the elderly not living in institutions -- 12 million seniors -- were limited by chronic conditions. Of these, three million (about 10 percent of all elderly) were unable to perform activities associated with independent living (such as bathing, shopping, dressing, or eating). In addition, an estimated 1.5 million elderly needing long-term care live in nursing homes.

While it is true that the elderly are more likely to have a chronic condition, they account for only about a quarter of all persons who live with chronic conditions. However, several of the conditions most prevalent among the elderly tend to be disabling, which accounts for the high rate of disability in this age group. Conditions such as arthritis, high blood pressure, and heart disease may begin in middle age, but often progress in terms of severity of symptoms and the degree to which they limit a person, as the person ages.

» Who Is At Risk for Chronic Conditions?

Chronic Conditions Affect All Ages

Increasing numbers of low-income youth have activity-limiting conditions due to acts of violence and accidents.

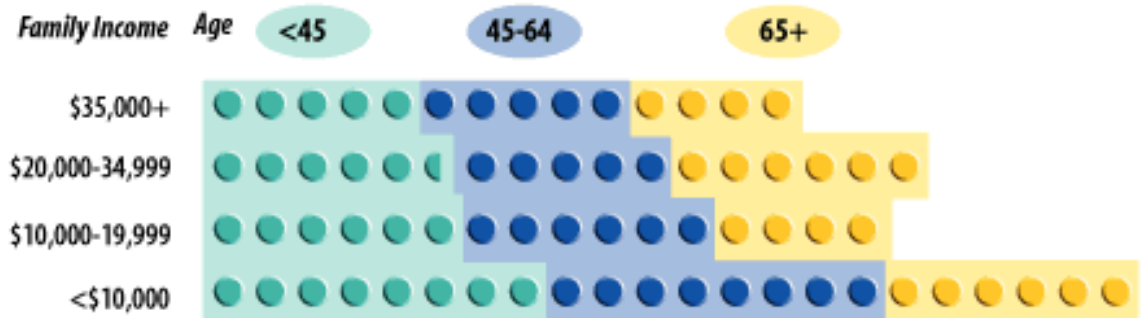
Babies born to low-income mothers are at risk for low birthweight, which is associated with lifelong developmental disabilities.

People in Poverty

People living in poverty are more vulnerable than most to the risks, situations, and illnesses that can result in permanent activity-limiting conditions. Certain conditions, such as asthma, arthritis, diabetes, high blood pressure, and heart disease, are more prevalent among poor Americans.

Certain Chronic Conditions Related to Poverty

Number of Persons with Asthma per 1,000 Persons, by Family Income, 1994




Each dot represents 10 people

SOURCE:

Guralnick, Jack M., et al. "Aging in the Eighties: The Prevalence of Comorbidity and Its Association with Disability." *Advance Data from Vital and Health Statistics*, No. 170. Hyattsville, MD: National Center for Health Statistics, 1989.

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[Nearly 40 Million Americans Have More Than One Chronic Condition - CMYK](#) Size:378K

[Nearly 40 Million Americans Have More Than One Chronic Condition - Grayscale](#) Size:113K



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[Majority of People with More Than One Chronic Condition Are Middle-Aged or Older - CMYK](#) Size:132K

[Majority of People with More Than One Chronic Condition Are Middle-Aged or Older - Grayscale](#)
Size:50K

» [Who Is At Risk for Chronic Conditions?](#)

Chronic Conditions Affect All Ages

People with More Than One Chronic Condition

A "comorbidity" -- the technical term for having more than one condition at a time -- adds to a person's health burden. Over 40 percent of people with any kind of chronic condition, from sinusitis to heart disease, have more than one condition to manage. When the conditions are serious, comorbidity puts people at greater risk of disability, and can result in physical limitation (such as the inability to walk) and role limitation (such as not being able to work).

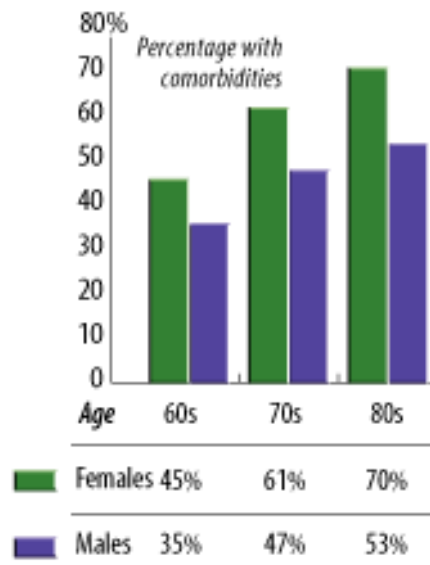
People with more than one chronic condition have substantially more physician contacts and are more likely to be hospitalized each year than those with only one chronic condition. They are also far more likely to have difficulty with their personal care. As a person's chronic conditions increase in number, so do his or her chances of being limited in the basic activities of daily living (such as eating and bathing).

The risk of comorbidity is greatest among the elderly.

As the elderly age, they face an increasing risk of having multiple chronic conditions.

Although comorbidities tend to accumulate with age, over two million children have more than one chronic condition. Compared to those with only one chronic condition, these children are more likely to be limited in their activity, experience more days spent in bed, and have more school absences.


Women Have More Comorbidities Than Men



SOURCES:

Guralnick, Jack M., et al. "Aging in the Eighties: The Prevalence of Comorbidity and Its Association with Disability." *Advance Data from Vital and Health Statistics*, No. 170. Hyattsville, MD: National Center for Health Statistics, 1989.

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[Adding Indirect Costs Brings the Costs of Chronic Conditions to \\$659 Billion - CMYK](#) Size:373K

[Adding Indirect Costs Brings the Costs of Chronic Conditions to \\$659 Billion - Grayscale](#) Size:109K

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[Almost Two-Thirds of Chronic Health Care Dollars Are Spent on Hospital Care and Physician Services - CMYK](#) Size:258K

[Almost Two-Thirds of Chronic Health Care Dollars Are Spent on Hospital Care and Physician Services - Grayscale](#) Size:106K



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[Medical Care Costs More for People with Chronic Conditions - CMYK](#) Size:243K

[Medical Care Costs More for People with Chronic Conditions - Grayscale](#) Size:90K

How Much Do Chronic Conditions Cost the U.S.?


The Opportunity Costs of Chronic Care

America's lack of investment in an adequate system of chronic care carries an opportunity cost; that is, when money is spent on "X" -- usually acute care services -- it is not available to spend on "Y" -- early, up-front prevention and treatment of chronic conditions, or coordinated systems of supportive services.

Examples:

More money spent on...	could mean	Less money spent on...
screening, nutrition, education to prevent heart attacks	emergency room treatment and subsequent care for a heart attack victim
relatively inexpensive preventive care for a person with diabetes	complications leading to amputation and lifelong disability
breast cancer screening for early detection, when treatment is less expensive and more effective	chemotherapy, radiation or surgery for breast cancer
modest cost of installing a handrail to prevent falls	hip replacement surgery
adult day care	nursing home care

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Chronic Care in America: A 21st Century Challenge

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[Public Funds Pay the Largest Share of Direct Chronic Care Costs - CMYK](#) Size:276K

[Public Funds Pay the Largest Share of Direct Chronic Care Costs - Grayscale](#) Size:100K

How Is Chronic Care Financed?

Medicare, like Social Security, is an example of a social insurance benefit. All people over age 65 and younger people with a certain level of disability are entitled to receive Medicare. Medicare dollars come from Federal tax revenues and premium payments. The program pays for acute medical care, skilled nursing in the home, and a limited number of home health care visits.

The fact that Medicare -- contrary to popular belief -- does not finance most nursing home and home care services has led to public confusion and general lack of preparation for the potentially catastrophic financial risk of paying for chronic care for the elderly.

Medicaid is a "means-tested" program, which finances medical care for the poor and near-poor (those who lack the financial means to pay for health care). In 1993, poor elderly and non-elderly disabled represented 27 percent of total Medicaid enrollees, but used 59 percent of all Medicaid dollars. Impoverished adults and children, on the other hand, represented 73 percent of enrollees, but consumed only 27 percent of all Medicaid dollars. (The remaining 14 percent of Medicaid expenditures were payments to "Disproportionate Share Hospitals," a category of hospital that serves a great number of indigent patients.)

Disabled and Elderly Are Main Recipients of Medicaid	
Average Medicaid Payments per User, Eligibility Group, 1993	
Children	\$1,013
Adults 18-64	\$1,813
Disabled and Blind	\$7,706
Elderly	\$8,168

SOURCE:

Health Care Financing Administration.
"Statistical Report on Medical Care: Eligibles,
Recipients, Payments and Services, HCFA
Form-2082." *Health Care Financing Review*,
1995 Statistical Supplement, table 112.


» [Continue](#)



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[Long-Term Care Costs Drain Both Public and Individual Resources - CMYK](#) Size:391K

[Long-Term Care Costs Drain Both Public and Individual Resources - Grayscale](#) Size:126K



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[Chronic Conditions Limit Access to Private Insurance, Force Reliance on Public Insurance - CMYK](#)

Size:260K

[Chronic Conditions Limit Access to Private Insurance, Force Reliance on Public Insurance - Grayscale](#)

Size:85K

How Is Chronic Care Financed?

Government is relied upon for such a large share of the costs of chronic conditions in part because millions of Americans have no private health insurance; and, importantly, the most disabled people are the least likely to be privately insured.

Working-age disabled adults are far less likely than others to be able to obtain private health insurance coverage, particularly if they are unable to work. The more disabled a person is, the less chance of securing private insurance, while the likelihood increases of qualifying for public insurance such as Medicare or Medicaid. For example, among severely disabled working-age adults (who need help with self care), about 40 percent are covered solely by public insurance and another 25 percent have a combination of public and private insurance. In contrast, 78 percent of people without disabilities have private health insurance and only about 4 percent are covered solely by public insurance.

Another potential problem for people with chronic conditions is being underinsured -- the risk that an individual or family will have high out-of-pocket expenses for medical care because their insurance coverage is restricted and pays only part of their costs.

» [Continue](#)

Trends in Chronic Care


● **Home care and other community-based alternatives**

People with functional limitations who once might have gone to a nursing home now have alternatives, such as home care, assisted living, and adult day care. Perhaps the single most salient trend in chronic care is the rapid emergence of home health care as a multifaceted source of services, ranging from intravenous infusion of medications to physical therapy. Between 1979 and 1990, the number of home health agencies providing Medicare services doubled. Agencies that cater to private payers increased in number as well, primarily among for-profit and hospital-based home health agencies. Home care expenditures almost doubled between 1990 and 1993. The average home care visit in 1993 cost about \$66. Yet the quality of home care services varies widely because the industry does not have consistent standards, accrediting or licensing requirements, and few formal credentials are required for home health aides.

In sum, this state of flux represents both risks and opportunities: there is an opportunity for services to become more person-centered and responsive, and for inefficient bureaucracies to be replaced. At the same time, questions remain of how to effectively target and allocate services within limited budgets, and of how

best to measure and monitor the quality of care delivered by a widening range of personnel in an expanding array of settings.

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[Nursing Home Beds Down, Home Care Expenditures Up - CMYK](#) Size: 275K

[Nursing Home Beds Down, Home Care Expenditures Up - Greyscale](#) Size: 102K



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[Increasing Numbers of Persons with Chronic Conditions Receiving Care at Home - CMYK](#) Size: 241K

[Increasing Numbers of Persons with Chronic Conditions Receiving Care at Home - Greyscale](#) Size: 89K

Managed Care: Promise vs. Reality

The promise...

Managed care holds great promise for providing the range of integrated services required by people with chronic conditions. One underlying reason for this is the capitation system of financing on which many managed care plans are based, in whole or in part.

The basic idea behind capitation is that each provider receives a pool of funds (a given amount per patient) in advance of treatment. In contrast, more traditional forms of financing -- under commercial indemnity insurance or fee-for-service Medicare, for example -- use a system in which services are provided on a pay-as-you-go basis. Under a capitated system, providers should have the flexibility to treat a patient with a chronic condition, or refer him or her to an appropriate mix of medical and non-medical services. Ideally, membership in an HMO or similar prepaid health plan could enable an individual to have access to an array of services for a single fee.

A capitated system of care has another advantage to a person with chronic conditions. It provides a financial incentive for keeping people healthy and functioning

as fully as possible. Hence, managed care programs should and often do emphasize prevention services and attempt to avoid use of emergency rooms and costly acute care services, except when necessary.

» [Continue](#)

Sources of Chronic Care

Supportive Housing

Supportive housing includes housing units that have been modified (via handrails, ramps, or emergency call buttons) or service-enriched (such as on-site case management or homemaking help) to enable persons with disabilities (especially the frail elderly) to remain as independent as possible. Examples of supportive housing include assisted living facilities, continuing care retirement communities (CCRCs), and board-and-care homes. The services provided range from housing modifications, to case management, to the linking of housing facilities with outside providers of the services residents require. Board-and-care homes and assisted living facilities typically provide room, board, and some degree of supervision or 24-hour protection and oversight.

There are an estimated 2.9 million individual dwelling units that have been modified with supportive features such as grab bars and handrails. In addition, there are up to 450,000 persons living in continuing care retirement communities, and an estimated 1 million people living in licensed and unlicensed board-and-care and assisted living facilities. Service-enriched housing developed by the U.S. Department of Housing and Urban Development currently serves an estimated 1.76 million people.

How Is Chronic Care Financed?

Medicaid has traditionally paid for acute care and also chronic care such as nursing home care, home and community-based health and social services, and care within other residential settings, such as facilities for persons with mental retardation. As this book goes to press, both the Medicare and the Medicaid program are under intensive review. The fact that Medicaid does finance long-term chronic care services has led to financial strains on the program. Since few people have private long-term care insurance to cover the high costs of nursing home care, many chronically ill people find their savings depleted by the costs of care. They quickly impoverish themselves and therefore become eligible for Medicaid financing of nursing home and home care services.

Because Medicaid benefits are funded by both federal and state revenues, and because Medicaid's role as a funder of chronic care has grown rapidly, state governments (which cannot rely on deficit financing) have become increasingly interested in seeking alternatives to expensive nursing home care. For instance, the federal government has allowed limited experimentation in the areas of home and community-based benefits under the Medicaid program. In addition, due to the popularity of home and community-based care, several states have committed state funds to pay for such services, without

the support or the constraints of the federal government.

Smaller federal programs (funded under the Older Americans Act, the Rehabilitation Act, and Social Services Block Grants) also finance selected chronic care services, sometimes at the discretion of individual states.

» [Continue](#)

» How is Chronic Care Financed?

Confronting the Chronic Care Financing Challenge

New financing mechanisms are being demonstrated and evaluated both nationally and in smaller, state-level initiatives. These initiatives fully capitate (i.e., set a dollar limit for a given time period) payments on behalf of enrollees, and use (or in some cases, combine) money from Medicare, Medicaid, and premiums paid by enrollees. Two of these mechanisms are profiled below.

Partnership for All-Inclusive Care for the Elderly (PACE)

Who:

- Frail elderly people who are certified as needing a nursing home level of care.

Goal:

- To enable the participant to continue living in the community by financing all necessary medical, restorative, social, and supportive services.

Description:

- A multidisciplinary professional team assesses participant needs, formulates care plans, directly delivers most services (including primary care), manages the care given by contracted providers, monitors treatment results, and adjusts the care plan as needed.
- Utilizes the day health center as its primary delivery setting
- Features a comprehensive, consolidated service package, expert case management, prepaid financing under pooled capitation payments by Medicare and Medicaid, and assumption of risk by the provider.

» [Continue](#)

» [How is Chronic Care Financed?](#)

Confronting the Chronic Care Financing Challenge

Social Health Maintenance Organization (S/HMO)

Who:

- Primarily functionally independent older adults and some functionally impaired/frail elderly.

Goal:

- To integrate acute and some extended care services for older adults under the Medicare program, and to prevent or delay nursing home placement

Description:

- Coordinates acute and some chronic care services within a managed care setting and refers the individual to appropriate services based on an evaluation of the individual's needs.
- Uses a case management system to coordinate and authorize long-term care services for enrollees who meet certain disability criteria

- Funding provided through prepaid capitation of pooled Medicare and Medicaid dollars, as well as enrollee premiums. Voluntarily enrolled Medicare beneficiaries pay a monthly premium and assign their Medicare benefits to the S/HMO.

» [Continue](#)

How Is Chronic Care Financed?

Are initiatives in private long-term care insurance a way to finance chronic care?

Is privately purchased long-term care insurance a solution to the problem of how to finance home care and nursing home services for Americans? Perhaps.

Privately purchased long-term care insurance generally covers nursing home care, skilled nursing care in the home, home health care, personal care, and adult day care, among other things. These insurance policies vary in terms of guaranteed renewability, guards against inflation, stipulations regarding preexisting conditions, waiting periods, and duration of benefits; some also have age limitations for eligibility.

Although more insurance companies are offering such policies, and a growing (but still small) number of people are purchasing them, private long-term care insurance still represents only a fraction of the total financing "pie."

Though the private insurance market may continue to expand, many policymakers hold that private insurance alone cannot be relied upon to resolve basic problems in financing nursing home care, home care, and other chronic care services. Long-term care financing, they argue, must continue to be seen as a complex issue requiring public discussion and action.

Several other innovations in long-term care financing have emerged and are being tested. Among them are the so-called long-term care insurance "partnership" models, which combine private long-term care insurance with Medicaid funds at the state level. In addition, several states are considering or have created various social insurance approaches to pay for long-term care, including statewide trust funds.

Long-Term Care Policies Increasingly Popular, But Still Not Highly Prevalent



NOTE:

Long-term care policies include a variety of plans: individual, group association, employer-sponsored, and accelerated death benefits specifically for long-term care.

SOURCE:

Coronal, S. "Long-term care insurance in 1992." Health Insurance Association of America. Washington, D.C., February 1994.

» [Continue](#)

Trends in
Chronic Care

Managed Care: Promise vs. Reality

The reality...

In reality, the managed care industry is just beginning to recognize and respond to the needs of people with chronic conditions. Some HMOs do offer important preventive measures for people with chronic conditions. For instance, research has found that some HMOs:

- arrange for handrails to be placed in the homes of people who are frail or disabled;
- create support groups for patients;
- screen enrollees to identify those with chronic problems;
- provide early intervention services.

However, the managed care industry overall has yet to implement these and other practices that would meet the needs of people with chronic conditions. Some spokespeople representing the disability and chronic illness community complain that because they are potentially heavy users of expensive services, they have been shunned from managed care plans. Others who are enrolled in managed care plans report being denied access to treatment and services that they need, and of being assigned to primary care physicians who are not as well-acquainted with their condition as a specialist might be.

» [Continue](#)

Trends in
Chronic Care

Managed Care: Promise vs. Reality

The future possibilities...

As the population ages, and as managed care spreads throughout the public and private health sectors, the hope is that managed care can evolve to better serve the needs of people with chronic illness and disability. How might it do so? By:

- integrating primary, preventive, and specialty care;
- coordinating medical care with home and community-based services;
- including the patient in the decision-making process;
- responding to the episodic nature of chronic care.

» [Continue to Part III](#)

Sources of Chronic Care

Other Services

Among the other supportive services currently available in some areas are respite care, adult day care, and hospice care. These services are provided by various agencies, in settings ranging from the individual's home to facilities built especially for providing the service. Respite care involves short-term care that attends to the needs of the person with a disability, allowing his or her informal caregiver (e.g., a family member) to attend to other matters, or to rest. Adult day care programs provide a mix of health, social, and related support services to persons with functional impairments. This care is delivered within a designated facility, for periods less than 24 hours in duration. Hospice care is delivered in a person's home, or in a homelike setting, and is designed to meet the physical, emotional, and spiritual needs of those who are nearing death. Hospice care includes pain management, and focuses on working with the dying person's immediate family, the clergy, and the person's medical care providers.

Nursing Homes

Nursing homes today vary widely in size, ownership, and mission. In general, nursing homes are defined as institutional, convalescent settings providing care for people with chronic illness, and for those recovering from an acute illness. The most recent estimate of the

number of nursing homes indicates that there are approximately 15,500 facilities, housing approximately 1.5 million people at any given time. Beyond room and board, nursing homes provide services ranging from care and supervision for persons with Alzheimer's disease to sophisticated medical care such as ventilator care or infusion therapy. In addition, some nursing homes offer rehabilitative care, dietary guidance, and social services, among other services.

» [Continue](#)

Widespread Unmet Need

Today, many people who have lost or never acquired the ability to perform basic tasks of daily living receive care through a system that simply does not help them enough. Thousands of health care and social service programs (community-based, hospital-based, and volunteer) and several financing options, including Medicare and Medicaid, are already in place nationwide. Despite these efforts, many people with chronic conditions need, but are not getting, help with the elementary tasks of personal care and living in a complex world.

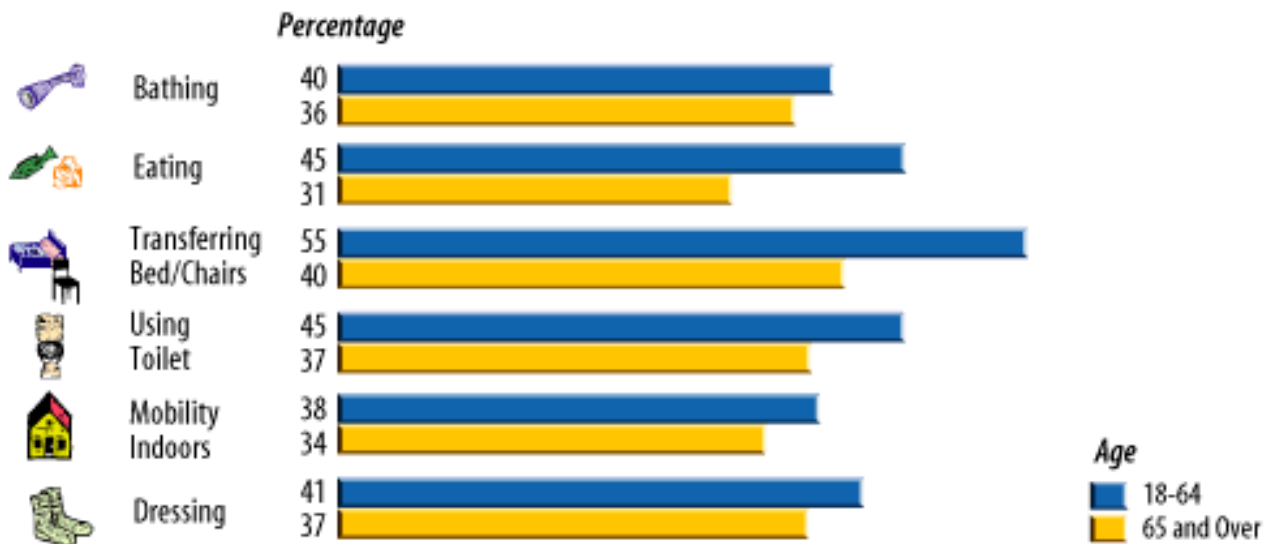
How does the fact that people's needs are going unmet create a stress in the nation's system of chronic care? Ultimately, unmet needs lead to exacerbated health problems, costly treatments, and unnecessary pain and suffering, some of which might have been avoided. Unmet needs of individuals, taken in the aggregate, result in a health care system that is burdened by increasing numbers of people with multiple or complex -- and often preventable -- chronic conditions, creating strain on personnel, resources, and financing.

[»Continue](#)

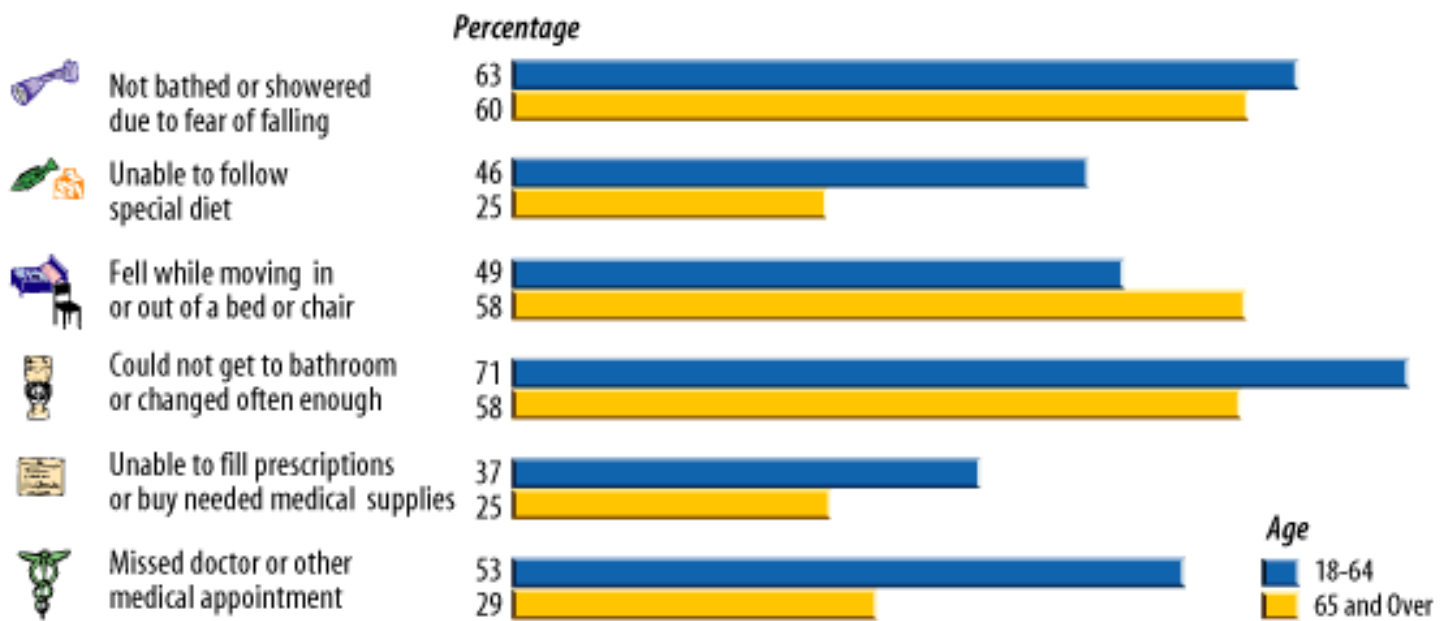
» Widespread Unmet Need

Without Assistance, Adverse Consequences Occur

Prevalence of Unmet Need for Assistance Among Persons with Need for ADL Help, by Age Group



The Consequences of Unmet Need for Help, by Age Group



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An individual's level of disability is frequently categorized based on the amount of assistance required in both basic and instrumental activities of daily living.


Activities of Daily Living (ADLs): dressing, eating, walking, and other include bathing, personal care activities.

Instrumental Activities of Daily Living (IADLs) include preparing meals, shopping, using the telephone, managing money, taking medications, doing light housework, and other measures of living independently.

SOURCE:

Mor, V. and Allen, S. Unpublished results from the Springfield, Massachusetts Study of Populations with Disabilities. Brown University, Providence, Rhode Island, 1994.

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[Without Assistance, Adverse Consequences Occur - CMYK](#) Size: 449K

[Without Assistance, Adverse Consequences Occur - Greyscale](#) Size: 152K

Widespread Unmet Need

This is not a new problem. Analysis of the 1984 National Long-Term Care Survey, based on 6,000 people living in the community and another 1,700 living in institutions, found:

- One-third of disabled elderly who live in the community report having unmet needs with activities of daily living, such as getting around inside the house, getting out of a bed or chair, bathing, dressing, eating, or using a toilet.
- Needs for adaptive equipment such as ramps, raised toilets, and extra-wide doors are not being met. For example, nearly one million elderly need, but do not have handrails in their residences. Lack of this simple piece of hardware increases the risk of falling, a known risk factor for severe injury and deterioration of health.

Analysis of the 1990 National Health Interview Survey showed:

- More than 2.5 million persons reported an unmet need for assistive technology devices such as wheelchairs, walkers, hearing aids, braces, and artificial limbs.

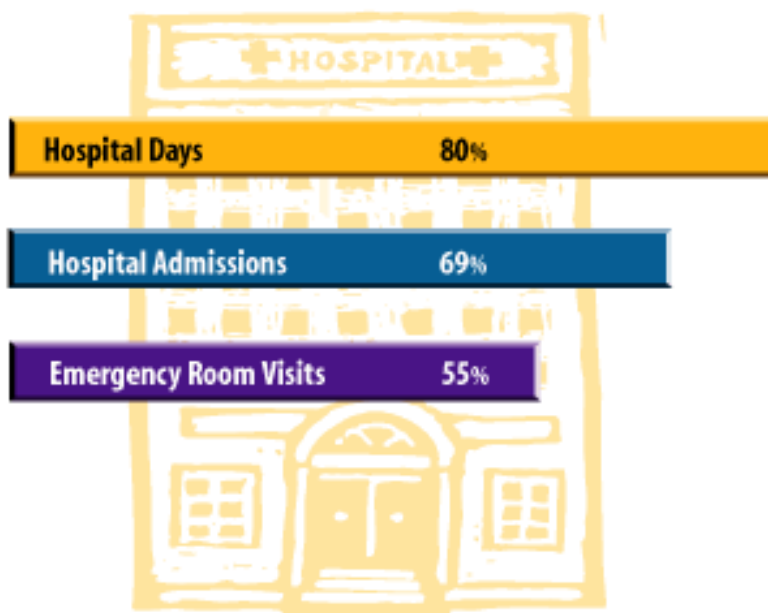
- Nearly half of those reporting unmet need for assistive technology devices were working-age (25-64 years old).
- 61 percent report the reason for not having the needed device is that they cannot afford it.
- According to another survey of family members, two out of three persons with severe mental illness need but do not have formal services that engage them in productive activities, such as school, employment, or structured day programs.

» [Continue](#)

» Extensive Use of Health Services

People with Chronic Conditions Use More Hospital-Based Services


Proportion of Medical Services Used by Persons with Chronic Conditions, by Type of Service



[Download](#)

SOURCE:

Hoffman, Catherine, and Rice, Dorothy P. Estimates based on the 1987 National Medical Expenditure Survey. University of California, San Francisco -- Institute for Health & Aging, 1995.



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[People with Chronic Conditions Use More Hospital-Based Services - CMYK](#) Size: 200K

[People with Chronic Conditions Use More Hospital-Based Services - Greyscale](#) Size: 80K

Crisis in Caregiving

But the supply is decreasing:

Among the factors that are at work shrinking the pool of possible caregivers are decreasing birth rates, and family networks that are getting smaller and more top-heavy, with more older than younger family members. Women have entered the work force in increasing numbers since the 1960s and are no longer as available as they once were for the traditional female role as unpaid family caregiver. People are marrying and having children at later stages of their lives, which may increase the size of the "sandwich generation," that is, those simultaneously caring for children and for their own parents or elderly relatives. As average family size decreases, fewer children will be available for caregiving, and sibling support networks will decrease in size.

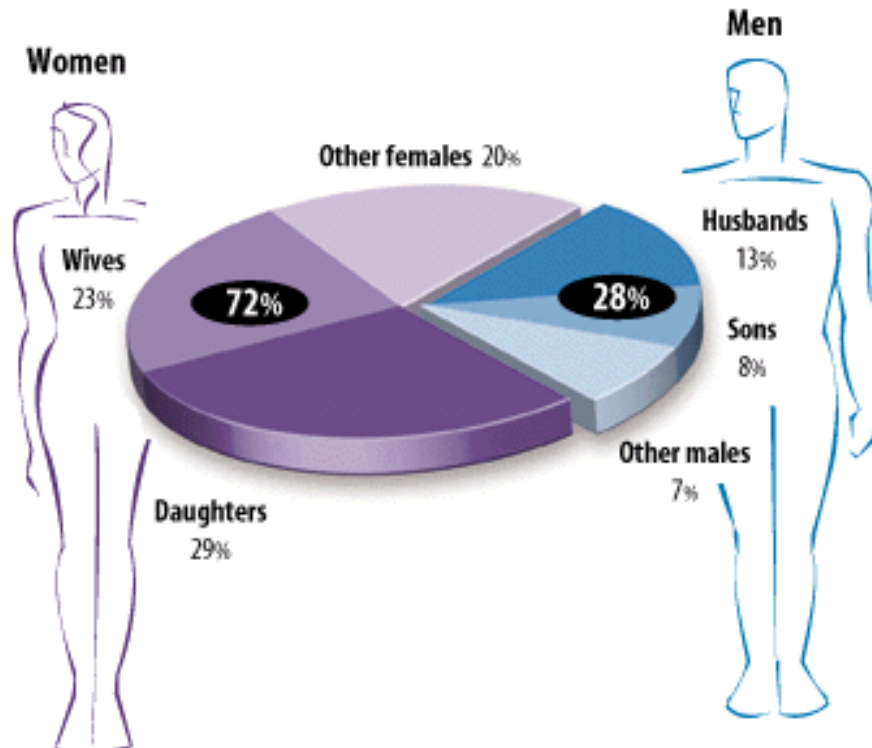
For instance, almost 60 percent of employed caregivers report that caregiving interferes with their work. Either they accommodate by working fewer hours, rearranging schedules, taking time off without pay, or they quit work altogether to become a full-time caregiver. Few companies have employee benefit policies, such as family illness days and flexible hours, to assist their employee caregivers.

» [Continue](#)

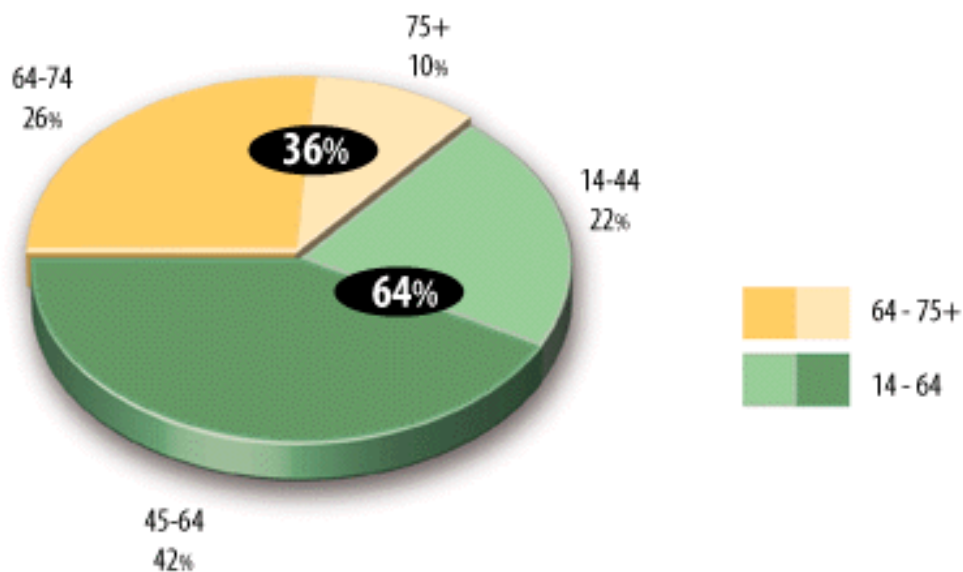
[» Crisis in Caregiving](#)

Most Caregivers are Middle-Aged Women

Who Are Caregivers?



Age of Caregivers



[Download](#)

Three out of four caregivers are women, many caring simultaneously for children or adolescents and parents. Their average age is 57, but one in four of these care providers is between ages 65 and 74, and 10 percent are over 75.


NOTE:

These data are drawn from the 1982 Long-Term Care Survey/Informal Caregivers Survey, which focused on two million caregivers aged 14 years or older who provide unpaid assistance to approximately 1.5 million impaired elderly persons needing help with one or more activities of daily living.

SOURCE:

House of Representatives Select Committee on Aging.
 "Exploding the Myths: Caregiving in America." Comm. Pub.
 No. 100-665. Washington, D.C.: U.S. Government Printing
 Office, August 1988.

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[Most Caregivers are Middle-Aged Women - CMYK](#) Size: 558K

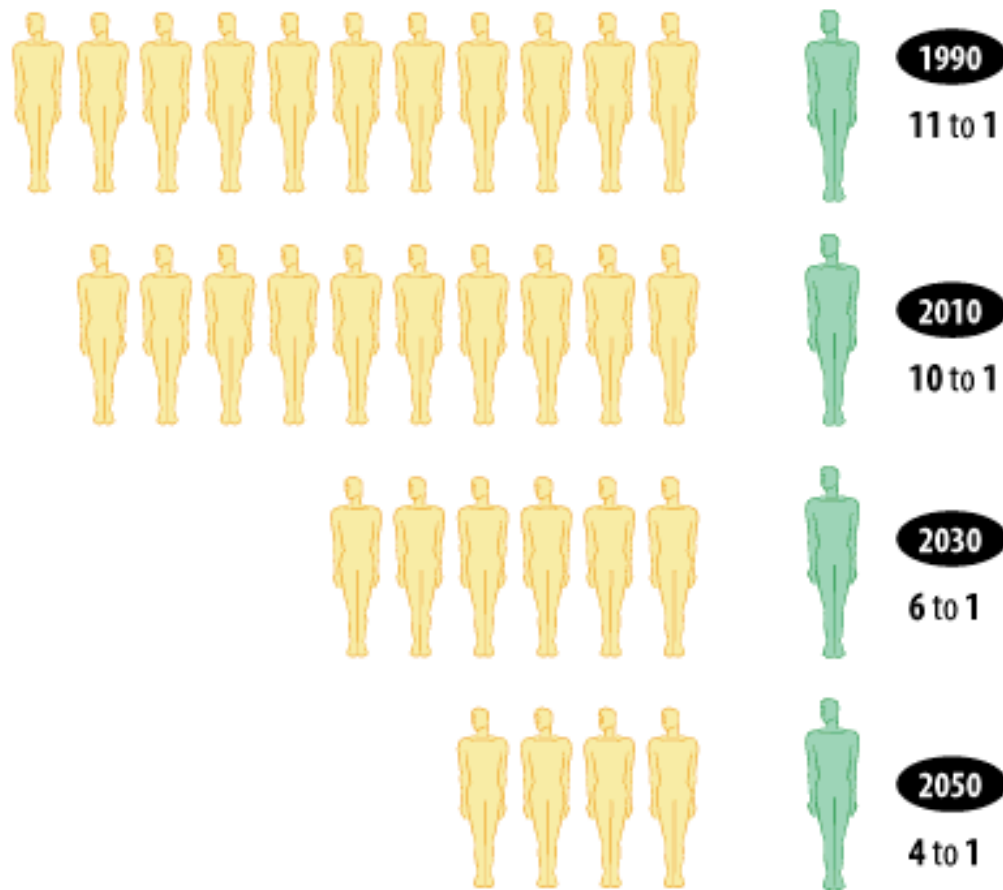
[Most Caregivers are Middle-Aged Women - Greyscale](#) Size: 170K

PART III Stresses in the System

Charts

» Crisis in Caregiving

The Shrinking Pool of Potential Caregivers

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In 1990, the ratio of the population in the average caregiving age range, ages 50 to 64, to the population aged 85 and older was 11 to 1. By 2050, there will be only 4 potential caregivers for every elderly person.

NOTE:


This ratio is the population aged 50-64 years divided by the population 85 years and older.

SOURCES:

1) U.S. Bureau of the Census. *Statistical Abstract of the United States: 1993* (113th edition) Washington, D.C., 1993. (1970 & 1990).

2) U.S. Bureau of the Census, *Current Population Reports, P25-1092, Population Projections of the United States, by Age, Sex, Race, and Hispanic Origin: 1992-2050*. Washington, D.C.: U.S. Government Printing Office, 1992. (2010-2030-2050).

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[The Shrinking Pool of Potential Caregivers - CMYK](#) Size: 265K

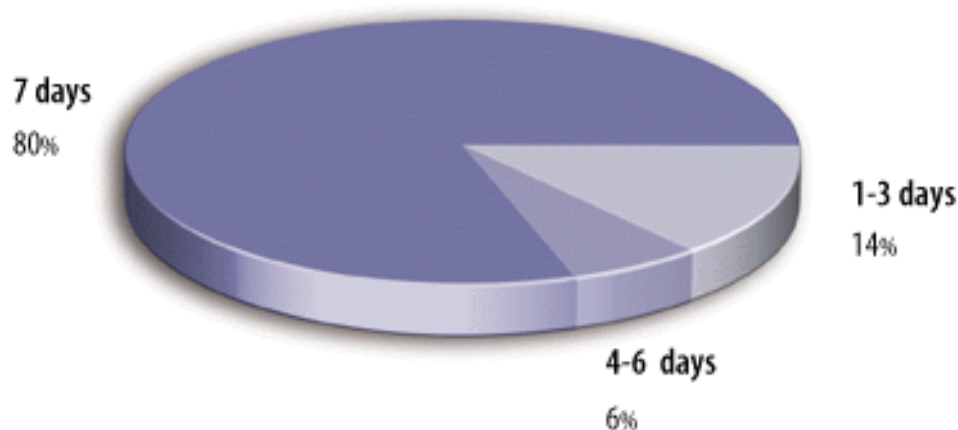
[The Shrinking Pool of Potential Caregivers - Greyscale](#) Size: 106K

» [Crisis in Caregiving](#)

Caregiving: More Than a Part-time Job

Elder-Caregiver Commitment

Percentage of Caregivers by Numbers of Helping Days per Week

[Download](#)

Eighty percent of caregivers for elderly disabled people provide help seven days a week, spending an average of four hours daily. Housekeeping, meal preparation, and shopping are common tasks, and two-thirds of caregivers also regularly help with feeding, bathing, dressing, and using the toilet.

Percentage of Caregivers by Caregiving Hours per Day

1-2 hours	42%
3-4 hours	25%
5+ hours	25%


NOTE:

Percentages may not total 100%.

SOURCE:

Stone. R, Cafferata, GL, and Sangl, J. "Caregivers of the frail elderly: A national profile." *The Gerontologist*, 27(5): 616-26, 1987.

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[Caregiving: More Than a Part-time Job - CMYK](#) Size: 239K

[Caregiving: More Than a Part-time Job - Greyscale](#) Size: 77K

PART IV Conclusion**Challenges for
the 21st Century****Creating the right mix of personal assistance and custodial care services.**

Communities, families, and individuals must rise to the challenge of meeting the needs of the chronically ill. Stigma, isolation, pain, and suffering can be addressed by community-wide volunteer efforts, and a commitment to fostering full participation of chronically ill citizens in community life. Enhancing the spirit of and commitment to volunteerism is vital -- and beneficial in that it generates increased community spirit and commitment to the common good. We also need adequate numbers of quality nursing homes and other forms of custodial care for those who cannot live outside an institution.

Creating processes to coordinate, manage, and allocate resources so that the right services get to the right people.

We will need to devise different means of delivering health care and related services. Creation of true system-wide integration, the development of tools and practices to emphasize functional styles and quality of life, and linking home and community services with medical care, are all critical challenges.

Medical science has made unprecedented strides in the 20th century toward curing and treating illness. For those who have and will have chronic conditions, however, their needs require not just a medical response, but a social, organizational, and economic one as well. As we move into the 21st century, U.S. health policymakers face a profound challenge: how to meet the needs of a rapidly growing number of Americans whose lives are circumscribed by long-term, debilitating chronic conditions.

» [Continue to Appendixes](#)

APPENDIXES

Profiles: Confronting the Chronic Care Challenge Today

Supportive
Housing

**Shawnee Health Service and
Development Corporation
Country Court West
Carterville, IL 62918
(618) 985-8221**

Who:

- Elderly living in rural areas.

Goal:

- To help maintain frail elderly in their homes and prevent premature institutionalization.

Description:

- A private, nonprofit corporation established in 1971.
- Manages a 13-county case coordination unit for the area agency on aging's long-term care program.
- Developed a 13-county nursing home ombudsman program, providing regular visitors for nursing home residents, and monitoring for regulation violations and abuse or neglect of residents.

- Developed a community-oriented health promotion program for the elderly including health screening by nurses in local senior citizen centers.
- Manages three federally funded community health centers, one federally funded adolescent health center, and one federally funded farmworker health center.

» [Continue](#)

APPENDIXES

Profiles: Confronting the Chronic Care Challenge Today

Supportive
Housing

**Corporation for
Supportive Housing
342 Madison Avenue
Suite 505
New York, NY 10173
212) 986-2966**

Who:

- Individuals who are homeless or at risk of being homeless, with special chronic care needs such as diabetes, mental illness, or alcoholism.

Goal:

- To expand the quantity and quality of service-enriched permanent housing.

Description:

- Established in 1991, Corporation for Supportive Housing (CSH) is a national, nonprofit organization linking national and local philanthropies with government and nonprofit groups.

- Currently has projects in Illinois, Connecticut, Minnesota, California, New York, and Georgia.
- Successful in helping housing and social service organizations to plan, design, finance, and manage buildings together.
- Successful in rehabilitating vacant, dilapidated SRO apartment buildings, creating single, furnished, low-cost rooms with "blended management" providing both social services and property management.
- Provided funds in the form of grants to nonprofit organizations, leveraged funds from state agencies, and provided access to financing for private corporate investment.

» [Continue](#)

APPENDIXES

Profiles: Confronting the Chronic Care Challenge Today

Informal
Caregiving

**Rocky Mountain HMO
Time Bank
P.O. Box 60129
Grand Junction, CO 81506
(970) 248-5197**

Who:

- The frail elderly and disabled.

Goal:

- To help the elderly and disabled remain independent as long as possible, and prevent premature hospitalization by recruiting volunteers to provide supportive preventive services.

Description:

- Service credit banking programs recruit volunteers to provide supportive and preventive services in exchange for credits that can be redeemed from the program for similar services when needed.

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APPENDIXES

Profiles: Confronting the Chronic Care Challenge Today

Informal
Caregiving

West Austin Caregivers
2601 Exposition Street
Austin, TX 78703
(512) 472-6339

Who:

- People with HIV.

Goal:

- To promote independent living and reduce preventable institutionalization by providing supportive services through community-based interfaith coalitions.

Description:

- One of eight interfaith voluntary caregiving coalitions in the greater Austin area.
- Established in 1984.
- Grassroots faith-group coalitions with approximately 550 volunteers serving more than 1,200 recipients.

- Volunteers provide such services as transportation, shopping, handy helping, paperwork services, and friendly visiting.

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Profiles: Confronting the Chronic Care Challenge Today

Informal
Caregiving

**R.A.I.N. (Regional AIDS
Interfaith Network) Arkansas
2002 Fillmore #12
Little Rock, AR 72204
(501) 664-4346**

Who:

- People with HIV.

Goal:

- To provide emotional and custodial supportive services enabling people with HIV to live independently as long as possible.

Description:

- Congregation-based care teams provide assistance in meal support, light housekeeping, friendly visiting, respite for family and friends, transportation, and grocery shopping.
- Care teams are comprised of seven or more individuals ranging in age from nine to 85.

- Two care team co-leaders coordinate support given by the team.
- Referrals from case managers, congregations, physicians, and AIDS organizations.
- Program replicated in New York State, Oregon, Louisiana, Tennessee, Oklahoma, North Carolina, Texas, Missouri, and London, England.

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Technical Appendix on the Costs of Chronic Care

- The final step was to apply the estimated 1990 per capita expenditures by gender and age to the future estimated number of persons with chronic conditions for selected years, 1995-2050.

Methodology for Projecting the Indirect Costs of Chronic Care

Mortality costs are the value of lost productivity due to premature deaths from chronic conditions. These costs take into account life years lost and the number of years that an individual would have been productive, based on the number of deaths, years of life expectancy remaining at age of death, and the present discounted value of future earnings.

Morbidity costs are the value of goods and services not produced because of a chronic condition. To the degree that chronic conditions prevent or deter individuals from producing goods and services in the marketplace, the public sector, or the household, the value of these losses is the cost borne by society. These costs involve applying average earnings to work-years lost and imputing a dollar value to housekeeping services for those unable to perform them.

APPENDIXES

Profiles: Confronting the Chronic Care Challenge Today

Community-Based
Supportive
Services

**Sunshine Terrace
Adult Day Center
225 North 200 West
Logan, UT 84321
(801) 752-9321**

Who:

- People with chronic cognitive disorders, particularly dementia, and their caregiving families.

Goal:

- To provide therapeutic activities that promote optimal mental, physical, and social functioning of dementia patients. Also, to provide respite for the caregivers of people with dementia.

Description:

- To provide therapeutic activities that promote optimal mental, physical, and social functioning of dementia patients. Also, to provide respite for the caregivers of people with dementia.

- Offers a broad scope of services including overnight and weekend respite services, and an innovative music therapy program.
- By offering respite to caregivers, the quality of their lives is improved and they may maintain their caregiving abilities longer.

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Profiles: Confronting the Chronic Care Challenge Today

Service
Coordination

SeniorLink
(Open Options Inc.)
3217 Broadway, Suite 100
Kansas City, MO 64114
(816) 513-4454

Who:

- The frail elderly.

Goal:

- To establish a comprehensive network of existing service provider agencies to assist in avoiding premature institutionalization.

Description:

- Case managers provide assessment for senior consumers and connect them to a collaborating network of providers.
- Project increases identification of at-risk elderly, reducing in-hospital or nursing home referrals.

- Partners include: Boatman's Trust Company, the Hall Family Foundation, and H&R Block Foundation.

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