

What is Long-Term Care?

By: Family Caregiver Alliance

Individuals need long-term care when a chronic condition, trauma, or illness limits their ability to carry out basic self-care tasks, called *activities of daily living* (ADLs), (such as bathing, dressing or eating), or *instrumental activities of daily living* (IADLs) (such as household chores, meal preparation, or [managing money](#)). Long-term care often involves the most intimate aspects of people's lives—what and when they eat, personal hygiene, getting dressed, using the bathroom. Other less severe long-term care needs may involve household tasks such as preparing meals or using the telephone.

A report prepared by the U.S. Senate Special Committee on Aging (February, 2000) described long-term care as follows:

It [long-term care] differs from other types of health care in that the goal of long-term care is not to cure an illness, but to allow an individual to attain and maintain an optimal level of functioning...

Long-term care encompasses a wide array of medical, social, personal, and supportive and specialized housing services needed by individuals who have lost some capacity for self-care because of a chronic illness or disabling condition.¹

Because long-term care needs and services are wide-ranging and complex, statistics may vary from [study](#) to study. Sources for the following information are cited at the conclusion of this Fact Sheet. For additional information, see the Family Caregiver Alliance Fact Sheet on [Selected Caregiving Statistics](#).

Who Needs Long-Term Care?

- An estimated 10 million Americans needed long-term care in 2000.²
- Most but not all persons in need of long-term care are elderly. Approximately 63% are persons aged 65 and older (6.3 million); the remaining 37% are 64 years of age and younger (3.7 million).³
- The lifetime probability of becoming disabled in at least two activities of daily living or of being cognitively impaired is 68% for people age 65 and older.⁴
- By 2050, the number of individuals using paid long-term care services in any setting (e.g., at home, residential care such as [assisted living](#), or skilled nursing facilities) will likely double from the 13 million using services in 2000, to 27 million people. This estimate is influenced by growth in the population of older people in need of care.⁵
- Of the older population with long-term care needs in the community, about 30% (1.5 million persons) have substantial long-term care needs (three or more ADL limitations). Of these, about 25% are 85 and older and 70% report they are in fair to poor health.⁶ 40% of the older population with long-term care needs are poor or near poor (with incomes below 150% of the federal [poverty level](#)).⁷
- Between 1984 and 1994, the number of older persons receiving long-term care remained about the same at 5.5 million people, while the prevalence of long-term care use declined from 19.7% to 16.7% of the 65+ population. In comparison, 2.1%, or over 3.3 million, of the population aged 18–64 received long-term care in the community in 1994.⁸
- While there was a decline in the proportion (i.e., prevalence) of the older population receiving long-term care, the level of disability and cognitive impairment among those who received assistance with daily tasks rose sharply. The proportion receiving help with three

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- to six ADLs increased from 35.4% to 42.9% between 1984 and 1994. The proportion of cognitive impairment among the 65+ population rose from 34% to 40%.⁹
- The prevalence of cognitive impairment among the older population increased over the past decade, while the prevalence of physical impairment remains unchanged.¹⁰
 - In 2002, the percentage of older persons with moderate or severe memory impairment ranged from about 5% among persons aged 65–69 to about 32% among persons aged 85 or older.¹¹
 - Individuals 85 years and older, the oldest old, are one of the fastest growing segments of the is expected to increase to 19.4 million by 2050.¹³ This means that there could be an increase from 1.6 million to 6.2 million people age 85 or over with severe or moderate memory impairment in 2050.¹⁴

Where do People Receive Long-Term Care and from Whom?

Family and Informal Caregivers

Informal caregiver and *family caregiver* are terms used to refer to unpaid individuals such as family members, partners, friends and neighbors who provide care. These persons can be primary (i.e. the person who spends the most time helping) or secondary caregivers, full time or part time, and can live with the person being cared for or live separately. Formal caregivers are volunteers or paid care providers associated with a service system.^{15,16}

Estimates vary on the number of family and informal caregivers in the U.S., depending on the definitions used for both caregiver and care recipient as well as types of care provided.

- **52 million** informal and family caregivers provide care to someone aged 20+ who is ill or disabled.¹⁷
- **44.4 million** caregivers (or one out of every five households) are involved in caregiving to persons aged 18 or over.¹⁸
- **34 million** caregivers provide care for someone aged 50+.¹⁹
- 27.3 million family caregivers provide personal assistance to adults (aged 15+) with a disability or chronic illness.²⁰
- **5.8²¹ to 7²² million** people (family, friends and neighbors) provide care to a person (65+) who needs assistance with everyday activities.²³
- **8.9 million** informal caregivers provide care to someone aged 50+ with dementia.²⁴ By the year 2007, the number of caregiving households in the U.S. for persons aged 50+ could reach 39 million.²⁵
- Over three-quarters (78%) of adults living in the community and in need of long-term care depend on family and friends (i.e., informal caregivers) as their only source of help; 14% receive a combination of informal and formal care (i.e., paid help); only 8% used formal care or paid help only.²⁶
- Even among the most severely disabled older persons living in the community, about two-thirds rely solely on family members and other informal help, often resulting in great strain for the family caregivers.²⁷
- The use of informal care as the only type of assistance by older Americans aged 65 and over increased from 57% in 1994 to 66% in 1999. The growth in reliance upon informal care between 1994 and 1999 is accompanied by a decline in the use of a combination of informal and formal care from 36% in 1994 to 26% in 1999.²⁸
- 30% of persons caring for elderly long-term care users were themselves aged 65 or over; another 15% were between the age of 45–54.²⁹

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- For the family caregiver forced to give up work to care for a family member or friend, the cost in lost wages and benefits is estimated to be \$109 per day.³⁰

Home and Community-Based Care

- Most people—nearly 79%—who need Long-Term Care live at home or in community settings, not in institutions.³¹
- More than 13.2 million adults (over half younger than 65) living in the community received an average of 31.4 hours of personal assistance per week in 1995.³²
 - Only 16% of the total hours were paid care (about \$32 billion), leaving 84% of hours to be provided (unpaid labor) by informal caregivers.³³
- The trend towards community-based services as opposed to nursing home placement was formalized with the Olmstead Decision (July, 1999)—a court case in which the Supreme Court upheld the right of individuals to receive care in the community as opposed to an institution whenever possible.
- The proportion of Americans aged 65 and over with disabilities who rely entirely on formal care for their personal assistance needs has increased to 9% in 1999 from 5% in 1984.³⁴
- Between 2000 and 2002, the number of licensed assisted living and board and care facilities increased from 32,886 to 36,399 nationally, reflecting the trend towards community-based care as opposed to nursing homes.³⁵ Most assisted living facilities, however, are unlicensed.
- Most assisted living facilities (ALFs) discharge residents whose cognitive impairments become moderate or severe or who need help with transfers (e.g. moving from a wheelchair to a bed.) This limits the ability of these populations to find appropriate services outside of nursing homes or other institutions.³⁶

Nursing Home Care

- The risk of nursing home placement increases with age—31% of those who are severely impaired and between the ages of 65 and 70 receive care in a nursing home compared to 61% of those age 85 and older.³⁷
- In 2002, there were 1,458,000 people in nursing homes nationally.³⁸ Older individuals living in nursing homes require and receive greater levels of care and assistance. In 1999, over three-quarters of individuals in nursing homes received assistance with four to six ADLs.³⁹
- Of the population aged 65 and over in 1999, 52% of the nursing home population was aged 85 or older compared to 35% aged 75–84, and 13% aged 65–74.⁴⁰
- Between 1985 and 1999 the number of adults 65 and older living in nursing homes increased from 1.3 million to 1.5 million. In 1999, almost three-quarters (1.1 million) of these older residents were women.⁴¹

Long-Term Care Expenditures

- Estimated public and private spending on long-term care services exceeded \$180 billion in 2002. \$37.2 billion, or 21%, was paid for out-of-pocket by individuals and families.⁴²
- In 2002, \$103.2 billion dollars were spent on nursing home care compared to \$36.1 billion dollars for care in the community.⁴³
- In 2000, the estimated economic value of informal (i.e., unpaid) caregiving is more than both community care and nursing home care combined—\$257 billion.⁴⁴
- Despite the trend toward community-based care as opposed to institutionalized care, only 18.2% of long-term care expenditures for the elderly are for community-based care.⁴⁵

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- In 2002, 16.4 billion Medicaid dollars were spent for home and community-based services within long-term care. This figure has increased at a 25% rate annually since 1990.⁴⁶
- Expenditures for skilled nursing facility (SNF) care are much greater than care provided in other settings. Average expenses per older adult in a skilled nursing facility can be four times greater than average expenditures for that individual receiving paid care in the community.⁴⁷
- In 2003, Medicaid paid \$83.8 billion dollars for long-term care services, roughly one-third of all Medicaid spending. 27.8 billion of these dollars were spent on community-based long-term care services. Home and community-based (HCBS) waivers accounted for roughly two-thirds of community-based long-term care expenditures.⁴⁸
In 2000, spending for older adults aged 65 or older accounted for 57% of Medicaid dollars, with the remaining 43% spent on those under age 65.⁴⁹
- 31.9% of the annual estimated home care expenditures were paid for by Medicare in 2003, a little over 18% were paid for out-of-pocket or by private insurance, and approximately 13% were covered by Medicaid.⁵⁰
- Only 7% of residents receive Medicaid coverage for assisted living.⁵¹
- Studies have shown that the delivery of home or community-based long-term care services is a cost-effective alternative to nursing homes. Care in the home or community—not nursing home care—is what most Americans would prefer.^{52,53}
 - In 2004, the average daily rate for a private room in a skilled nursing facility was \$192 for a private room or \$70,080 annually, and \$169 or \$61,685 annually for a semi-private room. The hourly rate for a home health aide was \$18.12.⁵⁴
 - In 2000, annual cost estimates were \$13,000 for adult day care and \$25,300 for assisted living.⁵⁵
- Over two-thirds of the current health care dollar goes to treating chronic illness; for older persons the proportion rises to almost 95%.⁵⁶
- The aging of the population, especially those 85+—the most in need of long-term care—is expected to result in a tripling of long-term care expenditures, projected to climb from \$115 billion in 1997 to \$346 billion (adjusted for inflation) annually in 2040.⁵⁷

Future Issues

- Research suggests that if savings rates are not increased and government programs to assist the elderly are not strengthened, many retirees will face serious problems attaining needed health and long-term care services in the future. By 2030, many retirees will not have enough income and assets to cover basic expenditures or any expenses related to a nursing home stay or services from a home health provider.⁵⁸
- Shorter hospital stays and increased usage of outpatient procedures—changes that have increased the effectiveness of medical care—have shifted responsibility toward unpaid providers of care from paid providers, increasing burdens on family caregivers.⁵⁹

Notes

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Resources

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Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, brain injury, Parkinson's and other debilitating cognitive disorders that strike adults.

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