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Fact Sheet : Selected Caregiver Statistics

Definitions

The term *caregiver* refers to anyone who provides assistance to someone else who is, in some degree, incapacitated and needs help: a husband who has suffered a stroke; a wife with Parkinson's disease; a mother-in-law with cancer; a grandfather with Alzheimer's disease; a son with traumatic brain injury from a car accident; a child with muscular dystrophy; a friend with AIDS.

Informal caregiver and *family caregiver* are terms that refer to unpaid individuals such as family members, friends and neighbors who provide care. These individuals can be primary 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.^{1,2} Figures reflected in this Fact Sheet are national in scope and focus primarily on unpaid caregivers for adults.

For additional information, see FCA's Fact Sheet on [Selected Long-Term Care Statistics](#).

Who Are the Informal Caregivers?

Magnitude

- There is wide latitude in the estimates of the number of informal caregivers in the U.S., depending on the definitions and criteria used. See citations below for source information.
 - **52 million** informal and family caregivers provide care to someone aged **20+** who is ill or disabled.³
 - **29.2 million** family caregivers provide personal assistance to adults (**aged 18+**) with a disability or chronic illness.⁴
 - **34 million** adults (16% of population) provide care to adults **50+ years**.⁵
 - **8.9 million** caregivers (20% of adult caregivers) care for someone **50+ years who have dementia**.⁶
 - **5.8⁷ - 7⁸ million** people (family, friends and neighbors) provide care to persons **65+** who need assistance with everyday activities.⁹
 - Unpaid family caregivers will likely continue to be the largest source of long-term care services in the U.S. and are estimated to reach 37 million caregivers by 2050, an increase of 85% from 2000.¹⁰

Gender

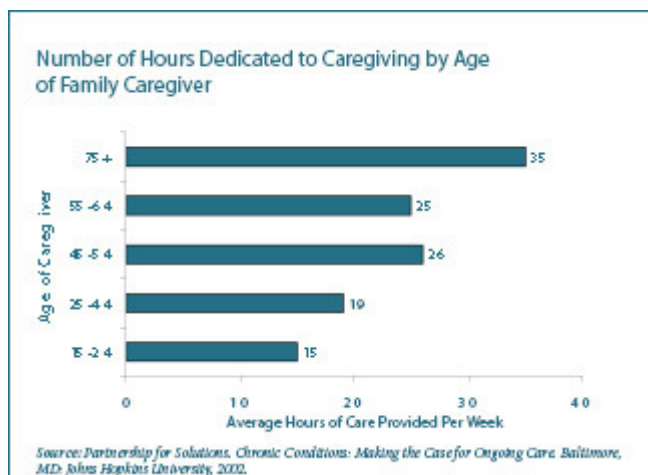
- More women than men are caregivers. An estimated 59% to 75% of caregivers are female.^{11,12,13}
- Research suggests that the numbers of male caregivers may be increasing and will continue to do so due to a variety of social demographic factors.¹⁴ One report documents a 50% increase in men becoming primary caregivers between 1984 and 1994.¹⁵
- While men may be sharing in caregiving tasks more than in the past, women still shoulder the major burden of care. For example, while some studies show a relatively equitable distribution of caregiving between men and women, female caregivers spend 50% more time providing care than male caregivers.¹⁶ However, among caregivers 75+, both sexes provide equal amounts of care.¹⁷
- Other studies have found that women caregivers handle the most difficult caregiving

tasks (i.e., bathing, toileting and dressing) when compared with their male counterparts who are more likely to help with finances, arrange care, and other less burdensome tasks.^{18,19}

- A number of studies have found that female caregivers are more likely than males to suffer from anxiety, depression, and other symptoms associated with emotional stress due to caregiving.^{20,21}

Age

- While caregivers can be found across the age span, the majority of caregivers are middle-aged (35-64 years old).^{22,23}
- The average age of family caregivers caring for someone aged 20+ has been estimated at 43.²⁴
- Of those caring for someone aged 50+, the average age of family caregivers is estimated at 47.²⁵
- Many caregivers of older people are themselves elderly. Of those caring for someone aged 65+, the average age of caregivers is 63 years with one third of these caregivers in fair to poor health.²⁶
- Similarly, it has been shown that the number of hours dedicated to caregiving increases with the age of the caregiver:²⁷



Ethnicity ²⁸

- Rates of caregiving vary somewhat by ethnicity. Among the U.S. adult population (18+), approximately one-fifth (21%) of both the white and African-American populations are providing informal care, while a slightly lower percentage of Asian-Americans (18%) and Hispanic-Americans (16%) are engaged in caregiving.²⁹
- However, in another national survey which looked only at people 70+ years old, 44% of Latinos were found to receive informal home care compared to 34% of African-Americans and 25% of non-Hispanic whites.³⁰
- Studies show that ethnic minority caregivers provide more care than their white counterparts^{31,32} and report worse physical health than white caregivers.³³
- African-American caregivers experience less stress and depression and get more rewards related to caregiving when compared to white caregivers.^{34,35,36} However, Hispanic and Asian-American caregivers exhibit more depression than white caregivers.³⁷
- Ethnic differences are also found with regard to the care recipient. Among people aged 70+ who require care, whites are the most likely to receive help from their spouses; Hispanics are the most likely to receive help from their adult children; and African Americans are the most likely to receive help from a nonfamily member.³⁸

Relationships between Caregivers and Care Recipients

- The person most likely to be providing care to an older person is an adult child:

Relationship to Older Person	% of All Caregivers (caring for person 65+) ³⁹	% of All Caregivers (caring for person 50+) ⁴⁰
Child	41%	44%
Spouse	23%	6%
Other relative	27%	24%
Nonrelative	8%	14%

- As can be seen from the chart above, as care recipients age, there is a much higher likelihood of receiving care from a spouse. Nearly one-quarter (22%) of caregivers who are themselves 65+ are caring for a spouse.⁴¹
- Some studies have found that a significant percentage of caregivers, 17%⁴² to 24%,⁴³ are caring for a friend or neighbor as opposed to a family member.
- In a national sample of caregivers who live with their care recipients, spouses account for about 62% of *primary* caregivers while adult children comprise 26%. *Secondary* caregivers are more likely to be adult children (46%) than spouses (16%).⁴⁴

Employment Status

- A significant portion of those in the workforce are also providing elder care to family members. Between 25% to 35% of all workers report that they are currently providing, or have recently provided, care to someone 65+.^{45,46}
- Most caregivers are employed. Among baby boomer caregivers (aged 50-64 years old), an estimated 60% are working full or part-time.⁴⁷ Among adult caregivers generally, the majority are employed:⁴⁸

Employment Status	% of All Caregivers
Employed full-time	48%
Employed part-time	11%
Retired	16%
Not employed	9%

- Working caregivers often suffer many work-related difficulties due to their dual caregiving roles. Among working caregivers caring for a family or friend aged 65+, two-thirds report having to rearrange their work schedule, decrease their hours or take an unpaid leave in order to meet their caregiving responsibilities.⁴⁹ Difficulties due to work and caregiving are even higher among those caring for someone with dementia.⁵⁰
- Working women caregivers may suffer a particularly high level of economic hardships due to their caregiving. Women caregivers are likely to spend 12 years out of the workforce raising children and caring for an older relative or friend.⁵¹ One recent study found that women who had assumed caregiver roles during their working years were 2.5 times more likely to live in poverty when they became elderly compared to women who had not been caregivers during their lifetime.⁵²

Time Spent Caregiving

Hours per Week

- Nearly half of caregivers provide fewer than eight hours of care per week, while nearly one in five provide more than 40 hours of care per week.⁵³
- Older caregivers often spend the most hours providing care.⁵⁴ Nearly one-third (28%) of caregivers who provide more than 40 hours of care per week are 65+ years.⁵⁵
- The amount of time spent caring increases substantially as cognitive impairment worsens. Among people 70+ years old, those with no dementia receive an average of 4.6 hours per week of care, while those with mild dementia receive 13.1 hours of care weekly. For persons with severe dementia, hours of informal care received rises to 46.1 hours per week.⁵⁶ Similarly, nearly one-quarter (23%) of caregivers of someone 50+ with some type of dementia provide 40+ hours of care per week compared to

16% of those helping someone 50+ without dementia.⁵⁷

- A study of California Caregiver Resource Center caregiving clients indicates that the average number of hours of care per week is 81.⁵⁸

Years Providing Care

- The duration of caregiving can last from less than a year to more than 40 years. In a 2003 study, caregivers were found to spend an average of 4.3 years providing care.⁵⁹ In another national study, over 40% of caregivers had been providing assistance for 5 or more years, and nearly one-fifth had been doing so for 10+ years.⁶⁰
- Older caregivers (50+) are more likely to have been caregiving for more than 10 years (17%) when compared to younger caregivers (9%).⁶¹

Geographic Distance between Caregiver and Care Recipient

- The majority of caregivers (42%) live within twenty minutes of the care recipient. One-quarter of care recipients (24%) live with the caregiver and another one-fifth (19%) live within an hour of the care recipient. The remaining 15% of caregivers live more than an hour from the care recipient.⁶²
- Estimates of the number of long-distance caregivers in the U.S. who are caring for an older relative range from 5.1⁶³ to nearly 7 million.⁶⁴ Long-distance caregivers are generally defined as living more than one hour from the older adult needing assistance.
- Estimates of travel time for long-distance caregivers to visit the care recipient range from 4 hours⁶⁵ to 7.23 hours.⁶⁶

Impact of Caregiving on Caregivers' Physical Health

- While researchers have long known that caregiving can have deleterious mental health effects for caregivers, research shows that caregiving can have serious physical health consequences as well.
- Studies have found that caregivers may have increased blood pressure and insulin levels,⁶⁷ may have impaired immune systems⁶⁸ and may be at increased risk for cardiovascular disease⁶⁹ among other adverse health outcomes.
- A study of elderly spousal caregivers (aged 66-96) found that caregivers who experience caregiving-related stress have a 63% higher mortality rate than noncaregivers of the same age.⁷⁰
- Many caregivers are themselves in poor health; studies show that approximately one-third of caregivers provide intensive care although they are themselves in "fair to poor" physical health.^{71,72}

Mental and Emotional Effects of Caregiving Experienced by Caregivers

- Psychological health appears to be the aspect of the family caregiver's life that is most affected by providing care. Studies consistently report higher levels of depressive symptoms and mental health problems among caregivers than among their noncaregiving peers.⁷³
- Depression appears to be the most common psychological disorder, with 20% to 50% of caregivers reporting depressive disorders or symptoms.^{74,75} The higher levels of depression are mostly attributed to people caring for individuals with dementia. Studies show that 30%⁷⁶ to 40%⁷⁷ of dementia caregivers suffer from depression and emotional stress.
- Several studies have shown that caregivers use prescription and psychotropic drugs more than noncaregivers.⁷⁸
- Stress in family caregivers is inversely correlated to income: the less income a caregiver has, the more stress he or she is likely to experience.⁷⁹
- Particularly stressful caregiving situations may put caregivers at risk of engaging in harmful behaviors towards care recipients. One study has shown that spousal

caregivers who are at risk of clinical depression and are caring for a spouse with significant cognitive impairment and/or physical care needs are more likely to engage in harmful behavior towards their loved one.⁸⁰

- While caregiving can be a very stressful situation for many caregivers, studies also show that there are beneficial effects, including feeling positive about being able to help a disabled spouse, feeling appreciated by the care recipient, and feeling that their relationship with the care recipient had improved.^{81,82,83}

Economic Value and Costs of Informal Caregiving

- What is the estimated economic value of informal caregiving? If the services provided by informal caregivers (i.e. family, friends, neighbors) had to be replaced with paid services, it would cost an estimated \$257 billion (in 2000 dollars).⁸⁴
- At the estimated value of \$257 billion nationally, informal caregiving greatly exceeds the costs associated with home health care (\$32 billion) and nursing home care (\$92 billion) combined.⁸⁵
- Studies suggest that the cost of informal caregiving in terms of lost productivity to U.S. businesses is \$11 to \$29 billion annually.⁸⁶
- Caring for older persons with dementia (as opposed to caring for someone with a physical disorder) costs more than \$18 billion a year in additional time spent by family and friends.⁸⁷
- One study of community-residing Alzheimer's disease care recipients found that on average each care recipient receives \$23,436 worth of informal care from family and friends. In comparison, only \$8,064 of professional home care services per year are used by care recipients.⁸⁸
- As a result of their caregiving, informal caregivers are estimated to each lose an average of \$25,494 in Social Security benefits, an average of \$67,202 in pension benefits and an average of \$566,433 in wage wealth. Combined, the result is a loss of \$659,139 over a lifetime.^{89,90}
- Long-distance caregivers spend an average of \$392/month on travel and out-of-pocket expenses as part of their caregiving duties.⁹¹

Caregiver Assistance/Support

- Most people who need long-term care depend exclusively on their family and friends. The vast majority of adults (78%) in the U.S. who receive long-term care at home get all their care
- from unpaid family and friends, mostly wives and adult daughters. Another 14% receive some combination of family care and paid help; only 8% rely on formal care alone.⁹²
- Forty-eight percent of caregivers reported using at least one of seven outside services (e.g., transportation, home-delivered meals, respite, etc.) to supplement their caregiving.⁹³
- Caregivers are often unaware of the availability of support services. One recent study of Alzheimer's caregivers found that 75% had unmet needs; only 9% used respite services and only 11% participated in support groups.⁹⁴ A study of California caregivers similarly found that 75% did not know where to access services that they would have used.⁹⁵
- Caregiver interventions benefit both the caregiver and the care recipient. Use of caregiver support services has been shown to have clinically significant outcomes in improving caregiver
- depression, anxiety and anger.^{96,97,98} Specific caregiver interventions which appear to be most beneficial include those that work with both the caregiver and the care recipient, those that emphasize behavioral skills training, and those that are both multi-component and tailored to caregivers' specific needs.^{99,100,101}
- People with moderate dementia have been able to defer institutionalization by nearly a year when their family members receive caregiver support services, including counseling, information and ongoing support.¹⁰²

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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.

FCA's National Center on Caregiving 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, ALS, traumatic brain injury, Parkinson's and other debilitating disorders that strike adults.

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