



Southern Caregiver Resource Center

Caring for those who care for others

Fact Sheet: Caregiver Statistics: Health, Technology, and Caregiving Resources

Definitions

A **caregiver**—sometimes called an **informal caregiver**—is an unpaid individual (for example, a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks. **Formal caregivers** are paid care providers providing care in one's home or in a care setting (day care, residential facility, or long-term care facility). For the purposes of the present fact sheet, displayed statistics generally refer to caregivers of adults.

The figures below reflect variations in the definitions and criteria used in each cited source. For example, the age of care recipients or relationship of caregiver to care recipient may differ from study to study.

Impact of Caregiving on Caregiver's Physical Health

- While researchers have long known that caregiving can have harmful mental health effects for caregivers, research also shows that caregiving can have serious physical health consequences. Further supporting this is the fact that 17% of caregivers feel their health in general has gotten worse as a result of their caregiving responsibilities. [AARP Public Policy Institute. (2008). Valuing the Invaluable: The Economic Value of Family Caregiving.]

- Toll of caregiving on caregiver health worsens over time. Caregivers reporting fair or poor health increases from 14% within first year to 20% after 5 years or more of providing care. Those caring for a spouse are most likely to report fair or poor health (27% versus 15% for all other relationships). [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Research shows an estimated 17-35% of family caregivers view their health as fair to poor. Higher hour caregivers are even more likely to rate their health as fair or poor (22%) and less likely to report excellent or very good health (40%). [AARP Public Policy Institute. (2011). Valuing the Invaluable: The Economic Value of Family Caregiving.]
- Those who are more likely to rate physical strain of caregiving "high" are the following:
 - Those providing care for a year or longer (23% versus 16% for less than a year);
 - Older caregivers (23% age 65+ versus 17% age 18-49);
 - Those who have a higher level of burden (31% versus 16%, of those with a moderate level of burden and 9% of those with a low level);

- Alzheimer's or dementia caregivers (28% versus 17% for other caregivers);
- Those who are living with their care recipient (25% versus 17% who don't live together). [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- 11% of family caregivers report that caregiving has caused their physical health to deteriorate. This effect is proportional to the number of Activities of Daily Living (ADLs) caregivers perform. Only 16% of caregivers who do not perform ADLs reported detrimental effects on health, versus 20% of those performing 1-2 ADLs, 28% of those performing 3-5 ADLs, and 41% of those performing 6 or more ADLs. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- 23% of older caregivers caring for persons 65+ report a higher degree of physical strain compared to 17% who are younger. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Females (16%) more than males (11%) report being more stressed while performing caregiving responsibilities (4-5 on a 5-point scale). [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Caregivers who provide care for persons with dementia risk comprising their immune systems for up to 3 years after their caregiving experience ends, thus increasing their chances of developing a chronic illness themselves. [National Alliance for Caregiving and AARP. (2009). Caregiving in the U.S.]
- The physical and emotional impact of dementia caregiving resulted in an

estimated \$9.7 billion in healthcare costs in 2014. [Alzheimer's Association. (2015). 2015 Alzheimer's Disease Facts and Figures.]

- Negative effects of caregiving are greatest for persons aged 18-29, followed by 30- to 40-year-olds. Caregivers who work full-time say they suffer from poorer physical health than their non-caregiving counterparts. 16% of caregivers working full-time have a Physical Health Index (PHI) score of 77.4%, which is significantly lower than 83.0% for non-caregivers. [Gallup-Healthways. (2011). Gallup-Healthways Well-Being Survey: In U.S., Caregivers Suffer from Poorer Physical Health.]

Physical Health Index by Age

	CAREGIVERS	NON-CAREGIVERS	DIFFERENCE
TOTAL	77.4	83.0	-5.6
18-29	79.0	85.7	-6.7
30-40	72.2	83.3	-6.1
45-64	77.0	81.5	-4.5
65+	79.1	81.8	-2.7

[Gallup-Healthways. (2011). Gallup-Healthways Well-Being Survey: In U.S., Caregivers Suffer from Poorer Physical Health.]

Mental and Emotional Effects of Caregiving

- 40% to 70% of family caregivers have clinically significant symptoms of depression. About a quarter to half of these caregivers meet the diagnostic criteria for major depression. [Zarit, S. (2006). Assessment of Family Caregivers: A Research Perspective.]
- 20% of employed female caregivers aged 50+ report symptoms of depression compared to 8% of their non-caregiving peers. [MetLife Mature Market Institute. (2010). Still Out, Still Aging: The MetLife Study of Lesbian, Gay, Bisexual, and Transgender Baby Boomers.]

- Caregivers whose care recipient has emotional or mental health problems are more likely than others to report a decline in their own health (25% versus 14%). [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- About 40% of family caregivers of people with dementia suffer from depression compared to 5-17% of non-caregivers of similar ages. Rates of depression increase with the severity of cognitive impairment of the person with dementia. [Alzheimer’s Association. (2015). 2015 Alzheimer’s Disease Facts and Figures.]
- Caregivers who work full-time and are aged 45 years or less show the greatest emotional and physical health deficit in contrast to non-caregivers. [Gallup-Healthways. (2011). Gallup-Healthways Well-Being Survey: In U.S., Caregivers’ Emotional Health Often Suffers.]

Emotional Health Index by Age

	CAREGIVERS	NON-CAREGIVERS	DIFFERENCE
TOTAL	78.0	81.9	-3.9
18-29	78.2	82.3	-4.1
30-40	77.0	81.1	-4.1
45-64	78.1	81.9	-3.8
65+	84.1	87.0	-2.9

[Gallup-Healthways. (2011). Gallup-Healthways Well-Being Survey: In U.S., Caregivers’ Emotional Health Often Suffers.]

- The well-being index composite score for working caregivers is significantly lower than the 70.2 among non-caregivers. [Gallup-Healthways. (2011). Gallup-Healthways Well-Being Survey: In U.S., Working Caregivers Face Wellbeing Challenges.]
- Roughly 4 in 10 (38%) family caregivers find their situation highly stressful (score 4 or 5), 25% report moderate stress (score of 3), and 36% report little to no stress (rating of 1 or 2 based on a 5-

point scale). [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]

- Both caring for a spouse or parent and co-residence contribute to emotional stress. 45% of those caring for spouse or parent reported stress compared with 35% for another relative and 18% for non-relative. 52% of co-resident caregivers experienced stress compared with 34% of non-resident caregivers. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Reports show a correlation exists between a caregiver’s health and income. Of caregivers with less than \$30,000 in household income, 30% report fair or poor health as compared with 7% of caregivers with \$100,000 or more. The same pattern is also found with a caregiver’s level of education. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- 1 in 12 (8%) of caregivers feel their overall health is improved by caring for a loved one. [Zarit, S. (2006). Assessment of Family Caregivers: A Research Perspective.]

Religion and Spirituality

- About 75% of caregivers pray regularly to cope with the demands of their caregiving responsibilities. [National Alliance for Caregiving and AARP. (2004). Caregiving in the U.S.]
- Caregivers report praying with the following frequencies:
 - More than once per day: 24.6%
 - Once per day: 21.5 %
 - A few times a week: 25.7% [Rathier, L., Davis, J., Papandonatos, G., Grover, C., &

Tremont, G. (2013). Religious Coping in Caregivers of Family Members with Dementia.]

- Typical content of prayers include: requests for strength to handle caregiving duties (73.8%), guidance to manage caregiving demands (48.2%), expressions of gratitude (30.4%), divine intervention (27.2%), and forgiveness (15.2%). [Rathier, L., Davis, J., Papandonatos, G., Grover, C., & Tremont, G. (2013). Religious Coping in Caregivers of Family Members with Dementia.]
- 42% of caregivers attend religious services at least once a week. [Hebert, R., Dang, Q., & Schulz, R. (2012). Religious Beliefs and Practices are Associated with Better Mental Health in Family Caregivers of Patients with Dementia: Findings from the REACH Study.]
- 70% of caregivers report that their spiritual/religious faith has “a great deal” of importance in their lives. [Hebert, R., Dang, Q., & Schulz, R. (2012). Religious Beliefs and Practices are Associated with Better Mental Health in Family Caregivers of Patients with Dementia: Findings from the REACH Study.]

Caregiver Assistance and Support

- 59% of caregivers report using at least one type of assistance on behalf of their care recipients. The most common types of support caregivers seek out include the following:
 - Modifications to the care recipient’s home: 34%
 - Requests for financial assistance resources: 28%
 - Respite services: 15%

- Transportation services: 23% [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]

- Caregivers who have been caregiving for more than one year are more likely to have sought out financial help (35%), made modifications to their care recipient’s home (42%), used transportation services (27%), or used respite services (16%). [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- 25% of caregivers say it is very difficult to get assistance that is both affordable and helpful. Higher-hour caregivers are more likely to report having difficulty (29%). [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Transportation is a vital component of the care provided by family caregivers. 39% of Medicare beneficiaries accompany care recipients to medical appointments. Family or friends provide transportation for 1.4 billion visits per year for older relatives aged 70+ who do not drive themselves. [AARP Public Policy Institute. (2011). Valuing the Invaluable: The Economic Value of Family Caregiving.]
- With respect to caregiver training:
 - One in five (19%) caregivers has been trained, but seeks additional resources.
 - 26% of caregivers who received training for medical/nursing tasks were trained by a family member or friend, while 60% learned from healthcare staff.

- 84% of caregivers need more help and information with at least 14 specific topics related to caregiving. The top three (3) topics of concern to caregivers are the following:
 - Keeping their loved one safe (42%)
 - Managing their own stress (42%)
 - Making end-of-life decisions (22%)
- Caregivers in high care burden situations are more likely to seek help (83% versus 73% of low-burden caregivers).
- Caregivers' demand for information has increased in the last five years (84% versus 77% in 2009). [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- 66% of caregivers find it very easy or somewhat easy to coordinate care prescribed by health professionals and service providers while 25% have some difficulty. Half of all caregivers use other unpaid caregiver help (50%), and 32% use paid help. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Caregivers under the age of 50 are more likely than older adults to use the benefits of caregiving technology.
 - Early adopters of technology report they would likely try each of the technologies available, but cost was a concern.
 - Racial and ethnic minorities ages 50+ are more likely than non-minority caregivers of the same age to rate technology as helpful. Among younger caregivers no difference was noted by race.
 - Caregivers with a medium to high burden of care are more likely than those with a low burden of care to use technology. [National Alliance for Caregiving & UnitedHealthcare. (2011). e-connected Family Caregiver: Bringing Caregiving into the 21st Century.]
- A Pew Research Center study indicates that family caregivers are more technologically savvy than the general population, even controlling for factors such as age, educational level, and other demographic factors.
 - 87% of family caregivers have a cell phone compared to 84% of non-caregivers.
 - 86% of family caregivers have access to the Internet compared to 78% of non-caregivers. [Pew Research Center. (2012). Family Caregivers Online.]
- 40% of family caregivers obtained assistive technology on behalf of their care recipient. Assistive technology not only slows the rate of functional decline, but can also reduce caregiving costs and prevent physical disability due to falling. [Mann, W.C., Ottenbacher, K.J.,

Caregivers and Technology

Receptiveness to Caregiving Technology

- Caregivers are most receptive to technologies that help them deliver, monitor, track, or coordinate their loved one's medical care. [National Alliance for Caregiving & UnitedHealthcare. (2011). e-connected Family Caregiver: Bringing Caregiving into the 21st Century.]

Fraas, L., Tomita, M., & Granger, C.V. (1999). Effectiveness of Assistive Technology and Environmental Interventions in Maintaining Independence and Reducing Home Care Costs for the Frail Elderly: A Randomized Controlled Trial.]

Caregivers are Active Healthcare Consumers

- 24% of online caregivers have consulted online reviews of particular drugs or medical treatments compared with 13% of non-caregivers. 22% of online caregivers have consulted online rankings or reviews of doctors or other providers compared with 14% of non-caregivers. 19% of online caregivers have consulted online rankings or reviews of hospitals or other medical facilities compared with 10% of non-caregivers. [Pew Research Center. (2013). Family Caregivers are Wired for Health.]
- The most important technological benefits reported by caregivers are saving time (77%), caregiving made logistically easier (76%), making the care recipient feel safer (75%), increasing their feelings of being effective (74%), and reducing stress (74%). [National Alliance for Caregiving & UnitedHealthcare. (2011). e-connected Family Caregiver: Bringing Caregiving into the 21st Century.]

Seeking Help for Health Issues

- 70% of caregivers say they turn to friends and family members for information, care, or support compared with 54% of non-caregivers who do the same, either online or offline. 30% of caregivers say they turn to others who have the same health condition compared with 21% of non-caregivers who do so. [Pew Research Center.

(2013). Family Caregivers are Wired for Health.]

- Caregivers largely use the Internet to assist them with their caregiving responsibilities through connecting with other caregivers, researching health information such as data on Alzheimer's disease and other forms of dementia, and searching for information about long-term care options. [Pew Research Center. (2012). Family Caregivers Online.]
- 84% of caregivers with Internet access use the Internet to research health topics compared to 64% of non-caregivers with Internet access. Caregivers are significantly more likely than other Internet users to say that their last search for health information was on behalf of someone else (63% versus 47%). [Pew Research Center. (2013). Family Caregivers are Wired for Health.]
- Most people (79% of caregivers versus 64% of non-caregivers) report that the last time they had a health issue, they received information, care, or support from a doctor or other health professional, either online or offline. [Pew Research Center. (2012). Caregivers are Active Health Care Consumers.]

Caregivers are Social

- Caregivers are more likely than other Internet users to take advantage of social tools related to health: 44% of online caregivers have read someone else's personal health story online compared with 29% of non-caregivers. 28% of online caregivers who use websites like Facebook have followed their friends' personal health experiences or health updates compared with 21% of non-caregivers

who use such sites. [Pew Research Center. (2012). Family Caregivers Online.]

Resources

Southern Caregiver Resource Center

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The Southern Caregiver Resource Center offers services to family caregivers of adults with chronic and disabling health conditions and is for residents of San Diego and Imperial counties. Services include information and referral, counseling, family consultation and case management, legal and financial consultation, respite care, education and training, and support groups.

Family Caregiver Alliance National Center on Caregiving

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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.