FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

Statistical Portrait of Caregivers in the US

Part III: Caregivers' Physical and Emotional Health; Use of Support Services and Technology

[Note: This fact sheet is the third in a three-part FCA Fact Sheet series with *Part I: Demographics* and *Part II: Work and Caregiving*]

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. 17% of caregivers feel their health in general has gotten worse as a result of their caregiving responsibilities.
  [AARP Public Policy Institute Valuing the Invaluable: 2008 Update. The Economic Value of Family Caregiving] - **Updated: November 2012**
- 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% vs 15% for all other relationships).
  [National Alliance for Caregiving and AARP (2015), Caregiving in the U.S., Bethesda, MD: National Alliance for Caregiving, Washington, DC] - **Updated: August 2015**
- 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%)
  [Valuing the Invaluable: 2011 Update, The Economic Value of Family Caregiving. AARP Public Policy Institute.] - **Updated: November 2012**
- Those who are more likely to rate physical strain of caregiving "high" are those providing care for a year or longer (23% vs 16% for less than a year), older caregivers (23% age 65+ vs 17% age 18-49), have a higher level of burden (31% vs. 16%, of those with a moderate level of burden and 9% of those with a low level), Alzheimer's or dementia caregivers (28% vs 17% for other caregivers), or are living with their care recipient (25% vs. 17% who don't live together).
  [National Alliance for Caregiving and AARP (2015), Caregiving in the U.S., Bethesda, MD: National Alliance for Caregiving, Washington, DC] - **Updated: August 2015**
- 11% of family caregivers report that caregiving has caused their physical health to deteriorate. This effect is proportional to the number of ADLs caregivers perform: only 16% of caregivers who perform no 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.
  [The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S. National Alliance for Caregiving. Washington, DC.] - **Updated: August 2015**
- 23% of older caregivers caring for those 65+ report a higher degree of physical strain, compared to 17% who are younger.
  [The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S: National Alliance for Caregiving. Washington, DC] - **Updated: August 2015**
- Women (16%) more than men (11%) report having more stress in caregiving responsibilities, (4-5 on a 5 point scale).
  [The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S: National Alliance for Caregiving. Washington, DC] - **Updated: August 2015**

- Caring for persons with dementia is reported to impact a person's immune system for up to 3 years after their caregiving experience ends, thus increasing their chances of developing a chronic illness themselves.
  [The National Alliance for Caregiving and AARP (2009), Caregiving in the U.S: National Alliance for Caregiving. Washington, DC] - **Updated: November 2012**
- Negative effects of caregiving are greatest for those 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 (findings based on Gallup-Healthways Well-Being Index).
  [Gallup Healthways Wellbeing Survey, In U.S., Caregivers Suffer From Poor Physical Health, Febuary 2011] - **Updated: November 2012**
- The physical and emotional impact of dementia caregiving resulted in an estimated $9.7 billion in health care costs in 2014
  [Alzheimer's Association. (2015). 2015 Alzheimer's disease facts and figures. Chicago] - **Updated: August 2015**

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 Wellbeing Survey, In U.S., Caregivers Suffer From Poorer Physical Health, Febuary 2011] - **Updated: November 2012**

Mental and Emotional Effects of Caregiving

- Caregivers working full-time who are younger than 45 showed the greatest emotional and physical health deficit relative to non-caregivers
  [Gallup Healthways Wellbeing Survey, In U.S., Caregivers' Emotional Health Often Suffers, May 2011] - **Updated: November 2012**

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 Wellbeing Survey, In U.S., Caregivers' Emotional Health Often Suffers, May 2011] - **Updated: November 2012**

- The well-being index composite score for working caregivers was also significantly lower than the 70.2 among non-caregivers.
  [Gallup Healthways Wellbeing Survey, In U.S., Working Caregivers Face Well-being Challenges, December 2011] **- Updated: November 2012**
- Approximately 40% of family caregivers of people with dementia suffer from depression, compared with 5 to 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. Chicago]. **- Updated: August 2015**
- 40% to 70% of family caregivers have clinically significant symptoms of depression with about a quarter to half of these caregivers meeting the diagnostic criteria for major depression.
  [Zarit, S. (2006) Assessment of Family Caregivers: A Research Perspective in Family Caregiver Alliance (Eds.), Caregiver Assessment: Voices and Views from the Field. Report from a National Consensus Development Conference (Vol. II) (pp. 12-37). San Francisco: Family Caregiver Alliance.] **- Updated: November 2012**
- Reports show there is a correlation 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.
  [The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S: National Alliance for Caregiving. Washington, DC] **- Updated: August 2015**
- Caregivers whose care recipient has emotional or mental health problems are more likely than others to report a decline in their own health as a result (25% vs. 14%).
  [The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S. National Alliance for Caregiving. Washington, DC.] **- Updated: August 2015**
- 4 in 10 (38%) 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).
  [The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S. National Alliance for Caregiving. Washington, DC.] **- Updated: August 2015**
- Caring for a spouse or parent and co-residence both contribute to emotional stress of caregiving. 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.
  [The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S. National Alliance for Caregiving. Washington, DC.] **- Updated: August 2015**
- 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 in Family Caregiver Alliance (Eds.), Caregiver Assessment: Voices and Views from the Field. Report from a National Consensus Development Conference (Vol. II) (pp. 12 - 37). San Francisco: Family Caregiver Alliance.] **- Updated: November 2012**
- 20% of employed female caregivers over 50+ report symptoms of depression compared to 8% of their non-caregiving peers.
  [MetLife: Still Out, Still Aging 2010. Study of Lesbian, Gay, Bisexual, and Transgender Baby Boomers] **- Updated: November 2012**

Religion and Spirituality

- Around 75% of caregivers pray regularly to cope with the demands of caregiving
  [National Alliance for Caregiving and AARP (2004), Caregiving in the U.S: National Alliance for Caregiving, and Washington, DC: AARP.] **- Updated: August 2015**

- 70% of caregivers report their spiritual/religious faith to be "a great deal" important. *[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. The American Journal of Geriatric Psychiatry,292-300.]* **–Updated August 2015**
- 42% attend religious services at least weekly. *[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. The American Journal of Geriatric Psychiatry,292-300.]* **–Updated August 2015**
- 24.6% of caregivers pray more than once per day, 21.5% just once per day, and 25.7% a few times a week. Typical content of prayers included: 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. Journal of Applied Gerontology.]* **–Updated August 2015**

Caregiver Assistance/Support

- 59% of caregivers reported use of at least one type of help on behalf of their care recipient. Most commonly used was modifications to recipient's home (34%), followed by requesting resources for financial assistance (28%). 15% used a respite service and 23% used a transportation service. Caregivers who have been caregiving for more than one year are more likely to have sought out financial help (35%), made modifications to 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: National Alliance for Caregiving, and Washington, DC: AARP.]* - **Updated: August 2015**
- 25% of caregivers say it is very difficult to get assistance that is both affordable and helpful. Higher-hour caregivers were more likely to report having difficulty (29%). *[National Alliance for Caregiving and AARP (2015), Caregiving in the U.S: National Alliance for Caregiving, and Washington, DC: AARP.]* - **Updated: August 2015**
- One in five caregivers report having had training (19%) but seek additional resources. 84% report needing more help and information with at least 14 specific topics related to caregiving. Caregivers in high-burden situations are more likely to seek help (83% vs. 73% of low-burden caregivers). The top three topics of concern to caregivers are: keeping their loved one safe (42%); managing their own stress (42%); and making end-of-life decisions (22%). The demand for information by caregivers has increased in the last five years (84% vs. 77% in 2009). But in 2009, caregivers who expressed a desire to find more time for themselves decreased (30% vs. 35% in 2004). *[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S., Bethesda, MD: National Alliance for Caregiving. Washington, DC]* - **Updated: August 2015**
- 26% of providers who received training for medical/nursing tasks were trained by a family member or friend while 60% learned from health care staff. *[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S., Bethesda, MD: National Alliance for Caregiving. Washington, DC.]* - **Updated: August 2015**
- Caregivers responded positively to interventions such as individual/group therapy, educational/training support, home-based visits or technology, depending on how they are delivered. *[The National Alliance for Caregiving and AARP (2009), Caregiving in the U.S: National Alliance for Caregiving. Washington, DC]* - **Updated: November 2012**
- 66% of caregivers find it very or somewhat easy to coordinate care given by health professionals and service providers while 25% had some difficulty. Half of all caregivers report using other unpaid caregiver help (50%), and 32% used paid help.

[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S., Bethesda, MD: National Alliance for Caregiving. Washington, DC] **- Updated: August 2015**

- More than half (54%) of caregivers report either no future care plans (32%) or uncertainty about future care plans (22%) for their recipient. 52% expect their caregiving duties to continue during the next 5 years.
  [The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S., Bethesda, M D: National Alliance for Caregiving. Washington, DC] **- Updated: August 2015**
- Transportation is a vital component provided by the family caregiver (spouses, adult children); 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 (70+) who do not drive themselves.
  [Valuing the Invaluable: 2011 Update: The Economic Value of Family Caregiving. AARP Public Policy Institute.] **- Updated: November 2012**

Caregivers and Technology

Who is most receptive to caregiving technology?

- 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% vs. 47%. *[Pew Research Center's Internet & American Life Project, Family Caregivers are Wired for Health, June 2013. Caregivers in the US.]***- Updated: August 2015**
- Most people say that the last time they had a health issue, they got information, care, or support from a doctor or other health professional, either online or offline. Fully 79% of caregivers say that, compared with 64% of non-caregivers.
  *[Pew Research Center's Internet & American Life Project. Caregivers are Active Health Care Consumers, July 2012]***- Updated: November 2012**
- 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 and older 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.
  *[e-connected Family Caregiver: Bringing Caregiving into the 21st Century. National Alliance for Caregiving with United Health Care (2011)]***- Updated: November 2012**
- The most important technological benefits reported by caregivers are saving time (77%), caregiving made easier logistically (76%), making the care recipient feel safer (75%), increasing their feelings of being effective (74%), and reducing stress (74%).
  *[e-connected Family Caregiver: Bringing Caregiving into the 21st Century. National Alliance for Caregiving with United Health Care (2011)]***- Updated: November 2012**
- Caregivers are most receptive to technologies that help them deliver, monitor, track, or coordinate their loved one's medical care.
  *[e-connected Family Caregiver: Bringing Caregiving into the 21st Century. National Alliance for Caregiving with United Health Care (2011)]***- Updated: November 2012**
- A Pew Research Center study found that family caregivers are more technologically savvy than the general population. 87% of family caregivers have a cell phone, compared to 84% of non-caregivers, and 86% of family caregivers have access to the internet, a higher percentage than non-caregivers (78%), even when controlled for age, educational level, and other demographic factors. Caregivers largely use the internet to assist with their caregiving responsibilities through connecting with other caregivers, researching health information such as data on Alzheimer's and

dementia, and looking up information about long-term care options.
[Pew Research Center's Pew Internet & American Life Project, July 2013: Family Caregivers Online, July 2013]- **Updated: August 2015**

- 40% of informal 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 WC, Ottenbacher KJ, Fraas L, Tomita M, Granger CV. Effectiveness of assistive technology and environmental interventions in maintaining independence and reducing home care costs for the frail elderly. A randomized controlled trial. Archives of Family Medicine 1999;8(3):210-217.] – **Updated: August 2015**

Caregivers are active health care 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's Internet & American Life Project, Family Caregivers are Wired for Health, June 2013. Caregivers in the U.S. (main report)]- **Updated: August 2015**

Where do caregivers seek help for a health issue?

- 70% of caregivers say they turned to friends and family members for information, care, or support, compared with 54% of non-caregivers who did the same, either online or offline. 30% of caregivers say they turned to others who have the same health condition, compared with 21% of non-caregivers who did so.
  [Pew Research Center's Internet & American Life Project, Family Caregivers are Wired for Health, June 2013. Caregivers in the U.S. (main report)]- **Updated: August 2015**

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's Pew Internet & American Life Project, July 2012: Family Caregivers Online, July 2012]- **Updated: November 2012**

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Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research, and advocacy.
National Center on Caregiving offers information on current social, public policy and caregiving issues, provides assistance in the development of public and private programs for caregivers, and assists caregivers nationwide in locating resources in their communities.
For San Francisco Bay Area residents, FCA provides direct family support services for caregivers of those with Alzheimer’s disease, stroke, ALS, head injury, Parkinson’s disease, and other debilitating health conditions that strike adults.

*Statistical Fact Sheets receive frequent updates due to the high volume of information now available from surveys, research, and policy studies. Each statistic contains the research citation. Some key studies, while older, will remain until updates become available if the information is viewed as a critical or unique finding. Updates will continue on a rolling basis as new statistical information becomes available. All statistics include the FCA update: e.g., November 2012, and will be "date-stamped" as to month and year of placement on the Fact Sheets.