

Statistical Portrait of Caregivers in the US

Part I: Demographics

[Note: This fact sheet is the first in a three-part FCA Fact Sheet series with *Part II: Work and Caregiving* and *Part III: Caregivers' Physical and Emotional Health; Use of Support Services and Technology*]

Definitions

A caregiver—sometimes called an *informal caregiver*--is an unpaid individual (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 (daycare, residential facility, long-term care facility). For the purposes of this Fact Sheet, statistics generally refer to caregivers of adults.

Although there may appear to be discrepancies in estimates of the number of informal caregivers in the U.S., the figures cited below reflect variations in the definitions and criteria used in each study. For example, the age of care recipients or relationship of caregiver to care recipient may differ from study to study. We will update this Fact Sheet periodically as new information becomes available.*

How Many Caregivers in the US?

- 43.5 million caregivers make up 18.2% of the U.S. adult population. They provide care to someone who is ill, disabled, or aged.
[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S. National Alliance for Caregiving. Washington, DC.] - Updated: August 2015
- The majority care for one other adult (82%), while 15% care for 2 adults, and 3% for 3 or more adults.
[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S. National Alliance for Caregiving. Washington, DC.] - Updated: August 2015
- 39.8 million caregivers provide care to adults (aged 18+) with a disability or illness or 16.6% of Americans.
[Coughlin, J., (2010). Estimating the Impact of Caregiving and Employment on Well-Being: Outcomes & Insights in Health Management, Vol. 2; Issue 1] - Updated: November 2012
- 43.5 million of adult family caregivers care for someone 50+ years of age and 15.7 million care for someone who has Alzheimer's disease or other dementia.
[Alzheimer's Association. (2015). 2015 Alzheimer's disease facts and figures. Chicago] - Updated: August 2015
- An increasingly older population: the number of Americans aged 65-84 is projected to grow by 35 million from 2000 to 2050, while the 85 and older population is expected to increase by nearly 20 million. Currently, dementia affects 3% of individuals aged 65-74, 19% of those aged 75-84, and 47% of those above 85.
Evans, D. (1989). Prevalence of Alzheimer's disease in a community population of older persons. Higher than previously reported. JAMA: The Journal of the American Medical Association, 2551-2556. – Updated August 2015

Economic Value

- The value of services provided by informal caregivers has steadily increased over the last decade, with an estimated economic value of \$470 billion in 2013, up from \$450 billion in 2009 and \$375 billion in 2007.
[Valuing the Invaluable: 2015 Update, The Economic Value of Family Caregiving. AARP Public Policy Institute.] - Updated: August 2015
- The value of unpaid family caregivers will likely continue to be the largest source of long-term care services in the U.S. The aging population 65+ will more than double between the years 2000 and 2030, increasing to 71.5 million from 35.1 million in 2000.
[Coughlin, J., (2010). Estimating the Impact of Caregiving and Employment on Well-Being: Outcomes & Insights in Health Management, Vol. 2; Issue 1] - Updated: November 2012
- At \$450 billion in 2011, the value of informal caregiving exceeded the value of paid home care, more than total Medicaid spending in 2009, as much as Wal-Mart sales (\$408 billion), and nearly exceeding total expenditures for the Medicaid program in 2009 (\$509 billion).
[Valuing the Invaluable: 2011 Update, The Economic Value of Family Caregiving. AARP Public Policy Institute.] - Updated: November 2012
- The economic value of the care provided by family and other unpaid caregivers of those with Alzheimer's disease or other dementias was \$217.7 billion in 2014.
[Alzheimer's Association. (2015). 2015 Alzheimer's disease facts and figures. Chicago] - Updated: August 2015

Gender

- 65% of care recipients are female, with an average age of 69.4. This changes with the age of the recipient: 45% of recipients aged 18-45 are male, while among recipients ages 50 or higher 33% are male.
- *[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S. National Alliance for Caregiving. Washington, DC.] - Updated: August 2015*
- More women than men are caregivers: 3 out of every 5 caregivers are female (60%). The average age of a female caregiver is 48.0.
[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S. National Alliance for Caregiving. Washington, DC.] - Updated: August 2015
- Male caregivers are less likely to provide personal care, but 24% helped a loved one get dressed compared to 28% of female caregivers. 16% of male caregivers help with bathing versus 30% of females. 40% of male caregivers use paid assistance for a loved one's personal care. Approximately 14.5 million caregivers are men out of the 43.4% who care for an older family member.
[The National Alliance for Caregiving and AARP (2009), Caregiving in the U.S. National Alliance for Caregiving. Washington, DC.] - Updated: November 2012
- Research suggests that the number of male caregivers may be increasing and will continue to do so due to a variety of social demographic factors.
[Kramer, B. J. & E. H. Thompson, (eds.), "Men as Caregivers," (New York: Prometheus Books, 2002).] - Updated: November 2012

Gender & Care Tasks

- Men may be sharing in caregiving tasks more than in the past, but 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 more time providing care than men do (21.9 vs. 17.4 hours per week).

[The National Alliance for Caregiving and AARP (2009), Caregiving in the U.S. National Alliance for Caregiving. Washington, DC.] - Updated: November 2012

- Higher-hour caregivers (21 hours or more weekly) are nearly 4 times more likely to be caring for a spouse/partner.

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

- However, among spousal caregivers 75+, both sexes provide equal amounts of care.
[McCann, J.J., Hebert, L.E., Beckett, L.A., Morris, M.C., Scherr, P.A., & Evans, D.A., Comparison of informal caregiving by black and white older adults in a community population (2000) Journal of the American Geriatrics Society 48:1612-1617.] - Updated: November 2012
- Other studies have found that 36% of women caregivers handle the most difficult caregiving tasks (i.e., bathing, toileting, and dressing) when compared with 24% for their male counterparts, who are more likely to help with finances, arrange care, and other less burdensome tasks.

[The National Alliance for Caregiving and AARP (2009), Caregiving in the U.S. National Alliance for Caregiving. Washington, DC.] - Updated: November 2012

Caregiving in the Lesbian, Gay, Bisexual, and Transgender Communities

- There are at least 3 million LGBT people aged 55 and older in the U.S. This number is expected to double in the next two decades.

[Espinoza, R. (2014). Out and Visible: The Experiences and Attitudes of Lesbian, Gay, Bisexual and Transgender Older Adults, Ages 45-75. SAGE.] – Updated: August 2015

- Both men and women are likely to be caregivers in near equal proportions: 20% men vs. 22% women in the LGBT group, and 17% men vs. 18% women in the general population sample. Male caregivers reported providing more hours of care than female caregivers: the average weekly hours of care provided by women from both the LGBT and general population samples is similar—26 vs. 28 hours—but LGBT men provide far more hours of care than men from the comparison sample: 41 hours versus 29. This reflects that about 14% of the gay men indicate that they are full-time caregivers, spending over 150 hours per week in this capacity, compared to 3% of the lesbian and 2% of the bisexual respondents.

[MetLife: Still Out, Still Aging. 2010. Study of Lesbian, Gay, Bisexual, and Transgender Baby Boomers] - Updated: November 2012

- 9% of caregivers self-identify as LGBT

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

- LGBT individuals are more likely to be very concerned about having enough money (51% vs 36%), experiencing loneliness in old age (32% vs 19%), declining physical health (43% vs 33%), not being able to take care of themselves (43% vs 34%) or not having anybody to take care of them (30% vs 16%) compared to non-LGBT.

[Fredriksen-Goldsen, K. I., Kim, H.-J., Emler, C. A., Muraco, A., Erosheva, E. A., Hoy-Ellis, C. P., Goldsen, J., Petry, H. (2011). The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults. Seattle, WA: Institute for Multigenerational Health.] – Updated: August 2015

- Nearly 40% of older LGBT individuals report that their healthcare providers do not know about their sexual orientation—often for fear of judgment or inferior care.

[Fredriksen-Goldsen, K. I., Kim, H.-J., Emler, C. A., Muraco, A., Erosheva, E. A., Hoy-Ellis, C. P., Goldsen, J., Petry, H. (2011). The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults. Seattle, WA: Institute for Multigenerational Health.] – Updated: August 2015

- 20% of older LGBT individuals and 44% of older transgender individuals felt their relationship with their healthcare provider would be adversely affected if their sexual orientation/gender was known.

[Fredriksen-Goldsen, K. I., Kim, H.-J., Emlert, C. A., Muraco, A., Erosheva, E. A., Hoy-Ellis, C. P., Goldsen, J., Petry, H. (2011). *The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults*. Seattle, WA: Institute for Multigenerational Health.] – **Updated: August 2015**

- LGBT respondents are slightly more likely to have provided care to an adult friend or relative in the past six months: 21% vs. 17%.
[*MetLife: Still Out, Still Aging 2010. Study of Lesbian, Gay, Bisexual, and Transgender Baby Boomers*] - **Updated: November 2012**
- LGBT older adults are: twice as likely to age as a single person; twice as likely to live alone; and three to four times less likely to have children
[*MetLife: Still Out, Still Aging 2010. Study of Lesbian, Gay, Bisexual, and Transgender Baby Boomers*] - **Updated: November 2012**

Caregiving Tasks

- Caregivers reported in a Gallup survey that they spend a lot of time on different tasks related to looking after the care recipient. The majority of caregivers (55%) in the Gallup study reported they had cared for three years or more. The average days per month spent on shopping, food preparation, housekeeping, laundry, transportation, and giving medication is 13, and 6 days per month on feeding, dressing, grooming, walking, bathing, and assistance toileting.
[*Gallup Healthways Wellbeing Survey, Most caregivers Look After Elderly Parent; Invest a Lot of Time, July 2011*] - **Updated: November 2012**
- Some caregivers spend fewer days—on average, six per month—performing personal tasks, (eating, dressing, or helping with bathroom tasks). This may correlate with 64% of caregivers who say the person they care for does not live with them. Caregivers reported that they spend an estimated 13 hours per month researching care services or information on disease, coordinating physician visits or managing financial matters.
[*Gallup Healthways Wellbeing Survey, Most Caregivers Look After Elderly Parent; Invest a Lot of Time, July 2011*] - **Updated: November 2012**
- The Home Alone study—a study of family caregivers who provide complex chronic care—found that nearly half the caregivers surveyed (46% or 777) performed medical & nursing tasks. More than 96% (747) also provided help with activities of daily living (ADLs) (e.g., personal hygiene, dressing/undressing, getting in and out of bed) or instrumental activities of daily living (IADLs) (e.g., taking prescribed medications, shopping for groceries, transportation, or using technology), or both. Of these caregivers nearly two-thirds (501) did all three types of tasks. Of the non-medical family caregivers, two-thirds (605) provided IADL assistance only.
[*Home Alone: Family Caregivers Providing Complex Chronic Care, AARP with United Health Hospital Fund October 2012*] - **Updated: November 2012**
- Caregivers in the Home Alone study reported which tasks were more difficult, comparing ADLs with more clinical tasks. 67% found using incontinence equipment or supplies and administering enemas more difficult. 66% reported wound care was difficult (bandages, ointment, prescription drugs for skin care, treating pressure sores, or post-surgical wounds) or ostomy care. 61% of caregivers reported managing medications, including IV & injections, difficult.
[*Home Alone: Family Caregivers Providing Complex Chronic Care, AARP with United Health Hospital Fund October 2012*] - **Updated: November 2012**
- When asked if they had a choice about performing clinical tasks, 57% of caregivers in the Home Alone study reported they did not, but stated it was self-imposed—43% felt it was their personal responsibility for reasons such as no one else to do it or insurance wouldn't pay a professional. 12% said pressure came from the care receiver and 8% said it came from another family member.
[*Home Alone: Family Caregivers Providing Complex Chronic Care, AARP with United Health Hospital Fund October 2012*] - **Updated: November 2012**

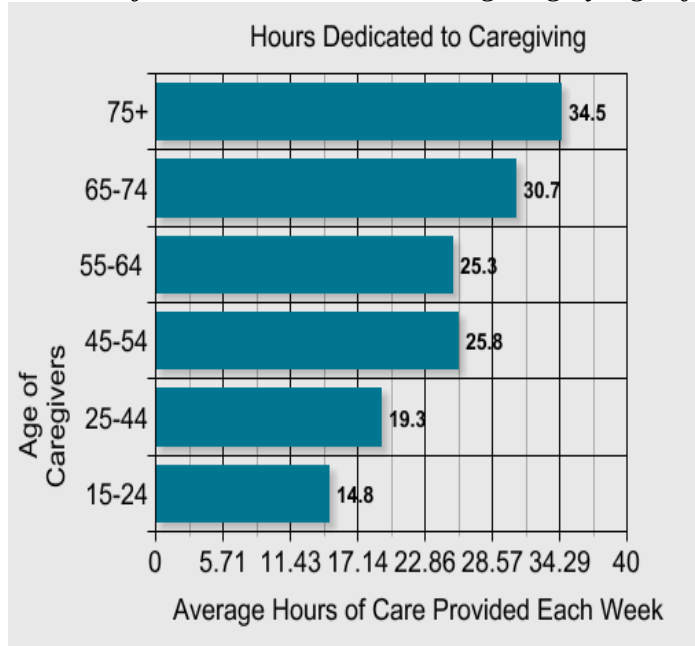
- On average, caregivers help with 1.7 of 6 ADLs (Activities of Daily Living). Most commonly: getting in and out of beds and chairs (43%). Higher-hour caregivers help with 2.6 ADLs on average.
[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S., Bethesda, MD: National Alliance for Caregiving. Washington, DC.] - Updated: August 2015
- Of the 7 Instrumental Activities of Daily Living (IADL), caregivers perform on average 4.2 IADLS, most commonly transportation (78%), grocery or other shopping (76%), and housework (72%)
[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 commonly hold significant decision-making authority regarding monitoring recipient's condition and adjusting care (66%), communicating with health care professionals on behalf of recipient (63%), and acting as an advocate with care providers, community services, or government agencies (50%).
- *[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S., Bethesda, MD: National Alliance for Caregiving. Washington, DC.] - Updated: August 2015*

Age

- While caregiving crosses the age span, the average age of caregivers is 49.2 years. About 48% of caregivers are between the ages of 18 and 49; 34% are age 65 or older
[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S., Bethesda, MD: National Alliance for Caregiving. Washington, DC.] - Updated: August 2015
- The average age of caregivers has remained the same since 2009 after an increase from 2004. The average age was 49.2 years in 2015 and 2009, compared to 46.4 in 2004.
[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S. National Alliance for Caregiving. Washington, DC.] - Updated: August 2015
- The number of hours dedicated to caregiving increases with the age of the caregiver. Higher-hour caregivers are, on average, 51.8 years of age; lower-hour caregivers average 48 years of age.
[Partnership for Solutions, Chronic Conditions: Making the Case for Ongoing Care. Johns Hopkins University, Baltimore, M.D. (2004).] - Updated: November 2012
- According to the survey, older caregivers are more likely to care for a spouse or partner (6% of caregivers aged 18-49, 9% of caregivers aged 50-64, 24% of caregivers aged 65-74, and 46% of caregivers aged 75 and older). The average age of spousal caregivers is 62.3 years.
[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S.: National Alliance for Caregiving. Washington, DC.] - Updated: August 2015
- The age of the caregiver tends to reflect the age of the recipient. The average recipient age increases from 63.5 for caregivers aged 18-49 to 77.1 for caregivers aged 75 and older. *[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S.: National Alliance for Caregiving. Washington, DC.] - Updated: August 2015*
- Many caregivers of older people are themselves growing older. Of those caring for someone aged 65+, the average age is 63 years with one third of these caregivers in fair to poor health.
[Administration on Aging, NFCSP: Complete Resource Guide, 2005] - Updated: November 2012
- Nearly 1 in 10 caregivers is 75 years of age or older (7% of all caregivers). Older caregivers are more likely to be: caring for their spouse, without unpaid help, unemployed or retired, managing finances for their recipient.
[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S.: National Alliance for Caregiving. Washington, DC.] - Updated: August 2015
- Currently more than half of care receivers (53 %) are under age 75, 14% are between 18 and 49 years of age, and 47% are over the age of 75. The average age of recipients is 69.4.
[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S., Bethesda, MD:

National Alliance for Caregiving. Washington, DC.] - Updated: August 2015

Number of Hours Dedicated to Caregiving by Age of Family Caregiver



[Graph Data: Partnership for Solutions, Chronic Conditions: Making the Case for Ongoing Care. Johns Hopkins University, Baltimore, MD. (2004).] - Updated: November 2012

Time Spent Caregiving

- 4 in 10 (40%) caregivers are in high-burden situations, 18% medium burden, and 41% low burden based on the Level of Care Index (1997). Burden of care increases with hours of care provided- 92% of providers providing 21 or more hours per week are high burden versus 16% of lower hour providers.

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

- A 2011 report found that primary family caregivers of people with dementia reported spending an average of 9 hours per day providing help to their relatives.

[Fisher GG, Franks MM, Plassman BL, Brown SL, Potter GG, Llewellyn D, et al. Caring for individuals with dementia and cognitive impairment, not dementia: Findings from The Aging, Demographics, and Memory Study. Journal of the American Geriatrics Society 2011;59(3):488–94.] – Updated August 2015

Hours per week

- On average, caregivers spend 24.4 hours per week providing care. Nearly 1 in 4 (23%) spend 41 hours or more per week providing care.

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

- Those who live with their care recipient spend 40.5 hours per week caring for that person, 44.6 hours per week if the recipient is a spouse/partner. Those caring for a child under age 18 spend 29.7 hours per week.

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

- Older caregivers who are 75+ provide 34 hours in an average week on caregiving; middle aged caregivers report spending 21.7 hours. Older caregivers are more likely than younger caregivers to bathe and shower the care recipient (33% vs. 22%).
[National Alliance for Caregiving and AARP (2015), Caregiving in the U.S., Bethesda, MD: National Alliance for Caregiving, Washington, DC] - Updated: August 2015
- In 2014, the 15.7 million family and other unpaid caregivers of people with Alzheimer’s disease and other dementias provided an estimated 17.9 billion hours of unpaid care. This represents an average of 21.9 hours of care per week, or 1,139 hours of care per caregiver per year valued at \$12.17 per hour--an estimated \$217.7 billion in 2014. *[Alzheimer's Association. (2015). 2015 Alzheimer's disease facts and figures. Chicago]- Updated: August 2015*

Months & Years Providing Care

- Measured by duration of care, Alzheimer's and dementia caregivers provide care on average 1 to 4 years more than caregivers caring for someone with an illness other than Alzheimer's disease (43% vs. 33%). They are also more likely to be providing care for five years or longer (32% vs. 28%).
[Alzheimer's Association. (2015). 2015 Alzheimer's disease facts and figures. Chicago]- Updated: August 2015
- The average duration of a caregiver's role is 4 years. Only 3 in 10 caregivers provided care for less than a year. Similarly, caregivers cared for a loved one for 1 to 4 years, and 24% of caregivers cared for 5 years or more with 15% reporting caring for 10 or more years. Higher-hour caregivers are twice as likely to have been in their role for 10 years or more.
[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S. National Alliance for Caregiving. Washington, DC] - Updated: August 2015
- Regardless of employment status, caregivers report that positive activities in their daily life are reduced by 27.2% as a result of caregiving responsibilities, and the effect on their personal life is 3 times more than the effect on employment.
[Coughlin, J., (2010). Estimating the Impact of Caregiving and Employment on Well-Being: Outcomes & Insights in Health Management, Vol. 2; Issue 1] - Updated: November 2012

LENGTH OF TIME CARING	PERCENTAGE
Less than 6 months	4%
6 months to 1 year	10%
1 year to less than 2	14%
2 to less than 3 years	17%

[Gallup Healthways Wellbeing Survey, Most Caregivers Look After Elderly Parent; Invest a Lot of Time, July 2011] - Updated: November 2012

Ethnicity

- Rates of caregiving vary somewhat by ethnicity. Among the caregiving U.S. adult population 18+, approximately 62% are white; 13% are African-American; 17% are Hispanic; 6% are Asian-Americans.
[The National Alliance for Caregiving and AARP (2015), Caregiving in the U.S: National Alliance for Caregiving. Washington, DC.] - Updated: August 2015
- Hispanics have the highest reported prevalence of caregiving at 21%; 20.3% of African Americans, 19.7% of Asian Americans, and 16.9% of white Americans.

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

- White caregivers (52.5) were on average older than African American (44.2), Hispanic (42.7) or Asian American (46.6) caregivers. They were also more likely to be married (63%) than caregivers overall (57%).

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

- Studies show that 27% of Hispanic caregivers indicate their health is fair or poor compared to 15% for white caregivers and 15% for Asian-Americans.

[The National Alliance for Caregiving and AARP (2009), Caregiving in the U.S.: National Alliance for Caregiving, Washington, DC] - Updated: November 2012

- Hispanic (45%) and African-American (57%) caregivers experience higher burden from caregiving on average than white (33%) or Asian-American (30%) caregivers. They also spend more time caregiving on average (approximately 30 hours per week) compared with white (20 hours per week) or Asian-American caregivers (16 hours per week).

- *[Alzheimer's Association. (2015). 2015 Alzheimer's disease facts and figures. Chicago]- Updated: August 2015*

- More than half of African-American caregivers find themselves "sandwiched" between caring for an older person and a younger person under age 18, or caring for more than one older person. African-American caregivers are also more likely to live with the care recipient and spend an average of 20.6 hours per week providing care. In addition, 66 percent of African-American caregivers are employed full or part-time.

[The National Alliance for Caregiving and AARP (2009), Caregiving in the U.S., Bethesda, MD: National Alliance for Caregiving, Washington, DC] - Updated: November 2012

- Ethnic differences are also found with regard to the needs of the care recipients. African-American caregivers (41%) were more likely to provide help with more than three activities of daily living (ADLs) than white caregivers (28%) or Asian-Americans (23%), (e.g., getting in and out of bed, dressing, feeding, managing incontinence or getting to and from the toilet).

[Alzheimer's Association, 2011 Alzheimer's Disease Facts and Figures, Alzheimer's and Dementia , Vol.7, Issue 2.] - Updated: November 2012

Relationships between Caregivers and Care Recipients

- The percentage of caregivers caring for individuals over 85 years of age has increased across all three of the national surveys of informal caregivers conducted by National Alliance for Caregiving in the U.S. and AARP, in 1997, 2004, 2009. Parent care continues to be the primary caregiving situation for mid-life caregivers with 70% of the caregivers between the ages of 50 and 64.

[Wagner D. Takagi, E. Health Affairs: Informal Caregiving; By and for Older Adults, February 2010] - Updated: November 2012

- A Gallup survey found 72% of caregivers cared for a parent, step-parent, mother-in-law, or father-in-law, and 67% of caregivers provided care for someone age 75 or older.

[Gallup Healthways Wellbeing Survey, Most Caregivers Look After Elderly Parent; Invest a Lot of Time, July 2011] - Updated: November 2012

- Most care recipients reside in their own home (48%), and one in three (35%) live in their caregiver's home. 3 in 10 care recipients who are not in assisted-living or skilled nursing facilities live alone (31%).

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

Caregivers: Whom Do They Live With?		
Lives Alone	43% (2009)	47% (2004)
Lives with Spouse	27% (2009)	26% (2004)
Lives with Grown Children	13% (2009)	11% (2004)
Lives with someone else	1%	1%

[National Alliance for Caregiving and AARP (2009), *Caregiving in the U.S., A Focused Look at Those Caring for Someone Age 50 or Older*, Bethesda, MD: National Alliance for Caregiving, Washington, DC] - Updated: November 2012

Figure 20: Where Care Recipient Lives by Burden of Care

	Low Burden (n=501) A	Medium Burden (n=216) B	High Burden (n=513) C
With Caregiver	19%	27% ^A	54% ^{AB}
In his/her own home	59 ^C	53 ^C	34
Community/care facility	14 ^C	13 ^C	6

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

- The relationship between the caregiver and care recipient is a close relationship with shared emotions, experiences, and memories, which may place caregivers at higher risk for psychological and physical illness. Caregivers of recipients with dementia or Alzheimer’s provide care for a longer time, on average, than other caregivers.
[Alzheimer’s Association. (2015). *2015 Alzheimer’s disease facts and figures*. Chicago]- Updated: August 2015
- A majority of caregivers (85%) care for a relative: 42% care for a parent (31% care for their mother, 11% for their father) and (15%) care for a friend, neighbor or another non-relative.. One in seven caregivers care for their child (14%). One in twelve provides care to a parent-in-law (7%) or a grandparent or grandparent-in-law (7%).
- [The National Alliance for Caregiving and AARP (2015), *Caregiving in the U.S: National Alliance for Caregiving*. Washington, DC] - Updated: August 2015

Elder Abuse

- The Department of Health defines abuse as “a violation of an individual’s human and civil rights by another person or persons.” Abuse can be physical, psychological, sexual, financial, discrimination, or neglect. Cooper, C., Selwood, A., & Livingston, G. (2008). *The prevalence of elder abuse and neglect: A systematic review*. *Age and Ageing*, (37), 151-160.- Updated August 2015
- As many as 25% of elder care recipients report significant levels of abuse (based on 5-item Likert scale).

Cooper, C., Selwood, A., & Livingston, G. (2008). *The prevalence of elder abuse and neglect: A systematic review. Age and Ageing, (37), 151-160.* - **Updated August 2015**

- Using the Psychological Elder Abuse scale: 25% of elders reported psychological abuse, 1% physical, 20% neglect, and 6-18% financial abuse.
[Wang JJ. *Psychological abuse behavior exhibited by caregivers in the care of the elderly and correlated factors in long-term care facilities in Taiwan. Journal of Nursing Research 2005; 13: 271-80.*] -**Updated August 2015**
- One study using The Caregiver Psychological Elder Abuse Test, found that 99% of caregivers in a long term care facility had witnessed at least some abuse
[Wang JJ. *Psychological abuse and its characteristic correlates among elderly Taiwanese. Archives of Gerontology and Geriatrics 2006; 42: 307-18.*] -**Updated August 2015**
- In another random survey of a long-term care facility: 10% of caregivers reported committing physical abuse, and 40% reported committing at least one act of psychological abuse over the previous year.
[Pillemer K, Moore DW. *Abuse of patients in nursing- homes—Findings from a survey of staff. Gerontologist 1989; 29: 314-20.*] -**Updated August 2015**
- Although more than 80% of caregivers in long term-care facilities reported observing abuse, only 2% of incidents are actually reported to home management.
[Saveman BI, Astrom S, Bucht G, et al. *Elder abuse in residential settings in Sweden. Journal of Elder Abuse & Neglect 1999; 10: 43-60.*] **Updated- August 2015**
- It is estimated that only 1 in 14 elder abuse cases are ever reported to authorities.
[National Research Council. (2003) *Elder mistreatment: Abuse, neglect and exploitation in an aging America. Washington, DC: The National Academies Press.*] -**Updated: August 2015**
- According to the New York State Elder Abuse Prevalence Study, for every 1 case of elder abuse known to programs and agencies there are 24 unknown cases.
[Lifespan of Greater Rochester, Inc., Weill Cornell Medical Center of Cornell University. & New York City Department for the Aging. (2011) *Under the Radar: New York State Elder Abuse Prevalence Study. New York: Author.*] -**Updated: August 2015**
- Caregivers who have provided care for longer, have higher burden, or care for elders with dementia or other mental illnesses are more likely to report abuse. Nearly half of dementia patients have been abused by their caregivers.
[Coyne, A., Reichman, W., & Berbig, L. (1993). *The relationship between dementia and elder abuse. American Journal of Psychiatry AJP, (150), 643-646.*] – **Updated August 2015**
- Elder abuse, even modest abuse, increases risk of death by 300% compared to elders who had not been abused.
[Dong X, Simon MA, Beck T, Farran, C., McCann, J., Mendes de Leon, C, et al. (2011). *Elder abuse and mortality: The role of psychological and social wellbeing. Gerontology, 57(6), 549-558.*
Lachs MS, Williams CS, O'Brien S, Pillemer KA, & Charlson ME. (1998). *The mortality of elder mistreatment. Journal of the American Medical Association, 280(5),428-432.*] –**Updated: August 2015**
- Abuse contributes to significantly higher levels of psychological distress, lower perceived self-efficacy, and a number of additional health problems such as bone/joint problems, digestive issues, depression/anxiety, chronic pain, high blood pressure, and heart problems.
[Comijs, H.C., Penninx, B.W.J.H., Knipscheer, K.P.M., & van Tilburg, W. (1999). *Psychological distress in victims of elder mistreatment: The effects of social support and coping. Journal of Gerontology, 54B(4), 240-245.*
Bitondo Dyer C., Pavlik V. N., Murphy K. P., and Hyman D. J. (2000). *The high prevalence of depression and dementia in elder abuse or neglect. Journal of the American Geriatrics Society. 48, 205-208.*
Burt, M. and Katz, B. (1985). *Rape, robbery, and burglary: Responses to actual and feared*

criminal victimization, with special focus on women and the elderly. Victimology: An International Journal, 10, 325-358.]- Updated: August 2015

Geographic Distance Between Caregiver and Care Recipient

- The majority of caregivers (75%) live within 20 minutes of the care recipient. 13% live between 20 minutes and an hour of the care recipient, a decline from 19% in 2004.
[National Alliance for Caregiving and AARP (2015), Caregiving in the U.S., Bethesda, MD: National Alliance for Caregiving, Washington, DC] - Updated: August 2015
- 48% of care recipients live in their own home. Higher-hour care recipients are less likely to live at home (28%) than lower-hour recipients (57%). Inversely, higher-hour recipients are more likely to live in their caregiver's home (62%) than lower-hour recipients (22%).
[National Alliance for Caregiving and AARP (2015), Caregiving in the U.S., Bethesda, MD: National Alliance for Caregiving, Washington, DC] - Updated: August 2015
- As the age of the caregiver increases, distance from their recipient decreases. 84% of caregivers above 75 live within 20 minutes of their care recipient, compared with 76% of caregivers aged 65-74, 72% aged 50-64, and 74% aged 18-49. *[National Alliance for Caregiving and AARP (2015), Caregiving in the U.S., Bethesda, MD: National Alliance for Caregiving, Washington, DC] - Updated: August 2015*
- The proportion of caregivers reporting they live less than 20 minutes from the home of the person they provide care for has increased during the past 10 years (44% in 2004, 51% in 2009, and 75% in 2015).
[National Alliance for Caregiving and AARP (2015), Caregiving in the U.S., Bethesda, MD: National Alliance for Caregiving, Washington, DC] - Updated: August 2015
- Long-distance caregivers had the highest annual expenses (\$8,728) compared to co-resident caregivers (\$5,885) or those who cared for a loved one nearby (\$4,570).
[AARP Public Policy Institute Valuing the Invaluable: 2008 Update. The Economic Value of Family Caregiving] - Updated: November 2012
- There are an estimated 5-7 million long-distance caregivers in the United States (~15% of all caregivers). This number is projected to double by 2020.
[National Council on Aging (2006, March). Nearly 7 million long-distance caregivers make work and personal sacrifices.] – Updated: August 2015
- Long-distance Caregivers live an average of 450 miles (724 km) from their care recipients (or approximately 7 hours travel time).
[National Alliance for Caregiving and the MetLife Mature Market Institute Miles Away. The MetLife study of long-distance caregiving. NAC/MMMI, Bethesda, MD/New York (2004)] – Updated: August 2015
- At least one-third of long-distance caregivers are not secondary helpers—they are primary caregivers or share responsibility equally.
[Koerin , B. B. and Harrigan , M. P. 2002. P. S. I love you: Long-distance caregiving. Journal of Gerontological Social Work, 40(1-2): 63-81.] – Updated: August 2015
- More men (58%) than women (42%) are long-distance caregivers.
[MetLife. (2004, July). Miles away: The MetLife study of long-distance caregiving: Findings from a national study.] – Updated: August 2015
- Long-distance caregivers were more likely to report emotional distress (47%) than caregivers either living with their care recipient (43%) or living less than one hour away (28%).
[National Alliance for Caregiving & American Association of Retired Persons. (2004, April). Caregiving in the U.S.] – Updated: August 2015
- A Gallup poll shows caregivers who do not live with their care receiver live the following distances from those for whom they care:
-

10 miles or less	66%
11-25 miles	13%
26 miles or more	21%

[Gallup Healthways Wellbeing Survey, Caregiving Costs U.S. Economy \$25.2 Billion in Lost Productivity, July 2011] - **Updated: November 2012**

Caregiving in Rural Areas

- More than half of the 65 million Americans living in rural areas are over the age of 50. Elders in rural areas (about a quarter of all elders) are more likely to live alone, near or at the poverty level, and suffer from a chronic condition or physical disability. They require an average of 46 miles of travel to get to the nearest health professional.
[HHS Rural Task Force Report/U.S. Department of Health and Human Services Rural Task Force, 2002] – **Updated: August 2015**
- 3-6 million Americans are distance caregivers who provide care for a family member that lives an average of 450 miles away.
[National Alliance for Caregiving & AARP. (2005). Caregiving in the U.S. Bethesda, MD: Authors] – **Updated: August 2015**
- Only 51% of caregivers in rural areas used any community-based services.
Buckwalter, K., & Davis, L. (n.d.). Elder Caregiving in Rural Communities. Rural Caregiving in the United States, 33-46. – **Updated: August 2015**

Older Adults with Developmental Disabilities

- There are an estimated 641,000 adults aged 60 and older with intellectual (mental retardation) and other disabilities (e.g., cerebral palsy, autism, epilepsy, and those with brain injury who qualify). Higher numbers are projected to double to 1,242,794 by 2030, coinciding with the population of aging baby boomers born between 1946 and 1964 that began turning 65 on January 1, 2011. One age-related concern is providing support to the family caregivers who themselves may be experiencing diminished capacity.
[Heller, T., Ph.D., Strength for Caring. Older Adults with Developmental Disabilities and Their Aging Family Caregivers (2011)] - **Updated: November 2012**
- Families are still the primary caregivers for adults with developmental disabilities and are themselves aging. Approximately, 76% of individuals with developmental disabilities live at home and in 25% of these homes, the family caregiver was over age 60. Of these households, the average age of the individual with a developmental disability was age 38.
[Heller, T., Ph.D., Strength for Caring. Older Adults with Developmental Disabilities and Their Aging Family Caregivers (2011)] - **Updated: November 2012**

Veterans

- There are a total of 5.5 million caregivers caring for former or current military personnel in the United States (1.1 million post 9/11).
[Ramchand, R., Tanielian, T., Fisher, M., Vaughan, C., Trail, T., Batka, C., Voorhies, P., Robbins, M., Robinson, E., Ghosh-Dastidar, B. (2014). Key Facts and Statistics from the RAND Military Caregivers Study.] – **Updated: August 2015**

- Military caregivers after 9/11 are: more likely to be employed (63% vs 47%), less likely to have a support network (47% vs 71%), younger (37% under 30 years old vs 11%), more likely to be caring for a recipient with a behavioral health condition (64% vs 36%) or a VA disability rating (58% vs 30%).
[Ramchand, R., Tanielian, T., Fisher, M., Vaughan, C., Trail, T., Batka, C., Voorhies, P., Robbins, M., Robinson, E., Ghosh-Dastidar, B. (2014). Key Facts and Statistics from the RAND Military Caregivers Study.] – Updated: August 2015
- Veteran care recipients (post 9/11) are more likely to: have no health insurance (32% vs 23%) or regular source of health care (28% vs 14%), have a mobility limiting disability (80% vs 66%) or mental health/substance abuse condition (64% vs 33%), and meet criteria for probable depression (38% vs 20%) compared to civilians.
[Ramchand, R., Tanielian, T., Fisher, M., Vaughan, C., Trail, T., Batka, C., Voorhies, P., Robbins, M., Robinson, E., Ghosh-Dastidar, B. (2014). Key Facts and Statistics from the RAND Military Caregivers Study.] – Updated: August 2015
- 9 in 10 (96%) of caregivers of veterans are female and 70% provide care to their spouse or partner. 30% of veterans' caregivers care for a duration of 10 years or more as compared to 15% of caregivers nationally. 88% report increased stress or anxiety as a result of caregiving, and 77% state sleep deprivation as an issue.
[National Alliance for Caregiving and United Health Foundation, Caregivers of Veterans: Serving on the Home Front (2010)]- Updated: November 2012
- Veterans suffer more frequently from Traumatic Brain Injury (29%), Post-traumatic Stress Disorder, Diabetes (28%), and paralysis or Spinal Cord Injury (20%).
[National Alliance for Caregiving and United Health Foundation, Caregivers of Veterans: Serving on the Home Front (2010)]- Updated: November 2012

Family Caregiver Alliance
National Center on Caregiving

785 Market Street, Suite 750
San Francisco, CA 94103
(415) 434-3388
(800) 445-8106

Website: www.caregiver.org

E-mail: info@caregiver.org

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.

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