45 Facts About Family Caregivers

A Supplement to the Family Caregiving 2011 Year in Review

March 2012

“You will need the patience of a saint,
the mind of a doctor,
and the strength of Hercules—to take care of your loved one.”

- Family Caregiver
  Newhall, CA
Family Caregiver Alliance and the National Center on Caregiving

Founded in 1977, Family Caregiver Alliance serves as a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy. Long recognized as a pioneer among caregiver organizations, FCA operates programs at local, state and national levels. In 2001, FCA established the National Center on Caregiving to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country.

This project was supported, in part, under a grant from the U.S. Department of Health and Human Services, Administration on Aging. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. These contents, however, do not necessarily represent the policy of the U.S. Department of Health and Human Services, and you should not assume endorsement by the Federal Government.
45 Facts about Family Caregivers

As part of Family Caregiver Alliance’s report, “Family Caregiving 2011: Year in Review” this brief highlights 45 data points based on research released in 2011 focused on family caregivers in the United States and Internationally.

Research on Caregivers

- The majority of caregivers are female (65%), and more than 80% are caring for a relative or friend who is age 50 or older.¹
- Twenty-one percent of Americans who make $36,000 or less report that they are caregivers, while only 15% of high income ($90,000+) employees report serving as caregivers.²
- Alzheimer’s: The health impacts on the estimated 15 million Alzheimer’s and dementia caregivers in the U.S. is enormous with 60% reporting high levels of stress because of the prolonged duration of caregiving and 33% of caregivers reporting symptoms of depression.³
- A study of 30 spousal family caregivers for people with mild cognitive impairment (MCI) finds that the day-to-day challenges of caregiving can not only increase the levels of cortisol, but these caregivers also had slower rates of decline of their cortisol levels.⁴
- 1/3 of California caregivers live with the care recipients, and they provide 36 hours of care per week. Only 7.4% of caregivers report receiving compensation for the care they provide, and 20% report that they spent over $250 of their own money on caregiving in the past month.⁵
- Of people aged 80 and older who live in the community (not institutional care), women were more likely than men to need assistance with personal care activities (14.8% vs. 10.2%). Of these activities, women were more likely than men to need assistance with bathing/showering (12.1% vs. 8.1%), dressing (9.1% vs. 7%), and eating (3.9% vs. 2.4%).⁶

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Caregiving and Trying to Keep Your Job

- While 71% of caregivers report that their employer knows of their caregiving role, only about a quarter of employees have access to employer caregiver programs.⁷
17% of the American full-time workforce are caregivers, and this amounts to a combined 126,222,624 missed workdays each year, at an estimated cost to the economy of $25.2 billion in lost productivity.\(^8\)

Carl Sorabella worked for a real estate company in Massachusetts for 14 years, but when he requested a flexible schedule so that he could accompany his wife to medical appointments for her stage 4 cancer, he was fired.\(^9\)

Paid Sick Leave Laws were enacted in Connecticut, Philadelphia, and Seattle, but defeated in Denver. In Wisconsin, the Governor enacted legislation nullifying Milwaukee’s Paid Sick Leave.

"Most employers report that California’s Paid Family Leave had either a "positive effect" or "no noticeable effect" on productivity (89 percent), profitability/performance (91 percent), turnover (96 percent), and employee morale (99 percent)."\(^{10}\)

Only 9% of primary caregivers in Australia who cared for 40 hours a week were also able to work full time.\(^{11}\)

Long-Term Care and Healthcare Costs

- Two-thirds of respondents in a CA survey worry about the cost of LTC and two-thirds could not afford more than three months of nursing home care if they were paying for it themselves.\(^{12}\)

- Brand name drugs facing generic competition in 2010 increased their retail prices by 51% from 2004 to 2010 (from $1,842 to $2,610 for a year of therapy).\(^{13}\)

- Out-of-pocket expenses for cancer patients in one study totaled $1,266 a month with prescription medication representing the largest expense at $523 a month. 47% of participants reported using all or part of their savings, 30% did not fill prescriptions, 20% took less medication than prescribed, and 40% borrowed money to pay for prescriptions.\(^{14}\)

- On average, patients who received palliative care incurred $6,900 less in hospital costs during a given admission than a matched group of patients who received usual care.\(^{15}\)

- 36% of respondents to a survey report that they delayed routine or elective medical procedures in 2011 because of the economy, as compared to 20% in 2009.\(^{16}\)

Veterans and their Families

- As high as 20% (about 400,000) of the two million soldiers who served in Iraq and Afghanistan have developed or are at risk of developing PTSD.\(^{17}\)

- As of November 2011, more than 1,800 Family Caregivers were approved for the Department of Veterans Affairs’ (VA) Program of Comprehensive Assistance for Family Caregivers. The average monthly stipend for caregivers is between $1,500 and $1,800, and 400 more family caregivers also received health care through the program that they didn’t previously have.\(^{18}\)
• The VA will be required to report in May 2013 on the feasibility of expanding the caregiver program beyond solely 9-11 veterans, who only comprise about 10% of the veteran population.19

• The VA’s Caregiver Support Line received 25,000 phone calls and emails during its first year, and Caregiver Support Coordinators responded to over 8,000 referrals through the program.20

**The Financial Impact of Caregiving**

• An average caregiver aged 50 or older who stops work to be a caregiver full-time will forego $303,880 worth of wages, Social Security, and pensions benefits.21

• Close to half (47%) of single female seniors are economically insecure, while more than half of all seniors of color do not have the resources required to support themselves over the remainder of their lives.22

• In a survey about long-term care needs, of family caregivers who helped pay for a loved one’s long-term care needs, 93% of caregivers reported using their own current income sources to help pay for care, 74% personally provided care in a loved one’s home, 54% brought their loved one into their home, and 49% used their own savings to help pay for care.23

• More than 51.4 million Americans of all ages live in a multigenerational household in 2011, a greater than 10% increase since the start of the recession in 2007. Reasons include:
  o current economic climate (66%);
  o job loss/change/underemployment (40%);
  o health care costs (20%); and
  o foreclosures or other housing loss (14%).24

• Adults aged 50-59 who are food-insecure are almost twice as likely to be diabetic, five times more likely to suffer from depression, and more than twice as likely to have at least one activity of daily living limitation.25

**Programs that Support Caregivers**

• In California, 7 agencies oversee 36 different programs serving the elderly and disabled.26

• In a national survey of Area Agencies on Aging, 60.5% reported cutting budgets in all or some departments in 2010, 52.7% reported increased caseloads, 50.2% eliminated or reduced salary increases, 49.3% reduced staff through attrition, by not replacing personnel who left the agency; 24.2% reported converting full-time positions to part-time positions, and 23.3% used lay-offs.27

• The Center for Medicare Advocacy filed a lawsuit in November, 2011 against the federal government based on Medicare patient stays being designated as outpatient or observational status as compared to in-patient status.28
• Ohio provided a $55.6 million increase for PASSPORT, resulting in 4,800 more Ohioans being able to access home and community-based services at about 1/3 of the cost of nursing home care.39

• California’s In Home Supportive Services program, the state's Personal Care Service Program, paid for, on average, 21.4 hours of week in 2008, while the authors of a study note that the national average of care provided (both paid and unpaid) is 31.4 hours a week.30

• Paying spouses, parents, and other relatives through California’s In Home Supportive Services program had no financial disadvantages and some advantages (lower average Medicaid expenditures and fewer nursing home admissions).31

• The hours of unmet need for care more than doubles from 62 million hours to 143 million hours when family caregivers in the United Kingdom are removed from the equation of social care (assistance with activities of daily living) for older adults.32

### Home and Community-Based Services versus Nursing Home Care

• The number of people on waiting lists for Medicaid HCBS Waivers increased by 17% from 2009 to 2010, with a total of 428,571 individuals on waiting lists for 149 waivers, and an average length of time on a wait list of 22 months. A federal class action lawsuit is seeking relief for more than 19,000 Florida residents with developmental disabilities who are on a years-long waiting list.33

• The number of minority elders living in nursing homes increased from 1999 to 2008, the number of elderly Hispanics grew by 54.9%, elderly Asians increased 54.1%, and elderly black residents increased 10.8%, while the number of elderly whites in nursing homes decreased by 10.2%.34

### How Technology Is Changing Caregiving

• A nursing home in Australia announced in June, 2011 that it would begin fitting patients with dementia with GPS tracking devices.35

• Minnesota’s information and referral service for seniors began offering an instant messaging service, staffed by 45 experts that is expected to generate 20,000 requests for help annually.36

• Oklahoma became the first state to fully automate Medicaid enrollment online, meaning you can apply and receive a decision online.37

• 15.5 million older Americans will experience poor transit access by 2015.38

### Quality, Costs, and Litigation for Nursing Homes

• The national average cost of nursing home care is 241% of the average annual household income of older adults.39
• 43% of nursing homes in North Carolina from 2007 to 2009 incorporated pre-dispute binding arbitration provisions in their admission contracts.\(^{40}\)

• Non-profit/government nursing homes and smaller nursing homes (49 or fewer beds) had the highest ratings for patient safety culture, highest rating of respondents who would tell friends this is a safe nursing home, and the highest percentage of respondents who gave their nursing homes an overall rating of "excellent" or "very good."\(^{47}\)

**Direct Care Workers**

• The median hourly wage for direct care workers in 2009 was $10.58 as compared to the median for all U.S. workers of $15.95. In addition to low wages, direct care workers also face a lack of hours (48% in 2009 worked less than full-time year-round), and lack access to health care, with an estimated 900,000 direct-care workers in 2009 lacking health care coverage.\(^{42}\)

• Each turnover of a direct care worker in Iowa costs $3,749 in direct expenses for the employer, and if indirect costs are included, each turnover costs a total of $6,793.\(^{43}\)

• A county judge in Washington State ruled that the Department of Social and Health Services (DSHS) owes 22,000 home-care workers about $96 million in back pay and accrued interest. The lawsuit is based on a 2003 decision by the state to pay caregivers 15% less if they lived in the same household as the care recipient (in the state's Medicaid program).\(^{44}\) Minnesota and California proposed similar cuts that would impact family caregivers in 2011 and 2012.\(^{45}\)

**FCA's Favorite Quotes from 2011**

So why are we not leaning out our windows, in the midst of our own personal lightning storms, shouting, 'I'm mad as hell and I'm not going to take this anymore,' like characters in the movie 'Network'? Denial, I'm told; ours is a death-denying culture. We do the right thing by our parents, and when it's over, we squeeze our eyes shut.\(^{46}\)

> -Jane Gross, author of *A Bittersweet Season* and founder of the New Old Age Blog

"In the four weeks prior to his death, my father lived under the care of five different institutions in two states. Only the last place, the hospice, appeared willing or able to provide care and comfort to a man who was obviously at the end of his life. Each facility admitted its failure to address my father's needs by moving him on; each transition increased his stress and suffering. It was torture for me and my sister to watch."\(^{47}\)

> -Sarah A. Stephens, Daughter in Massachusetts

"The laws, regulations, and qualifications regarding home health care entitlements are confusing, contradictory, arcane, vague, and sometimes, arbitrary and capricious...If something is not changed, large numbers of us, or our children, will be faced with severe financial burdens or the dilemma of making quality of life choices that satisfy no one."\(^{48}\)
“I had more support and I felt so validated, finally, people believe me, they saw our struggles, they didn't try to downplay anything, I didn't have to fight for help, I didn't have to plead my case, I didn't have to defend my husband's condition or actions. Finally I wasn't alone anymore, finally I have a support system.”

-Jennifer Conlon, Wife and Caregiver of an Iraq Veteran, writing about VA program

Medicaid: a "highly imperfect form of insurance as it essentially comes with a deductible of nearly all of your income and assets.”

-Jeffrey Brown and Amy Finkelstein, authors of “Insuring Long Term Care in the US”

"At minimum, a change in Medicare policy that would allow for long-term care, whether outside or inside the home, without requiring that the recipient be impoverished - a policy shift that would ease the financial anxieties of both generations and surely assuage some of their psychological anxieties as well.”

-Lillian Rubin, Mother and Author of 60 On Up: The Truth About Aging in America

"There are those who every day-like my husband, Tom-receive terminal diagnoses and display great courage, surprising their family and friends, and perhaps even themselves. It's not unique to the human experience, and as people enter this last stage of life, they deserve the knowledge to make the choices that are right for them.”

-Eleanor Clift, Wife, Journalist, Author of Two Weeks of Life: A Memoir of Love, Death and Politics

More Information . . .

If you would like to stay informed on caregiving issues, research, grant opportunities, and best practices, Family Caregiver Alliance publishes three free e-newsletters, including:

- Caregiving PolicyDigest: a twice-monthly briefing on current federal and state legislation, new programs and funding initiatives for long-term caregiving.

- The Newsletter of the Technical Assistance Centers brings timely information to the aging and lifespan respite networks about best practices, key research findings, and policy trends related to family caregiving and lifespan respite.

- Connections: Focuses on issues and information important to caregivers.

You can subscribe for all three on our website: www.caregiver.org and click on the “Newsletters” tab at the top of the homepage.
"What you give... will come back to you. It will be me one day."

- Ms. Crystal M.
Baton Rouge Caregiver


FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving
785 Market Street, Suite 750
San Francisco, CA 94103
Phone (415) 434-3388
Fax (415) 434-3508
www.caregiver.org
Email: info@caregiver.org

Connect with FCA online:
Endnotes


5. Hoffman GJ and Mendez-Luck CA. Stressed and Strapped: Caregivers in California. Los Angeles, CA:


