



Southern Caregiver Resource Center

Caring for those who care for others

Fact Sheet:

Caregiving

Introduction

Caregiving takes many forms. Many of us help older, sick, or disabled family members and friends every day. We know we are helping, but we don't think of ourselves as caregivers. We are glad to do this and feel rewarded by it, but if the demands are heavy, over time we can also become exhausted and stressed. We think we should be able to handle caregiving roles on top of busy work and family schedules and begin to feel guilty and depressed as our stamina wanes.

About 44 million Americans provide 37 billion hours of unpaid, "informal" care each year for adult family members and friends with chronic illnesses or conditions that prevent them from handling daily activities such as bathing, managing medications or preparing meals on their own. Family caregivers, particularly women, provide over 75% of caregiving support in the United States. In 2007, the estimated economic value of family caregivers' unpaid contributions was at least \$375 billion, which is how much it would cost to replace that care with paid services.¹

Caregiving: A Universal Occupation

Who Are Caregivers?

The short answer is most of us, at some point in our lives. Caregivers are daughters, wives, husbands, sons, grandchildren, nieces, nephews, partners and friends. While some people receive care from paid caregivers, most rely on unpaid assistance from families, friends and neighbors.

Caregivers manage a wide range of responsibilities. In your family, for example, are you the person who:

- Buys groceries, cooks, cleans house or does laundry for someone who needs special help doing these things?
- Helps a family member get dressed, take a shower and take medicine?
- Helps with transferring someone in and out of bed, helps with physical therapy, injections, feeding tubes or other medical procedures?
- Makes medical appointments and drives to the doctor and drugstore?
- Talks with the doctors, care managers and others to understand what needs to be done?
- Spends time at work handling a crisis or making plans to help a

family member who is sick?

- Is the designated "on-call" family member for problems?

In small doses, these jobs are manageable. But having to juggle competing caregiving demands with the demands of your own life on an ongoing basis can be quite a challenge.

With the 65+ age group expected to double to 70 million people by 2030,² family caregivers increasingly provide care for aging parents, siblings, and friends, most of whom have one or more chronic conditions³ and who wish to remain in their own homes and communities as they age.⁴ Others belong to the "sandwich generation," caring for children and parents at the same time.

Caregiving roles and demands are impacted by a number of other factors, including:

- **Type of illness.** Caring for someone with Alzheimer's disease, other dementias, or other brain-impairing disorders can be more stressful than caring for someone with a physical impairment. Caring for someone with a cognitive disorder can be a 24/7 job due to the unpredictability of the care recipient's behavior.⁵
- **Long-distance caregiving.** Long-distance caregiving is usually defined as care provided by a caregiver living more than an hour away from the care recipient. Caring from a distance is difficult both emotionally and logistically, and is most common in situations where adult children and their parents do not live in

the same area. In these cases, the caregiver's role is not as much "hands-on" as it is gathering information about available resources, coordinating services and putting together a "team" of family, friends and paid help that can meet the care recipient's needs.

- **Urban versus rural settings.** Caregivers living in rural settings face unique challenges. These include fewer available formal services, fewer physicians and health education services, transportation difficulties, weather problems in winter, geographic distance and isolation.⁶
- **Different cultural approaches to caregiving.** The United States' great diversity means that families bring their own histories, traditions and rituals to caregiving. In many cultures, there are family expectations about the caregiving roles of adult children; this is especially true in cultures where daughters or daughters-in-law are expected to assume the primary caregiver role for aging parents.

For some people, caregiving occurs gradually over time. For others, it can happen overnight. Caregivers may be full- or part-time; live with their loved one or provide care from a distance. Caregivers provide a wide range of services, from simple help such as grocery shopping, to complex medical procedures. For the most part, friends, neighbors, and most of all, families, provide—without pay—the vast majority of healthcare in this country.

First Steps: Help for New Caregivers

It is easy to become overwhelmed as a new caregiver. Five steps that can help are:

- **Start with a diagnosis.** Learning about a family member's diagnosis helps caregivers understand the disease process and plan ahead realistically.
- **Talk about finances and healthcare wishes.** Having these conversations can be difficult, but completing Durable Powers of Attorney for finances and healthcare can help relieve anxiety and better prepare for the future.
- **Consider inviting family and close friends to come together and discuss the care needed.** If possible, it's helpful to include the care recipient in this meeting. This meeting gives caregivers a chance to say what they need, plan for care and ask others for assistance.
- **Take advantage of community resources such as Meals on Wheels and adult day programs.** These resources help relieve the workload and offer a break. Look for caregiver educational programs that will increase knowledge and confidence.
- **Find support.** The most important thing is for caregivers to not become isolated as they take on more responsibility and as social life moves into the background. Online and in-person groups can be very helpful in connecting with others

in the same circumstances.

Caregivers can call Family Caregiver Alliance at (800) 445-8106 to learn about local services, or visit www.caregiver.org, and click on "Family Care Navigator."

Caregiving in the U.S.

Data from many studies and reports reveal the following information about caregivers:

- The "typical" U.S. caregiver is a 46-year-old woman who works outside the home and spends more than 20 hours per week providing unpaid care to her mother.⁷ Most caregivers are married or living with a partner.⁸
- While caregivers can be found across the age span, the majority of caregivers are middle-aged (35-64 years old).⁹
- Most caregivers are employed. Among caregivers age 50-64 years old, an estimated 60% are working full or part-time.¹⁰
- Studies show that ethnic minority caregivers provide more care than their white counter-parts¹¹ and report worse physical health than white caregivers.¹²
- Many caregivers of older people are themselves elderly. Of those caring for someone aged 65+, the average age of caregivers is 63 years with one third of these caregivers in fair to poor health.¹³
- Nearly half of caregivers provide fewer than eight hours of care per week, while nearly one in five provide more than 40 hours of care per week.¹⁴ A statewide

California study of caregivers of adults with cognitive disorders such as Alzheimer's showed that caregivers provided an average of 84 hours of care per week, the equivalent of more than two full-time jobs.¹⁵ Older caregivers often spend the most hours providing care¹⁶ and the amount of time spent caring increases substantially as cognitive impairment worsens.¹⁷

- Caregiving can last from less than a year to more than 40 years. In a 2003 study, caregivers were found to spend an average of 4.3 years providing care. Older caregivers (50+) are more likely to have been caregiving for more than 10 years (17%).¹⁸
- Most caregivers live near the people they care for. Eighty-three percent of caregivers care for relatives, with 24% living with the care recipient, 61% living up to one hour away, and 15%—or about 7,000,000 caregivers—living a one- to two- hour drive or more away.¹⁹

Effects of Caregiving

Impact on Physical and Emotional Health

Recent medical advances, shorter hospital stays, increasing life spans with better management of chronic illnesses, limited discharge planning, a shortage of homecare workers, and the expansion of home care technology have increased the caregiving responsibilities of families. Family caregivers are being asked to shoulder greater burdens for longer periods of

time. In addition to more complex care, conflicting demands of jobs and family, increasing economic pressure, and the physical and emotional demands of long-term caregiving can result in major health impacts on caregivers.²⁰

Over all, caregivers who experience the greatest emotional stress tend to be female. They are at risk for high levels of stress, frustration, anxiety, exhaustion and anger, depression, increased use of alcohol or other substances, reduced immune response, poor physical health and more chronic conditions, neglecting their own care and have higher mortality rates compared to noncaregivers.²¹

In addition, most caregivers are ill-prepared for their role and provide care with little or no support;²² yet more than one-third of caregivers continue to provide intense care to others while suffering from poor health themselves.²³ An influential factor in a caregiver's decision to place an impaired relative in a long-term care facility is the family caregiver's own physical health.²⁴

Financial Issues

Long term caregiving has significant financial consequences for caregivers, particularly for women. Informal caregivers personally lose about \$659,139 over a lifetime: \$25,494 in Social Security benefits; \$67,202 in pension benefits; and \$566,443 in forgone wages.

Caregivers face the loss of income of the care recipient, loss of their own income if they reduce their work hours or leave their jobs, loss of employer-based medical benefits, shrinking of savings to pay caregiving costs, and a threat to their retirement income due to

fewer contributions to pensions and other retirement vehicles.²⁵

Work and Eldercare

Caregiving also has a substantial impact on business. Lost productivity due to informal caregiving costs businesses \$17.1 billion annually.²⁶ Absenteeism, replacing employees who quit in order to provide care and other caregiving-related activities also have serious financial consequences to employers. For instance

- The cost to businesses to replace women caregivers who quit their jobs because of their caregiving responsibilities has been estimated at \$3.3 billion.
- Absenteeism among women caregivers due to caregiving responsibilities costs businesses almost \$270 million.
- The cost to businesses because of partial absenteeism (e.g., extended lunch breaks, leaving work early or arriving late) due to women's caregiving has been estimated at \$327 million. Caregiving-related workday interruptions add another \$3.8 billion to the burden borne by businesses.²⁷

Working caregivers often suffer many work-related difficulties due to their "second careers" as caregivers. Sixty-seven percent of family caregivers report conflicts between caregiving and employment, resulting in reduced work hours or unpaid leave.²⁸

The importance of eldercare is now recognized by a growing number of employers, with movement toward more flexible work schedules, "cafeteria style"

benefits, in-house support groups, and education, information, and referrals provided through employee assistance programs.

Policy changes have also supported family caregivers. Companies with 50 or more employees must comply with the Family and Medical Leave Act (FMLA), which allows for up to 12 weeks of unpaid leave to care for a seriously ill parent, spouse or child, while protecting job security. Smaller firms can use the FMLA guidelines to provide support for individual employees. Paid Family Leave (PFL) provides workers with a maximum of six weeks of partial pay each year while taking time off from work to care for a seriously ill parent, child, spouse or registered domestic partner, and has been instituted in several states, including California. Policy changes that could also benefit family caregivers include paid sick leave that can be used by employees for themselves or to care for family members and expanding FMLA beyond immediate family members to include care for siblings, in-laws and grandparents.²⁹

Legal Issues

It is important to make legal preparations in the event a parent becomes cognitively impaired. Typical concerns include who will manage the confused person's money, who will make important health care decisions and how to plan for long-term care.

An attorney can help plan for the financial aspects of long-term care needs, assist with surrogate decision-making tools such as the durable power of attorney (DPA) and a durable power of attorney for health care (DPAHC), and provide guidance in obtaining a

conservatorship should the care recipient lack the capacity to make decisions. A conservatorship provides the legal authority to manage a person's finances, estate, personal affairs, assets and medical care.³⁰

The Need for Support

Because of the multi-faceted role that family and informal caregivers play, they need a range of support services to remain healthy, improve their caregiving skills and remain in their caregiving role. Support services include information, assistance, counseling, respite, home modifications or assistive devices, caregiver and family counseling, and support groups. While many services are available through local government agencies, service organizations, or faith-based organizations, employers' programs also can mitigate the impact that caregiving can have on workers.

Services that improve caregiver depression, anxiety and anger benefit both the caregiver and the care recipient.³¹ Evidence also shows that caregiver support delays or prevents nursing home placement; people with moderate dementia have been able to defer placement by nearly 1.5 years when their family members receive caregiver services, including counseling, information and ongoing support.³²

Policy Implications

Family caregiving is the backbone of the United States' long term care system as well as the core of what sustains frail elders and adults with disabilities, yet caregivers often make major sacrifices to help loved ones remain in their homes. A federal investment in family

caregiver support is needed now more than ever.

A national agenda is needed that:

- Supports the National Family Caregiver Support Program (NFCSP) to provide caregivers with information and assistance, counseling, support groups, respite, caregiver training and limited supplemental services.
- Funds Lifespan Respite Care so that family caregivers can take a break from the demands of providing constant care
- Expands the Family and Medical Leave Act (FMLA) and paid leave policies to increase financial support for workers providing essential care for family members.
- Promotes financial incentives, career advancement, geriatric education and training, and long-term care policies to expand the geriatric care workforce.
- Enacts legislation providing refundable tax credits for family caregivers to defray long-term care costs and compensate for expenses that family and informal caregivers at all income levels incur.
- Strengthen Social Security by recognizing the work of family caregivers who leave the workforce to provide full-time support and care for an ill, disabled or an elderly family member.

Conclusion

With the dramatic aging of the

population, we will be relying even more on families to provide care for their aging parents, relatives and friends for months and years at a time. Yet, the enormous pressures and risks of family caregiving—burnout, compromised health, depression and depletion of financial resources—are a reality of daily life for millions of American families and pose great strain on family caregivers, many of whom are struggling to balance work and family responsibilities.

Families need information and their own support services to preserve their critical role as caregivers, but frequently they do not know where to turn for help. When they do seek assistance, many community agencies cannot provide adequate supports due to funding constraints and outdated policies. The federal government can help by taking steps to ensure that all family caregivers have access to caregiver assistance and to practical, high quality, and affordable home and community-based services. These are tough economic times, but supporting family caregivers is one of the most cost-effective long-term care investments we can make. As long as caregivers are able to provide care, they are often able to delay costly nursing home placements and reduce reliance on programs like Medicaid.

Credits

Family Caregiver Alliance, "2009 National Policy Statement."

Family Caregiver Alliance, Family Caregiving and Long-Term Care: A Crucial Issue for America's Families, Policy Brief. San Francisco, CA, June 2004.

Family Caregiver Alliance, Caregiver Assessment: Principles, Guidelines and Strategies for Change, Volume 1. San Francisco, CA, April 2006.

Family Caregiver Alliance, Caregiving and Retirement Planning: What Happens to Family Caregivers Who Leave the Work Force, Policy Brief, December 2003.

Family Caregiver Alliance, "Caring in Rural Communities," Update, Winter 2006.

AARP Public Policy Institute, Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update, November 2008.

American Journal of Nursing, "State of the Science: Professional Partners Supporting Family Caregivers." 108, N0. 9 Supplement. New York, NY: Lippincott Williams & Wilkins, September 2008.

Easter Seals and National Alliance for Caregiving, Caregiving in Rural America, October 2007.

HarrisInteractive and GlaxoSmithKline, "Improving the Patient-Physician Relationship," 2003.

National Alliance for Caregiving and AARP, Caregiving in the U.S., April 2004.

References

¹ National Alliance for Caregiving and AARP. Caregiving in the U.S. Bethesda: Washington, DC: AARP Public Policy Institute, Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update. Washington, DC: 2008; Family Caregiver Alliance, Family Caregiving and Long-Term Care: A Crucial Issue for America's Families,

- Policy Brief. San Francisco, CA: June 2004.
- ² Family Caregiver Alliance, Family Caregiving and Long-Term Care: A Crucial Issue for America's Families, Policy Brief. San Francisco, CA: June 2004.
- ³ Chronic Care in America, GlaxoSmithKline and HarrisInteractive, 2003.
- ⁴ Beyond 50.05: A Report to the Nation on Livable Communities, AARP, May 2005.
- ⁵ Family Caregiver Alliance Fact Sheet, Is This Dementia and What Does It Mean?, 2008; Fact Sheet, Caregiver's Guide to Understanding Dementia Behaviors, 2008; National Alliance for Caregiving and AARP; Caregiving in the U.S.
- ⁶ Family Caregiver Alliance, Caring in Rural Communities; Easter Seals and the National Alliance for Caregiving, Caregiving in Rural America, October 2007.
- ⁷ National Alliance for Caregiving and AARP. Caregiving in the U.S. Bethesda: National Alliance for Caregiving, and Washington, DC: AARP, April 2004.
- ⁸ National Alliance for Caregiving and AARP; Caregiving in the U.S. Bethesda: National Alliance for Caregiving, and Washington, DC: AARP, 2004.
- ⁹ National Alliance for Caregiving and AARP. Caregiving in the U.S. Bethesda: National Alliance for Caregiving, and Washington, DC: AARP, 2004; Alecxih, L. M. B., S. Zeruld, and B. Olearczyk, Characteristics of Caregivers Based on the Survey of Income and Program Participation, Falls Church, VA: The Lewin Group, 2001.
- ¹⁰ AARP. Beyond 50.03: A Report to the Nation on Independent Living and Disability. Washington DC: AARP, 2003.
- ¹¹ McCann, J.J., L.E. Hebert, L.A. Beckett, M.C. Morris, P.A. Scherr, and D.A. Evans. 2000. "Comparison of Informal Caregiving by Black and White Older Adults in a Community Population." *Journal of the American Geriatrics Society* 48:1612-1617;
- Pinquart, M. and S. Sorenson. 2005. "Ethnic Differences in Stressors, Resources, and Psychological Outcomes of Family Caregiving: A Meta-Analysis." *The Gerontologist* 45: 90-106.
- ¹² Pinquart, M. and S. Sorenson. 2005. "Ethnic Differences in Stressors, Resources, and Psychological Outcomes of Family Caregiving: A Meta-Analysis," *The Gerontologist* 45: 90-106.
- ¹³ Administration on Aging, NFCSP Complete Resource Guide, September 9, 2004
- ¹⁴ National Alliance for Caregiving and AARP. Caregiving in the U.S. Bethesda: National Alliance for Caregiving, and Washington, DC: AARP, 2004.
- ¹⁵ Family Caregiver Alliance, "Caregivers at Risk," 2004/05.
- ¹⁶ Partnership for Solutions. "Chronic conditions: Making the case for ongoing care." Baltimore: Johns Hopkins University, 2002.
- ¹⁷ Langa K.M., M. Chernew, M. Kabeto, A.R. Herzog, M.B. Ofstedal, R. Willis, R. Wallace, L. Mucha, W. Straus, AM. Fendrick. 2001. "National Estimates of the Quantity and Cost of Informal Caregiving for the Elderly with Dementia." *Journal of General Internal Medicine* 16: 770-778.
- ¹⁸ National Alliance for Caregiving and AARP. Caregiving in the U.S. Bethesda: National Alliance for Caregiving, and Washington, DC: AARP, 2004.
- ¹⁹ National Alliance for Caregiving and AARP. Caregiving in the U.S. Bethesda: National Alliance for Caregiving, and

Washington, DC: AARP, 2004.

²⁰ Family Caregiver Alliance, "Caregiving in California." Issue Paper #1, 2007.

²¹ Family Caregiver Alliance, Caregiving in California: Issue Paper #1, 2007; National Alliance for Caregiving and AARP. Caregiving in the U.S. Bethesda: National Alliance for Caregiving, and Washington, DC: AARP, 2004.

²² National Alliance for Caregiving & AARP. (2004). Caregiving in the U.S. Alzheimer's Association & National Alliance for Caregiving. (2004); Families Care: Alzheimer's Caregiving in the United States. Chicago, IL: Alzheimer's Association and Bethesda, MD: National Alliance for Caregiving; Family Caregiver Alliance (2006). Caregiver Assessment: Principles, Guidelines and Strategies for Change. Report from a National Consensus Development Conference (Vol. I). San Francisco: Author.

²³ Navaie-Waliser, M., Feldman, P.H., Gould, D.A., Levine, C.L., Kuerbis, A.N. & Donelan, K. (2002). "When the caregiver needs care: The plight of vulnerable caregivers." American Journal of Public Health, 92(3), 409-413

²⁴ Buhr, G.T., Kuchibhatla, M., & Clipp, E. (2006). "Caregivers' reasons for nursing home placement: Cues for improving discussions with families prior to the transition." The Gerontologist, 46(1): 52-61; Whitlatch, C.J., Feinberg, L.F., & Sebesta, D.S. (1997).

"Depression and health in family caregivers." Journal of Aging and Health, Vol.9 (2), 222-243; Whitlatch, C.J., Feinberg, L.F., & Stevens, E.J. (1999). "Predictors of institutionalization for persons with Alzheimer's disease and the impact on family caregivers." Journal of Mental Health and Aging, Vol. 5(3). 275-288; Lieberman, M.A. & Kramer, J.H. (1991). "Factors affecting

decisions to institutionalize demented elderly." The Gerontologist, 31, 371-374.

²⁵ AARP Public Policy Institute, Valuing the Invaluable: The Economic Value of Family Caregiving, 2008 Update. Washington, DC: AARP, November 2008.

²⁶ Family Caregiver Alliance, 2009 National Policy Statement.

²⁷ Metropolitan Life Insurance Company and National Alliance for Caregiving. (1997, June). The Metlife study of employer costs for working caregivers. Connecticut: Metropolitan Life Insurance Company.

²⁸ Family Caregiver Alliance, 2009 National Policy Statement.

²⁹ Family Caregiver Alliance, Fact Sheet: Work and Eldercare Fact Sheet, 1999; Family Caregiver Alliance, 2009 National Policy Statement.

³⁰ Family Caregiver Alliance, Fact Sheet: Work and Eldercare, 1999.

³¹ Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L.M., Belle, S.H., Burgio, L., Gitlin, L., Coon, D., Burns, R., Gallagher-Thompson, D., and Stevens, A. 2002. "Dementia Caregiver Intervention Research: In Search of Clinical Significance." The Gerontologist 42:589-602; Bookwala, J., Zdaniuk, B., Burton, L., Lind, B., Jackson, S., Schulz, R. 2004. "Concurrent and Long-Term Predictors of Older Adults' Use of Community-Based Long-Term Care Services: The Caregiver Health Effects Study." Journal of Aging and Health 16: 88-115; Zarit, S.H., Stephens, M.A.P., Townsend, A. and Greene, R. 1998. "Stress Reduction for Family Caregivers: Effects of Adult Day Care Use." Journal of Gerontology: Social Sciences 53B:S267-S277.

³² AARP Public Policy Institute, Valuing the Invaluable: The Economic Value of

Family Caregiving, 2008 Update. Washington, DC: AARP, November 2008; Mittelman, M. S., Haley, W., & Roth, D. 2006. "Improving Caregiver Well-being Delays Nursing Home Placement of Patients with Alzheimer's Disease." *Neurology*, 67, 1592-1599.

Resources

Southern Caregiver Resource Center
3675 Ruffin Road, Suite 230
San Diego, CA 92123
(858) 268-4432; (800) 827-1008 (in CA)
E-mail: scrc@caregivercenter.org
Web site: www.caregivercenter.org

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**
235 Montgomery Street, Suite 950
San Francisco, CA 94103
(415) 434-3388; (800) 445-8106
Web site: 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. FCA's 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, publishes

timely reports, newsletters and fact sheets, and assists caregivers nationwide in locating resources in their communities.

Family Care Navigator
<https://caregiver.org/family-care-navigator>

Fact Sheets

Alzheimer's Disease & Caregiving

Caregiver Health

*Caregiver's Guide to Understanding
Dementia Behaviors*

Is This Dementia & What Does It Mean?

Legal Issues in Planning for Incapacity

*Taking Care of YOU: Self-Care for
Family*

*Women and Caregiving: Facts and
Figures*

Work and Eldercare

Eldercare Locator
www.eldercare.gov

Medicare
www.medicare.gov

National Alliance for Caregiving
www.caregiving.org

AGIS
www.agis.com

AARP
www.aarp.org