



Southern Caregiver Resource Center

Caring for those who care for others

Fact Sheet:

Work and Eldercare

Introduction

More than ever before, caregiving is recognized as a key element of everyday life for millions of families throughout the United States. As our population ages, more families are providing care for an older adult at home, and an increasing number of people will need such care in the future. Current demographic and healthcare trends make this issue even more significant:

- The massive Baby Boomer generation is at prime caregiving age, and soon many will become care recipients themselves.
- Although we are living longer, debilitating, age-related illnesses such as Alzheimer's disease, Parkinson's, arthritis, diabetes and stroke are occurring with increasing frequency.
- Hospital stays are becoming shorter, meaning more care is needed at home.
- Women, who have traditionally been the caregivers for both children and the elderly, are now in the workforce and less available to provide full-time care.
- More men are assuming caregiving responsibilities.

Caregiving impacts not only a growing number of individuals, but their families and their workplaces as well. According to recent studies, as many as 42 percent of employed Americans (more than 54 million people) have provided eldercare in the last five years; 17 percent currently provide care. The average age of caregivers is 49—a peak year for earnings and for career achievement. Women take on slightly more responsibility for care, but men are greatly impacted also.

What Kinds Of Care Do Family Caregivers Provide?

The types of care ranges from personal (bathing, dressing, helping with toileting, feeding) to every-day tasks and activities (preparing meals, providing transportation, handling finances, managing medications, coordinating services, communicating with healthcare professionals). The average caregiver provides care for more than four years, with some care extending for decades. Few caregivers use paid help: fully 76 percent of working caregivers rely only on their families and themselves. At times, caregiving can seem like a second job.

Thus millions of working adults—an estimated one in four households—juggle the competing demands of caring for a chronically ill relative, raising a

family, and managing a career. Work disruptions due to employee caregiving responsibilities result in productivity losses to businesses of an estimated \$2110 per year per employee—a loss of up to \$33.6 billion per year for full-time employees as a group.

Negative effects on working caregivers may include poorer health, time lost from work and lower productivity, leaving a job to give care, lost career opportunities, lost employer paid health benefits and lower current and future earnings, including Social Security and pension income. Eventually, 10 percent, over the time they are caregiving, report quitting their jobs to provide care full-time, resulting in an average loss of more than \$303,880 each in wage, Social Security income and pension income over a lifetime.

This fact sheet reviews the key issues that caregivers face; suggests measures they can take to help manage their work and care conflicts; reviews legal options to clarify financial and healthcare decision-making; and discusses cost-efficient ways employers can retain valued employees by offering programs that are supportive to caregivers. The *Resources* listed at the end of the fact sheet offer additional information and sources of help.

First Steps for Caregivers: Assessing Needs

Many community resources exist to help caregivers and their ill or frail loved ones. Your challenge as a caregiver is to determine how to best utilize the time and energy you have available for caregiving in addition to the demands of your job and family responsibilities. In sorting out your family's needs, and

deciding where you need help, consider the following steps:

- Make a list of all you do as a caregiver. For example, I do the grocery shopping; help Mom dress every morning; take Dad to the doctor; pay his bills; do her laundry.
- Make a second list of what you might be able to delegate to others and the times you need help. For example, keep Mom company and prepare her lunch while I'm at work, or give Dad a ride to the senior center on Tuesdays and Thursdays at 9:00 a.m.
- Consider what type of care is needed (companion, chore work, food preparation, or nursing) and whether the care can be delivered at home, a senior center, an adult day care center, or another location.
- Determine how much money your loved one or your family can afford to pay for outside help. Generally, long-term care is not covered by health insurance unless you have purchased a long-term care policy. Even then, there may be limitations on what kinds of home care are covered. Medicare pays only for medically necessary care or equipment. If you meet the income qualifications, Medicaid (Medi-Cal in California) may pay for some services.
- Explore care options in your community or near your parent's home. Ask friends and neighbors about their experience with local

services they have used and care providers for hire.

Assessing Your Options

Finding Community Resources

Information and Referral: These are services to help you locate programs and services. Senior or community organizations maintain lists of resources, by geographic area, to help you get started in finding the services you need. Some employers also offer information through Employee Assistance Programs (EAP).

The internet provides resource listings and online support groups where you can seek information. Family Caregiver Alliance's (FCA) online **Family Care Navigator** offers information on public resources for every state, including local Area Agencies on Aging. The national **Eldercare Locator** provides information on Area Agencies on Aging and other services. Even if your parent lives far away, you can find services to help.

Informal Arrangements

There may be chores that can be done by friends, family, neighbors or faith group members. Simple tasks include preparing meals, providing rides, helping with grocery shopping or laundry, providing reassuring phone calls or companionship for your relative. Local senior centers or colleges often have programs for community volunteers. Websites such as www.LotsaHelpingHands.com provide password-protected sites to help you schedule help and keep family and friends notified of your loved one's condition.

A **family meeting** can be very helpful in discussing difficult medical and legal issues. Identifying needs, sharing concerns and delegating tasks should be done in an open, supportive environment where family members can identify potential solutions together. The meeting can be held in-person, by phone or by video-conference.

To work through certain family dynamics or conflicts, it's often helpful to involve a person outside the family. A **social worker, geriatric care manager** or other professional skilled in group interaction and family dynamics can be hired to help the family and caregiver make a care plan and, if needed, help with care arrangements and monitoring. This may be especially helpful if your ill parent lives far from you.

In-Home Care

Care at home can be formal (paid) through a home care agency or privately hired personal attendant, or informal (unpaid) – a friend, family member, or volunteer. (Sometimes, through a formal Personal Care Agreement, a family member can be paid to provide care.) If no medical or personal care is needed, look for a caring, responsible, person who could be a welcome companion for your relative. Personal referrals are the best way to find this person, or an ad can be placed online or in a local newspaper to search for a part-time companion and chore worker. If care involves toileting or bathing, you will need a person who is trained, competent and sensitive. Similarly, if lifting the person and/or a wheel chair is necessary, be sure the worker is trained and physically able to do the work. Always do criminal background checks and call at least three past employer references.

When medical or health care is required, such as giving medications, providing catheter care or monitoring a feeding tube, you may decide to hire a certified nursing assistant (CNA) or a licensed practical nurse (LPN or LVN in California) depending on the level of education and skill required. A registered nurse (RN) is needed only when more complex medical care is necessary (such as treating wounds, or managing a ventilator). Medicare may be able to cover medically necessary part-time care for a homebound older person in limited, specific situations.

Adult Day Care

Adult day care centers provide a range of social and therapeutic activities outside the home for older adults and adults with a disability. These centers, located primarily in urban areas, vary in their service mix. Most offer social services and activities in a safe, supportive environment. Depending on the program, some offer transportation, personal health care (such as bathing and incontinence care), and medical or allied health care (such as physical therapy and occupational therapy), may be available. It is important to check eligibility criteria. Some centers may not accept participants who are disruptive, have certain health problems or are incontinent (loss of bladder/bowel control). Participants generally attend several hours per day, up to five days a week (weekend adult day care is rarely available), making it possible for the caregiver to go to work assured that the care recipient is in a safe place.

Other Community Resources

In California, eleven Caregiver Resource Centers (CRCs) provide a

range of supportive services to family caregivers of adults with disabling health conditions (e.g., Alzheimer's, Parkinson's, stroke, traumatic brain injury, Parkinson's disease). CRCs help caregivers with information, educational programs and emotional support, as well as planning for and arranging services for a loved one. Most services are free of charge. More information can be found by visiting FCA's list of California's Caregiver Resource Centers.

Many other community services are available to help, including care management services, home-delivered meals, transportation services, temporary overnight care, hospice (for terminally ill individuals), and support groups (for either the caregiver or the ill individual). Your local Area Agency on Aging or senior center can help you locate these.

Residential Placement

When a parent or relative can no longer be cared for at home, it may be necessary to consider a residential facility such as an assisted living residence or nursing home. Arriving at this decision can be quite painful. Both you and your parents are likely to have strong feelings about nursing homes, and financing is always an issue. You may want to discuss the decision with other family members, a counselor or spiritual advisor.

Ultimately, it is important to evaluate your parent's current living situation and carefully assess how care needs can be met. Consider your parent's safety, isolation, ability to be left alone, medical needs, and available help for basic daily

activities (e.g., eating, dressing, toileting, bathing, moving around).

In addition, the daily strain on the caregiver must not be ignored. If you, your sibling or parent are the primary caregiver, it is critical to recognize when caregiving demands – especially when combined with work and other family demands - exceed what is possible for you, your family and friends. If you determine that home is no longer a good or safe place to be, it is time to look at other viable residential care options:

- Senior residences or assisted living facilities (ALF) offer maximum independence, apartment-style living with additional services such as meals, house cleaning, transportation, recreation and social activities and, sometimes, an on-call nurse. Depending on the state, ALFs may or may not be licensed to accept Medicaid reimbursement.
- **Residential Care Facilities** (also called **board and care homes or adult foster homes**), are group homes for individuals who cannot live alone, but do not need skilled nursing. These facilities offer help with personal care and hygiene, meals, social interaction with others, and bedside care. They have 24-hour staff in case of emergencies. Depending on the state, this type of residence may or may not be licensed and may not accept Medicaid reimbursement.
- **Skilled Nursing Facilities (SNF)** provide nursing care to residents and must be equipped to

administer medications, injections and provide other nursing functions. Under certain limited conditions, Medicare may pay some nursing home costs, but for a limited time only.

Legal/Financial Issues

If your parent becomes impaired, you may face a host of new legal and financial issues. 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 you plan for the financial aspects of your parent's care needs. At a minimum, a suitable attorney should have experience in estate and financial planning, probate and wills, and be familiar with public benefits including Medicaid, Social Security, special needs trusts, tax planning, and housing and health care contracts. Some ways to locate an attorney include: your local County Bar Association or National Association of Elder Law Attorneys referral service, senior centers, legal aid organizations, or a personal recommendation from a friend or fellow support group member.

Making decisions for a person with an illness such as Alzheimer's disease or a stroke can be difficult and emotionally charged. The process can be simplified significantly, however, if your parent or relative has completed a Durable Power Of Attorney (DPA) and a Durable Power Of Attorney for Health Care (DPAHC) and Advance Health Care Directive. These documents enable your parent to

designate another person to manage his or her finances and healthcare decisions. The legal authority to make those decisions begins only when and if the person becomes incapable of doing so on their own. It is a good idea to have DPA and DPAHC forms reviewed by an attorney experienced in estate planning to ensure that the person's wishes are clearly expressed and the information is complete.

If your parent is already suffering from dementia and does not have the capacity to make decisions, you may need to obtain a conservatorship. A conservatorship provides legal authority to manage a person's finances, estate, personal affairs, assets and medical care. This is a court procedure.

Using Technology

In addition to providing access to a wealth of medical and caregiving information available 24 hours a day on your computer, tablet or cell phone, digital technology may also be useful for such things as ordering prescriptions, communicating with healthcare professionals, staying in contact with friends and family, scheduling home care, learning new skills through webinars, tracking movement, and even visually checking on loved ones during the day or providing surveillance of your parent's home when you can't be there.

What Employers Can Do

Caregiving as a workplace issue is now recognized by a growing number of employers. Larger corporations are sometimes able to offer support in ways small ones cannot, but there are actions that companies of any size can take to support employees who have caregiving responsibilities:

- The most requested work adjustment is flexibility in work hours. This may include allowing a shift in schedules (e.g., working 10:00 a.m. to 6:00 p.m. instead of 9 to 5; a compressed work schedule (four ten- hour days instead of five eight- hour days); a part- time schedule; job sharing; or telecommuting. A limit on mandatory overtime is also helpful. Studies have shown that flexible scheduling improves job performance, decreases tardiness and employee turnover, and increases job satisfaction and retention (even for employees who are not currently caregivers).
- Human Resource or Employee Assistance Program staff can provide information on helpful internet sites, local community services, care managers or resource centers, and should provide information about leave programs and other company policies.
- Training for supervisors enhances understanding of the conflicting demands of work and caregiving and ensures that mandates for family leave and antidiscrimination regulations are met.
- Various state regulations and certain sections of the ADA (Americans with Disabilities Act) prohibit employers from discriminating against caregiving employees (for example, passing over employees for promotion, stereotyping employees because of caregiving status).

- Companies with 50 or more employees must comply with the federal Family and Medical Leave Act (FMLA), which allows for up to 12 weeks of unpaid leave (or 26 weeks to care for an active service member). The leave may be used to care for a seriously ill parent, spouse or child. Job and health insurance are protected. However, approximately half of US companies have fewer than 50 employees and therefore are exempt from FMLA requirements. Nonetheless, many use FMLA guidelines to provide support for individual employees.
- Paid Family Leave (PFL) is a mandated benefit that covers caregivers of a seriously ill parent, child, spouse or registered domestic partner, as well as new parents. California and only a handful of other states currently offer paid family leave. In California, employees may receive up to 55% of their wages for six weeks of leave. Job security is not protected. Workers who already pay in to the existing State Disability Insurance (SDI) system--you will see it as a deduction on your paycheck--are eligible for paid family leave.
- Some larger employers offer "cafeteria style" employee benefits which allow employees to select supplemental dependent care coverage to partially reimburse costs for in-home care or adult day care. A few companies offer subsidized payments for geriatric care managers.
- Sometimes larger businesses organize in-house caregiver support groups, informational "brown-bag" lunch sessions, or coordinate with local community groups or hospitals so that employees can attend an outside support group.
- Some employers arrange group purchase of long-term care insurance for employees, spouses and dependents.
- Other supportive, low-cost things employers can do include publicizing a telephone hot-line for caregivers, or publishing a list of key contacts or advice in the employee newsletter.

Handling Stress

Caring for an ill or disabled parent can be particularly challenging as you attempt to balance the competing demands of work, family and caregiving. Negotiating adequate time off from work, coping with tension filled family dynamics and having time to cope with your own fears and concerns about your parents well-being all contribute to increased stress. Taking care of yourself will help ensure that you are physically and emotionally able to care for your family member. To help care for you, consider the following steps:

- Obtain up-to-date information. For example, the Caregiver Resource Centers have a variety of fact sheets and other materials (see the *Resources* section below), to help you make informed decisions. A wealth of caregiver information is available online.

- Ask for help. Say yes when people offer assistance. Don't try to do everything yourself - a sibling, relative or friend may be able to assist you. Some organizations offer specialized care planning guidance to help you get through the "maze" of long-term care options.
- If you're feeling highly stressed, consider joining a support group or speaking with a professional therapist.
- Exercise is a great stress-reducer. Although your time is limited, try to fit in some physical exercise, even if it's just a quick walk around the block.
- Eating regular meals including a selection of healthy foods will help to support your immune system and general overall health.
- Be as patient and flexible as you can. There will be good days and bad days. Learn how to communicate effectively with your loved one without laying blame. Let go of things that don't have to be done. Understand that it will take some time to arrange services that address all your loved one's needs, and those needs will most likely change over time.
- Give yourself a break. Remember to schedule some time to relax. "Respite care" is designed to allow a break for the caregiver, and can last an hour, a day, or even a week. A few organizations even offer weekend retreats for caregivers or ill or elderly family

members. Check your local resources for helpful programs.

Whether you are caring for a parent out of love and devotion, or simply being responsible by honoring a familial obligation, assuming the role of caregiving daughter or son is never easy. Your decision to care may occur all of a sudden when you receive an emergency call from the hospital, or it may be planned, having over time prepared for your parent to live with or near you. In either case saying, "Of course I'll help and take care of you" is often the only right response to a situation when your parent needs help. Family friendly workplace policies can go a long way towards making your caregiving journey less stressful and doable.

Credits

Caregiving in the US 2009. National Alliance for Caregiving and AARP.

Employer Best Practices for Workers with Caregiving Responsibilities. US Equal Opportunity Commission. 2011.

Enforcement Guidance: Unlawful Disparate Treatment of Workers with Caregiving Responsibilities. US Equal Opportunity Commission. 2011.

Family and Medical Leave Act. Department of Labor. Accessed July, 2012

Leaves That Pay: Employer and Worker Experiences with Paid Family Leave in California. Eileen Appelbaum, Ruth Milkman. Center for Economic and Policy Research. January 2011.

The MetLife Study of Caregiving Costs to Working Caregivers: Double

Jeopardy for Baby Boomers Caring for Their Parents. MetLife Mature Market Institute, National Alliance for Caregiving, Center for Long Term Care Research and Policy, New York Medical College. June 2011.

Paid Family Leave California. California Work and Family Coalition. Accessed August 2012.

Valuing the Invaluable: 2011 Update. The Growing Contributions and Costs of Family Caregiving. Lynn Feinberg, Susan C. Reinhard, Ari Houser, Rita Choula. AARP Public Policy Institute. July 2011.

"Working caregivers: Issues, challenges, and opportunities for the aging network." National Family Caregiver Support Program Issue Brief Neal, Margaret B., and Donna L. Wagner. (2002): 1-31.

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 94104
(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. Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers.

Family Care Navigator
Online directory of resources for caregivers in all 50 states. Includes resources for older or disabled adults living at home or in a residential facility, and information on government health and disability programs, legal resources, disease-specific organizations and more.

Organizations

Eldercare Locator
(800) 677-1116
www.eldercare.gov

Medicare
(800) MEDICARE or (800) 633-4227
www.medicare.gov

National Academy of Elder Law Attorneys
1577 Spring Hill Road, Suite 310
Vienna, VA 22182
(703) 942-5711
www.naela.org

Aging Life Care Association
3275 West Ina Road, Suite 130
Tucson, AZ 85741
(520) 881-8008
www.aginglifecare.org

Families and Work Institute
(212) 465-2044
FWINews@familiesandwork.org
www.familiesandwork.org

Labor Project for Working Families
www.familyvaluesatwork.org/laborproject

National Council on Aging
www.ncoa.org
Offers BenefitsCheckUp.

Social Security
(800) 772-1213
www.ssa.gov

Recommended Readings

Best Practices in Workplace Eldercare.
National Alliance for Caregiving and
ReACT (Respect a Caregiver's Time).
March 2012.

Loverde, Joy. *The Complete Eldercare
Planner.* 2009. Three Rivers Press.

Morris, Virginia. *How to Care for Aging
Parents.* 2004. Workman Publishing.

Neal, Margaret B.; Hammer, Leslie B.,
*Working Couples Caring for Children
and Aging Parents: Effects on work and
well-being.* 2007. Mahwah, NJ, US:
Lawrence Erlbaum Associates
Publishers.

Fact Sheets

*Caregiving at Home: A Guide to
Community Resources*

Hiring In-Home Help

Legal Issues in Planning for Incapacity

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

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