

Fact Sheet: Work and Eldercare

The 21st century will be marked by a dramatic increase in the size of the older population as the baby boom generation ages. An increase in older adults will mark a corresponding increase in dementing illnesses such as Alzheimer's disease, Parkinson's disease and stroke. These disorders affect not only the individual, but can also be devastating to the family. Already, millions of working adults are juggling the competing demands of caring for a chronically ill or disabled parent, raising a family, and managing a career.

If you are a caregiver, you are not alone. An estimated one out of four U.S. households is involved in caring for a loved one aged 50 or older. As many as 12.8 million Americans of all ages need assistance from others to carry out everyday activities. While there is no reliable estimate of the number of family caregivers, at least 7 million Americans are caring for a parent at any given time.

Between one-third to one-half of all caregivers are also employed outside the home. Working caregivers sacrifice leisure time, and often suffer stress-related illnesses. Negative effects on working caregivers include time lost from work, lower productivity, quitting a job to give care, lost career opportunities and lower future earnings. Eventually, some 12 percent quit their jobs to provide care full-time. Work disruptions due to employee caregiving responsibilities result in productivity losses of \$1, 142 per year per employee. In California, this translates to more than \$1 billion—\$2 billion if part-time employees are included.

Getting Started

A range of community resources exists to help caregivers and their impaired loved ones. The arrangements can be informal (e.g., your family, friends and neighbors) or formal (service agencies

and programs). In assessing your family's needs consider the following:

- Make a list of what you need help with and the times you need it. For example, *I need someone to keep my mother company and prepare her meals during work hours, or I need someone to give Dad a ride to the senior center on Tuesdays and Thursdays at 9:00 a.m.*
- Consider what level of care is needed (companion, chore work, nursing) and whether the care can be delivered at home or at an adult day care center.
- Consult your or your parents' insurance policy to see if any coverage is available. Determine how much money you and your family can afford to spend on outside resources. (Generally, long-term care is not covered by health insurance policies.)
- Explore care options in your community or near your parent's home.

Finding Community Resources

Information and Referral (I&R): These are services to help you locate programs and services in your community. Senior or community I&R services maintain lists of resources, by geographic area, to help you get started in finding the services you need. In California, Caregiver Resource Centers (see next page) can help you. In addition, if you have access to the internet, there are a growing number of resource listings, news groups and chat groups where you can seek out information on your own. 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 church 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.

A family meeting can be very helpful in discussing difficult medical and legal issues. Identifying needs, airing concerns and delegating tasks should be done in an open, supportive environment where all necessary family members can be involved.

To work through certain family dynamics or conflicts, an outside person can be useful. A **geriatric care manager** can be hired to help the family and caregiver make a care plan and, if need be, to help with care arrangements and monitoring. This may be especially helpful if your ill parent lives far from you.

In-Home Care

Home care can be either formal (home care agency or personal attendant) or informal (friend, family, or volunteer). If no medical or personal care is needed, any caring, responsible person may be suitable. An ad can be placed in your local community or college newspaper to search for a responsible part-time companion and chore worker. If care involves toileting or bathing, you will need a person who is trained and competent. Similarly, if lifting the person and/or a wheel chair is necessary, be sure the worker is physically able to do the work. Always check references carefully.

If medications are to be dispensed, or nursing care is required, you will likely need a licensed vocational nurse (LVN). 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 home-bound older person.

Adult Day Care

Adult day care centers provide a therapeutic environment for older adults outside the home. They provide social services and activities in a safe, supportive environment. Depending on the program, health and therapeutic care may or may not be available. It is important to check eligibility criteria. Some centers may not accept participants who are

disruptive, have other health problems or are incontinent. Participants generally attend several hours per day, up to five days a week. Transportation to and from the adult day care center may also be provided.

Other Community Resources

In California, **Caregiver Resource Centers (CRCs)** provide a range of supportive services to family caregivers of brain-impaired adults (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 brain-impaired loved one.

Other community services include case 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 I&R service can help you locate these.

Residential Placement

When a parent can no longer be cared for at home, it may be necessary to consider a residential facility. Arriving at this decision can be quite painful. Both you and your parents are likely to have strong feelings about nursing homes. 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. Concerns about safety, your parent's ability to be left alone, medical needs, and adequate help for basic daily activities (e.g., eating, dressing, toileting, bathing, moving around) should be considered. In addition, the daily strain on the caregiver should not be ignored. If you, your sibling or parent is the primary caregiver, it is vital to recognize when care giving demands exceed what is humanly possible. If you determine home is no longer a viable option, it is time to look at residential placements.

Residential care options are not limited to what most people refer to as nursing homes. A range of options exist for residential care. For maximum

independence, **senior residences** or **assisted living facilities** offer apartment-style living with additional services such as meals, house cleaning, transportation, recreational activities and, sometimes, an on-call nurse.

Residential Care Facilities (also called board and care 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. RCFs do not accept Medicaid (Medi-Cal in California) reimbursement since medical care is not administered.

Skilled Nursing Facilities (SNF) provide nursing care to residents and must be equipped to administer medications, injections and provide other nursing functions. SNFs do not typically provide rehabilitative care (e.g., physical or speech therapy). Medicare will pay for up to 100 days of *medically-necessary* skilled nursing care in a SNF. Medicare pays 100% of the first 20 days. As of 1998, days 21-100 require a \$95.50 per day co-payment. Medicare will not pay for "custodial care."

Some nursing homes and hospitals have **Special Care Units** for individuals with Alzheimer's disease. These facilities should provide specialized care, trained staff, and secured premises. Since there is currently no federal care standard for special units, it is important to obtain information on staff credentials, resident-to-staff ratio, and the specific services offered to ensure that the unit provides a clear benefit.

Legal/Financial Issues

If a parent becomes cognitively impaired, you are likely to face a host of new legal 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 long-term care needs. At a minimum, a suitable attorney should have experience in estate and financial planning, probate and wills. In addition, it is helpful for your attorney to be familiar with public benefits (e.g., Medicaid—or Medi-Cal in California), 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 (attorney referral service), senior legal aide, or a personal recommendation from a friend or fellow support group member.

Surrogate decision-making for a person with memory loss can be difficult and emotionally-charged. The process can be simplified significantly, however, if your parent has completed a **durable power of attorney** (DPA) and a **durable power of attorney for health care** (DPAHC). These two very different documents enable your parent to designate another person to manage his/her finances and health care decisions. To complete a DPA or DPAHC, the person must be mentally competent at the time the documents are signed. The legal authority to make surrogate decisions will begin only when and if the person becomes incompetent. It is a good idea to have DPA and DPAHC forms reviewed by an experienced attorney to ensure that the person's wishes are clearly expressed and the information is complete.

In the case where 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 the legal authority to manage a person's finances, estate, personal affairs, assets and medical care. In order to obtain a conservatorship, a friend, family member or public official must petition the court with facts about why the individual can no longer manage financial or personal affairs. At a hearing, the judge determines what special powers may be granted to the conservator. Conservatorships tend to be complex; the legal agreements are court supervised and the conservatee's (impaired person's) assets and income become part of the public record. In addition, prospective conservators may face substantial costs for court, legal, investigator and conservator's fees.

Handling Stress

Caring for an ill or disabled parent can be particularly challenging while juggling the competing demands of work, family and caregiving. It is important to get the emotional and practical support you need to cope with the stress of being a caregiver. Taking care of yourself will help ensure that you are physically and emotionally able to care for your impaired parent.

- Obtain up-to-date information. For example, Caregiver Resource Centers have a variety of caregiver-related fact sheets and other materials to help you make informed decisions.
- Ask for help. Don't try to do everything yourself. A sibling, relative or friend may be able to help you. Some organizations offer specialized care planning guidance to help you get through the "maze" of long-term care options.
- When highly stressed, consider joining a support group or speaking with a professional therapist.
- Be patient. There may be good days and bad days. Learn how to communicate effectively with your parent without laying blame. It will take some time to arrange services that address all needs.
- 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. Check your local resources.

What Employers Can Do

Eldercare is now recognized by a growing number of employers. Support for employees who have caregiving responsibilities can take a variety of forms:

- Employers can offer "cafeteria style" employee benefits which allow employees to select supplemental dependent care coverage to reimburse costs for in-home care or adult day care. Benefits also should cover

therapeutic counseling for the employee to help cope with the stresses of caregiving.

- Human Resource or employee assistance program staff can provide information on helpful Internet sites, local I&R services or resource centers.
- Larger businesses can organize in-house caregiver support groups or coordinate with local community groups or hospitals so that employees can attend an outside support group.
- One of the most critical benefits for an employee with caregiving responsibilities is time. Flexible work hours, family illness days, and leave time are key. Data from the Bureau of National Affairs (1993) found that flexible scheduling improved job performance, decreased lateness and employee turnover, and increased job satisfaction.
- 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.
- Other ideas include holding a company "caregiver fair" or a series of lunchtime seminars on issues such as hiring a home care attendant, or coping skills for caregivers. Employers can establish a telephone hot-line, or publish a list of key contacts in their employee newsletter.
- Offer private long-term care insurance coverage for employees, their spouses, and dependents. Information on available insurance packages is available from the Health Insurance Association of America (see listing under **Resources**).

Resources

Family Caregiver Alliance

180 Montgomery Street, Suite 1100
San Francisco, CA 94104
(800) 445-8106
(415) 434-3388
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 and provides assistance in the development of public and private programs for caregivers. For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, ALS, head injury, Parkinson's and other debilitating brain disorders that strike adults.

Eldercare Locator

To find local Area Agencies on Aging throughout the U.S., as well as state Long-Term Care Ombudsman offices for nursing homes, call:
<http://www.eldercare.gov/> (800) 677-1116

National Academy of Elder Law Attorneys

1604 Country Club Road
Tucson, AZ 85716
(520) 881-1076

United Seniors Health Cooperative

409 3rd Street SW, 2nd Floor
Washington, D.C. 20024
(202) 479-6973
www.unitedseniorshealth.org

Assisted Living Federation of America

10300 Eaton Plaza, Suite 400
Fairfax, VA 22031
(703) 691-8100

National Association of Professional Geriatric Care Managers

1604 No. Country Club Road
Tucson, AZ 85716
(520) 881-8008

Washington Business Group on Health

777 North Capitol St., NE, Suite 800
Washington DC 20002
(202) 408-9320
www.wbgh.com

Ceridian (formerly Work/Family Directions)

930 Commonwealth Ave. West
Boston, MA 02215
(800) 635-0606

Families and Work Institute

330 Seventh Avenue, 14th Floor
New York, NY 10001
(212) 465-2044
www.familiesandwork.org

Labor Project for Working Families

Institute of Industrial Relations
2521 Channing Way
Berkeley, CA 94720
(510) 643-6814

Health Insurance Association of America

555 13th St. NW, suite 600E
Washington, D.C. 20004-1109
(202) 824-1600
www.hiaa.org

Credits

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For Additional Resources Call:

Caregiver Resource Center
St. Jude Community Services
130 West Bastanchury Road
Fullerton, CA 92835
(714) 446-5030 (800) 543-8312 fax (714) 446-5996
www.caregiveroc.org

Providing support and assistance to family caregivers in Orange County. Services include Information & Referral, family consultations, support groups, legal clinics, educational seminars and a respite planning.

The CAREGIVER RESOURCE CENTER, sponsored by St. Jude Medical Center, is part of a statewide system of Caregiver Resource Centers contracted through the California Department of Mental Health. Additional funding comes from the California Department of Aging funds from the federal Older Americans Act, as allocated by the Orange County Board of Supervisors. Rev. 11-10