



Fact Sheet: Caregiving

An estimated 19-22% of families across the U.S. may be caring for an adult with a cognitive impairment. Cognitive impairments include a variety of diseases and disorders such as Alzheimer's disease, Parkinson's disease, stroke, head injury or AIDS dementia. Although each disorder has its own unique features, family members and caregivers often share common problems, situations and strategies, regardless of the diagnosis.

Cognitively impaired persons typically require special care, including (often 24-hour) supervision, specialized communication techniques, management of bizarre or difficult behaviors, incontinence, and help with activities of daily living (ADLs), e.g., bathing, eating, transferring from bed to a chair or wheelchair, toileting and/or other personal care.

While each caregiving situation is different, caregivers are likely to experience enormous stress from their responsibilities in caring for a loved one. Many individuals become depressed or anxious and others report physical ailments associated with the stress of caregiving. For this reason, finding practical ways to cope and get help are especially important.

Caring at Home

Caregivers often learn through trial and error the best ways to help an impaired relative maintain routines for eating, hygiene and other activities at home. Special training in the use of assistive equipment and managing difficult behaviors may be needed. It is also important to follow a safety checklist.

Be aware of potential dangers from:

- Fire hazards such as stoves, other appliances, cigarettes, lighters and matches;
- Sharp objects such as knives, razors and sewing needles;
- Poisons, medicines, hazardous household products;
- Loose rugs, furniture and cluttered pathways;
- Inadequate lighting;
- Water heater temperature-adjust setting to avoid burns from hot water;
- Car keys and/or spark plugs-do not allow an impaired person to drive;
- Items outside that may cause falls, such as hoses, tools, gates.

Be sure to provide:

- Emergency exits, locks to secure house, and, if necessary, door alarms or an identification bracelet and a current photo;

- Bathroom grab bars, non-skid rugs, paper cups rather than glass;
- Supervision of food and alcohol consumption to ensure proper nutrition and to monitor intake of too much or too little food;
- Emergency phone numbers and information.

Managing Problem Behaviors

Individuals with cognitive impairment may experience a range of behavioral problems including communication difficulties, perseveration (fixation on/repetition of an idea or activity), aggressive or impulsive behaviors, lack of motivation, memory problems, incontinence, poor judgment and wandering. Helpful suggestions for managing these problems include keeping language simple and asking one question at a time. Break down tasks and questions. For example, instead of asking, "would you like to come in and sit down and have a snack?", use simple commands such as, "come here," "sit down," and "here's a snack."

Wandering and poor judgment may signify the need for 24-hour supervision. Be sure to run through the home safety checklist. In addition, learn whom to contact in your community in case of an emergency. You may wish to consult with friends, family, church groups, social service agencies, senior centers and support groups. If wandering or aggressive behaviors are problems, contact with emergency police, fire and medical systems may be necessary. Further readings on behavior management strategies are included under the Recommended Readings section in this fact sheet.

Taking Care Of Yourself

Some caregivers are reluctant to acknowledge the strain associated with the many tasks, responsibilities and long hours devoted to the caregiving role. Many feel overwhelmed or burned out. It is important not only to give yourself credit for the work you are doing as a

caregiver, but also to arrange for some support and an occasional break from daily duties. While extended vacations may not be realistic, it is critical for everyone to schedule some relaxation time for themselves. This may be a short outing, quiet time at home, a visit with a friend, etc. In order to get time off, the caregiver may require respite care/assistance from others to stay with the patient.

Monitor your own health; stress may contribute to a variety of health problems. Balanced meals, adequate sleep, and attention to persistent ailments are essential ways to take care of yourself. They will also enhance your physical ability, coping skills and stamina to provide care. By taking care of yourself, you will be better able, both physically and emotionally, to provide care for your loved one.

The isolation often felt while caring for an impaired loved one at home can be devastating in itself. For many, this is eased by attending support group meetings with other persons in similar situations. Support groups provide emotional support and caregiving tips, as well as information on community resources from others who have learned from experience. Online support groups on the Internet can be very helpful. Therapeutic counseling may also be beneficial for further problem solving. A professional counselor can help you cope with feelings of anger, frustration, guilt, loss, or competing personal, work and family demands.

Defining Needs and Planning for the Future

Financial and legal planning are important to consider. Issues such as financing long-term care, protecting your assets, obtaining the authority for surrogate decision-making, and other matters often need attention. Make an appointment with an attorney knowledgeable in estate planning, probate, and, if possible, public benefits planning.

Other areas often requiring planning include coordination between community services and

other involved friends and family members. Decisions about placement in a nursing home or other care options can often be facilitated by a professional familiar with brain impairments, caregiving and community resources.

It is a good idea to take some time to evaluate, in writing, both short and long-term needs. This can be done by first listing the things you may need help with, now or in the future. Next, list all your informal supports (e.g., family, friends, neighbors) and decide how each person might help meet the needs. List any advantages and disadvantages which might be involved in asking these people to help. Write down ideas for overcoming the disadvantages. Repeat the list for formal supports (e.g., community services, home care workers, day programs). It is important to set a time frame for any action or activities planned.

Recommended Readings

The 36-Hour Day, Nancy Mace and Peter Rabbins, 1999 edition, The Johns Hopkins University Press, Hampden Station, Baltimore, MD 21211, (800) 537-5487.

Caregiving: The Spiritual Journey of Love, Loss and Renewal, Beth Witrogen McLeod, 1999, John Wiley and Sons, Inc., 605 Third Ave., New York, NY 10158, (202) 850-6011.

The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers, Maria Meyer and Paula Derr, 1998, CareTrust Publications LLC, P.O. Box 10283, Portland, OR 97296, (800) 565-1533.

Options for Supporting Informal and Family Caregiving: A Policy Paper, Lynn Friss Feinberg, 1997, prepared for the American Society on Aging, available from Family Caregiver Alliance, (415) 434-3388.

Mainstay, Maggie Strong, 1997, Bradford Books, 160 Main Street, Northampton, MA 01060, (413) 584-4597.

The Complete Eldercare Planner, Joy Loverde, 1997, Warner Books, Inc., Time & Life Building, 1271 Avenue of the Americas, New York, NY 10020 (212) 522-6982.

How to Care for Aging Parents, Virginia Morris, 1996, Workman Publishing Co., 708 Broadway, New York, NY 10003-9555, (800) 722-7202.

Helping Yourself Help Others: A Book for Care-givers, 1994, Rosalynn Carter and Susan Golant, Times Books, Random House, 201 East 50th St., New York, NY 10022, (800) 733-3000.

Long-Distance Caregiving, Angela Heath, 1993, Impact Publishing, P.O. Box 1094, San Luis Obispo, CA 93406, (805) 543-5911.

Credits

Family Caregiver Alliance, 1999, Incidence and Prevalence of the Major Causes of Adult-Onset Brain Impairment in the United States and California. San Francisco, CA.

U.S. Congress Office of Technology Assessment, 1990, US Government Printing Office, Confused Minds, Burdened Families, Washington, DC.

Resources

The number of services for cognitively-impaired adults, their families and caregivers is growing, although in some communities, agencies may be difficult to locate. Caregivers should consider contacting senior centers, independent living centers, Area Agencies on Aging, local chapters of national organizations and foundations such as the Alzheimer's Association, Brain Injury Association, Multiple Sclerosis Society and others. Nursing home ombudsman programs, community mental health centers, social service or case management agencies, schools of nursing, and church groups may be other sources of assistance. There is a wealth of information on the web.

The following listings also offer information, publications, and referrals.

Mountain Caregiver Resource Center
2491 Carmichael Drive, Suite 400
Chico, CA 95928
(530) 898-5925
(800) 995-0878
www.caregiverresources.org

Mountain Caregiver Resource Center offers a full complement of family services designed to assist caregivers of adults with brain disorders. Most services are offered free or on a low-cost sliding scale.

Services include: specialized information, family consultation and care planning, support groups, short-term counseling, respite care, legal and financial assistance, in addition to family and professional training.

Family Caregiver Alliance
690 Market Street, Suite 600
San Francisco, CA 94104
(415) 434-3388
(800) 445-8106 (in CA)
Website: <http://www.caregiver.org>
E-mail: info@caregiver.org

Family Caregiver Alliance supports and assists caregivers of brain-impaired adults through education, research, services and advocacy. FCA's information Clearinghouse covers current medical, social, public policy and caregiving issues related to brain impairments.

For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, traumatic brain injury, Parkinson's and other debilitating brain disorders that strike adults.

AARP
601 "E" Street, NW
Washington, DC 20049
(800) 424-3410
(202) 434-2277 (publications on caregiving)
www.aarp.org/caregiving

Children of Aging Parents
Woodburn Office Campus
1609 Woodburn Rd., Ste. 302A
Levittown, PA 19057
(215) 945-6900
(800) 227-7294

Eldercare Locator
927 15th Street, NW, 6th Floor
Washington, DC 20005
(800) 677-1116 (nationwide Area Agency on Aging listings) www.aoa.dhhs.gov/elderpage/locator.html

National Federation of Interfaith Volunteer Caregivers
One West Armour Blvd., Suite 202
Kansas City, MO 64111
(816) 931-5442
www.NFIVC.org

Well Spouse Foundation
P.O. Box 30093
Elkins Park, PA 19027
(800) 838-0879
www.wellspouse.org
Email: info@wellspouse.org

Home Instead Senior Care
1104 S. 76th Ave., Suite A
Omaha, NE 68124
(402) 391-2555
www.homeinstead.com

Food From Home
236 Falls Rd.
Hudson, NY 12534
(888) DINNERS
www.foodfromhome.com

Selected Disease-Specific Organizations

ALS Association
(800) 782-4747
www.alsa.org

Alzheimers Association
(800) 272-3900
www.alz.org

American Brain Tumor Association
(800) 886-2282
www.abta.org
American Cancer Society
(800) 227-2345
www.cancer.org

Brain Injury Association
(800) 444-6443
www.biausa.org

Huntington's Disease Society of America
(800) 345-HDSA
www.hdsa.org

Multiple Sclerosis Society
(800) FIGHT-MS
www.nmss.org

National AIDS Clearinghouse
(800) 458-5231
www.cdcna.org

National Parkinson Foundation
(800) 327-4545
www.parkinson.org

Stroke Connection
(800) 553-6321
www.americanheart.org

Prepared by Family Caregiver Alliance in cooperation with the State of California's Caregiver Resource Centers, a statewide system of resource centers serving families and caregivers of brain-impaired adults. Funded by the California Department of Mental Health. Revised September 1999. ©All rights reserved

Revised 09/27/02