



Southern Caregiver Resource Center

Caring for those who care for others

Fact Sheet: Caring for Adults with Cognitive & Memory Impairments

Caregiving: A Universal Occupation

Most people will become caregivers, or will need one, at some point in their lives. A caregiver is anyone who provides basic assistance and care for someone who is frail, disabled, or ill and needs help. Caregivers perform a wide variety of tasks to assist someone else in his or her daily life; i.e., balancing a checkbook, grocery shopping, assisting with doctor's appointments, giving medications; or helping someone to eat, take a bath, or dress. Many family members and friends do not consider such assistance and care "caregiving"—they are just doing what comes naturally to them: taking care of someone they love. But that care may be required for months or years and may take an emotional, physical, and financial toll on caregiving families.

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. For the most part, friends, neighbors, and most of all families provide (without pay) the vast majority of care.

Many American families care for an adult with a cognitive (brain) impairment.

Cognitively-impaired people have difficulty with one or more of the basic functions of their brain such as perception, memory, concentration, and reasoning skills. Common causes of cognitive impairment include Alzheimer's disease and related dementias, stroke, Parkinson's disease, brain injury, brain tumor, or HIV-associated dementia. Although each disorder has its own unique features, family members and caregivers often share common problems, situations, and strategies.

Caregiving and Cognitive Impairments

We know that cognitive and memory impairments can change how a person thinks, acts, and/or feels. These changes often present special challenges for families and caregivers. An ordinary conversation, for example, can be quite frustrating when your loved one has difficulty remembering from one moment to the next what has been said.

Individuals with moderate to severe dementia or another cognitive impairment often require special care including supervision (sometimes 24 hours a day), specialized communication techniques, and management of difficult behavior. They may need help with activities of daily

living (called “ADL’s”) such as bathing, eating, transferring from bed to a chair; or wheelchair, toileting, and/or other personal care.

Challenging Behaviors

Individuals with cognitive impairment may experience a range of behavioral problems that can be frustrating for caregivers. These might include communication difficulties, perseveration (fixation on/repetition of an idea or activity), aggressive or impulsive behaviors, paranoia, lack of motivation, memory problems, incontinence, poor judgment, and wandering. Some people may develop behavioral problems early on while others go their entire illness with only minor issues. Most cognitively-impaired persons fall somewhere in the middle having good days and bad days (or even good or bad moments). Anticipating that there will be ups and downs and maintaining patience, compassion, and a sense of humor will help you cope more effectively with difficult behavior. It’s important to remember that it’s the disease, not the person, causing the behavior.

Helpful suggestions for managing these problems include communication techniques such as keeping language simple and by 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 statements such as, “Sit down here,” and “Here’s a snack for you.”

Wandering and poor judgment may signal the need for 24-hour supervision. Be sure to review the home safety checklist on page 4 and know who to contact in your community in case of an

emergency. If wandering or aggressive behaviors are problems, you may need to contact emergency, police, fire, or medical systems. (For additional information, see fact sheets *Caregiver’s Guide to Understanding Dementia Behaviors*, and *Dementia, Caregiving and Controlling Frustration*.)

Ten Steps to Get You Started

Whether you have moved into the role of caregiver gradually or suddenly, you may feel alone, unprepared, and overwhelmed by what is expected of you. These feelings as well as other emotions—fear, sadness, anxiety, guilt, frustration, and even anger—are normal and may come and go throughout your time of providing care. Although it may not seem possible, along with challenges will come the unanticipated gifts of caregiving—forgiveness, compassion, courage—that can weave hardship into hope and healing.

Each caregiving family faces unique circumstances, but some general strategies can help you navigate the path ahead. As a traveler in new terrain, it is wise to educate yourself as best you can about the landscape and to develop a plan accordingly with the flexibility to accommodate changes along the way. Below are ten steps to help you set your course.

Step 1. Lay the foundation.

Establishing a baseline of information lays the groundwork for making current and future care decisions. Talk with your loved one, family, and friends: What was mom “normally” like? How has she changed? How long has she been forgetting to take her medicine? When did she stop paying her bills? Answers to questions such as these help create a

picture of what is going on and for how long. This basic information not only gives you a realistic view of the situation but also provides an important foundation for professionals who may be called in to make a more formal assessment.

Step 2. Get a medical assessment and diagnosis. It's very important for your loved one to get a comprehensive medical exam from a qualified health care team that reviews both physical and mental health. Many medical conditions can cause dementia-like symptoms such as depression and medication interactions. Often these conditions can be reversed if they are caught early enough. Additionally, new drug treatments for diseases such as Alzheimer's and Parkinson's diseases may be most effective in the early stages of the disease. A confirmed diagnosis is essential in accurately determining treatment options, identifying risks, and planning for the future. Take your loved one to a memory disorder clinic, if one exists in your community, to get an accurate diagnosis.

Step 3. Educate yourself, your loved one, and your family. Information is empowering. Talk to doctors, health and social service professionals, and people going through similar experiences. Read books and brochures. Do research at the library and on the Internet. Learn how the disease progresses, the level of care that will be needed, and what resources may be available to help. Keep a notebook and a file folder of information you collect that you can refer back to when needed. Knowledge will increase your confidence and may reduce the anxiety and fear that many of us feel in the face of the unknown. (See

the fact sheet, *Caregiving at Home: A Guide to Community Resources* for more information about finding help in your community.)

Step 4. Determine your loved one's needs. Care assessment tools include a variety of questionnaires and tests designed to determine the level of assistance someone needs and to establish their personal preferences for care; e.g., bathing in the morning rather than the afternoon. Each situation is different. While one person in the beginning stages of Alzheimer's may need assistance with grocery shopping and bill paying, another in later stages may have problems with dressing, eating, and hygiene.

Assessments usually consider at least the following categories:

- **Personal Care:** bathing, eating, dressing, toileting, grooming
- **Household Care:** cooking, cleaning, laundry, shopping, finances
- **Health Care:** medication management, physician's appointments, physical therapy
- **Emotional Care:** companionship, meaningful activities, conversation
- **Supervision:** oversight for safety at home and to prevent wandering

Some hospitals, Area Agencies on Aging (AAAs), city or county agencies, Caregiver Resource Centers, or other government or private organizations offer consultation and assessments specifically designed for older people (called *geriatric* or *needs assessments*) for little, if any, cost. Another option is

hiring for a fee a geriatric care manager or licensed clinical social worker. (See Resources below for help in locating someone near you.) These professionals can be helpful in guiding you to the best care in your area, in advising you on community resources, in assisting in arranging for services, and in providing you and your loved one with continuity and familiarity throughout the illness.

Step 5. Outline a care plan. Once your loved one has received a diagnosis and completed a needs assessment, it will be easier for you, possibly with help from a professional, to formulate a care plan—a strategy to provide the best care for your loved one and yourself. It’s a good idea to take some time to think about both short- and long-term needs.

This plan will always be a “work in progress” as your loved one’s needs will change over time. To start developing a plan, first list the things you are capable of, have time for, and are willing to do. Then list those things that you would like or need help with now or in the future. Next, list all your “informal supports” such as siblings, other family, friends, neighbors, and think about how each person might be able to provide assistance. List any advantages and disadvantages that might be involved in asking these people to help. Write down ideas for overcoming the disadvantages. Repeat the list for “formal” support such as community services, paid home care workers, and day programs.

It is important to set a time frame for any action or activities planned. Also, it is wise to have a back-up plan should something happen to you both for the short-term and the long-term.

Step 6. Look at finances. Most people prefer to keep their financial affairs private. In order to best prepare and to provide for a loved one’s care, however, you will need to gain a full understanding of his or her financial assets and liabilities. This transition can be uncomfortable and difficult. Consider having an attorney or financial planner assist you through the process (see the fact sheet, *Legal Planning for Incapacity*). Assistance from a trained professional may reduce family tension and, if desired, provide you with a professional financial assessment and advice. Try to include your loved one as much as possible in this process.

Next, develop a list of financial assets and liabilities: checking and savings accounts, Social Security income, certificates of deposit, stocks and bonds, real estate deeds, insurance policies and annuities, retirement or pension benefits, credit card debts, home mortgages and loans, and so forth. It’s best to keep all these records in one or two places such as a safety deposit box and a home file cabinet and regularly update them. Keep a record of when to expect money coming in and when bills are due. You may need to establish a system to pay bills—perhaps you’ll need to open a new checking account or add your name to an existing one.

Step 7. Review legal documents. Like finances, legal matters can also be a delicate, but necessary, subject to discuss. Clear and legally binding documents ensure that your loved one’s wishes and decisions will be carried out. These documents can authorize you or another person to make legal, financial, and health care decisions on behalf of

someone else. Again, having an attorney bring up the issue and oversee any necessary paperwork can take the pressure off of you as well as provide assurance that you are legally prepared for what lies ahead. (For more information about types of legal documents, see fact sheet *Legal Planning for Incapacity*.)

Other legal documents that you will want to find and place in an accessible location include Social Security numbers, birth, marriage and death certificates, divorce decrees and property settlements, military records, income tax returns, and wills (including the attorney's name and executor), trust agreements, and burial arrangements. (See worksheet/form *Where to Find My Important Papers*.)

At some point, you may need to determine eligibility for such public programs as Medicaid. It's helpful to speak with an elderlaw specialist. Information about low-cost elder legal services may be available through the Area Agency on Aging in your community.

Step 8. Safety-proof your 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. You may need special training in the use of assistive equipment and managing difficult behavior. 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, and hazardous household products;
- Loose rugs, furniture, and cluttered pathways;
- Inadequate lighting;
- Water heater temperature—adjust setting to avoid burns from hot water;
- Cars—do not allow an impaired person to drive; and
- Items outside that may cause falls such as hoses, tools, and gates.

Be sure to provide:

- Emergency exits, locks to secure the house, and, if necessary, door alarms; or, an identification bracelet and a current photo in case your loved one wanders;
- Bathroom grab bars, non-skid rugs, and 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; and
- Medication monitoring.

Step 9. Connect with others. Joining a support group will connect you with other caregivers facing similar circumstances. Support group members provide one another with social and emotional support as well as practical information and advice about local resources. Support groups also provide a safe and confidential place for caregivers to vent frustrations, to share ideas, and to learn new caregiving

strategies. If you can't get away from the house, online support groups offer opportunities to connect with other caregivers nationwide. (See Resources below to find a support group.) Another way to meet others going through a similar experience is by attending special workshops or meetings sponsored by organizations such as the local chapter of the Alzheimer's Association or the Multiple Sclerosis Society.

Step 10. Take care of yourself.

Although this step appears last on this list, it is the most important step.

Caregiving is stressful particularly for those caring for someone with dementia. Caregivers are more likely than their noncaregiving peers to be at risk for depression, heart disease, high blood pressure, and other chronic illnesses, even death. Caregivers of persons with dementia are at even higher risk for poor health. The following simple, basic preventative healthcare and self-care measures can improve your health and your ability to continue providing the best care for your loved one.

- **Practice daily exercise.**

Incorporating even a small amount of regular exercise into your daily routine can do wonders—it can improve your night's sleep, reduce stress and negative emotions, relax muscular tension, and increase your mental alertness and energy levels. The latest research shows health benefits from walking just 20 minutes a day, three times a week. Talk to your doctor about an exercise routine that is best for you.

- **Eat nutritious meals and snacks.** Caregivers often fall into poor eating habits—eating too much or too little, snacking on junk food, skipping meals, and so on. Much of eating is habit, so make it a point each week to add a new healthy eating habit. For example, if breakfast is simply a cup of coffee, try adding just one healthy food—a piece of fresh fruit, a glass of juice, or whole-grain toast. Small changes add up and can be realistically incorporated into a daily schedule.
- **Get adequate sleep.** Many caregivers suffer from chronic lack of sleep resulting in exhaustion, fatigue and low energy levels. Depleted physical energy, in turn, affects our emotional outlook increasing negative feelings such as irritability, sadness, anger, pessimism, and stress. Ideally, most people need six to eight hours of sleep in a 24-hour period. If you are not getting enough sleep at night, try to take catnaps during the day. If possible, make arrangements to get at least one full night's rest each week or several hours of sleep during the day. If the person you care for is awake at night, make arrangements for substitute care or talk to his or her physician about sleep medication.
- **Get regular medical check-ups.** Even if you have always enjoyed good health, being a caregiver increases your risk for developing a number of health problems.

Regular medical (and dental) check-ups are important health maintenance steps. Inform your doctor of your caregiving role and how you are coping. Depression is a common and treatable disease. If you are experiencing symptoms such as a lingering sadness, apathy, and hopelessness, tell your doctor. (See the fact sheet, *Depression and Caregiving*)

- **Take time for yourself.** Recreation is not a luxury, it is a necessary time to “recreate”—to renew yourself. At least once a week for a few hours at a time, you need time just for yourself—to read a book, to go out to lunch with a friend, or to go for a walk. (See the fact sheet, *Taking Care of YOU: Self-Care for Family Caregivers* for more helpful tips.)

Respite: A Key to Preventing Caregiver Burnout

If you care for a person with dementia, you face even greater risks for health problems than other caregivers. You are particularly at risk for caregiver burnout—a state of mental and physical exhaustion brought on by the physical, mental, emotional, and/or financial stresses of providing ongoing care usually over a long period of time. Symptoms include difficulty concentrating, anxiety, irritability, digestive problems, depression, problems sleeping, and social withdrawal. Caregiver burnout puts both you and your loved one at risk. It is one of the most cited reasons for caregivers placing a loved one in a nursing home or other long-term care facility.

One of the most effective ways to prevent caregiver burnout is by taking care of your physical health needs as well as your mental and social health needs. Essential to meeting these needs is to schedule regular time off from your caregiving duties. If you do not have a neighbor, family member, or friend nearby who can provide dependable weekly help, look into respite services in your community. (See Resources below.)

Respite literally means a rest—a break away from the demands of caregiving. Respite can be arranged for varying lengths of time—a few hours, overnight, a weekend, even for a week or longer. It can be provided in your home or in a facility such as adult day care or a nursing home. In-home attendants may be employed by an agency, self-employed, or volunteers. Respite care can be arranged privately for a fee paid for by some long-term care insurance policies or sometimes provided by government or private organizations.

Locating Caregiver 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. A good place to start is the Eldercare Locator, a free nationwide toll-free service that is designed to assist older adults and their caregivers to find services in their community. (See Resources below for contact information.)

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, Parkinson's groups, 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. In California, regional Caregiver Resource Centers offer information and services. Most supportive organizations are listed in the phone book under "Social Services" or "Seniors" and many are on the Internet. Each time you talk to someone, ask for referrals and phone numbers of others who may assist you.

Online Resources

The Internet provides a wealth of information for caregivers from an organization's mission and contact information to online support groups and to articles about overcoming the challenges of caregiving. Most public libraries, universities, and many senior centers have computers and Internet access available for free public use. If you do not know how to use a computer or how to access the Internet, don't be shy, organization personnel are trained to show you how to get the information you are looking for. Once you get to a search engine such as Yahoo or Google, type in the search terms, which is the general information you are seeking such as "adult day care Sacramento, California" or "Alzheimer's disease support groups," and you will usually get a number of options to choose from. If you do not succeed the first time, try changing the search terms such as "respite care Sacramento California" or "caregiver support groups."

One word of caution: as with any printed

material, read with a healthy skepticism—just because it is on the Internet does not make it true. If in doubt, check the information with another independent resource, and talk to your loved one's doctor before proceeding especially in regard to medications. Remember, just because a product is called "natural" or "herbal" does not mean it is harmless particularly when mixed with other medications.

A number of caregiver resources are available to you—all you need to do is ask for help. You do not have to do it alone.

Credits

AARP. (2003). *My Parents - How Do I Know If They Need Help?* Retrieved January 28, 2004, from www.aarp.org

AARP (2003). *New Caregivers*. Retrieved January 28, 2004, from www.aarp.org

Family Caregiver Alliance. (1999). *FCA Fact Sheet: Caregiving*.

Vikki L. Schmall, Marilyn Cleland, and Marilyn Sturdevant . (2000). *The Caregiver Helpbook: Powerful Tools for Caregiving. Legacy Caregiver Services*.

Bob Rosenblatt and Carol Van Steenberg (2003). *Handbook for Long-Distance Caregivers*. Family Caregiver Alliance.

Resources

Southern Caregiver Resource Center
3675 Ruffin Road, Suite 230
San Diego, CA 92123
(858) 268-4432; (800) 827-1008 (in CA)
Fax: (858) 268-7816
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. 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.

AARP

601 E. Street, NW
Washington, DC 20049
(888) 687-2277
www.aarp.org

Administration on Aging

www.aoa.gov

BenefitsCheckUp

www.benefitscheckup.org

Designed by the National Council on Aging, this Website enables you to complete a questionnaire to find federal, state, and local programs that you might be eligible for and how to apply.

Eldercare Locator

Phone: (800) 677-1116
www.eldercare.gov

National Association of Professional Geriatric Care Managers

(520) 881-8008
www.caremanager.org

Well Spouse Association

63 West Main Street, Suite H
Freehold, NJ 07728
(800) 838-0879
www.wellspouse.org

Financial and Legal Services

National Academy of Elder Law Attorneys

www.naela.org

Disease-Specific Organizations

Alzheimer's Association

(800) 272-3900
www.alz.org

ALS Association

(800) 782-4747
www.alsa.org

American Brain Tumor Association

(800) 886-2282
www.abta.org

American Cancer Society

(800) 227-2345
www.cancer.org

American Stroke Association

(Division of American Heart Association)
(800) 553-6321
<http://asa.healthology.com>

Brain Injury Association

(800) 444-6443
www.biausa.org

Huntington's Disease Society of America

(800) 345-4372

www.hdsa.org

Multiple Sclerosis Society

(800) 344-4867

www.nmss.org

Centers for Disease Control and Prevention (CDC)

National Prevention Information Network (NPIN)

(800) 458-5231

www.cdcnpin.org

National Parkinson Foundation

(800) 327-4545

www.parkinson.org

Recommended Reading

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

Caregiving: The Spiritual Journey of Love, Loss and Renewal, Beth

Witrogen McLeod, 1999, John Wiley and Sons, Inc.

The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers,

Maria Meyer and Paula Derr, 1998, CareTrust Publications LLC.

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.

Mainstay, Maggie Strong, 1997, Bradford Books.

The Complete Eldercare Planner, Joy Loverde, 1997, Warner Books, Inc., Time & Life Building.

How to Care for Aging Parents, Virginia Morris, 1996, Workman Publishing Co.

Helping Yourself Help Others: A Book for Caregivers, 1994, Rosalynn Carter and Susan Golant, Times Books, Random House.

Handbook for Long-Distance Caregivers, 2003, Bob Rosenblatt and Carol Van Steenberg, Family Caregiver Alliance.

The Caregiver Helpbook: Powerful Tools for Caregiving, 2000, Vikki L. Schmall, Marilyn Cleland, and Marilyn Sturdevant, Legacy Caregiver Services.

Fact Sheets

Advance Health Care Directives and POLST

Caregivers Guide to Understanding Dementia Behaviors

Caregiving at Home: A Guide to Community Resources

Dementia, Caregiving, and Controlling Frustration

Depression and Caregiving

Legal Planning for Incapacity

Taking Care of YOU: Self-Care for Family Caregiver

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