



Fact Sheet: Caregiving at Home: A Guide to Community Resources

The diagnosis of a dementing illness or disabling health condition marks a new stage in your life and your family's life. Important decisions about care arise, along with uncertainty and anxiety. Some choices might need to be made right away. Others lie ahead.

If you're caring for someone at home, you may be helping your loved one with a range of activities such as bathing, dressing, transportation, and food preparation. In addition, you may have to take care of legal and financial matters such as making medical decisions and handling bills and budgets. Fortunately, a variety of community care options are available to assist you and your loved one.

This fact sheet presents an overview of the different services and programs available to caregivers and individuals with cognitive disorders or other chronic health conditions. Organizations listed throughout the Fact Sheet can help you locate specific assistance. Additional information is provided in the *Resources* section at the end of the fact sheet.

Assessing Needs, Values, and Preferences

Defining your family's particular needs is the first step in determining what kind of help and support will best suit your circumstances. With so many services available to caregivers, you will need to first

outline your specific concerns. It's also useful to think about the values and preferences of your loved one regarding the types of help he or she will accept. It might be helpful to hold a family meeting (see fact sheet, *Holding a Family Meeting*) to discuss care needs and help with decision-making. Try asking yourself the following questions and writing the answers on a sheet of paper:

- What type of help does my loved one need now to live as independently as possible? (Nutrition services, dressing, bathing, lifting, medication management, supervision, companionship, housekeeping, transportation?)
- What types of help might be needed in the future?
- Who in the family will take charge of caregiving and/or make arrangements for care?
- How much money is available to pay for outside resources? Will insurance cover any services?
- What days and times do I need help?
- What kind of assistance can I provide myself?
- Do I have a job that will affect the amount of care I can provide?
- What types of help are my friends and family members willing to provide?

- Can we get used to having a stranger in our home to help us?
- Can we adjust to someone who speaks a different language?
- Would a male or female helper be preferred?
- Do we want out-of-home care? What kind? How often? How long?

Community Care Options

Community care programs and services vary in different states, counties and communities. Most areas now have support services specifically designed for people with Alzheimer's, stroke, Parkinson's and other chronic health conditions. Each community, however, differs in the services available and their eligibility requirements. This section outlines the main community care options for the care recipient and their caregivers.

Informal Care involves the help of friends, family, religious communities, neighbors and others who can share the responsibilities of caregiving. This "informal" support network can help with specific tasks (e.g., household chores), provide emotional support to you and your loved one, and help the care recipient maintain a healthy level of social and recreational activity. Making a list of your informal "helper" network and their contact information will be an invaluable source of support for routine assistance or in times of emergency.

Information and Referral (I&R) helps you identify your local resources. California's Caregiver Resource Centers (www.caregiver.org/californias-caregiver-resource-centers), national Area Agencies on Aging (AAAs), senior centers, or community mental health programs are good resources that can help you find

potential services, such as adult day care programs, respite care, and meals.

Staff members have information about the availability and appropriateness of services, whom to contact, eligibility requirements and hours of operation. The organizations listed in our "Resources" section offer I&R as part of their services. FCA's Family Care Navigator (www.caregiver.org/family-care-navigator) provides information on caregiving support services for all 50 states.

Care Management Services can locate and, if needed, provide hands-on management of services for your loved one. Professional care managers (also called case managers) usually have a background in counseling, social work or a related healthcare field and are trained to assess your individual situation and to implement and monitor a care plan to meet the needs of your loved one. They work with you, the physician, and patient to identify and arrange services such as transportation, home care, meals and day care. Additionally, care managers can help determine eligibility for entitlement programs, assist with family meetings, plan for long-term care, and intervene in crisis situations.

If you meet eligibility requirements, it may be possible to obtain free care management services through federal, state, or county programs such as Medicare or Medicaid (Medi-Cal in California). Free or low-cost care consultation sometimes can be found through hospitals, mental health programs, home health agencies, social service agencies (e.g., Catholic Charities, Jewish Family Services, or Adult Protective Services) and other health-related programs. In addition, it is possible to hire a private care manager, often called a *geriatric care manager*, who will typically charge between \$75 and \$150 per hour.

Legal and Financial Counseling is often needed when your loved one cannot manage legal and/or financial affairs. Areas of concern to family caregivers include Advance Directives for healthcare decisions, management of assets, public benefits planning and, in some cases, litigation. For individuals aged 60 or over and their caregivers, legal referrals and advice may be obtained from services provided by local Area Agencies on Aging. California residents may be eligible for a legal consultation through a California Caregiver Resource Center.

Another way to locate an attorney is through personal referrals or an attorney referral service. The Bar Association in your community may have a panel that refers callers to lawyers in elder law or other specializations. Initial consultations generally include a nominal fee.

Transportation Services. The Americans with Disabilities Act requires transit agencies to provide curb-to-curb paratransit service to individuals unable to use regular public transportation. Paratransit generally consists of wheelchair-accessible vans or taxis for people with disabilities. Paratransit may be run by private, nonprofit, and/or public organizations and is usually free or low-cost. To find out about paratransit in your community, contact your local Area Agency on Aging. Discounted taxi and ride-sharing services might also be available in your community.

Nutrition Programs provide meals—usually lunch—in a group setting. Many churches, synagogues, housing projects, senior centers, community centers, schools and day programs offer meals and opportunities to socialize as a service to elders in the community for a minimal fee.

For homebound individuals unable to shop

for or prepare their own meals, home-delivered meals may be an option. Programs such as Meals on Wheels are offered in most communities, funded partially through government monies or by charitable organizations. The delivery includes a friendly visit and quick safety check for your loved one. Meals may only be delivered on weekdays, so you'll need to be sure there is adequate food for the weekends. Most groups providing home-delivered meals charge a nominal fee (determined by each individual's ability to pay) to help cover costs.

Respite Care offers relief for family, partners and friends so they can take a break—a respite—from the demands of providing constant care. Respite care can be crucial in deterring premature institutionalization of the patient and reducing physical and emotional stress for the caregiver. Respite care includes adult day care and home care services (see below), as well as overnight stays in a facility, and can be provided a few hours, a weekend or even a week. Many caregiver support programs offer respite assistance as part of their services. Some organizations offer volunteer respite workers who provide companionship or protective supervision only. For information on respite care in your community, contact your Area Agency on Aging.

Adult Day Care offers participants the opportunity to socialize, enjoy peer support and receive health and social services in a safe, familiar environment. It also provides a break for caregivers responsible for a person who can't be left alone but who does not require 24-hour nursing care in a residential facility.

Adult day care services may include: care and supervision; small group and individual activities; nutritious meals; transportation;

care management; recreation and exercise; nursing care; education; family counseling; dispensing medications; assistance with activities of daily living; and occupational, speech and physical therapies.

There are two types of adult day care: Adult day care provides social activities, meals, recreation and some health-related services. Adult day health care offers socializing along with more intensive health, therapeutic and services for individuals with more severe medical problems and those at risk of requiring nursing home care. Adult day care is particularly helpful for caregivers who cannot stay at home all day to provide the care, supervision and companionship needed by a loved one. Although programs vary, participants ordinarily attend several hours a day, up to five days a week. The National Adult Day Services Association and your local Area Agency on Aging can help you find adult day care services. If eligibility requirements are met, Medicaid may help cover fees for adult day health services.

Home Care combines health care and supportive services to help homebound sick or disabled persons continue living at home as independently as possible. The hours, types of services, and level of care provided are determined by the health and needs of the care recipient and the caregiver; physician approval may be needed. Aides can be hired directly or through a staffing agency.

There are two types of home care available to you: *home health care services* and *non-medical home care services*. Home health care services provide a wide range of medical services, including medication assistance, nursing services and physical therapy. Nonmedical home care services include companionship, housekeeping, cooking and many other household activities and chores.

The cost of home care depends on the level of care needed—a nonmedical home care attendant will charge less than a nurse who is monitoring the person’s medical needs and condition. Fees vary so you might want to shop around. Medicare, Medicaid (Medi-Cal in California) and some private insurance or long-term care policies pay for limited home health care with certain restrictions. In other cases, you may have to pay out of pocket. Nonmedical home care aides can be located through personal referrals or a private home care agency, hospital, social service agency, public health department or other community organizations. In some areas nursing schools may be of assistance. For information on home care in your community, contact your local Area Agency on Aging.

Hospice Care. Hospice offers special services to improve the quality of life for terminally ill persons by controlling the symptoms of the illness and restoring dignity for the person until death. A team of professionals and volunteers work collaboratively with the patient and family to meet the physical, psychological, social and spiritual needs. They provide medical and nursing care, social services, dietary consultation, counseling and emotional support to both the patient and the caregiver. Equipment such as hospital beds and wheelchairs is also provided.

Individuals receive ongoing scheduled visits as well as round-the-clock care when needed. Intrusive or “heroic” medical interventions are usually waived, depending on the patient’s wishes, and relief of severe pain is a common goal. Support to surviving loved ones usually continues during the bereavement period. Insurance coverage for hospice care is available through Medicare, Medicaid and most private insurance plans. For information on hospice care, contact the

National Hospice and Palliative Care Organization.

Caregiver Support Groups bring together friends and family members who meet regularly to share information and discuss practical solutions to common problems. They are a good source of information on available resources. Support groups also provide caregivers with the opportunity to give and receive encouragement, understanding and support from others who have similar concerns. Interacting with other caregivers can be a real help in reducing stress. Support groups can be found through hospitals, mental health programs and support organizations (e.g., your local Caregiver Resource Center or Alzheimer's Association chapter). Support groups for people with early Alzheimer's disease or other disorders are also offered in some communities. Online support groups are available to caregivers with computer access. Family Caregiver Alliance offers three online groups.

Employee Assistance Programs are a benefit that your workplace may or may not offer. Types of assistance vary widely and are available more frequently at larger companies. Programs generally provide employees with counseling for personal issues such as depression, stress, addiction, financial crisis, and illness or death in the family. Some programs may also assist with locating eldercare and childcare resources. Paid or unpaid leave from your job may also be available for caregivers through federal, state and/or employer-provided programs. Ask your human resources department for information.

Contacting Programs and Services

Once you have assessed your needs and identified the types of resources available in

your community, you can begin contacting community care services. Be aware that it can be a time-consuming experience to locate and arrange appropriate services. You may need to make a series of phone calls or go through a maze of referrals before you find the right program or person to help you. If you have a care manager or other health care provider who helped assess your needs, he or she should be able to help—it's a care manager's job to help you find resources, so don't be afraid to ask for assistance.

The following suggestions will help guide you through the process:

- Begin looking for resources before your situation becomes overwhelming. By planning ahead and anticipating certain needs, you can avoid having to make important decisions during a crisis.
- Write down all information you are given. Be sure to document the date and name of each agency you called, phone number or website, who you spoke with, which services you requested, and any agreed-upon decisions.
- When you make your call, be prepared with specific information, such as physician's name, diagnostic information, insurance coverage and Medicare, Medicaid (Medi-Cal in California) and Social Security numbers. Be prepared to answer questions such as "What type of care is the patient currently receiving and who is providing it?" and "Is there any special equipment in the home to assist with patient care?"
- When dealing with agencies, be assertive and specific about your needs.

- Mornings are usually the best time to call.
- Don't hang up until you understand the follow-up procedures and next steps.
- Be aware that you might be placed on a waiting list. The demand for existing dementia-related services, in particular, has increased while the funding for some service programs has decreased. If you can anticipate your needs and the needs of your loved one, you'll minimize the length of this waiting period.
- If a fee is charged for the service, be sure to ask for a rate sheet that documents the service provided for each fee.
- "Free" online referral services, especially for senior housing may only promote those facilities who pay for a listing or placement fee. The listing or recommendation is not an indication of the quality of care provided.
- Don't hesitate to ask for help. The purpose of most community agencies is to provide services to individuals who need help. You are entitled to these services since many of them are paid for by your taxes, contributions, or fees for service.
- Keep in mind that not everyone is familiar with the needs of caregivers. Therefore, many professionals remain uninformed about stresses on you and your loved one. You might find yourself in situations where you need to educate professionals in the community before you can obtain services successfully.
- Don't give up!

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
 Website: 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

(415) 434-3388 | (800) 445-8106
 Website: 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.

Aging Life Care Association

www.aginglifecare.org

Eldercare Locator

www.eldercare.gov

Meals on Wheels America

www.mealsonwheelsamerica.org

Medicare and Medicaid (Medi-Cal in California)

www.cms.gov

National Adult Day Services Association

www.nadsa.org

National Hospice and Palliative Care Organization

www.nhpco.org

Offers information for families and caregivers through the website caringinfo.org, including downloadable Advance Directives for every state.

National Volunteer Caregiving Network

www.nvcnetwork.org

Visiting Nurses Association of America

www.vnaa.org

Recommended Reading

The Caregiver Helpbook: Powerful Tools for Caregiving, Vikki L. Schmall, Marilyn Cleland, and Marilynn Sturdevant (3rd Edition). Available in Spanish.

The 36 Hour Day: A Family Guide to Caring for Persons With Alzheimer Disease, Related Dementing Illnesses, and Memory Loss, Nancy Mace and Peter Rabins, Fifth Edition (2012), The Johns Hopkins University Press. Available in paperback.

The Complete Eldercare Planner, Revised and Updated Edition: Where to Start, Which Questions to Ask, and How to Find Help, Joy Loverde, (2009). Available in Paperback.

Fact Sheets

Holding a Family Meeting

Hiring In-Home Help

Residential Care Options

Making End-of- Life Decisions: What Are Your Important Papers?

Understanding Palliative/ Supportive Care: What Every Caregiver Should Know