ORANGE Caregiver Resource Center
A PROGRAM OF ST JUDE MEDICAL CENTER

Community Care Options

As a caregiver, you may need to help your loved one with a broad range of activities, such as bathing, dressing, cooking and eating. In addition, you may have to take care of legal and financial matters, such as making medical decisions, paying bills, handling investments and budgeting accounts. Fortunately, a variety of community care services are available to assist you and your loved one. This Fact Sheet presents an overview of the different options available to caregivers and persons with cognitive disorders and other chronic health conditions. Organizations listed throughout the Fact Sheet can help you locate specific services. Contact information for these organizations is provided at the end of the Fact Sheet under "Resources."

Assessing Your Needs

Defining your 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. You may find it useful to ask yourself the following questions and write out the answers on a sheet of paper:

- What type of help does my loved one need to live as independently as possible? (Nutrition services? Health care? Supervision? Companionship? Housekeeping? Transportation?)
- How much money is available to pay for outside resources? Will our insurance cover any of the services?
- What days and times do I need help?
- What assistance can I provide myself?
- What types of help are my friends and family members willing to provide?

Community Care Options

Community care programs and services vary in different states, counties and communities. Most areas now have services specifically designed for persons with Alzheimer's, stroke, Parkinson's and many 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 phone numbers 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, 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 housing, meals and adult day care programs.

Staff members have information about the availability and appropriateness of services, whom to contact, eligibility requirements and hours of operation. The Resources Organizations listed at the end of this Fact Sheet all provide I&R as part of their services.

Case Management Services can locate and provide hands-on management of services for your loved one. Professional 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, therapist and patient to

identify and arrange services such as transportation, home care, meals and day care. Additionally, case managers can help determine eligibility for entitlement programs, plan for long-term care and intervene in crisis situations.

If you meet eligibility requirements, it is possible to obtain free case management services through federal, state, or county programs such as Medicare or Medicaid (Medi-Cal in California). Free or low cost case management can be found through hospitals, mental health programs, home health agencies, social service agencies (e.g., Catholic Charities, Jewish Family Services, Adult Protective Services) and other healthcare-related programs. In addition, it is possible to hire a private case manager, often called a *geriatric case manager*, who will typically charge between $60 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 future 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 also be obtained from senior legal 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 an attorney referral service. *The Bar Association* in your community may have a panel that refers callers to lawyers in various 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 those individuals who are 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 Project Action, which maintains a national paratransit database, or your local AAA.

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 as a service to elders in the community for a minimal fee.

For homebound individuals who are unable to shop for or prepare their own meals, home-delivered meals may be an option. Programs such as “Meals-on-Wheels” are provided by various groups and may be funded partially through government monies or by charitable groups. In general, meals are delivered on weekdays so you will need to be sure there is an adequate supply of 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 week or for a weekend. Many caregiver support programs offer respite assistance as part of their services. Some service organizations offer volunteer respite workers who provide companionship or protective supervision only. For information on respite care in your community, contact your AAA.

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

There are two types of adult day care: *Adult socialday care* provides social activities, meals, recreation and some health-related services. *Adult day health care* offers more intensive health, therapeutic and social services for individuals with severe medical problems and those at risk of

requiring nursing home care. Adult day care works well for caregivers who cannot stay at home all day to provide care, supervision and companionship. 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 AAA can help you find adult day care 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.

There are two types of home care available to you: *home health care services* and *nonmedical 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 may charge a relatively low fee whereas a nurse who is monitoring the person's condition and treatment will be more expensive. Fees vary so you may want to shop around. Medicare, Medicaid (Medi-Cal in California) and some private insurance 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 at 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 a local AAA.

Hospice Care provides special services and therapies so individuals who are terminally ill can remain at home. Hospice attempts 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 hospice care team of professionals and volunteers tries to meet the physical, psychological, social and spiritual needs by providing medical and nursing care, social services, dietary consultation, and emotional support to both the patient and the caregiver. Individuals receive ongoing scheduled visits as well as round-the-clock care when needed. Support to surviving loved ones usually continues during the bereavement period. Insurance coverage for hospice care is available through Medicare, Medicaid and some private insurance plans. For information on hospice care, contact Hospice Foundation of America.

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 great 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). There are also online support groups available to caregivers with computer access. Family Caregiver Alliance offers three online groups for caregivers.

Employee Assistance Programs are an employment benefit that your workplace may or may not offer. Types of assistance vary widely, though 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.

Contacting the Resources

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 confusing and time consuming—although ultimately worthwhile—experience to locate, arrange and receive appropriate services. You may need to make a series of seemingly endless phone calls or go through a maze of referrals before you find the appropriate service or person to help you. If you have a case manager or other health care provider who helped assess your needs, he or she should be able to assist you in locating appropriate resources as well. It is a case manager's job to help you find resources, so don't be afraid to ask for help. The following is a list of

suggestions to guide you through the process of locating and accessing appropriate services:

- 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 time of crisis.
- Write down all of the information you are given. Be sure to document the name of each agency you called, the phone number or website, the contact person(s) with whom you spoke, the date of your conversations, the services requested, the services promised 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 (i.e., who calls whom, what will be done next, what you need to do next).
- 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. By anticipating your needs and the needs of your loved one, you minimize the length of this waiting period.
- 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 professionalsin the community before you can obtain services successfully.
- Don't give up!

Recommended Readings

Caregiver Guide: Tips for Caregivers of People with Alzheimer's Disease, National Institute on Aging (2001), Gaithersburg, MD. Available by calling (800) 222-2225.

The Caregiver Helpbook: Powerful Tools for Caregiving, Vikki L. Schmall, Marilyn Cleland, and Marilynn Sturdevant (2000), Legacy Caregiver Services. Available by calling (503) 413-6578.

Consumer Reports Complete Guide to Health Services for Seniors 2000, Trudy Lieberman and the editors of *Consumer Reports*, Three River Press, A Division of Random House. Available by calling (800) 500-9760 or on the web at www.consumerreports.org.

Alzheimer's Early Stages: First Steps in Caring and Treatment, Daniel Kuhn (1999), Hunter House Publishers, P.O. Box 2914, Alameda, CA 94501-0914, (800) 266-5592.

Caring for the Parkinson's Patient: A Practical Guide (2nd Edition), J. Thomas Hutto, M.D., Ph.D. and Raye Lynne Dippel, Ph.D. (Eds.), (1999), Prometheus Books, 59 Glenn Dr., Amherst, NY 14228-2197, (800) 421-0351.

The 36 Hour Day: A Family Guide to Caring for Persons With Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life, Nancy Mace and Peter Rabins, Revised Edition (April, 2001), The Johns Hopkins University Press, 2715 N. Charles Street, Baltimore, MD 21218-4319, (800) 537-5487.

Because We Care: A Guide for People Who Care, Administration on Aging (2001), an online resource for caregivers of an older family member, adult child with disabilities, or older friend. Available free, www.aoa.gov/

Credits

Lieberman, Trudy and the editors of Consumer Reports (2001). *Is Assisted Living the Right Choice?* Consumer Reports.

Mace, Nancy and Peter Rabbins (2001). *The 36-Hour Day*. The Johns Hopkins University Press, Hampden Station, Baltimore, MD 21211.

Schmall, Vikki L., Marilyn Cleland, and Marilynn Sturdevant (2000). *The Caregiver Helpbook: Powerful Tools for Caregiving*. Legacy Caregiver Services, Portland, OR 97210.

Resources

Family Caregiver Alliance
180 Montgomery Street, Suite 1100
San Francisco, CA 94104
(415) 434-3388
(800) 445-8106
Website: www.caregiver.org
E-mail: info@caregiver.org
Online support groups

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 advice and information on current social, public policy and caregiving issues and provides assistance in the development of public and private caregiver support programs. 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, brain injury, Parkinson's and other chronic health conditions that strike adults.

Eldercare Locator
Phone: (800) 677-1116
Website: www.eldercare.gov
The Eldercare Locator helps older adults and their caregivers find local services including health insurance counseling, free and low-cost legal services and contact information for Area Agencies on Aging (AAAs).

Medicare and **Medicaid**
Phone: (800) MEDICARE

Medi-Cal (California's version of Medicaid)
Phone: (800) 952-5253
www.medi-cal.org

Alzheimer's Association
225 N. Michigan Ave., Ste. 1700
Chicago, IL 60601-7633
Phone: (800) 272-3900
Website: www.alz.org

The American Parkinson's Disease Association
1250 Hylan Blvd., Ste. 4B
Staten Island, NY 10305-1946
Phone: (800) 223-2732
Website: www.apdaparkinson.com

National Stroke Association
9707 East Easter Ln.
Englewood, CO 80112-3747
Phone: (800) 787-6537
Website: www.stroke.org

National Association of Professional Geriatric Care Managers
1604 N. Country Club Rd.
Tucson, AZ 85716-3102
Phone: (520) 881-8008
Website: www.caremanager.org

National Association of Adult Day Services
c/o National Council on the Aging
409 Third St. SW, Ste. 200
Washington, DC 20024
Phone: (202) 479-1200
Website: www.ncoa.org

Visiting Nurses Associations of America
11 Beacon St., Ste. 910
Boston, MA 02108
Phone: (888) 866-8773
Website: www.vnaa.org

Hospice Foundation of America
2001 S. St. NW #300
Washington DC 20009
Phone: (800) 854-3402
www.hospicefoundation.org

Project ACTION-Easter Seals Transportation
700 13th St., NW, Ste. 200
Washington, DC 20005
Phone: (202) 347-3066
Website: www.projectaction.org

Meals-on-Wheels Association of America
1414 Prince St., Ste. 302
Alexandria, VA 22314

Phone: (703) 548-5558 Website: http://meals-on-wheels.com/

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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 program.

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