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Serving: Del Norte, Humboldt, Mendocino, Lake, Sonoma,  
Napa & Solano Counties



# Fact Sheet Community Care Options

The burden of caregiving can be overwhelming for the friends and family members of someone with a dementing illness. Caregivers are responsible for a broad spectrum of care needs including physical tasks (e.g., bathing, lifting, providing medications), household chores (e.g., cooking, cleaning, shopping), long-term care planning (e.g., obtaining a power of attorney), and providing emotional support and other daily needs (e.g., respite, recreation, medical appointments). This fact sheet presents an overview of the community care options available to caregivers and demystifies the process of determining your needs and finding help.

## Assessing Your Needs

Defining your needs is a first step in determining what kind of help and support will benefit you, the care-giver, the most. With the myriad of services available, it is often difficult to determine exactly what you need, especially when you may be emotionally and physically overwhelmed from caregiving. Making lists of your needs and problems as they arise helps to clarify the kinds of assistance you may need. Asking yourself the following questions will also help you begin the process of assessing your situation.

- What is my loved one's level of functioning?
- What type of help does my loved one need to live as independently as possible? Nutrition services? Health care? Adult day care? Companionship? Homemaking?
- How much money is available to pay for outside resources? Will my insurance cover any of the services?
- What days and times do I need the help?

- What assistance can I provide myself?
- What types of help are my friends and family members willing to provide?
- What specific types of help are still needed?

## Community Care Options

Programs and services available to assist you vary in different communities. Some communities have services specifically for persons with Alzheimer's or a related dementia, while other locations may modify existing support services to serve the dementia population. Each community differs in the types of services available and their eligibility requirements.

**Informal Care** involves the help of friends, family, neighbors, church members and others who can share the responsibilities of caregiving and alleviate some of the burden of care. This "informal" support network can take on specific tasks, provide emotional support to you and the person with dementia, and participate in social and recreational activities. Making a list of your informal network with their phone numbers may prove invaluable as a source of support for regular chores or in times of emergency.

Although your informal support network is essential in providing care, it cannot always address all areas of needed support. Sometimes community services such as home health care and home-delivered meals are needed.

**Information and Referral (I & R)** helps identify what resources exist.

The local Caregiver Resource Center, Senior I & R, Area Agency on Aging (AAA), senior center or community mental health program are good places to begin searching. A telephone

call to your local I & R program serves as a point-of-entry into the system by providing information about potential resources such as housing, food programs and adult day care. Staff members can usually answer questions about the availability and appropriateness of services, whom to contact, eligibility requirements and hours of operation.

**Case Management Services** provide assistance in both locating and managing services for your ongoing needs. Professional case managers usually have a background in counseling, social work or related health care 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. You may find case managers at hospitals, mental health programs, home health agencies, social service agencies (e.g., Catholic Charities, Jewish Family Services, Adult Protective Services) and other health care-related programs. Fees for a private case manager usually run \$60 to \$150 per hour.

**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 day social 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 can't stay at home all day to provide care, supervision and companionship. Although programs vary, participants ordinarily attend for several hours a day, up to five days a week.

Since not all day care programs are designed for individuals with dementia, you should check eligibility criteria. You may be able to work with a facility in your community interested in developing a special service for persons with dementia.

**Transportation Services** provide transportation to and from medical appointments, day programs and other services. Transportation may be provided by volunteer drivers, bus, taxi or specially equipped van service. Service generally is requested in advance and may be used to pick up individuals on a regular schedule to go to their weekly appointments. There is usually a fee for riding. Unfortunately, in most communities the demand for transportation often outstrips the availability of services.

**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 the 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.

**Home Care** combines health care and supportive services enabling homebound sick or disabled persons to continue their accustomed way of life as much as possible. The hours, types of services and level of care provided are determined by the health and needs of the person

with dementia and his/her caregiver; physician approval may be needed. Home care aides can be located through personal referrals or at a private home health agency, hospital, social service agency, public health department or other community organizations such as a church group. In some areas nursing schools may be of assistance.

For those homebound individuals in need of skilled nursing, a specialized, coordinated plan of treatment is prescribed by a physician or other health care professional. Professional home care workers may include nurses, social workers, speech pathologists, physical or occupational therapists and dietitians. These individuals can assist with medical care (e.g., administering medications, changing dressings), personal care (e.g., bathing, dressing, eating), and nutrition.

For persons with dementia, intensive nursing care is not usually needed unless there are additional medical problems. If this is the case, you might want to hire a homemaker, chore worker or home health aide to help for a few hours a day or week to assist in household duties or personal care (e.g., bathing, dressing, shopping, and cleaning). These services can be arranged with less highly skilled individuals.

The cost of home care depends on the level of care needed—a “friendly visitor” may be free of charge whereas a nurse who is monitoring the person’s condition and treatment regimen will be more expensive. Fees vary so you may want to shop around. Medicare, Medicaid and some private insurance policies pay for limited home health care with certain restrictions.

**Respite Care** offers relief for family and friends so they can take a break—a respite—from the demands of providing constant care. Respite care includes adult day care and home care services, as well as overnight stays in a facility, and can be provided a few hours a week or for a weekend. Respite care can be crucial in deterring premature institutionalization of the patient and reducing physical and emotional stress for the caregiver.

**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 try 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.

**Support Groups** bring together friends and family members of individuals with dementia 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. Knowing you are not alone is a major benefit of attending a support group. Support groups can usually be found at hospitals, mental health programs and disease-specific support organizations (e.g., your local Caregiver Resource Center or Alzheimer’s Association chapter).

## Contacting the Resources

Once you have assessed your needs and identified the types of available resources, you can begin contacting community care services. Be aware that it can be a confusing and discouraging 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. The case manager or other health care provider who helped assess your needs should be able to assist you in locating appropriate resources. This is his/her job, so don’t be afraid to ask for help. The following is a list of suggestions to guide you through this 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 time of crisis.
- Write down all of the information you are given. Be sure to document the name of the agency you called, the contact person(s) with whom you spoke, the date of your conversation, the services requested, the services promised and any agreed-upon information.
- 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 (e.g., 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 has increased while the funding for many service programs has decreased. By anticipating your needs and the needs of the person with dementia, 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 dementia. Therefore, many professionals remain uninformed about dementia and its impact 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.

## Recommended Readings

***Home Care for Older People: A Consumer's Guide***, Anne P. Werner and James Firman, 1994, United Seniors Health Cooperative, 1331 H. St., NW, Washington, DC 20005-4706.

***Homes That Help: Advice From Caregivers for Creating a Supportive Home***, Richard V. Olsen, et al., 1993, New Jersey Institute of Technology, 323 Martin Luther King Blvd., Newark, NJ 07102-1982.

***Now What? A Handbook of Activities for Adult Day Programs***, Vikki Thews, et al., (eds.), 1993, Dementia Care & Respite Services Program, Bowman Gray School of Medicine of Wake Forest University, Dept. of Psychiatry and Behavioral Medicine, Medical Center Blvd., Winston-Salem, NC 27157-1087.

***The Caregivers Guide: Helping Elderly Relatives Cope With Health & Safety Problems***, Carolyn Rob and Janet Reynolds, 1991, Houghton-Mifflin Company, 2 Park St., Boston, MA 02108.

## Credits

Community Services Planning Council, 1987, *Consumer Guide to In-Home Care*. Community Services Planning Council, 909 12th St., Ste. 200, Sacramento, CA 95814.

Health Advocacy Services Program Department, 1988, *A Handbook About Care in the Home*. American Association of Retired Persons, 1909 K Street, N.W., Washington, DC 20049.

## Resources

**National Association of Area Agencies on Aging**  
112 – 16th St., NW, Ste. 100

Washington, DC 20036  
(202) 296-8130  
(800) 677-1116 (elder care locator)

**National Association of Professional Geriatric Care Managers**

1604 No. County Club Rd.  
Tucson, AZ 85716  
(602) 881-8008

**National Association on Adult Day Care**

c/o National Council on the Aging  
409 Third St., SW, Suite 200  
Washington, DC 20024  
(202) 479-1200  
(800) 424-9046

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