



A caregiver's resource guide

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Most stroke survivors want to continue living in their own homes and communities. But while most of us would want to support that desire and keep our family member at home, illness or disability may make it difficult.

A variety of community services have been developed to help stroke survivors and their families to remain at home.

Many of these services provide vital assistance with the daily activities of independent living, including needs of safety, health, mobility and nutrition. A range of services available is briefly described in this article. Some may be available through county social service agencies, Public Health Nursing Services, or other governmental, non-profit, or private agencies.

Some of these programs require fees which are often calculated on a sliding fee scale determined by your ability to pay. Other services may be free because they are provided by volunteers, government, or charitable organizations.

If your area has an information and referral service, check that first to find out what's available in your community. Next, try your county social services agency.

In this publication, when a program or service is widely known by more than one name, it is listed under the most common "generic" name. Other widely used names also appear in this alphabetical listing, but refer to the "generic" name for the description.

Adult Day Care: specialized program for people who are not physically and/or mentally capable of full-time independent living and need professional protective supervision in a social setting during the day. Programs vary but most offer some health and medical monitoring, meals, and rehabilitation or maintenance therapies. These might include physical, occupational, and speech therapy, blood pressure checks, and assistance with medical problems (i.e., catheters). All programs provide recreational group activities. Socializing with others is a key component. Staff also provide counseling with the adult's family and make referrals to other services.

Adult Foster Care: provides supervised care in approved (licensed) private homes for individuals no longer able to function independently in their own homes; useful for frail, handicapped, or vulnerable adults who are ambulatory and able to attend to their own basic needs for at least short period of time. They receive meals, lodging, and some personal care. Private homes must meet standards of safety and care to be licensed.

Chore Services: provides such tasks as necessary yard work and snow removal, seasonal heavy cleaning, installation of safety devices, minor repairs, and winterizing homes. In some counties, chore service also consists of assistance with household chores, such as grocery shopping, laundry, meal preparation, and cleaning.

Companions (see Friendly Visitor): persons, usually paid, who provide companionship and supervision for someone who cannot be left alone. They may help with light cleaning, food preparation, daily personal care in the individual's home, nursing home, or other facility. Paid companions are also available in some areas to stay through the evening and night.

Congregate Dining (see Meals-on-Wheels): federally sponsored nutrition program for the elderly which provides low cost, hot, nutritious meals in a group setting in community and senior centers, high rises, or other such facilities. Persons 60 and older (and their spouses regardless of age) may participate and contribute voluntarily toward the cost of the meal. It often includes some recreational and social activities.

Counseling: assisting the client and his or her family to cope with social, mental, emotional, and sometimes medical factors affecting their total well-being. The aim of counseling for the client usually is to reduce stress, make decisions, improve communication skills, and spur personal growth. Referral services determine the client's needs, then locate and contact service agencies (such as health aide, transportation, income assistance, etc.) for a client and/or family who need services beyond those already being used.

Day Treatment: structured services operating less than 24 hours per day which teach independent living skills and socialization skills, and offer psychosocial rehabilitation and psychotherapy to increase independent and effective functioning. Day treatment is designed for individuals who are mentally ill or have a disorder of thought or need that significantly impairs judgment, behavior, or capacity to recognize reality.

Friendly Visitor, Telephone Reassurance (see Companions): a program of regular visits or calls to homebound persons with disabilities or illness; provides companionship and a safety check. As a "formal" service this is usually performed under social worker supervision.

Home-Delivered Meals (see Meals-on-Wheels): federally-sponsored meal program for home-bound or disabled persons 60 and older (and their spouses regardless of age), prepared and delivered directly to their homes. This is a federally-funded program, along with congregate dining.

Home Health Aide Services (see also Personal Care Services): in-home personal care assistance with bathing, eating, toileting, mobility, etc., or the training of the client in the performance of these procedures as appropriate. If performed by certified home health agency, direct care staff will have received training and will be supervised by a registered nurse.

Homemaker Assistance: supervised trained personnel help with light cleaning, shopping, laundry, some food preparation, and other household duties. Homemakers also may assist with household management and provide social support.

Meals-on-Wheels (see also Home Delivered Meals): hot nutritious meals prepared by churches, or other local volunteer groups off-site and delivered to home-bound persons. Unlike Home-Delivered Meals, age eligibility and payment request vary from program to program.

Personal Care Services (see also Home Health Aid Services): assistance with bathing, feeding, walking, or other personal care activities. These services are beyond the scope of the homemaker responsibilities. Care is often instructed or supervised by a registered nurse. Many family members informally provide these services without supervision of an agency.

Pre-Admission Screening: a mandatory screening process for applicants to nursing homes who are 65 and older, and who are now eligible for Medical Assistance (Medicaid) or who are expected to be eligible within 180 days of nursing home admission. Screening determines client's suitability for alternative services that will enable individual to remain in their own home or community. The screening team consists of a nurse and social worker who

assess the individual's health and social service needs. They develop a plan of care and assist the individual in obtaining needed services if the person accepts that recommendation. There is no charge for screening a person "MA eligible" or "180-day MA eligible." Others 65 or older may request a screening for which they may be charged a small fee.

Public Health Nursing Services: health promotion, education, health assessment, screening, follow-up patient care and home health care to unhospitalized ill or disabled persons who need nursing care in the home. If needed, other services such as physical therapy, speech therapy, and home health aide services are provided.

Respite Care: supervision and assistance by individuals who come into the home for a limited time to provide family members a break in responsibility for a frail, handicapped, ill or disabled person; or the impaired person may stay at a nursing home, hospital, foster home, or community residential facility for a short period of time, such as during a vacation or family emergency of the usual caregiver.

Senior Companion Program and Volunteer Companions (see also companions): persons who provide companionship, friendship, and support to adults with special needs, especially the elderly, in and outside of the adult's residence. These companions do not provide housekeeping or personal care services. Senior Companions are elderly volunteers.

Transportation Services: assists clients with travel to and from community resources and facilities for routine and/or scheduled needs (i.e., medical, social, nutritional).

Services available differ by state and by area within a state. Looking for resources can involve many phone calls and a lot of time and energy on your part. Keep a log of phone calls, including the date, name of the person you talked to and the topic that was discussed.

Caregiver Organizations:

Well-Spouse Foundation
1-800-838-0879
610 Lexington Ave
Suite 814
New York, NY 10022

Family Caregiver Alliance
415-434-3388 (non-Calif residents)
1-800-445-8106 (California residents only)
425 Bush St
Suite 500
San Francisco, CA 94108

National Family Caregiver Association
1-800-896-3650
9621 East Bexhill Dr.
Kensington, MD 20895-3104

American Association of Retired Persons
1-800-424-2277
601 East Street Northwest
Washington, DC 20049