

Community Care Options for the Alzheimer Family

**The New York City
Department for the Aging
Alzheimer's & Caregiver Resource Center**

Alzheimer's disease changes the life of the entire family. As families take on the tremendous responsibility of caregiving, they must cope with a multitude of physical, emotional and financial concerns.

The Department for the Aging's Alzheimer's & Caregiver Resource Center is here to help ease those burdens. Our professional staff are experts in dementia and long-term care issues. We can develop a plan to benefit both family and patient.

Our services are free and strictly confidential.

We offer:

- _ Individual assessment
- _ Referrals to medical diagnostic centers, community-based services and support groups
- _ Guidance on medical, legal and financial issues, including public benefits
- _ Information on long-term care options
- _ Assistance with nursing home placement process
- _ Advocacy
- _ Training for professionals and caregivers
- _ Educational presentations

For information on these and other City services, call 311.

Five Million Americans Have Alzheimer's Disease

Like you, millions of families—from all ethnic groups and cultures, and all walks of life—are faced with the challenges of caring for a loved one with Alzheimer's disease (AD).

AD is the most common form of dementia, caused by changes in brain cells and nerve endings, which interfere with normal brain function. People with AD gradually lose their ability to remember, learn new tasks, or perform routine activities. Eventually, assistance with the most basic activities of daily living becomes necessary. Significant changes in personality and behavior may also occur. Certain medications can slow the progress of the symptoms, but as of now, there is no prevention or cure for this disease.



***First Rule for Caregivers:
Know That You are a Caregiver***

***Second Rule:
Know That Help is Available***

Families provide most of the care for those with Alzheimer's disease. While caregiving can be a rewarding experience, the demands of prolonged caring can also be overwhelming. Stopping by to bring groceries or to take the older person to medical appointments is caregiving in its earliest stage. In time, conditions such as Alzheimer's disease and other chronic illnesses demand more of your time and attention.

Your role as caregiver can create conflicts with other areas of your life. Remember that it is okay to acknowledge the difficulties of giving care. It does not mean that you love the recipient of your caregiving any less. Community services were established to help the ill person remain at home for as long as possible. Using these services can also help you maintain *your* health while providing or overseeing the needed care. Learn about the resources available in your community and seek them out.



Look to the future

Long-term care can be a complex and expensive responsibility. It is important to plan early for the payment of care needed now and in the future. A lawyer specializing in elder care can help you make necessary legal and financial arrangements. A geriatric care manager can provide assistance with planning, coordinating and managing other necessary services. This booklet briefly describes your community options from the early onset of AD when you're caring for your family member at home to the later stages of the disease when it may be necessary to consider a nursing home.

***Call the Department for the Aging's
Alzheimer's & Caregiver Resource Center
for assistance with obtaining the help
you need.***



Community Services

Caring for your loved one at home can be emotionally trying as you cope with behaviors that may be erratic and difficult. Know that you are not alone in your feelings. Never feel guilty, ashamed or embarrassed to take advantage of community resources. Community-based services help the elderly maintain as much independence as possible and are a valuable aid to those in the earlier stages of Alzheimer's disease. Designed to meet the needs of the ill at home, these services include support groups, home-delivered meals, transportation, friendly visiting, adult day services, respite care and home care.

Support Groups for the family caregiver and those with an early Alzheimer's diagnosis usually meet weekly.

Participants gain strength by:

- Expressing emotions and frustrations
- Sharing experiences
- Participating in group activities
- Learning how to cope with an uncertain future
- Finding sources of help

Home-Delivered Meals

are sponsored by the New York City Department for the Aging. A voluntary contribution is requested.



Transportation is sponsored by the New York City Department for the Aging, providing door-to-door group rides to health and social service appointments. A voluntary contribution is requested.

The MTA-New York City Transit sponsors **Access-A-Ride** door-to-door rides for a small fee.

Many voluntary neighborhood and religious organizations offer other services such as light housekeeping, shopping, or friendly visiting. There may be a fee.



Adult Day Services provide social, recreational, nutritional and health-related activities in a supervised group setting.

Benefits include:

- Help in maintaining the participant's physical and cognitive functioning
- Opportunities to socialize and enjoy peer support
- Providing relief to a caregiver who cannot leave the person with Alzheimer's alone



A good program should:

- Assess the individual's abilities and needs
- Offer an active social and recreational program
- Develop a plan and monitor progress by conducting regular care plan meetings with the program participant, caregiver and facility staff
- Provide a safe, secure environment
- Have qualified, trained staff and volunteers
- Clearly explain policies regarding termination of applicant's participation

Call 311 for the Alzheimer's & Caregiver Resource Center, which can assist you in locating a program near you.

There are two models of adult day services, social and medical.

The social model provides:

- Supervised socialization, recreation
- Meals, snacks
- Transportation to most programs

Activities in dementia-specific programs are appropriate to the level of participant's abilities and conducted by staff who have received specialized dementia training.

The social model may be paid for privately, on a sliding scale, by contribution, or through government funding.

The medical model provides:

- The same services as the social model, PLUS
- Access to routine medical and rehabilitative care

Payment for the medical model is through private pay, Medicaid, or, if rehabilitation is required, Medicare. All medical models are located in or affiliated with a nursing home, with medical care generally on-site or nearby.

Out-of-Home Respite Care is offered by some nursing homes.

This service allows:

- Short-term overnight care
- Payment through private pay, sliding scale or Medicaid

A maximum of 42 days of nursing home care per calendar year is permitted for a community-based Medicaid client. If the client is enrolled in the Lombardi Program or a Medicaid managed care program, consult with your provider about respite services provided.

In-home Assistance Fills a Range of Needs

Various levels of home care are available. Your choice, of course, depends on the help you need to manage and your budget:

- Companions give the caregiver time off and may do light shopping or housekeeping.
- Personal care aides provide help with activities of daily living, routine needs and ensuring the safety of the patient.
- Home health attendants provide personal care and limited nursing care.
- Other services that may be provided include skilled nursing care, social work services, and physical, occupational, and speech therapies.

Where to find home care workers:

- **Informal networks** — Friends, neighbors and other family members who have used aides, local newspaper ads, or places of worship are some examples of sources. Often, workers in these networks have not received formal dementia or home care training and are not certified.
- **Registries and employment agencies** — Although home care workers may be screened, they may not be trained in dementia care or certified.
- **Licensed home care agencies** — Licensing requires

- that these agencies follow state regulations and guidelines for providing home care. The agency will evaluate the needs of the individual, develop a care plan, provide a certified home care worker and supervise care. Insurance may cover care from a licensed agency as long as the need for skilled nursing care can be medically documented.

What to look for in a home care worker:

- Training and experience in caring for individuals with dementia
- An understanding of the disease process and behaviors
- Compatibility with the recipient of care
- Dependability

In choosing an agency, look for one that:

- Clearly tells you what services are provided
- Listens to your needs
- Trains aides to work with individuals with dementia
- Will provide another aide if one doesn't work out

Payment — Generally, you will have to pay for home care services. Varying hours of coverage are available through the following programs, but strict eligibility rules apply:

- Private Medigap and long-term care insurance, with limitations and exclusions according to policy
- Limited Medicare coverage in circumstances requiring skilled nursing care, home care assistance, physical, speech or occupational therapies, or social work services after hospitalization
- Medicaid for those who meet financial requirements and have extensive medical needs

- EISEP (Expanded In-home Services for the Elderly Program), a New York State program operated through the New York City Department for the Aging, with limited hours of home care for those not eligible for Medicaid. Payment is on a sliding-scale basis.

The Alzheimer's & Caregiver Resource Center staff can help you determine your eligibility for financial assistance and plan for the care you need.

When Living at Home is No Longer an Option



Private Assisted Living Facilities

may be a good choice for an Alzheimer's individual who is:

- In the early or middle stages of the disease
- Medically stable
- Not a danger to self or others
- Does not wander

Services provided include:

- Limited services of home health aide, nurse and therapists
- Medication monitoring
- Personal care and limited assistance



- Meals and housekeeping
- Supervision
- Social activities

To select the most appropriate facility, verify:

- Services provided, especially for Alzheimer's residents
- Specifics on all charges
- Health care services
- Discharge policy
- Staffing levels
- Cleanliness
- Appearance of residents
- Activities
- Security



Some assisted living facilities may have a specialized dementia care program.

Fees for private assisted living facilities in New York City range from \$2,000 to \$8,000 per month. Additional charges are incurred for increased personal assistance hours and other services.

When the resident's funds are depleted and the monthly fees can no longer be met, alternate living arrangements must be made.

Note: New York State sponsors an Assisted Living Program that identifies a limited number of beds in certain adult homes that will accept Medicaid reimbursement.

For more information on this housing option, call 311 for the Alzheimer's & Caregiver Resource Center.

Nursing Homes

Many families try to keep the person with Alzheimer's at home for as long as possible. However, nursing home placement may come to be the most appropriate option for the health and safety of both caregiver and care recipient.

Don't wait for a crisis to begin thinking about nursing home placement.

Do start planning early. Finding, applying to and getting a bed in a suitable nursing home takes time. In selecting a nursing home, look for:



- Location for ease of visiting
- Cleanliness of facility
- Appearance of residents
- Menus with well-balanced meals
- Age- and ability-appropriate recreation activities
- Ratio of nurse aides to residents
- Staff trained and experienced in working with Alzheimer's disease
- Dementia unit
- Security system on floor with dementia residents and at front door
- Posting of residents' rights and latest Department of Health facility survey

Nursing home care is expensive. Monthly costs in the tri-state area range from \$7,000 to more than \$10,000. Medicare and Medigap insurance do not pay for long-term care in nursing homes.

There are several payment options:

- Private pay utilizing care recipient or family funds — Once the care recipient's savings and assets are depleted, an application for Medicaid may be completed.
- Long-term care insurance offered through private insurance companies — While these policies do offer nursing home plans, many exclude dementia and other pre-existing medical conditions, and will provide only limited coverage.
- Medicare — Some degree of coverage is provided for the qualified individual who requires placement in a skilled nursing facility, up to a maximum of 100 days. A Medicare HMO may provide more than Original Medicare's limit.
- Medicaid — In New York State Medicaid will cover nursing home care, provided the care recipient's income and assets meet established criteria.

Medicaid regulations are complicated and frequently change. For this reason, it is crucial to seek legal and financial advice early. Call the Alzheimer's & Caregiver Resource Center for information and referrals.

Local and National Resources

In addition to the New York City Department for the Aging's Alzheimer's & Caregiver Resource Center, the following agencies provide information and other services:

Local Organizations

Alzheimer's Association
New York City Chapter
360 Lexington Avenue, 5th floor
New York, NY 10017
1646-744-2900
www.alz.org/nyc

Alzheimer's Foundation of Staten Island
460 Brielle Avenue
Staten Island, NY 10314
1-718-667-7110
www.sialzheimers.org

Long Island Alzheimer's Foundation
5 Channel Drive
Port Washington, NY 11050
1-516-767-6856
www.liaf.org

Access-A-Ride
MTA-New York City Transit
1-877-337-2017
1718-393-4999 (Outside of New York City)
www.mta.info

Friends and Relatives of the Institutionalized Aged
18 John Street, Suite 905
New York, NY 10038
1-212-732-4455
www.fria.org

Medicare Rights Center
520 8th Avenue
North Wing, 3rd floor
New York, NY 10018
1-800-333-4114
www.medicarerights.org
(Note that this is not a walk-in center.)

Well Spouse Association
NJ office
1-800-838-0879
www.wellspouse.org

State Organizations
New York State Substate Long Term Care
Ombudsman Program
11 Park Place, Suite 1110
New York, NY 10007
1-212-962-2720
www.nyfsc.org

New York State Department of Health
1-866-893-6772
www.nyhealth.gov

National Association of Professional Geriatric
Care Managers
1-520-881-8008
www.caremanager.org

National Organizations

National Alzheimer's Association
1-800-272-3900
www.alz.org

Alzheimer's Disease Education and Referral Center
(ADEAR)
1-800-438-4380
www.alzheimers.org

Children of Aging Parents
P.O. Box 167
Richboro, PA 18954
1-800-227-7294
www.caps4caregivers.org

Family Caregiver Alliance
180 Montgomery Street
San Francisco, CA 94104
1-415-434-3388
www.caregiver.org

National Academy of Elder Law Attorneys
1577 Spring Hill Road
Suite 220
Vienna, VA 22182
1-703-942-5711
www.naela.org

National Alliance for Caregiving
4720 Montgomery Lane, 2nd floor
Bethesda, MD 20814
www.caregiving.org

Publications

You may request free informational material from the Alzheimer's & Caregiver Resource Center, including:

- *Caring: A Guide to Caring for Persons with Alzheimer's Disease**
- *Alzheimer's Disease: Where to Go for Help in New York City*
- *Placing Your Relative with Dementia in a Nursing Home*
- *Preparing for Long Term Care: A Legal & Financial Guide for New Yorkers**

*Available in Spanish, Chinese, and Russian

For information on all City services



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www.nyc.gov/aging