


*Understanding*  
**Alzheimer's**  
**Disease**  
**And**  
**Where**  
**to Turn for**  
**Help**



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

Michael R. Bloomberg, Mayor, City of New York  
Edwin Méndez-Santiago, LCSW, Commissioner



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.

## What is Alzheimer's Disease?

It is a progressive brain disease that gradually results in the loss of memory and mental ability. Alzheimer's disease (AD) is the most common form of dementia, producing significant changes in personality and behavior. Eventually the person can no longer perform even simple activities of daily life.

AD is not a normal part of aging; it can be diagnosed in adults of any age. The greatest risk is among the very old. Nearly one-half of those age 85 and older experience symptoms of Alzheimer's.

Alois Alzheimer, a German physician, first described the disease in 1906. Scientists still have not discovered exactly what causes the changes in brain cells and nerve endings that disrupt normal brain functioning.

AD affects men and women of all ethnic groups and cultures in all walks of life, rich and poor, and people of all educational levels. Approximately 4 million Americans currently have the disease.

Because more people are living longer, that number is expected to increase to 14 million in 50 years unless a cure or way to prevent the disease is found.



## **The Early Signs of Alzheimer's Disease**

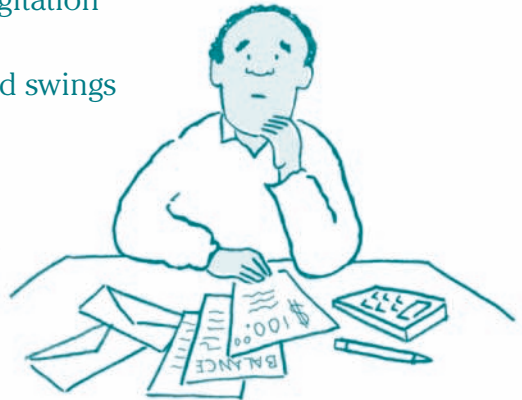
**Don't** think you have AD just because you can't recall names as well as you used to or don't always remember where you put your glasses.

**Do** be concerned when forgetfulness interferes with the ability to function at work and in social situations.

AD may start with:

- Forgetting what happened at yesterday's meeting, the names of grandchildren or home address
- The inability to handle simple finances like making change or buying a newspaper
- Increased anxiety, agitation and anger
- Unpredictable mood swings

***If this sounds like you or someone you know, call the Alzheimer's & Caregiver Resource Center to find the help you need.***



# Diagnosing Alzheimer's Disease Is Important

## Symptoms May Be Caused by a Curable Condition

**Don't** assume it's Alzheimer's. AD is the most frequent cause of dementia, but it's not the only one. Keep in mind, a large percentage of the people who go to the doctor because of suspected dementia have a problem that can be reversed.

**Do** go to a physician whose specialty is geriatrics, neurology or clinical psychiatry for the diagnosis.

Diagnosis requires a thorough medical, neurological and psychiatric evaluation to rule out other illnesses. The work-up includes:

- Complete history and physical examination
- Lab tests, electrocardiogram and chest x-ray
- Neurological tests
- Psychiatric evaluation
- Tests to measure memory, language skills and other cognitive skills



***Seek a diagnosis at the first signs of AD. Early diagnosis can be the key to maintaining independence longer.***

## Alzheimer's Symptoms Can Be Treated

### Medication:

- Your doctor can prescribe cholinesterase inhibitors, which act on the brain. These may slow, but not stop, the progression of the disease.
- Mood stabilizers and anti-depressant drugs are useful and often necessary.
- Be aware that medication can sometimes have negative side effects.

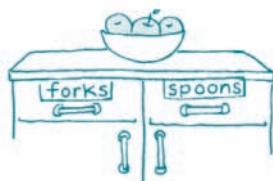
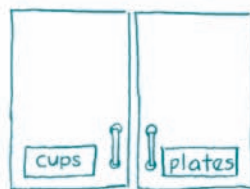
*Be proactive.* Take steps to keep your loved one functioning for as long as possible.

*In the early stages,* keeping socially involved and physically active can maintain the quality of life longer for both patient and family.

*Written reminders* help fill memory gaps:

- A calendar with appointments
- Content labels on drawers and cabinets
- Simple task instructions
- Guides to finding items
- Safety instructions

*A balanced diet* is important to maintain good health and prevent malnutrition.



***The earlier treatment begins, the better.***

## **What to Expect as Alzheimer's Disease Progresses**

Symptoms may change from day-to-day and vary with each person, but usually progress in the following stages:

### **Earlier Stage**

#### **Symptom**

Forgetfulness interferes with normal activities  
at home or at work  
Difficulty handling finances or marketing  
May get lost

#### **Patient's Response**

Anxiety  
Denial  
Emotional withdrawal

#### **Care Options**

Begin AD diagnosis  
Simplify social activities  
Discuss possible retirement  
Avoid stressful situations  
Monitor or take over  
finances  
Increase watchfulness  
Safe Return identification bracelet may be helpful  
Begin estate planning with elder law attorney



***Be aware, this stage may last several years.***

## **Middle Stage**

### **Symptom**

- Loses time and place orientation
- Difficulty choosing appropriate clothing
- Needs reminder to change clothes
- Needs assistance bathing and toileting
- Avoids bathing
- Wandering

### **Patient's Response**

- Anger
- Agitation
- Delusions
- Suspicion
- Unexplained tearfulness



### **Care Options**

- Provide full-time supervision
- Get training to handle behavior
- Prohibit driving
- Obtain part-time help to relieve caregiver stress
- Use adult day services
- Change behavior by refocusing attention to different activity
- Be flexible with bath time
- Safe Return identification bracelet may be helpful

## **Late Stage**

### **Symptom**

Incontinence  
May not recognize family or spouse  
Loses ability to walk or speak  
Difficulty swallowing  
Weight loss  
Can't sit up independently  
Recurrent infections

### **Patient's Response**

Apathy  
Reduced interaction with environment

### **Care Options**

Medication therapy  
Respite for caregiver  
Home health aide and/or nursing assistance  
Move arms and legs for gentle exercise  
Maintain loving communication, touch and attention  
Soft diet and nutritional supplements  
Possible nursing home placement

***Remember: Extreme changes in behavior may occur as AD progresses. The actions of your loved one may disturb or anger you, but should not be taken personally.***

## The Alzheimer's Patient Needs Your Support and Understanding

The family's involvement in the daily care makes a great difference in the patient's well being.

**KEEP** your loved one participating in family life as much as possible.

**Recreational activities** — exercise, hobbies and favorite pastimes:

- Bring enjoyment
- Reduce agitation
- Improve sleep at night
- May alleviate the need for anti-agitation medication



**Simple household tasks** — setting the table, gardening, watering houseplants, sorting and folding laundry:

- Provide sensory stimulation
- Give a sense of usefulness
- Decrease restlessness



**KEEP** communicating even when the ability to speak and understand deteriorates:

- Speak simply and slowly
- Speak in a calm, reassuring voice
- Express affection

**KEEP** home safe and secure:

- Remove or safeguard potentially dangerous objects, including the stove, knives, poisonous cleaning products
- Secure windows and doors so the patient doesn't wander outside
- Prevent falls by clutter-free and well-lit rooms

## ***You Don't Have to Manage Alone***

### **Services for the Alzheimer's Patient and Caregiver**

As a caregiver, you will be faced with multiple responsibilities and complex decisions. Guidance and services are available to help Alzheimer's families care for their loved ones at home or in residential facilities.

#### ***Legal and financial planning***

Begin immediately to make the best arrangements to pay for the care of your loved one and cope with the increased demands upon you, the caregiver.

From the moment dementia is suspected, through each caregiving stage, the Department for the Aging's Alzheimer's & Caregiver Resource Center can:

- Assess your particular need
- Refer you to the appropriate services and professionals
- Advise you of available public entitlements
- Help you plan your next steps

We can help you find out more about care options and assist you in obtaining the services you need:

- Adult day services
- Home care
- Physical, occupational and speech therapy
- Respite care
- Adult care residence
- Assisted living residence
- Nursing home



## **Caring for the Caregiver**

You will be a more effective caregiver if you take care of yourself.

Alzheimer's families experience conflicting feelings of:

- Denial
- Fear
- Embarrassment
- Frustration
- Isolation
- Guilt
- Anger

Caregiving stress may be compounded by tensions in handling a job and caring for children. Unrelieved stress can lead to burnout and even abusive behavior toward the Alzheimer's patient.

Give yourself time off to:

- Socialize with friends
- Take a walk
- Maintain religious or spiritual activities
- Maintain sports and other recreational activities

**Support groups** help Alzheimer's caregivers deal with their emotions and burdens by sharing their concerns, frustrations and ways of coping with everyday problems.

***The Department for the Aging's Alzheimer's & Caregiver Resource Center can connect you with a local support group.***

## **Local and National Resources**

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

### **Local Organizations**

Alzheimer's Association  
New York City Chapter  
360 Lexington Avenue, 4th floor  
New York, NY 10017  
1-212-983-0700  
[www.alzheimernyc.org](http://www.alzheimernyc.org)

Alzheimer's Foundation of Staten Island  
789 Post Avenue  
Staten Island, NY 10310  
1-718-667-7110

Long Island Alzheimer's Foundation  
5 Channel Drive  
Port Washington, NY 11050  
1-516-767-6856  
[www.liaf.org](http://www.liaf.org)

### **National Organizations**

National Alzheimer's Association  
1-800-272-3900  
[www.alz.org](http://www.alz.org)

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

Family Caregiver Alliance  
690 Market Street, Suite 600  
San Francisco, CA 94104  
1-415-434-3388  
[www.caregiver.org](http://www.caregiver.org)

National Alliance for Caregiving  
4720 Montgomery Lane, 5th floor  
Bethesda, MD 20814  
[www.caregiving.org](http://www.caregiving.org)

National Association of Professional  
Geriatric Care Managers  
1-520-881-8008  
[www.caremanager.org](http://www.caremanager.org)

## Publications

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

*Alzheimer's Disease: Where to Go for Help in  
New York City\**

*Caring: A Guide to Caring for Persons with  
Alzheimer's Disease\**

*Preparing for Long Term Care: A Legal & Financial  
Guide for New Yorkers\**

\*Available in Spanish, Chinese, and Russian

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