



# Early Alzheimer's Disease

## Patient and Family Guide

Clinical Practice Guideline, Number 19, Consumer Version

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### Terms You Need to Know

**Dementia** is a medical condition that interferes with the way the brain works. Symptoms include anxiety, paranoia, personality changes, lack of initiative, and difficulty acquiring new skills. Besides Alzheimer's disease, some other types or causes of dementia include: alcoholic dementia, depression, delirium, HIV/AIDS-related dementia, Huntington's disease (a disorder of the nervous system), inflammatory disease (for example, syphilis), vascular dementia (blood vessel disease in the brain), tumors, and Parkinson's disease.

**Alzheimer's disease** is the most common form of dementia. It proceeds in stages over months or years and gradually destroys memory, reason, judgment, language, and eventually the ability to carry out even simple tasks.

**Delirium** is a state of temporary but acute mental confusion that comes on suddenly. Symptoms may include anxiety, disorientation, tremors, hallucinations, delusions, and incoherence. Delirium can occur in older persons who have short-term illnesses, heart or lung disease, long-term infections, poor nutrition, or hormone disorders. Alcohol or drugs (including medications)

also may cause confusion.

*Delirium may be life-threatening and requires immediate medical attention.*

**Depression** can occur in older persons, especially those with physical problems. Symptoms include sadness, inactivity, difficulty thinking and concentrating, and feelings of despair. Depressed persons often have trouble sleeping, changes in appetite, fatigue, and agitation. Depression usually can be treated successfully.

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## Purpose of this Booklet

This booklet is about Alzheimer's disease and other types of dementia. It presents information for patients, family members, and other caregivers. It talks about the effects Alzheimer's disease can have on you, your family members, and your friends.

The booklet describes the early signs and symptoms of Alzheimer's disease. Sources of medical, social, and financial support are listed in the back of the booklet. This booklet is not about treating Alzheimer's disease.

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## What Is Alzheimer's Disease?

In Alzheimer's disease and other dementias, problems with memory, judgment, and thought processes make it hard for a person to work and take part in day-to-day family and social life. Changes in mood and personality also may occur. These changes can result in loss of self-control and other problems.

Some 2 to 4 million persons have dementia associated with aging. Of these individuals, as many as two-thirds have Alzheimer's disease.

Although there is no cure for Alzheimer's disease at this time, it may be possible to relieve some of the symptoms, such as wandering and incontinence.

The earlier the diagnosis, the more likely your symptoms will respond to treatment. Talk to your doctor as soon as possible if you think you or a family member may have signs of Alzheimer's disease.

Research is under way to find better ways to treat Alzheimer's disease. Ask your doctor if there are any new developments that might help you.

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## Who Is Affected?

The chances of getting Alzheimer's disease increase with age. It usually occurs after age 65. Most people are not affected even at advanced ages. There are only two definite factors that increase the risk for Alzheimer's disease: a family history of dementia and Down syndrome.

## Family History of Dementia

Some forms of Alzheimer's disease are inherited. If Alzheimer's disease has occurred in your family members, other members are more likely to develop it. Discuss any family history of dementia with your family doctor.

## Down Syndrome

Persons with Down syndrome have a higher chance of getting Alzheimer's disease. Close relatives of persons with Down syndrome also may be at risk.

## What Are the Signs of Alzheimer's Disease?

The classic sign of early Alzheimer's disease is gradual loss of short-term memory. Other signs include:

- Problems finding or speaking the right word.
- Inability to recognize objects.
- Forgetting how to use simple, ordinary things, such as a pencil.
- Forgetting to turn off the stove, close windows, or lock doors.

Mood and personality changes also may occur. Agitation, problems with memory, and poor judgment may cause unusual behavior. These symptoms vary from one person to the next.

Symptoms appear gradually in persons with Alzheimer's disease but may progress more slowly in some persons than in others. In other forms of dementia, symptoms may appear suddenly or may come and go.

If you have some of these signs, this does not mean you have Alzheimer's disease. Anyone can have a lapse of memory or show poor judgment now and then. When such lapses become frequent or dangerous, however, you should tell your doctor about them immediately.

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## Possible Signs of Alzheimer's Disease

**Do you have problems with any of these activities:**

- Learning and remembering new information. Do you repeat things that you say or do? Forget conversations or appointments? Forget where you put things?
- Handling complex tasks. Do you have trouble performing tasks that require many steps such as balancing a checkbook or cooking a meal?
- Reasoning ability. Do you have trouble solving everyday problems at work or home,

- such as knowing what to do if the bathroom is flooded?
- Spatial ability and orientation. Do you have trouble driving or finding your way around familiar places?
  - Language. Do you have trouble finding the words to express what you want to say?
  - Behavior. Do you have trouble paying attention? Are you more irritable or less trusting than usual?

***Remember, everyone has occasional memory lapses. Just because you can't recall where you put the car keys doesn't mean you have Alzheimer's disease.***

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## Consulting the Doctor

Identifying mild cases of Alzheimer's disease can be very difficult. Your doctor will review your health and mental status, both past and present. Changes from your previous, usual mental and physical functioning are especially important.

Persons with Alzheimer's disease may not realize the severity of their condition. Your doctor will probably want to talk with family members or a close friend about their impressions of your condition.

The doctor's first assessment for Alzheimer's disease should include a focused history, a physical examination, a functional status assessment, and a mental status assessment.

### Medical and Family History

Questions the doctor may ask in taking your history include: How and when did problems begin? Have the symptoms progressed in steps or worsened steadily? Do they vary from day to day? How long have they lasted?

Your doctor will ask about past and current medical problems and whether other family members have had Alzheimer's disease or another form of dementia.

Education and other cultural factors can make a difference in how you will do on mental ability tests. Language problems (for example, difficulty speaking English) can cause misunderstanding. Be sure to tell the doctor about any language problems that could affect your test results.

It is important to tell the doctor about all the drugs you take and how long you have been taking them. Drug reactions can cause dementia. Bring all medication bottles and pills to the appointment with your doctor.

***Do you take any medications? Even over-the-counter drugs, eye drops, and alcohol can cause a decline in mental ability. Tell your doctor about all the drugs you take. Ask if the drugs are safe when taken together.***

### Physical Examination

A physical examination can determine whether medical problems may be causing symptoms of dementia. This is important because prompt treatment may relieve some symptoms.

## Functional Status Assessment

The doctor may ask you questions about your ability to live alone. Sometimes, a family member or close friend may be asked how well you can do activities like these:

- Write checks, pay bills, or balance a checkbook.
- Shop alone for clothing, food, and household needs.
- Play a game of skill or work on a hobby.
- Heat water, make coffee, and turn off stove.
- Pay attention to, understand, and discuss a TV show, book, or magazine.
- Remember appointments, family occasions, holidays, and medications.
- Travel out of the neighborhood, drive, or use public transportation.

Sometimes a family member or friend is not available to answer such questions. Then, the doctor may ask you to perform a series of tasks ("performance testing").

## Mental Status Assessment

Several other tests may be used to assess your mental status. These tests usually have only a few simple questions. They test mental functioning, including orientation, attention, memory, and language skills. Age, educational level, and cultural influences may affect how you perform on mental status tests. Your doctor will consider these factors in interpreting test results.

### **Alzheimer's disease affects two major types of abilities:**

1. The ability to carry out everyday activities such as bathing, dressing, using the toilet, eating, and walking.
2. The ability to perform more complex tasks such as using the telephone, managing finances, driving a car, planning meals, and working in a job.

When a person has Alzheimer's disease, problems with complex tasks appear first and over time progress to more simple activities.

## Treatable Causes of Dementia

Sometimes the physical examination reveals a condition that can be treated. Symptoms may respond to early treatment when they are caused by:

- Medication (including over-the-counter drugs).
- Alcohol.
- Delirium.
- Depression.
- Tumors.

- Problems with the heart, lungs, or blood vessels.
- Metabolic disorders (such as thyroid problems).
- Head injury.
- Infection.
- Vision or hearing problems.

**Drug reactions** are the most common cause of treatable symptoms. Older persons may have reactions when they take certain medications. Some medications should not be taken together. Sometimes, adjusting the dose can improve symptoms.

**Delirium and depression** may be mistaken for or occur with Alzheimer's disease. These conditions require prompt treatment. See the inside front cover of this booklet for more information on delirium and depression.

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## Special Tests

Gathering as much information as possible will help your doctor diagnose early Alzheimer's disease while the condition is mild. You may be referred to other specialists for further testing. Some special tests can show a person's mental strengths and weaknesses and detect differences between mild, moderate, and severe impairment. Tests also can tell the difference between changes due to normal aging and those caused by Alzheimer's disease.

If you go to a special doctor for these tests, he or she should return all test results to your regular family doctor. The results will help your doctor track the progress of your condition, prescribe treatment, and monitor treatment effects.

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## Getting the Right Care

When the diagnosis is Alzheimer's disease, you and your family members have serious issues to consider. Talk with your doctor about what to expect in the near future and later on, as your condition progresses. Getting help early will help ensure that you get the care that is best for you.

When tests do not indicate Alzheimer's disease, but your symptoms continue or worsen, check back with your doctor. More tests may be needed. If you still have concerns, even though your doctor says you do not have Alzheimer's disease, you may want to get a second opinion.

***Whatever the diagnosis, followup is important.***

Report any changes in your symptoms. Ask the doctor what followup is right for you. Your doctor should keep the results of the first round of tests for later use. After treatment of other health problems, new tests may show a change in your condition.

Recognizing Alzheimer's disease in its early stages, when treatment may relieve mild

symptoms, gives you time to adjust. During this time, you and your family can make financial, legal, and medical plans for the future.

## Coordinating Care

Your health care team may include your family doctor and medical specialists such as psychiatrists or neurologists, psychologists, therapists, nurses, social workers, and counselors. They can work together to help you understand your condition, suggest memory aids, and tell you and your family about ways you can stay independent as long as possible.

Talk with your doctors about activities that could be dangerous for you or others, such as driving or cooking. Explore different ways to do things.

## Telling Family and Friends

Ask your doctor for help in telling people who need to know that you have Alzheimer's disease members of your family, friends, and coworkers, for example.

***Alzheimer's disease is stressful for you and your family. You and your caregiver will need support from others. Working together eases the stress on everyone.***

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## Where To Get Help?

Learning that you have Alzheimer's disease can be very hard to deal with. It is important to share your feelings with family and friends.

Many kinds of help are available for persons with Alzheimer's disease, their families, and caregivers. Turn to the back of this booklet for a list of resources for patients and families. These resources include:

- **Support groups.** Sometimes it helps to talk things over with other people and families who are coping with Alzheimer's disease. Families and friends of people with Alzheimer's disease have formed support groups. The Alzheimer's Association has active groups across the country. Many hospitals also sponsor education programs and support groups to help patients and families.
- **Financial and medical planning.** Time to plan can be a major benefit of identifying Alzheimer's disease early. You and your family will need to decide where you will live and who will provide help and care when you need them.
- **Legal matters.** It is also important to think about certain legal matters. An attorney can give you legal advice and help you and your family make plans for the future. A special document called an advance directive lets others know what you would like them to do if you become unable to think clearly or speak for yourself.

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## Other Booklets Are Available

The information in this booklet is based on *Recognition and Initial Assessment of Alzheimer's Disease and Related Dementias: Clinical Practice Guideline No. 19*. The *Clinical Practice Guideline* is scheduled to be released later this year (Winter 1996). A multidisciplinary panel of physicians, psychiatrists, psychologists, neurologists, nurses, a geriatrician, a social worker, and two consumer representatives developed the guideline. The Agency for Health Care Policy and Research (AHCPR), an agency of the U.S. Department of Health and Human Services, supported its development. Other AHCPR guidelines may be helpful to families affected by Alzheimer's disease. They include:

- *Depression Is a Treatable Illness: Patient Guide* discusses major depressive disorder, which usually can be treated successfully with the help of a health professional. (AHCPR Publication No. 93-0053)
- *Recovering After a Stroke: Patient and Family Guide* tells how to help a person who has had a stroke achieve the best possible recovery. (AHCPR Publication No. 95-0664)
- *Understanding Urinary Incontinence in Adults: Patient Guide* describes why people lose urine when they don't want to and what can be done about it. (AHCPR Publication No. 96-0684)
- *Preventing Pressure Ulcers: Patient Guide* discusses symptoms and causes of bed sores and ways to prevent them. (AHCPR Publication No. 92-0048)
- *Treating Pressure Sores: Consumer Guide* describes basic steps of care for bed sores. (AHCPR Publication No. 95-0654)

For more information on these or other guidelines, or to receive printed copies of this booklet, call toll-free: 800-358-9295.

Or write to:

Agency for Health Care Policy and Research  
Publications Clearinghouse  
P.O. Box 8547  
Silver Spring, MD 20907

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## Resources for Patients and Families

Many kinds of help are available for patients with Alzheimer's disease, their families and caregivers. The list below gives information for contacting national organizations. They can refer you to local chapters and other resources where you live.

### **Alzheimer's Association**

Chicago, IL  
(312)335-8700  
800-272-3900

### **Alzheimer's Disease Education and Referral (ADEAR) Center**

Silver Spring, MD  
800-438-4380

**Administration on Aging**

Washington, DC  
(202)619-1006

**Eldercare Locator**

Washington, DC  
800-677-1116

**American Association of Retired Persons (AARP)**

Washington, DC  
(202)434-2277  
800-424-3410

**Children of Aging Parents**

Levittown, PA  
(215)945-6900

**Help for Incontinent People**

Spartanburg, SC  
(803)579-7900  
800-BLADDER

**Insurance Consumer Helpline**

Washington, DC  
800-942-4242

**Medicare Hotline**

Baltimore, MD  
800-638-6833

**National Hospice Organization**

Arlington, VA  
(703)243-5900  
800-658-8898

**Social Security Information**

800-772-1213  
(open 7 am-7 pm in all time zones)

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