

# PARTNERING WITH YOUR DOCTOR:

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*A Guide for Persons  
with Memory Problems  
and Their Care Partners*



**Alzheimer's  
Association**



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# When is Memory Loss a Problem?

**Many people** worry about becoming more forgetful as they get older. Some assume that memory loss is a normal part of aging and do nothing about it. Others are afraid that memory problems are the first sign of Alzheimer's disease or a related illness.

It is true that most people experience some problems remembering things as they get older. However, experts now know that serious memory loss and confusion are not a part of the normal aging process.

There are many conditions that can cause memory loss. Often, memory improves when the condition causing the problem is treated. Even if the diagnosis is Alzheimer's disease or a related illness, much can be done to treat the patient and help the family.

**If you or someone you care for is having memory problems, you should see the doctor right away.**

## *Possible Causes of Memory Problems*

- Medication overuse/underuse
- Serious depression
- Alcohol abuse
- Poor nutrition
- Thyroid problems
- Head injury
- Tumors
- Stroke
- Heart or lung disease
- Infection
- Delirium
- High fever
- Severe dehydration
- Dementia

**In addition** to Alzheimer's disease, there are other types of dementia. Some of these include vascular dementia (stroke), dementia with Lewy bodies, Pick's disease, and more. Different types of dementia need different treatment.

## Finding Out What's Wrong

The first step is to make an appointment with your doctor. Explain the reason for your visit.



## What is Dementia?

Some people think the word dementia means “crazy”, but dementia is really a word used to describe a group of symptoms, such as memory loss and behavior changes, that are caused by serious problems with the way the brain works. The most common type is *Alzheimer's disease*.



# What is Alzheimer's Disease?

**Alzheimer's** disease is a disease that attacks the brain and causes problems with memory, thinking, and behavior. It gets worse over time.

About 4 million Americans have Alzheimer's disease. In a national survey, 19 million Americans said they had a family member with Alzheimer's disease, and 37 million said they knew someone with the disease.



## Symptoms

- Gradual memory loss that affects daily living
- Difficulty learning new things
- Difficulty performing familiar tasks, such as cooking
- Problems naming common objects
- Getting lost easily, even in familiar places
- Poor or decreased judgment
- Changes in mood, behavior and personality
- Loss of interest in hobbies

## Medical Evaluation

A complete medical evaluation for memory loss should include:

- A medical and psychiatric history
- A physical and neurological exam, which may include brain imaging techniques, such as CT or MRI scans
- Lab tests (blood and urine)
- An evaluation of the patient's ability to perform common daily activities, such as balancing a checkbook or taking medications
- A 'mental status exam' to measure the patient's thinking and memory
- A family or caregiver interview

### Get Prepared

Doctors only have a limited amount of time to spend with each patient. You can help by being prepared.

- Take all medications, both over-the-counter (vitamins, aspirin) and prescription, to the visit.
- Take a list of past and current medical problems. Have other family members had illnesses that caused memory problems?
- Answer the doctor's questions honestly and to the best of your ability.
- Write a list of symptoms, when they began, and how frequently they occur.
- Be specific. For example, "Last Tuesday, I (my husband) got lost on the way home from the store. It was scary."
- Ask the doctor to explain any tests and how long it will take to get a diagnosis.



# How is a Diagnosis Made?

**There is** no single test that can tell if a person has a serious memory problem. A diagnosis is made through a complete assessment that considers all possible causes.

If the evaluation does not indicate Alzheimer's disease or a related illness, but the symptoms continue to get worse over time, your doctor may need to order more tests. If you are still not satisfied, you may want to get a second opinion from a specialist (e.g. neurologist).

A diagnosis of 'probable Alzheimer's disease' is accurate 80% – 90% of the time.



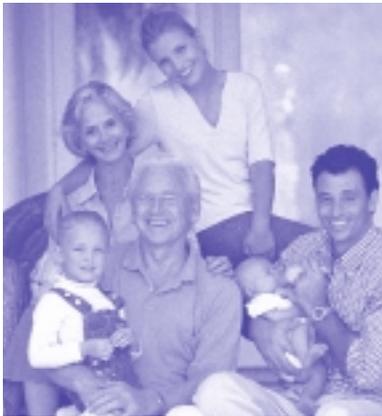
## Your Doctor Should:

**Explain** the diagnosis, let you know what to expect in the future, and tell you where to get more information and help.

**Tell** you about the possible treatments. Together, you can select what's best for the patient.

**Schedule** your next visit and let you know how often he/she would like to see you before you leave.

**A diagnosis** of Alzheimer's disease or a related illness is the first step in mapping out the treatment and care for the patient. For some, having an explanation of the symptoms brings a sense of sadness, but relief. A proper diagnosis offers a chance to get help and plan for the future. Forming a partnership with your doctor can help, and you can start by understanding the disease and its treatment.



# When the Diagnosis is Alzheimer's Disease or a Related Illness

## Questions to ask your doctor

### Diagnosis

- What does the diagnosis mean?
- Can you explain it in a way that I will understand?
- What can we expect in the near future and over time?
- Do you have any written material on this disease? If not, who does?
- Are there any organizations or community services that can help?

### Treatment

- Are there any treatments that don't involve medications?
- Is there anything that we can change at home to make things easier or safer?
- What medications are available for memory loss?  
For behavior changes? What are the risks and benefits?  
What are the side effects? How long will the patient take this medicine? Is there anything else we should know?
- Should we consider participating in a drug trial?  
What are the risks and benefits?

**Don't worry** if you get home and realize you have forgotten to ask some of your questions. Write them down and call the doctor, or bring them to the next visit.

### Other Concerns

- Will the patient continue to be able to work? To drive?
- What will our regular appointment schedule be?
- Under what circumstances should we contact your office?
- Can we schedule our next appointment?



# Working with Your Doctor to Get the Best Care

**Good communication** with your doctor is very important and often takes time and effort.

Together with the family, the doctor should develop a reasonable plan for meeting the needs of the patient. Over time, these needs will change. Regular doctor visits (about every six months or right away if a sudden change occurs) will help you and your family get the best care.



**Remember, care provided by everyone working together will always be better than care given by the doctor, patient or loved one alone.**

**Medications**, such as *cholinesterase inhibitors*, may temporarily improve memory or slow down memory loss. Vitamin E may slow the progression of the disease, and other drugs are available to help with mood and behavior changes. Talk to your doctor about what treatment is best for you or your loved one. Medications are being developed and you can contact the Alzheimer's Association for the most recent information on available treatments.

## Tips for Follow-Up Visits

### ☑ Be Prepared

Make a list of the types of issues you want to discuss with your doctor.

- Changes in symptoms
- General health
- Caregiver health
- Help needed
- Questions to ask

### ☑ Ask Questions

If you don't understand something, ask questions until you do. Don't be afraid to speak up and to share your point of view.

### ☑ Gather Information

Take notes during the visit, make time to write notes afterward, or even bring a tape recorder.



# Guide for Follow-up Doctor Visits

## Assessment

At each visit, your doctor will evaluate or assess the patient's progress. You can help by keeping track of changes in the patient's condition and reporting them to the doctor. Whether you are the patient or the caregiver, keeping a list of questions, concerns, changes in routine, etc. may be helpful. Review the following questions before your next visit and write down the answers.

- Have you noticed changes in the patient's health, memory or mood?
- When did you first notice the change?
- How often does it happen? When does it happen?

## Examples

Changes in Symptoms	Description (Be specific. When did it start?)
Health (e.g., pain, illness)	"Bob complains of pain in his lower back almost every day. This started about three weeks ago and has slowly gotten worse."
Memory	"Bob seems really confused a lot lately. He forgot how to get home from the store yesterday."
Mood (e.g., restlessness, hearing things that aren't there, hitting, screaming, sadness, crying, strange ideas, etc.)	"Bob isn't sleeping at night. He cries often and is obviously upset about something. This started about a month ago and keeps getting worse."

**Check** with your primary doctor before taking a new medication from another doctor or a new over-the-counter drug.

## Treatment

Your doctor may prescribe medication or other treatments for the patient. It's your job to keep track of how things are working (or not working).

- Are the prescribed treatments working?  
What has improved? What has gotten worse?
- Have you noticed any side effects of the medications? Are they causing problems?
- Have you noticed any new problems that may need treatment?

## See the doctor right away if the patient:

- Becomes suddenly more confused
- Has a major change in memory or mood
- Has a black-out, faints or falls
- Is suddenly unable to speak or move any part of the body
- Has a fever or is suddenly incontinent (having 'accidents' or wetting the bed)



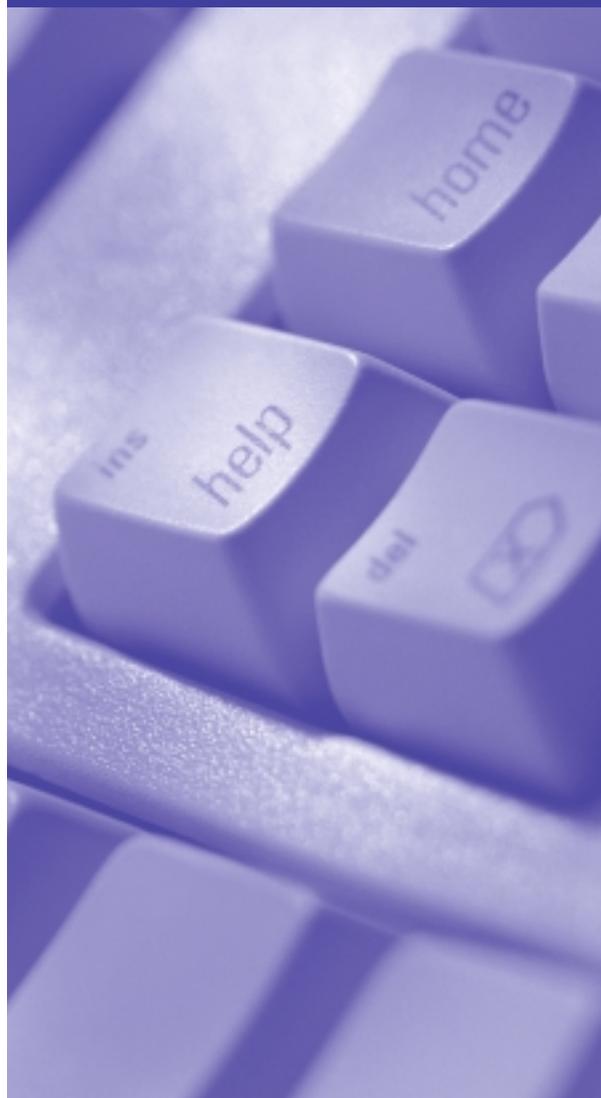


## An advance directive

allows you to say what kind of medical care you want in the future or to say who you would like to manage your money if you were too sick to do it yourself.

- ❑ **Make** a list of any health problems the caregiver is having and share them with the doctor. You can schedule a few minutes alone with the doctor before the visit or even make two appointments, one for you and one for your loved one.
- ❑ **Help** the patient make sure that his or her wishes will be followed in the future. Ask the doctor or talk to a lawyer about *advance directives*.
- ❑ **Be aware** that the patient may be at higher risk for being taken advantage of or may suffer *abuse* by others.
- ❑ **Get informed** about resources and services that can help you and your family.
- ❑ **Enroll** in the *Safe Return identification program*. Contact the Alzheimer's Association for more information.

**Abuse may be physical, emotional or financial. It is the caregiver's responsibility to protect the patient. It is the doctor's responsibility to report any signs of neglect or abuse.**



# Doctor Visit Worksheet

**Remember,** your time in the doctor’s office may be short. Get to the point quickly. Make a list of your top three concerns for the next visit.

Concerns	
1	Example
2	
3	

Notes

There will be many challenges as you deal with this disease. Working together with your doctor can help you get the best care possible. Start building a partnership with your doctor today.

**Alzheimer's Association**  
**1-800-272-3900**

**[www.alz.org](http://www.alz.org)**

## Places To Call For Help

- **Alzheimer's Association:**

For care consultation, Safe Return identification program, support groups, local resources and more.

**1-800-272-3900**

or

**[www.alz.org](http://www.alz.org)**

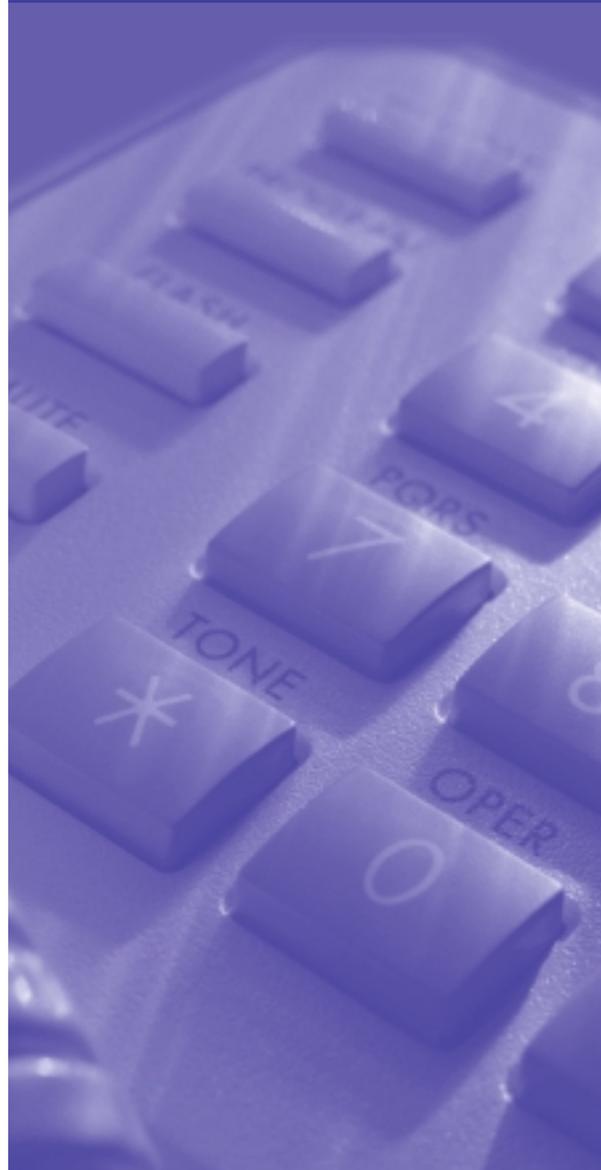
- **Eldercare Locator:**

For information and referral to local senior services.

**1-800-677-1116**

or

**[www.eldercare.gov](http://www.eldercare.gov)**



# *Alzheimer's Association*

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This booklet is based in part on the California *Guidelines for Alzheimer's Disease Management*, which were developed by the California Workgroup to help doctors give the best quality care to their patients with Alzheimer's disease and related illnesses.

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