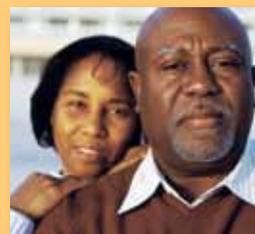




Caring for a Person with Alzheimer's Disease

Your Easy-to-Use Guide
from the National Institute on Aging



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National Institute on Aging
National Institutes of Health

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About this Guide

This guide is for people who care for family members or others with Alzheimer's disease (AD) at home. AD is an illness that changes the brain. It causes people to lose the ability to remember, think, and use good judgment and to have trouble taking care of themselves. Over time, as the disease gets worse, they will need more help.

Sometimes, taking care of the person with AD makes you feel good because you are providing love and comfort. Other times, it can be overwhelming. Also, each day brings new challenges. You may not even realize how much you have taken on because the changes can happen slowly over a long period of time.

We've written this guide to help you learn about and cope with these changes and challenges. Starting on page 94, you will find suggestions for taking care of yourself, which help you to be a good caregiver.

The information in this guide comes from other caregivers and from medical research, such as that funded by the National Institute on Aging (NIA). NIA is part of the National Institutes of Health, the nation's medical research agency. NIA leads the federal effort to find the cause of and treatment for Alzheimer's disease.



The guide tells you how to:

- Understand how AD changes a person
- Learn how to cope with these changes
- Help family and friends understand AD
- Plan for the future
- Make your home safe for the person with AD
- Manage everyday activities like eating, bathing, dressing, and grooming
- Take care of yourself
- Get help with caregiving
- Find out about helpful resources, such as websites, support groups, government agencies, and adult day care programs
- Choose a full-time care facility for the person with AD if needed
- Learn about common behavior and medical problems of people with AD and some medicines that may help
- Cope with late-stage AD

This guide contains a lot of information. Please don't feel that you have to read it all at one time. You can use the tools listed below to find what you need quickly.

Table of Contents:

Use the Table of Contents to help find the topics that interest you. See page 1.

Words to Know:

Check this section for definitions of medical words and how to say them. See pages 101–103.



Understanding AD

Sometimes, you may feel that you don't know how to care for the person with AD. You're not alone. Each day may bring different challenges. Learning about AD can help you understand and cope with these challenges. Below, we discuss the stages of AD and tell you how to learn more about the illness.

Stages of AD and What They Mean

Alzheimer's disease consists of three main stages: mild (sometimes called early-stage), moderate, and severe (sometimes called late-stage). Understanding these stages can help you plan ahead. You will find information about coping with behavior problems often seen in each stage of AD starting on page 12.

Mild Alzheimer's disease. In mild AD, the first stage, people often have some memory loss and small changes in their personality. They may forget recent events or the names of familiar people or things. They may no longer be able to solve simple math problems. People with mild AD also slowly lose the ability to plan and organize. For example, they may have trouble making a grocery list and finding items in the store.





Moderate Alzheimer's disease. This is the middle stage of AD. Memory loss and confusion become more obvious. People have more trouble organizing, planning, and following instructions. They may need help getting dressed and may start having problems with incontinence. This means they can't control their bladder and/or bowels. People with moderate-stage AD may have trouble recognizing family members and friends. They may not know where they are or what day or year it is. They also may lack judgment and begin to wander, so people with moderate AD should not be left alone. They may become restless and begin repeating movements late in the day. Also, they may have trouble sleeping. Personality changes can become more serious. People with moderate AD may make threats, accuse others of stealing, curse, kick, hit, bite, scream, or grab things.

Severe Alzheimer's disease. This is the last stage of Alzheimer's and ends in the death of the person. Severe AD is sometimes called late-stage AD. In this stage, people often need help with all their daily needs. They may not be able to walk or sit up without help. They may not be able to talk and often cannot recognize family members. They may have trouble swallowing and refuse to eat.

How to Learn More About AD

Here are some ways to help you learn more about AD:

- Talk with a doctor or other health care provider about AD. Ask your doctor to refer you to someone who specializes in AD.
- Ask your doctor or AD specialist about good sources of information.
- Check out books, CDs, DVDs, or videos on AD from the library.
- Go to educational programs and workshops on AD.
- Visit websites on AD such as www.alzheimers.gov, www.nia.nih.gov/alzheimers, or www.alz.org. Use search engines to find more information.
- Talk about AD with friends and family to get advice and support.
- Try to find a support group for caregivers. You want a group in which the caregivers are taking care of someone who is in the same stage of AD as the person you are caring for. Also, you may be able to find an Internet-based support group. This is helpful for some caregivers, because it means they don't have to leave home to be a part of the group. The Alzheimer's Association (www.alz.org) is a good resource to help find support groups.

For copies of this book or other information on AD, contact the Alzheimer's Disease Education and Referral (ADEAR) Center. Phone: 1-800-438-4380 www.nia.nih.gov/alzheimers

The ADEAR Center is a service of the National Institute on Aging.



Caring for a Person with AD

Understanding How AD Changes People—Challenges and Coping Strategies

Alzheimer's disease is an illness of the brain. It causes large numbers of nerve cells in the brain to die. This affects a person's ability to remember things and think clearly. People with AD become forgetful and easily confused. They may have a hard time concentrating and behave in odd ways. These problems get worse as the illness gets worse, making your job as caregiver harder.

It's important to remember that the disease, not the person with AD, causes these changes. Also, each person with AD may not have all the problems we talk about in this book.

The following sections describe the three main challenges that you may face as you care for someone with AD:

1. changes in communication skills
2. changes in personality and behavior
3. changes in intimacy and sexuality

Each section includes information on how to cope with these challenges.



1. Challenge: changes in communication skills

Communication is hard for people with AD because they have trouble remembering things. They may struggle to find words or forget what they want to say. You may feel impatient and wish they could just say what they want, but they can't. It may help you to know more about common communication problems caused by AD. Once you know more, you'll have a better sense of how to cope.

Here are some communication problems caused by AD:

- Trouble finding the right word when speaking
- Problems understanding what words mean
- Problems paying attention during long conversations
- Loss of train-of-thought when talking
- Trouble remembering the steps in common activities, such as cooking a meal, paying bills, getting dressed, or doing laundry
- Problems blocking out background noises from the radio, TV, telephone calls, or conversations in the room
- Frustration if communication isn't working
- Being very sensitive to touch and to the tone and loudness of voices

Also, AD causes some people to get confused about language. For example, the person might forget or no longer understand English if it was learned as a second language. Instead, he or she might understand and use only the first language learned, such as Spanish.



“Talking with Dad is hard. Often, I don't understand what he is trying to say or what he wants. We both get pretty frustrated sometimes.”

How to cope with changes in communication skills

The first step is to understand that the disease causes changes in these skills. The second step is to try some tips that may make communication easier. For example, keep the following suggestions in mind as you go about day-to-day care.

To connect with a person who has AD:

- Make eye contact to get his or her attention, and call the person by name.
- Be aware of your tone and how loud your voice is, how you look at the person, and your “body language.” Body language is the message you send just by the way you hold your body. For example, if you stand with your arms folded very tightly, you may send a message that you are tense or angry.
- Encourage a two-way conversation for as long as possible. This helps the person with AD feel better about himself or herself.
- Use other methods besides speaking to help the person, such as gentle touching to guide him or her.
- Try distracting someone with AD if communication creates problems. For example, offer a fun activity such as a snack or a walk around the neighborhood.

To encourage the person with AD to communicate with you:

- Show a warm, loving, matter-of-fact manner.
- Hold the person’s hand while you talk.
- Be open to the person’s concerns, even if he or she is hard to understand.
- Let him or her make some decisions and stay involved.
- Be patient with angry outbursts. Remember, it’s the illness “talking.”
- If you become frustrated, take a “timeout” for yourself.

To speak effectively with a person who has AD:

- Offer simple, step-by-step instructions.
- Repeat instructions and allow more time for a response. Try not to interrupt.
- Don't talk about the person as if he or she isn't there.
- Don't talk to the person using "baby talk" or a "baby voice."

Here are some examples of what you can say:

- "Let's try this way," instead of pointing out mistakes
- "Please do this," instead of "Don't do this"
- "Thanks for helping," even if the results aren't perfect

You also can:

- Ask questions that require a yes or no answer. For example, you could say, "Are you tired?" instead of "How do you feel?"
- Limit the number of choices. For example, you could say, "Would you like a hamburger or chicken for dinner?" instead of "What would you like for dinner?"
- Use different words if he or she doesn't understand what you say the first time. For example, if you ask the person whether he or she is hungry and you don't get a response, you could say, "Dinner is ready now. Let's eat."
- Try not to say, "Don't you remember?" or "I told you."



Helping a Person Who Is Aware of Memory Loss

AD is being diagnosed at earlier stages. This means that many people are aware of how the disease is affecting their memory. Here are tips on how to help someone who knows that he or she has memory problems:

- Take time to listen. The person may want to talk about the changes he or she is noticing.
- Be as sensitive as you can. Don't just correct the person every time he or she forgets something or says something odd. Try to understand that it's a struggle for the person to communicate.
- Be patient when someone with AD has trouble finding the right words or putting feelings into words.
- Help the person find words to express thoughts and feelings.

For example, Mrs. D cried after forgetting her garden club meeting. She finally said, "I wish they stopped." Her daughter said, "You wish your friends had stopped by for you." Mrs. D nodded and repeated some of the words. Then Mrs. D said, "I want to go." Her daughter said, "You want to go to the garden club meeting." Again, Mrs. D nodded and repeated the words.

- Be careful not to put words in the person's mouth or "fill in the blanks" too quickly.
- As people lose the ability to talk clearly, they may rely on other ways to communicate their thoughts and feelings.

For example, their facial expressions may show sadness, anger, or frustration. Grasping at their undergarments may tell you they need to use the bathroom.

Caring for a Person with AD

"Every few months I sense that another piece of me is missing. My life... my self... are falling apart. I can only think half-thoughts now. Someday I may wake up and not think at all."

— From "The Loss of Self"

2. Challenge: changes in personality and behavior

Because AD causes brain cells to die, the brain works less well over time. This changes how a person acts. You will notice that he or she will have good days and bad days.

Here are some common personality changes you may see:

- Getting upset, worried, and angry more easily
- Acting depressed or not interested in things
- Hiding things or believing other people are hiding things
- Imagining things that aren't there
- Wandering away from home
- Pacing a lot of the time
- Showing unusual sexual behavior
- Hitting you or other people
- Misunderstanding what he or she sees or hears

Also, you may notice that the person stops caring about how he or she looks, stops bathing, and wants to wear the same clothes every day.



Other factors that may affect how people with AD behave

In addition to changes in the brain, the following things may affect how people with AD behave.

How they feel:

- Sadness, fear, or a feeling of being overwhelmed
- Stress caused by something or someone
- Confusion after a change in routine, including travel
- Anxiety about going to a certain place

Health-related problems:

- Illness or pain
- New medications
- Lack of sleep
- Infections, constipation, hunger, or thirst
- Poor eyesight or hearing
- Alcohol abuse
- Too much caffeine

Problems in their surroundings:

- Being in a place he or she doesn't know well.
- Too much noise, such as TV, radio, or many people talking at once. Noise can cause confusion or frustration.
- Stepping from one type of flooring to another. The change in texture or the way the floor looks may make the person think he or she needs to take a step down.
- Misunderstanding signs. Some signs may cause confusion. For example, one person with AD thought a sign reading "Wet Floor" meant he should urinate on the floor.
- Mirrors. Someone with AD may think that a mirror image is another person in the room.

Caring for a Person with AD

Changes in Behavior

You may see changes in behavior that the disease didn't cause. For example, certain medicines, severe pain, poor eyesight or hearing, and fatigue can cause behavior changes. If you don't know what is causing the problem, call the doctor.

How to cope with personality and behavior changes

Here are some ways to cope with changes in personality and behavior:

- Keep things simple. Ask or say one thing at a time.
- Have a daily routine, so the person knows when certain things will happen.
- Reassure the person that he or she is safe and you are there to help.
- Focus on his or her feelings rather than words. For example, say, “You seem worried.”
- Don’t argue or try to reason with the person.
- Try not to show your anger or frustration. Step back. Take deep breaths, and count to 10. If safe, leave the room for a few minutes.
- Use humor when you can.
- Give people who pace a lot a safe place to walk. Provide comfortable, sturdy shoes. Give them light snacks to eat as they walk, so they don’t lose too much weight, and make sure they have enough to drink.

“I finally figured out that it’s me who has to change. I can’t expect my husband to change because of the disease.”



Use distractions:

- Try using music, singing, or dancing to distract the person. One caregiver found that giving her husband chewing gum stopped his cursing.
- Ask for help. For instance, say, “Let’s set the table” or “I really need help folding the clothes.”

Other ideas:

- Enroll the person in the MedicAlert®+Alzheimer’s Association Safe Return® Program. If people with AD wander away from home, this program can help get them home safely (www.alz.org).
- Talk to the doctor about any serious behavior or emotional problems, such as hitting, biting, depression, or hallucinations.

See page 75 for more information about behavior problems and some medicines that may help.

How to cope with sleep problems

Evenings are hard for many people with AD. Some may become restless or irritable around dinnertime. This restlessness is called “sundowning.” It may even be hard to get the person to go to bed and stay there.

Here are some tips that may help:

- Help the person get exercise each day, limit naps, and make sure the person gets enough rest at night. Being overly tired can increase late-afternoon and nighttime restlessness.
- Plan activities that use more energy early in the day. For example, try bathing in the morning or having the largest family meal in the middle of the day.
- Set a quiet, peaceful mood in the evening to help the person relax. Keep the lights low, try to reduce the noise levels, and play soothing music if he or she enjoys it.
- Try to have the person go to bed at the same time each night. A bedtime routine, such as reading out loud, also may help.
- Limit caffeine.
- Use nightlights in the bedroom, hall, and bathroom.



Caring for a Person with AD

“I’m exhausted. I can’t sleep because I have to watch out for my wife. She wanders around the house, takes out all kinds of stuff from the kitchen. I don’t know what she’s going to do.”

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