

# The Medical Side of AD

## Medicines to Treat AD Symptoms and Behaviors

This chapter contains medical terms and drug names.

### **People with AD may take medications to treat:**

- The disease itself
- Mood or other behavior changes
- Other medical conditions they may have

Caregivers need to know about each medicine that a person with AD takes.

### **Ask the doctor or pharmacist the questions below and write down the answers:**

- Why is this medicine being used?
- What positive effects should I look for, and when?
- How long will the person need to take it?
- How much should he or she take each day?
- When does the person need to take the medicine?

- What are the side effects?
- What can I do about these side effects?
- Can the medicine be crushed and mixed into foods such as applesauce?
- Can I get the medicine in a liquid form?
- Can this medicine cause problems if taken with other medicines?
- Is this medicine available as a generic?

## **Reminders to take medicine**

People with AD often need help taking their medicine. If the person still lives alone, you may need to call and remind him or her. It's also helpful to buy a pillbox and put pills for each day in the box. That way all the pills for the day are in one place. You can get pillboxes at a drugstore. **As the disease gets worse, you will need to keep track of the person's medicines. You also will need to make sure they take the medicine or you will need to give them the medicine.** Ask the doctor or pharmacist about when to give the medications.

## **Medicines to treat AD**

Both caregivers and doctors need to remember that no two people with AD are alike. This means that medications may work differently in different people.

### **Many factors may play a role in the disease, such as:**

- Genes
- Lifestyle
- Earlier treatments
- Other illnesses or problems
- The person's surroundings
- Stage of AD

Work closely with the doctor to learn which medicines to use for AD, how much to use, and when to use them. Check with the doctor to see if Medicare or private insurance will cover the cost of the medicines. Also, find out if you can buy the non-brand, also called generic, type of medicines. They often cost less than brand-name medicines.

There are five medicines available to treat AD. Other promising new medicines are being tested.

**It's important to understand that none of these medicines can cure or stop the disease.** What they can do, for some people, is help slow down certain problems, such as memory loss. Slowing down memory loss can allow many people with AD to be more comfortable and independent for a longer time.

## **Medicines for mild to moderate AD**

Medicines to treat mild to moderate AD all work in a similar way and may help reduce some symptoms.

### **The names of these medicines are:**

- Aricept<sup>®</sup> (AIR-uh-sept), brand name;  
donepezil (doe-NEP-uh-zil), generic name
- Exelon<sup>®</sup> (EKS-uh-lawn), brand name;  
rivastigmine (riv-uh-STIG-meen), generic name
- Razadyne<sup>®</sup> (RAZZ-uh-dine), brand name;  
galantamine (guh-LAN-tuh-meen), generic name

## **Medicines for moderate to severe AD**

Aricept<sup>®</sup> is also approved to treat moderate to severe AD. Another medication,

Namenda<sup>®</sup> (nuh-MEN-duh), may decrease symptoms, which could allow some people to do more things for themselves, such as using the toilet. The generic name of this drug is memantine (MEH-man-teen).

Sometimes doctors use more than one medicine to treat moderate to severe AD. For example, they might use Aricept<sup>®</sup> and Namenda<sup>®</sup>, which work in different ways. Another medication, Namzaric<sup>®</sup> (nam-ZAR-ic), combines donepezil and memantine in a single pill.

## Ask the doctor about side effects

Check with the doctor or pharmacist about any possible side effects of medication. Some side effects can be serious.

## Medicines to treat behavior problems related to AD

Behavior problems that can occur in AD include restlessness, anxiety, depression, trouble sleeping, and aggression. Other medical conditions or changes from AD may cause behavior problems. Experts agree that medicines to treat these behavior problems should be used **only after** other strategies that don't

use medicine have been tried. Some of these tips are listed on pages 20–38.

If other strategies don't work and the person with AD continues to be upset, restless, depressed, or aggressive, he or she may need medicine. Talk with the person's doctor to figure out the cause of behavior changes and come up with an effective treatment plan to help with these problems.

### **Remember the following tips about medicines:**

- Use the lowest dose possible.
- Watch for side effects. Be prepared to stop the medicine if they occur.
- Allow the medicine a few weeks to work.

Below is a list of medicines used to help with depression, aggression, restlessness, and anxiety.

**Antidepressants** are drugs used to treat depression and worry (also called anxiety). There are many other medicines to treat depression and anxiety. Talk about these medicines with the doctor.

### **Examples of these medicines include:**

- Celexa<sup>®</sup> (Sa-LEKS-a), brand name; citalopram (SYE-tal-oh-pram), generic name

- Remeron<sup>®</sup> (REM-er-on), brand name; mirtazapine (MUR-taz-a-peen), generic name
- Zoloft<sup>®</sup> (ZO-loft), brand name; sertraline (SUR-truh-leen), generic name
- Wellbutrin<sup>®</sup> (wel-BYU-trin), brand name; bupropion (byoo-PROE-pee-on), generic name
- Cymbalta<sup>®</sup> (sim-BOL-te), brand name; duloxetine (doo-LOX-e-teen), generic name
- Tofranil<sup>®</sup> (toe-FRA-nil), brand name; imipramine (im-IP-ra-meen), generic name

## Know about medicines

Information about medicines changes over time. Check with the doctor, AD specialist, or pharmacist about the latest medicines. The doctor may prescribe newer drugs with different names than those listed in this guide. Also, remember that some medicines have both generic and brand names.

## Medicines to be used with caution

**There are some medicines, such as sleep aids, anti-anxiety drugs, anticonvulsants, and antipsychotics, that the person with AD should take only:**

- After the doctor has explained all the risks and side effects of the medicine
- After other, safer non-medication options have not helped treat the problem

You will need to watch closely for side effects from these medications.

**Sleep aids** are used to help people get to sleep and stay asleep. People with AD should **NOT** use these drugs regularly because they make the person more confused and more likely to fall.

### **Examples of these medicines include:**

- Ambien<sup>®</sup> (AM-bee-un), brand name; zolpidem (zole-PI-dem), generic name
- Lunesta<sup>®</sup> (lu-NES-ta), brand name; eszopiclone (ess-ZOP-eh-klone), generic name
- Sonata<sup>®</sup> (SO-nah-ta), brand name; zaleplon (ZAL-ee-plon), generic name

**Anti-anxiety** drugs are used to treat agitation. These drugs can cause sleepiness, dizziness, falls, and confusion. For this reason, doctors recommend using them only for short periods of time.

**Examples of these medicines include:**

- Ativan<sup>®</sup> (AT-eh-van), brand name; lorazepam (lor-AZ-eh-pam), generic name
- Klonopin<sup>®</sup> (KLON-uh-pin), brand name; clonazepam (klo-NAY-zeh-pam), generic name

**Anticonvulsants** are drugs sometimes used to treat severe aggression. Side effects may cause sleepiness, dizziness, mood swings, and confusion.

**Examples of these medicines include:**

- Depakote<sup>®</sup> (DEP-uh-cote), brand name; sodium valproate (so-DEE-um VAL-pro-ate), generic name
- Tegretol<sup>®</sup> (TEG-ruh-tall), brand name; carbamazepine (KAR-ba-maz-ee-peen), generic name
- Trileptal<sup>®</sup> (tri-LEP-tall), brand name; oxcarbazepine (oks-kar-BAZ-eh-peen), generic name

**Antipsychotics** are drugs used to treat paranoia, hallucinations, agitation, and aggression. See pages 27–34 for more about these conditions. Side effects of using these drugs can be serious, including increased risk of death in some older people with dementia. They should **ONLY** be given to people with AD when the doctor agrees that the symptoms are severe.

### **Examples of these medicines include:**

- Risperdal<sup>®</sup> (RISS-per-doll), brand name;  
risperidone (riss-PAIR-eh-dohn), generic name
- Seroquel<sup>®</sup> (SAIR-o-kwell), brand name;  
quetiapine (KWE-tye-uh-peen), generic name
- Zyprexa<sup>®</sup> (zye-PREKS-uh), brand name;  
olanzapine (o-LAN-zuh-peen), generic name

### **Medicines that people with AD should NOT take**

**Anticholinergic drugs** are used to treat many medical problems such as sleeping problems, stomach cramps, incontinence, asthma, motion sickness, and muscle spasms. Side effects, such as confusion, can be serious for a person with AD.

These drugs should **NOT** be given to a person with AD. You might talk with the

person's doctor about other options.

## **Examples of these medicines include:**

- Atrovent<sup>®</sup> (AT-row-vent), brand name;  
ipratropium (EYE-pra-troe-pee-um), generic name
- Dramamine<sup>®</sup> (DRA-me-meen), brand name;  
dimenhydrinate (dye-men-HYE-dri-nate), generic name
- Diphenhydramine (dye-fen-HYE-dra-meen), generic name—includes brand names such as Benadryl<sup>®</sup> (BEN-a-dril) and Nytol<sup>®</sup> (NYE-tal)

## **Medicines to treat other medical conditions**

Many people with AD also have other medical conditions such as diabetes, high blood pressure, or heart disease. They may take different medicines for these conditions. It's important to track all the medicines they take. Make a list of the person's medicines and take the list with you to every visit to a doctor.

## **Common Medical Problems in People with AD**

A person with AD may have other medical problems over time, as we all do. These problems can cause more confusion and behavior changes. The person may not be able to tell you what is wrong. You need to watch for signs of

illness and tell the doctor about what you see.

## The most common medical problems

### Fever

Having a fever means that the person's temperature is 2 degrees above his or her normal temperature.

#### A fever may be a sign of:

- Infection, caused by germs
- Dehydration, caused by a lack of fluids
- Heat stroke
- Constipation (discussed later in this section)

Don't use a glass thermometer because the person might bite down on the glass. Use a digital thermometer, which you can buy at a grocery store or drugstore.

## Call the doctor

Call the doctor right away if the person with AD has a fever.

## Flu and pneumonia

These diseases spread quickly from one person to another, and people with AD are more likely to get them. **Make sure that the person gets a flu shot each year and a pneumonia shot once after age 65. Some older people need to get more than one pneumonia vaccine.** The shots lower the chances that the person will get flu or pneumonia. For more information on these illnesses, visit the Centers for Disease Control and Prevention website, [www.cdc.gov](http://www.cdc.gov).

### Flu and pneumonia may cause:

- Fever (Not everyone with pneumonia has a fever.)
- Chills
- Aches and pains
- Vomiting
- Coughing
- Breathing trouble

# Make sure the person sees the doctor

Make sure the person with AD sees a health professional on a regular basis. This is the best thing you can do to help prevent medical problems.

## Falls

As AD gets worse, the person may have trouble walking and keeping his or her balance. He or she also may have changes in depth perception, which is the ability to understand distances. For example, someone with AD may try to step down when walking from a carpeted to a tile floor. This puts him or her at risk for falls.

### To reduce the chance of a fall:

- Clean up clutter.
- Remove throw rugs.
- Use chairs with arms.
- Put grab bars in the bathroom.

- Use good lighting.
- Make sure the person wears sturdy shoes with good traction.

## **Dehydration**

Our bodies must have a certain amount of water to work well. If a person is sick or doesn't drink enough fluid, he or she may become dehydrated.

### **Signs of dehydration to look for include:**

- Dry mouth
- Dizziness
- Hallucinations (Don't forget that hallucinations may be caused by the AD itself.)
- Rapid heart rate

Be aware of how much fluid the person is drinking. This is even more important during hot weather or in homes without air conditioning. Also, look for signs of dehydration during the winter months when heat in your home can create a lot of dry air.

## Constipation

**People can have constipation—trouble having a bowel movement—when they:**

- Change what they eat
- Take certain medicines, including Namenda®
- Get less exercise than usual
- Drink less fluid than usual

Try to get the person to drink at least 6 glasses of liquid a day.

**Besides water, other good sources of liquid include:**

- Juice, especially prune juice
- Gelatin, such as Jell-O®
- Soup
- Milk or melted ice cream
- Decaffeinated coffee and tea
- Liquid cereal, such as Cream of Wheat®



Have the person eat foods high in fiber. Foods like dried apricots, raisins, or prunes; some dry cereals; or soybeans might help ease constipation.

If possible, make sure that the person gets some exercise each day, such as walking. Call the doctor if you notice a change in the person's bowel habits.

## **Diarrhea**

Some medicines, including Alzheimer's medications, may cause diarrhea—loose bowel movements. Certain medical problems also may cause diarrhea. Make sure the person takes in lots of fluids when he or she has diarrhea. Also, be sure to let the doctor know about this problem.

## **Incontinence**

Incontinence means a person can't control his or her bladder and/or bowels. This may happen at any stage of AD, but it is more often a problem in the later stages. Signs of this problem are leaking urine, problems emptying the bladder, and soiled underwear and bed sheets. Be sure to let the doctor know if this happens. He or she may be able to treat the cause of the problem.

## **Here are some examples of things that can be treated:**

- Urinary tract infection
- Enlarged prostate gland
- Too little fluid in the body (dehydration)
- Diabetes that isn't being treated
- Taking too many water pills
- Drinking too much caffeine
- Taking medicines that make it hard to hold urine

## **When you talk to the doctor, be ready to answer the following questions:**

- What medicines is the person taking?
- Does the person leak urine when he or she laughs, coughs, or lifts something?
- Does the person urinate often?
- Can the person get to the bathroom in time?
- Is the person urinating in places other than the bathroom?

- Is the person soiling his or her clothes or bed sheets each night?
- Do these problems happen each day or once in a while?

### **Here are some ways you can deal with incontinence:**

- Remind the person to go to the bathroom every 2 to 3 hours.
- Show him or her the way to the bathroom, or take him or her.
- Make sure that the person wears loose, comfortable clothing that is easy to remove.
- Limit fluids after 6 p.m. if problems happen at night. Do not give the person fluids with caffeine, such as coffee or tea.
- Give the person fresh fruit before bedtime instead of fluids if he or she is thirsty.
- Mark the bathroom door with a big sign that reads "Toilet" or "Bathroom."
- Use a stable toilet seat that is at a good height. Using a colorful toilet seat may help the person identify the toilet. You can buy raised toilet seats at medical supply stores.
- Help the person when he or she needs to use a public bathroom. This may

mean going into the stall with the person or using a family or private bathroom.

## **Things you may want to buy:**

- Use adult disposable briefs or underwear, bed protectors, and waterproof mattress covers. You can buy these items at drugstores and medical supply stores.
- Use a drainable pouch for the person who can't control his or her bowel movements. Talk to the nurse about how to use this product.

Some people find it helpful to keep a record of how much food and fluid the person takes in and how often he or she goes to the bathroom. You can use this information to make a schedule of when he or she needs to go to the bathroom.

## **Pain Alert**

Always remember that the person with AD may not be able to tell you when he or she is in pain. Watch the person's face to see if it looks like he or she is in pain or feeling ill. Also, notice sudden changes in behavior such as increased yelling or striking out. If you are unsure what to do, call the doctor for help.

## **Dental problems**

As AD gets worse, people need help taking care of their teeth or dentures.

### **Check the person's mouth for any problems such as:**

- Sores
- Decayed teeth
- Food "pocketed" in the cheek or on the roof of the mouth
- Lumps

**Be sure to take the person for dental checkups. Some people need medicine to calm them before they can see the dentist.**

## **Other medical problems**

People with AD can have the same medical problems as many older adults. Research suggests that some of these medical problems may be related to AD.

For example, some heart and blood circulation problems, stroke, and diabetes are more common in people who have AD than in the general population.

Diseases caused by infections also are common.

## Visiting the doctor

It's important that the person with AD gets regular medical care.

### **Here are some tips to help you get ready for a visit to the doctor's office:**

- Make an appointment during the person's best time of day and when the office is not very crowded.
- Let the office staff know before the visit about the person's AD. Ask them for help to make the visit go smoothly.
- Don't tell the person with AD about the visit until the day of the visit or even right before it is time to go if visiting the doctor makes the person nervous. Be positive and matter of fact.
- Take something he or she likes to eat or drink and any materials or activities the person enjoys.
- Have a friend or family member go with you, so that one of you can stay with the person while the other speaks with the doctor.
- Take a brief summary listing the person's medical history, primary care doctor, and current medications.

## **Going to the emergency room**

A trip to the emergency room (ER) can be very stressful for both the person with AD and you.

### **Here are some ways to cope with ER visits:**

- Take a list of medicines, insurance cards, the health care provider's name and phone number, and advance directives. Advance directives are signed documents, such as a living will, that spell out a patient's wishes for end-of-life care.
- Ask a friend or family member to go with you or meet you in the ER. He or she can stay with the person while you answer questions.
- Be ready to explain the symptoms and events leading up to the ER visit. You may have to repeat this more than once to different staff members.
- Tell ER staff that the person has AD. Explain how best to talk with the person.
- If the person with AD must stay overnight in the hospital, try to have a friend or family member stay with him or her.

# Hospitalization

Get more tips in **Hospitalization Happens** at [www.nia.nih.gov/alzheimers/publication/hospitalization-happens](http://www.nia.nih.gov/alzheimers/publication/hospitalization-happens). Or call **1-800-438-4380**.

## Coping with the Last Stages of AD

### Coping with Late-Stage AD

When a person moves to the later stages of AD, caregiving may become even harder. This section offers ways to cope with changes that take place during severe or late-stage AD.

**If caring for the person has become too much for you, see the chapter on “When You Need Help,” starting on page 92, for possible sources of help.**



## When the person with AD can't move

If the person with AD can't move around on his or her own, contact a home health aide, physical therapist, or nurse. Ask the doctor for a referral to one of these health professionals. They can show you how to move the person safely, such as changing his or her position in bed or in a chair.

Also, a physical therapist can show you how to move the person's body joints using range-of-motion exercises. During these exercises, you hold the person's arms or legs, one at a time, and move and bend it several times a day. Movement prevents stiffness of the arms, hands, and legs. It also prevents pressure or bedsores.

## How to make someone with AD more comfortable

**Here are some ways to make the person with AD more comfortable:**

- Buy special mattresses and wedge-shaped seat cushions that reduce pressure sores. You can purchase these at a medical supply store or drugstore or online. Ask the home health aide, nurse, or physical therapist how to use the equipment.
- Move the person to a different position at least every 2 hours.

- Use a lap board to rest the person's arms and support the upper body when he or she is sitting up.
- Give the person something to hold, such as a wash cloth, while being moved. The person will be less likely to grab onto you or the furniture. If he or she is weak on one side, stand on the weak side to support the stronger side and help the person change positions.

## **How to keep from hurting yourself when moving the person with AD**

### **To keep from hurting yourself when moving someone with AD:**

- Know your strength when lifting or moving the person; don't try to do too much. Also, be aware of how you position your body.
- Bend at the knees and then straighten up by using your thigh muscles, not your back.
- Keep your back straight, and don't bend at the waist.
- Hold the person as close as possible to avoid reaching away from your body.
- Place one foot in front of the other, or space your feet comfortably apart for a wide base of support.



- Remember to cook
- Eat enough different kinds of foods

This means the person may not be getting the foods or vitamins and minerals needed to stay healthy. Here are some suggestions to help the person with late-stage AD eat better. Remember that these are just tips. Try different things and see what works best for the person.

### **You might try to:**

- Serve meals at the same time each day.
- Make the eating area quiet. Turn off the TV, CD player, or radio.
- Offer just one food at a time instead of filling the plate or table with too many things.
- Use colorful plates so the person can see the food.
- Control between-meal snacks. Lock the refrigerator door and food cabinets if necessary.
- Make sure the person's dentures are tight fitting. Loose dentures or dentures with bumps or cracks may cause choking or pain, making it hard to eat. Take poorly fitting dentures out until the person can get dentures that fit.

- Let the doctor know if your family member loses a lot of weight, for example, if he or she loses 10 pounds in a month.

## **Here are specific suggestions about foods to eat and liquids to drink:**

- Give the person finger foods to eat such as cheese, small sandwiches, small pieces of chicken, fresh fruits, or vegetables. Sandwiches made with pita bread are easier to handle.
- Give him or her high-calorie, healthy foods to eat or drink, such as protein milk shakes. You can buy high-protein drinks and powders at grocery stores, drugstores, or discount stores. Also, you can mix healthy foods in a blender and let the person drink his or her meal.



Use diet supplements if he or she is not getting enough calories. Talk with the doctor or nurse about what kinds of supplements are best.

- Try to use healthy fats in cooking, such as olive oil. Also, use extra cooking oil, butter, and mayonnaise to cook and prepare food if the person needs

more calories. If the person has heart disease, check with the doctor about how much and what kinds of fat to use.

- If the person has diabetes or high blood pressure, check with the doctor or a nutrition specialist about which foods to limit.
- Have the person take a multivitamin—a tablet, capsule, powder, liquid, or injection that adds vitamins, minerals, and other important things to a person's diet.
- Serve bigger portions at breakfast because it's the first meal of the day.

## What to do about swallowing problems

As AD progresses to later stages, the person may no longer be able to chew and swallow easily. This is a serious problem. If the person chokes on each bite of food, there is a chance that the food could go into the lungs. This can cause pneumonia, which can lead to death.

### **The following suggestions may help with swallowing:**

- Make sure you cut the food into small pieces, and make it soft enough to eat.
- Grind food or make it liquid using a blender or baby food grinder.

- Offer soft foods, such as ice cream, milk shakes, yogurt, soups, applesauce, gelatin, or custard.
- Don't use a straw; it may cause more swallowing problems. Instead, have the person drink small sips from a cup.
- Limit the amount of milk the person drinks if it tends to catch in the throat.
- Give the person more cold drinks than hot drinks. Cold drinks are easier to swallow.
- Don't give the person thin liquids, such as coffee, tea, water, or broth, because they are hardest to swallow. You can buy **Thick-It**<sup>®</sup> at most pharmacies. You add **Thick-It**<sup>®</sup> to liquids to make them thicker. You also can use ice cream and sherbet to thicken liquids.



### **Here are some other ideas to help people swallow:**

- Don't hurry the person. He or she needs time to chew and swallow each mouthful before taking another bite.

- Don't feed a person who is drowsy or lying down. He or she should be in an upright, sitting position during the meal and for at least 20 minutes after the meal.
- Have the person keep his or her neck forward and chin down when swallowing.
- Stroke (gently) the person's neck in a downward motion and say "swallow" to remind him or her to swallow.
- Find out if the person's pills can be crushed or taken in liquid form.

Helping the person with AD eat can be exhausting. Planning meals ahead and having the food ready can make this task a little easier for you. Also, remember that people with AD may not eat much at certain times and then feel more like eating at other times. It helps to make mealtime as pleasant and enjoyable as possible. But, no matter how well you plan, the person may not be hungry when you're ready to serve food.

## **Dental, skin, and foot problems**

Dental, skin, and foot problems may take place in early and moderate stage AD, but most often happen during late stage AD. Please see page 139 for more on dental problems.

## Body jerking

Myoclonus is a condition that sometimes happens with AD. The person's arms, legs, or whole body may jerk. This can look like a seizure, but the person doesn't pass out. Tell the doctor right away if you see these signs. The doctor may prescribe one or more medicines to help reduce symptoms.

## Skin problems

Once the person stops walking or stays in one position too long, he or she may get skin or pressure sores.

### **To prevent skin or pressure sores, you can:**

- Move the person at least every 2 hours if he or she is sitting up.
- Move the person at least every hour if he or she is lying down.
- Put a 4-inch foam pad on top of the mattress.
- Check to make sure that the foam pad is comfortable for the person. Some people find these pads too hot for sleeping or may be allergic to them. If the foam pad is a problem, you can get pads filled with gel, air, or water.
- Check to make sure the person sinks a little when lying down on the pad.

Also, the pad should fit snugly around his or her body.

### **To check for pressure sores:**

- Look at the person's heels, hips, buttocks, shoulders, back, and elbows for redness or sores.
- Ask the doctor what to do if you find pressure sores.
- Try to keep the person off the affected area.

### **Foot care**

It's important for the person with AD to take care of his or her feet. If the person can't, you will need to do it.

### **Here's what to do:**

- Soak the person's feet in warm water; wash the feet with a mild soap; and check for cuts, corns, and calluses.
- Put lotion on the feet so that the skin doesn't become dry and cracked.
- Cut or file their toenails.
- Talk to a foot care doctor, called a podiatrist, if the person has diabetes or sores on the feet.

## End-of-Life Care

Caring for someone in the final stage of life is always hard. It may be even harder when the person has AD. Of course, you want to make the person as comfortable as possible, but he or she can't tell you how. You may become frustrated because you don't know what to do.

Also, it can be upsetting because you want the person to talk with you, share memories and feelings, and say goodbye. While the person with AD may not be able to say these things, you can. It's really important to say the things in your heart, whatever helps you to say goodbye.

When the person with AD dies, you may have lots of feelings. You may feel sad, depressed, or angry. You also may feel relieved that the person is no longer suffering and that you don't have to care for the person any longer. Relief sometimes may lead to feelings of guilt. All of these feelings are normal.

Planning for the end of a person's life and knowing what to expect can make this time easier for everyone. Geriatric care managers, grief counselors, and hospice care staff are trained to help you through this time. You might want to contact hospice staff early for help on how to care for the dying person.

These professionals can help make the person more comfortable. For more information about these services, see pages 102–105.

## End-of-Life Care

The National Institute on Aging offers helpful information on caregiving, including end-of-life care. Its publications may be ordered free or viewed on the NIA website:

[www.nia.nih.gov/health/publication/end-of-life](http://www.nia.nih.gov/health/publication/end-of-life)

Phone: **1-800-222-2225**

# Caring for Yourself

Taking care of yourself is one of the most important things you can do as a caregiver. This could mean asking family members and friends to help out, doing things you enjoy, using adult day care services, or getting help from a local home health care agency. Taking these actions can bring you some relief. It also may help keep you from getting ill or depressed.

## How to Take Care of Yourself

**Here are some ways you can take care of yourself:**

- Ask for help when you need it.
- Join a caregiver's support group.
- Take breaks each day.
- Spend time with friends.
- Keep up with your hobbies and interests.
- Eat healthy foods.
- Get exercise as often as you can.
- See your doctor on a regular basis.

- Keep your health, legal, and financial information up-to-date.

## Getting help

Everyone needs help at times. It's okay to ask for help and to take time for yourself. However, many caregivers find it hard to ask for help. You may feel:

- You should be able to do everything yourself
- That it's not all right to leave the person with someone else
- No one will help even if you ask
- You don't have the money to pay someone to watch the person for an hour or two

**If you have trouble asking for help, try using some of the tips below.**

- It's okay to ask for help from family, friends, and others. You don't have to do everything yourself.
- Ask people to help out in specific ways like making a meal, visiting the person, or taking the person out for a short time.
- Join a support group to share advice and understanding with other caregivers.
- Call for help from home health care or adult day care services when you need it.

- Use national and local resources to find out how to pay for some of this help, or get respite care services.

You may want to join a support group of AD caregivers in your area or on the Internet. These groups meet in person or online to share experiences and tips and to give each other support. Ask your doctor, check online, or contact a local chapter of the Alzheimer's Association.

If you are a veteran or are caring for one, the Veterans Administration might be of help to you. To learn more, visit their caregivers' website at [www.caregiver.va.gov](http://www.caregiver.va.gov). You might also call their toll-free support line at **1-855-260-3274**.

## AD Information

You also can call the Alzheimer's and related Dementias Education and Referral Center at no cost. The phone number is **1-800-438-4380**. Visit on the Internet at [www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers).

For more information on how to get help, see pages 92–118, "When You Need Help."



*“He has given me so much all my life, and now he can only take. Yet his presence now, as always, provides deep comfort to my soul. Now I give to him in every way I can. I realize that my giving to him is a result of his giving to me: emotional support, love, spiritual direction, wisdom, and advice.”*

## **Your emotional health**

You may be busy caring for the person with AD and don't take time to think about your emotional health. But, you need to. Caring for a person with AD takes a lot of time and effort. Your job as caregiver can become even harder when the person you're caring for gets angry with you, hurts your feelings, or forgets who you are. Sometimes, you may feel really discouraged, sad, lonely, frustrated, confused, or angry. These feelings are normal.

## Here are some things you can say to yourself that might help you feel better:

- I'm doing the best I can.
- What I'm doing would be hard for anyone.
- I'm not perfect, and that's okay.
- I can't control some things that happen.
- Sometimes, I just need to do what works for right now.
- Even when I do everything I can think of, the person with AD will still have problem behaviors because of the illness, not because of what I do.
- I will enjoy the moments when we can be together in peace.
- I will try to get help from a counselor if caregiving becomes too much for me.

## Meeting your spiritual needs

Many of us have spiritual needs. Going to a church, temple, or mosque helps some people meet their spiritual needs. They like to be part of a faith community. For others, simply having a sense that larger forces are at work in the world helps meet their spiritual needs. As the caregiver of a person with AD, you may need more spiritual resources than others do.

## **Meeting your spiritual needs can help you:**

- Cope better as a caregiver
- Know yourself and your needs
- Feel recognized, valued, and loved
- Become involved with others
- Find a sense of balance and peace

## **Other caregivers made these suggestions to help you cope with your feelings and spiritual needs:**

- Understand that you may feel powerless and hopeless about what's happening to the person you care for.
- Understand that you may feel a sense of loss and sadness.
- Understand why you've chosen to take care of the person with AD. Ask yourself if you made this choice out of love, loyalty, a sense of duty, a religious obligation, financial concerns, fear, a habit, or self-punishment.
- Let yourself feel day-to-day "uplifts." These might include good feelings about the person you care for, support from other caring people, or time to spend on your own interests and hobbies.

- Keep a connection to something “higher than yourself.” This may be a belief in a higher power, religious beliefs, or a belief that something good comes from every life experience.



***“I feel lonely sometimes. I spend almost all of my time taking care of Mom. Going to church and being with friends helps me feel better.”***

# Joining a Clinical Trial



A clinical trial is a research study to find out whether new medicines or other treatments are both safe and effective. Clinical trials most often take place at research centers and universities across the United States. Joining a clinical trial, also called a research study, is a way for you and the person with AD to help find ways to prevent or treat AD.

A clinical trial gives the person a chance to get a new treatment from researchers, before the government approves it. The new treatment might be a new medicine or a new way to care for someone with AD. A clinical trial is another way to get care from experts. Being in a study also gives you and the person with AD a chance to help others who have the disease.

But, you should keep in mind that clinical trials may have some risks. Be sure to look at the benefits and risks of a clinical trial before you decide whether or not to participate.

## How can a person join a clinical trial?

To join, you first must find a study that is looking for people like you or the person with AD.

For more information about AD clinical trials and studies, visit [www.nia.nih.gov/alzheimers/volunteer](http://www.nia.nih.gov/alzheimers/volunteer). You can also call **1-800-438-4380**. An information specialist can help you look for a clinical trial.

### **You may also want to visit these clinical trials websites:**

- Alzheimer's Association  
[www.alz.org/trialmatch](http://www.alz.org/trialmatch)
- Galaxy  
[www.galaxybraintrust.org/research](http://www.galaxybraintrust.org/research)
- National Institutes of Health  
[www.nih.gov/health/clinicaltrials](http://www.nih.gov/health/clinicaltrials)  
[www.clinicaltrials.gov](http://www.clinicaltrials.gov)
- Research Match  
[www.researchmatch.org](http://www.researchmatch.org)

## What else do I need to know about clinical trials?

The government has strict rules to protect the safety and privacy of people in clinical trials. The researchers conducting the study are required by law to tell the patient and/or family members all of the risks and benefits of taking part in the study. This is called the informed consent process.

As part of this process, the person reads an informed consent form. The form explains the study, its risks and benefits, and the rights of the person taking part in the study. The laws and rules about informed consent differ across States and research centers.

Some clinical trials will pay you back for transportation costs, child care, meals, and lodging; others won't. Talk with the study coordinator about these costs.

For more information, read **Participating in Alzheimer's Research** at [www.nia.nih.gov/alzheimers/publication/participating-alzheimers-research](http://www.nia.nih.gov/alzheimers/publication/participating-alzheimers-research).

# Summary

Thank you for reading this guide. We hope it helps you—the caregiver—and the person with AD.

## Here are some main points to remember:



- Learn about AD to help you cope with challenges.
- Plan how to care for someone with AD to make things easier.
- Create a safe home for the person with AD.
- It's important for you to take care of yourself as well as the person with AD.
- You aren't alone. It's okay to ask for and get help. Check the resources listed in this book.
- You can find the right place for the person with AD if he or she can no longer live at home.
- Learn about medicines used for people with AD.
- Find out how to cope with late-stage AD.

# Words to Know

**Aggression** (uh-GRESH-un). When a person lashes out verbally or tries to hit or hurt someone.

**Agitation** (aj-uh-TAY-shun). Restlessness and worry that some people with AD feel. Agitation may cause pacing, sleeplessness, or aggression.

**Alzheimer's disease (AD)** (ALLZ-high-merz duh-ZEEZ). Disease that causes large numbers of nerve cells in the brain to die. People with AD lose the ability to remember, think, and make good judgments. At some point, they will need full-time care.

**Anti-anxiety** (an-tye-ang-ZYE-eh-tee) drugs. Drugs used to treat agitation and extreme worry. Some can cause sleepiness, falls, and confusion. These drugs should be taken with caution.

**Anticholinergic** ((an-tye-KOL-in-er-gik) drugs. Drugs used to treat stomach cramps, incontinence, asthma, motion sickness, and muscle spasms. **These drugs should not be given to people with AD.**

**Anticonvulsants** (an-tye-kon-VUL-sunts). Drugs sometimes used to treat severe aggression.

**Antidepressants** (an-tye-dee-PRESS-unts). Drugs used to reduce depression and worry.

**Antipsychotics** (an-tye-sye-KOT-iks). Drugs used to treat paranoia, hallucinations, sleeplessness, agitation, aggression, and other personality and behavior disorders. These drugs should be taken with caution.

**Assisted living facility.** Type of living facility that provides rooms or apartments for people who can handle most of their own care, but may need some help.

**Caregiver.** Anyone who takes care of a person with AD.

**Clinical trial.** Research study to find out whether new medicines or other treatments are both safe and effective.

**Constipation.** (kon-sti-PAY-shun). Trouble having a bowel movement.

**Continuing care retirement community.** Community of homes, apartments, and rooms that offer different levels of care for older people.

**Deductible** (dee-DUK-ti-bul). The amount of medical expenses that a person must pay per year before the insurance company will cover medical costs.

**Dehydration** (dee-hye-DRAY-shun). Condition caused by lack of fluids in the body.

**Delusions** (duh-LOO-zhuhns). False beliefs that someone with AD believes are real.

**Diarrhea** (dye-uh-REE-uh). Loose bowel movements.

**Do Not Resuscitate (DNR) Form.** Document that tells health care staff that the person with AD does not want them to try to return the heart to a normal rhythm if it stops or is beating unevenly.

**Durable Power of Attorney for Finances.** Legal permission for someone to make legal and financial decisions for the person with AD, after he or she no longer can.

**Durable Power of Attorney for Health Care.** Legal permission for someone to make health care decisions for the person with AD, after he or she no longer can.

**Hallucinations** (huh-loo-suh-NAY-shuns). One possible effect of AD, in which the person sees, hears, smells, tastes, and/or feels something that isn't there.

**Home health care.** Service that provides care and/or companionship in the home for the person with AD.

**Hospice services.** Services that provide care for a person who is near the end of life and support for families during this time.

**Hypersexuality** (hi-pur-sek-shoo-AL-uh-tee). Condition in which people with AD become overly interested in sex.

**Incontinence** (in-KON-ti-nunts). Trouble controlling bladder and/or bowels.

**Inpatient facility.** Hospital or other medical facility where people stay in the facility.

**Intimacy.** Special bond between people who love and respect each other.

**Living trust.** Legal document that tells a person called a trustee how to distribute a person's property and money.

**Living will.** Legal document that states a person's wishes for end-of-life health care.

**Multivitamin** (mull-tee-VYE-tuh-min). A tablet, capsule, powder, liquid, or injection that adds vitamins, minerals, and other nutritional elements to the diet.

**Myoclonus** (mye-o-KLO-nuss). Condition that sometimes happens with AD, in which a person's arms, legs, or whole body may jerk. It can look like a seizure, but the person doesn't pass out.

**Nursing home.** Home for people who can't care for themselves anymore. Some have special AD care units.

**Palliative** (PAL-ee-uh-tiv) **care.** Services to treat or reduce symptoms (like pain and stress) for a person with a serious illness.

**Paranoia** (pare-uh-NOY-uh). Type of delusion in which a person believes—without good reason—that others are being unfair, unfriendly, or dishonest. Paranoia may cause suspicion, fear, or jealousy in a person with AD.

**Respite** (RES-pit) **services.** Short-term care for the person with AD that allows caregivers to get a break.

**Sexuality.** Important way that people express their feelings physically and emotionally for one another.

**Spirituality** (SPEAR-uh-choo-al-ity). Belief in a higher power or in larger forces at work in the world. Going to church, temple, or mosque helps some people meet their spiritual needs. For others, simply having a sense that larger forces are at work in the world helps meet their spiritual needs.

**Sundowning.** Restlessness in a person with AD that usually starts around dinnertime or in the evening and may make it hard to get the person to go to bed and stay there.

**Urinary tract infection** (YUR-in-air-ee tract in-FEK-shun). An illness, usually in the bladder or kidneys, caused by bacteria in the urine.

**Will.** Legal document that tells how a person's money and property will be divided after his or her death.



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