

Alzheimer's Disease: Caring for Someone with Alzheimer's Disease

What is Alzheimer's disease?

Alzheimer's disease (AD) affects brain cells. It slowly destroys memory and thinking skills. Over time the ability to speak, remember, control emotions, and make decisions may be lost.

People with AD may have a range of symptoms such as:

- Mild anxiety
- Memory loss, including more trouble remembering recent events than events in the past
- Agitation, such as pacing, pinching, scratching, hitting others, or shouting
- Trouble concentrating or solving problems
- Being unable to talk

In the very early stages, most people with AD are aware of their problem and may try to hide it. As the disease gets worse, they are no longer aware of the problem. Family and friends may not be aware of the problem or acknowledge it until it gets more severe.

People with AD may not like to be around other people. Other people may shun them because of their strange behaviors. These behaviors can be harmful to the person with Alzheimer's disease and to others.

People with AD often have sleep problems. They may sleep more during the day and less during the night. This is very hard for caregivers because they can become exhausted from stress and lack of sleep.

What should I do as a caregiver for someone with AD?

Caring for someone with AD calls for extra patience and understanding. You want to keep the person safe but still allow them to be as independent as possible. Try to avoid things that cause a lot of stress and unusual behaviors. Some ideas are:

- Do whatever you can to simplify the person's life. For example, reduce stress by not changing routines and surroundings. People with AD do better with a regular routine.
- Only do for them the things that they can no longer do. People with AD may be able to do part of a task. Let them do whatever they are able to do successfully.
- Do not tease or argue with them. It does not work because they can no longer reason.
- Do not let them get too tired.

- Don't plan complicated trips. Short day trips to familiar places can be fun. Long-distance travel is tiring and disorienting. It is also complicated for a caregiver to manage.
- Try to limit the number of new people that are around at any one time. New people can increase stress for someone with AD.
- Watch for and avoid situations that may cause unwanted behavior. For example, crowds and noise may increase anxiety. If you must take someone with AD into a busy or crowded place, try to keep one person always with them throughout the activity.
- Give choices, but limit the number of choices to two. Multiple choices can be hard for people with AD to handle. Simple choices can sometimes help to guide behavior. If they resist cleaning up, ask, "Do you want to wipe your chin or shall I?" instead of asking, "Can I wipe your chin?"
- Celebrate what they can do well. Don't focus on what they cannot do. Don't remind them of what they used to do. Don't try to get them to act like they used to act. Make time for fun and togetherness in the present time, even if they forget quickly.
- When people with AD cannot control unwanted behaviors, divert them to something else. For example, say, "Let's do this now, over here," rather than trying to tell them why they shouldn't do something.
- Listen to what the person with AD is saying. Try to understand the feeling behind the person's words. Don't argue with the **content** of the person's thought. Agree with the **feeling**. For example, don't tell the person that his or her mother is dead when the person is looking for her. Instead say, "Oh, you miss your mother. What would you say to her if she were here?" Then gradually change the subject.
- Let emotional moments happen, as long as the person with AD is not doing anything harmful as well. A spell of crying while feeling sad is OK. A companion or caregiver can let the time pass and the person with AD usually will get over their spell of sadness. As the emotion passes, the caregiver can just talk about something different or start a different activity.
- Try to understand their past experiences and habits. Make current routines as much like the past as possible.

How should I respond to a problem behavior?

Remember that problem behavior is a symptom of the disease. Don't take it personally.

Who is the behavior affecting? Is the behavior really a problem or not? For example, a person who talks to an imaginary person but does not bother other people does not have a problem behavior. Examples of behaviors that may be a problem are:

- Arguing with another resident or a family member
- Using foul language
- Pacing

- Calling out for help
- Resisting personal care, such as bathing or help going to the bathroom
- Being restless at night
- Hitting other people

Change the way you respond, rather than trying to change the behavior. People with AD do not know that their behavior is inappropriate. People with AD will often mirror the emotions of the people around them. The way you respond can have a calming effect or make the situation worse. If you are calm, they will be calm. If you are upset or angry, it may increase their agitation. Do not try to argue or explain what is happening. Rather, divert their attention, stay calm, and reassure them. Use a slow, calm tone of voice. Avoid sudden movements with your hands or body.

Change any routines that may have started the problem behavior. Plan to have events at the best time of day for the person with AD. Provide frequent breaks from stressful activities, offer snacks, or return to a nonstressful familiar activity.

Change the surroundings if you think it may prevent a problem behavior from happening. For example, a person who wanders may need several types of locks installed on doors or a bolt put up higher than expected. For a person who rummages through drawers, provide a special drawer, dresser, or closet for items that he or she can rummage through.

In some cases medicine may be the best way to manage problems such as depression and distorted thinking. However, medicine is not the best answer for every health or behavior problem. Healthcare providers try to avoid prescribing medicines that could cause serious side effects, such as antihistamines, antispasmodics, antipsychotics, medicines to treat incontinence, and sleeping pills. Some medicines can make problems such as agitation and confusion worse. Medicines generally are used only when other approaches have failed. Many problem behaviors in people who have AD, such as pacing, wandering, and calling out, cannot be helped with medicines.

What should I do if I see changes in behavior?

If the person with AD seems to get worse over a few days, with more disruptive and confused behavior, they may be getting sick. Even head colds are distressing, and bronchitis or a bladder infection can really bother the person with AD. As a caregiver, you should make sure the person with AD sees their healthcare provider for a checkup. If you notice something particular about the behavior change – for example, urinating in the wrong place more often – tell the healthcare provider. Your information helps the provider decide what testing to do.

Where can I get help as a caregiver?

As a caregiver, you need help and support as the behavior and needs of the person you are caring for change. It's easy to feel alone because of the demands made on you for care and attention. It is common to feel that no one else understands what

you are going through. Support groups can help by giving you a chance to meet others with similar experiences. A support group is made up of caregivers, family members, and friends of people with AD or other dementia. Meetings provide information but are also social events for you.

Topics discussed in support groups usually focus on feelings about caregiving, ideas to help you, and other issues related to AD. Caregivers feel more in control of their lives when they understand more about the disease and learn from others in the group. The shared experiences and the encouragement given and received are important functions of a support group.

Ask friends or neighbors to stay with your loved one so you are free to attend a support group. Some groups may also offer care for your loved one during the meeting time.

To find help through support groups in your community, contact either of these 2 organizations (local chapters may be in your area):

- The Alzheimer's Association
<http://www.alz.org>
24-hour helpline: 1-800-272-3900 (TDD: 1-866-403-3073)
- The Alzheimer's Foundation of America
<http://www.alzfdn.org>
1-866-232-8484

Ask your healthcare provider about local agencies that also provide help for caregivers. In addition to support groups, a variety of services may be available such as:

- Homemakers
- Home health aides
- Companions
- Licensed practical nurses or registered nurses
- Social workers
- Therapists
- Respite care
- Adult day care centers
- Transportation services
- Grocery shopping services
- Chore services

How many hours are you devoting to caregiving? It's like a job with night-duty hours. Remember, it is as important to care for yourself as it is to care for the person with AD. If you are healthy, you can do the work of caregiving, but if you get sick, you and the person with AD may both be in trouble. Be good to yourself and try to arrange some time away from care-giving every day.

Respite care programs provide a break to families who care for people with AD at home. Many churches offer respite programs or other elder care assistance. Services can vary from a few hours to a few weeks. Adult day care programs offer care during daytime hours. These programs offer respite for the caregiver and

different surroundings for the person with AD. Brief stays in nursing homes can also be arranged through your healthcare provider.

Many communities offer assisted living or personal board and care homes with secured units for persons with AD. These facilities provide homelike, nonstressful environments for small numbers of people with AD. Call your local Area Agency on Aging or the Alzheimer's Association for information.

The local Area Agency on Aging, which may be called something slightly different in your area, can provide information about available services. These agencies belong to a network established by Congress. If you have trouble finding the phone number for your local Area Agency on Aging, call the toll-free Eldercare Locator phone number: 1-800-677-1116.

You can also get help through the Retired Senior Volunteers Program and senior centers.

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