

Caring for a Loved One Who Has Alzheimer's Disease

Developed by the American Pharmacists Association. Improving medication use. Advancing patient care.

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Alzheimer's disease (AD) gradually destroys brain cells. It is the leading cause of dementia. If your loved one has dementia, you may notice that his or her memory is getting worse and that he or she:

- Has difficulty thinking, making decisions, or finding the right words
- Can be confused and disoriented
- Has trouble learning
- Can no longer do everyday tasks

Brain cells die at various rates in different people, so predicting the course of the illness is impossible. AD may last for 3 years for one person and 20 years for another. On average, people with AD live 8 years after the first symptoms appear. Memory and thinking skills are lost first. Eventually, the disease destroys all brain function and can be fatal in an otherwise healthy person. The cause of AD is unknown.

Nearly 3 out of every 4 people who have AD live at home and are cared for by their families and friends. Caregivers not only help with the loved one's daily activities but also may be responsible for making important legal decisions and monitoring changes in behavior.

Understanding Your Loved One's Medications

AD has no cure. Doctors prescribe medication to lessen the symptoms, slow the progress of the disease, and perhaps delay the need for nursing home care. Four medications are currently available to treat AD:

- Donepezil (Aricept®),
- Tacrine (sold as Cognex®),
- Rivastigmine (Exelon®), and
- Galantamine (Reminyl®).

These drugs are from a family of medications called cholinesterase inhibitors, and they work to prevent the breakdown of a brain chemical that is needed for memory and thinking skills. Of these

four, only donepezil (Aricept®) has been shown to work in controlled 1-year studies. Aricept is given just once a day.

Any of these drugs can cause the side effects of nausea, vomiting, loss of appetite, and increased frequency of bowel movements. AD patients may refuse to take medication or, in the later stages of the disease, have trouble swallowing. Ask your pharmacist if a liquid form of medication is available or if the medicine can be crushed and mixed with applesauce or pudding. Avoid giving your loved one antihistamines because they can prevent the AD medication from working as well as it should. The caregiver should consult with a doctor or pharmacist to suggest an alternative to antihistamines.

Future Medications and Alternative Treatments

Researchers are exploring the use of vitamin E to slow brain cell damage and medications to manage agitation and other behavioral problems your loved one may exhibit.

Although a number of alternative treatments—for example, ginkgo biloba, huperzine A, and phosphatidylserine—have been suggested to treat AD, none has been proven to be safe and effective. The purity of such substances is not guaranteed, and side effects have not been adequately studied. Even seemingly harmless dietary supplements can cause bad reactions or interact with prescribed medications. Never give your loved one an alternative therapy without first talking with his or her health care professional.

Special Challenges for the AD Caregiver

An AD patient's behavior can make your life as a caregiver difficult. Your loved one may no longer recognize you and may act strangely—yelling, hitting, swearing, or wandering away from home. Such changes may make it hard for you to think of your loved one as the same person he or she was before becoming ill.

As a caregiver, you may need to become your loved one's memory. You may help him or her remember family and friends, read or watch TV, understand what others say, and find the right words. You can help your loved one hold on to his or her personal dignity.

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Caregiving Recommendations

What to Do	What to Avoid Doing
Observe your loved one's behavior closely. Actions may replace words.	Don't expect too much. Avoid criticizing failures and mistakes.
Call your loved one by name often. Get his or her attention before going on.	Try not to interrupt or hurry a response.
Speak in short sentences. Use simple words.	Don't talk to your loved one as if he or she were a small child. Don't talk about him as if he weren't there.
Maintain a calm and gentle tone of voice.	Don't give too much information at once. Provide step-by-step instructions if your loved one needs prompting.
Keep activities simple. Use your loved one's current abilities.	Avoid doing too much for your loved one. Allow him or her to do as much as possible.
Set up a routine for the day and stick to it. Keep your environment predictable—for example, keep the furniture in the same place.	Don't announce upcoming events too far in advance. For example, wait until the day of the appointment to tell your loved one he or she is going to see the doctor.
Plan ahead for all activities. For example, assemble everything you'll need to give your loved one a bath before bringing him or her into the bathroom.	Too many choices—for example, too many foods on a plate or too many choices of what to wear—might be overwhelming. Don't eliminate choices, but keep decisions simple.
Install childproof latches on cupboards that contain medications, cleaning supplies, alcohol, or dangerous utensils. Protect your loved one from these dangers just as you would a small child.	Don't wait for your loved one to ask to go to the bathroom. Take him or her to the bathroom about every 3 hours during the day to avoid accidents.

Caregiver Stress

As you care for your loved one, you also need to take care of your own emotional and physical needs. You won't be able to help your loved one if you don't take care of your own mental and physical health. Watch for signs of depression, changes in your other relationships, and exhaustion. Allow others to help you, or seek out respite care in your community.

Staying Informed

Learning as much as you can about AD will help you care for your loved one and meet your own needs as a caregiver. The following organizations are good sources of both help and information:

- Alzheimer's Association, 800-272-3900, www.alz.org
- U.S. Administration on Aging, 202-619-0724, www.aoa.dhhs.gov
- Alzheimer's Disease Education and Referral Center, 800-438-4380, www.alzheimers.org/adear
- American Association of Retired Persons, 800-424-3410, www.aarp.org
- Children of Aging Parents, 800-227-7294, www.caps4caregivers.org
- Eldercare Locator, 800-677-1116, www.eldercare.gov
- National Family Caregivers Association, 800-896-3650, www.nfcares.org
- National Institute of Neurological Disorders and Stroke, 800-352-9424, www.ninds.nih.gov/health_and_medical/disorders/alzheimersdisease_doc.htm
- National Institute on Aging/Information Center, 800-222-2225, www.nia.nih.gov
- Family Caregiver Alliance, 415-434-3388, www.caregiver.org