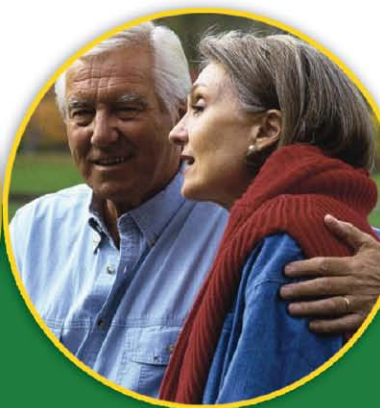


Alzheimer's Disease:

A Guide for Patients and Families



FEATURING
Deborah Norville

DVD
INSIDE

ACP

AMERICAN COLLEGE OF PHYSICIANS
INTERNAL MEDICINE | *Doctors for Adults*



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Welcome

It can be very difficult to find out that you or a member of your family has Alzheimer's disease. You may have feelings of shock and sadness. You might be thinking, what's next?

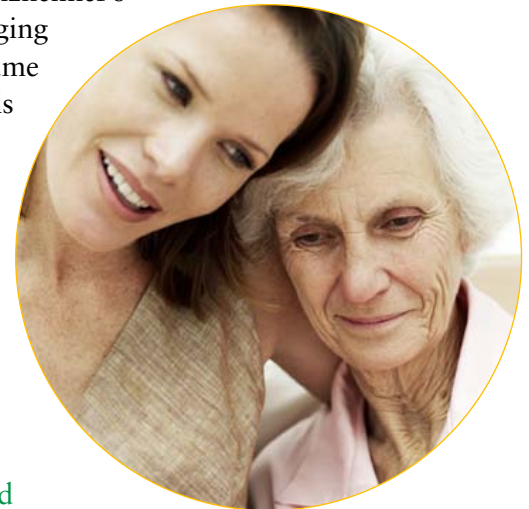
It can help to learn more about Alzheimer's disease. You and your family can find out what to expect and plan for the future.

You can also learn about treatment options. Medication may help slow the progression of symptoms.

Caring for a person with Alzheimer's disease can be very challenging and yet rewarding at the same time. Fortunately, support is available to help family members plan ahead.

This DVD and guidebook program can help you and your family:

- Understand treatment options
- Find the support you need
- Plan for the future



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For further information contact:

Conrad & Associates, LLC
10415 Stapleford Hall Drive
Potomac, MD 20854
(800) 553-0504
(301) 983-6417

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What Is Alzheimer's Disease?

Alzheimer's disease is a medical illness that affects the brain. It involves the loss of nerve cells in the brain. It affects memory, thinking, and behavior. We don't know why it happens, but certain cells in the brain stop working and die. These cells produce important chemicals needed for memory, language, and thinking. As the chemicals decrease, so does the ability to remember and think clearly.

Sometimes no one realizes that a loved one might have Alzheimer's disease until troubling events start to happen: Unpaid bills start to pile up until the electricity gets cut off, or the loved one starts driving through red lights or gets lost while walking through a familiar neighborhood.

Such events may be the defining moment when patients and caregivers know something is wrong, and they go to see a healthcare professional to find out if the cause might be Alzheimer's disease. Fortunately, Alzheimer's disease can be detected much earlier, before a crisis occurs.

Possible Warning Signs of Alzheimer's Disease

- Forgetting things more and more often
- Trouble with familiar activities, such as preparing a meal or making a phone call
- Often having trouble finding the right word
- Poor judgment, such as wearing several layers on a hot day or little clothing on a cold day
- Trouble doing simple math
- Often misplacing things or putting things in unusual places, such as a wristwatch in the refrigerator
- Mood swings—going from calm to tears to anger for no clear reason
- Personality changes, such as becoming very confused, suspicious, fearful, or dependent
- Becoming very passive; for example, watching TV for many hours, not wanting to do usual activities, or sleeping more than usual

Dementia

Alzheimer's disease is the most common form of *dementia*. Dementia, once referred to as senility, is a general term for memory loss that interferes with daily activities. Changes in memory, personality, and behavior might indicate dementia. Several different diseases can affect the brain and cause dementia.

A person with Alzheimer's disease might remember things from the past but have trouble remembering recent events. It might also be hard to remember the names of friends and family members. It might become difficult to solve simple math problems.

Many people worry about becoming more forgetful as they get older. It can be hard to tell the difference between dementia and normal changes that come with aging. A healthcare professional can help.

Symptoms and Changes

Over time, a person with Alzheimer's disease slowly becomes more and more forgetful. As the disease progresses, daily activities become more difficult. It gets harder to do tasks such as brushing teeth and getting dressed.

Personality changes may develop. A person with Alzheimer's disease may become very confused, suspicious, fearful, aggressive, or passive. The person might repeat things over and over.

There is currently no cure for Alzheimer's disease. However, medical treatment can help slow the progression of symptoms.

Who Is at Risk?

Up to 4.5 million Americans suffer from Alzheimer's disease. Scientists are trying to learn what causes Alzheimer's disease. They know that the risk of getting it increases with age. It usually begins **after** age 65.

One risk factor for Alzheimer's disease is a family history that includes all forms of dementia. This is only one factor among several—it does not mean everyone in your family eventually will develop Alzheimer's disease. Family members should simply be aware of the history.

- The risk of getting Alzheimer's disease increases with age.
- Alzheimer's disease usually begins after age 65.
- Nearly half of people over the age of 85 may have Alzheimer's disease.

What can you do?

• Stay physically active

Physical activity, such as walking, swimming, or even dancing, might help protect the brain, but scientists do not know for sure. Staying physically active is important for controlling blood pressure and cholesterol. It is also very important for your overall health.

• Stay mentally active

Reading and other mental activities, such as doing crossword puzzles, might help protect the brain. No one knows for sure.



Diagnosing Alzheimer's Disease

The earlier Alzheimer's disease is diagnosed, the more time you have to plan for the future. An early diagnosis allows family members to discuss future care, living arrangements, and financial plans. In the early stage, a person with the disease is able to join in making decisions.



An early diagnosis may also be helpful for treating symptoms. Treatment for Alzheimer's disease may delay the progression of symptoms. It may allow a person with Alzheimer's disease to stay independent longer.

To help figure out whether or not your symptoms are due to Alzheimer's disease, a healthcare professional may do the following:

- Ask about your general health and past health problems
- Ask about memory or other problems that concern you
- Do a physical exam
- Do neurological tests (balance, coordination, muscle strength, and reflexes)
- Ask simple questions to check your "mental status" (attention, memory, judgment, and language skills)
- Blood tests
- Magnetic resonance imaging (MRI)
- Computerized tomography (CT scan)
- Positron emission tomography (PET scan)

Stages of Alzheimer's Disease



Alzheimer's disease often begins slowly. At first it might seem like normal, age-related memory loss. The disease progresses differently in each person, but there are three main stages:

1. Mild stage

Forgetfulness may seem normal and age related. It might get harder and harder to remember recent events and familiar names. The person might lose the ability to do simple math, such as balancing a checkbook.

2. Moderate stage

Forgetfulness starts to make daily activities harder. Brushing teeth and getting dressed may require help.

The person might feel confused. It may be hard to speak, understand, read, or write. Familiar people and places might begin to seem strange.

3. Severe stage

The person may need help with all daily care. Some people become anxious, aggressive, or very passive. Some try to wander away. Eventually, patients need total care, day and night.

On average, Alzheimer's disease patients live from 8 to 10 years after they are diagnosed. In some people, the disease progresses faster. Others may live with Alzheimer's disease for up to 20 years.

Treatment Choices

Medicine may be helpful at each stage of Alzheimer's disease.

For Alzheimer's disease, two types of medicine are available. Some medicines are used for mild to moderate symptoms and others for moderate to severe symptoms. Some healthcare professionals recommend taking both medicines for moderate to severe symptoms, based upon early research evidence that suggests two medicines may work better than one.

The goals of treatment of these medicines are to slow down the progression of the symptoms of Alzheimer's disease, such as memory loss and daily functioning.

Your doctor will determine which medication is best for you. As with any medication, side effects may occur, however, it is important to continue taking the medication as directed by your healthcare professional.

Patients with Alzheimer's disease may experience other symptoms that may be treated with other types of medicines. These symptoms could include agitation, sleeping difficulties, anxiety, and depression.



Getting Support

In the early stage of Alzheimer's disease, it is often possible to live independently. When symptoms are still mild, you still can care for yourself and make decisions for yourself. This is a good time for you and your family to talk about the future.



As Alzheimer's disease symptoms progress, you will need more and more assistance from family members, friends, and caregiving professionals. Your healthcare team, family members, and other caregivers can help determine when you need more support. People you trust will need to help decide:

- When it is no longer safe to drive
- When to provide help managing money
- When it may be time to change living arrangements

Planning ahead helps give you more control later on. You can use the planning tools in the "Planning Ahead" section of this guidebook.

Support for Caregivers

A person with Alzheimer's disease needs more and more support over time. Family members and other caregivers can expect the demands to increase. As they give more and more support, caregivers also need to get more support for themselves.



It can feel very rewarding to care for a loved one. At the same time, family members might feel very tired, angry, guilty, or overwhelmed. They might feel grief or too much stress. As the physical and emotional challenges of caregiving increase, caregivers often need outside help.

Fortunately, help is available. Caregivers who use support services often feel better. With support, family members can often keep their loved one at home for longer.

- **Adult day care programs.** Adult day care centers offer programs for people with Alzheimer's disease and other types of dementia. Activities may include music, exercise, and discussion groups. Caregivers can get a break during the day and feel reassured that their loved one is in good hands.
- **Respite services.** These services provide overnight care for a limited number of days. The setting may be like a nursing home.
- **In-home health care.** A professional caregiver comes to the home either part-time or full-time. The caregiver may be hired privately, through an agency, or as part of a government program.

- **Support groups for caregivers.** Support groups have meetings where caregivers share their feelings and concerns. Caregivers often get helpful ideas and resources from other members. For those who do not have time to attend meetings, there are Internet-based support groups.

To learn about programs in your community, ask your doctor, other healthcare professionals, friends, relatives, religious groups, caregiving professionals, or hospital social workers. Your healthcare team can provide valuable information and support. Doctors, counselors, social workers, home health aides, and others can help with emotional and physical needs. They can help family members as well as patients.

Your local Area Office on Aging can provide information about housing, day care, and other types of support. To find your local office, you can call the Eldercare Locator at 800-677-1116 or visit www.eldercare.gov.

Additional resources include:

- **Alzheimer's Disease Education and Referral Network (ADEAR).** Call 800-438-4380 or visit www.nia.nih.gov/Alzheimers/Caregiving/HomeAndFamily/.
- **Alzheimer's Association.** Call 800-272-3900 or visit www.alz.org. Offers an Internet-based support group.
- **The Family Caregiver Alliance.** Call 800-445-8106 or visit www.caregiver.org.

Living Arrangements

For many caregivers, the time will come when they are no longer able to take care of their loved one at home. It is not too soon to start exploring your choices for the future. Possible living arrangements include:

- Continuing care communities
- Assisted living facilities
- Nursing home care
- In-home health care



Planning Ahead



In the early stage of Alzheimer's disease, when symptoms are still mild, you and your family can plan together for the future. It is very helpful to learn more about the disease and plan for needs that will change as symptoms progress.

Family members need to work together to plan treatment, daily care, future living arrangements, transportation, finances, legal decisions, and long-term care. Members of your healthcare team can help. They can answer many of your questions and direct you to the right resources.

The following tools can help you plan ahead.

Treatment and Support

Talk with your healthcare team to help determine the best treatment plan. Ask your healthcare professional:

What are the treatment choices?



How can we tell if a medicine is working?

What are the possible side effects?

Also ask about resources where family caregivers can get support. Use the space below to note important resources in your community.

Adult day care programs:

Respite services:

In-home healthcare providers or agencies:

Caregiver support groups:



Future Living Arrangements

There may come a time when you need the skills of a full-time healthcare professional. Explore your options and discuss them with a family member or trusted friend. The sooner you start planning, the more likely you will find the options you prefer. Ask your healthcare team about local programs and facilities. Consider the following options:



- **Continuing care communities.** These communities often have an assisted living facility next to a nursing home, so that a person can move if necessary.
- **Assisted living facilities.** In a home-like environment, residents receive some help with daily living. Programs may include meals, recreation, and help with bathing, dressing, medication, and housekeeping.
- **Nursing home care.** Nursing homes offer services and supervision 24 hours per day. This is an option many consider at the late, severe stage of Alzheimer’s disease.
- **In-home health care.** Many people use a local agency to hire a professional caregiver to come to their home.



Local Resources: Use this space to record information about long-term care facilities and services in your community.

Facility/Service
Location
Contact Information
Comments

Facility/Service
Location
Contact Information
Comments



Facility/Service
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Comments

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Comments



Future Care Costs

Work with a trusted family member or friend to estimate costs for your future care. Also work with a financial advisor if possible.

Healthcare Expenses	Estimated Cost
Healthcare visits	\$
Prescription medicines	\$
Caregiver services	\$
Housing	\$
Transportation	\$

Income and Other Resources	Estimated Amount
Insurance and Medicare	\$
Personal savings	\$
Investments	\$
Employee or retirement benefits	\$
Government assistance*	\$
Assistance from community based organizations	\$

*Government assistance which may include:

Medicaid. Covers some or all nursing home costs for persons with limited income and assets. Eligibility and benefits vary from state to state.

Social Security Disability. Assists wage earners under age 65 who can no longer work because of disability.

Supplemental Security Income Program. Guarantees a limited income to persons age 65 and over who are disabled and have limited income and assets.



Legal Arrangements

You should consider getting help from an elder law attorney, an estate attorney, or a public legal assistant in your community. The following legal documents are important in planning ahead:

- **Living will.** This states your choices for future medical care decisions. You state if you want to limit or forego the use of medical or life-support systems to keep you alive.
- **Durable power-of-attorney for health care.** “Durable” means the person you choose can make decisions for you after you can no longer make decisions for yourself. You may choose a trusted family member or friend to make healthcare decisions for you. This person will make decisions about healthcare providers, medical treatment, and end-of-life treatment.
- **Durable power-of-attorney.** You may choose a family member or friend to make legal and financial decisions for you when you can no longer make them on your own.
- **Living trusts.** You can set up a trust and appoint someone else (or a bank) to act as trustee. The trustee’s job is to carefully manage and invest your assets.
- **Will.** Your will names an “executor” who will manage your estate and beneficiaries who will receive your estate at the time of your death.





Moving Forward

This DVD and guidebook program are intended to help you and your family plan ahead.

There will be challenges, but there will also be meaningful times together. You can look forward to the rewards of caring and spending time together.

Resources

Contact the following organizations or find them on the Internet for more information about Alzheimer's disease and support for patients and caregivers.

Alzheimer's Association

800-272-3900

www.alz.org

Alzheimer's Disease Education and Referral Network (ADEAR)

National Institute on Aging

800-438-4380

www.alzheimers.org

Family Caregiver Alliance

800-445-8106

www.caregiver.org

MedlinePlus

National Library of Medicine

www.nlm.nih.gov/medlineplus/alzheimersdisease.html

www.nlm.nih.gov/medlineplus/alzheimerscaregivers.html

National Institute on Aging

Information Center

800-222-2225

www.nia.nih.gov

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Partner

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Established in 1915, the American College of Physicians (ACP) is the nation's largest medical specialty organization and second largest physician group. Its mission is to enhance the quality and effectiveness of health care by fostering excellence and professionalism in the practice of medicine. ACP membership includes about 119,000 members including medical students. Members are physicians in general internal medicine and related subspecialties, including cardiology, gastroenterology, nephrology, endocrinology, hematology, rheumatology, neurology, pulmonary disease, oncology, infectious diseases, allergy and immunology, and geriatrics. Internists treat the majority of adults in the United States.

For more information about internal medicine physicians, please visit:
www.doctorsforadults.com.



Credits

Alzheimer's Disease: A Guide for Patients and Families has been made possible through the expertise, time, and efforts of many individuals who are committed to the health and well-being of Alzheimer's disease patients, caregivers, and family members. Special gratitude to:

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Partner

American College of Physicians

Patrick C. Alguire, MD, FACP

Director, Education and Career Development

Contributors to the Video

Lisa Granville, MD, FACP

Professor and Associate Chair, Department of Geriatrics

Florida State University College of Medicine

William J. Hall, MD, MACP

Director, Center for Healthy Aging

Highland Hospital

University of Rochester Medical Center

Special Thanks to:

Deborah Norville



Project Manager

Adam Blair

Conrad Productions

Author

Nancy Henderson

Freelance Health Writer

Washington, DC

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Alzheimer's Disease:

A Guide for Patients and Families

If you or a member of your family has Alzheimer's disease, learning what to expect and planning ahead can be very helpful. This guidebook and DVD will help you and your family understand Alzheimer's disease and plan for the future.



The DVD features Deborah Norville, anchor of NBC's *Inside Edition*, whose grandmother had Alzheimer's disease. Leading experts will also offer advice in important areas affecting Alzheimer's disease patients and their caregivers.

This program will help you:

- Understand Alzheimer's disease treatment options
- Find the support you need
- Plan future care and living arrangements

