

A Family's Guide to Alzheimer's



See the signs. Start a conversation.
Make a difference.

Contents



What is Alzheimer's disease?

2



What are the signs of Alzheimer's disease?

4



Why is getting a diagnosis important?

6



How do I talk to my loved one?

8



How and where do I get a diagnosis?

10



What are the stages of Alzheimer's?

14



How do I care for my loved one after a diagnosis?

16



Resources and Support

19

What is Alzheimer's disease?



Are you noticing changes in a loved one's memory or how they act? Are you worried it might be Alzheimer's disease?

Even though it can be scary to know that a loved one is having problems that might be Alzheimer's, it is necessary to have a conversation about it and find out the cause.

Alzheimer's is a brain disease that slowly damages memory, thinking ability, and eventually the ability to carry out daily activities. Alzheimer's symptoms start slowly and get worse over time. The changes caused by Alzheimer's are not a normal part of aging.

Alzheimer's is the most common form of dementia. Dementia is the general term for a group of brain disorders that cause problems with thinking, memory, and behavior severe enough to interfere with daily activities of life. Dementia can be caused by disease or other conditions. Getting a diagnosis for what is causing dementia symptoms is important because some of the conditions that cause dementia are reversible with the right treatment.

If it is Alzheimer's, there are potential treatments to help with symptoms and quality of life, and resources to help family caregivers. You should see a doctor as soon as possible if someone you love is experiencing memory problems or changes in behavior.



Quick Facts:

The second most common form of dementia is cerebrovascular, which is caused by strokes or other problems with blood flow to the brain.

Some other causes of dementia are Lewy body disease, frontotemporal dementia, Parkinson's disease, and mixed dementia (dementia from more than one cause).¹

Thinking and memory problems can also be caused by conditions like depression, thyroid problems, vitamin deficiencies, certain medications, or excessive use of alcohol. Dementia that is due to these conditions can potentially be reversed with appropriate treatment.²

Family and friends who provide support and services to someone with dementia can be considered caregivers. This booklet has useful information, tips, and resources for caregivers.

What are the signs of Alzheimer's disease?

This checklist can help you spot signs of Alzheimer's.³

- | | |
|--|---|
| 1. Memory loss that disrupts daily life | <input type="checkbox"/> Typical Age-Related Change: Sometimes forgets names or appointments but remembers them later.
<input type="checkbox"/> Sign of Alzheimer's: Needs frequent reminders about the day's schedule, asks the same question over and over, or forgets family birthdays or children's names. |
| 2. Challenges in planning or solving problems | <input type="checkbox"/> Typical Age-Related Change: Makes occasional errors when managing finances or household bills.
<input type="checkbox"/> Sign of Alzheimer's: Has trouble following a familiar recipe or paying monthly bills. |
| 3. Difficulty completing familiar tasks | <input type="checkbox"/> Typical Age-Related Change: Needs occasional help with the microwave or recording a TV show.
<input type="checkbox"/> Sign of Alzheimer's: Has trouble getting to a familiar location. |
| 4. Confusion with time or place | <input type="checkbox"/> Typical Age-Related Change: Gets confused about the day of the week but figures it out later.
<input type="checkbox"/> Sign of Alzheimer's: Loses track of dates, seasons, and the passage of time. Forgets where they are and how they got there. |
| 5. Trouble understanding visual images and spatial relationships | <input type="checkbox"/> Typical Age-Related Change: Has vision changes due to cataracts.
<input type="checkbox"/> Sign of Alzheimer's: Has difficulty with reading, judging distance, or colors. |



6. New problems with words in speaking or writing

- Typical Age-Related Change:** Sometimes has trouble finding the right word.
- Sign of Alzheimer's:** Has trouble with familiar vocabulary (such as calling a “watch” a “hand clock”) or difficulty joining or keeping up with a conversation.

7. Misplacing things and losing the ability to retrace steps

- Typical Age-Related Change:** Misplaces things from time to time and has to retrace steps to find them.
- Sign of Alzheimer's:** Puts things in unusual places such as house keys in the refrigerator. Loses things and is unable to retrace steps to find them. May accuse others of stealing items they can't find.

8. Decreased or poor judgment

- Typical Age-Related Change:** Makes a bad decision or mistake once in a while, like neglecting to change the oil in the car.
- Sign of Alzheimer's:** Displays poor judgment when handling money. Pays less attention to grooming or personal hygiene.

9. Withdrawal from work or social activities

- Typical Age-Related Change:** Sometimes needs a break from work, family, or social obligations.
- Sign of Alzheimer's:** Withdraws from hobbies and activities that involve people or has trouble following a favorite team.

10. Changes in mood and personality

- Typical Age-Related Change:** Becomes irritable when a routine is disrupted.
- Sign of Alzheimer's:** Shows extreme anxiety or anger with a change in routine.

Why is getting a diagnosis important?



There is no cure or effective long-term treatment that can stop or reverse Alzheimer's. Some medications may help manage the symptoms for a while, but the condition gets worse over time. In general, treatments are more effective when they are started early. See a doctor as soon as you notice symptoms that are different from normal aging.

Benefits to early intervention

- A doctor can determine the cause of the symptoms. Some conditions that cause dementia can be treated or reversed.
- In the early stage of Alzheimer's, medication may help manage some of the symptoms and provide a higher quality of life.
- Diet, exercise, and activity can help manage some of the symptoms and can help protect overall health.
- When Alzheimer's is diagnosed early, your loved one can be involved in expressing their wishes and priorities.
- Families have more time to make long-term plans, including legal, financial, and care decisions as the symptoms change.
- Families have more time to decide who will provide care and how to support one another.

“Trust what you are seeing with your loved one. It may not be the thing you fear most, but you need to get a diagnosis to be sure.”

PATTY BORDIE, DIRECTOR, AREA AGENCY ON AGING OF THE CAPITAL AREA
AND A CAREGIVER FOR A PARENT WITH DEMENTIA



Quick Fact:

Planning is about more than managing the disease with your doctor. It's also about deciding how to share the diagnosis with friends and family, get support, and take care of yourself as you take care of your loved one.

How do I talk to my loved one?



Discussing your concerns with a loved one is the first step in early intervention. It may feel awkward or uncomfortable when you notice changes in a parent or spouse. However, by the time you notice problems with memory or behavior, changes are already occurring in the brain. The sooner you start the conversation, the sooner you can get help.

See the signs. Start a conversation.⁴

- Choose a time to have the conversation when you and your loved one aren't busy or tired.
- Pick a place that is familiar, comfortable, and quiet.
- Decide in advance what you're going to say.
- Keep your words simple, gentle, and reassuring.
- Begin by asking if they've noticed any differences in their behavior.
- Say you're concerned and give a few examples why.
- Listen when they express worry about memory loss or difficulty doing usual activities.
- Say "tell me more" to show your concern and that you're willing to talk about it.
- Encourage them to see a doctor to find out what is causing memory loss.
- Offer to go to the doctor with them for support.



Quick Facts:

In a recent survey, 85% of people said they would want to know early if they had Alzheimer's. Most people said they want to participate in planning, get early treatments, and know what is happening to them.¹

Everyone age 65 and older who has Medicare can receive a cognitive assessment as part of their annual wellness visit. A cognitive assessment includes an exam, medical history, and a series of questions. Experts recommend getting annual memory screenings as part of routine health care, much like how tracking blood pressure can help identify possible heart disease.

How and where do I get a diagnosis?



Most people begin by talking with their loved one's primary doctor, if they have one. You can request an appointment for a cognitive assessment (tests for thinking and memory) or family meeting to share your concerns. Decide in advance who will attend the appointment and who will take notes during the visit. If you have information to share with the doctor that might be upsetting to your loved one, contact the office staff before the appointment and ask the doctor to review the information. Not everyone can be diagnosed in a single visit. Be prepared to follow up with the doctor to ensure they have all the information needed to make a diagnosis.

What do I take to the doctor appointment?

- A list of all prescription and non-prescription medications and the doses your loved one takes or take the medication bottles with you.
- A list of your loved one's current health conditions.
- Specific examples of changes in memory, thinking, or behavior, along with a timeline of when you first noticed changes and how they have changed over time.
- A list of questions or concerns you want to ask or discuss with the doctor.
- Be prepared to be open and honest with any questions they may have.
- Consider asking another family member to attend to take notes.

What should I expect from the appointment?

- You should have time to discuss your top concerns and the changes you have observed. Refer to your notes to make sure you cover everything. You can also share your notes with the doctor.
- The doctor may conduct tests during the appointment to assess memory and thinking or may refer you to a specialist. See page 13 for a list of specialists who diagnose dementia.
- Discuss what medications and non-medical treatments are appropriate.
- Discuss whether in-home health care is needed to help your family provide daily care for your loved one.
- Discuss a care plan for your loved one. The care plan describes how often your loved one will see the doctor, what treatments they will follow, and what other health care professionals will be involved. The doctor may recommend a counselor or social worker who can talk with your family about your loved one's needs and direct you to resources.



Quick Fact:

The doctor may not observe a problem with your loved one during the appointment. It is common for people to act normal for short periods. You may need to ask for additional testing or a referral to a specialist, and in some cases, you may also want to get a second opinion from another doctor.

Potential questions you may want to ask the doctor:

- Tests to get a diagnosis
 - > *What tests are needed to make a diagnosis?*
 - > *Can you assess thinking and memory skills to make a dementia diagnosis? Or does my loved one need to see a specialist?*
- Treatments and care plan
 - > *What medications are available?*
 - > *How will you help us create a care plan and coordinate care with other health care professionals my loved one is seeing?*
- Community resources
 - > *What community resources are available to help my family?*
- Safety
 - > *Should my loved one be driving?*
- Clinical trials
 - > *Should I consider a clinical trial for a new treatment or medication?*
 - > *Can you help me find a clinical trial that might be right for my loved one?*
- Next appointment
 - > *When is our next doctor visit?*
 - > *How often should we schedule doctor visits?*



Quick Fact:

When you don't understand something, it is okay to ask the doctor to explain it again. Use statements like these:

- *I don't understand what you are telling me. Will you please explain it in a different way?*
- *Here's what I heard you say. Is this accurate?*
- *Will you please review your care instructions to make sure I wrote them down correctly?*

How does a doctor make a diagnosis?

There is no single diagnostic test that can determine if a person has Alzheimer's. Getting a diagnosis may require several tests and assessments, including:

- A thorough medical history and physical exam;
- Laboratory tests such as blood work and urinalysis that can indicate physical causes of the changes;
- Imaging tests such as an MRI or CT scan that show the structure of the brain;
- Depression screening;
- Cognitive assessment to evaluate thinking and memory; and
- Interviews with people who know the person well and can describe the changes.

What if my loved one does not have a primary doctor?

- Check with your local [Alzheimer's Association](#) for information about getting a free memory screening in your community.
- Contact your local [Area Agency on Aging](#) for information.
- Many communities have health clinics that offer screenings and can connect you with health services. See Resources and Support beginning on page 19 for more information.
- Make an appointment with a local specialist (examples listed below) who is experienced in diagnosing dementia or with a memory disorders clinic. Be aware that it may take several months to get an appointment because there is currently a shortage of specialists in Texas.
- Specialists who may be able to evaluate memory and thinking issues and diagnose dementia:⁵
 - > Neurologist – medical doctor who specializes in treating diseases of the brain.
 - > Geriatric psychiatrist – medical doctor who specializes in mental health for older adults.
 - > Neuropsychologist – mental health professional with special training in brain disorders.
 - > Geriatrician – primary care doctor who specializes in treating older adults.
- In Texas, there is one national center of excellence in dementia care and research called the Biggs Institute for Alzheimer's and Neurodegenerative Diseases at The University of Texas (UT) Health San Antonio. The Resources and Support section beginning on page 19 provides contact information.

What are the stages of Alzheimer's?



Changes to the brain begin years before Alzheimer's is diagnosed. The disease affects people in different ways, and symptoms appear at different times. Most people move through three general stages of Alzheimer's. These stages are described below to give you an idea of what to expect as the disease changes over time.⁶

Early-stage Alzheimer's (mild)

A person may function independently and may work, drive (in certain conditions), and have normal social activities. They may be aware of memory problems, such as forgetting common words or where they put everyday items. Family members and close friends may notice they have problems with memory and ordinary tasks.

This is a critical time for family planning and focusing on aspects of their life that are most important. Talk with your loved one about their wishes for their future care. Prepare legal, financial, and health care documents you will need. To help with symptoms, make changes to diet and health routines. Begin the discussion about whether it is safe for your loved one to drive.

Middle-stage Alzheimer's (moderate)

This is typically the longest stage and can last for many years, with symptoms getting worse over time. The person may get frustrated or angry, have changes in their personality and behavior, and need help with routine tasks. They should not be driving. This is the stage where wandering, sleeplessness, and confusion appear.

During this stage, the person may live at home but will need daily help. Simplify tasks as much as possible.

Late-stage Alzheimer's (severe)

Over time, the person loses the ability to respond to their environment, carry on a conversation, and eventually control movement. They need help around the clock.

In this stage, the person cannot initiate conversations or interactions but may still enjoy being with others through activities like listening to music.

Adapted from the [Alzheimer's Association](#).⁶



Quick Fact:

About 1 in 9 Americans age 65 and older has Alzheimer's. Increasing age is the greatest known risk factor.¹

How do I care for my loved one after a diagnosis?



Getting an Alzheimer's diagnosis can be overwhelming. You may need time to adjust before you share the information with others, but you should begin making long-term plans as soon as possible. There are steps that can help you feel more in control and prepared for the future.

Make a plan for long-term care.

Talk with your loved one about their wishes for long-term care. Determine whether in-home care support is needed now. Consider what changes the family can make to provide care in the home for as long as possible and learn about options for later on.

Make legal and financial decisions now.

Discuss legal and financial matters with your loved one while they can make their wishes known. Talk with your attorney, if you have one, about the legal documents you need for financial and health care matters. Discuss changes to your employment and who will pay bills and make medical decisions. The Resources and Support section beginning on page 19 provides suggestions for legal resources if you do not have an attorney.

Make the living environment safe.

Determine the needs of your loved one. Reduce the risk of falls, cooking accidents, wandering, and other common hazards. Removing rugs, adding locks, improving lighting, and making other changes around the house can make it safer for a person to live at home longer. Talk about whether it is safe for your loved one to drive.

Make a care team with family and friends.

Caregivers often divide up responsibilities for transportation, shopping, meal preparation, giving medication, staying with the loved one when the primary caregiver needs a break, and other activities. Some families find that a private shared online calendar or private social networking page are good ways to share information. Designate one person who will keep family and close friends informed.

Connect with caregiver resources.

Contact local support organizations like the Alzheimer's Association and the Area Agencies on Aging for information about Alzheimer's, what changes to expect, ways to care for your loved one at home, and how to care for yourself as a caregiver. Consider a caregiver support group to learn from other caregivers about providing care to a loved one and caregiver self-care.

Here are some tips shared by caregivers who are caring for a loved one with Alzheimer's.

- Take advantage of caregiver education, support, and respite (when caregivers need a break) programs, especially if you are the sole caregiver. If you burn out or get sick, it will be harder on you and your loved one and could make it difficult for them to live at home.
 - Keep a running list of notes, questions, and behaviors you notice to share with the doctor. Keep the list in a safe and accessible location.
 - Make sure the doctor knows about your own health concerns and issues in your life that may affect your loved one's care plan.
 - Include your family and close friends (if possible) in understanding how to care for your loved one.
 - If you are stressed for time, connect with helplines you can call any hour of the day or night, or take advantage of technology to connect with online support groups.
 - Every family has a different journey but connecting with other caregivers helps you find common concerns and share tips. It helps to know you are not alone.
-

“My recommendation is that you have a family meeting to discuss who will be the primary caregiver and what role each person will play. It’s difficult, but in the long run it’s best to make decisions early rather than waiting until you have to make them.”

ANDREA TAURINS, CAPITAL OF TEXAS ALZHEIMER'S ASSOCIATION



Caregiver Advice:

You will have to reach out to many different resources to get the help and information you need. There is not a single resource that does it all. You will likely have to talk with many types of professionals as well as other caregivers to best care for your loved one and yourself. Don't be surprised if you have to leave messages and a contact phone number for many resources in the community. Be patient. They will call you back.

Resources and Support

Alzheimer's Support Organizations in Texas

These resources provide information and support for people with Alzheimer's disease and other dementias and their caregivers, families, and friends. Contact them for information about getting a diagnosis, treatment, disease management, risk factors, and family caregiver information and support.

Alzheimer's Association

800-272-3900 (24/7 Helpline)

TDD: 866-403-3073

alz.org

Alzheimer's Alliance of Smith County (Tyler)

903-509-8323

alzalliance.org

Alzheimer's Texas (Central Texas)

512-241-0420 (24/7 Helpline)

txalz.org

Resources Available Through Texas Health and Human Services Commission (HHSC)

Call 2-1-1

211texas.org

2-1-1 is a hotline service for people looking for community and care services.

Area Agencies on Aging (AAA)

800-252-9240

apps.hhs.texas.gov/contact/aaa.cfm

The 28 area agencies on aging provide services to help people age 60 and older, their family members, and caregivers with information and referrals, benefits counseling, and assistance for Medicare and Medicaid, care coordination, caregiver support services, in-home support services, legal awareness, nutrition services, and an ombudsman program for information on care facilities.

Aging and Disability Resource Center (ADRC)

855-937-2372

hhs.texas.gov/services/aging/long-term-care/aging-disability-resource-center

ADRCs can help you find and apply for long-term care programs for seniors and people with disabilities.

Resources for Getting a Diagnosis

The Biggs Institute for Alzheimer's and Neurodegenerative Diseases at UT Health San Antonio

210-450-9960

biggsinstitute.org

This is a National Institute on Aging (NIA)-designated Alzheimer's Disease Research Center. Contact them for information about getting a diagnosis, clinical trials, and educational resources.

Federally Qualified Health Centers (FQHCs)

Health Resources & Services Administration (HRSA) Contact Center: 877-464-4772; TTY: 877-897-9910

findahealthcenter.hrsa.gov

FQHCs are community-based health care providers that receive funds from the HRSA Health Center Program to provide primary care services in underserved areas. They provide services regardless of patients' ability to pay and charge for services on a sliding fee scale. Use this search tool to find an FQHC in your area.

Resources for Legal Support and Advance Directives

Legal Hotline for Texans

800-622-2520

tlsc.org

The Legal Hotline for Texans offers free legal advice, self-help publications, and referrals for Texans over the age of 60 and Texans who receive Medicare.

Texas Health and Human Services Commission (HHSC) Advance Directives

hhs.texas.gov/laws-regulations/forms/advance-directives

Provides information about legal, financial, and health directives and free forms.

Caregiver Support

Take Time Texas

apps.hhs.texas.gov/taketimetexas

Respite care is a temporary rest or a break from providing care for others so that primary caregivers may take time to care for themselves. Visit the Take Time Texas website to learn more about respite care in your area.

AARP Caregiver Resource Center (National)

877-333-5885 (888-971-2013 in Spanish)

aarp.org/caregiving

Caregiver Action Network (National)

855-227-3640

caregiveraction.org

Family Caregiver Alliance (National)

800-445-8106

caregiver.org

National Resources to Learn About Alzheimer's and Other Dementias

Alzheimers.gov (In English)

alzheimers.gov/es (En Español)

Provides information in English and Spanish on Alzheimer's and other dementias, resources for people living with dementia and their family caregivers, and clinical trials.

Alzheimer's Disease and Related Dementias

Education and Referral (ADEAR) Center

800-438-4380; TTY: 800-222-4225

nia.nih.gov/health/alzheimers

Provides current and comprehensive information on Alzheimer's disease and other dementias from the National Institute on Aging.

Additional Information

Find out more about Alzheimer's disease, ways to start a conversation with your loved one, and available community resources in Texas at dshs.texas.gov/alzheimers.

Note: External links to other sites are intended to be informational and do not have the endorsement of the Texas Department of State Health Services. These sites may also not be accessible to persons with disabilities.

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TEXAS
Health and Human
Services

Texas Department of State
Health Services