

Diagnosis Packet

You are receiving this packet in response to your concern about your memory. We applaud you for reaching out for information and support.

This tip sheet includes excerpts and information from the Alzheimer's Association website (www.alz.org) regarding [diagnosis](#).

Alzheimer's is diagnosed through a complete medical assessment. If you have concerns about memory loss or other symptoms of Alzheimer's or dementia, it is important to be evaluated by a physician.

Having trouble with memory does not mean you have Alzheimer's. Many health issues can cause problems with memory and thinking. When dementia-like symptoms are caused by treatable conditions — such as depression, drug interactions, thyroid problems, excess use of alcohol or certain vitamin deficiencies — they may be reversed.

This packet includes the following:

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10 Steps to Approach Memory Concerns

What to do when you notice changes in yourself

If you've noticed changes in yourself and are concerned for your health — particularly when it's related to memory, thinking or behavior — it can be difficult to know what to do. It's natural to feel uncertain or nervous about discussing these changes with others, and sometimes voicing these worries can make them seem more “real.” However, these are significant health concerns and it's important to seek support. The steps below can help you feel more confident as you assess the situation and take action.

ASSESS THE SITUATION

1. What changes in memory, thinking or behavior are you noticing?

What's happening that feels out of the ordinary and is causing you concern?

2. What else might be going on?

Various conditions can cause changes in memory, thinking and behavior. Are there any health or lifestyle issues that could be a factor? E.g., family stress or medical problems like diabetes or depression.

3. Learn about the signs of Alzheimer's and other dementias and the benefits of an early diagnosis.

Visit [alz.org/10signs](https://www.alz.org/10signs) to educate yourself on the Association's 10 Warning Signs of Alzheimer's and why it's important to know if dementia or something else is causing the changes. Do you notice any of the signs in yourself?

4. Has anyone expressed concern to you about changes they've observed?

What did they notice?

HAVE A CONVERSATION

5. The unknown can be scary for many people, especially when it involves your health. Many people find it helpful to confide in someone they trust rather than face the issue alone. Who could you discuss your concerns with?

It could be a family member or friend, or a combination — whatever is most comfortable for you.

» Name(s): _____

6. Have a conversation as soon as possible. When is the best time to do so?

Is there a place where everyone will feel comfortable discussing your concerns?

» Date: _____

» Time: _____

» Location: _____

7. How will you approach the conversation?

Try the following:

» I've noticed [change] in myself, and I'm concerned. Have you noticed anything about me that worries you?

» Write additional conversation starters below.

8. Ask the person to go with you to the doctor.

When dealing with possible memory or behavioral issues, it can be helpful to bring someone you trust with you to the doctor. In addition to providing support, the person can help with asking the doctor questions and making sure you capture the information provided.

Try the following:

» I think it would give me peace of mind to see a doctor and find out what's going on. Would you be willing to go with me for support?

» Write your own ideas below.

9. If needed, have multiple conversations.

Some people may not take your concerns seriously and attribute them to stress or normal aging. However, you know yourself and the validity of your concerns best. Write down some notes about the experience to help plan for the next conversation — whether it's with the same person or someone else you trust.

- » Location took place: _____
- » Date/time of day: _____
- » What worked well? _____
- » What didn't? _____
- » What was the result? _____
- » What can be done differently next time? _____

REACH OUT FOR HELP

10. Turn to the Alzheimer's Association® for information and support.

- » Call our **24/7 Helpline (800.272.3900)** to speak with a master's-level clinician about your concerns and next steps.
- » Visit **Alzheimer's Association & AARP Community Resource Finder (alz.org/CRF)** to find local resources, such as health care professionals, and your closest Association chapter.
- » Explore **Evaluating Memory and Thinking Problems: What to Expect (alz.org/evaluatememory)** to learn what a typical medical evaluation may include.

10 Warning Signs of Alzheimer's

If you notice any of these signs, take action.

Use this form to note your concerns so you can address them with a friend, family member or doctor.

- 1. MEMORY LOSS THAT DISRUPTS DAILY LIFE.** One of the most common signs of Alzheimer's disease, especially in the early stage, is forgetting recently learned information. Others include forgetting important dates or events, asking the same question over and over again, or increasingly needing to rely on memory aids (e.g., reminder notes or electronic devices) or family members for things the person used to handle on their own.

What's a typical age-related change? Sometimes forgetting names or appointments, but remembering them later.

- 2. CHALLENGES IN PLANNING OR SOLVING PROBLEMS.** Some people living with dementia may experience changes in their ability to develop and follow a plan or work with numbers. They may have trouble following a familiar recipe or keeping track of monthly bills. They may have difficulty concentrating and take much longer to do things than they did before.

What's a typical age-related change? Making occasional errors when managing finances or household bills.

- 3. DIFFICULTY COMPLETING FAMILIAR TASKS.** People living with Alzheimer's disease often find it hard to complete routine tasks. Sometimes they may have trouble driving to a familiar location, organizing a grocery list or remembering the rules of a favorite game.

What's a typical age-related change? Occasionally needing help to use microwave settings or to record a TV show.

- 4. CONFUSION WITH TIME OR PLACE.** People living with Alzheimer's can lose track of dates, seasons and the passage of time. They may have trouble understanding something if it is not happening immediately. Sometimes they may forget where they are or how they got there.

What's a typical age-related change? Getting confused about the day of the week, but figuring it out later.

- 5. TROUBLE UNDERSTANDING VISUAL IMAGES AND SPATIAL RELATIONSHIPS.** For some people, vision problems are a sign of Alzheimer's. They may also have problems judging distance and determining color or contrast, causing issues with driving.

What's a typical age-related change? Vision changes related to cataracts.

- 6. NEW PROBLEMS WITH WORDS IN SPEAKING OR WRITING.** People living with Alzheimer's may have trouble following or joining a conversation. They may stop in the middle of a conversation and have no idea how to continue, or repeat themselves. They may struggle with vocabulary, have trouble naming a familiar object or use the wrong name.

What's a typical age-related change? Sometimes having trouble finding the right word.

- 7. MISPLACING THINGS AND LOSING THE ABILITY TO RETRACE STEPS.** A person living with Alzheimer's may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. He or she may accuse others of stealing, especially as the disease progresses.

What's a typical age-related change? Misplacing things from time to time and retracing steps to find them.

- 8. DECREASED OR POOR JUDGMENT.** Individuals may experience changes in judgment or decision-making. For example, they may use poor judgment when dealing with money, or pay less attention to grooming or keeping themselves clean.

What's a typical age-related change? Making a bad decision once in a while, like neglecting to change the oil in the car.

- 9. WITHDRAWAL FROM WORK OR SOCIAL ACTIVITIES.** A person living with Alzheimer's may experience changes in the ability to hold or follow a conversation. As a result, he or she may withdraw from hobbies, social activities or other engagements. They may have trouble keeping up with a favorite team or activity.

What's a typical age-related change? Sometimes feeling uninterested in family or social obligations.

- 10. CHANGES IN MOOD AND PERSONALITY.** Individuals living with Alzheimer's may experience mood and personality changes. They may be easily upset at home, at work, with friends or when out of their comfort zone.

What's a typical age-related change? Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

WHAT'S NEXT?

If you're concerned that you or someone you know is displaying any of these signs, take action:

Talk to someone you trust. It can be helpful to confide in a friend or family member. For tips on how to have a conversation, visit alz.org/memoryconcerns.

See a doctor. Get a full medical evaluation to determine if it's Alzheimer's or something else. Early diagnosis gives you a chance to plan for the future, access support services and explore medication that may address some symptoms for a time. Visit alz.org/evaluatememory to learn what an evaluation may include.

Get support and information. Call the **Alzheimer's Association 24/7 Helpline (800.272.3900)** or visit alz.org/10signs.

Note: This list is for information only and not a substitute for a consultation with a qualified medical professional.

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Preparing for Your Doctor's Visit

Fill out the information below to the best of your ability. Share it with your doctor. Be open and honest in answering any questions your doctor may ask you about the changes you've been experiencing.

Has your health, memory or mood changed?

How did it change?

When did you first notice the change?

How often does it happen?

When does it happen? Is it always at a certain time of day?

What do you do when it happens?

What behaviors are the same?

Do you have problems with any of the following?

Please check the answer.

Repeating or asking the same thing over and over?

- ☐ Not at all
- ☐ Sometimes
- ☐ Frequently
- ☐ Does not apply

Remembering appointments, family occasions, holidays?

- ☐ Not at all
- ☐ Sometimes
- ☐ Frequently
- ☐ Does not apply

Writing checks, paying bills, balancing the checkbook?

- ☐ Not at all
- ☐ Sometimes
- ☐ Frequently
- ☐ Does not apply

Shopping independently (e.g., for clothing or groceries)?

☐ Not at all ☐ Sometimes ☐ Frequently ☐ Does not apply

Taking medications according to the instructions?

☐ Not at all ☐ Sometimes ☐ Frequently ☐ Does not apply

Getting lost while walking or driving in familiar places?

☐ Not at all ☐ Sometimes ☐ Frequently ☐ Does not apply

Medications and medical history

List of medications (dosage, frequency) including over-the-counter and prescription:

List vitamins and herbal supplements:

List current medical conditions:

List past medical conditions:

Questions to ask the doctor

What are tests I need to take and how long will it take to get a diagnosis?

Will you refer me to a specialist?

Could the medicines I'm taking be causing my symptoms?

Do I have any other conditions that could be causing my symptoms or making them worse?

What should I expect if it is Alzheimer's?

Which treatments are available for Alzheimer's? What are the risks and benefits and possible side effects?

What about participating in a clinical trial? What are the risks and benefits?

Is there anything else I should know?

When should I come back for another visit?

Some information in this tool was developed for the Chronic Care Networks for Alzheimer's Disease (CCN/AD) project and is the joint property of the Alzheimer's Association and the National Chronic Care Consortium.

Diagnosis Information

Importance of Early Diagnosis

Although Alzheimer's disease cannot yet be prevented, reversed, or cured an early diagnosis allows people with dementia and their families:

- A better chance of benefiting from treatment.
- More time to prepare. Visit www.alz.org/i-have-alz and click on the Plan for Your Future section.
- Decreased anxiety about unknown problems.
- Increased chances of participating in drug studies and helping to find a cure or better treatments. Visit <https://trialmatch.alz.org/find-clinical-trials> to learn about studies you can join.
- An opportunity to participate in decisions about care, transportation, [living options](#), [financial](#) and [legal matters](#). Visit www.alz.org/i-have-alz for more information.
- Time to develop a relationship with doctors and to build a stronger support network.
- Benefit from care and support services, making it easier for them and their family to manage the disease. [Alzheimer's Navigator](#) (www.alzheimersnavigator.org) can help identify needs and create action plans. In-office and telephone-based care consultations with a trained dementia specialist are also available.

Finding the right doctor

Experts estimate a skilled physician can diagnose Alzheimer's with more than 90 percent accuracy. The first step in following up on symptoms is finding a doctor you feel comfortable with. Many people contact their regular primary care physician or internist about their concerns regarding memory loss. Primary care doctors often oversee the diagnostic process themselves. Your primary care doctor may refer you to a physician who specializes in the diagnosis and treatment of Alzheimer's disease and related dementias.

Specialists include:

- **Neurologists**, who specialize in diseases of the brain and nervous system.
- **Psychiatrists**, who specialize in disorders that affect mood or the way the mind works.

Contact the 24/7 Helpline at 800.272.3900 or go to the website (www.alz.org/greatermissouri) for a list of options for specialists in your county.

Steps to diagnosis

There is no single test that proves a person has Alzheimer's. A diagnosis is made through a complete assessment that considers all possible causes.

As part of the diagnostic procedure a physician might:

- Ask about your **medical history and review your current medications.**
- Conduct a **physical exam to check for other physical concerns that could cause confusion.**
- Conduct a **neurological exam**, including testing **memory, problem-solving, and other thinking skills.**
- Conduct a **mood assessment** to detect depression or other mood disorders.
- Order **lab tests.**
- Order **brain imaging** (such as MRI, CT or PET scan).

Making the Visit Easier

- **Call ahead and explain your concerns.**

Let the doctor and office staff know in advance that you have been experiencing some increased confusion. It may be possible for them to schedule the visit for a time when there may not be a long wait and when the office may not be crowded to reduce the stress of the situation. You may also want to schedule the appointment for your best time of day.

- **Plan your trip in advance.**

Know where you are going, where to park, how long it will take to get there, and if you need to use stairs or elevators. Allow enough time without rushing, but not so much time that you will be early and have to wait longer.

- **Bring a pad of paper and a pencil.**

You may be receiving a large amount of important information from your doctor and it may be difficult to remember everything said at the appointment. Keeping a record of the appointment and the information you received can be helpful and can also be shared with family members. Have a family member or friend help to take notes while you listen.

- **Take someone with you.**

Ask your spouse, a friend, or a family member to go with you. A second person could be the one to bring blank paper and take notes while talking with the doctor.

- **Bring distractions in case of a wait.**

You could bring snacks or things that could keep you busy while waiting to see the doctor. You could also take a walk and check-in once in a while with the office staff.

Evaluating Memory and Thinking Problems: What to Expect

Your doctor will likely take multiple steps in order to evaluate your memory and thinking. The evaluation may be divided into several visits, allowing time to gather information to accurately determine the cause of your concerns and rule out other possibilities. Understanding the type and purpose of the tests your doctor(s) may order and knowing what to expect during an evaluation can be empowering and help to ease anxiety.

Medical history and physical exam



To obtain information to assist with diagnosis, your doctor may:

- Ask you about your past and current medical problems and concerns.
- Review all of the medications you currently take, as well as those you took in the past.
- Ask you about your diet and use of alcohol.
- Ask you about medical conditions present in your family.

With your permission, the doctor may also talk to your family members to gain additional insight that can help with reaching a diagnosis.

During a physical exam, your doctor may:

- Check your blood pressure, temperature and pulse.
- Listen to your heart.
- Perform other procedures to assess your overall health.

Lab tests



The doctor may order various lab tests to assist in detecting potential causes for your symptoms.

- **Bloodwork.** Your doctor may order bloodwork to check for a thyroid hormone or vitamin deficiency, to rule out infection or to check how organs such as your liver and kidneys are functioning.
- **Urinalysis.** The doctor may request a urine sample to screen for infection and assess kidney function.
- **Cerebrospinal fluid (CSF) analysis.** In some cases where additional information is needed, the doctor may order an analysis of proteins in CSF. During this procedure, a sample of CSF is collected via a spinal tap.

Evaluating Memory and Thinking Problems: What to Expect

Mental health and cognitive status tests

Depression screening. Your doctor may ask you questions to determine if you have symptoms of depression, because depression can cause memory and thinking problems.



Mental cognitive status tests. These tests are used to evaluate your memory, your problem-solving skills and other thinking skills.

- Some tests are very brief. For example, you may be asked about the date and time, asked to remember a short list of words or asked to do simple math calculations. Other tests can involve more time and complex problem solving.
- Some doctors may ask you to participate in a more comprehensive evaluation known as a neuropsychological exam, which uses multiple tests and evaluates many cognitive areas, including executive function, judgment, attention and language.

Brain imaging

Imaging technology is used to evaluate the structure and function of the brain.



- **Computed tomography (CT)** and **magnetic resonance imaging (MRI)** scans are used to see the structure of the brain. These scans can show brain shrinkage. They can also rule out conditions that may cause symptoms similar to Alzheimer's disease, but that require different treatment (such as a brain tumor, aneurysm, bleeding in the brain, nerve injury, stroke or the buildup of fluid in the brain). An MRI scan yields higher-resolution images and usually takes a bit longer than a CT scan. Your doctor may order an MRI scan to provide more information about an abnormality seen on a CT scan.
- **Positron emission tomography (PET)** and **single photon emission computed topography (SPECT)** scans are used to evaluate brain function. In both, a radioactive tracer (radiopharmaceutical) is injected into the bloodstream. Analyzing the movement of the tracer helps the doctor to evaluate functions such as blood flow through the brain or the brain's use of glucose.

Results and Next Steps

If lab tests were ordered, the doctor may be able to discuss preliminary results of some of the tests, but complete results may take several days.

What Now?

If a problem has been identified, further tests or follow-up visits may be needed. The doctor may refer you to a specialist, such as a neurologist or psychiatrist for a more in-depth diagnosis.

Treatment may be recommended by the doctor depending on the diagnosis. Medication may be prescribed, so you may need to consider who will help you to manage the medicine.

People often receive a diagnosis of Alzheimer's disease or other types of dementia with no discussion about the medical assistance that may be available to treat symptoms of the disease. You should be prepared to:

- **Ask about current treatments for your diagnosis**

Some medicines may help you maintain higher levels of functioning for longer periods of time. If you have not been prescribed any medicine for AD, ask the doctor about the possible benefits of Aricept, Exelon, Razadyne, or Namenda. There are also many different drug studies currently underway across the country, and you may be able to participate. Call the 24/7 Helpline at 800.272.3900 or visit the website (www.alz.org/greatermissouri) for information about research for new medications.

- **Receive treatment for any other medical conditions**

Other health problems can worsen the symptoms of AD. These problems include: urinary tract infections or any kind of inflammation, thyroid disturbance, vitamin deficiencies, and viruses. Make sure to consult with the doctor regarding any condition which may worsen the symptoms of AD.

- **Discuss any mood or behavior changes**

Doctors can treat some of the symptoms of AD including: depression, irritability, agitation, or sleeplessness. Often the symptoms associated with AD respond to these medications. This will help you to cope with the disease.

- **Ask about community resources**

Resources and support services are available on the website or by calling the 24/7 Helpline, including lists of Neurologists, Psychiatrists, Geriatric Assessment Programs, local community resources, and information about specific programs for people with memory loss.

Life After Diagnosis

“If we’d had a correct diagnosis even two years earlier, it would have given us more time to plan, to do the things that can result in a good quality of life and to accomplish things we always wanted to do that got postponed for this reason or that.” –Person with memory loss.

Once testing is complete, the doctor will review results and share conclusions.

A diagnosis of Alzheimer’s disease reflects a doctor’s best judgment about the cause of a person’s symptoms. You may want to ask the doctor to explain:

- Why is the diagnosis Alzheimer’s?
- Where am I in the course of the disease?
- What can I expect in the future?

Find out if the doctor will manage care going forward and, if not, who will be the primary doctor. The diagnosing doctor can then schedule the next appointment or provide a referral.

A diagnosis of Alzheimer’s disease is life-changing for both diagnosed individuals and those close to them. While there is currently no cure, treatments are available that may help relieve some symptoms. **Research has shown that taking full advantage of available treatment, care and support can make life better.**

Finding support

The Alzheimer’s Association is here to help you live with Alzheimer’s disease and other types of dementia.

- Call our 24/7 Helpline (800.272.3900) for information, referrals, and care consultation.
- Contact www.alz.org/greatermissouri to learn about our programs and services tailored to your needs including *Let’s Talk* (founded by Ted Grazman), a phone support program where those with early stage dementia can discuss their experiences. Other programs include *Living with Alzheimer’s*, our time-limited education and support program, and opportunities including Meet Up and Cardinals Reminiscence League that provide fun, social and cultural activities.
- Visit www.alz.org/i-have-alz to learn more about your condition.
- Join our online message board community at www.alzconnected.org. There is a special forum specifically for people living with Alzheimer’s to connect with others and share support.
- Go to our free online tool, www.alzheimersnavigator.org, to receive a customized action plan and step-by-step guidance on topics including driving and home safety.
- Call the 24/7 Helpline to schedule a care consultation, a free one-on-one appointment with a trained dementia specialist to help you clarify next steps and learn how to live with the disease.

Planning for Your Future

Planning for the future plays an important part in making life better for those living with Alzheimer’s and their families. The Alzheimer’s Association has many resources to assist you in planning for the future. Visit the Caregiver Center (www.alz.org/care) for more information.

PRINCIPLES FOR A DIGNIFIED DIAGNOSIS

The first statement of its kind written by people living with dementia on the subject of the Alzheimer's disease diagnosis experience.

Talk to me, the person living with dementia, directly.

I am the person living with the disease, and though those close to me will also be affected, I am the person who needs to know first.

Tell the truth.

Even if you don't have all of the answers, be honest about what you do know and why you believe it to be so.

Test early.

Helping me get an accurate diagnosis as soon as possible gives me more time to cope, live to my fullest potential and access information and resources.

Take my memory concerns seriously, regardless of my age.

Age may be the biggest risk factor for Alzheimer's, but Alzheimer's is not a normal part of aging. Don't discount my concerns because of my age. At the same time, don't forget that the disease can also affect people in their 40s, 50s and 60s.

Deliver the diagnosis in plain but sensitive language.

My diagnosis may be one of the most important things I ever hear. Please use language that I can understand and be sensitive to how this may make me feel.

Coordinate with other care providers.

I may be seeing more than one doctor. It's important that you talk to my other care providers to ensure everyone has the information so that changes can be identified early and I won't have to repeat tests unnecessarily.

Explain the purpose of different tests and what you hope to learn.

Testing can be very physically and emotionally challenging. It would help me to know the purpose of the test, how long it will take and what you expect to learn from the process. I would also appreciate the option of breaks during longer tests and an opportunity to ask questions.

Give me tools for living with this disease.

Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, what medical treatments are available, and what support and resources are offered through the Alzheimer's Association® and my community.

Work with me on a plan for living a quality life.

Medication may help modify some of my neurological symptoms, but I am also interested in recommendations for keeping myself as healthy as possible through diet, exercise and social engagement.

Recognize that I am an individual and the way I experience this disease is unique.

This disease affects each person in different ways and at a different pace. Please be sure to couch your explanation of how this disease may change my life with this in mind.

Alzheimer's is a journey, not a destination.

Treatment doesn't end with the writing of a prescription. Please continue to be an advocate — not just for my medical care but for my quality of life as I continue to live with Alzheimer's disease.

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