

Greater Missouri Chapter 24/7 Helpline: 800.272.3900

www.alz.org/greatermissouri
serving 96 counties in MO and Western IL

Diagnosis Packet

You are receiving this packet in response to your concern about a family member or friend with memory loss. 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 a loved one with 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 someone has 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:

- Know the 10 Signs
- Preparing for Your Doctor's Visit
- Diagnosis Information
 - Importance of Early Diagnosis
 - Finding the Right Doctor
 - Steps to Diagnosis
- The Person with Memory Loss Refuses to Go to the Doctor
- Making the Visit Easier
- Results and Next Steps
 - o What Now?
 - Life After Diagnosis
 - Finding Support





Have you noticed any of these warning signs?

Please list any concerns you have and take this sheet with you to the doctor.

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

1. Memory loss that disrupts daily life. One of the most common signs of Alzheimer's, especially in the early stages, is forgetting recently learned information. Others include forgetting important dates or events; asking for the same information over and over; relying on memory aides (e.g., reminder notes or electronic devices) or family members for things they used to handle on their own. What's typical? Sometimes forgetting names or appointments, but remembering them later.
2. Challenges in planning or solving problems. Some people 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 typical? Making occasional errors when balancing a checkbook.
3. Difficulty completing familiar tasks at home, at work or at leisure. People with Alzheimer's often find it hard to complete daily tasks. Sometimes, people may have trouble driving to a familiar location, managing a budget at work or remembering the rules of a favorite game. What's typical? Occasionally needing help to use the settings on a microwave or to record a television show.
4. Confusion with time or place. People 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 typical? Getting confused about the day of the week but figuring it out later.
5. Trouble understanding visual images and spatial relationships. For some people, having vision problems is a sign of Alzheimer's. They may have difficulty reading, judging distance and determining color or contrast. In terms of perception, they may pass a mirror and think someone else is in the room. They may not recognize their own reflection. What's typical? Vision changes related to cataracts.

6. New problems with words in speaking or writing. People 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 they may repeat themselves. They may struggle with vocabulary, have problems finding the right word or call things by the wrong name (e.g., calling a watch a "hand clock"). What's typical? Sometimes having trouble finding the right word.
7. Misplacing things and losing the ability to retrace steps. A person with Alzheimer's disease may put things in unusual places. They may lose things and be unable to go back over their steps to find them again. Sometimes, they may accuse others of stealing. This may occur more frequently over time. What's typical? Misplacing things from time to time, such as a pair of glasses or the remote control.
8. Decreased or poor judgment . People with Alzheimer's may experience changes in judgment or decision making. For example, they may use poor judgment when dealing with money, giving large amounts to telemarketers. They may pay less attention to grooming or keeping themselves clean. What's typical? Making a bad decision once in a while.

9. Withdrawal from work or social activities. A person with Alzheimer's may start to remove themselves from hobbies, social activities, work projects or sports. They may have trouble keeping up with a favorite sports team or remembering how to complete a favorite hobby. They may also avoid being social because of the changes they have experienced. What's typical? Sometimes feeling weary of work, family and social obligations.
10. Changes in mood and personality. The mood and personalities of people with Alzheimer's can change. They can become confused, suspicious, depressed, fearful or anxious. They may be easily upset
at home, at work, with friends or in places where they are out of their comfort zone. What's typical? Developing very specific ways of doing things and becoming irritable when a routine is disrupted.
If you have questions about any of these warning signs, the Alzheimer's Association recommends consulting a physician. Early diagnosis provides the best opportunities for treatment, support and future planning.

For more information, go to alz.org/10signs or call 800.272.3900.

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Preparing for Your Doctor's Visit

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

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

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:	9 0
List current medical conditions:	
List past medical conditions:	*
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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.



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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/care and click on the Plan for the Future section.
- Decreased anxiety about unknown problems.
- Increased chances of participating in drug studies and helping to find a cure or better treatments. Visit www.alz.org/research to learn about clinical trials available.
- An opportunity to participate in decisions about care, <u>driving cessation</u>, <u>living options</u>, <u>financial</u> and <u>legal matters</u>. Visit <u>www.alz.org/care</u> 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. <u>Alzheimer's Navigator</u> (<u>www.alzheimersnavigator.org</u>) can help identify needs and create
 actions plans. In-office and telephone-based care consultations with a trained dementia specialist
 are also available. Call the 24/7 Helpline (800.272.3900) to schedule an appointment.

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. The primary care doctor may make a referral 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 Alzheimer's Association, Greater Missouri Chapter, for a list of options for specialists in your county by calling us at 800.272.3900.

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 the patient's medical history and review their current medications.
- Conduct a physical exam to check for other physical concerns that could cause the 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).



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The Person with Memory Loss Refuses to Go to the Doctor

If you are having trouble getting the person with memory loss to understand the need for a doctor visit or if he/she one refuses to go to the doctor, the following ideas may be helpful.

Seize the opportunity.

Suggest a check-up if the individual expresses any concern about "not remembering things lately." You could explain that there are new medications that may help with memory, but they must be prescribed by a doctor. Ask permission to make an appointment.

Focus on treatment.

Many people fear going to the doctor because they are afraid of being diagnosed with dementia or Alzheimer's. Reassure them by letting them know there are other treatable conditions that can cause memory problems. Focus on possible treatments and encourage them not to delay getting treated. The words Alzheimer's and dementia can be a red flag for many seniors so it may be helpful to use terms like "memory concerns" or "confusion" in their place when discussing visiting the doctor.

Tell the doctor your concerns.

Ask if the office could call the person with memory loss to schedule an "overdue check-up." Ask them to not mention any type of memory testing. If the individual is on prescription medications ask their doctor or pharmacist to tell the person that they need a regular checkup in order to continue their prescription.

Ask for a personal favor.

At times, people will do something for others that they would not do for themselves. Ask them to see a doctor as a favor to you.

Schedule an appointment with the doctor for yourself.

Ask the individual to come with you to your appointment. Tell the doctor ahead of time to give you a check-up. However, inform the doctor that the *real* purpose of this visit is for the individual. Ask the doctor to *personally* invite him/her to have a check-up after you have had your "physical."

Schedule an appointment for the patient.

Consider waiting to tell the individual until a few minutes before it is time to get in the car. If they hesitate or refuse, then you could suggest that they call to cancel the appointment. He or she may reconsider rather than "having to explain" the cancellation. Keep in mind, however, that some doctor offices may charge a fee for canceling the appointment less than 24-hours before the meeting.

Go somewhere fun or relaxing.

Tell you're the individual you are going to get ice cream, going out for a "special lunch," or going to the park. When you are almost there, say, "We need to stop by and see Dr. Brown this morning." While this may seem deceitful, the overall mission is to protect their health, safety and well being.

Use other physical problems as an excuse.

If the individual is experiencing any other health issues, you could explain that the doctor will give him or her something to help with that particular problem. Tell the doctor in advance that you are also concerned about their memory.

See if the doctor will do a home visit.

It may be rare today, but there are still some visiting physicians. If not the doctor, a nurse practitioner or a visiting nurse may be able to do an assessment. This person can then report the results to the physician.

Do not get involved in a debate or argument.

Never argue with a person who has memory loss. It is best to simply downplay or even ignore objections. For example, if they say, "I will not go to the doctor," you could reply with, "We will stop for ice cream on our way home."

Call Protective Services if needed.

If the individual has become a danger to themselves, or if their well-being is in jeopardy, outside help might be required. Protective Services may be able to help convince them to see a doctor. In Missouri call 800.392.0210, in Illinois call 800.642.5429.



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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.



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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 <u>www.alzconnected.org</u>. 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, <u>www.alzheimersnavigator.org</u>, 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.