

Patient-Doctor Discussion Guide

Whether you or a loved one is at risk for Alzheimer's disease or already experiencing symptoms, the journey will be different for everyone, and it's important to be aware of your options. Clinical research is exploring potential treatment options for Alzheimer's disease, and you may be considering participating in a clinical research study. Use this guide to start a conversation with your doctor about whether participating in a research study is an appropriate option for you.

If you think of other questions or don't have the opportunity to find out all the information you need at your appointment, ask your doctor or nurse for the best way to contact them in between appointments with follow-up questions.

Questions to Discuss with Your Healthcare Team About Alzheimer's Disease

Questions to Understand Alzheimer's Disease		NOTES
Understanding Alzheimer's Disease and Memory Loss	<ul style="list-style-type: none">• What should I do if I'm having trouble remembering things?• What's the difference between dementia and Alzheimer's disease?• What should I do if I am at risk or have a history of Alzheimer's disease in my family?• What are some of the symptoms of Alzheimer's disease?	

Let's explore together.



Questions to Understand Treatment Options for Alzheimer's Disease		NOTES
Testing and Medicines	<ul style="list-style-type: none">• If I or a loved one is experiencing memory loss, how do we find out if it's Alzheimer's disease?• Even if I or a loved one is not experiencing memory loss, is there a way we can assess our risk?• Are there medicines that you prescribe for Alzheimer's disease or memory loss?• Are there medicines that you prescribe for people at risk of developing Alzheimer's disease or memory loss?• If you prescribe medicine, will symptoms appear or return if we stop taking this medicine?• How long do we wait to see if the medicine is working?• If this medicine doesn't work for me, are there other treatment options?	
Questions to Understand Clinical Research as an Option		NOTES
Research	<ul style="list-style-type: none">• What kind of clinical research studies testing investigational medicines are available for people with Alzheimer's disease?	





Questions to Understand Clinical Research as an Option		NOTES
Research	<ul style="list-style-type: none">• What kind of clinical research studies testing investigational medicines are available for people who are at risk of developing Alzheimer's disease?• Would you still be my doctor if I join a research study?• Would participation in a research study testing investigational medicines for people with or at risk of developing Alzheimer's disease be an option for me?	





Glossary

When discussing Alzheimer’s disease and memory loss with your healthcare team, it may help to know some key terms. This guide can help you become more comfortable with important words and terms and help you prepare for your next conversation with your doctor.

Terms Related to the Condition

Beta-amyloid

One of two proteins that become toxic and cause changes in the brain in Alzheimer’s disease.¹ As part of this process, beta-amyloid accumulates and clumps together to form amyloid plaques.

Cognitive ability

The ability to carry out mental processes such as judgment, problem-solving, remembering, and reasoning.²

Dementia

The loss of the ability to carry out mental processes such as problem-solving, remembering, and reasoning—to such an extent that it interferes with daily life and activities.³ Alzheimer’s disease is a type of dementia.

Early Alzheimer’s disease

A stage of Alzheimer’s disease where individuals have mild cognitive impairment and are at risk for further cognitive and functional decline.⁴

Hippocampus

An area of the brain that is responsible for learning and memory. Damage to the brain of a person with Alzheimer’s disease begins in this region and affects one’s ability to think, remember, make decisions, or function independently.⁵

Neurons

Nerve cells in the brain that communicate with each other through electrical signals. Neurons enable us to move, dream, remember, and see. Alzheimer’s disease can cause neurons to die.⁵



Tau

One of two proteins that become toxic and cause changes in the brain in Alzheimer's disease.¹ As part of this process, tau accumulates inside the brain and forms tangles.

Terms Related to Clinical Research

Clinical research study

Also called a clinical trial, it is the primary way that researchers test and find out if an investigational medicine is safe and effective.⁶

Investigational medicine

A medicine that has been tested in the laboratory and has obtained permission for further testing in research studies with people.⁷

Placebo

An inactive substance that looks like the medicine or treatment being tested.⁸ Placebos are used in research studies testing new medicines to help determine if the investigational medicine is safer and more effective than no medicine at all.

Standard of care

Treatment that most medical experts agree is an appropriate choice and that is widely used by healthcare professionals.⁹



Sources

¹ <https://jamanetwork.com/journals/jamaneurology/fullarticle/1817720#>

² <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4996474/>

³ <https://www.nia.nih.gov/health/what-is-dementia#>

⁴ <https://www.alz.org/alzheimers-dementia/stages>

⁵ <https://www.nia.nih.gov/health/what-happens-brain-alzheimers-disease>

⁶ <https://www.clinicaltrials.gov/ct2/about-studies/learn#WhatIs>

⁷ <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/investigational-drug>

⁸ <https://www.nia.nih.gov/health/placebos-clinical-trials>

⁹ <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/standard-therapy>