

Share:    

Participating in Alzheimer's Disease and Related Dementias Research

Scientists continue to make great strides in identifying potential new ways to [diagnose](#), [treat](#), and even [prevent](#) Alzheimer's disease and related dementias. These medical advances would not be possible without the participation of a diverse range of clinical trial and study volunteers.

When you choose to participate in research, you become an important part of scientific discovery. Your contribution may also help your family, community, and future generations lead healthier lives.

Why participate in Alzheimer's and related dementias research?

There are many reasons you might choose to participate in Alzheimer's and related dementias research. You may want to:

- Help people, including family members, who may be at risk for developing Alzheimer's or a related dementia in the future
- Feel like you're playing a more active role in your health
- Learn more about dementia and your health, including symptoms and risk factors
- Find out about resources, such as educational materials and support groups

Why I Participate in Alzheimer's Research - Keretha's Story (Full version)



Learn more about [why people participate in research](#).

How do researchers decide which interventions to test in people?

Before a clinical trial is designed and launched, scientists perform laboratory tests and often conduct studies in animals. These tests evaluate the safety and effectiveness of a particular intervention, such as a new drug. If these studies show favorable results, the U.S. Food and Drug Administration (FDA) [approves the intervention](#) to be tested in humans.

Learn more about [clinical research](#) and how the [safety of participants](#) is protected.

Who can participate in dementia research?

Nearly everyone can participate in Alzheimer's and related dementias research. To ensure that prevention strategies and treatments help as many people as possible, volunteers are needed from a wide variety of communities and backgrounds. You do not need to be an older adult or be living with dementia to participate in clinical trials and studies.

Volunteers include:

- Participants of different genders, races, ethnicities, and life experiences
- Both younger and older individuals
- People diagnosed with [Alzheimer's](#) or a related dementia, such as [Lewy body dementia](#), [vascular dementia](#), [frontotemporal disorders](#), or [limbic-predominant age-related TDP-43 encephalopathy \(LATE\)](#)
- People with symptoms of dementia who have no diagnosis or an uncertain diagnosis
- People who may have an increased risk of Alzheimer's or a related dementia, given their family history, [genetic makeup](#), or [biomarkers](#), which are measures that could signal very early stages of disease
- People living with [Down syndrome](#), who are at higher risk for Alzheimer's



[Read and share this infographic](#) about the types of volunteers needed for dementia research.

- People without memory loss or dementia
- Caregivers of people living with dementia

Should I Participate in a Clinical Trial?



Are you looking for something short-term or research that follows participants over a longer time? Do you want to be part of in-person research, or would you be more interested in taking online surveys? Many different types of clinical trials and studies are available, and there are likely options that would work for you.

Researchers carefully screen all volunteers to ensure they are appropriate for particular studies. The screening may involve cognitive and physical tests, and you may be asked questions about your health, medications, and family history. Researchers also need to make certain that people are a good fit for safety reasons. For example, if a study involves MRI, the research team will ask questions to confirm that type of scan is safe for you.

To take part in a clinical trial or study, you may need to have certain characteristics called inclusion criteria. These criteria might include age, stage of dementia, gender, genetic profile, and whether or not you have a study partner who can accompany you.

What is a study partner?

Most Alzheimer's clinical trials require that each research participant enroll with a study partner — someone who knows the participant well, usually a family member or close friend. The

study partner goes with the participant to research appointments and can provide insights about how their memory, thinking, and behavior changes over time.

Learn more about [being a study partner](#) in Alzheimer's research.

Some people are unable to participate in certain clinical trials because they have particular characteristics, which are called exclusion criteria. These criteria can include factors such as specific health conditions or medications that could interfere with the study. Most of the time, you can only participate in one research study at a time.

Learn more about [how researchers decide](#) who participates in clinical research studies.

What new approaches are researchers exploring?

When people think of research, they often think of a clinical trial that is testing a new drug. But there are many types of research that need participants. Here are some of the areas related to Alzheimer's and related dementias that researchers are exploring:

- **Medications.** Drug trials evaluate the safety and effectiveness of medications and therapies designed to help prevent disease or slow disease progression.
- **Non-medication strategies.** These studies evaluate the safety and effectiveness of lifestyle and behavioral changes, such as exercise, changes in diet, or brain training, to help prevent disease, slow disease progression, or improve quality of life for people with dementia.
- **Diagnostic tools.** New approaches, such as a blood test or a new type of brain scan, are tested to see whether they can accurately diagnose Alzheimer's or a related dementia.
- **Medical devices.** Medical devices are instruments, tools, and other equipment that can monitor and manage disease symptoms. Examples include electronic devices that directly stimulate the brain and digital assistants to help with everyday tasks. Studies of medical devices determine whether they are safe and effective.
- **Treatments for changes in mood and personality.** These studies test medication and non-medication strategies to treat common behavioral symptoms of Alzheimer's, including sleeplessness, wandering, agitation, anxiety, aggression, restlessness, and depression.
- **Support for caregivers.** Caring for someone with dementia can be challenging. Researchers are testing ways to reduce stress and increase overall well-being for caregivers and quality of life for people living with dementia.
- **Attitudes and knowledge.** Some studies are designed to learn people's views about dementia, caregiving, or particular treatments, or to test educational tools to increase people's knowledge.

What will new drugs to treat Alzheimer's mean for clinical research?

In 2023, the FDA approved [a new drug](#) that can slow Alzheimer's in its early stages — the first such drug to receive

full FDA approval. Other drugs to treat the disease are also showing promise in clinical research. But current drugs can't cure the disease, and not every medication will work in every person. That's why scientists continue to search for effective treatments.

More clinical research is needed to understand Alzheimer's and other types of dementia, and to find new approaches to diagnose and treat these diseases. We also need research to discover more about who's at risk for the disease and whether it can be prevented.

How can I learn about dementia research near me?

Looking for clinical research about Alzheimer's or a related dementia? Talk to your health care provider and use online resources to:

- Sign up for a [registry or a matching service](#) that may invite you to participate in studies or trials when they are available in your area.
- Contact one of the NIA-funded [Alzheimer's Disease Research Centers](#) near you. They offer information about diagnosis and treatment, research participation opportunities, and support groups.
- Search the [Alzheimers.gov Clinical Trials Finder](#).
- Explore [clinical trials and studies sponsored by NIA](#).

After you find one or more clinical trials or studies that you are interested in, the next step is for you or your doctor to contact the research staff and ask questions. You can usually find contact information in the description of the study.

Let your health care provider know if you are thinking about joining a clinical trial or study. Your provider may want to talk to the research team to ensure the research is safe for you and to help coordinate your care.

Brain donation: Another way to contribute to dementia research

Research participants are sometimes given the option to donate their brain to science after they die. Brain donation enables researchers to learn about how the brain works in ways that aren't possible while a person is alive. By studying the brains of

people who have died — both those who had a brain disorder and those who didn't — researchers learn more about how different types of dementia affect the brain and how we might better treat and prevent these diseases.

Learn more about [brain donation](#), including why people donate their brains, the process of donation, and how you can enroll to make this generous gift.

How do researchers ensure that someone with dementia understands and agrees to a study?

Typically, before someone decides to participate in a clinical trial or study, research coordinators will go over all the key details with that person. If the volunteer understands and agrees to participate in the trial, they sign a form. During the study, the researchers will continue to provide information to the participant and answer any questions. This process of going over the research details, signing the form, and having ongoing communication is called informed consent.

Informed consent can work differently with research participants who have dementia. While some people with dementia can still make decisions for themselves about participating in research, others cannot. The “decision-making capacity” of a person living with dementia is determined by their health care provider or someone from the research team. If the person cannot provide informed consent because of cognitive impairment, an authorized legal representative or [health care proxy](#) may give permission for the person to participate.

After the research is explained, the person or their legal representative will be asked to sign the informed consent form, which states that they understand what the study involves and agree to participate. This document is not a contract — you can leave the study at any time and for any reason. You should feel free to discuss any concerns with the study coordinators.

Read more about [informed consent and other safeguards](#) to protect clinical research volunteers.

What questions should I ask before participating in clinical research?

Choosing to participate in research is an important decision for you and your family. Take your time deciding whether a clinical trial or study is right for you. Get answers to your questions and know your options before you decide. Here are a few questions you might ask the research team when thinking about participating:

- What is this study trying to find out?
- How is the study different from standard medical care?
- If the study tests a treatment, what are the possible [risks, side effects, and benefits](#)?
- Where will the study take place and how long will it last?
- Will I learn any information about my own brain health or risk factors?
- Will I and/or my study partner be paid for our time or reimbursed for travel expenses?

- How will the research team protect my health while I participate?
- What happens if I withdraw from the study early?
- What can I expect after the study ends?

Read [more questions you might want to ask](#) before participating in clinical research.

You may also be interested in

- Learning more about [clinical trials and studies](#)
- Downloading or sharing an infographic about [why people volunteer for clinical research](#)
- Finding out more about the [benefits, risks, and safety](#) of clinical research

Sign up for email updates

Receive weekly tips and resources on Alzheimer's disease and related dementias from NIA's Alzheimers.gov

*Email Address

Subscribe

For more information about participating in Alzheimer's and related dementias research

NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center

800-438-4380

adear@nia.nih.gov

www.nia.nih.gov/alzheimers

The NIA ADEAR Center offers information and free print publications about Alzheimer's and related dementias for families, caregivers, and health professionals. ADEAR Center staff answer telephone, email, and written requests and make referrals to local and national resources.

Alzheimers.gov

www.alzheimers.gov

Explore the Alzheimers.gov website for information and resources on Alzheimer's and related dementias from across the federal government.

Clinical Research Trials and You

National Institutes of Health

www.nih.gov/health-information/nih-clinical-research-trials-you

ClinicalTrials.gov

www.clinicaltrials.gov

This content is provided by the NIH National Institute on Aging (NIA). NIA scientists and other experts review this content to ensure it is accurate and up to date.

Content reviewed: September 28, 2023

[Return to top](#)

Newsletters

Sign up to receive updates and resources delivered to your inbox.

Sign up

nia.nih.gov

An official website of the [National Institutes of Health](#)