Alzheimer's New Jersey®

Common Questions About Participating in Alzheimer's and Related Dementias Research

Why Would I Participate in a Clinical Trial?

There are many reasons why you might choose to join an Alzheimer's or dementia clinical trial. You may want to:

- Help others, including future family members, who may be at risk for Alzheimer's disease or a related dementia
- Receive regular monitoring by medical professionals
- Learn about Alzheimer's and your health
- Test new treatments that might work better than those currently available
- Get information about support groups and resources

What Else Should I Consider?

Consider both benefits and risks when deciding whether to volunteer for a clinical trial. While there are benefits to participating in a clinical trial or study, there are some risks and other issues to consider as well.

Risk. Researchers make every effort to ensure participants' safety. But, all clinical trials have some risk. Before joining a clinical trial, the research team will explain what you can expect, including possible side effects or other risks. That way, you can make an informed decision about joining the trial.

Expectations and motivations. Single clinical trials and studies generally do not have miraculous results, and participants may not benefit directly. With a complex disease like Alzheimer's, it is unlikely that one drug will cure or prevent the disease.

Uncertainty. Some people are concerned that they are not permitted to know whether they are getting the experimental treatment or a placebo (inactive treatment), or may not know the results right away. Open communication with study staff can help you understand why the study is set up this way and what you can expect.

Time commitment and location. Clinical trials and studies last days to years. They usually require multiple visits to study sites, such as private research facilities, teaching hospitals, Alzheimer's research centers, or doctors' offices. Some studies pay participants a fee and/or reimburse travel expenses.

Study partner requirement. Many Alzheimer's trials require a caregiver or family member who has regular contact with the person to accompany the participant to study appointments. This study partner can give insight into changes in the person over time.

What Happens When a Person Joins a Clinical Trial or Study?

Once you identify a trial or study you are interested in, contact the study site or coordinator. You can usually find this contact information in the description of the study. Study staff will ask a few questions on the phone to determine if you meet basic qualifications for the study. If so, they will invite you to come to the study site. If you do not meet the criteria for the study, don't give up! You may qualify for a future study.

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What Is Informed Consent?

It is important to learn as much as possible about a study or trial to help you decide if you would like to participate. Staff members at the research center can explain the study in detail, describe possible risks and benefits, and clarify your rights as a participant. You and your family should ask questions and gather information until you understand it fully.

After the research is explained and you decide to participate, you will be asked to sign an informed consent form, which states that you understand and agree to participate. This document is not a contract. You are free to withdraw from the study at any time if you change your mind or your health status changes.

Researchers must consider whether the person with Alzheimer's disease or another dementia is able to understand and consent to participate in research. If the person cannot provide informed consent because of problems with memory and thinking, an authorized legal representative, or proxy (usually a family member), may give permission for the person to participate, particularly if the person's durable power of attorney gives the proxy that authority. If possible, the person with Alzheimer's should also agree to participate.

How Do Researchers Decide Who Will Participate?

Researchers carefully screen all volunteers to make sure they meet a study's criteria.

After you consent, you will be screened by clinical staff to see if you meet the criteria to participate in the trial or if anything would exclude you. The screening may involve cognitive and physical tests.

Inclusion criteria for a trial might include age, stage of dementia, gender, genetic profile, family history, and whether or not you have a study partner who can accompany you to future visits. Exclusion criteria might include factors such as specific health conditions or medications that could interfere with the treatment being tested.

Many volunteers must be screened to find enough people for a study. Generally, you can participate in only one trial or study at a time. Different trials have different criteria, so being excluded from one trial does not necessarily mean exclusion from another.

Source: https://www.nia.nih.gov/health/common-questions-about-participating-alzheimers-and-related-dementias-research