

Care Partner Information

Alzheimer's Disease and Related Dementia Caregiving Tips

Participating in Alzheimer's Disease Research

What is Clinical Research?

Clinical research involves testing a new drug or treatment for a disease to see if it really works to help make people better. Many treatments we use today for most medical problems are the result of clinical research.

Why Is Clinical Research Important for Alzheimer's Disease?

Currently, there is no way to prevent or cure Alzheimer's disease. Clinical research is the way researchers can find treatments that work and are safe. There will never be any good treatments without research.

More people are always needed to be part of research studies. If you volunteer, you will help researchers better understand or treat Alzheimer's disease. Most importantly, when you are part of research, you help others.

What Happens with Clinical Research?

There are many kinds of clinical research. Some types of research test new drugs. Other types test ways of giving care. Still others test things like physical activity or diet.

In clinical research, people volunteer to be research "subjects." Some of the subjects will get the new treatment being tested. A "control group" will receive a placebo (sugar pill), or "usual care." The study then tests if the new treatment works better than the placebo or usual care.

Some research looks at people who already have Alzheimer's disease to see if the new treatment can make them better. Other studies test treatments to prevent Alzheimer's disease in people who don't yet have it.

Who Pays for Clinical Trials?

If you volunteer for research, the costs related to the study will usually be covered, but be sure to ask about it. Sometimes the research is run by a drug company. Other times it is run by a branch of the US government. Either way, covered costs usually include any drugs, lab tests, x-rays, and study visits with doctors and nurses.

This Care Partner Information page is part of a series on caregiving tips. They are written to help family and community caregivers, direct care workers and community health representatives care for someone with Alzheimer's disease or other types of dementia. Available in English and Spanish at www.aging.arizona.edu

Is Clinical Research Safe?

Because the treatments being tested are new, there is always a risk of problems. But, there are safeguards in place to keep the risk of problems as low as possible. There are often special experts that follow the study to quickly detect problems if they occur. Before you enroll in a study, you will be told about the risks, benefits, and costs. You will also be given time for questions. This process is called “informed consent.” Never sign up unless you are sure you understand. It may help to bring home the consent form to review so you don’t feel rushed into a decision.

What are the Risks of Being in Clinical Research?

The main risks include having bad effects from the treatment being tested or that the treatment might not work. After hearing about the risks, you can decide if it is right for you or the person you care for. If the person has advanced dementia and cannot give consent, their guardian or health care power of medical attorney will have to sign for them.

What are the Benefits of Being in Clinical Research?

- You help people in the future who might get Alzheimer’s disease.
- You may get a new treatment not yet available to the public.
- You may get expert medical care at leading health care facilities, related to the research study.
- If the treatment is effective, you or your loved one may be the first to benefit.

Can Everyone With Alzheimer’s Disease Be In Clinical Research?

Every research study is different. You will be checked to see if you fit the specific study. Whether someone fits depends on their medical condition and whether they have early or advanced Alzheimer’s disease. Some people may fit some research studies, but not others.

Where Can I Find Out About Clinical Research Near Me?

Alzheimer’s disease research is taking place in hundreds of locations around the country. For information about Alzheimer’s disease clinical research, contact the following:

- Alzheimer’s Association TrialMatch – visit alz.org/TrialMatch or call (800) 272-3900
- National Institute on Aging, National Institutes of Health, U.S. Department of Health and Human Services – <http://www.nia.nih.gov/alzheimers/publication/participating-alzheimers-research/introduction>
- Banner Alzheimer’s Institute - <http://www.banneralz.org/clinical-trials>

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