



# Supporting a Loved One in a Clinical Trial

A **clinical trial is a research study** that helps doctors learn whether a potential new approach — such as investigational medication, medical device, prevention strategy, or behavior change — is safe and effective. Some trials test investigational treatments. Others focus on early detection, prevention, or improving quality of life.

**Families choose clinical trials for multiple reasons, including to help advance research and be part of exploring investigational treatment options.**

## Benefits of participating in a clinical trial

- Access to investigational treatments
- More frequent medical monitoring and detailed health assessments than standard care typically provides
- Access to specialists in a specific condition
- Contributing to research that may help others in the future







## Potential drawbacks

- The time commitment of participating
- Travel requirements
- Possible side effects
- You may not benefit from the investigational treatment

*These aren't reasons to rule out a trial — they're things to discuss with the care team to make a fully informed decision.*

## The Caregiver's Role in Clinical Trials

In many trials, caregivers are part of what makes participation possible. You are not only providing rides or reminders — you are often the primary observer of day-to-day changes. Here's what that can look like in practice:

-  Finding and comparing potential trials
-  Tracking symptoms, side effects, mood, sleep, and cognition
-  Supporting investigational medication schedules and study requirements
-  Communicating questions and concerns to the research team
-  Coordinating transportation and logistics
-  Keeping the rest of the care team informed

Your observations can help the care team understand how an investigational treatment affects everyday life, along with lab results.



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# Questions Caregivers Often Ask About Clinical Trials

## What research is done before a clinical trial begins?

Before a drug or treatment can be approved for use, it undergoes rigorous screening and preclinical testing to measure safety and efficacy. Before a clinical trial can begin, researchers typically conduct years of testing. Every clinical trial includes a detailed informed consent process to make sure you and your loved one understand what participation involves and whether any side effects have been experienced by previous participants.

## How is safety measured?

The safety of the patients is a top priority for everyone involved in the trial. Before a clinical trial can even begin, it's reviewed by an institutional review board (IRB), a committee of doctors, scientists, and community members responsible for protecting clinical trial participants. This review ensures that, both before and during the trial, steps are taken to protect the rights and safety of the trial participants. During the clinical trial, participants' safety is closely monitored.

## Can my loved one participate if we don't live near a major hospital or research facility?

Yes. Regional hospitals and smaller research facilities also run clinical trials. In addition, some clinical trials—particularly those for rare diseases—compensate patients who need to travel to participate.

## Is there a cost to participate?

The costs of a clinical trial are typically covered by the study's sponsor. Patient care costs that sponsors do not cover are often covered by the participant's health insurance. Before enrolling in a trial, ask the research team about the costs your loved one would be expected to pay, and then confirm coverage with your loved one's health insurance carrier. Reimbursement for travel, meals, and time may also be available.

## Where can I find a suitable clinical trial?

Visit [www.caregiveraction.org/clinical-trial](http://www.caregiveraction.org/clinical-trial) to learn about featured Alzheimer's Disease clinical trials. Or you can visit [ClinicalTrials.gov](http://ClinicalTrials.gov), which is an online database of nationwide clinical trials where you can search by any disease or condition, location, or a specific medication. Many pharmaceutical companies and research facilities also have their own websites that provide information about available clinical trials.