

# Dementia research

**This help sheet discusses the importance of dementia research, ways to participate, your rights as a participant and how to find current research studies seeking participants.**

Dementia is the second leading cause of death in Australia and research will help minimise the impact of dementia in the future.

Researchers are working to:

- understand the causes of dementia and ultimately, find a cure
- reduce the risk of developing dementia
- accurately diagnose different types of dementia
- discover and validate drug therapies that slow the progression of dementia
- find ways to best manage the symptoms of dementia
- improve the care and support that people living with dementia, as well as their carers, receive.
- increase the awareness and understanding of rights, needs and experiences of people living with dementia, their carers and families.

## Participating in research

There are opportunities for people living with dementia, their family members and carers to participate in research projects.

Participating in a research study can be a very rewarding experience.

Reasons for getting involved in research include:

- helping researchers find out what causes dementia and work towards finding a cure, better treatments, and ways to prevent dementia developing
- being able to share your experiences to improve the care that people living with dementia receive
- playing an active role in your own health care

- learning about your own situation, as a person living with dementia, family member or carer
- having a useful and worthwhile experience, even if studies do not aim to directly benefit you.

## Types of research

- Researchers may use questionnaires, surveys or interviews to examine issues related to dementia care, or how the condition affects people or their families.
- Many dementia research studies involve cognitive assessments to test of memory and thinking ability. This information can be used to determine the person's stage of dementia or to detect changes (for example, improvements) after receiving a treatment or intervention as part of the research.
- A longitudinal study usually requires multiple testing sessions during the course of the study. The testing occurs over a period of time to examine long-term changes or effects.
- A randomised trial is a study where participants are randomly assigned to two or more groups and each group receives a different intervention, one of which may be a 'control' group, such as a placebo (a 'pretend' drug or treatment that has no medical effect).
- To prevent the results being affected by people's expectations of the intervention, participants may not be told which intervention they are receiving. A double-blind trial is one where neither the researchers nor the participants know who is receiving what intervention, medication or treatment.
- A clinical trial is a study which tests the safety and effectiveness of a new drug or treatment. Clinical trials are conducted in phases. In the early phases, the new intervention is tested in a small number of participants to assess safety and effectiveness. If the intervention is promising, it may move to later phases of testing where the number of participants is increased to collect more information on effectiveness and possible side effects. Many clinical trials are conducted as 'randomised double-blind placebo-controlled trials'.

## Questions to ask before deciding to participate

Researchers are required to obtain 'informed consent' from their participants by providing a written Participant Information Sheet, explaining the details of the study and answering any questions the participant has.

Here are some of the important questions the Participant Information Sheet should answer.

- What is the main purpose of the research?
- Where will the study take place? Will it be online (for example, a questionnaire), by phone, face-to-face at home or in a hospital, university or laboratory?
- Will there be any discomfort and how often will any uncomfortable procedures such as blood tests occur?
- How long will the study last?
- How much time will you be expected to commit? For example, will there be appointments and how long will they be? How long will it take to complete any questionnaire or interview?
- Will family members and carers be allowed to come to any appointments? Will they be able to be present for interviews?
- How will you get to the appointments? Is transport assistance available?
- Will there be reimbursement for time, travel or out-of-pocket expenses?
- What happens if the person participating cannot finish the study or wants to withdraw?
- Who will have access to the information from the study?
- Has the study been approved by the appropriate Human Research Ethics Committee?
- Can medications prescribed by the participant's regular doctor continue to be taken?
- How will the participants safety be monitored?
- Who within the research team can be contacted if there is a query about the research?

### **Extra questions to ask about a clinical drug trial:**

- Is it important to take drugs at a set time? Does the researcher need to be told if this does not happen?
- How will drugs be administered (by tablets, injections or other means)?
- Is there a possibility that the person with dementia could get worse as a result of the trial?
- What are the potential benefits, risks and side effects of the drug?
- Who from the research team should be contacted if the person with dementia experiences side effects or becomes concerned about developing side effects?
- What are the alternative treatments besides the one being tested in the trial?
- Can the new drug continue to be taken once the trial has concluded?

### **Consent**

‘Informed consent’ is an important part of all research projects. It means potential participants are given information about the key facts of a research study before deciding whether to take part and are provided with information on new developments throughout the study.

Participation in any research project is entirely voluntary. You may withdraw from a study at any time without giving a reason. People living with dementia can make decisions about participating and give informed consent on their own. Supported decision-making may be used as their dementia progresses, where decisions may need to be made with a trusted person who knows them well, for example, a family member, guardian or nominated decision-maker. The rules about giving consent on behalf of someone else vary, depending where you are in Australia.

### **Participant rights**

All research projects involving humans must conform to the National Statement on Ethical Conduct in Human Research. Based on these guidelines, it is the right of all participants in research to:

- Be fully informed and understand all the procedures involved in the research and the possible associated benefits, risks, discomforts, side effects and inconveniences.

- Have all identifying information about themselves and other participants kept confidential, unless they have agreed otherwise.
- Provide voluntary informed consent to participate at the very beginning of the study after receiving all relevant information.
- Withdraw their participation at any time, without giving an explanation.
- Have access to any future treatment by doctors or hospitals involved in the research, not jeopardised by withdrawal from the research.

Before participating, your rights should all be explained in the Participant Information Sheet provided by the researchers.

## How to get involved in dementia research

- **Dementia Australia Research Foundation**

The Dementia Australia Research Foundation features a list of current Australian researchers recruiting for participants.

Visit: [dementia.org.au/research/participate/get-involved-research](https://dementia.org.au/research/participate/get-involved-research)

- **StepUp for Dementia Research**

StepUp for Dementia Research connects people who want to participate in dementia-related research with researchers looking to recruit participants for their studies. To register your details:

Visit: [stepupfordementiaresearch.org.au/SignUp](https://stepupfordementiaresearch.org.au/SignUp)

Call: **1800 7837 123**

- **Australian Dementia Network (ADNet)**

The Australian Dementia Network (ADNet) has set up a volunteer register for persons over the age of 50 years who would like to participate in research into the causes, prevention and treatment of dementia. To register:

Visit: [australiandementianetwork.org.au/research-volunteer-portal](https://australiandementianetwork.org.au/research-volunteer-portal)

Call: **(03) 9035 9635**

Email: [jo.robertson@unimelb.edu.au](mailto:jo.robertson@unimelb.edu.au) or

[adnet-screening@unimelb.edu.au](mailto:adnet-screening@unimelb.edu.au)

## Additional reading and resources

- Dementia Australia library service  
Visit: [dementia.org.au/library](https://dementia.org.au/library)
- Dementia Australia Research Foundation  
Visit: [dementia.org.au/research](https://dementia.org.au/research)

### Further information

Dementia Australia offers support, information, education and counselling.

**National Dementia Helpline: 1800 100 500**

**For language assistance: 131 450**

**Visit our website: [dementia.org.au](https://dementia.org.au)**