

Research

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ABOUT DEMENTIA

This Help Sheet provides a broad overview of current research into dementia and discusses some of the issues involved in participating in research studies.

Major advances in understanding dementia have been made in recent years, and there is much optimism that slowing the progression of dementia is possible. It is not yet possible to say with certainty if dementia is preventable. However we may be able to reduce the risk through amyloid modifications, genetics, cholesterol reducing drugs and addressing cardiovascular risk factors.

Research conducted over the past decade indicates that a healthy lifestyle and physical and mental activity may help delay the onset of dementia. Some of the risk factors associated with dementia can be managed through lifestyle or appropriate medical treatments.

For example:

- Healthy diet may be able to control risk factors such as high cholesterol levels and diabetes
- Exercise may help manage cardiovascular risk factors, increase blood flow to the brain and stimulate nerve cell growth and survival

Greater understanding of the neuro-degenerative processes involved in dementia has opened avenues for the development of new treatments. Assessment and management techniques have also improved, although there is much more that can be achieved in these areas.

Alzheimer's Australia provides up to date and detailed information about research into dementia on its web site.

Visit www.alzheimers.org.au and go to the Research section.

Participating in research

People with dementia, their family and carers are sometimes asked to participate in studies or research projects. Participating in these studies

can be a useful and worthwhile experience, even in studies that do not aim to produce any direct benefit to the participants.

Families and carers often report feeling helpless or powerless over the condition. Participating in research can help to combat these feelings by fostering a sense that there is something that they can do to contribute toward finding the causes of dementia, as well as treatments and a cure. Participants may also learn more about their own situation by participating in research.

Types of research

- Therapeutic research aims to produce some direct benefit to the participants
- Non-therapeutic research does not aim to produce direct benefit to the participants. Instead it aims to produce knowledge, which may in the future be used to produce a new form of treatment or management
- A clinical trial is a study which tests the safety and effectiveness of a new drug or treatment
- A randomised trial is a clinical trial used to compare two different types of medication and treatment. Participants are divided into two or more groups, and each group receives a different medication or treatment
- A blind trial is one in which participants are not told which medication or treatment they are receiving. This is to prevent the results being affected by people's expectations of the medication or treatment
- A randomised double blind placebo controlled trial is where neither the participant nor doctor knows who is on what treatment. A placebo is a pill which has absolutely no medical effect

Contact the National Dementia Helpline on **1800 100 500**

Visit Alzheimer's Australia at www.alzheimers.org.au

Questions to ask before deciding to participate

- What is the main purpose of the research or clinical trial?
- Where will the study take place? At home, in a hospital or in a laboratory?
- How much discomfort will be involved and how often will any uncomfortable procedures such as blood tests occur?
- How long will the study last?
- How much time will it take?
- Can appointments be changed at short notice?
- Will family members and carers be separated from the person with dementia during the appointments?
- How will you get to the appointments? What will it cost to get there?
- What happens if the person with dementia cannot finish the study?
- Who will have access to the information from the study?
- Has the study been approved by the appropriate Ethics Committee?
- Can the person with dementia continue to see their doctor while they are participating in the study?
- Can medications prescribed by the participant's regular doctor continue to be taken?
- How will participant's safety be monitored?
- Who can be contacted if there is a query about the research?

Extra questions to ask about a drug trial

- Is it important to take drugs at a set time? Does the researcher need to be told if this does not happen?
- Will drugs be difficult to swallow?
- How will they be administered?
- Is there any possibility that the cognitive ability of the person with dementia will get worse as a result of the trial?
- What are the potential risks, benefits and side effects of the drug? Ask about side-effects such as incontinence, sleep disturbance and irritability
- Who should the family call if the person with dementia has side effects

- Who can be contacted if there is a query about the drug treatment or trial?
- What are the alternative treatments besides the one being tested in the trial?
- Will the new drug continue to be able to be taken once the trial is concluded?

It is the right of all participants in research to:

- Have the research project conform with the "National Guidelines for Good Clinical Research Practice", as well as complying with the appropriate Ethics Committee guidelines
- Be fully informed and understand all the procedures involved in the research and the possible associated risks, discomforts, side effects and inconveniences
- Have all identifying information about them kept confidential, unless they have agreed otherwise
- Provide voluntary consent that can be withdrawn at any time without giving an explanation, or refuse to take part in a particular aspect of the research
- Have access to any future treatment by that doctor or hospital not jeopardised by such withdrawal

Further Information

Alzheimer's Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**.

For further information and to view other Help Sheets visit our web site at **www.alzheimers.org.au**

For up to date and detailed information about dementia research on the web site go to the *Research* section.