DEMENTIA RESEARCH

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 more effective treatments for dementia will be found. Current research around the world is making advances in understanding the causes of dementia, making an accurate diagnosis of the type of dementia affecting an individual, better ways to manage the condition, and drug therapies that slow the disease process rather than just treating the symptoms.

Researchers are also investigating how we may be able to reduce the risk of dementia or delay the onset. Findings indicate that some of the risk factors associated with dementia can be managed through lifestyle or appropriate medical treatments. Physical and mental activity and effective treatment of cardiovascular risk factors including high blood pressure and high cholesterol have been found to be associated with reduced risk of dementia. Detailed information about dementia risk reduction research is available at https://healthybrains.org.

Greater understanding of the brain degeneration involved in Alzheimer's disease, frontotemporal dementia, Lewy body disease and vascular dementia has opened avenues for the development of new treatments. Knowledge of the genetics of dementia has also made significant advances. Assessment and diagnosis techniques have also improved, using brain imaging and measuring proteins in the cerebrospinal fluid. Research is ongoing as there is much more that can be achieved in all these areas.

It is hoped that the outcomes of this research will ultimately lead to the ability to identify the presence in the brain of Alzheimer's disease and other causes of dementia before symptoms begin, and then provide treatments that will stop the disease progressing and prevent the onset of dementia. To achieve this goal, increased funding for dementia research is desperately needed.

Participating in research

People with dementia, their family and care partners can participate in 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 care partners 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, better treatments and a cure. Participants may also learn more about their own situation by participating in research. Current dementia related research projects are listed at the Research section of the Alzheimer's Association website.

Types of research

- Social research may use questionnaires, surveys or interviews to examine issues related to dementia care or how the condition affects people or their families.
- Longitudinal studies are performed over a period of time to examine long-term effects and usually involve multiple testing sessions over the course of the study.
- Many dementia research studies involve cognitive assessments, tests of memory and thinking abilities to determine the person's stage of dementia or investigate improvements with treatment.
- A clinical trial is a study which tests the safety and effectiveness of a new drug or non-drug treatment.
- A randomized trial is a clinical trial in which participants are divided into two or more groups, and each group receives a different medication or treatment, one of which may be a placebo (a pretend drug or treatment that has no medical effect). Participants are randomly assigned to a group.
- 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 randomized double-blind placebo controlled trial is where neither the participant nor researcher knows who is on what treatment. Most clinical trials of new drugs are conducted in this way.

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 this information should answer.

- What is the main purpose of the research or clinical trial?
- Where will the study take place? At home, in a hospital, university or laboratory?
- Will any discomfort be involved and how often will any uncomfortable procedures such as blood tests occur?
- How long will the study last?
- How many appointments will be needed and how much time will appointments take?
- Will family members and care partners be separated from the person with dementia during the appointments?
- How will you get to the appointments? Is transport assistance available?
- 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 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 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 (tablets, injections, etc)?
- Is there any possibility that the person with dementia will get worse as a result of the trial?
- What are the potential benefits, risks and side effects of the drug?
- Who should the family call if the person with dementia has side effects?
- 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 to the "National Statement on Ethical Conduct in Human Research", as well as the appropriate Ethics Committee guidelines?
- Be fully informed and understand all the procedures involved in the research and the possible associated benefits, risks, discomforts, side effects and inconveniences.
- Has all identifying information about them kept confidential, unless they have agreed otherwise?
- Provide voluntary informed consent that can be withdrawn at any time without giving an explanation
- Refuse to take part in a particular aspect of the research.
- Have access to any future treatment by doctors or hospitals involved in the research not jeopardized by withdrawal from the research.

All of this should be explained in the Participant Information Sheet provided by the researchers.

FURTHER INFORMATION: locally call Dementia Friendly Wyoming 307-461-7134 or visit our website http://www.dwfsheridan.org or The Sheridan Senior Center 307-672-2240. Nationally contact the Alzheimer's Association at 1-800-272-3900, or visit their website at http://www.alz.org.