The aim of research is to find out new knowledge that could lead to changes in treatment, policies and care. Research into dementia can be divided into three basic themes: cause, cure and prevention, and care.

**Cause** Scientific, laboratory based research at the cellular level that will advance our understanding of dementia: its causes, its effects and its diagnosis.

**Cure and prevention:** Clinical research into treatment and management of dementia, involving testing of drugs, therapies, etc.

**Care:** Social science research which focuses on the best ways of caring for and supporting people with dementia, their partners and families.

**Cause**

**Scientific research**

Scientific research is essential to the understanding of how the disease progresses and the development of new treatments and methods of prevention. However, people who take part in this type of research are unlikely to benefit from it themselves. This research works towards treatment for those in the future.

**Brain tissue donation**

Much of our current understanding of Alzheimer’s disease and other types of dementia, as well as advances in treatment, has come through looking at brain tissue generously donated by individuals and families over the years. It cannot be underestimated how valuable donated brain tissue is. Dementia research needs brain tissue from people with dementia and brain tissue from people who have not had the illness, for comparison.

For more information on brain tissue donation visit [www.alzscotdrc.ed.ac.uk](http://www.alzscotdrc.ed.ac.uk)

**Cure**

**Treatment and therapies**

Clinical trials are research studies which compare the effects, in humans, of a new or different type of treatment with the best treatment currently available. They test whether the new or different treatment is safe, effective and/or any better than what already exists. No matter how promising a new treatment may appear during tests in a laboratory, it must go through clinical trials before its benefits can be confirmed.

Many trials are known as randomised controlled trials (RCTs). An RCT compares two groups of similar people, an experimental group that receives the new treatment (this may be a drug or another type of treatment) and a control group, who receive the standard treatment. This might include medicines routinely prescribed, or a placebo (dummy) tablet in cases where there is no similar treatment for comparison. The control group allows researchers to see whether the treatment they are testing is any more or less effective than usual or standard treatment. RCTs are considered the most robust scientific method for research like this. Not all drug trials are successful at producing a viable treatment option, but they still help to advance scientific understanding by eliminating one theory. This allows scientists to focus on research that is more likely to help others.
Care

Social research

Social research can benefit people with dementia, their partners and family members. It often involves meeting with a researcher to share personal experience of living with dementia. Approaches to social research include interviewing, focus groups, observation and questionnaires. Often, this allows researchers to collect ‘qualitative’ information. This information is unique and detailed about lived experience, feelings, opinions or thoughts.

People’s experience of events in their life, particularly ill health, is invaluable to researchers and is often used in service planning and policy development.

This type of research is covered by the NHS Research Governance Framework for health and social care.

What to be aware of

There are regular headlines in the newspapers and on the internet making claims about new, promising breakthroughs in the treatment and or prevention of Alzheimer’s and other types of dementia. Many of these should be treated cautiously. Many of the studies only involve animal models, rather than human clinical trials, or very small numbers of people, which does not indicate what the effects would be for a larger population.

For further clarification on research call the 24 hour Dementia Helpline free on 0808 808 3000 or email helpline@alzscot.org

You should speak to your GP (or hospital consultant) before considering any drug or vitamin described in the papers or on the internet as being a promising treatment or a ‘cure’. Taking any medication could do more harm than good and could even be dangerous if combined with other drugs.

You may become aware of adverts on TV, radio or in the press seeking volunteers for new research studies in dementia. These will usually give a contact number for you to call. You can expect to be asked some questions about your health and any medication that you are taking. From this, you may be invited to attend for a screening visit to further assess your suitability for the study. You should bear in mind the information contained in this information sheet when making your decision. Some of these clinics are not within the NHS. They are, however, subject to all the same laws and regulations.

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Registered office: 22 Drumsheugh Gardens, Edinburgh EH3 7RN. It is recognised as a charity by the Office of the Scottish Charity Regulator. no. SC022315