

Brain donation

This sheet provides information to help you make a decision about donating your brain or your loved-one's brain for research and how to go about it.

Should people with dementia consider donating their brain for research?

Dementia is an illness of the brain, with causes such as Alzheimer's disease that damage the brain and its ability to function. In order to understand brain diseases, researchers need access to brain tissue from people generous enough to donate their brain after death. This process is organised through the Australian Brain Bank Network donor programs, which register participants and collect medical details to assist with research into dementia that will improve our understanding of the underlying causes and lead to better treatments. The brain tissue is stored in 'brain banks' which coordinate its collection, storage and distribution for research.

Why is brain tissue needed for research?

The human brain is a complex organ that is difficult to study in living people. Much of the research into brain diseases, including those that cause dementia, relies on studies of donated brain tissue. This research allows scientists to examine brain cells and investigate the underlying causes of dementia. Better understanding of the underlying disease is the first step towards better treatments, and ultimately a cure. To ensure this research is thorough, it is vital that researchers have access to enough brain tissue. More donations of brain tissue for research are very much needed.

Who can register as a brain donor?

Anyone 18 years and older is able to volunteer for brain donation and play a vital role in medical research. Dementia research relies on brain tissue from people with all types of dementia. A person's next of kin is able to provide consent for brain donation if the person is not able to do so themselves.

Importantly, brain tissue from people who do not have a brain disease is also needed. This is known as normal control tissue and is required to compare with

brain tissue from people with dementia. Therefore, unaffected family members may also wish to consider registering as brain donors.

No matter where you live in Australia, you are able to register as a brain donor. For those living in rural Australia, in most cases brain donation arrangements can be made with the nearest regional hospital that performs post-mortem examinations.

Unfortunately not everyone can register. People who have an infectious disease such as HIV, Hepatitis B & C or Creutzfeldt-Jakob disease are unable to participate.

What does brain donation involve?

The brain is removed at an autopsy restricted to the tissues being donated. The post-mortem examination is an orderly procedure supervised by a pathologist at a hospital or mortuary. Ideally this should take place within 24 hours after death but can be performed up to 72 hours after death.

The donor is treated with the utmost respect, and brain removal occurs in such a way as to minimise visible marks. Brain donation does not require examination of other body organs; however, brain donation can take place as part of a full body post-mortem examination when appropriate.

All the information collected about a donor will be kept strictly confidential. The clinical information and brain tissue are securely stored using codes. When tissue and medical information is sent to researchers it is in a form in which you cannot be identified. No donor is ever identified in any publications or presentations that result from the research.

How do you become a brain donor?

If you are interested in donating your brain for research, you should contact the appropriate state Brain Donor Coordinator (see page 4). The staff will be happy to talk to you about the process and answer all

National Dementia Helpline 1800 100 500

dementia.org.au

your questions. They will explain exactly what you need to do and send you the relevant information. Let the Brain Donor Coordinator know if you are involved in any other research projects, as information may be able to be shared.

You should read the information carefully and discuss your decision with your family. Inform your family, the Executor of your will, your General Practitioner and your Specialist. These people need to know about your wishes so that brain donation can be arranged after your death.

It is important to make the arrangements as early as possible, so that family members have an opportunity to discuss any concerns and all the relevant people can be informed about your wishes. If you should change your mind at any time, you can withdraw your consent and there will be no questions asked.

If you have a relative with dementia who is no longer able to decide for themselves whether their brain should be donated for research, donation can still occur. In most circumstances the person with dementia's next of kin can arrange for and consent to brain donation.

What happens when the donor dies?

Brain donors are given written instructions, including 24 hour contact details. When the donor dies, a family member or the person's doctor needs to notify the Brain Donor Coordinator as soon as possible. They will make arrangements for the donor's body to be taken to the appropriate hospital or mortuary for removal of the brain. This procedure will not interrupt the normal funeral arrangements and will not result in any additional cost to the family.

What happens to the brain tissue?

The donated brain tissue is processed in two ways to ensure the maximum information can be obtained from it. Some of the tissue is frozen so that it can be used in biochemical and genetic studies. The remainder is fixed in formalin to preserve it for microscopic examination. All the tissue is stored by the brain bank for future distribution to researchers for appropriate projects.

The brain tissue undergoes a thorough examination to make an accurate diagnosis of any illness the donor may have had. The diagnosis of Alzheimer's disease and most other dementias can only be confirmed by a

post-mortem examination. Occasionally, the post-mortem diagnosis is different from the clinical diagnosis made while the person was alive. The donor's doctor will be sent a report, which the doctor can discuss with the donor's family if they wish.

You cannot be advised in advance exactly which research your tissue will be used for. However, researchers will only be able to access stored tissue and medical information after obtaining approval for their research project from their institution's Human Research Ethics Committee and the relevant state brain bank Scientific Advisory Committee. This ensures the tissue is used ethically and is only provided to research projects with scientific merit.

Why consider becoming a brain donor?

The donation of brain tissue for research is essential to further our understanding of the causes of brain diseases and to develop more effective diagnostic tools and treatments. Many research techniques that provide this valuable information cannot be performed during life. The research would not be possible without the generosity of those willing to donate their brain.

Most brain donors are motivated by the knowledge that their action provides a benefit to medical research and science. Their donation may help others affected by brain disease now and in future generations. It can also provide an altruistic outcome to a family member's death for their loved ones. The donor's family may also benefit from the provision of an accurate diagnosis of the donor's condition.

The decision to donate your brain for research is a deeply personal and important one. You are encouraged to take your time reaching a decision about whether or not to become a brain donor, and to discuss the decision with your family. They will be the ones who will need to follow through on your wishes after your death, so they need to be involved well in advance.

If you are making the decision on behalf of a relative with dementia who can no longer decide for themselves, there will be additional issues to consider. The whole family should be involved and you will probably want to consider what the person with dementia would have wanted.

The Australian Brain Bank Network

The work of the ABBN is extremely important, and preparing and examining each brain for diagnosis, and storing and distributing tissue to researchers, is very costly. This work is supported predominantly by grant funding, but also by the community. If you would like to contribute to this vital work through a donation or bequest, or asking people to donate money in lieu of flowers at your funeral, contact your local Brain Donor Coordinator.

The State Brain Donor Coordinators can be contacted as follows:

New South Wales and Australian Capital Territory

Sydney Brain Bank
02 9399 1707
sydneybrainbank@neura.edu.au

NSW Tissue Research Centre
02 9351 6143
nswbbn@sydney.edu.au

Queensland

No longer collecting tissue due to lack of funding

South Australia and Northern Territory

Ms Robyn Flook
08 8204 4393
Robyn.Flook@flinders.edu.au

Victoria and Tasmania

Ms Fairlie Hinton
03 8344 1900
fairlie.hinton@florey.edu.au

Western Australia

Ms Caroline Casely
08 9224 1192
caroline.casely@health.wa.gov.au

Further Information

Additional information about brain donation is available at the Australian Brain Bank Network website austbrainbank.org.au

FURTHER INFORMATION

Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at dementia.org.au



For language assistance phone the Translating and Interpreting Service on **131 450**