

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.

Conditions such as Alzheimer's disease and other dementias affect only humans. Therefore, the donation of post mortem brain tissue for research is of fundamental importance to further our understanding of the causes of dementias, and to develop more effective diagnostic tools and treatment for these conditions.

What is brain donation?

Brain donation is when a person and their family decide to donate their brain for medical research following their death.

Why is Brain Donation Important?

Although over the past decades many advances have been made in our understanding of dementias, there are still no cures for these illnesses. Modern brain imaging techniques, blood tests and genetic markers are helping to improve the characterisation of brain diseases, but without understanding the changes that occur in the brain, the impact of these advances will be limited.

In order to develop more effective treatments for dementias, studies are needed to identify the specific cellular changes occurring in the brain of people with dementia compared with healthy subjects.

What is meant by brain tissue?

We mean the whole brain. The brain is a very complex structure and it is necessary to look at all the different parts of the brain.

Is tissue from normal brains needed?

Yes. Progress can be made towards finding the cause of dementias if researchers can compare brains from those affected with brains from those who were not affected by such conditions. Normal brain tissue can also be used to study ageing of the human brain. Normal brain tissue is known as 'control' tissue. People not affected by brain and mind disorders are encouraged to consider registering as donors of tissue that may be used as controls in the research process.

I am an organ donor. Can I still donate my brain?

Yes. There is no interruption to the organ donation processes and this will preclude the brain donation. Neither procedure will be affected by your decision to be an organ or brain donor.

I am a full body donor (or whole body donor). Can I still donate my brain?

No. It is not currently possible to be both a full body donor and a brain donor. This is due to the embalming procedure used when donating your whole body to research.

I have an infectious disease. Can I still donate my brain?

No. People with infectious diseases cannot be donors due to the safety of the Australian Brain Bank staff and researchers. These include Hepatitis B and C, HIV and AIDS, and Creutzfeldt-Jakob disease.

Can I become a donor if I live in regional areas?

Yes, however this does vary between States. To be useful to researchers, post-mortem tissue must be collected and stored as soon as possible after death. This will not always be possible as obstacles of timing, distance or available resources may sometime arise; however this should not deter people from registering as donors.

Does my doctor need to know that I intend to donate my brain upon my death?

Your family doctor will be asked to complete the death certificate at the time of death. It is important that your doctor is aware of your wish to donate your brain in order to complete the death certificate in an expedient manner. In addition, your doctor will provide medical information useful for researchers (consent to access medical information forms part of the brain donation consent form).

What does a 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 forensic institute mortuary. Ideally the procedure should take place within 24 hours after death but can be performed up to 48 hours after death.

National Dementia Helpline 1800 100 500

dementia.org.au

Will the brain donation affect the funeral arrangements?

No. The post mortem procedure does not interfere with the normal course of events associated with a funeral.

The post mortem does not affect the ability to have a viewing or open casket funeral as the brain is removed in such a way as to minimise visible marks.

Is there any cost involved with donating my brain?

No. The brain bank will cover all costs involved with transportation of the body for the procedure and all costs associated with the brain donation (including neuropathological diagnosis). However, all other aspects of the funeral arrangements remain the responsibility of the family.

What happens to the brain tissue?

The brain is processed in two ways to allow maximum information to be obtained and to ensure the tissue is usable in research for many years to come. Half the tissue is frozen and is used for research. The remaining tissue is fixed in formalin and allows for both neuropathologic diagnosis and research.

What research is performed on the brain tissue?

We cannot advise you as to the exact nature of this research as researcher's needs change with time and there are continuing advances in technology which affect the nature of scientific research. However, researchers will only be able to access stored tissue and clinical information after obtaining approval for their research projects from their institutions Human Research Ethics Committee and the relevant State Scientific Advisory Committee. This is to ensure the tissue is used ethically and is only provided to feasible research projects with scientific merit.

When should plans be made to ensure brain tissue donation occurs after death?

It is important to make the necessary arrangements well in advance, since family members need time to discuss this very important issue.

Discussion with your senior available next of kin and family members will also help ensure your wishes are considered. It is preferable to state your wishes in writing by using the brain donation consent forms designed for this purpose by the brain donor programs.

Contact the brain bank for a copy of this documentation.

If you become a donor will this information be private and confidential?

Yes. The personal and health information of all registered donors is held securely in password-protected computer files and in locked files at a separate location to ensure confidentiality. Once the donation has occurred, the tissue is stored securely at a one of our Brain Banks and is identified only by a unique identification number.

Researchers have access to selected tissues and specified clinical information only through the unique identifier. No donor is ever identified by name in any publications or presentations that result from the research.

Australia's Brain Banks are covered by the rules for handling personal information set out in Federal and State legislation, and adherence to the National Privacy Principles. Brain Banks are committed to protecting the donor and their family's privacy.

You have the right to access any personal information that the relevant Brain Bank holds about you. You can ask to correct, update or amend personal and health information, such as your current address.

For more detailed information on the Privacy Act contact the Office of the Federal Privacy Commissioner by visiting privacy.gov.au or on **1300 363 992**, or your relevant state legislative authority.

How long will the tissue be stored and how will it be disposed of?

The donated tissues are stored indefinitely. The tissues are preserved in such a way that ensures their continued use in research. If we have to dispose of tissue that is no longer suitable for research it is done in an ethical and respectful manner, in accordance with prevailing national regulations.

What if I decide to withdraw after giving consent?

You are free to withdraw your consent at any time, by signing the withdrawal section on your consent form. Your decision will be fully respected and no questions will be asked. Your decision will not affect your relationship with any medical institute or area health service. All your electronic records will be deleted and your paper file will be destroyed.

Can I make a donation to the running of the Brain Banks?

The cost of preparing, examining each brain for diagnosis and distribution of tissue to researchers is very costly. Monetary donations to the Brain Banks within the national network are gratefully accepted. Donations over \$2.00 are tax deductible. Sporadic or regular donations can be made in the form of cash, cheque or credit card. Bequest donations in your will are also welcomed.

Individuals or organisations interested in supporting Australia’s Brain Banks should contact the Brain Bank closest to you.

How can I ask people to donate money in lieu of flowers at the funeral?

The appropriate state brain bank can provide a document to be available at the funeral to facilitate cheque or credit card donations. Contact your Brain Bank for details.

How do I find out more or become a registered brain tissue donor?

This process is organised through the donor programs of the Australian Brain Banks listed below.

NEW SOUTH WALES/ACT

Sydney Brain Bank
Tel: +61 2 9399 1707
Email: sydneybrainbank@neura.edu.au

NSW Brain Tissue Resource Centre
Tel: +61 2 9351 6143
Email: nswbbn@sydney.edu.au

For further information visit New South Wales Brain Banks: nswbrainbank.org.au/

SOUTH AUSTRALIA/NORTHERN TERRITORY

Dr Rebecca Ormsby
Tel: +61 8 8204 4393
Email: rebecca.ormsby@flinders.edu.au

For further information visit South Australia Brain Bank Network: flinders.edu.au/neuroscience/lab_brainbank.html

VICTORIA/TASMANIA

Ms Fairlie Hinton
Tel: +61 3 8344 1900
Email: fairlie.hinton@florey.edu.au

For further information visit Victoria Brain Bank: florey.edu.au/vic-brain-bank

WESTERN AUSTRALIA

Ms Caroline Casely
Tel: +61 8 9224 2925
Email: caroline.casely@health.wa.gov.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**