

QUEENSLAND BRAIN BANK

For Diagnosis and Research into Neurological Disorders

The Queensland Brain Bank is based at The University of Queensland's School of Chemistry and Molecular Biosciences. As part of the Australian Brain Bank Network, it provides services for Australian and international clinicians and researchers to investigate neurological diseases and conditions.

Donated post-mortem (autopsy) brain tissue is fundamentally important to researching the causes of neurological conditions and to developing more effective diagnostic tools and treatments for such conditions.

The Queensland Brain Bank, a research-based resource centre, was established to provide a service to medical science. Its purpose is to support medical research that seeks the causes and develops treatments and cures for neurological disorders.

The Queensland Brain Bank offers people the opportunity to aid medical research by making a post-mortem brain donation.

What is brain tissue?

'Brain tissue' is the whole brain. The brain is a very complex structure; scientists need to look at each part of the brain in their research.

Why is brain tissue needed for scientific research?

Alzheimer's disease, Motor Neurone disease, Parkinson's disease, Huntington's disease, Multiple Sclerosis, and other neurological conditions affect only humans. The brains of people with these conditions are essential for research that is devoted to finding treatments and cures.

Is tissue from normal brains needed?

Yes. Researchers can make progress towards finding the cause of neurological conditions by comparing brains from unaffected people with brains from affected people. The unaffected spouse or family members may also consider registering as donors.

How will information obtained from a brain examination benefit the family?

Examining the brain after death enables clinicians and researchers to accurately diagnose the condition that affected the donor during their lifetime. A report stating the final diagnosis can be sent to the donor's doctor, who can make it available to the senior Next-of-Kin. Occasionally, a post-mortem diagnosis is different to a diagnosis made while the donor was alive, and is one which could only have been made after a post-mortem examination.

What cost is involved in a brain donation?

The Queensland Brain Bank covers any costs associated with undertaking a post-mortem.

The brain donor, their family or friends may wish to make a cash donation to support the Brain Bank and its associated research. Donations can also be made in lieu of flowers at the funeral. Please contact the Queensland Brain Bank Coordinator for donation cards and further details on how to make a cash donation. The Brain Bank is sincerely thankful for each and every gift.

What happens to the brain tissue?

The brain is processed in two ways in order to obtain the most information possible, and to ensure the tissue can be used in research for many years to come.

Half the tissue is frozen and used for research. The remaining tissue is fixed in formalin, allowing for both neuropathologic diagnosis and research.

If brain tissue is no longer suitable for research, it will be disposed of ethically and respectfully, and in accordance with the Queensland Brain Bank's procedures, Australian laws and regulations, and the donor's wishes.

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

Yes. To be useful to researchers, post-mortem brain tissue must be collected and stored as soon as possible, up to 72 hours, after death. Obstacles of time and distance can arise, but should not deter you from registering as a donor. In most cases, the post-mortem can be arranged with the nearest regional hospital.

What research is performed on the brain?

As researchers' needs change with time, cures are found and technology advances, we cannot advise exactly what research will be performed with the donated brain.

However, we can advise that researchers will only be able to access stored tissue and clinical information after obtaining approval from their institutional Human Research Ethics Committee and the Queensland Brain Bank's Scientific Advisory Committee. In this way, the Brain Bank ensures the tissue is used ethically, and is only provided to feasible research projects with scientific merit.

If I become a donor, will my information be kept private and confidential?

Yes. Brain tissue is stored securely at the Queensland Brain Bank based at The University of Queensland, and identified only by a unique identification number. Brain donor details are held securely on digital files, and in locked files at a separate location to ensure confidentiality.

Researchers have access to the tissue and clinical information only through the unique identification number. No donor is ever identified by name in any publication or presentation that results from research.

What effect will making a brain donation have on funeral arrangements?

None. The post-mortem 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 minimize visible marks.

What if I decide to withdraw my consent?

You are free to withdraw your consent at any time without prejudice. Your decision will be fully respected and no questions will be asked.

Is brain donation the same as tissue or organ donation such as cornea or kidney?

No. The donated brain is not used for transplant, but solely for research and study. Consequently, your separate consent is required in order to make a brain donation for scientific research.

When should plans be made for this procedure?

You should make arrangements well in advance, as family members often need time to discuss this very important issue with you.

It is important to share your wish to donate with your senior Next-of-Kin and other family members. You may also like to add your wish to your Will. Your senior Next-of-Kin, or the executor of your Will, will be responsible for making sure your wishes are fulfilled.

How do I make preparations for a post-mortem brain donation?

Please contact the Queensland Brain Bank Coordinator for more information about how to make a brain donation. Answers to your questions, consent forms, will-wording, and further instructions are available from the Coordinator, at the contact details provided below.

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