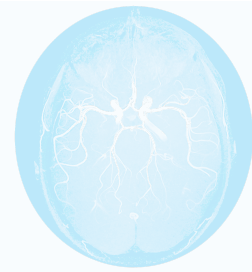


# Brain Donation for Ageing & Neurodegeneration research



We would like you to consider participating in our brain donor programme. The purpose of this programme is to provide tissue for research into changes occurring in the brain with normal ageing and in neurodegenerative diseases like Alzheimer's Disease, Pick's Disease, Parkinson's Disease and other similar conditions. We also hope to discover how genes interact to influence these degenerative disease processes. You, or a member of your family may have one of these conditions, or you may participate as part of a comparison group for donors without neurodegenerative disease. We hope that you will help by agreeing to donate your brain for neuropathological research following your death.

***We are aware that making the decision to donate tissue after death is a very personal and difficult one. We appreciate that the death of a loved one is an emotional and stressful time for those left behind and will strive to ensure that brain donation does not add to the stress.***

Part of the programme asks for participation in annual questionnaires concerning your basic health, lifestyle and family history. Since some information is only available following examination by a doctor, we ask for permission to access relevant medical records for details of your clinical presentation and progression. For some diseases, it will also be important to obtain DNA for study. We also therefore ask for your permission to extract DNA from the brain samples for research. Both the brain tissue and the DNA will be stored for future detailed analysis. Participation in every aspect of the research is voluntary and you should not feel obliged to participate in every, or any, aspect if you do not feel comfortable about being involved. For people who are unable to give their own consent, we ask that the senior available next of kin consider our request on behalf of the person. We cannot guarantee that you will receive any benefits from this research. Any information that is obtained in connection with the research will remain confidential. You may withdraw your consent at any time without prejudice.

The research outcomes may be published in scientific journals or presented at national or international conferences. In all cases, information will be provided in such a way that you or the person for whom you have provided consent cannot be identified. However, please be aware that it is not always possible to report in a way that is completely anonymous to all family members. The research projects will be carried out according to the principles of the National Health and Medical Research Council statement on ethical conduct in research involving humans. Both the samples and any data from this research will be stored for at least 15 years. Data will be stored on a secure database at the Prince of Wales Medical Research Institute.

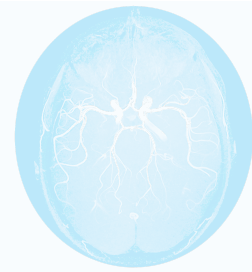
The following researchers and institutions are conducting this research. In addition to the chief investigators, other researchers may participate under the supervision of the chief investigators.

[University of Sydney](#) Prof. Jillian Kril (Ph 02 9036 7118)

[Prince Of Wales Medical Research Institute](#) Prof. Glenda Halliday (Ph 02 9399 1000)

[Brain Bank Manager](#) Dr. Claire Shepherd (Ph 02 9399 1090)

[Brain Donor Programme Coordinator](#) Catherine O'Connor (Ph 02 9399 1107)



## Frequently Asked Questions

---

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

No. The donated brain is not used for transplantation, but solely for research purposes. Consequently, separate permission is required for brain donation for scientific research.

### What should I do now to ensure that brain tissue donation occurs after death?

1. Call the Brain Donor Coordinator to be sent an information package and consent forms.
2. Read the information sheet and consent form, and discuss with your family.
3. Complete the Researcher's copy of the consent form and return to: Brain Donor Coordinator, Prince of Wales Medical Research Institute, Barker St, Randwick, NSW, 2031 (a reply paid envelope is provided)
4. Complete the consent form (Participant's or Next of Kin copy) and keep in a safe place that all family members are aware of.
5. Inform all family members and the Executor of your will of your wish.
6. Inform your General Practitioner.
7. If applicable, inform your Specialist Medical Practitioner (this could be a Neurologist, Geriatrician, Psychiatrist or Neuropsychologist). If you are suffering from a brain disease and have not seen a specialist, please consider doing so.
8. At the time of death, the instructions below should be followed (also reproduced on the consent form).

### What does brain donation involve?

Apart from removal of the brain, brain donation involves documentation of existing diseases. After receiving consent to donate for those with or without a neurodegenerative disease, the Brain Donor Coordinator will send out a survey requesting your medical and family history, and a detailed questionnaire to ascertain your cognitive and motor performance. Thereafter, follow-up surveys will be posted annually to determine whether there has been any change in your health status. Your General Practitioner and Specialist Medical Practitioner (if applicable) will also be contacted about your medical history on an annual basis.

### What to do when the donor dies?

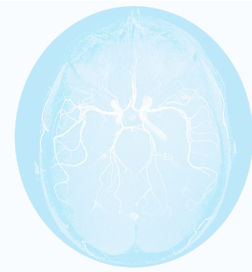
- Notify the researchers as soon as possible after death using the 24 hour contact details on the consent form.
- If the donor dies at home or in a nursing home, the General Practitioner is required to certify the death and supply a death certificate. If the donor dies in hospital, the attending doctor will sign the death certificate.
- Funeral directors appointed by the family are informed
- The researcher will then contact the funeral director and make the necessary arrangements for the donor's body to be taken to the hospital 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.
- The body of the donor is transported to a hospital for brain tissue removal. Two documents must accompany the body:
  1. The death certificate
  2. A signed consent form.

### Is there a preferred funeral director?

No. The choice of funeral director is entirely up to the family.

### Is there any cost involved?

No. The Brain Bank Coordinator will ask the funeral directors to charge the Brain Donor Programme for any additional costs involved in transferring the body to the hospital where the autopsy is carried out.



## Frequently Asked Questions

---

### What happens to the tissue?

Tissue samples are processed in two main ways to allow the maximum information to be obtained and all tissue is held at the Brain Bank of the Prince of Wales Medical Research Institute so that scientists either in Australia or overseas can use the material for ethically approved research projects. Some of the tissue is frozen so that it can be used for DNA extraction or biochemical studies. If DNA is extracted, a number of samples are prepared and stored for future testing. For participants with a strong family history of disease, the DNA may be screened for genes in which rare mutations have already been associated with neurodegeneration (eg. presenilins, amyloid precursor gene, tau, alpha-synuclein, parkin). The remaining tissue is fixed in formalin to preserve it for microscopic examination. This information allows comparison between DNA and tissue findings as well as tissue diagnosis and typing.

### What do the researchers' do if they find out sensitive genetic information?

Some people may be concerned about their genetic material being stored or tested in a laboratory. Discovery of a mutation in a person may have implications for his or her children in terms of their risk of developing the disease, their ability to obtain insurance and other issues. In most circumstances the research findings from the study of an individual's DNA do not have any implications for the person concerned, so there is often no information to be provided to people, or their families. Very occasionally, this kind of research uncovers non-paternity or non-maternity of a presumed natural parent. It is not normal practice to disclose this information if it is found. However, if a disease-causing genetic mutation is identified in a family member and appropriate consent is given, this information will be made available.

### Privacy and confidentiality

Any information that is obtained in connection with this study and that identifies an individual will remain confidential and will be disclosed only with permission or as required by law. Only the researchers identified, or researchers they supervise, or colleagues who will sign legal agreements not to disclose details, will be allowed access to any potentially sensitive research information from these tissue studies. The tissue samples and information will be kept in a potentially identifiable form (that is, it will be coded). In the event of withdrawal from the study, the tissue samples and information will either be deidentified or destroyed depending on the option chosen.

### Use of research information in the future

It is possible that the results of the research may lead to discoveries and the development of intellectual property which may be commercialised. However as no information can be generated from an individual sample, there is no financial benefit to individual subjects through participation in this type of research. Sometimes research institutions enter into collaborations with other research institutions, or private companies, to get financial assistance to carry out further research in a particular area. In exchange for the financial assistance, the other organisation or company may require commercial rights to the collection of tissue (often referred to as a tissue bank) developed as a result of research such as this. If research information is given to another organisation or company by one of the participating institutions it would be done in such a way that personal details can not be linked to samples.

### Participation in other possible studies

We may ask you to participate in research using brain imaging, or we may ask you to consider giving a blood sample for laboratory studies. We will ask you to consider signing additional consent forms if these are requested.

*We hope that the information provided will help you reach a decision. However, if you have any questions or if there are any problems with these procedures, please telephone the Brain Donor Coordinator on 93991107 who will be happy to discuss these with you further.*