

Brain Donation is an Invaluable Gift

to help us to understand the cause of many neurological diseases and the effects of modern treatment.

Thank you for taking the time to consider the gift of brain donation. Your interest in helping research into neurological diseases may help to alleviate or prevent the suffering of future generations. We hope you will feel that your donation is a valued contribution to the improved understanding and treatment of neurological diseases.

Despite great progress in clinical neurosciences following the sequencing of the human genome and the development of sophisticated techniques to image the living brain, many questions can only be investigated by the direct study of brain tissue. This includes fundamental questions such as 'Which cells produce a newly discovered molecule?', 'How is this molecule altered in disease compared with normal brain?', 'What are the effects (and side effects) of new treatments?'

If you would like to help us answer these important questions and are considering donating your brain for medical research after death, please read this leaflet. We can be contacted at the John Radcliffe Hospital via the contact details provided on the last page of this leaflet.

Your Legacy Can Help Future Generations

Progress in understanding human brain diseases needs help from people like you. If you or a close relative are considering donating brain tissue for research, this leaflet may help. It describes what the Thomas Willis Oxford Brain Collection is, the research it is involved in and what you can do to help this research.

The Oxford Brain Bank

The Oxford Brain Bank is a local and national resource for research into neurological diseases, including Parkinson's disease, Alzheimer's disease and other causes of dementia, Motor Neuron Disease and Ataxia. It also has stewardship of the UK Brain Bank for autism and related developmental research (www.brainbankforautism.org.uk). Presently the NHS, Oxford University and MRC fund us but we are seeking further support for our Brain Collection. The Collection is based in the Department of Neuropathology at the John Radcliffe Hospital in Oxford, and has close links with the Department of Clinical Neurology at Oxford University.

What can you do to help?

Brain donation after death provides researchers with the opportunity to investigate and try to understand disease processes that occur in life. To understand neurological diseases it is important to study the whole brain so that all aspects of the disease can be examined. In some diseases, it is important to examine the brain and spinal cord together to give a full picture of the disease.

Brain donation involves you or your next of kin giving consent for donation after death. You may choose to limit your donation to the brain and/or spinal cord. If you or your next of kin wish to consent to a donation, a donation consent form must be completed. If you prefer, the form can be completed with the help of a tissue coordinator, *your doctor or a research nurse*. *You can complete the form without professional assistance but* if you wish to consent for donation of your brain before your death, you do need to sign the consent form in the presence of a witness.

What if you do not have a neurological disease but are thinking of brain donation?

We would also like to hear from you. It is important in research to have healthy brains (known as control brains) to compare with those affected by disease. These healthy brains are commonly called 'controls' and can be used in many types of research. There is a shortage of healthy brain tissue donated after death, and any donations of this kind are as important as the donation of diseased tissue.

Giving Consent to Donation

If you wish to donate your brain after your death you may prefer to discuss any concerns you might have with a tissue coordinator, your doctor or research nurse before completing the consent form. These professionals should be able to answer any questions you might have and we will allow plenty of time for you to consider your decision. There is no need for any delay to funeral arrangements following brain donation.

Consent from your next of kin is not a legal requirement for you to donate tissue but it is unlikely we would go against any wishes of your family after your death. It is very important therefore that you talk with your family about your decision to donate and inform them of what to expect when the time comes. Your next of kin can also consent to donation after your death if they believe that you would have wanted this.

When you are happy with your decision you may wish to arrange a meeting with the tissue coordinator to sign the donation consent form or you may wish to fill the form in the presence of a witness in your own time and return the form in your own time.

It is also good practice to inform your GP that you have consented to donate brain tissue after your death.

After you have signed the consent form, we will record your request so that arrangements for brain donation can be made as quickly as possible after you die.

What happens when you die?

When you die your next of kin or medical staff will initiate procedures for brain donation according to your wishes.

If you die in hospital

If you die in hospital your family will be asked to confirm they have no objection to donation. A mortuary will be contacted so the brain donation can take place as quickly as possible (ideally within 12-48 hours). If the hospital is not local to Oxford, it will be important for your next of kin to let the tissue coordinator * know so that appropriate arrangements are made. Usually, a funeral director will transfer your body to the mortuary of the John Radcliffe Hospital for the donation and afterwards your body is returned to the funeral directors. When the hospital is remote to the Oxford area the tissue coordinator may make arrangements at the hospital's local mortuary. There should be no need for delaying funeral arrangements as a result of a brain donation.

If you die at home or in a nursing home

If you die at home your next of kin will have to first contact your GP and then contact the tissue coordinator in order to make arrangements for the brain donation. Your GP will have to sign the death certificate before the donation can take place.

A tissue coordinator usually arranges for a funeral director to help by transferring your body to the hospital for the donation and then returned to the funeral directors after the donation. The costs related to donation of this will be covered by the Collection.

If your home or nursing home is not local to Oxford, it is important for your next of kin to let the tissue coordinator know as soon as possible so that appropriate arrangements are made. There should be no need for delaying funeral arrangements as a result of brain donation.

* The tissue coordinators' contact details are at the end of this document.

What happens next?

Your brain/spinal cord tissue will be examined by the pathologist. If you specify, we can arrange for information to be sent to your family GP where your family can discuss results.

Should your family wish to read further information on the progress of the research carried out by the Brain Collection, they can view Newsletters on

www.ouh.nhs.uk/services/departments/neurosciences/neuropathology/

Contact Information

The Oxford Brain Bank, Department of Neuropathology, John Radcliffe Hospital, Oxford OX3 9DU

General Enquiries: Tel. 01865-234904

Tissue Coordinators: via Neuropathology Enquiries above