

# Donating brain and spinal cord tissue for research



Thank you for taking the time to consider the donation of brain tissue for research into neurological diseases. Your interest in helping this research may help to alleviate or prevent the suffering of future generations.

This leaflet will help you decide if donating neurological tissue is something your relative would have wanted to do.

## Why is human tissue needed for research?

Doctors and scientists can understand disease better by studying human tissue. They can also try out different drugs and tests on the tissue before testing them on human volunteers. These studies may lead to the development of new medicines and other treatments, as well as improving ways of detecting diseases earlier.

## What is the Oxford Brain Bank (OBB)?

The Oxford Brain Bank (OBB) collects, stores and manages the use of neurological tissue which has been donated for research into neurological diseases. The OBB is used as a national resource for researchers. It is located in the John Radcliffe Hospital at Oxford University Hospitals NHS Foundation Trust, and has close links with the Nuffield Department of Clinical Neurosciences at the University of Oxford.

## What are the benefits of donation?

Tissue donated to the Oxford Brain Bank (OBB) will be used for research into Parkinson's disease, Alzheimer's disease and other causes of dementia, Motor Neuron disease and Ataxia. OBB is also involved with research into autism and other related developmental research.

## Why is brain and spinal cord tissue donation important?

There has been great progress in clinical neurosciences following the sequencing of the human genome and the development of sophisticated techniques to image the living brain. However, many questions can only be investigated by the direct study of brain tissue.

- Which cells produce a newly discovered molecule?
- How is this molecule altered in diseased compared with normal brains?
- What are the effects (and side effects) of new treatments?

Brain donation to the Oxford Brain Bank 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. To understand some diseases, like Motor Neuron disease, it is important to examine the brain and spinal cord together to give a full picture of the disease.

## What can I do to help?

Our hospital Tissue Co-ordinator will check if your relative joined the organ donor register while they were alive. If they are not on the register, you can still give consent for them, if you believe it is what they would have wanted.

## How do I give consent for donation?

Our Tissue Co-ordinator may contact you to give you information about tissue donation; if so, you will be able to ask questions. If you wish to give consent, they will call you by telephone or, if there is enough time, they may arrange to meet you at the hospital. The Tissue Co-ordinator will ask you some medical and lifestyle history questions. If you want to go ahead with donation, they will complete a consent form with you. If anything is not clear to you, or you would like more information, please ask.

## What happens if I change my mind?

You can withdraw your consent at any time whilst the tissue is in storage. If you wish to do this, please call us using the contact details at the end of this leaflet.

## Who can be a donor?

Many people up to 75 years of age may be able to donate brain and spinal cord tissue for research. The Tissue Co-ordinator will only contact you if this is possible.

## If my relative has a neurological disease can they still be a donor?

Yes. The Oxford Brain Bank needs donations of brains from people with and without neurological diseases.

## How quickly does this need to take place?

In order for the brain and spinal cord tissue to be used effectively for research it needs to be donated within 48 hours after death.

## Where does the donation take place?

A specially trained team will perform the retrieval procedure in a specialist mortuary (usually the John Radcliffe Hospital mortuary). If your relative is going to have a post mortem examination, then the donation of brain and spinal cord may happen at the same time.

## What type of procedure is used?

For the brain donation, a surgical incision is carefully made across the back of the head (from behind the ears). The brain is very gently removed and the incision is sewn up very carefully and usually hidden in the hairline. For the spinal cord donation, an incision is made from the back just below the head and down to the bottom of the spine. The spinal cord is very gently removed and the incision is sewn up very carefully.

## Will the donation affect the appearance of the donor?

There is only a very small risk (less than 1%) that the appearance of the donor will be affected; please ask us if you wish to know more details. After donation you may see the donor if you wish.

## Will it affect the funeral arrangements?

No. The funeral arrangements should not be delayed.

## Where is the tissue used?

After the donation, the tissue will be stored in the Oxford Brain Bank (OBB), and scientists will send in requests to use it. OBB will make sure all research requests are reviewed and comply with

legal, ethical and safety requirements, and then send out the tissue for research studies in hospitals, universities, non-profit institutes or commercial laboratories worldwide.

## Will the tissue be used for genetic tests?

Yes, but research using these tests would only focus on comparing tissue from people with known diseases to those without disease. Information about the donors will be kept anonymous. Research involving genetic testing may help to reveal differences that may help develop new tests and drugs.

## Will information about the donor be needed?

Yes. Information about your relative's medical condition and treatment can add meaning to research studies. Information provided to researchers won't include your relative's name or identifying details.

## Will I find out about the results of the research?

Yes. Information about the research may be forwarded to you afterwards. We will also send copies of Oxford Brain Bank newsletters and invite you to their open days. This will confirm how valuable your relative's donation has been to improve understanding and treatment of neurological diseases.

## How do I ask for more information?

If you would like to ask for any further information or would like to talk to us at any time, please contact us using the following details.

## To contact the Tissue Co-ordinator (regarding donation)

**Please call:**

**01865 220 076** (office hours)

**01865 741 166** (weekends and after office hours)

Ask for the 'Heart Valve Bank on-call service'

**Or write to:**

**Oxford Heart Valve Bank**

Level 0, Oxford Heart Centre

John Radcliffe Hospital

Oxford OX3 9DU

## To contact the Oxford Brain Bank (for other enquiries)

**Please call:**

**01865 234 904** (office hours)

**Or write to:**

**The Oxford Brain Bank**

Department of Neuropathology

Level 1, West Wing

John Radcliffe Hospital

Oxford OX3 9DU

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **[PALSJR@ouh.nhs.uk](mailto:PALSJR@ouh.nhs.uk)**

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