Brain donation for research into Neurodegenerative disorders

Information sheet for donors and relatives

You are probably familiar with organ donations of the heart, kidneys or eyes, to sustain the health or even the life of people in need. Similarly, the donation of brain tissue to research is a precious and unique gift. It is of fundamental importance to further our understanding of the causes of neurological and psychiatric conditions (such as Motor Neurone disease (MND) and Alzheimer’s disease) and to develop more effective diagnostic tools and treatments.

Thank you for considering giving your permission for a post mortem examination (also called autopsy or necropsy) to be held on the body of yourself or your relative. We appreciate that this is a difficult decision for you. This information sheet aims to give you practical information about post-mortem examinations and tissue donation. It is important that you feel that you have enough information before making a decision about whether to agree to a post-mortem examination and the donation of brain tissue for research into neurodegenerative disorders. Active research is in progress and many medical and scientific articles have been published using donor samples.

The MRC London Neurodegenerative Diseases Brain Bank is a well-established resource for the collection and distribution of human brain tissue for research into the causes and more effective treatment of psychiatric and neurological diseases. Doctors and scientists working at leading research centres in the United Kingdom and abroad regularly request tissue from the Brain Bank for their research studies. Since the majority of these studies can be carried out on a small amount of tissue, each donated brain provides a large number of samples for many research groups.

It is important to register your intention to donate brain tissue so that all of the arrangements for the removal of tissue can take place as quickly as possible after death, preferably within twenty-four hours. In due course, a pathological report is sent to the referring clinician, General Practitioner, and where requested to next-of-kin.

Consent can be withdrawn at any time. Your decision will be respected and no questions will be asked.

What is a post-mortem examination?

A post mortem is a careful internal examination of the person who has just died and can give valuable information about an illness and its effects on the body. A definite diagnosis of disease can only be made on the basis of a post-mortem examination of the brain and in the case of MND and Frontotemporal dementia, the spinal cord as well. However, it should be borne in mind that even the most detailed post-mortem investigation can leave some questions unanswered.
Post-mortem examinations are carried out by a pathologist, who is a doctor specialising in the laboratory study of disease and of diseased tissues. They are carried out in special facilities provided in a hospital mortuary. In certain circumstances they may be carried out in a local public mortuary, or in a regional centre for specialist post mortem. The body will be moved respectfully from the place of death to where the examination is to be carried out.

Pathologists perform post-mortem examinations to standards set by the Royal College of Pathologists. These standards include carrying out the examination in a respectful manner and with regard to the feelings of bereaved relatives.

We are requesting your consent for a limited post-mortem of your relative, which will entail the removal of the brain and, for MND, Frontotemporal dementia and control donors (without a neurological or psychiatric disease), the spinal cord as well. The brain and, where necessary, the spinal cord will be examined to assess the presence of disease and will then be kept at the Brain Bank as a research resource for future studies into neurodegenerative disorders. These studies go through a two-stage procedure to assess their viability, validity, compliance with participant consent and compliance with research standards. Tissue is only provided to studies approved by recognised Human Research Ethics committees.

It is important to remember that the pathologist will only examine organs and/ or tissue which have been agreed by you. This may, however, mean that no information will be available about possible abnormalities present in other organs if a full post mortem is not carried out.

Some of your other questions answered...

When will the post-mortem be carried out?
The initial post-mortem examination is carried out as soon as possible after death, usually within a maximum of two to three working days. You will be given time to discuss the request to carry out a post-mortem examination.

Will a post-mortem delay a funeral?
As the post-mortem is normally carried out within two to three working days after death, funeral arrangements should not need to be delayed. Your relative's body is usually released to the undertakers on the day of the post-mortem.

Will the body be disfigured?
No - after the post-mortem the mortuary technicians will prepare your relative's body so that open casket or other traditional funeral arrangements can take place.

Will the brain donation cost the family anything?
No. All costs relating to the transport for donation will be borne by the study.

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. In some neurological conditions the spinal cord is also essential for the confirmation of diagnosis and for research.

Why is brain tissue needed for scientific research?
Many conditions such as Alzheimer's disease, bi-polar disorder, motor neuron disease, Huntington's disease, schizophrenia, autism and other neurological and psychiatric conditions only affect humans. Brains from people affected are essential for research devoted to finding treatments and cures.
Further information on research activities and groups carrying out research using donated tissue can be found on the Brain Bank website www.iop.kcl.ac.uk/brainbank.

What if the donor does not have a neurological illness?
A donation from an individual without a neurological or psychiatric illness (so-called ‘control’) is equally valuable for research, because every research project requires control tissue for comparative purposes. We therefore gratefully welcome such donations and encourage unaffected spouses and family members to consider registering as donors of control tissue.

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

How will information obtained from a brain examination benefit the family?
Examination of the brain after death enables clinicians and researchers to accurately diagnose the illness that the donor was suffering from. Occasionally post mortem diagnoses are different to those made when the donor was alive. Sometimes the diagnosis is important for those in whom the disease may have a hereditary or familial association. If you or a close relative have such a disease, the diagnosis and subsequent research may then be relevant for a child or grandchild at risk of developing the disorder.

Will the relatives be able to find out the results of the post-mortem examination?
A report on the post-mortem examination is routinely sent to the consultant who looked after your relative and to the general practitioner. If requested, a report can also be sent to the family. However, experience has shown that because of the detailed nature of the pathological examination it is often more appropriate to send the report directly to the clinician, and so enable the family to discuss the findings with them, should they wish.

Will confidentiality be kept?
Donor details and consent will be entered onto a secure database. Confidentiality will be maintained by coding all entries. Information will only be passed on to other health professionals, such as the GP, with appropriate consent. Data collected by the study will only be analysed by approved members of research groups working on neurodegenerative disorders. Once a donation has occurred the tissue is given a unique identification number and stored securely.

Disposal of tissues
Brain tissue is usually kept for an indefinite period because donated tissue is of immense value for a number of studies carried out over time. Subsequently, tissue samples are disposed of in a lawful, respectful way following Human Tissue Authority guidelines, unless the family/next of kin specifically wish to do this.

Thank you again, for your kindness and consideration at this time.

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