

Brain tissue donations

Many people with dementia and their relatives are interested in the possibility of brain donation for research after their death. Donations from people without dementia are equally important to enable comparisons to be made. Scientists are very grateful for the generosity of the families concerned, especially as this process has to be carried out soon after the person's death.

Points to consider

- It is best to begin to consider the issues well before the person is likely to die. Family members need time to discuss the issue and to explore their feelings before making a decision.
- Before someone dies, a person's family cannot consent to the donation of any part of their relative's body. At this point it is important for the person with dementia to make their wishes known to family members, possibly by adding this wish to their will, and for family members to discuss the issues involved.
- Once a person dies, their family has the right to refuse or consent to the donation of parts of their relative's body.
- You will need to contact an appropriate research centre. You will find a list of research centres carrying out research into Alzheimer's disease and other forms of dementia in this sheet. While we have made every effort to ensure that information is up to date, there may have been changes and it should be used only as general guidance. It should be noted that some centres are only able to accept donations when people have been involved in regular assessments or research programmes while they were alive. The situation is changing all the time and there may be other centres which have not been included.
- You can telephone or write to your nearest research centre and ask if they would be interested in receiving a brain donation. Each research centre requires certain information and has its own procedures, which should be explained to you. Some research centres like to talk to the relatives and the person with dementia.
- The research centre will ask the doctor in charge of the patient's care for details about their condition and for the name of a local pathologist who would be able to perform the donation at the nearest appropriate hospital. The research centre will then liaise directly with the pathologist concerned.
- Arranging a tissue donation may involve certain expenses and not all research centres are able to meet these. You will obviously want to be clear about this in advance. The amounts involved will vary from place to place but they are usually confined to transport costs.
- Written permission must be given to the pathologist when the time comes. This can be on an official form from the research centre or a signed and dated letter from the next of kin giving permission for the removal of brain tissue from the donor for research. This is best kept in the patient's medical notes, either at the GP surgery, hospital or nursing home.
- You may need to remind the doctor at the time of death that arrangements have been made for a donation in case this gets overlooked.
- The person's doctor should contact the pathologist when they die. If they die in hospital, the hospital should be told about the donation, which should take place before the person is transferred to the funeral director's premises. If the person dies at home or in a nursing home, the funeral director can contact the pathology department to arrange for the donation to take place.

- The removal of the brain will not cause any apparent disfigurement nor should it delay the funeral arrangements since it is carried out soon after death.
- The pathologist will need to remove the brain within 48 hours of death if at all possible as tissue starts to deteriorate when blood is no longer flowing through it. If the body is stored in refrigerated premises, however, it may be possible to accept tissue that has been removed within 72 hours.
- It is important to be clear about what will be removed and what will be retained by the brain bank. This should be explicit in the information sheet that you are given by the brain bank. In most cases, the whole brain is removed, although for some diseases the brain bank may request the donation of the brain and spinal cord. The brain bank will usually retain the brain permanently in its collection as this is how the donation will be most useful for research.
- Once the brain has been removed and correctly stored, there is no need for urgency. You should check on the information sheet that you are given to see whether all the research will be carried out at the brain bank organising the donation or whether tissue will also be shared with other brain banks to help additional research studies. It is a good idea for relatives to contact the research centre themselves to inform the pathologist of the person's death and to ask to be kept informed of the subsequent arrangements.
- The research centre will make arrangements to collect the brain.
- One of the incidental benefits of making a brain donation is that you may receive a diagnosis of your relative's condition, although this may not be for some months. Check with the brain bank whether it provides feedback about diagnosis.
- Many relatives feel that making a brain tissue donation is a way of making a valuable contribution to research into the causes and potential treatments of dementia.

Research centres for brain tissue donations

Cambridge Brain Bank

A division of Addenbrooke's Histopathology Tissue Bank

Manager: Mr Mark A Staveley

Telephone: 012 2359 6099

Co-ordinator: Sr Angela O'Sullivan

Telephone: 012 2321 7336

Box 235

Addenbrooke's NHS Trust

Hills Road

Cambridge

CB2 2QQ

Email: brbank@addenbrookes.nhs.uk

Criteria for accepting donations

All degenerative neurological disease including Alzheimer's disease and normal controls from individuals without neurological or psychiatric illness.

Regional coverage for accepting donations

Eastern region only.

Feedback given to family (if any)

Newsletter and personal contact.

Source and security of funding

Donations and through research programmes.

London Brain Bank for Neurodegenerative Diseases

Director: Dr S Al-Sarraj

Co-ordinator: Dr Saliha Aszal

Department of Neuropathology

De Crespigny Park

London

SE5 8AF

Telephone: 020 7848 0290

Fax: 020 7708 3895

Email: brainbank@iop.kcl.ac.uk

Criteria for accepting donations

Well-characterised brain and spinal cord tissue from a variety of neurodegenerative conditions including Alzheimer's disease, motor neurone disease, frontotemporal dementias, CJD and movement disorders. Also 'control' cases from individuals without neurological or psychiatric illness.

Regional coverage for accepting donations

Receives donations from all parts of the UK and provides tissue to research groups locally, nationally and internationally.

Feedback given to family (if any)

Letter of gratitude and condolence. Copy of diagnostic report (if requested).

Source and security of funding

Medical Research Council.

Manchester Brain Bank

Director: Professor David Mann

Greater Manchester Neurosciences Centre
Humphrey Booth Building
Hope Hospital
Stott Lane
Salford
M6 8HD

Telephone: 016 1787 2580
Fax: 016 1787 2993
Email: david.mann@man.ac.uk

Criteria for accepting donations

Alzheimer's disease, fronto-temporal dementia, Huntington's disease, motor neurone disease. Ideally cases should have been clinically assessed prior to donation.

Regional coverage for accepting donations

North west England/West Yorkshire.

Feedback given to family (if any)

When news of a patient's death is received, letter sent to family expressing sympathy and gratitude. When report of diagnosis becomes available, letter sent to relatives explaining diagnosis in relation to clinical diagnosis and expressing thanks and sympathy.

Source and security of funding

Funded by NHS and supported by the University of Manchester.

Newcastle Brain Tissue Resource

Director: Sir Miles Irving
Co-ordinator: Dr Jenny Court

MRC Building
Newcastle General Hospital
Westgate Road
Newcastle upon Tyne
NE4 6BE

Telephone: 019 1444 4412
Fax: 019 1444 4402
Email: j.a.court@ncl.ac.uk

Criteria for accepting donations

Happy to help the general public but currently only accepting brains from people within studies conducted at the centre.

Regional coverage for accepting donations

North east England.

Feedback given to family (if any)

Diagnostic feedback if specifically requested, but the majority of donations are made on the basis of contribution to ongoing research.

Source and security of funding

NBTR is funded by the MRC in collaboration with the NHS Department of Neuropathology. MRC funding is via an MRC Centre development grant (ending in December 2004) and through two separate programme grants (ending in September 2004).

Northern Ireland Regional Neuropathology Service

Director: Dr M Mirakhur

Regional Neuropathology Service
The Royal Victoria Hospital
Grosvenor Road
Belfast
BT12 6BA

Telephone: 02890 632319

Criteria for accepting donations

Do not have a formal brain bank but will carry out brain donation on behalf of doctors and the Alzheimer's Society. Has an archive of brain tissue and paraffin blocks available for research.

Regional coverage for accepting donations

Northern Ireland.

Source and security of funding

Funded by the NHS.

Nottingham Brain Bank

Director: Professor J Lowe

Co-ordinator: Ruth Musson/Lianne Ward

Pathology
Queen's Medical Centre
Nottingham
NG7 2LH

Telephone: 0115 970 9269
Email: bank@qmctrust.org.uk

Criteria for accepting donations

Any neurodegenerative disease and normal controls.

Regional coverage for accepting donations

Local donations only.

Feedback given to family (if any)

Phone, letter and visit as requested by the family.

Source and security of funding

'Soft' money and Department of Health. Funding expires 2003.

Queen Square Brain Bank for Neurological Disorders

Director: Professor AJ Lees/Professor T Revesz
Co-ordinator: Susan Stoneham

Institute of Neurology
1 Wakefield Street
London
WC1N 3BG

Telephone: 020 7837 8370
Fax: 020 7278 4993
Email s.stoneham@ion.ucl.ac.uk

Criteria for accepting donations

Uncommon forms of dementia - fronto-temporal dementia, Pick's disease, PSP, Parkinson's disease, multi system atrophy (MSA), uncommon movement disorders and unaffected donors (controls).

Regional coverage for accepting donations

Whole of UK.

Feedback given to family (if any)

Feedback given by phone, letter or visit, as requested by the family.

Source and security of funding

PSP Association, Reta Lila Weston Foundation.

South West Brain Bank

Director: Professor GK Wilcock
Acting co-ordinator: Ms Julia Ford

Department of Care of the Elderly
John James Building
Frenchay Hospital
Bristol
BS16 1LE

Telephone: 011 7970 1212 ext 2270
Fax: 0117 918 6665

Criteria for accepting donations

Alzheimer's disease, other related disorders, nonaffected donors (controls).

Regional coverage for accepting donations

Mainly south west England, and other regions on request.

Feedback given to family (if any)

Diagnosis is provided.

Source and security of funding

University of Bristol Faculty of Medicine and Dentistry. Until further notice - permanent.

Southampton University

Director: Professor James R Nicholl

Neuropathology - School of Medicine
Level E (813) South Block
Southampton General Hospital
Southampton
SO16 6YD

Telephone: 023 8079 6634
Fax: 023 8079 6603
Email: j.nicholl@soton.ac.uk

Criteria for accepting donations

No current brain bank, but considering setting up one in the future. Has a collection of paraffin embedded sections available for local use.

UK Multiple Sclerosis Tissue Bank

Director: Professor Richard Reynolds
Co-ordinator: Dr Abni Vora

Division of Neuroscience and Psychological Medicine
Imperial College
Charing Cross Campus
Fulham Palace Road
London
W6 8RF

Telephone: 020 8846 7324
Fax: 020 8846 7500
Email: msbank@ic.ac.uk

Criteria for accepting donations

Donations are accepted from patients with MS, with neurological conditions other than MS, with non-neurological conditions and 'healthy' controls.

Regional coverage for accepting donations

Whole of UK.

Feedback given to family (if any)

Newsletter after or at time of letter of condolence. Diagnostic report sent to GP.

Source and security of funding

Wholly funded by the MS Society. Funding ends February 2008 but is secure in longer term.

UK Parkinson's Disease Tissue Bank

Director: Dr David Dexter/Dr Ron Pearce

Department of Neuroinflammation
Imperial College Faculty of Medicine
Charing Cross Campus
Fulham Palace Road
London
W6 8RF

Telephone: 020 8846 7594

Fax: 020 8846 7025

Email: d.dexter@ic.ac.uk

Criteria for accepting donations

Patients with Parkinson's disease and other movement disorders. Also 'healthy' control donors.

Regional coverage for accepting donations

Whole of the UK.

Feedback given to family (if any)

Neuropathological confirmation of diagnosis of neurodegenerative disease, information on research being carried out using tissue that has been donated - as a newsletter.

Source and security of funding

Funded by the UK PDS until December 2006.

University of Wales, Cardiff

Director: Dr J W Neal
Department of Pathology
Heath Park
Cardiff
CF4 4XN

Telephone: 029 2074 2705

Fax: 029 2074 2701

Criteria for accepting donations

Not a formal brain bank, but department is willing to carry out autopsies for families who wish to donate brain tissue for research.

Regional coverage for accepting donations

South Wales region.

Source and security of funding

The service is funded by the NHS Clinical Pathology Service.

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