

The Manchester Brain Bank
Cerebral Function Unit,
Greater Manchester
Neuroscience Centre,
Salford Royal
NHS Foundation Trust,
Stott Lane, Salford. M6 8HD
0161 206 2561

BRAINS FOR DEMENTIA RESEARCH

Increasing knowledge - Finding a cure

A partnership between the Alzheimer's Research Trust and
Alzheimer's Society in association with the Medical Research Council

CONSENT BY PARTICIPANT FOR THE DONATION OF CENTRAL NERVOUS SYSTEM TISSUE FOR DIAGNOSIS AND RESEARCH AFTER DEATH

(Please initial boxes)

I have read the information sheet on donation of brain and spinal cord tissue. I understand that by agreeing to consent to a limited post mortem and donation the tissue will be used to make a diagnosis and for ethically approved studies of neurodegenerative disease. A post mortem confined to the head is sufficient for removal of the brain. Donation of the spinal cord requires additional examination of the chest and abdomen. I have had time to discuss with other family members, and had opportunity to ask questions.

I understand that I, or my Nominated Representative (if applicable) can withdraw consent at any time before the donation has taken place without giving a reason, and without my medical treatment or legal rights being affected.

SECTION 1: AGREEMENT TO CLINICAL ASSESSMENT

I consent to testing of memory and thinking ability, behaviour and living skills using standard measures once a year (once every 2 years for non-memory impaired individuals).

SECTION 2: AGREEMENT TO REMOVAL OF CENTRAL NERVOUS SYSTEM TISSUE

I agree that my Brain and Spinal Cord may be removed after my death and I am not aware that another family member has objections to this.

Note: It is very helpful to receive both brain and spinal cord but especially so in motor neurone disease, fronto-temporal dementia, ataxia and normal controls. Removal of the spinal cord entails examination of the chest and abdomen.

I agree that a copy of the final results of the autopsy will be sent to my GP and referring consultant (if appropriate).

I would like the autopsy results to be sent to my Nominated Representative's GP: Dr
at
so he/she can discuss the report with them.

I would like my Nominated Representative to receive a letter stating disease diagnosis only.

SECTION 3: USE OF RETAINED TISSUE

I agree to the tissue being used as normal control material, if appropriate.

I agree to the use of the tissue in any research agreed by the Management Committees of Brains for Dementia Research and Manchester Brain Bank. I understand that the Manchester Brain Bank and Brains for Dementia Research will undertake custodianship of the donated tissue in full compliance with guidelines agreed by National Research Ethics Committee, Human Tissue Authority, and Medical Research Council.

I agree to the use of the tissue by commercial/pharmaceutical companies. I understand neither I, nor my Nominated Representative nor family members will receive any financial benefit from tissue donation.

Note: Much research is carried out by commercial companies who are able to fund this, often working in partnership with NHS and academic institutions.

I agree to the genetic analysis/study of the tissue if required.

I agree to samples of the tissue being used in projects outside the UK which are approved by the management committees of Brains for Dementia Research and Manchester Brain Bank.

Note: Studies on the interaction between genetic and environmental influences often require large numbers of samples only achievable by collaboration between a number of tissue banks.

I agree that tissue retained for research may be used as a reference for other clinical cases, for medical education, audit and quality control.

SECTION 4: INFORMATION FROM MEDICAL RECORDS

I give access to my medical records, psychometric data and other research study information.

Note: The identity of the donor is not known to the researcher but it can be helpful to know more of the medical history of the person who has died. The identity of the donor is never given in publications.

SECTION 5: AFTER THE RESEARCH

I agree to the hospital disposing of the tissue in a lawful and respectful way (by cremation), when it can be of no further use.

Note: After completion of investigation and research, any remaining tissue or associated biological samples must be disposed of in a lawful way, according to guidelines agreed by the Royal College of Pathologists, the Medical Research Council, and the Human Tissue Authority.

OR

I agree that the Brain Bank will contact my Nominated Representative
(name & address)

.....
.....

once the tissue is no longer required for research, who will arrange for lawful disposal. I understand this

would be months or years after the funeral.

SECTION 6: THANK YOU

The doctors and scientists who carry out research are very grateful for the tissue donation you are intending to make, and would like to keep you informed about ongoing research that relies on donated brain tissue. Please tell us your preferences.

I would like to receive your newsletter which includes information on research.

SECTION 7: OTHER REQUESTS

Please write in any other requests/concerns you have here:

SECTION 8: NOMINATED REPRESENTATIVE APPOINTMENT AND SIGNATURES

I confirm I still wish to participate in Brains for Dementia Research project and brain donation even in the event that my capacity to make such a decision is diminished.

I appoint of
(print name) (address)

to be my Nominated Representative with respect to Brains for Dementia Research.

.....
Name of donor (please print) Date Signature

.....
Name of Witness (please print) Date Signature

.....
Witness Address

.....
Name of Second Witness Date Signature
(If consent is taken verbally)

.....
Second Witness Address

SECTION 9: CONTACT INFORMATION

DONOR

Name

Address (Home/Nursing Home/Hospital):

.....
.....

Telephone: Date of birth:

Neuropsychiatric diagnosis (if known/applicable):.....

Contact name(if donor is in nursing home/hospital).....

Consultant caring for donor (if applicable):

Consultant telephone:

NOMINATED REPRESENTATIVE

Name:

Address:

.....

Relationship to donor:

Telephone:

GENERAL PRACTITIONER

Name:

Address:

.....

Telephone:

SECTION 10: SIGNATURE OF MEMBER OF STAFF SEEKING CONSENT
(If applicable)

- I confirm that:
- I have explained to the person giving consent the procedures involved.
- I have ensured there are no known objections to donation of the tissue specified (in section 2).
- I have offered the information leaflet on brain donation
- I have discussed the case (if applicable) with Prof/Doctor

Signature: Print name:

Date: Position:

SECTION 11: CONSENT TO BRAIN DONATION
(TO BE COMPLETED AFTER DEATH)

I am the Nominated Representative of

I confirm that I agree with the decision of and wish their brain
(and spinal cord)* to be donated to Brains for Dementia Research.
(*delete as appropriate)

Signature: Date.....

Print Name:

Relationship to donor:

Address and contact details:

.....

Signature of Witness:

Print Name:.....

Address and contact details:

.....

.....

THANK YOU

The doctors and scientists who carry out research are very grateful for the gift of your partner's/relative's/friend's tissue at such a difficult time, and would like to write to you to express their thanks. Please tell us your preferences.

I would like to receive a letter of thanks from the hospital.

I would like to receive your newsletter which contains information on the types of research doctors and scientists are involved in.

This will be sent to the address above unless you give a different address here:

INFORMATION FOR DONORS' FAMILIES

We need to ensure that your wishes to donate can be carried out when the time comes. We will hold a copy of the consent form at the Brain Bank and send copies to your nominated representative, General Practitioner, and the Nursing Home/hospital (if that is where the donor is receiving care). We recommend that the relatives closest to the donor, the executor(s) of their Will and solicitors also be informed of the decision to donate.

CONTACTING THE BRAIN BANK

In the event of death when consent has been given please telephone **0161 206 2561** (9am to 5pm, Mon—Fri) as soon as possible so the Brain Bank can make the appropriate arrangements. A death certificate needs to have been issued by the GP/hospital doctor before the body can be temporarily transferred (at our expense) to the mortuary for removal of consented tissue.

Outside office hours, weekends, public holidays please telephone **0161 206 2561** and ask for the Brain Bank staff to be contacted. Please give your name, message and telephone number where you can be reached. In the event of a death outside normal hours the Brain Bank advises that the body should be taken to the mortuary (if in hospital) or funeral directors, and be kept cold. We apologise for the fact that post mortem arrangements cannot be made until the next working day due to circumstances beyond our control.

We appreciate the effort you are making, at a time you least feel like it. If you do not hear from the Brain Bank and are wondering what to do, please continue with your plans. We will fit in with your arrangements.