

DONATION OF CENTRAL NERVOUS SYSTEM TISSUE FOR DIAGNOSIS AND RESEARCH AFTER DEATH—CONSULTEE DECLARATION

(Please initial boxes)

I have read the information sheet on donation of brain and spinal cord tissue. I understand that following 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 or back] I have had time to discuss with other family members, and had opportunity to ask questions. As a Consultee I have been asked about the donor's thoughts and wishes, and advise that taking part in this tissue donation project is something the potential donor would have done.

I understand I can change my mind at any time before or after the donation has taken place without giving a reason, and without the participant's medical treatment or legal rights being affected.

SECTION 1: AGREEMENT TO CLINICAL ASSESSMENT

I agree to testing of memory and thinking ability, behaviour and living skills of the potential donor, using standard measures once a year.

SECTION 2: AGREEMENT TO REMOVAL OF CENTRAL NERVOUS SYSTEM TISSUE

I agree that the Brain and Spinal Cord and other small samples may be removed from the body of and I am not aware that he/she* had any objections, or that another family member has objections to this. I understand that in some circumstances it may only be possible to collect the brain.

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/back. A small blood sample would be collected at the same time. Some studies may also wish to examine small samples of nervous, vascular and other tissues if you agree to this. However, depending on circumstances at the time of donation, it is sometimes only possible to collect the brain.

I would like the results in a letter stating disease diagnosis only.

And/or

I would like a copy of the final results of the autopsy to be sent to the donor's GP and referring consultant (if appropriate).

Or

I would like the results of the autopsy to be sent to my GP:
Dr

at
.....so he/she can discuss the report with me.

SECTION 3: USE OF PROJECT DATA AND RETAINED TISSUE

I agree to the use of the project data and tissue in any research agreed by the Management Committees of Brains for Dementia Research and Newcastle Brain Tissue Resource. I understand that the Newcastle Brain Tissue Resource and Brains for Dementia Research will undertake custodianship of the project data and donated tissue in full compliance with guidelines agreed by National Research Ethics Committee, Human Tissue Authority, and Medical Research Council. I understand that according to these guidelines, researchers will be asked to make a contribution to the cost of providing tissue samples.

I agree to the use of the project data and tissue by commercial/pharmaceutical companies. I understand neither the donor, nor the donor’s representative will receive any financial benefit from tissue donation.

Note: Much research is carried out by commercial companies, often working in partnership with NHS and academic institutions.

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

I agree to the project data and tissue being used in research conducted outside the UK which is approved by the Management Committees of Brains for Dementia Research and Newcastle Brain Tissue Resource. *Note: Studies on the interaction between genetics and environmental influences often require large numbers of samples only achievable by collaboration between a number of brain tissue banks.*

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

I agree to the use of tissue and data in projects involving animals if necessary. *Note: It is rare that tissue will be used directly in projects with animals but many projects such as development of new drug treatments may have involved work with animals in the early stages.*

SECTION 4: INFORMATION FROM MEDICAL RECORDS

I agree that Brains for Dementia Research and Newcastle Brain Tissue Resource can access the medical records, psychometric data and other research study information of the donor, if this will be helpful in research.

Note: The identity of the donor is not known to the researcher but it can be helpful to know a bit 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 (usually by incineration), 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 the donor’s representative below:

Name:..... Address:

.....
once the tissue is no longer required for research, and the appropriate representatives will arrange for lawful disposal. I understand this would be months or years after the funeral.

SECTION 9: CONTACT INFORMATION

DONOR DETAILS

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:

CONSULTEE DETAILS

Name:

Address:

.....

Telephone:

Relationship to donor:

DONOR'S GENERAL PRACTITIONER

Name: Telephone:.....

Address:

.....

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

- I confirm that:
 I have explained to the consultee what taking part in the project involves.
- I have ensured there are no known objections to donation of tissue specified in section 2.
- I have offered the information leaflet on brain donation
- If applicable I have discussed the case with Professor/Doctor

Signature: Print name: Date:

Position:

Organisation Address:

.....

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

I am the Consultee/Representative of

*I confirm my agreement / that I agree with(named in section 8) (*delete as appropriate)

and wish the brain and spinal cord* (*delete as appropriate) of(donor)

to be donated to Newcastle Brain Tissue Resource/Brains for Dementia Research. I understand that in some circumstances it may only be possible to collect the brain.

Signature: Date:

Print Name:.....

If you are not the person who completed Section 8 please let us know the following details:

Relationship to donor:

Address:

Contact phone number:

IS PERSON CONFIRMING BRAIN DONATION DIFFERENT TO PERSON IN SECTION 8? IF YES, PLEASE TELL US YOUR PREFERENCES BELOW

THANK YOU

The doctors and scientists who carry out research are very grateful for the gift of your partner/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

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 for your friend/relative to donate brain ± spinal cord can be carried out when the time comes. We will hold a copy of this agreement at the Newcastle Brain Tissue Resource (NBTR) and send copies to you, the donor's General Practitioner, and the Nursing home/Hospital (if that is where the donor is receiving care). We recommend that relatives closest to the donor, the executor(s) of their Will and solicitor also be informed of the decision to donate.

CONTACTING THE BRAIN BANK

In the event of death of the donor please telephone **0191 208 1345 as soon as possible** so the NBTR 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 the brain ± spinal cord tissue.

Outside office hours, at weekends, or during public holidays please telephone **0191 208 1345**. Please give your name, message and telephone number where you can be reached and someone will call you back. In the event of a death outside normal hours the NBTR 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 for removal of consented tissue 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 NBTR and are wondering what to do, please continue with your plans. We will fit in with your arrangements.