



# Tissue donation for motor neurone disease research

**People with motor neurone disease (MND) and healthy individuals can make a vital contribution towards research by donating their brain and spinal cord tissue after their death. This information sheet explains how donated tissue may be used and how to go about arranging for donation.**

If after reading this information you decide that you would like to donate your tissue for use in research you will need to make the necessary arrangements with a tissue bank. Please ensure that you make your wishes known to your family and everybody who is involved in your care. You should also pass on to them the contact details of the tissue bank you have chosen.

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## **What is tissue donation and why is it important to MND research?**

### **What do we mean by tissue?**

Tissue is the word used for a collection of specialised cells within the human body that perform a specific job. All organs are made up of tissues. Researchers investigating MND are particularly interested in the whole of the brain and spinal cord tissue, collectively called the central nervous system (CNS).

### **Why is tissue donation important to MND research?**

Tissue donation plays a pivotal role in MND research. Many areas of research require careful examination of parts of the body which are often affected by MND (eg the CNS). Researchers believe that changes found in the CNS can help explain the causes of MND and may provide vital clues about how to combat the disease. Examination of the CNS also sheds light on the effects of MND-targeted medication and can therefore help to improve treatments.

### **I do not have MND, is my tissue useful?**

Yes, it is just as important for research into MND to examine the brain and spinal cord tissue from people who do not have a neurodegenerative disease. By comparing this tissue from both groups of people, researchers are able to study the damage specifically caused by MND. Donating tissue, whether you have MND or not, means that you can make a lasting gift in the fight against MND.

## What will I need to do to donate my tissue?

**If you are considering tissue donation it is better if you can make arrangements well in advance. This allows you time to discuss your wishes with family, your next of kin and healthcare professionals. Tissue obtained soon after death is of greatest value to the researcher and it can make a difficult time easier if arrangements have been made beforehand.**

### **Step 1: Contact a tissue bank**

In the first instance, you should contact one of the tissue banks listed at the end of this information sheet. There are a number of centres in the UK that have the facilities to store and preserve brain and spinal cord tissue donations for MND research - these are known as tissue banks.

Tissue banks are usually on hospital premises with strong links to academic medical research laboratories. Each tissue bank will do things in different ways, which is briefly mentioned below. The tissue donation process will be explained to you fully when you contact the tissue bank.

### **Step 2: Consent to tissue donation**

For legal purposes, your next of kin or legal representative will be asked to sign a consent form; you may also be asked to sign a form to state that you want to donate your tissue for research. This is to ensure that you have given your informed consent for your body to be used in this way.

These forms will then be witnessed by your doctor or a healthcare professional. This will also give you the chance to discuss donation with people involved in your care and ensures that they are aware of your decision. If you are under the care of a hospice or hospital the forms can be signed and witnessed there.

Once these forms have been sent off to your chosen tissue bank, you may find it useful to contact them again to ensure that they have received everything that you have sent.

In relation to any tissue donation it is important to have the fullest possible medical and clinical history; permission to access your medical records will therefore be required (your personal details will remain confidential to the tissue bank).

### **Step 3: Tell everybody**

It is **extremely** important that you discuss your decision with your family, carers and healthcare professionals, so that all the arrangements can take place as quickly as possible after death. For this reason it may be a good idea to write down the name, telephone and out of hours contact details of your chosen tissue bank. You may also like to consider choosing a funeral director in advance to ensure that the tissue bank is aware of these arrangements after your death.

## What will happen to my body?

After the tissue bank has been contacted and a death certificate has been issued, the funeral director will usually transport your body to the chosen tissue bank or, in some cases, the nearest regional hospital.

A *post mortem* examination will be carried out and the donated brain and spinal cord tissue will be removed and prepared for storage. After the tissue has been removed, your body will be transported to the chapel of rest until your funeral. If the *post mortem* was performed at a local hospital, the tissue will be sent on to the tissue bank you have chosen.

### **How will the tissue I donate be used?**

Upon removal, the whole brain and spinal cord tissue samples will be stored securely at the tissue bank. In all cases, the samples are coded so the identity of each donor remains strictly confidential to the tissue bank.

The tissue will first be studied to determine the specific diagnosis; for example, the particular type of MND may be confirmed. These 'neuropathological findings' can often be communicated to the family (see information on individual tissue banks given at the end of this sheet). The tissue bank will then usually retain the tissue permanently in its collection for use in research and education.

**It is important to know** that it will not be possible for the bank to provide families with information on how individual samples are used in research, or what was learned from studying them.

### **Who will do research on donated tissue?**

Primarily, researchers based at the tissue bank where the tissue was collected will carry out the research. However, tissue banks may also be participating in collaborative studies with other universities, hospitals and private companies.

## Frequently asked questions about tissue donation

**Making the decision to donate your brain and spinal cord tissue for MND research is not an easy one. There are many questions that may concern you and your relatives that need careful consideration.**

### **How much does it cost?**

For most tissue banks listed on this information sheet, there are no costs involved in tissue donation. Unfortunately, for other tissue banks no funding is available for the transport of the donor to the tissue bank where the donation occurs. At these tissue banks, the family of the donor are asked to pay the transport costs, although there may be local charities that can provide some financial assistance. The costs involved can vary according to the distance to the centre, and the funeral director transporting the body. Typical figures may range from £40 - £300+.

### **Will it affect my funeral arrangements?**

No. The *post mortem* examination and removal of tissue is carried out in such a way that it will not prevent an open casket or other traditional funeral arrangements. The examination and removal of tissue usually takes place on the day following death and therefore should not cause a delay to the funeral.

In some cases, it may not be possible for the tissue bank to arrange the *post mortem* immediately. This sometimes happens when a tissue donor dies at the weekend, even if the tissue bank concerned has an out-of-hours service (see information on individual tissue banks at end of sheet). However, the *post mortem* and removal of tissue can usually be arranged for the following Monday. This is still soon enough for the tissue to be used by researchers.

### **Will the tissue bank cover the cost of my funeral?**

No, tissue banks cannot provide any monetary awards to assist with the cost of your funeral.

### **Will donation still be possible if I have not arranged it beforehand?**

Yes, your next of kin can arrange the donation of your tissue after your death. To do this they need to contact one of the tissue banks listed at the end of this sheet as soon as possible. We would however **strongly** recommend registering beforehand to help the donation proceed smoothly when the time comes and to reduce the need for your next of kin to deal with administrative issues at a distressing time.

### **Can I change my mind?**

Yes, you are free at any point to change your mind but it is important that you tell everyone involved, especially your next of kin or legal representative.

### **Are there any circumstances which may prevent the donation?**

There is a small possibility that the tissue bank with which you have registered is unable to accept your donation when the time comes. The most likely reason for this is that too much time elapses between your death and the removal of your tissue (usually more than 72 hours). We would recommend discussing this issue with your family to prepare them for the slight possibility that your wishes will not be carried out. The co-ordinators at each brain bank will be happy to answer any questions you have about this.

### **I carry a donor card, will this prevent donation of tissue for research purposes?**

A donor card lets people know that you want your body to be used for *transplant* purposes. It is not usually possible to donate your body for transplant purposes and also for medical research because of the complexity of the arrangements that would be necessary. If you wish to donate your brain and spinal cord to MND research and you carry a donor card, there may be some confusion at the time of your death about your wishes and this may cause your family distress at a difficult time. It is important to make your wishes clear to your next of kin.

With the exception of corneas, the organs of people with MND can be accepted for life-saving transplants if they die in an accident. As with all organ donations, the transplant clinicians will take into account any medical history, assess the condition of the donor organ and use it if it is suitable. However, organ donation for transplant is *not* usually possible after somebody dies *from* MND, particularly if they die at home or in a hospice.

If you wish to register as an organ donor, the NHS Organ Donor Register can be contacted on **[www.organdonation.nhs.uk](http://www.organdonation.nhs.uk)** or **0300 123 2323**

### **Acknowledgements**

The MND Association is very grateful to the pathologists and co-ordinators of the tissue centres listed for their help in compiling this information sheet.

## Studies that used tissue donation samples

The positive impact of tissue donation can be best shown by explaining the research studies where they have been used. Below are brief summaries of selected studies that used tissue from brain banks.

### **ALS-FUS pathology revisited: singleton FUS mutations and an unusual case with both a FUS and TARDBP mutation**

*King, A., Troakes, C., Smith, B., et al. (2015) Acta Neuropathologica Communications*

One of the genes that causes MND has been found to be the 'FUS gene'. Disruptions in this gene result in creation of toxic 'clumps' in motor neurones, eventually leading to degeneration and death. Researchers in this study aimed to look at the detailed composition and location of these clumps when their formation is caused by the faulty FUS gene. The study used the brains and spinal cords of seven patients with a diagnosis of MND due to mutations in the FUS gene.

The tissue was subjected to a number of analyses: *genetics*, where the tissue is screened for various genes known to cause MND; *immunochemistry*, in which thin slices of the brain are stained with special chemicals to show the presence of clumps; and *neuropathological analysis*, in which the number of clumps within the brain and the amount of neuronal loss in the spinal cord is observed. These analyses revealed that the FUS-related clumps are located mostly in the lower motor neurones (in the spinal cord rather than the brain). The researchers also found that the composition and number of clumps was different in each patient. Further studies looking at possible subtypes of the FUS-specific MND might therefore be required in the future.

### **Genetic compendium of 1511 human brains available through the UK Medical Research Council Brain banks Network Resource**

*Keogh, M. J., Wei, W., Wilson, I., et al. (2016) Genome Research*

In order to analyse the possible genetic causes of any neurodegenerative disorder, researchers organise extensive studies in which they look at tens to hundreds of brains taken from patients as well as healthy individuals. The purpose of this study was to create a detailed overview of the most common neurodegenerative diseases and describe the genetic mutations that are likely to contribute to their development. The researchers looked at 252 brains of patients with MND and FTD, alongside of over 1,200 brains of patients with other neurological disorders (eg Alzheimer's disease, Parkinson's disease).

All brains underwent a neuropathological examination, in which a diagnosis was confirmed by a pathologist. In the first stage, slices of brains were sent out for a DNA extraction; this includes an extraction of cells from the brain tissue using a special DNA extraction robot and application of various chemicals and mechanic processes to obtain the purest form of DNA. Further stages involved more detailed analyses of chunks of DNA to reveal the genes that are present in that specific DNA sample. Finally, the presence of genes was tracked back to each tissue sample and associated with their specific disease. Using this approach, the researchers were able to confirm that 149 genetic mutations that were previously thought to be adverse do not in fact lead to a development of neurodegenerative diseases. Such findings will make it easier for researchers to only focus on the relevant genes in the future.

## **How do I choose which centre to contact?**

Although tissue donation is easier to arrange in areas local to the tissue bank, some of them can accept donations from a wider area (see the guide below for details).

If you have any specific questions, we suggest that you discuss them directly with the tissue bank involved. To ensure that you completely understand the principles of tissue donation, it may help to go through the issues raised on this information sheet with the tissue bank that you have chosen.

Some tissue banks are not contactable out of hours. If you choose such a bank, it may be a good idea to discuss with them what would happen if you were to die during a weekend or bank holiday.



## MND tissue banks contact details

| Location & Institute   | Contact address  | Out of hours*   | Regional coverage  | Feedback given to family  | Source of funding   |
|--|--|---|--|---|---|
| <b>Belfast</b><br>Northern Ireland<br>Regional<br>Neuropathology | <b>Dr Brian Herron</b><br>Regional Neuropathology Service<br>The Royal Victoria Hospital<br>Grosvenor Road<br>Belfast BT12 6BA<br><br><b>T: 028 9063 2319</b><br>brian.herron@belfasttrust.hscni.net   | Available 24 hours,<br>7 days a week<br><br><b>T: 07801866678</b>   | Mainly Northern<br>Ireland, but will co-<br>ordinate with<br>facilities in Republic<br>of Ireland.                       | Information on<br>neuropathological<br>findings<br>(diagnosis) will be<br>provided to the<br>donor's next of<br>kin or clinician if<br>requested.   | Any additional<br>expenses for<br>the family (eg<br>undertakers) are<br>funded.                                 |
| <b>Cambridge</b><br>Cambridge Brain<br>Bank                      | Dr Bev Haynes/Mrs Jenny Wilson<br>Department of Histopathology<br>Box 235<br>Addenbrooke's Hospital<br>Cambridge University Hospitals NHS<br>Foundation Trust<br>Hills Road<br>Cambridge CB2 0QQ<br><br><b>T: 01223 217336</b><br><b>F: 01223 256122</b><br>brbank@addenbrookes.nhs.uk | Currently not<br>available. After<br>5:30pm please<br>leave a message<br>with the Brain Bank<br>who will respond<br>on the next working<br>day. | East Anglia only –<br>Bedfordshire,<br>Cambridgeshire,<br>Essex,<br>Hertfordshire,<br>Norfolk, Suffolk and<br>Northants. | Information on<br>neuropathological<br>findings<br>(diagnosis) will be<br>provided to the<br>patient's next of<br>kin or clinician if<br>requested. | Transport costs<br>to and from the<br>patient's local<br>hospital will be<br>met by<br>Cambridge<br>Brain Bank. |

\* Please note that out of hours services are not for registering your interest

| Location & institute  | Contact details   | Out of hours*  | Regional coverage  | Feedback given to family   | Source of funding  |
|---|---|--|--|--|--|
| <p><b>London</b><br/>MRC London Neurodegenerative Diseases Brain Bank</p> | <p>Dr Claire Troakes<br/>London Neurodegenerative Diseases Brain Bank<br/>PO Box 65<br/>Institute of Psychiatry, Psychology and Neuroscience<br/>King's College London<br/>De Crespigny Park<br/>London SE5 8AF</p> <p><b>T:</b> 0207 848 0290<br/><b>F:</b> 0207 848 0275<br/>brain.bank@kcl.ac.uk</p> | <p>Via Institute of Psychiatry switchboard</p> <p><b>T:</b> 0207 848 0002; ask for the Brain Bank staff to be paged</p>  | <p>Mainly London and South East of England but can be accepted from throughout UK.</p> | <p>A copy of the final neuropathology report can be sent to the family. A copy of the report is sent to the clinician in charge of the patient's care.</p> | <p>The costs of tissue donation are met by the Medical Research Council.</p> |
| <p><b>London</b><br/>NeuroResource, UCL Institute of Neurology</p>        | <p>Dr J Newcombe<br/>NeuroResource<br/>UCL Institute of Neurology<br/>University College London<br/>1, Wakefield Street<br/>London<br/>WC1N 1PJ</p> <p><b>T:</b> 020 7278 1338<br/><b>F:</b> 020 7278 4993<br/>j.newcombe@ucl.ac.uk</p>   | <p>Via the UCL Hospitals' switchboard</p> <p><b>T:</b> 0845 1555 000; please ask for the NeuroResource tissue bank.</p> <p>Dr Newcombe will give a mobile number to patients &amp; carers.</p> | <p>Throughout England and Wales</p>  | <p>Information on neuropathological findings (diagnosis) will be provided to the patient's next of kin or clinician if requested.</p>                      | <p>Tissue donation costs met; transport costs covered if requested.</p>      |

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| Location & institute   | Contact address   | Out of hours*       | Regional coverage  | Feedback given to family   | Source of funding  |
|--|---|---------------------|--|--|--|
| <b>Manchester</b><br>Greater Manchester Neurosciences Centre | Steve Chew-Graham<br>Greater Manchester Neurosciences Centre<br>Salford Royal NHS Foundation Trust<br>Stott Lane<br>Salford<br>M6 8HD<br><br><b>T:</b> 0161 7897373 ext 2561<br><b>F:</b> 0161 2060388<br>brainbank@manchester.ac.uk  | Possible on request | North West England (Greater Manchester, Merseyside, North Wales, Lancashire)   | <i>Post mortem</i> report on brain examination issued through local Consultant Physician or Family Doctor, if requested.     | Funding is dependent upon Donations to Research. No external support.                    |
| <b>Nottingham</b><br>Nottingham Brain Research Archive       | Ruth Musson or Tracy Locke<br>Pathology Specialist Nursing Team<br>Nottingham University Hospital<br>Brain Research Archive<br>Department of Histopathology<br>Queen's Medical Centre<br>Derby Road<br>Nottingham<br>NG7 2UH<br><br><b>T:</b> 0115 9709726<br><b>F:</b> 0115 849 3348<br>ruth.musson@nuh.nhs.uk | Not available       | Donors need to have been under the care of a clinician from the Nottingham University Hospital Trust. Donation for research is one of the options for dealing with the tissues once diagnosis is complete. | Information on neuropathological findings (diagnosis) will be provided to the donor's next of kin or clinician if requested. | The family would need to meet the costs of transport to and from Queen's Medical Centre. |

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| Location & institute                                   | Contact address  | Out of hours*   | Regional coverage   | Feedback given to family   | Source of funding   |
|--|--|---|---|--|---|
| <b>Oxford</b><br>Thomas Willis Oxford Brain Collection | Dr Olaf Ansorge<br>Department of Neuropathology<br>John Radcliffe Hospital<br>Headley Way, Headington<br>Oxford OX3 9DU<br><br><b>T:</b> 01865 234904<br><b>F:</b> 01865 231157<br>olaf.ansorge@ndcn.ox.ac.uk  | Tissue co-ordinators via Oxford Cell and Tissue Biobank, John Radcliffe Hospital, Oxford<br><b>T:</b> 01865 220076. | Midlands, Thames Valley, South and South-West of England. No costs to the family. Logistics may prevent donation in some cases. | Information on neuropathological findings (diagnosis) will be provided to the donor's next of kin or clinician if requested. | The Oxford Brain Bank is supported by the Medical Research Council, Brains for Dementia Research and the Oxford Biomedical Research Centre. |
| <b>Newcastle</b><br>Newcastle Brain Tissue Resource    | Dr Tim Williams<br>Consultant Neurologist<br>Newcastle MND Care Centre<br>Dept of Neurology<br>Royal Victoria Infirmary<br>Queen Victoria Road<br>Newcastle upon Tyne<br>NE1 4LP<br><br><b>T:</b> 0191 282 3693<br><b>F:</b> 0191 2825027<br>marian.dent@ncl.ac.uk | <b>T:</b> 0191 2481345<br>(answer machine – checked daily including weekends and holidays)                          | Northumberland, North Cumbria and Tyneside  | We will give feedback on request in terms of tissues stored and any additional findings at <i>post mortem</i> .              | The costs of tissue donation are met by the Newcastle MND Centre.   |

Last revised: January 2017

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