A Guide to Brain and Tissue Donation for Research

Introduction

This factsheet has been developed to provide information about supporting research into Multiple System Atrophy (MSA) through brain and tissue donation. It is aimed at those considering whether to donate their tissues for research and those who have already decided to donate. In this factsheet ‘tissue’ refers to the ‘brain’, and on occasion, spinal cord tissue too.

Brain donation is a highly sensitive subject and can evoke strong emotions. This factsheet has been compiled to help those affected by MSA and their families make a decision about whether brain donation is right for them. Having read the factsheet, if there is anything you would like to talk about further, please contact a brain bank coordinator (see final section) or the Trust’s MSA Nurse Specialists.

What are Brain Banks?

A brain bank is a scientific facility that receives donated brains, carries out neuropathological examinations to obtain a definite diagnosis and stores samples of the donated tissue to distribute to researchers worldwide in order to further research into neurological disorders. There are about a dozen of these facilities in the United Kingdom with differing areas of specialism and not all will use the donated tissue to research MSA. The brain banks do, however, work collaboratively, especially where rare disorders are concerned. Researchers working on MSA can request tissue from a bank where MSA is not a specialism. In addition, any research into neurological disorders can broaden knowledge of other related disorders. So if your preferred, or local, brain bank does not directly research MSA the donation could still support MSA research.

Medical research is needed to further neurologists’ understanding of all neurological diseases, including MSA. Many research projects require tissue from people affected by diseases as well as those who were not affected. People who do not have a neurodegenerative disease act as a control group so differences caused by the disease can be identified. By furthering knowledge of MSA, researchers stand a better chance of developing early and accurate diagnostic tests. This takes the process a step closer to greater understanding and hopefully, one day, a cure.

The brain and tissues donated to a bank can be stored under a licence from the Human Tissue Authority and used in research studies for many years. A researcher will request the use of tissue samples from a bank but in order to be successful in the application the study must meet strict ethical and legal requirements.

Why do people donate?

Most commonly people with MSA are given their diagnosis by a process of elimination. Neurological investigations are conducted to rule out other diseases, leaving MSA as the most probable disease. However, it is only under microscopic examination of the brain tissue that a definite diagnosis of MSA can be achieved. Examination of the spinal cord may also be very helpful in cases of MSA. Therefore, people often agree to this process in order to gain a definite diagnosis.

As MSA is a rare and still relatively unknown disease, the chance to further medical investigation is a strong reason for people to donate their brain for research. Those with MSA and their families often feel this is something they can do to help prevent future families experiencing what they are going through. Families often report that receiving certainty of diagnosis after the donation is helpful in coping with their loss and grief.

How do I decide to donate my tissues?

The first step in donating your tissues is to gather as much information as you feel you need so your decision can be made with the benefit of knowledge and the full facts. It is also important to talk to family members so they understand your wishes. Please note, however, that donation is not a fixed decision, so you are free to change your mind at any time.

There are a series of checks and registration details that the bank will need to collect. Some brain banks may also wish to contact you at regular intervals as the information you provide at various stages can further benefit research. For this reason it is important that having made the decision to donate, you register with the centre of your choice as soon as possible. This will ensure all arrangements can be made well in advance and allow you plenty of time to talk through the process with the bank.

Brain bank staff are experienced at dealing with any questions you may have about the registration process and will be pleased to help. Asking questions does not commit you to taking part and, of course, brain banks have trained staff who will impartially talk you through the donation process.

What happens at the time of donation?

When you register for tissue donation with a brain bank they will be able to talk you through the process of the actual donation. Normally, the next of kin will notify the brain bank as soon as possible following death. There are tight timescales for the use of brains and tissues after death so it is important that your next of kin know what to do. The brain bank will then make all the arrangements for the donation to take place and they will keep your family updated as much as they wish. Donation usually takes place at your local hospital mortuary however, on rare occasions when they may be too busy; the next nearest mortuary would be approached. Your family should also notify the GP to obtain a death certificate and notify the funeral director.

Once it is received at a brain bank, the brain and tissue are preserved in a fixative or rapidly frozen. The brain is examined and samples selected for examination using a microscope to determine diagnosis. This process is known as histopathology and it can take several months to fully determine whether destructive changes were the result of MSA. Next of kin can then be informed, if that was the donor's expressed wish.

The most common questions

The topic of brain donation is a sensitive and very personal one. Brain donation contributes towards a greater understanding of MSA and is still the only way of accurately diagnosing the disease. To clarify some concerns about the process of donation we talked with Professor Janice Holton, Neuropathologist and Ms Karen Shaw, Nurse Specialist from the Queen Square Brain Bank (QSBB) for Neurological Disorders at the UCL Institute of Neurology.

Some of the information presented is specific to the QSBB and some is more general. All is included to give you a greater understanding of the process, but you should check specific details with the brain bank to which you are thinking of donating.

How do I go about arranging to donate my brain and tissues?

You can contact a brain bank local to you (see our list at the end of this factsheet) or one that is specifically interested in MSA. They will provide forms for you to consent to brain and tissue donation.

Will my brain and tissues go to the nearest brain bank or to a specific one for MSA research?

Each brain bank has its own research speciality. The most benefit to MSA can be gained if the donation is made to a brain bank with a research programme for MSA.

Can I specify that I want my tissues to be used for MSA research?

Yes, if that brain bank is researching MSA, although samples from your brain could also be useful in studies of other related disorders. For this reason it is important to allow researchers to choose which studies samples from each brain can be used for. Allowing the samples to be used for research into other diseases that are related to MSA, such as Parkinson's disease, may provide vital clues to understanding MSA itself.

Who must be notified after my death for donation to happen?

Your GP and the brain bank you have registered with will need to be notified. This will preferably be on the day of death; however, if refrigeration of the body has been prompt, donation may take place up to three days after death. Brain banks may differ in their guidelines in this respect, so check with the brain bank you decide to contact.

They will co-ordinate with the funeral director, the local hospital and others as necessary. The brain bank should liaise with the funeral director to make sure your body is safely returned to your family and there should be no delay to funeral arrangements.

Will my body still look OK after tissue donation?

Yes, there will be no disfigurement. However, if agreed, removal of the spinal cord will result in a longer scar on either the front or back of the body. This is not visible once the body has been prepared for the funeral.

Can I also donate the rest of my body to medical research?

Whole body donation is only for the purposes of medical education; they need the whole body and this will not usually be used for research. However, if a body is donated for surgical technique training, then the brain may still be able to be donated to the brain bank.

Will my family get any information about what is found from my donation?

Your family will be provided with information about the diagnosis if this was requested. Any information provided usually takes around six months and the brain bank staff will also be able to explain anything technical or complex. However, information about subsequent research projects will not be provided on an individual basis.

Is there counselling support available prior to making a decision and for my family afterwards?

Generally, yes. Brain bank staff are trained and experienced in dealing with the sensitivities involved in brain donation. Brain banks are subject to governance and good practice guidelines and will offer the same level of care and support to donors and their families. There may be slight differences in the detail of support provided so you should discuss any of the questions above with the specific brain bank you approach.

It is important to note that, sadly, on the odd occasion and despite the best planning, donation cannot happen due to circumstances beyond the brain bankôs control. This is rare and all parties work hard to prevent this from happening. If you are concerned then please talk to the brain bank you register with.

Please see overleaf for a directory of Brain Banks in the UK and Ireland.

Brain Banks in the UK and Ireland

The following list is a guide to the brain banks around the UK; it gives details of current research, and is accurate at the time of publication (August 2015) and will be reviewed every two years.

The Cambridge Brain Bank

Department Histopathology, Level 5 Box 235, Addenbrooke's Hospital, Hills Road, Cambridge,
CB2 0QQ

T: 01223 217 336 | E: brbank@addenbrookes.nhs.uk

The Cambridge Brain Bank collects brains from people who have registered from within East Anglia only. They hold ethical approval to collect brain donations but do not carry out their own research. They supply tissue samples for research that has ethical approval. A brain donor can request that the brain be used for MSA research only.

London Neurodegenerative Disease Brain Bank (LNDBB)

Institute of Psychiatry, Box PO65, King's College London, De Crespigny Park, London, SE5 8AF

T: 020 7848 0290 | E: brain.bank@kcl.ac.uk

The LNDBB accept brain and spinal cord tissue from a variety of neurodegenerative conditions and also 'control' cases from individuals without neurological or psychiatric illness. A potential donor may request that the donated tissue be used for MSA research but usually not exclusively for MSA research.

Manchester Brain Bank

Cerebral Function Unit, Greater Manchester Neuroscience Centre, Hope Hospital, Stott Lane,
Salford, M6 8HD

T: 0161 789 7373 (ext. 2561) | E: brainbank@manchester.ac.uk

The Manchester Brain Bank collects brains for research into disorders such as Alzheimer's disease, fronto-temporal dementia, Huntington's disease and motor neurone disease. They are currently researching MSA, specifically looking for markers to develop diagnostic tests. They are interested in brain donations for specific use in MSA research but ideally cases should have been clinically assessed prior to donation.

Multiple Sclerosis and Parkinson’s Tissue Bank

Wolfson Neuroscience Laboratories, Imperial College Faculty of Medicine, Hammersmith Hospital Campus, Burlington Danes Building, 160 Du Cane Road, London, W12 0NN

T: 020 7594 9734 | E: d.gveric@imperial.ac.uk

The Multiple Sclerosis and Parkinson’s Tissue Bank is a national tissue bank which collects tissue from individuals with MS, Parkinson's and other neurological conditions including MSA. They have previously supported research into MSA and are interested in donations to further their research.

The Parkinson’s UK tissue bank collects donations, including those with MSA. It is not possible to specifically donate a brain to be used solely for MSA research but they are a source of excellent quality tissue and supply tissue samples for ethical research into MSA projects.

Newcastle Brain Tissue Resource (NBTR)

Institute for Ageing and Health, Newcastle University, Campus for Ageing and Vitality, Newcastle upon Tyne, NE4 5PL

T: 01912 481 231 | E: nbtr@ucl.ac.uk

The NBTR encourage donations with generic consent for use in all neurological research. The bank does not conduct research itself, but supplies tissue samples for research projects that they consider are scientifically and ethically sound.

Oxford Brain Bank

Neuropathology Dept, Level 1, West Wing, John Radcliffe Hospital, Headley Way, Headington, Oxford, OX3 9DU

T: 01865 234 904/01865 234403 | E: olaf.ansorge@ndcn.ox.ac.uk

The Oxford Brain Bank is a local, national and international brain bank which supports research into neurological diseases such as MND, Parkinson’s Disease and MS.

Queen Square Brain Bank for Neurological Disorders (QSBB)

UCL Institute of Neurology, 1 Wakefield Street, London, WC1N 1PJ

T: 020 7837 8370 | E: l.haddon@ucl.ac.uk

The QSBB is involved with research into MSA, PSP, Parkinson's disease and uncommon movement disorders as well as uncommon forms of dementia. They are heavily involved with research into MSA and other neurodegenerative disorders. Healthy individuals are also encouraged to join the donor scheme as this provides essential control tissue.

South West Dementia Brain Bank (SWDBB)

South West Dementia Brain Bank, University of Bristol, Level 1 Learning and Research,
Southmead Hospital, Bristol, BS10 5NB

T: 0117 414 7821 | E: laura.e.palmer@bristol.ac.uk
M: 07773 109 449

The SWDBB accepts donors of any age from the South West region who are affected by Alzheimer's disease or other dementias, and non-affected donors (controls) aged 65 or over. Registered control donors are asked to complete a yearly memory test which is performed by telephone and potential donors with dementia are not asked to undergo any assessments as clinical information relating to their condition is taken from medical records after their death.

Brains for Dementia Research (BDR)

Brains for Dementia Research (BDR) Co-ordinating Centre, Wolfson Centre for Age Related
Diseases, King's College London, St Thomas' Street, London, SE1 1UL

T: 020 7848 8377 | E: bdr.office@kcl.ac.uk
| W: www.brainsfordementiaresearch.org.uk

Brains for Dementia Research is a network of 5 university Brain Banks (Oxford, Newcastle, Bristol, Manchester, London (LNDBB) and a donation centre, Cardiff University). The brain banks work together to agreed standard protocols to enable the highest quality tissue to be provided to ethically approved research. There are a team of research nurses who carry out standard questionnaire based assessments. This data is available together with the donated tissue as the best possible resource to promote high quality research.

Wales

Cardiff Brain Donation Centre

Alzheimer's Disease Field Team
Institute of Psychological Medicine and Clinical Neuroscience, Cardiff University, Hadyn Ellis Building, Maindy Road, Cardiff, CF24 4HQ

Contact: Nicola Denning or Charlene Thomas
T: 02920 742018 | E: lammiega@cf.ac.uk

The Department of Neuropathology coordinates brain donation in Wales. If you would like to make a brain donation for medical research please use the contact details above.

Scotland

Edinburgh Brain Bank

Academic Department of Neuropathology, Centre for Clinical Brain Sciences, Chancellor's Building, 49 Little France Crescent, Edinburgh, EH16 4SB

T: 0131 465 9522 | E: tracey.millar@ed.ac.uk
| W: www.edinburghbrainbanks.ed.ac.uk

The Edinburgh Brain Bank collects and makes available to researchers, brain and spinal cord tissue from individuals with a range of neurodegenerative conditions, including MND, dementias, intracerebral haemorrhage, prion disorders and psychiatric conditions. It also collects control tissue from individuals with no known neurological illness or disease.

Ireland

Dublin Brain Bank

Dublin Brain Bank, Neuropathology Department, Beaumont Hospital, Dublin 9.

The Dublin Brain Bank is currently the only brain bank in Ireland and liaises with numerous hospitals to help facilitate donation throughout Ireland as a whole. More information can be found at:

www.iicn.ie/research/dublin_brain_bank.508.html or by contacting them at:

T: 01 809 2706 | E: brainbank@rcsi.ie | W: www.brainbank.ie

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The Trust’s contact details:

If you have any questions on the information contained on this sheet then please contact the Trust’s Nurse Specialists or individual brain bank co-ordinators.

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Emma Saunders T: 0330 221 1030 | E: emma.saunders@msatrust.org.uk

Details of the areas that the MSA Nurse Specialists cover can be found overleaf.

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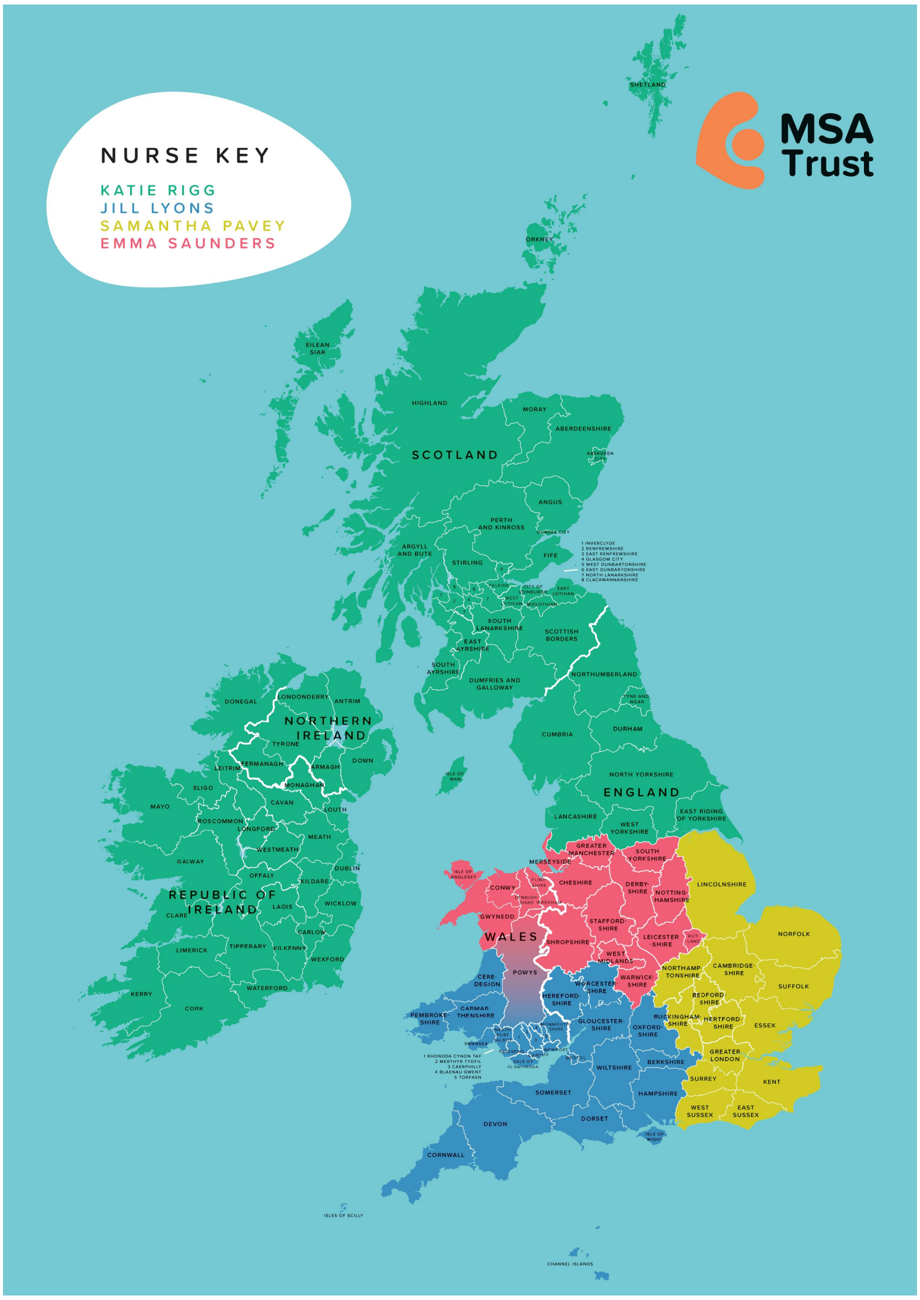

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References for this information sheet are available by contacting support@msatrust.org.uk

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