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A Guide to Brain and Tissue Donation for Research

This factsheet has been developed to provide information about supporting research into 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 sometimes, 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 our MSA Health Care 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 for research into 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. Or you may choose to donate your brain to a brain bank that specifically researches MSA.

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. Therefore, anyone can choose to donate their brains and tissues if they wish to. 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 are stored under a licence from the Human Tissue Authority and used in research studies for many years. A researcher can request the use of tissue samples from a bank, but the study must meet strict ethical and legal requirements in order for the samples to be released for use.

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 as the cause of symptoms. 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 knowledge is another 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 number of consents and registration details that the brain 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 and consent 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 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, some brain and tissue samples are preserved in a fixative and other are 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 in the brain were the result of MSA.

next of kin can then be informed of the neuropathological findings by trained medical or nursing staff, 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 Ms Karen Shaw, Nurse Specialist from the Queen Square Brain Bank (QSBB) for Neurological Disorders at the University College London Queen Square 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?

Please contact the MSA Trust who will put you in touch with your MSA Health Care Specialist who can provide you with more information about possible brain bank options in your area.

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 helpful to allow researchers to choose which studies tissue samples 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 as soon as possible. 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.

A Brain Bank team will co-ordinate the donation with assistance from the funeral director, the local hospital mortuary and others as necessary. They will liaise with the funeral director to make sure your body is safely returned to your family with 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 long scar on the 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 to eight months and a member of the brain bank clinical staff will 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 some occasions and despite the best planning, donation cannot happen due to circumstances beyond the brain bank's control. This is rare and all parties work hard to prevent this from happening. If you have any questions then please talk to the brain bank you register with.

Please contact the MSA Trust at support@msatrust.org.uk or call 0333 323 4591 who will put you in touch with the MSA Health Care Specialist for your area. They will provide you with information about possible Brain Bank options.

Currently the situation with individual brain banks is very fluid and your MSA Health Care Specialist will have the most up to date information available.

There are currently no operational brain banks in Northern Ireland or the Republic of Ireland.

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The Trust's contact details

We have MSA Health Care Specialists that support people affected by MSA in the UK and Ireland. If you would like to find the MSA Health Care Specialist for your area, contact us on the details below or use the interactive map here – <https://www.msatrust.org.uk/support-for-you/hcps/>.

T: 0333 323 4591

| E: support@msatrust.org.uk

W: www.msatrust.org.uk

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