

MS Society Tissue Bank
Centre for Neuroscience
Imperial College London
Hammersmith Hospital Campus
160 Du Cane Road
London W12 0NN

Phone +44(0)20 7594 9734
Fax +44(0)20 7594 9735
ukmstissuebank@imperial.ac.uk
www.ukmstissuebank.imperial.ac.uk



Donation of Tissue to the MS Society Tissue Bank

Thank you for wanting to find out more about donating tissue to research on multiple sclerosis. We have prepared some information for you in the format of answers to questions that we have often been asked. Please do take some time to read through the following pages, it is vital that you feel you have sufficient information to make the important decision of whether to become a tissue donor. Also, please discuss your bequest with your family; it is essential that they do not have any objections to your wishes. If you or members of your family would like to discuss any aspect of tissue donation, you are welcome to contact the Tissue Bank by telephone on 020 7594 9734 or e-mail on ukmstissuebank@imperial.ac.uk.

Why is tissue needed for research on multiple sclerosis?

The symptoms experienced by people living with multiple sclerosis are a result of damage taking place within their brain and spinal cord. Although there are a number of different ways to conduct research on MS, being able to study the very tissue that is damaged in this disease is vital to our developing better treatments. The MS Society Tissue Bank retrieves and stores tissue bequeathed by registered donors and makes samples of the material available to scientists carrying out research on MS. The donation of tissue is therefore a precious gift that will further our understanding of MS and make an essential contribution to finding a treatment for the disease.

Who can register as a donor?

People living with MS, those with conditions other than MS and those who are healthy can all register on our donor scheme and bequeath tissue for research on MS. Samples of tissue from people that did not have MS are of crucial importance since they allow scientists to compare tissue damaged by MS with the normal situation. Please contact us if you have any specific queries.

What tissues are needed?

Since MS is a disease that is specific to the brain and spinal cord, these tissues are of most use to research. The cerebrospinal fluid (CSF) bathes the brain and spinal cord; so, the study of CSF may also provide useful information. In order to explain why the damage in MS is restricted to the brain and spinal cord, scientists may wish to compare this organ with other tissues, for example, muscle. Therefore, we routinely remove the following tissues and fluid from our donors:

- the entire brain
- the entire spinal cord
- a sample of CSF
- a small sample of muscle from the back

Researchers have so far requested only this material, but it may be that sometime in the future scientists will need samples of tissue from other sites of the body in order to answer specific questions about MS. If this happens, we will always ask your next-of-kin's permission before removing any material in addition to that listed above.



Multiple Sclerosis Society

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When and how will the tissues be retrieved?

The tissues listed above are removed after the registered donor has died. Tissues of the brain and spinal cord change very quickly after death and so material that has been removed from the body within 24 hours of death is of greatest value to research. **The procedure that we follow is shown in the diagram below.** You will notice that we make the arrangements to make sure that everything is kept as straightforward as possible for your next-of-kin and carers at such a difficult times.

Death of registered donor (the next-of-kin requests GP's attendance for certification of death)

Tissue Bank informed by someone telephoning 07 566 950 965

A member of the Tissue Bank phones back for further details

Death certified by GP or hospital doctor

Body transported to hospital nearest to the place of death

Pathologist and post mortem technician at the hospital retrieve tissue

Member of on-call team travels to hospital to collect tissue

Body returned to undertakers for the funeral

Tissue brought back to Hammersmith hospital for processing and storage

Arranged by the Tissue Bank

Since it is vital that we are contacted as soon as possible after your death, preferably within a couple of hours, we would ask you to ensure that your next-of-kin or legal representative, and health care professionals looking after you are aware of your bequest. Everyone concerned should know that **in the event of your death someone needs to immediately telephone the Tissue Bank.** We are on standby 24 hours a day, every day of the year.

The 24-hour Emergency Donor Line number is **07 566 950 965**

When and why it is sometimes NOT possible to go ahead with the tissue retrieval?

On rare occasions when we are not able to retrieve and preserve tissues within 48 hours due to unforeseen circumstances we will not go ahead with the tissue retrieval.

This is because irreversible damage is induced in tissue samples after 48 hours and as such that tissue will not be useful for research. The Human Tissue Act introduced in 2006 clearly states that human tissue samples must not be taken if they are not to be used for the purpose specified in a given consent, i.e. medical research.

Major exclusion criteria for tissue retrieval:

- Presence of systemic infectious disease such as MRSA or septicaemia
- Unable to arrange retrieval within a specified time:
 - Death has to be certified by a coroner
 - Too long a delay in being informed of death
- Our ability to rapidly retrieve tissue from our donors is very much reliant on the good will of GPs and NHS post mortem technicians. Their availability to assist is therefore not guaranteed.

Please note that this is not a conclusive list and other circumstances may arise in the future. We do our utmost to avoid delays by closely liaising with families and professionals.

What happens to my body after the tissues have been removed?

The procedure used for removing the tissues will leave your body in a suitable state to be viewed at an open casket funeral. Since the tissues are removed as soon as possible after death, your donation to the Tissue Bank will not delay arrangements for the funeral. We will organise for the body to be transported from the hospital where the tissues were removed to the firm of undertakers that are going to be responsible for the funeral. No extra costs will be incurred by your relatives or carers as a result of these procedures.

How will my tissues be made available for research?

The brain and spinal cord that we collect will be brought back to the Tissue Bank laboratory to be processed into approximately 250 individual tissue samples, this is done to ensure that each donation provides material to as many research projects as possible. The tissues will be preserved and stored safely and securely by the Tissue Bank until their respectful and ethical use in research. All these procedures are performed with the utmost respect for the individual who donated the tissues.

We regularly promote our work in the scientific community so that the Tissue Bank will come to be identified as a valuable resource for scientists. These events also provide us with an opportunity to invite scientists to apply for tissue that they can use in their research on MS. Only once their applications have been received and reviewed, can we match their requirements with the tissue that we have available. Therefore, we cannot at this stage, predict what type of research your tissues will be used for, where or when the research will be carried out or by whom, but we assure you that we will try and supply as many research projects as possible to further our understanding of MS.

The Tissue Bank was set-up to act as a resource for research on MS, so we will consider applications from all scientists conducting research on MS whether they are working in or outside the UK or, in the public or private sector. Everyone receiving tissue from the Tissue Bank agrees to the same terms and conditions.

How long will my tissues be stored and how will they be disposed of?

Your tissues will be immersed in formaldehyde (a liquid fixative that preserves tissue) or stored frozen at -85°C . These preservation techniques ensure that tissues will remain usable in research for many years to come. Some research studies can be carried out on tissue that has been stored in this way for 10 years or more. If we have to dispose of your tissues because they are no longer suitable for research, we will do so only after consulting the MS Society and other appropriate organisations to make sure that it is done in an ethical and respectful manner. Samples of tissue that have been used in research are usually archived and after a suitable length of time respectfully disposed of by the researcher.

Does the Tissue Bank need to know my medical history?

Since it is essential to relate studies on samples of tissue to the medical history of the tissue donor, we need your permission to access your medical records. You give this permission by signing the "Consent for the Procurement of Tissue..." form enclosed. Once we have collected your tissues we will contact your general practitioner (and neurologist if necessary) and ask to consult your medical records. The information will be used to prepare a summary that will be supplied to the researchers who have received samples of your tissue. This medical summary will also help our neuropathologist to interpret his findings on examination of your brain and spinal cord. The neuropathology report that he prepares will be sent to your general practitioner who can then discuss the findings and their implications with your family if they have expressed a wish to do so.

What do I need to do now?

If, after having read all the information and discussed it with your family, you have decided to bequeath your tissues to MS research and none of your family have raised objections, then you and your next-of-kin will need to complete and return the three forms enclosed in the pack. We will keep your original registration forms and send you photocopies for your records. We will also send you your Tissue Bank Donor Card. Always carry your card so that in an emergency staff at a hospital will know immediately of your bequest to the Tissue Bank.

What if I do not wish to proceed or change my mind once I have registered?

We understand that the donation of tissue is not right for everyone. If you do not wish to register you do not need to do anything further. Thank you for reading through these pages, we hope that you have found the information interesting. If at any time after having registered you change your mind and for whatever reason decide to withdraw your consent, just let us know (by telephone, letter or e-mail) and we will return your original consent forms and remove your details from our computer database.

If you have **any** queries either whilst deciding whether to register or once you have registered, please contact us.

Will my personal details be kept confidential?

All consent forms and related paperwork are stored in secure filing cabinets. Personal details of our tissue donors are never divulged to researchers receiving tissue or anyone outside the Tissue Bank. The databases that store details of individuals that have requested information, registered as donors and those that have donated tissues are on a secure computer that is only accessed by Tissue Bank staff.

Who funds and oversees the work of the Tissue Bank?

The MS Society Tissue Bank is wholly funded by the multiple sclerosis society of Great Britain and Northern Ireland. The MS Society has put in place a system of governance that ensures that the work of the Tissue Bank is regularly reviewed by an independent panel that includes experts on MS, in tissue banking and in MS research; a person with MS is also a member of the panel. In addition, the literature, consent forms and procedures that are used by the Tissue Bank have all gained approval from the appropriate national ethics committee. The MS Society Tissue Bank is fully licensed by the Human Tissue Authority, a government regulatory body that oversees the use of human samples in research and we are inspected every two years to ensure compliance. Tissue donated to the Tissue Bank is a gift and therefore the Tissue Bank does not charge any of the researchers for the tissue that they have received.

Thank you again for reading through these pages and for finding out about making a very special contribution to discovering a treatment for multiple sclerosis.