



## BRAIN DONATION FOR MULTIPLE SCLEROSIS RESEARCH

### Contact Details

Brain and Mind Research Institute  
Room 723 Level 7 M02F  
94 Mallet Street  
Camperdown NSW 2050  
General Enquiries 1300 672 265

SSWAHS (RPAH ZONE) ETHICS PROTOCOL NUMBER X07-0238

### INFORMATION SHEET

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#### What is a brain bank?

A person can choose to donate his or her brain for the purposes of research after their death. A brain bank is a collection of this brain tissue. The MSRA Brain Bank is specifically for brains from people who have MS. We also aim to collect certain other tissues of the nervous system that are of particular interest in MS research. People who consent to the donation of these other tissues indicate this on the consent form.

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#### What research is being done and what are the benefits?

The cause of MS remains unknown and at present there are no treatments that significantly alter the progression of the disease. Recent research has shown that there is still a lot to be learned about the pathology of the disease, that is, the actual disease processes that are occurring in the brain. It is hoped that by studying the brain tissue carefully we can better understand these disease processes and thus solve the riddle of MS. The bank will allow us to apply the latest research techniques to the tissue. The tissue will be analysed to try to work out what causes the brain lesions in MS and why people get progressively worsening disease.

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#### I don't have MS. Can I donate?

Yes. Understanding the changes that occur in tissue with a neurological disease must be compared to normal 'control' tissue. Unaffected spouse or family members can register with the 'Using Our Brains' donor program available on (02) 9351 2410 or through our website [www.braindonors.org](http://www.braindonors.org).

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#### What if I register and later change my mind and do not wish to donate. What do I do?

You may withdraw from the brain donor programme at any time by simply notifying our office of your decision. There are no costs involved in withdrawing from the programme.

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#### Can I become a donor if I live in a regional area?

Yes. For tissue to be useful to researchers, it must be collected as soon as possible after death. Timing and distance are sometimes an obstacle. In most cases we can arrange for the donation to occur at a nearby regional hospital so this should not deter you from becoming a donor.



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#### Can I be an organ donor and a brain donor?

Yes. Please note that you are not automatically a brain donor if you are a registered organ donor. Separate permission is required for brain donation as the tissue will be used for scientific research, unlike other organ donor programs, where organs such as the kidney or cornea, are used for transplantation. The organ donor registry can be contacted through the local Medicare Office or by phoning 1800 777 203.

If you wish your brain to assist the search for the cause of and cure for MS, you must register separately for brain donation through the MSRA Brain Bank.

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#### Can I donate all of my body to MS Research?

The MSRA Brain Bank is interested in acquiring brain tissue and other tissues of the nervous system for MS research. The remainder of the body is not used and the usual funeral arrangements are the responsibility of the donor and the donor's next of kin.

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#### Will registering as a donor alter my medical care?

No. Registering will not make any difference to the way your doctor treats you. The decision to be a brain donor is voluntary and in no way changes your medical treatment.

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#### What does it cost me to donate my brain?

There are no costs involved in being a MSRA Brain Bank donor. The MSRA Brain Bank assumes all financial responsibility for any costs related to being a brain donor. Funeral expenses, however, remain the responsibility of the family the same as they would if donation were not made.

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#### Is there a preferred funeral director?

No. The choice of funeral director is entirely up to the family.

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#### How long will the tissue be kept?

The tissue will be kept as long as research projects require the tissue. Should the tissue no longer be required, it will be disposed of as per the donor's instructions on the consent form.



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#### Will brain donation interfere with funeral arrangements or having an open casket viewing?

No. The removal of the brain and other tissues of interest will not interfere with the family's plans for the funeral, cremation, or burial. Brain donation will not interfere with open casket viewing or traditional funeral services. Certain religions prohibit the removal of any part of the body before burial. Please check with your own religious leaders if you think this may apply to you.

#### Who will have access to the information about my brain and the post-mortem examination?

You and your personal details will not be disclosed when research is carried out on the tissue. As soon as we receive the tissue, it is assigned a unique identifying number. Only qualified and approved staff has access to post-mortem information. When researchers obtain brain tissue, only the unique code number identifies it. The names of the donors are not included.

#### What will happen to my body when I die?

Your next of kin will need to contact the funeral directors and the brain donor program coordinator. The body is then taken to the nearest mortuary with the facilities for brain removal. The brain and other tissues that you have consented to being taken are removed. These are then processed for appropriate storage and transferred to the university. The remainder of the body is then returned to the funeral directors and taken to the funeral parlour. The removal of the brain does not delay the burial. When a request to use the brain tissue for MS research is received, it is reviewed to ensure that both the research project is suitable and that the researchers are appropriately qualified. If these criteria are met, the tissue is sent out to the researchers for them to conduct the research.

#### How long after my death can the body be kept before the brain is removed?

The brain should be removed "as soon as possible" after death. However there is a maximum time limit before the brain is no longer of use. **Brain donation can take place up to 24 hours after death.** The brain bank contact number at the time of death operates 24 hours a day, seven days a week, to ensure this delay is minimised.

#### Can the brain tissue be used commercially?

No. The tissue is provided free of charge for approved researchers to use.



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#### How will results obtained be communicated?

When important research findings are made, they will be published in peer-reviewed medical journals for others to read. The identity of the donors will never be revealed and the articles will not contain any information that would enable the donor to be identified.

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#### Do I need to write in my will that I am a brain donor?

No. The consent form is sufficient for tissue donation.

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#### Can I donate my brain to the MSRA Brain Bank and the rest to a university in the name of science?

No. Donating one's body to science is a separate programme and we cannot use the brain for MS research if you donate your body to science.

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#### What should I do if I want to donate my brain?

The first step is to discuss it with your family. Speak especially to your nearest next of kin. You should also speak to your neurologist. Should you have further questions, you can call the MSRA Brain Bank direct on **1300 672 265** from anywhere in Australia. Once you have decided to donate, complete the consent form. If the Person with MS is unable to sign the form then the next of kin can sign the consent form. Submit the completed form to the MSRA Brain Bank and the process will be complete. We will notify you that we have received your consent form.

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#### What should I do if I have expressed a desire to donate my brain but am no longer able to sign the consent form?

Your next of kin (spouse, offspring, parent or sibling) can provide next of kin consent.

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#### What if my next of kin does not give their consent for the donation?

Consent from your next of kin is required before brain donation can take place. Ideally, you should discuss your decision to donate with your next of kin who is the person in the position to contact us after your death.



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#### What should I do now to ensure my brain donation occurs after death?

1. Call the MSRA Brain Bank on 1300 672 265 and ask for a Consent Kit to be mailed to you.
2. Read the information sheet and consent form, and discuss with your family, in particularly your next of kin.
3. Complete the Donor's Copy of the consent form and make your family members aware of the safe place you have stored the form.
4. Complete the MSRA Brain Bank Copy of the consent form, with signatures from you, the Donor, your next of kin and a witness and return to: Room 723, Level 7 M02F, 94 Mallet Street, Camperdown NSW 2050.
5. Inform all family members and the Executor of your will of your wish.
6. Inform your General Practitioner with the letter available in your Consent Kit.
7. If applicable, inform your Specialist Medical Practitioner (this could be your Neurologist, Geriatrician or neuropsychologist).
8. At the time of death, the family, medical or nursing staff or other delegates should follow the instructions available below (also available in your Consent Kit).

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#### What to do when a donor dies?

1. **Notify the MSRA Brain Bank Coordinator as soon as possible after death using the 24 hour contact details on the consent form.**
2. If the donor dies at home or in a nursing home, the General Practitioner is required to certify the cause of death and supply a death certificate. If the donor dies in hospital, the attending doctor will sign the death certificate.
3. Funeral directors appointed by the family are informed.
4. The researchers will then contact the funeral director and make the necessary arrangements for the donor's body to be taken to the hospital for removal of the brain. This procedure will not interrupt the normal funeral arrangements and will not result in additional cost to the family.
5. The body of the donor is transported to a hospital for brain tissue removal. Two documents must accompany the body:
  - a. The medical certificate of cause of death
  - b. A signed consent form