



STATEMENT OF INTENT

Donating Post-Mortem Tissue to ME/CFS Research

DONATING POST-MORTEM TISSUE

Donating your body to medical research

If you wish to donate your brain and spinal cord to post-mortem medical research into ME/CFS you must have had a firm diagnosis of ME/CFS from a doctor and understand that we can only proceed if you are aged 18 to 50 at the time of death.

If you wish to register your interest:

1. Complete the MEA Statement of Intent (below) and make sure that your next of kin and solicitor (if you have one) is aware of it.
2. Include this information if you are making a Power of Attorney for Health and Welfare.
3. Send a copy of the completed Statement of Intent by email to the Manchester Brain Bank (MBB).

Please note: If you have completed an earlier version of the MEA Statement of Intent, there is no need to do so again.

What will my family have to do when I die?

When a potential brain donor dies the next of kin, a family member, or a person nominated by the deceased, should contact the MEA by phone (01280 731575) or email (admin@meassociation.org.uk) as soon as possible. The MEA will then contact the Manchester Brain Bank to discuss whether it is possible to proceed with a research post-mortem.

If it is decided to proceed on the information provided, a member of the team at the Manchester Brain Bank (MBB) will then make all the necessary arrangements with the coroner, local hospital pathology department etc for the donation to take place.

The family of the donor will need to complete a consultee consent form from the Manchester Brain Bank at the time of death for donation to take place.

In the sad situation where a death is expected to take place a family member or representative can also get in touch with the MEA beforehand to discuss the situation.

What about funeral arrangements?

Brain and spinal cord donation do not interfere with or delay normal funeral arrangements and should not cause any additional expense. The MBB will provide detailed information at the time, and the MEA or MBB will cover any additional costs that may be involved.

More information

■ Please refer to the information published by the ME Association on its website in October 2023:

<https://tinyurl.com/yc2yb2ww>

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Part 1: To be completed in BLOCK CAPITALS by the donor.

PERSONAL DETAILS OF DONOR

Title Surname/Family name

Forname(s)

Address

Postcode

Telephone

Date of Birth

Religion

PERSONAL DETAILS OF NEXT OF KIN

Title Surname/Family name

Forname(s)

Address

Postcode

Telephone

DECLARATION

I wish to donate my brain and spinal cord after my death to the Manchester Brain Bank and give permission to the ME Association to help facilitate the arrangements. I wish my tissues to be used for medical research in connection with the medical condition that is known as Myalgic Encephalopathy, Myalgic Encephalomyelitis, or Chronic Fatigue Syndrome (ME/CFS).

Signature

Date



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Part 2: Witness declaration (To be completed in BLOCK CAPITALS by next of kin, GP, friend, etc.)

I confirm that I have witnessed: *(Insert name of donor)*

completing part A of this form.

PERSONAL DETAILS OF WITNESS

Title Surname/Family name

Forname(s)

Address

Postcode

Telephone

Relationship to Donor:

Signature

Date

**Please make sure that a copy of your completed Statement of Intent is sent by email
to phillip.tinkler@manchester.ac.uk**

If you do not have access to email, please send a paper copy to MEA head office and we will do this for you.

**In the event of death please contact the ME Association by phone (01280 731575)
or email (admin@meassociation.org.uk) as soon as possible.**

