



Donating Post-Mortem Tissue to ME/CFS Research

Statement of Intent

Donating Post-Mortem Tissue

If you would like to donate post mortem tissue for ME/CFS research then you need to make this clear in writing by completing a **Statement of Intent** which can be kept with your Will or in a Codicil to your Will. Your next of kin will also need to know about this instruction and where they can locate it.

One of the most important practical aspects in the whole process of post-mortem tissue collection is for someone (i.e. next of kin or solicitor) to notify The ME Association as soon as possible after a death has occurred.

This is because the sort of research that is being done at present requires removal and fixation of very specific tissues as soon as possible, preferably within 24 hours – and this obviously requires consent and co-operation from relatives, coroners, and pathologists at a very sensitive time.

What does donating your body tissues to medical research involve?

This would normally consist of removing very small samples of brain, nerve and muscle tissue at the time a post-mortem takes place. Afterwards the body will be returned for burial or cremation.

If we manage to establish The ME/CFS Post-mortem Tissue Bank, the type of tissue samples being removed may be extended to include other body organs.

The Statement of Intent

We need to be notified as soon as possible after death has occurred. Next of kin or a solicitor must be informed that they should make contact with The ME Association:

Tel: 01280 818964 or email: administration@meassociation.org.uk

We will then try and speak to the Coroner and relatives to make the necessary arrangements and try to find a neuropathologist who is willing to help.

It will be very helpful if you can attach to the Statement a separate note containing a brief summary of your ME/CFS history, in particular: date of onset, results of any investigations, who confirmed the diagnosis, key symptoms, medication and details of any other significant illnesses.

Different procedures may apply once an ME/CFS brain and tissue bank has been established.

The ME Association, 7 Apollo Office Court, Radclive Road, Gawcott, Bucks MK18 4DF

Tel: 01280 818964. Email: administration@meassociation.org.uk

Registered Charity Number 801279 Company Registration Number 2361986

Website: www.meassociation.org.uk



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Please note: we cannot guarantee that a neuropathologist will be available or that the post-mortem will in fact take place. But we will do our very best to ensure your wishes are honoured.

Part 1: To be completed in BLOCK CAPITALS by the person who wishes to donate their tissue samples to ME/CFS research after death

Personal Details of Donor:

Title		Surname	
Forename(s)			
Address			
Postcode		Telephone number	
Date of birth		Religion	

Personal Details of Next of Kin:

Title		Surname	
Forename(s)			
Address			
Postcode		Telephone number	

Declaration:

I wish to donate tissue samples and/or body organs after my death. I wish them to be used for medical research in connection with the illness variously known as Myalgic Encephalopathy, Myalgic Encephalomyelitis, and/or Chronic Fatigue Syndrome.

Signature:	
Date:	

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

I confirm that I have witnessed

(insert name of donor) completing Part 1 of this Statement of Intent.

Personal Details of Witness:

Title		Surname	
Forename(s)			
Address			
Postcode		Telephone number	
Relationship to Donor:			

Signature:

Date:

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