

STATEMENT OF INTENT

Donating Post-Mortem Tissue to ME/CFS Research

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 the statement of intent (below) 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. However, this would be an expensive project requiring millions of pounds to establish and one that is unlikely to be completed any time soon.

The Statement of Intent

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

Tel: 01280 818963 or email: admin@meassociation.org.uk

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

Please include with the Statement of Intent:

A summary of your medical history with ME/CFS, in particular date of onset, results of any recent investigations, who confirmed the diagnosis, key symptoms, medications, and details of other medical conditions.

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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
Forname(s)	
Address	
Postcode	Telephone
Date of Birth	Religion

PERSONAL DETAILS OF NEXT OF KIN

Title	Surname
Forname(s)	
Address	
	Telephone (Landline)
Postcode	Telephone (Mobile)

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 known as Myalgic Encephalopathy, Myalgic Encephalomyelitis, and/or Chronic Fatigue Syndrome (ME/CFS).

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 person who wants to donate tissue to ME/CFS research.)

PERSONAL DETAILS OF WITNESS

Title Surname

Forname(s)

Address

Postcode

Telephone

Relationship to Donor

Signature

Date