



How can people with ME donate their body to research into ME/CFS?

Our aim is to set up a comprehensive patient/donor register that will contain basic and on-going clinical information – as happens with the Multiple Sclerosis and Parkinson's disease brain banks.

This will run in parallel with a brain bank research unit that can cope with post-mortem tissue whenever the opportunity arises. The donor register may contain some restrictions on age, co-morbidity (i.e. having other diseases) etc but this will depend on the recommendations from a feasibility study taking place during 2010. No such restrictions apply at present.

In the meantime, the process of dealing with post-mortem requests is a rather hit-and-miss procedure and there is no guarantee that we can always find a neuropathologist who is willing to look at post-mortem tissue when we are notified about possible availability.

So the best we can do at present is to suggest that people who have ME and wish to donate their body to medical research into ME/CFS should place a short and very clear statement of intent with their Will.

What does donating your body to medical research into ME 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 set up a post-mortem and tissue bank, the type of tissue samples being removed may be extended to include other body organs.

Complete both parts of the Statement of Intent on the back of this page and keep it with your Will or legal papers.

Please also notify your GP, relatives, close friends and executors of your intentions and this consent. Someone will also need to know where it is kept. Please note that written consent must be given prior to death. It cannot be given by anyone else after your death.

As we need to be notified as soon as possible after death, the next of kin (or solicitor) must be informed that they should make contact with The ME Association – preferably within hours of a death occurring. Tel: 01280 818964 or email: meconnect@meassociation.org.uk

Someone 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 there is also a separate note containing a brief summary of your ME/CFS illness (in particular date of onset, results of any investigations, who confirmed the diagnosis, key symptoms, medication) as well as details of any other significant illnesses.

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

STATEMENT OF INTENT

Part A: to be completed in BLOCK CAPITALS by the person making the donation

TitleSurname/family name

Forename(s).....

Address

PostcodeTel no

Date of birth.....

Religion/faith group (if applicable)

I WISH TO DONATE MY BODY AFTER MY DEATH. I WISH IT TO BE USED FOR MEDICAL RESEARCH IN CONNECTION WITH THE ILLNESS VARIOUSLY KNOWN AS MYALGIC ENCEPHALOPATHY, MYALGIC ENCEPHALOMYELITIS, CHRONIC FATIGUE SYNDROME.

I wish that arrangements should be made, if possible, for my body to be returned to

.....

(state name, address and contact telephone) within three months of my death.

SignatureDate

Part B: Witness declaration (signature of next of kin, executor, GP, friend, etc)

I confirm that I have witnessed
(insert name of donor) completing **PART A** of this form.

Surname/family nameForename(s)

Address

PostcodeRelationship to donor.....

Signature.....Date