



12: Organ and tissue donation

This section looks at the options for organ and tissue donation if you have MND and what to do if you wish to go ahead.

The following information is an extracted section from our full guide *End of life: A guide for people with motor neurone disease*.

All of the extracted sections, and the full guide, can be found online at: www.mndassociation.org/eolguide

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org



End of life:
A guide for people with
motor neurone disease

12: Organ and tissue donation



This section looks at the options for organ and tissue donation if you have MND and what to do if you wish to go ahead.

Many people are keen to donate parts of their body after their death to assist others. This can be in the form of organs (parts of the body that perform a specific function, such as the liver), or tissue (groups of cells that work together to make up parts of the body).

It is important to emphasise that donation for transplant and donation for research are not the same:

Donation for transplant: means that organ or tissues are donated to directly help another individual, by transplant into the other person's body.

Donation for research: means that the body, organs or tissue are donated for research or education, often to assist a specific area of research.

The following provides an overview about each type of donation, but if this is something you wish to consider, you should also discuss this with your neurological consultant or specialist palliative care professionals. Each region may have different criteria or procedures that need to be taken into consideration.

See Further information at the end of Part 4: What else might I need to know? for details about our research information sheet on Tissue donation for motor neurone disease research.

Donation for transplant

Only a small proportion of all those who die in the UK each year can donate organs for transplantation.

Although not always possible, people with MND can donate their organs for life-saving transplants. However, the NHS Blood and Transplant authority advises this can only happen if the person dies in certain circumstances in hospital, and the cause is not directly related to MND. For example, following an accident.

In these instances, only organ transplantation is possible, but not use of tissues such as eyes, skin, heart valves and bone. Unfortunately, transplant of tissues is not accepted where MND has been diagnosed.

Organ transplantation can only succeed if organs are removed very quickly after death. This means the person needs to be receiving care in an emergency department, or intensive care unit of a hospital, at the time of their death. As with all organ donations, the transplant clinicians will:

- take into account any medical history
- assess the condition of the donor organ
- use it if it is suitable.

Making arrangements to donate for transplant or for MND research can be complex. If you wish to donate for research and at the same time you are registered as an organ donor (or carry a donor card in case of an accident), it may cause confusion at the time of your death. Ensure that your wishes are made clear to help avoid difficulty for your family at a sensitive time.

You are advised to make your wishes known to your family or those close to you, and to the health and social care professionals involved in your care.

You can change your mind at any point, but again, it is important that you tell everyone involved, including your family, your main health and social care professional contacts and any legal professionals that may have been involved in the original instructions.

If you wish to register as an organ donor, contact the NHS Organ Donor Register:

Telephone: **0300 123 23 23**

Website: **www.organdonation.nhs.uk**

If you live in Wales, The Human Transplantation Wales Act means that people in Wales need to register to say that they do not wish to donate their organs, rather than registering to donate them. Further details can be found by searching for *Human Transplantation Wales Act* at: **www.assemblywales.org**

Donation for research

Although various types of organ and tissue can be donated for research, MND research tends to focus on tissue from the brain and spinal cord.

The brain and spinal cord form the central nervous system of the body and researchers believe that changes found here can help explain the causes of MND and may provide clues about how to combat the disease.

“ I’ve decided to leave my brain to medical science. The consultant mentioned this and I decided to do it...I’ve completed two research projects with him, so I felt comfortable discussing it. My wife was with me at the time.”

People with MND can contribute towards this research by donating their brain and spinal cord tissue after their death. People without MND can also donate their brain and spinal cord tissue for MND research, as this can be used for comparison.

If you wish to donate tissue, try to make arrangements well in advance to ensure that:

- you have time to discuss your wishes with family, those close to you and healthcare professionals
- any necessary consent forms have been completed and signed
- everyone knows the procedure required, so that necessary arrangements happen as quickly as possible after death.

Tissue may not be usable if too much time elapses between your death and its removal. We recommend discussing this with your family to prepare them for the slight risk that it will not be possible to carry out your wishes.

Please note that in England and Wales, tissue can only be taken for research in premises licensed for that purpose.

Tissue banks

Brain and spinal cord tissue donations for MND research are stored and preserved at centres known as tissue banks. In all cases, the samples are coded so the identity of each donor remains strictly confidential. The tissue donation process will be explained to you fully when you contact the tissue bank.

See Further information at the end of Part 4: What else might I need to know? for details about our research information sheet on Tissue donation for motor neurone disease research which provides further information and a list of the tissue banks with contact details. Or contact our MND Connect helpline, also listed in Further information, who can direct you to your nearest tissue bank.

Tissue donation requires removal of the donated brain and spinal cord tissue after your death. The tissue is then prepared for storage. Following this, your body will be transported and retained by your funeral director until your funeral. If you have made arrangements with a tissue bank, you may wish to contact a funeral director in advance to ensure they are aware of what needs to happen after your death.

“ We talked about donating his brain to the tissue bank. The MND nurse became involved and made it easier for us to talk about it... in the end we didn't do this, but it was good to talk about it.”

Key points

- Some tissue banks are not contactable out of hours, so it may be a good idea to ask what would happen if you were to die during a weekend or bank holiday.
- It will not be possible for the tissue bank to provide families with information on how individual samples are used in research, or what was learned from studying them.
- There is usually no charge made for tissue donation, but some tissue banks do not have funding for the donor's body to be transported to them, where the donation occurs. In these cases, the family of the donor are asked to pay for the transport. The cost will vary according to the distance involved and the funeral director transporting the body. Ask the tissue bank and the funeral director for guidance.

Document dates:

Revised: 09/17
Next revision: 09/20
Version: 1

MND Association
PO Box 246, Northampton NN1 2PR
Tel: 01604 250505
Website: www.mndassociation.org

Registered Charity No. 294354

© MND Association 2014
All rights reserved. No reproduction, copy or
transmission of this publication without
written permission.

For references and acknowledgements please
refer to the full guide, *End of life: A guide for
people with motor neurone disease*.

The full guide can be ordered in hardcopy
from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org



The MND Association has been
certified as a producer of reliable
health and social care information.
www.england.nhs.uk/tis