Organ Donation and Neuromuscular Conditions

What is organ donation?
Organ donation is a way of helping people with a life changing Transplant. Organ transplantation is an expanding part of treating many previously untreatable conditions. It is a hugely successful medical advance for the treatment of kidney failure, major heart conditions, lung conditions like cystic fibrosis, liver failure and can include corneal grafting for the cure of some blindness.

‘One donor can give life to several people and restore the sight of two more’, says the NHS Donor Register leaflet.

‘There is a critical shortage of organs and the gap between the number of people waiting for a transplant and the number of organs donated is increasing.’ On average three people a day die before they can have a transplant because there are simply not enough organs available.

How could I help?
Many people with a neuromuscular disease or related conditions, such as SMA, may feel they are automatically ruled out of donating their organs at the end of their lives because of their condition. This is no longer so. Due to modern surgery and post-transplant care organs are now accepted from people who themselves have long-standing conditions.

Each donor will be assessed individually if they wish to donate their organs. Some people may be able to donate only certain ones, e.g. corneas. It will all depend upon their actual condition and how it affected them for instance, someone with heart failure could not donate their heart. It would also depend on what long term and short term medication or medical treatment they had undergone.

Could I be a living donor?
Living Donors are also a new advance particularly in the case of kidney transplants. Any one with neuromuscular disease would need to speak to the doctors involved in their care and have a full assessment and discussion with them about the implications of becoming a Living Donor.

Child Donors
If you are a parent or guardian of a very sick child with a neuromuscular condition and feel this is an option you would like to discuss, you need to talk with the medical staff looking after your child. Most hospitals have a Donor Co-ordinator who can help you with this decision.
If you and your child are aware that their life may be limited and organ donation may be an option you could talk about this as a family before any health crises arise so you know what your child might wish to happen.

What do I do if I want to donate organs after my death?
You can sign up to become an organ donor now by joining the NHS Organ Donor Register which records the details of people who have registered their wishes to be an organ and/or tissue donor after their death.

To join the NHS Organ Donor Register or to find out more about organ donation, you can:

- Call: 0300 123 23 23
- Visit www.organdonation.nhs.uk
- Pick up a leaflet in your local GP surgery

Do I need to tell my family?
If you do decide to sign up to become an organ donor, discuss this with your family and particularly your next of kin so they are aware and can support your wishes.

Many relatives say that they have found some comfort in knowing that the loss of their loved one has given someone else the chance to live.

It would also be a good idea for the doctors and any others involved in your care to also be aware of your wishes.

There are 16.9 million people in the UK already on the NHS Organ Donor Register and because you or your relative may have a muscle disease does not mean you cannot join them.

**Disclaimer**
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Here for you

The friendly staff in the care and support team at the Muscular Dystrophy UK’s London office are available on 0800 652 6352 or info@musculardystrophyuk.org from 8.30am to 6pm Monday to Friday to offer free information and emotional support.

If they can't help you, they are more than happy to signpost you to specialist services close to you, or to other people who can help.

www.musculardystrophyuk.org