

### **BLOOD AND ORGAN DONATION**

When you have ME/CFS

#### ME CONNECT HELPLINE: FREEPHONE 0800 538 5200

by Caroline Cavey

ME Essential Editor

Blood is always in high demand. Giving blood saves lives and the NHS needs around 5,000 blood donations every day to ensure they have the right mix of blood groups to meet patient needs. They need around 135,000 new donors a year to replace those who can no longer donate, including 30,000 new donors with priority blood types such as O-Negative. That's a lot of blood.

Giving blood is easy and it's safe. It takes just an hour, you can give blood a few times a year, and giving blood is probably one of the most vital services the general public can provide for the NHS and, in turn, patients in great need.

**Note:** Please read the box below (if you have ME/CFS you cannot donate blood - but family and friends still can if they are in good health).

My own blood type is B-Negative. B-Negative is one of the rarest blood types, so it is hard to find new donors as only 2% of blood donors have it. The most common blood type is O-Positive with 36% of

donors. The NHS also has increased demand for some rare subtypes, such as Ro (a variation of the Rh positive blood type), that are more common in people of black heritage and 40,000 more black people are needed to become blood donors as demand is increasing by 10-15% each year. Additionally, more young people are desperately needed to start giving blood to make sure there's enough blood in the future.

At any time in our lives it is possible that receiving donated blood may be necessary for treatment or even for our survival. But not everyone can give blood - making it all the more important that those who can, do.

As a general rule, you can give blood if you are fit and healthy, your weight is between 50kg and 158kg and you are aged between 17 and 66.

However, there are reasons some people cannot give blood and these include (but are not limited to) carriers of Hepatitis B and C, people who are HIV Positive, or, if within the last seven days you

Blood and Organ Donation when you have ME/CFS was written by Caroline Cavey (pictured above), Editor of ME Essential, the ME Association's quarterly magazine for MEA members. This leaflet featured as an article in the Summer 2021 issue of ME Essential.

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# THE CURRENT SITUATION REGARDING BLOOD DONATION FOR PEOPLE WITH ME/CFS

Ten years ago the Department of Health announced their intention to permanently exclude people with ME/CFS from giving blood in the UK. Other countries, including Australia, Canada and New Zealand, followed suit.

The ruling was made on the grounds of donor safety. ME/CFS is a relapsing condition which often starts with an infection, may be complicated by reactivation

of other viral infections, and also involves immune system dysfunction. A second reason for excluding people suffering from ME/CFS was to protect their own health – as an acute loss of blood could cause an exacerbation of symptoms.

The situation remains the same.
Blood donation cannot be
accepted from people with ME/
CFS, even if you are currently well.
If you have had ME/CFS, even if
you are now fully recovered, blood
donation is not an option.



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have had a covid vaccine, dental treatment or taken antibiotics, or have had a cough, sore throat or cold symptoms in the last 28 days, have a heart condition... or if you have ME/CFS.

### WHAT ABOUT ORGAN DONATION?

Even though donating blood is off the table, having ME/CFS doesn't prevent a person from becoming an organ donor.

Very few medical conditions exclude organ donation (cancer, ebola, CJD, HIV). Specialists will determine which organs are suitable at the time of donation.

#### WHAT IS AN ORGAN?

An organ is a part of the body that is composed of more than one tissue and forms a structural unit responsible for a particular function, or functions. Examples that are relevant here include the heart, liver, lungs and kidneys.

#### CHANGES TO ORGAN DONATION CRITERIA

In 2020, England changed the rules for organ donation to help save more lives.

Unless you have expressly made it known that you don't wish to donate your organs after death, your consent will be assumed.

You can make your wishes known in your will and/or by telling your family.

There are exclusions to this ruling. The law in Northern Ireland, Scotland, and Wales are different.

As well as opting out, you can also make decisions about which organs you are happy to donate. You have the option to choose to donate organs such as your heart, lungs, liver, kidneys, pancreas and small bowel. You can also choose what to do about donating your corneas and bone.

However you feel about organ donation, your decision is important. It's also important to remember that healthcare professionals have a duty of care



to save your life first! Only when death is inevitable, will organ donation be considered and only at this point would discussions begin with your next-of-kin.

If you really don't want to donate your organs, you can make the choice to opt out. To do this you need to record your decision on the NHS Organ Donation Register:

https://tinyurl.com/54fkv35a

MOST PEOPLE DO NOT
DIE IN CIRCUMSTANCES
THAT MAKE IT POSSIBLE
FOR THEM TO DONATE
THEIR ORGANS. IN FACT,
ONLY AROUND ONE IN 100
PEOPLE WHO DIE IN THE
UK ARE USUALLY ABLE TO
BE DONORS.

#### **FAMILY**

Rest assured that your family will always be consulted before an organ donation goes ahead, even within the 'opt out' system. If your family object to donation, even when you have given your permission, the specialist nurse will discuss the matter with them. They do not have the legal right to overrule your decision, but of course the matter will need to be dealt with sensitively, especially if it would cause great distress to family members.

It is therefore really important that you discuss your wishes with your family, but if you feel unable to make a decision, you can nominate someone to make it on your behalf. If you don't have any family you can add someone else, such as a long-standing friend, to the NHS Organ Donor Register and specify that they may act on

your behalf. To do this you'll need them to sign an online form in the presence of a witness.

#### **ORGAN DONATION TIMELINE:**

A post-mortem is normally carried out by a local hospital pathologist. Samples of tissue from the brain, spinal cord, skeletal muscle, adrenal glands, and intestinal lining will be removed.

The samples are then fixed to prevent further decay, frozen, and examined. The body is returned to relatives for burial or cremation.



#### MEDICAL DISCLAIMER

We recommend that the medical information in this leaflet is discussed with your doctor. It is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/CFS.





## ME CONNECT

The Support and Information Service for people affected by ME/CFS/PVFS and Long Covid

3 WAYS TO GET IN TOUCH:

by phone, email or social media private message





Freephone 0800 538 5200

Monday to Friday 10am - 6pm (Late night until 9pm on Thursdays) Saturday & Sunday 10am - 12 noon & 7pm - 9pm



#### **HERE TO LISTEN**

We are here to listen, validate and empathise with any issues you might be facing.



**VITAL SUPPORT** 

We are here to help you reach an informed decision.



#### SAFE ENVIRONMENT

We provide a safe, confidential and understanding environment where you can be heard and understood.

We're here for you!



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