

Becoming an eye donor and donating eyes for research after death

Many members have asked us about donating their eyes for medical research after their death. This document outlines the current procedure for organ donation and explains what you need to do.

Why we need donated eyes

Transplantation

There is a real need for corneal tissue for transplants – around 5,000 corneas a year are required to meet demand.

Research

Researchers need human eye tissue for research into ocular conditions including macular disease. The lack of eye tissue for research in the UK is holding back progress towards a cure for AMD.

Can I donate my eyes for research?

It is extremely rare for eyes to be used only for research purposes after death and in practice, anyone wanting their eyes to be used in research must consent first to becoming a transplant donor.

The cornea is the clear tissue covering the front of the eye, which can become cloudy, distorted or scarred due to accidents, illness or age. A corneal transplant replaces diseased corneal tissue with a disc of healthy tissue from a donor, in a simple operation lasting about an hour. 200 eye units around the UK perform corneal transplants. The sclera (white of the eye) and other ocular tissues can also be used in glaucoma surgery.

Age and health are not necessarily barriers to donating. In practice the upper age limit is 90 years but it can vary depending on the area you live in and which eye unit will use your corneas.

Having a macular disease such as age-related macular degeneration (AMD) does not exclude you from becoming a donor. Macular disease affects the retina, a different part of the eye altogether. However, strict conditions governing the suitability of organs for transplant mean that agreeing to become a donor does not guarantee your corneas can be used. Registering as a donor simply means you give permission for your eyes to be used if they are suitable.

Many hospitals employ a coordinator, called a Tissue and Eye Donation Partner. It is their job to liaise with family members of potential donors and ensure that donated eyes are retrieved as soon as possible after death.

Highly trained teams remove the eye and restore the facial appearance of the donor. The eyes are then sent to an eye bank, which evaluates and distributes the tissue for transplantation and research.

For members living in England and Wales

The law in England and Wales has changed to bring in an “opt-out” system for consent to organ donation. People living in England and Wales now have three choices:

- To be a donor you can register on the NHS Organ Donor Register, or do nothing;

- If you do nothing, you will be regarded as having no objection to donating your organs. This is called “deemed consent”.
- If you do not want to be a donor, you need to opt out on the NHS Organ Donor Register
- Tell your family that you wish to donate your corneas for transplant after your death. This is vital, as your family will be asked for their consent to the transplant. Even if you do not register with the NHS Organ Donor Register, you must talk to your family about your wishes. If they say no when the time comes, the procedure to remove your eyes for transplant will not take place.

If you are living in Scotland or Northern Ireland and would like your eyes to be used after your death to help restore sight to others and thereafter in research you need to:

1. Join the **NHS Organ Donor Register**. This is not essential, but if your family knows you’ve registered, it may make granting consent easier for them when the time comes.
2. You can join by phone on **0300 123 23 23**, via your GP or online at www.organdonation.nhs.uk
3. Tell your family that you wish to donate your corneas for transplant after your death. This is vital, as your family will be asked for their consent to the transplant. Even if you do not register with the NHS Organ Donor Register, you must talk to your family about your wishes. If they say no when

the time comes, the procedure to remove your eyes for transplant will not take place.

4. If you would like your other eye tissue to be used for research purposes once your corneas have been removed, tell your family this too, so they are aware of your wishes.
5. Tell your GP about your intentions. This is not essential but can be useful. Explain that you wish to be a corneal transplant donor on death, that you also give specific consent for eye tissue not suitable for transplant to be made available for research into eye disease and that you give the GP permission to disclose detailed medical information about your eye health when needed.
6. Give your family some basic information on your eye health. When they are contacted prior to the transplant procedure taking place, the transplant officer will find it helpful to know:
 - What eye condition(s) you had affecting your left and right eyes
 - When any eye conditions were diagnosed

The transplant coordinator will contact your GP to find out more, such as what treatments you received and when. Your GP will make all this information available to the transplant service.

Frequently asked questions

What should my family do if I die at home?

If you die at home your family needs to telephone the NHS Blood and Transplant Service **as soon as possible** to notify them of your wish to be a transplant donor. This is because the eyes must be retrieved within 24 hours of the donor's death.

The number to call for the NHS Blood and Transplant Service National Referral Centre is **0800 432 0559**.

Will my eyes definitely be used for transplant if I become a donor?

Eyes offered for transplant are subject to strict donor selection criteria, so even though you have given consent, it may not be possible to use the organ(s) you have offered to donate. Careful scrutiny of each potential donor's medical history is essential in order to assure the clinical safety of any donated organs or tissue. Whether or not your eyes can be used is determined on an individual basis by trained healthcare professionals. If your corneas cannot be used for transplant, no further action will be taken and your eyes will not be removed.

Will my family be consulted?

If it has been decided by healthcare professionals that your eyes are suitable for transplantation, your family will be asked whether they give consent for this to happen. If they do **not** give consent, the transplant procedure will **not** begin and your organs will **not** be used for transplant. Neither will they be used for research.

If your family agrees to the use of your eyes for corneal transplant, in many cases they will then be asked about the use

of other eye tissue for research, i.e. tissue that is not suitable for transplant. If this does not happen, please ask your family to raise the matter themselves. If your family does **not** give consent for this, then your corneas will still be able to be used for transplant, but the rest of your eyes will not be sent for research.

Should I register with the NHS Organ Donor service?

Even if you have registered with the NHS Organ Donor Register, if your family say no to the removal of any organs or tissue for transplant, your organs will not be used. This is why it is so important to talk to your family about your wishes, so that they are comfortable saying yes when the time comes. They may find the question distressing if you have not spoken to them about it already.

Does having a macular disease mean I cannot be a corneal transplant donor?

Since macular degeneration affects the retina there is no reason why a person with AMD or a juvenile dystrophy should not donate their corneas for transplant. Please note however that some eye units operate an upper age limit (80 or 90) for corneal donation.

What happens to my eyes once removed for transplant?

Eyes are removed by specialist retrieval teams who restore the facial appearance of the donor and send the eyes to one of the UK Eye Banks. At the Eye Bank the eyes are evaluated and, if approved as suitable for transplant, eye tissue is linked to patients on the waiting list. The tissue is then distributed for transplantation and research.

What happens to the rest of the eye after corneas have been removed for transplant?

Research needs are always considered secondary to transplantation needs. Eye Banks do however keep lists of researchers who use human eye tissue for experimentation and have ethical approval for conducting their projects. If, and only if, permission for research has been given **by the donor family** the eye bank staff will distribute non-transplantable ocular tissue to those who have registered their requirements.

Can I specify the type of research I would like to donate my eyes to?

Most of the eye tissue that is sent for research is considered to be normal and will be dispatched for research as healthy tissue unless information to the contrary has been given.

However for researchers investigating specific ocular conditions such as AMD, the 'diseased' tissue is extremely valuable. It is possible to express a wish for the tissue to be appropriately used in investigations relating to the causes and treatments of the eye disease that you suffered from. This can be relayed to Eye Bank staff through the transplant coordinators.

Why does the research lab need to know about the extent of my AMD or other eye conditions?

To avoid any tissue from an eye with AMD or other health conditions being sent to research labs as "normal" tissue and to ensure it is sent instead to an appropriate research laboratory.

It is important that your ocular condition is written on the assessment forms completed by the transplant coordinator when they interview your family. Providing a bit more information about your eye condition to the transplant

coordinator or in a document held by your GP (e.g. when condition was first diagnosed, whether AMD was wet or dry) would be helpful to those who are researching the condition.

Can I opt for research only and not be a corneal transplant donor?

No. Since there is no mechanism for retrieving organs or tissue except where consent has been given for transplant, it is extremely rare to donate eyes for research projects only.

Does my GP have to be involved?

They don't have to be, but it's useful to let them know your wishes. This is because when checking medical information for eye donation the donor's GP is always contacted. So your family is important for consent and your GP for detailed information relating to your eye health records.

I still carry a Macular Disease Society "Eye Donor" card – is it valid?

No. This scheme no longer exists. Instead, please inform your family of your wishes. The Macular Society is not able to arrange the retrieval of eyes for research.

Should I put all this in my Will?

Eye tissue is very delicate and needs to be stored under strict laboratory conditions at an eye bank. This transfer must take place within 24 hours of the donor's death. By the time a will is read, it may be too late for the eye to be of use.

The best way of making your wishes known is to talk to your family (so that they can give their consent quickly), let your GP know and register with the NHS Organ Donor Register.

What will happen to my eyes if I have donated my body to a medical school after my death?

By agreeing to donate your body after death to a medical school it may be used for anatomical examination, education, training or research. Certain circumstances may prevent the acceptance of a donated body, one of which is organs having been donated for transplantation. However, the donation of eyes for transplantation can be the exception and you need to check with the individual medical school.

Further information can be obtained from:

The Human Tissue Authority

www.hta.gov.uk/guidance-public/deceased-organ-donation

NHS Blood and Transplant

www.organdonation.nhs.uk