

Deceased Tissue Donation

Tissue donation after death takes place at a very difficult time for the donor's family. Most tissue donors are individuals who had been fit and well until their untimely death, therefore the families of tissue donors have often been very acutely bereaved.

We are very grateful to all the families who agree to consider tissue donation, making it possible for something wonderful to emerge from such a tragic event.

In Scotland, tissue donation after death includes the possibility of donating:

- heart valves,
- tendons,
- eyes

So one individual tissue donor may be able to help many different patients.

When happens when a potential tissue donor is identified?

A specialist nurses check the NHS Organ Donor Register to find out whether the potential donor had taken a decision in life about donating after death.

The donor's family is also contacted to check their loved one hadn't recently indicated a different decision to the one recorded on the NHS Organ Donor Register.

In the case of potential donors who had not registered on the NHS Organ Donor Register, their family is approached to find out whether donation after death is something that they felt the potential donor would have wanted to happen.

Read stories about those who have benefited from the gift of organ and tissue donation below:

<https://www.organdonation.scot/your-decision/why-it-matters/personal-stories?category=Organ%20and%20tissue%20donation>

As with all other types of donations – there is shared responsibility

It is important to minimise the risk of the donated tissue passing on either infection or disease (such as cancer). To make sure of this, all potential tissue donors are carefully assessed, in a manner similar to blood and bone donors.

The families of potential tissue donors are key to ensuring the safety of tissue donation.

Families who confirm the donor's willingness to make tissue donation happen are asked a number of questions to assess the potential donor's:

- medical,
- travel,
- lifestyle history.

Blood samples are tested for infections which can be passed through donated tissue such as:

- HIV,
- hepatitis,
- HTLV (Human T-cell lymphotropic virus),
- Syphilis.

What Tissues Can Be Donated?

Heart Valve Donations

Donated heart valves can be life-saving. Heart valves are needed for a number of different types of operations, including heart reconstruction in new born babies with heart defects, or to replace valves that have become infected or damaged in adults. Depending on the donor's age and medical history, an individual tissue donor can donate up to two heart valves (the aortic valve and the pulmonary valve).

Tendon Donations

Tendon donations are used in knee operations to strengthen the knee or to repair ligament injuries, for example after sporting injuries or traffic accidents, or for patients born with very loose joints. Such donations can allow a patient in chronic pain to go back to being pain-free. They can also allow someone to return to employment or to being able to play different types of sports again.

Eye Donations

Eye donations, specifically the cornea (the front part of the eye), are used in the treatment of some patients who are losing their eyesight. These donations are very precious, as they can be the difference between a patient losing their eyesight and keeping it.

Tissue donation needs to take place as soon as possible after death.

Eye donation needs to take place within 24 hours, and other tissue donations within 48 hours of the time of death.

FAQs: Tissue Donation after Death

Is tissue Donation similar to Organ Donation?

- **Yes** - Tissue donation has many similarities to organ donation. Indeed, most organ donors can also donate tissue, and some patients who are unable to donate organs may be able to donate tissue.

What are the differences between tissue donation and organ donation?

- There are a number of differences between tissue and organ donation. Organ donation needs to happen very quickly after death, so the organ has very little time to deteriorate and can continue to work well in the patient that receives it. However, there is a little more leeway with tissues: eye donation can still be successfully carried out up to 24 hours after death; and heart valves and tendons donation up to 48 hours.

What tissues can be donated after death?

- One donor can donate several different types of tissue, partly dependent on their age and partly dependent on their past medical history. At the moment in Scotland, an individual tissue donor can donate any or all of two eyes, two heart valves (aortic and pulmonary valves) and six tendons (two patellar tendons, two semitendinosus tendons and two Achilles tendons).

Are all patients who have died able to donate tissues?

- **No** – there are quite a few different criteria a tissue donor needs to meet. For example, it is important to know the exact time of death so donation can take place within the necessary timeframes for the particular type of tissue being donated. There are also different donor age limits depending on the tissue being donated, to make sure the donated tissue is in the best possible condition. A specialist nurse will assess the medical, travel and lifestyle history of the potential donor to make sure there are no other clinical barriers to tissue donation. Finally, a blood sample will be tested for the potential presence of infections that could be passed through donated tissue.

FAQs continued: Tissue Donation after Death

Do I have to agree to allow tissue donation from my loved one?

- **No, not at all.** First of all, it is important to find out whether your loved one had taken a decision in life such as joining the Organ Donor Register or having an Organ Donation Card. If this is the case, it is important that we aim to honour their decision (if donation is appropriate and possible). However, before tissue donation is progressed, we will always check with the family to make sure their loved one hadn't recently changed their mind. For those who hadn't registered their decision about donation while alive, their nearest relative will be approached to find out whether donation is something the person was likely to have agreed with or not.

Why do you need to ask so many questions before moving forward with tissue donation?

- Any donation from another human being can pass on infection or disease, and it is important this risk is minimised. To do this, the potential tissue donor's medical, travel and lifestyle histories need to be assessed. In the case of deceased donors, family members are approached for information to help work out the risk of passing on infection or disease (such as cancer).

What happens if my loved one's tissue donations are considered unsuitable for donation?

- If something in your loved one's medical history reveals the possibility of transmissible disease or infection, their tissues cannot generally be used. Sometimes donation might still be possible with additional testing, or it may be possible (if you agree) to donate tissues for training or research, but if not then we thank you for considering tissue donation.

Will tissue donation take place if the family don't want donation to go ahead?

- If the potential donor had decided in life to donate after death, ***it is important that this decision is honoured if possible.***
- However, if the individual had decided to donate tissue, but family members don't want it to happen, a discussion will be arranged with the family to explore their reasons. ***Donation will not go ahead if the family remain opposed to donation even after full explanations are given.***

FAQs continued: Tissue Donation after Death

What if family members cannot agree about tissue donation?

- By law, **the nearest relative** will be approached about the potential of tissue donation, and their approval is enough for the donation to go ahead.
- However, if family members disagree, the input from all parties will be taken into consideration.
- Donation will not proceed if the family continues to disagree, even after full explanations have been given.

Can I change my mind?

- **Yes.** If you've told us you want your loved one's tissue to be donated but then change your mind, you can withdraw consent right up to the point the tissue is used. If you do change your mind about tissue donation, we will need you to give us your new decision in writing.

What tests will you do on my relative's blood sample?

- It is important to minimise the risk of passing on infection or disease to patients, so we'll check for a number of infections that could be passed on through your loved one's donated tissue, for example HIV, hepatitis, HTLV and syphilis.

What if an infection is identified when my relative's blood sample is tested?

- In the unlikely event that we find an infection, we'll get in touch if there are potential health implications for family members. This will allow you to be tested too if necessary.

What quality checks are done on the tissue before it is used to treat other patients?

- Before being used to treat other patients, your loved one's tissue must pass a number of safeguard checks:
 - their medical, travel and lifestyle history information (provided by you) and their medical records are reviewed by a specialist nurse and a doctor;
 - their blood test results are reviewed to confirm there are no infections;
 - a sample of their donated tissue is sent for testing to confirm the tissue has not become contaminated, either from the environment or from their blood stream at the time of donation.

As long as the donated tissue passes all these quality checks, it will be released for the treatment of other patients.

FAQs continued: Tissue Donation after Death

What if my loved one's donation doesn't pass all the quality checks?

- If any of these checks reveal potential issues (for example, contamination or evidence of cancer), the tissue will not be released to treat patients. If there is consent that the tissue can be used for research, education, training, audit or quality assurance it may be released for one of these activities; otherwise it will be disposed of in a legal manner using locally agreed procedures.

How long will the tissue be stored for before it is used to treat patients?

- The tissue will be stored as soon as possible after donation, and held in quarantine until all safety checks have been carried out. How long these checks take (and how long the tissue is stored), depends on the type of tissue donated. If the donated tissue passes all the safety checks, it will then be released for use. Depending on need, the tissues could be used fairly quickly or remain in storage for some time. Different tissues can remain in storage for different lengths of time - for example, corneas can be stored for up to four weeks, tendons can be stored for up to five years, and heart valves can be stored for up to ten years.

What information will be stored about my loved one?

- A specialist nurse will ask you a number of questions about your loved one's medical history, travel history and lifestyle and a doctor will review their medical records to assess the risk of infection and/or disease. All this information, together with the results of your relative's blood tests, will be confidentially stored by the Scottish National Blood Transfusion Service (SNBTS). SNBTS is legally required to keep this information for at least 30 years after the donation has been used to treat a patient. As with all NHS held information, the information will be treated in a confidential manner.

Can I find out where my loved one's donation has been used?

- SNBTS has a duty of confidentiality both to its donors and its patients. We take this duty very seriously and would therefore never release information about the patient that received a particular tissue donation. We can, however, let you know whether the donation is still in storage or whether it has been used to treat a patient.

FAQs continued: Tissue Donation after Death

Can I see my loved one after tissue donation?

- Yes. The staff who carry out tissue donation do so respectfully and carefully and family members are welcome to see their loved one after donation if they wish.

Can my loved one also donate organs?

- Some tissue donors are also able to donate organs. If this is the case, organ donation will take place first and tissue donation later.

Will tissue donation delay the funeral?

- **No**, tissue donation will not delay funeral arrangements. The specialist nurse will check your family's funeral plans and make sure we do not delay them.

Where will tissue donation take place?

- If your loved one is also donating organs, then heart for heart valve donation is likely to take place at the same time as organ donation. If organ donation is not taking place, then your loved one will usually be moved to the mortuary at the Western General Hospital in Edinburgh to allow tissue donation to take place in a dedicated tissue donation suite. If the mortuary in the Western General Hospital is not available, then donation in a different mortuary will be arranged if possible. We will be responsible for moving your loved one from the hospital to the mortuary and back.

Why is there a difference between cornea donation and other types of tissue donation?

- Cornea donation needs to take place within 24 hours of the time of death to make sure that the lining of the cornea (the clear part to the front of the eye) remains of good quality. The cornea does not have a blood supply, which means the risk of passing on infection or disease through cornea donation is lower than through other types of tissue (for example heart valves). This means that most (but not all) patients who die with a history of cancer may still be suitable for cornea donation, but wouldn't be suitable for other types of tissue donation.

For more information on how to
register in Scotland:
[https://www.organdonation.scot/
your-decision/how-register](https://www.organdonation.scot/your-decision/how-register)