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## **TISSUE AND ORGAN DONATION IN PALLIATIVE CARE – A RESOURCE FOR HEALTH CARE PROFESSIONALS**

This resource aims to inform healthcare professionals about the options available to patients who wish to donate their organs and/or tissues after death. There are several options, though exclusions apply that may ultimately limit the overall choices available. The ultimate decision as to suitability for donation will lie with the staff of NHS blood and transplant.

For more information or to refer a potential donor please contact the:

National Referral Centre nurses on Freephone: 0800 432 0559 (organ)

or

NHS Blood and Transplant general enquires: 0300 123 2323 (tissue)

Alternatively for more information please visit: <https://www.organdonation.nhs.uk/>

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## Organ and Tissue Donation for Transplant

Organs that can be donated	Tissues that can be donated
Kidneys	Corneas
Heart	Bone
Liver	Skin
Lungs	Heart valves
Pancreas	Tendons
Small bowel	

### Background

Organ and tissue transplants can save or greatly enhance the lives of other people. There is a serious shortage of organs. On average three people a day die in need of an organ transplant because there are not enough organs available. In addition, fewer than 5,000 people each year in the UK die in circumstances where they can become an organ donor.

A patient does not need to be on the organ donor register to donate, however it can help medical professionals to respect the decision to donate and can remove some of the burden of decision making from the family. Family legally cannot veto or overrule a patient's decision to donate however there may be cases where medical professionals feel it would be inappropriate for donation to go ahead if it would cause distress to the family.

### Tissue Donation

The donation of tissue can save and dramatically improve the quality of life for many. One donor can help up to 50 recipients.

Many tissues can be donated including:

**Skin** – Skin grafts are used as dressings and in the management of serious burns.

**Heart Valves** – Can be used to treat congenital and acquired heart defects in adults and children.

**Bone** – Can be used in reconstructive surgery. Bone can also be donated as a living tissue during routine surgery.

**Tendons** – Used to help repair damaged joints.

**Corneas** – Used to help restore sight to people with cornea problems caused by eye disease, injury, or birth defects. (see below for further details)

### Safety

In order to ensure that the donated tissues are as safe as possible, the donor's medical and behavioural history is assessed by specialist nurses from the donation service. To further reduce the risk of transmitting infection a blood sample is taken from the donor after death and tested.

### Funeral Considerations

Tissue donation should not delay funeral arrangements as retrieval occurs as soon as possible after death. Tissue and organs are retrieved by specialists with the greatest of care and respect so it is possible for the family to see the body after donation.

### Donation Exclusions

Not all patients are suitable for tissue donation and the reasons a patient may not be able to donate tissues are subject to change. The tissue donation specialist nurses are able to assess the suitability of each individual potential donor.

Some patients may require a coronial post mortem but this is not an absolute contraindication to donation. However the coroner must give consent and specify which organs or tissues are suitable to be donated. If a patient's wishes are known prior to death it may be possible to proactively seek permission from the coroner in cases where their involvement is expected (eg mesothelioma cases).

Current exclusions for organ and tissue donation include but are not limited to:

- Systemic infection
- CJD
- Ebola
- HIV
- Hepatitis B or C
- Dementia and any other neurological-degenerative diseases

- Diseases of unknown aetiology
- Active tuberculosis
- Active cancer \*

\*Donors with a current or previous malignancy, other than a haematological malignancy may still be suitable for cornea donation.

To clarify an individual patients' suitability to donate please contact the appropriate referral number at the start of this document.

## **Cornea Donation**

### Suitability to donate

In patients with a malignancy cornea donation may be the only tissue they are able to donate. One donor can save and improve the sight of up to 10 people through cornea transplant. While the key contraindications to corneal donation are listed above, pre-existing eye disease or poor visual acuity are not absolute contraindications to donation. For donor specific advice please speak to the tissue donation team on the number at the start of this document.

### Role of transplant

Corneas can be transplanted into patients suffering from severe eye disease or injury to restore their sight and greatly improve their quality of life. Sometimes the sclerae, as well as the limbal cells are transplanted during reconstructive eye surgery however the eye is never transplanted whole.

Corneal transplants are successful sight-saving operations, with 93% of transplants still functioning after one year. By five years, 74% of transplants are still functioning and many more will continue for years after.

### Statistics

In 2017-18 there were 3504 people in England who had their sight restored through cornea transplant. Advances in corneal transplantation have brought about an increased demand. The number of increased requests cannot be met with the available supply resulting in cancelled corneal surgeries.

Donated corneas that are suitable for full transplant are stored for no longer than 28 days before they are issued out. Corneas that are not suitable for full thickness transplant and sclera can be stored for up to a year.

There is no age restriction for cornea donation. Donors of all ages are required.

### Donation process

During donation the whole eye is removed. The donor is then carefully reconstructed to appear as anatomically correct as possible. The procedure is straightforward and usually takes an hour to complete, and is carried out by a specialist retrieval team.

Retrieval can take place in a hospital, hospice or funeral home. However the need for refrigeration may influence whether retrieval occurs prior to moving a body from the place of death.

Corneas can be donated up to 24 hours after death however the sooner the donation takes place the better the transplant outcome. It is therefore recommended that the transplant team is contacted as soon as possible after death.

### Organ Donation

Very few people die in the right circumstances to make organ donation possible. Organ donation can only be achieved if the donor is in one of the following situations:

- Brain stem death - This is where a person no longer has activity in their brain stem due to a severe brain injury. They have permanently lost the potential for consciousness and the capacity to breathe. This may happen even when a ventilator is keeping the person oxygenated and they have a pulse.
- Circulatory death - Is the irreversible loss of function of the heart and lungs after a cardiac arrest from which the patient cannot or should not be resuscitated. It can also be the planned withdrawal of life-sustaining treatment from a patient within the Intensive Care Unit or the Emergency Department.

At the time, a qualified doctor responsible for the patient's care will decide whether some or all organs or tissue are suitable for transplant. For most patients' in a palliative care setting solid organ donation will not be a viable option as the above circumstances are highly unlikely to be met.

### How people can donate

\*\*\*There is an imminent change to the law in England that will introduce an "opt-out" system for organ donation and this is currently due to occur in early 2020.\*\*\*

At the present time only organs and tissue from a donor with their consent or with their family's consent after they die can be used. Consent is given by:

- Joining the NHS Organ Donor Register

or

- Telling a relative or close friend about the decision to donate

Donation is discussed with the family following death.

Everyone can join the NHS Organ Donor Register regardless of age, as long as they are:

- legally capable of making the decision, and
- live in the UK.

Children who cannot register themselves can be registered by the person with parental responsibility.

All patients should be encouraged to discuss their wish to donate with their family to ensure that their wishes are followed after death. Some patient's may specify their wishes via a will but this is often read too late to be enacted.

Further information is available by:

- calling the Organ donor line on 0300 123 2323
- or via the website <https://www.organdonation.nhs.uk/>

## Organ and Tissue Donation for Research

### Brain Banks

\*\*\* Please note that the local Brain Bank is Sheffield, but currently they are undergoing an audit period to coincide with a change in management. Therefore they are currently NOT accepting donations. The next nearest Brain Bank is Manchester. \*\*\*

For more information and a full list of all brain banks in England please visit:  
<https://mrc.ukri.org/research/facilities-and-resources-for-researchers/brain-banks/donating-brain-and-spinal-cord-tissue/>

### Which Brain Bank

There are many brain banks around the UK, recommended practice is to select the closest one geographically. The exact procedure and potential costs (eg for moving a body) vary between different locations.

Should a local brain bank be unable to accept a donation then it is possible to approach other locations, however due to potentially high costs when moving longer distances this may not be successful. In cases of rare diseases however there may be more scientific demand and cases should be discussed on an individual basis.

There are also some national brain banks specialising in specific conditions eg Parkinsons.

### Who can donate

Brain banks are interested in both healthy brains and those of patients with known disorders.

It should be noted that patients wishing to donate their brain would not be able to also bequest their body as discussed in the next section as a whole body must be bequeathed.

### Process

A person wishing to donate should be placed in refrigerated storage as soon as possible after death. Retrieval of tissue can then occur up to 72 hours after death. The brain is split into 2 hemispheres and one is preserved whilst the other is dissected to reach a definite diagnosis. Following diagnosis (which can take months-years) the preserved half is then used for research.

### Exclusion criteria

Brain banks will endeavour to accept all donations but may be unable to do so for various reasons including:

- some pre-existing medical conditions

- Coroner referral may prevent donation if there is a delay to retrieval being permitted.
- Other delays to the refrigeration and collection process

In all cases it is best to discuss with the local brain bank who will consider each donation offer on a case by case basis.

### **Ethical Tissue**

This is the local tissue bank which currently has approval to run until May 2022. It is run through Bradford University.

\*\*\*Please note that due to staffing the tissue bank is currently not accepting donations, this is due for review in February 2020.\*\*\*

Contact details:

Ethical Tissue  
The Institute of Cancer Therapeutics  
Tumbling Hill Street  
University of Bradford  
West Yorkshire  
BD7 1DP  
Tel: +44 (0)1274 235897  
Email: [enquiries@ethicaltissue.org](mailto:enquiries@ethicaltissue.org)

### **Bequests – Body Donation for Anatomical Examination**

This is the donation of a body for anatomical examination for education, training and research purposes.

Anatomical examination is defined in the Human Tissue Act 2004 as: “examination by dissection for the purposes of teaching, studying or research into the structure of the human body.”

The decision to make a bequest has to be made by the person bequeathing their body *prior to death*.

- **This consent has to be put in writing by the donor, signed and witnessed; it cannot be made by the relatives after death.**

If a person has completed a bequeathal prior to the Human Tissue Act 2004 then the paperwork is no longer valid even if it observes the above criteria. The person would be required to complete updated paperwork.

Bequests made within a will are not legally sufficient.

## Locally

The University of Leeds School of Medicine accepts bequests and the following information relates directly to their process. Other universities also have bequeathal processes, contact details can be found at the end of this section.

At Leeds, anatomy teaching is mainly to students of medicine, other healthcare students and related science students. They also teach qualified doctors and other health professionals undertaking further training i.e. surgical procedures or study. Part of the body may also be used for medically relevant research.

## Length of donation

There is no legal limit on the length of time a donated body can be used, but the donor can restrict the time if necessary. This can be done on the consent form. It is usual for the body to be kept for a period of 3 years, but this can be longer. At the end of this time the body can be returned to the family for burial or cremation or the University of Leeds can arrange a simple cremation at the local crematorium. Prior to cremation, a committal service is held within the University, relatives are not usually informed of this service or subsequent cremation. However, arrangements can be made for the ashes to be retained and returned to the relatives for private disposal. The university hosts an annual memorial service for those who have bequeathed their body which friends or relatives may attend.

In some circumstances parts of the bequest may be retained after the cremation for further study as it could benefit education and medical research. Consent for this needs to be made clear when filling in the consent form. At times, images of parts of a body may be used for teaching, training or research purposes, please be assured that if consent is given for images to be taken, they will not be identifiable. For registered organ donors whose organs are not used (excluding cornea) the bequest for anatomical examination can still be accepted.

## Exclusion criteria

Unfortunately, there is no guarantee a bequest will be accepted.

Reasons for not accepting a bequest include:

- Post mortem examination
- Transmissible disease (Hepatitis, HIV, septicaemia)
- Some forms of dementia
- Jaundice
- Severe bed sores or varicose ulcers
- Severe peripheral vascular disease
- Recent major surgery where the wound has not healed
- Some forms of cancer
- Very severe arthritic deformity of joints or spine
- Severe obesity
- Organs (other than corneas) removed for transplantation
- University storage limitations

### How Bequests are made

If a patient wishes to bequeath their body for anatomical examination a consent form needs to be completed. An information booklet and consent forms can be obtained from:

[https://medicinehealth.leeds.ac.uk/downloads/download/72/bequests\\_information](https://medicinehealth.leeds.ac.uk/downloads/download/72/bequests_information)

Two copies of the form are provided, both need to be completed, they need to be signed in the presence of a witness who should then complete the section on the reverse of the forms. One copy should be returned to the School of Medicine at Leeds to be registered. The second copy should be kept with the patient's will or personal papers. It is helpful if relatives, executor and doctor are aware of the patient's intentions.

If a patient changes their mind and wishes to withdraw consent this needs to be communicated in writing to:

Mrs Sarah Wilson  
Room 9.07  
Worsley Building  
University of Leeds  
Leeds  
LS2 9JT

### Procedure at time of Death

The patient's relatives or executor should notify the University of Leeds as soon as possible by phone following the death.

The bequest office is run by Mrs Sarah Wilson:

\*\*\*During major public holidays at Christmas and New Year the university is closed and is therefore unable to accept bequests. \*\*\*

Monday to Friday 8.30 – 4.30pm:

Tel 0113 343 4297 – a message can be left and the relatives will be called back.

Outside office hours – ring University Security:

Tel 0113 343 5494 they will pass on the information, it may be the following day before a call back if initial contact is made late in the evening.

Alternatively if unable to make contact on above numbers:

University of Leeds switchboard and ask for the office dealing with body donation:

Tel 0113 243 1751

Following death the body must be kept in refrigerated conditions (see Leeds university information booklet for further details). Once the University has been contacted they

will then speak to the last doctor in attendance to discuss the cause of death and any relevant medical history and decide if the bequest can be accepted. The relatives/executor will be informed within a short period of time about the decision.

### Accepted Bequests

If the bequest is accepted the relatives must then register the death telling the registrar about the bequest. A green certificate will then be issued (certificate of burial or cremation) and a death certificate

Information about registering a death is available on:

[www.gov.uk/when-someone-dies](http://www.gov.uk/when-someone-dies)

The completed authorisation form 1 (form provided by the university), a copy of the death certificate and the original deceased's consent form need to be sent to:

Mrs Sarah Wilson

Room 9.07

Worsley Building

University of Leeds

Leeds

LS2 9JT

Email: [bequests@leeds.ac.uk](mailto:bequests@leeds.ac.uk)

### Failed Bequests

If the bequest is not accepted the patient's relatives or executor should proceed with normal arrangements for burial or cremation

Other universities in the surrounding region accepting bequests:

- The University of Sheffield  
Mrs Wendy Howard  
The University Bequeathal Officer  
0114 222 4642  
[w.howard@sheffield.ac.uk](mailto:w.howard@sheffield.ac.uk)
- Newcastle University  
0191 208 6616  
[anatomy.bequests@ncl.ac.uk](mailto:anatomy.bequests@ncl.ac.uk)
- The University of Manchester  
Bequeathals Administrator  
0161 275 5241  
[bequeathals@manchester.ac.uk](mailto:bequeathals@manchester.ac.uk)

## Organ Donation and Religion

Overall all the major religions in the UK support the principals of organ donation and transplantation, however within each religion there are different schools of thought meaning that views can differ within each religion. Therefore it is an individual decision in all cases. The issues for the main religions are outlined below:

- **Buddhism:** Some Buddhists define the moment of death differently than in modern Western medicine and there are differing views as to the acceptability of organ donation.
- **Christianity:** No issues
- **Hinduism:** No issues
- **Islam:** Differing views both evidenced from the Qur'an as to whether organ donation is permissible. The Muslim Law Council UK issued a fatwa (religious opinion) in 1995 supporting organ transplant to relieve pain or save lives, the carrying of donor cards and next of kin may, with or without the presence of a donor card, give permission for donation to take place. However, some Muslim scholars believe that this is not in keeping with overriding Islamic principles. Therefore the decision is up to the individual and should be made in accordance with their understanding or after consulting a local Imam or scholar.
- **Judaism:** In principle there is support for organ donation to save lives but the decision to donate is down to the individual themselves. Each case is different and Jewish law requires consultation with a competent rabbinic authority before permission is granted.
- **Sikhism:** No issues
- **Jehovah witness:** Central guidance is inconsistent, so it's down to individual preference.

More information is available at <https://www.organdonation.nhs.uk/about-donation/organ-donation-and-my-beliefs/>

## **Information For Patients**

### Human Tissue Authority

This link opens a page with patient information on donation options:

<https://www.hta.gov.uk/guidance-public>

### NHS Bloods and Transplant

This link is for the blood and transplant website which has patient accessible information on donation:

<https://www.nhsbt.nhs.uk/>

This link is specifically for corneal donation:

<https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/what-can-you-donate/cornea/>