

TISSUE AND ORGAN DONATION IN PALLIATIVE CARE - A RESOURCE FOR HEALTH CARE PROFESSIONALS AND DONORS.

PART 1: HEALTHCARE PROFESSIONALS

PART 2: GENERAL PUBLIC/DONORS/RELATIVES

There are a number of options for organ and tissue donation available to patients with advancing disease. This resource aims to outline them and also point health care professionals in the direction of further information. It is worth being aware that there are contraindications to different types of tissues donation so not every donation may be acceptable, ultimately the decision lies with the transplant professional involved.

Contents

- Organ Donation. Page 2
- Tissue Donation Page 4
- Cornea Donation Page 6
- **Tissue Donation for Research - Ethical Tissue** Page 8 unavailable
- Bequests - Body Donation for Anatomical Examination Page 10
- Organ Donation and Religion Page 13

Organ Donation

Donation is giving an organ or tissue to help someone who needs a transplant.

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 a 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 a donor. Because organs have to be transplanted very soon after death, they can only be donated by someone who has

What can be donated?

- Kidneys
- Heart
- Liver
- Lungs
- Pancreas
- Small bowel
- Corneas
- Tissue

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's heart beating and oxygen is circulated through their blood.
- 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.

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

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.

Medical conditions

Having a medical condition does not always prevent people from becoming an organ or tissue donor. At death, a qualified doctor responsible for their care will decide whether some or all organs or tissue are suitable for transplant.

But, there are a few conditions that will exclude people from donating organs and tissue.

Absolute contra-indications

- Age >85 years old
- Any cancer with evidence of spread outside of the infected organ in the last 3 years.
- Melanoma
- Choriocarcinoma
- Active haematological malignancy
- CJD, vCJD
- TB (active and untreated)
- HIV disease (not HIV infection)

The number to call: **0300 123 23 23**

Tissue Donation

The donation of tissue such as skin, bone and heart valves 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 - Used as a temporary dressing for burns victims. It helps to reduce pain and infection, and prepare the underlying tissues for later cosmetic grafting. It also helps to reduce the scarring in these patients. The layer of skin donated is very thin and not noticeable under the donor's clothing.

Heart Valves - Can be transplanted to save lives of children born with heart defects and adults with damaged heart valves. Under clothing it would not be noticeable that the heart retrieval has taken place.

Bone - Used when bone needs to be replaced as a result of trauma or disease. It is used in bone revision surgeries such as hip and knee, as well as structural support in femoral reconstructive surgery. Bone grafts help to reduce patient's pain and improve or restore their mobility. Under clothing it would not be noticeable that bone has been donated.

Tendons - Used primarily to repair and rebuild damaged joints. The donor is reconstructed to appear as anatomically correct as possible.

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. To further reduce the risk of transmitting infection a blood sample is taken from the donor and tested.

Following death a blood sample needs to be taken within 24 hours to allow the aforementioned tissues to be donated up to 48 hours after death.

Tissue donation will not delay funeral arrangements.

To be a tissue donor you do not need to be signed up to the Organ Donor Register, although it is advantageous if you are.

You will not be able to donate if you have:

- **Systemic infection**
- **HIV**

- Hepatitis B or C
- Dementia and any other neurological-degenerative diseases
- Diseases of unknown aetiology
- Active tuberculosis

It is important to note:

- Donors with a current or previous malignancy will be suitable for eye only donation except those with a history of leukaemia, myeloma, lymphoma etc. who cannot be accepted for tissue donation.

There are many reasons a patient may not be able to donate tissues, but these reasons are subject to change. The specialist nurses are able to assess the suitability of each individual potential donor. If in doubt please contact the National Referral Centre using the details below.

Although not all tissue is suitable for clinical use there is also a need for human tissue for research and development purposes.

For more information or to refer a potential donor please contact the National Referral Centre nurses on Freephone: 0800 432 0559.

Or contact:

Mark Brown

Deputy Manager

National Referral Centre

14 Estuary Banks

Speke

Liverpool

L24 8RB

Tel: 0151 268 7211

Cornea Donation

One donor can save and improve the sight of 6-8 people.

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 scleras; the white outer coat of the eye, as well as the limbal cells are transplanted during reconstructive eye surgery.

- In 2015/16, 5251 corneas were donated, but there is still a major shortage. Many more people would benefit from a sight-saving transplant if more eyes were donated.
- In 2015/16 there were 3358 successful corneal transplants with a further 31 used for glaucoma surgery.
- Corneal transplants are successful sight-saving operations, with 93% of transplants functioning after one year. By five years, 74% of transplants are still functioning and many more will continue for years after.
- 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 transplant are stored for no longer than 28 days before they are issued out. Sclera can be stored for up to a year.
- The upper age limit for eye donation is subject to change. Please contact the National Referral Centre on the details provided for clarification. Successful transplants have been performed with corneas from donors in their 90s.

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.

Corneas can be donated up to 24 hours after death.

For cornea donation the age of the donor and recipient are as closely matched as possible, and donors of all ages are required.

You will not be able to donate if you have:

- HIV
- Hepatitis B or C
- Dementia and any other neurological-degenerative diseases
- Diseases of unknown aetiology
- Active tuberculosis

It is important to note:

- **Donors with a current or previous malignancy will be suitable for eye only donation except those with a history of leukaemia, myeloma, lymphoma etc.**

There are many reasons a patient may not be able to donate, but these reasons are subject to change. The specialist nurses are able to assess the suitability of each individual potential donor. If in doubt please contact the National Referral Centre using the details below.

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Ethical Tissue - University of Bradford

Unfortunately, the Tissue Donation After Death Service run by the University of Bradford is unavailable for the foreseeable future due to financial constraints.

It is hoped to restart the project in 2020

Ethical Tissue is the name of the licensed Research Human Tissue Bank that was initially established at the University of Bradford in 2006.

Tissues and bodily fluids are taken from the living and from the recently deceased to give researchers a wide range and comprehensive overview of diseased and healthy tissue. This helps them to develop early diagnostic tests, better treatments and cures for life limiting diseases such as Cancer, Diabetes, Heart, Lung and Skin disease to name a few.

Patients are being educated about this option before death, and importantly encouraged to share their thoughts and decisions with their family as similarly to tissue or organ donation, consent can only be legally obtained after they have died.

The relatives of the deceased will be fully informed of the research currently being undertaken and asked about the type, amount and number of tissues they would like to donate. This discussion and the taking of the consent will be done by Ethical Tissues' own Research Nurse: Joanne Mullarkey.

Ethical Tissue need to be contacted shortly after the death so they can initiate the transfer (see below for contact details).

Only marble sized amounts of tissue will be taken, not whole organs. The tissues are very precious and will be used in their entirety so there is no wastage. They only take the tissues that are specifically needed and the donor will be returned to pre donation appearance afterwards so the body can be viewed at the families' request.

Tissue retrieval will be undertaken at the Bradford Royal Infirmary Mortuary Facility (or sometimes at the Public and Forensic Mortuary in Bradford) and the donor will be then transferred to the mortuary and back to the preferred funeral home at no cost to themselves.

The Tissues are taken by a pathologist in a timely manner and there should be no delay to funeral arrangements. Tissue can be taken up to 72 hrs after death.

The tissues are completely anonymised, optimised and stored safely in their research laboratory initially, then sent directly in to approved research (>70% of tissues get used immediately).

99% of people can donate tissue after death for Biomedical Research, the only contraindications are HIV+/hep B + or have vCJD.

All tissue whether diseased or healthy, old or young (over 18) has biomedical merit and plays a vital part in finding better diagnostic tests and more successful treatments.

If the patient is unable or unwilling to donate whole organs/tissue for therapeutic reasons or bequest their whole body to medicine, this may be a good compromise as they are potentially helping millions of people in the future with minimal inconvenience.

Contact Ethical Tissue

Mrs Joanne Mullarkey

Research Nurse

Ethical Tissue

The ICT Bioincubator

University Of Bradford

West Yorkshire

BD7 1DP

01274 235849

j.mullarkey@bradford.ac.uk

There is an out of hour's answerphone message service: 07979616762.

Or contact:

Ethical Tissue

ICT Bioincubator

Tumbling Hill Street

University of Bradford

West Yorkshire

BD7 1DP

Tel: +44 (0)1274 235897

Fax: +44 (0)1274 236937

Email: enquiries@ethicaltissue.org

University of Leeds School of Medicine Bequest Information

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

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.**

The bequest of a body is an immensely generous act that is greatly appreciated and that has far reaching benefits for society.

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.

At Leeds, anatomy teaching is mainly to students of medicine, other healthcare subjects and related science subjects. We 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.

There is no legal limit on the length of time a donated body can be used, 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.

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 your 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. If you are registered as an organ donor and your organs are not used (apart from cornea) the bequest for anatomical examination will still be accepted.

Reasons for not accepting a bequest:

- Post mortem examination
- Transmissible disease
- Some forms of dementia
- Jaundice of infective origin
- Severe bed sores or varicose ulcers
- Peripheral vascular disease
- Recent major surgery
- Some forms of cancer
- Arthritic deformity
- Severe obesity

If having considered the above information and you wish to bequeath your body for anatomical examination a consent form needs to be completed. Forms and booklets can be obtained from:

http://medhealth.leeds.ac.uk/info/295/about_us/1360/bequests

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 so your wishes can be registered. The second copy should be kept with your will or personal papers you may also want to inform relatives, executor and doctor of your intentions.

If you change your mind and wish to withdraw consent then please write to:

Dr David Roberts

Designated Individual for Anatomy

Room 9.06a

Worsley Building

University of Leeds

Leeds

LS2 9JT

Email: bequest@leeds.ac.uk

Procedure at time of Death

Your relatives should notify the University as soon as possible by phone, the bequest office is run by Mrs Sarah Wilson:

- Monday to Friday 8.30 - 4.30pm
- Tel 0113 343 4297
- If necessary leave a message and you will get a phone call back.

Outside office hours - ring University Security

- 0113 343 5494 they will pass on the information, it may be the following day before you are called back if late in the evening.

Alternatively:

University of Leeds switchboard and ask for the office dealing with bequests.

- 0113 243 1751

During major public holidays including Christmas and New Year where bequests are not accepted throughout the 2 week period from 23rd Dec to the 3rd of January

Following death the body must be kept in refrigerated conditions. Once the University has been contacted they will then speak to the last doctor in attendance to discuss cause of death and any relevant medical history.

It is vital your relatives know your wishes, as they must then:

- Register the death telling the registrar about your wishes.
- A green certificate will then be issued (certificate of burial or cremation)
- Information about registering a death is available on www.directgov.co.uk
- The completed authorisation form 1, a copy of the death certificate and the original deceased's consent form needs to be sent to:

Dr David Roberts

Designated Individual for Anatomy

Room 9.06a

Worsley Building

University of Leeds

Leeds

LS2 9JT

Email: bequest@leeds.ac.uk

Once the formalities of acceptance are finished the relatives are only contacted if a pre-agreed consent has been given to inform them of the date and time of the memorial service and to let them know the ashes are available for private disposal. A memorial service is held annually, relatives and friends are invited to this together with the University staff and students. This service provides the opportunity to remember, celebrate and give thanks.

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 support 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** - Their central guidance is inconsistent, so it's down to individual preference.

A patient information leaflet entitled "Organ donation and religious perspectives" outlining all of the above and more is available in the information section of this pack.