

### Body, Brain and Tissue Donation Pack

Information on donating your body, brain or tissue for anatomical examination, research or education and training

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### Donation and the Human Tissue Authority

Donating your body, brain, or tissue to a medical school or research establishment is a valuable gift - your donation will become an important resource for training healthcare professionals or for research.

The Human Tissue Authority (HTA) does not collect or receive bodies or other human materials, but we license and inspect the organisations that do. Our role is to make sure that these organisations remove, store, and use brains, bodies and tissues in an appropriate, respectful and well-managed way, and that the wishes of individual patients and their families are respected.

The HTA's regulation helps ensure that tissue is stored to high standards, to be of most use to healthcare training and research.

We know that more people are willing to donate in the knowledge there is an effective regulator that monitors and inspects organisations against certain standards.



Body donations are highly valued by staff and students at anatomy establishments. A donated body can be used for a number of purposes, which may include:

- Anatomical examination teaching students or healthcare professionals about the structure and function of the human body.
- Research scientific studies which to improve the understanding of the human body.
- Education and training training healthcare professionals on surgical techniques.

#### How to donate your body

Anyone can decide to donate their body, and medical schools welcome the offer of a donation. If you are interested in donating your body, you will need to contact a medical school for further information and a consent form. For information about how to contact your local medical school, please visit www.hta.gov.uk, or call the HTA on 020 7269 1900.

Under the Human Tissue Act 2004, written and witnessed consent for anatomical examination must be given prior to death. Consent cannot be given by anyone else after your death. A consent form can be obtained from your local medical school and a copy should be kept with your Will. You should also inform your family, close friends, and GP that you wish to donate your body.

Medical schools which accept donated bodies will normally only accept donations from within their local area due to the transport costs involved. Offers of body donation from outside the area may be accepted on the condition that the donor's estate bears the cost of transporting the body. Full details can be obtained directly from the medical schools.

#### Do medical schools accept all bodies?

There are various reasons why medical schools may decline the offer of a donation; they can give you more information about this when you contact them. For example, certain medical conditions may lead to the offer being declined. If a post-mortem examination (sometimes referred to as an 'autopsy') is needed, this may also mean that a medical school declines the offer of a body donation.

Medical schools might not be able to accept donated bodies during holiday periods, such as Christmas. Donors should ensure that they have an alternative funeral plan should their body donation not be accepted. It is possible to donate brain tissue up to 48 hours after death so if body donation is not possible, brain donation may be an alternative option.

#### Donating your body, organs and tissue

Despite being separate donation systems, it is possible for a person to be registered as an organ donor, and to have registered their wish to donate their body to a medical school. However, medical schools will usually decline a body donation if the person has undergone surgery to remove organs for transplantation. If after their death, the person is found unsuitable to be an organ donor, it may be possible for body donation to a medical school to be taken forward by the relatives, solicitor or executor of the Will; as long as valid consent is in place.

If a person wishes to register for both organ donation and body donation, the HTA recommends that the person ensures that those closest to them are aware of their wishes and includes these wishes in their Will. Further information on organ donation can be found on the NHS Blood and Transplant website: www.organdonation.nhs.uk.

#### If I donate my body, will there be a funeral or memorial service?

Medical schools will usually arrange for donated bodies to be cremated, unless the family requests the return of the body for a private burial or cremation. Medical schools may also hold a committal, memorial or thanksgiving services. Further information on local arrangements can be obtained directly from the medical school.

#### Are there any costs or payments involved?

You will not receive any payment for donating your body. Some medical schools may request that the donor's estate contribute to the cost of transporting the body, particularly if the donation falls outside of the medical school's local area. Full details can be obtained directly from the medical school.

#### Body donation in the Isle of Man or Channel Islands

The Isle of Man and Channel Islands have no body donation process of their own. It might be possible for a medical school on the UK mainland to accept a body donation from the Isle of Man or Channel Islands, as long as the requirements of the Human Tissue Act 2004 are met.

If you live in in the Isle of Man or Channel Islands and are considering body donation, you may need to make financial arrangements with a local funeral director in relation to the transportation of your body to the medical school of your choice. To enquire about whether this is possible, please contact the medical school.

#### Body donation in Scotland

The HTA has no role in regulating anatomy teaching in Scotland. If you live in Scotland and wish to donate your body, you can find further information here: www.gov.scot/ Topics/Health/Policy/BurialsCremation/BodyDonation.

You will need to ensure that you discuss your wishes with your next of kin, include your wishes in your Will, and contact a university that has an anatomy department. There are five universities in Scotland with anatomy departments which receive bodies donated for anatomical examination, and their details can be found on the 'University Contact Details' page when you go to the above website:

- Aberdeen
- Dundee
- Edinburgh
- Glasgow
- St Andrews

#### Can I donate my body from abroad?

Body donations are required for training and education worldwide so you may wish to consider donating your body in your current country of residence. Where 'anatomical examination' is concerned, the Human Tissue Act 2004 (the 'HT Act') does not apply in areas outside England, Wales and Northern Ireland. However, the HT Act does allow 'imported' bodies and other human material to be stored and used for anatomical examination in England, Wales or Northern Ireland.

Although imported bodies and material are exempt from the HT Act's requirements for consent, death certification and registration, a medical school might ask potential donors to follow their usual consent procedures before a donation may be accepted.

It is possible that an anatomy establishment might not accept a donation from someone who has died abroad.

### **Brain Donation**

More people are suffering from brain diseases and disorders. There are no known cures for many of these conditions, and a high priority is given to research designed to improve our understanding of them, and find new treatments.

To ensure research is thorough, it is also important to have access to brain tissues from people who did not have the diseases being studied. These unaffected tissues are known as 'control tissues'. It is crucial that scientists have access to these so that they can be compared with tissues from people who had a disease. These valuable donations are essential for developing new and better treatments for people with diseases and in the search for a cure.

Brain donation has helped researchers and doctors to better understand diseases such as schizophrenia, Alzheimer's disease, Parkinson's disease and variant Creutzfeldt-Jakob Disease.

#### How to donate your brain for research

A list of human tissue banks which accept brain and spinal tissue for research is available on the HTA website or by phoning the HTA. Brain banking needs to take place as soon as possible after death. Individual brain banks may vary in their procedures and this should be discussed with the brain bank.

A person may consent for their tissue to be used for research, or, if there is no record of the deceased person's wishes, consent can be obtained from someone nominated by that person to act on his or her behalf or from someone in a **qualifying relationship** to them at the time of their death.

Although it is possible for a person to record a wish to donate their brain in their Will, the reading of the Will may occur too late after the person's death to allow the donation to take place. Potential brain donors are therefore encouraged to contact their chosen brain bank rather than relying only on the information contained in their Will. By contacting the brain bank, appropriate arrangements can be discussed and made. This improves the chances of a successful donation after the person has died.

### **Brain Donation**

#### Donating both brain and organs

Despite being separate donation systems, it is possible in certain circumstances for a person to donate their brain and spinal cord for research and be an organ donor – this will need to be discussed with the individual brain bank.

If a person wishes to register for both organ donation and brain donation, the HTA recommends that the person ensures that those closest to them are aware of their wishes. Further information on organ donation can be found on the NHS Blood and Transplant website: www.organdonation.nhs.uk.

#### Do brain banks accept all donations?

There are various reasons why brain banks may not be able to accept the offer of a donation; they can give you more information about this when you contact them. For example, certain medical conditions may lead to the offer being declined. If a death is referred to a Coroner for the cause of death to be confirmed, it may not be possible for the brain and spinal cord to be donated. There may be some circumstances where it is not possible for the brain and spinal cord to be donated to be donated within the required timeframe, as most brain banks require that the tissues are collected shortly after death.

It will not usually be possible for the brain and spinal cord to be donated for research if the body is being donated to a medical school for anatomical examination, as medical schools require the whole body, including the brain and spinal cord.

## Will brain or spinal cord donation affect plans for a funeral or memorial service?

Brain and spinal cord donation will not usually affect plans for a funeral, cremation or burial. The brain bank can give you more information about the timeframes for donation when you contact them.

### **Brain Donation**

#### Are there any costs or payments involved?

Brain banks do not pay donors or their families for brain or spinal cord donations, however some may cover expenses – you can discuss this with the individual medical school.

Tissue banks may charge for providing donated tissue samples to researchers, including those working for private companies, so they can cover their costs. The brain bank can give you more information about this when you contact them.

#### Brain and spinal cord donation in Scotland

The HTA has no role in regulating donation of tissue and research in Scotland. If you live in Scotland and wish to donate your brain and spinal cord, you should contact a local brain bank.

### **Tissue Donation**

By studying human tissue, scientists improve their understanding of how diseases start and progress, and what keeps us healthy. They may find different ways of diagnosing disease, or developing new treatments. Examples of research involving human tissue include:

- Developing screening tests for different types of cancer
- Testing new treatments for conditions such as heart disease and diabetes
- Exploring how the immune system works to help understand how it combats diseases
- Researching how stem cells can be used to treat conditions like Parkinson's, diabetes, and multiple sclerosis

#### How to donate your tissue

#### Tissue from living people

If tissue or cells are removed during the course of diagnosis or treatment, there may be some remaining that can be used for research.

If people do not want their tissue to be used for any medical research, or they want it to be used only for specific types of research, it is important that they make this clear to the healthcare professional seeking their consent, and that their wishes are documented.

#### Tissue from deceased people

If you are suffering from a disease or condition, you may be asked by the person treating you if you would like to donate tissue after your death. If you would like to donate and have not been approached, you could speak to your treating physician.

If you want your tissue to be used for any medical research, or if you want it to be used only for specific types of research, it is important that you make these wishes clear to the healthcare professional who seeks your consent, and that they are written on a consent form. However, some tissue establishments may not be able to use your tissue at all if you apply too many limits on how it can be used.

Consent is always required for research on human tissue from deceased patients unless the tissue samples were obtained before 1 September 2006. If there is no record of the deceased person's wishes, consent for research can be obtained from someone nominated by that person to act on on their behalf or from someone in a **qualifying relationship** to them at the time of their death.

### **Tissue Donation**

#### Donating to a tissue bank

A research tissue bank is a collection of tissue that may be used in different research projects. Tissue is often collected and stored according to a specific purpose or area of research. For example, a research tissue bank may contain tissue collected from people with a particular disease such as Alzheimer's disease or Parkinson's disease, or from a part of the body such as the liver or lungs.

Tissue banks may charge for providing donated tissue samples to researchers, including those working for private companies, so they can cover their costs. The tissue bank can give you more information about this when you contact them.

If you would like to donate tissue to a research tissue bank, you should contact the research tissue bank directly. They will be able to advise whether it is possible to donate tissue and give more information about what donation entails. Most research tissue banks or disease research charities that need donations have websites with contact information for potential donors.