Donation of solid organs and tissue for transplantation

Guide for the general public to Code of Practice F
A guide for the public to Code of Practice F: Donation of solid organs and tissue for transplantation

This guide is intended to be read alongside Code of Practice F: Donation of solid organs and tissue for transplant

This guide to our regulation of organ donation is written to address ‘you’ as a potential living donor or someone who is interested in donating after death.

Commonly used terms

Tissue and organs

Organs
Where we use the term organ, or organs, in this guidance, it refers specifically to a whole solid organ, or organs, including:

- Kidney
- Liver
- Heart
- Brain
- Eyes

The general definition of what constitutes an organ in this context is a body part which has a specific vital purpose.

Tissue
Where we use the term tissue, this refers to all other various human materials that are not whole solid organs.

Tissue and Organs
When we refer to “tissue and organs”, this is to make it clear there is a combination of both.

The role of the HTA

The Human Tissue Act 2004 (the Act) sets out the legal requirements for lawful living organ donation in England, Wales and Northern Ireland. In Scotland, this is set out in the Human Tissue (Scotland) Act 2006.
We regulate the donation of organs from both living and deceased people in the UK and provide advice and guidance about the Act. Before an organ donation can go ahead, appropriate consent must be in place, the requirements for this vary. The donation must also be approved by the HTA.

**Types of living organ donation**

There are several types of living organ donation. The information you will receive about your donation will vary depending on the type of donation.

The most common organ donated by living people is a kidney, as a healthy person can lead a completely normal life with only one functioning kidney. It is also possible for a living person to donate part of their liver (a liver lobe). In very rare circumstances, it may also be possible to donate a segment of a lung or part of the small bowel.

There are several different arrangements for a donation, depending on who is receiving the donation, and whether donor and recipient know one another.

<table>
<thead>
<tr>
<th>Directed donation</th>
<th>This is organ donation to a specific person where donor and recipient have a pre-existing genetic or emotional relationship. For example, siblings or close friends.</th>
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<tbody>
<tr>
<td>Directed altruistic donation</td>
<td>This is organ donation to a specific person where the donor and recipient do not have a pre-existing genetic or emotional relationship. These cases will normally involve a third party. For example, a social networking site for matching donors and recipients. We have published guidance on matching websites and social media.</td>
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| Non-directed altruistic donation | This is organ donation to an unknown person. In these cases, the donor and recipient are anonymous. This can be done either by donating:  
  - to a patient on the national transplant list, or  
  - into the paired / pooled scheme to create a 'chain' of transplants, (see below). |
| Non-directed altruistic donor chains (paired/pooled scheme) | This is also known as a paired / pooled donation. This is also organ donation to an unknown person.  
  
  NHS Blood and Transplant (NHSBT) matches two or more donors and recipients so they can carry out a chain of operations. The remaining organ at the end of the chain is then donated to the best-matched recipient on the national waiting list. |

Please refer to our website for further information on the different types of organ donations.
HTA Approval process for living organ donation

If you are assessed as a suitable donor, you will be referred to an Independent Assessor (IA). A suitable donor is someone who is medically suitable to donate and who has given informed consent.

IAs act as representatives of the HTA. They will interview you and the recipient to check the requirements of the Act are met. In most cases, interviews are carried out with donor and recipient both together and separately. In non-directed cases, the donor and recipient will not be interviewed together, to maintain anonymity. If you are a donor, the IA will ensure you understand the medical procedure. This includes the risks involved. The IA will also check that you are aware that you can withdraw consent.

As part of your interview, the IA will check that:

- you are not being forced to do something against your wishes;
- you have not asked for, or been offered a reward; and
- you have made an informed decision.

Following the interviews, the IA will submit a report of their interviews to us to make a decision.

If you are not happy with the decision, you can ask for a review.

Further information about our approval process is available here. If you have any concerns about the services you have received, please contact the HTA on either 020 7269 1900 or by using our online form.

Consent for living organ donation

You must give valid consent before you can donate an organ. We make sure that all donors give valid consent as part of our regulation. If you are a donor, this means that you have agreed to donate voluntarily and that you understand what you have agreed to. We do this through Independent Assessor (IA) interviews with all donors and recipients. After the interviews, the IA will send their report to us for a decision. Living organ donation cannot lawfully go ahead without our approval.

Limits to Consent

You have the right to decide what consent you give for donating organs or tissue for transplantation. You could, for example, give consent to donate specific organs, or an organ to a particular person during their lifetime.

If there are conditions on consent, any donation must comply with these conditions to be lawful. Only the donor can remove these conditions.

Aside from specifying a single person to receive your donation, you cannot use conditions to limit who receives your donation. For example, you cannot exclude recipients based on gender, race, colour, language, religion or political opinions.
Information you will receive before giving consent

You should receive the information you need to reach a decision that is right for you. This information should be clear and suitable for your understanding about organ donation. It should also include information on any material risks. A material risk is one which:

- you reasonably think is significant to making a decision, and
- your clinician would reasonably think you would consider significant.

Based on the information you receive, you should understand the particular risks and benefits in your circumstances, as well as in general.

The transplant team must also explain:

- the medical procedure, including any material short or long-term risks and the risk of death;
- that the donation is voluntary - you should not be pressured into donating;
- that the transplantation is not always successful - you should be told the likelihood of success for the transplant, the health benefits for the recipient as well as any side effects or complications;
- that you have the right to withdraw your consent at any time - you should also be told what this may mean for you and the person receiving your organ;
- that it is illegal to seek or receive payment or reward for donating organs for transplantation; and
- that you can be reimbursed for expenses resulting from your donation - this might include travel costs or loss of earnings.

Additional information for non-directed altruistic or paired/pooled donors

If you are a non-directed altruistic or paired/pooled donor, you should receive further information about how these systems work. For example, how suitable matches or recipients are found.

In addition, for these types of donations, your identity and the identity of the recipient must remain confidential. You are not allowed to know who will receive your organ until after the transplantation. Similarly, the recipient will not know your identity. However, after the transplantation, contact can be made between donor and recipient if both people are willing.

Donating organs after death

You can consent to offer all your organs and tissue for donation after your death, or you can specify which you consent to donate. However, even when consent is provided, donating organs after death is not guaranteed. In most cases, organs and tissue deteriorate quickly after death, and stop being suitable for donation. Donation is only possible when people die in specific circumstances, ‘brain stem death’ and ‘circulatory death’.

- Brain stem death occurs when 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.

**Consent for donating organs after death**

The HTA is responsible for providing guidance on what counts as lawful consent. Consent must be provided to allow organ donation to happen lawfully, but it cannot force a donation to happen. The doctor must still make that decision.

During your life, you can consent to donate in several ways. The most common is joining the Organ Donor Register (ODR), which is run by NHS Blood and Transplant (NHSBT). You can also specify your wishes in a legal document such as your Will, or nominate a representative to make your wishes known after your death. You can withdraw your consent at any time.

If you make it known that you do not consent to donating specific or any organs and tissue then donation cannot lawfully go ahead. No one can override this decision after your death. The same rules apply for any child who can make a competent decision.

If your wishes are not known, the hospital will first check if you nominated a representative, who would lawfully be able to give consent on your behalf. For children who had not made their wishes known, the consent of a single parent is enough for lawful donation.

If no representative has been nominated someone in a ‘qualifying relationship’ to you during life can give consent. This consent can be withdrawn at any time up until the donation itself.

**Qualifying relationships**

The Human Tissue Act 2004 includes a list of ‘qualifying’ relationships, which are ranked. When consent is sought for any process, such as a post-mortem examination, the person nearest the top of the list should be asked first to give consent for removal, storage or use of relevant material. Their decision has priority over someone below them on the list. The list is as follows:

1. spouse or partner (including civil or same sex partner)
2. parent or child
3. brother or sister
4. grandparent or grandchild
5. niece or nephew
6. stepfather or stepmother
7. half-brother or half-sister
8. friend of long standing

For these purposes, a person is considered a partner if they if live as partners in an enduring family relationship.
While the Human Tissue Act is clear on the hierarchy of relationships, there may be situations where relatives disagree on giving consent. There are procedures and advice on dealing with these conflicts in Code A: Guiding Principles and the fundamental principle of consent, paragraphs 30-39. We recommend that any decision on consent is sensitively discussed with other relatives of the deceased person. This may include relatives not on this list, for example, an aunt or uncle.