

Improving identification and consent rates for organ donation

Information for the public

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About this information

NICE clinical guidelines advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive. The information applies to people using the NHS in England and Wales.

This information explains the advice about improving identification and consent rates for organ donation that is set out in NICE clinical guideline 135.

Does this information apply to me?

Yes, if you are a family member, relative or legal guardian of a patient (an adult or child) who is a potential donor through brainstem death and circulatory death (see box below).

The guideline also looks at seeking consent from the patients where possible.

The guideline does not specifically look at:

- consent on organ donation from anyone other than families, relatives and legal guardians of potential donors through brainstem death and circulatory death
- donation of organs from living donors.

Explanations of terms

Brainstem death

Death is diagnosed after the brainstem (the part of the brain immediately above the spinal cord) stops functioning, and is confirmed using specific criteria.

Circulatory death

Death is confirmed by a doctor after cardiac arrest (where the heart stops beating).

Care for potential organ donors

Patients, their families and carers should be treated with dignity and respect. If possible, all care should be given with the informed consent of the patient. If the patient is not able to make decisions about their care, their healthcare professionals have a duty to talk to their parents, family or guardians unless the patient has specifically asked them not to. People have the right to be involved in discussions and make informed decisions about treatment and care with the healthcare team. People's choices are important and healthcare professionals should support these wherever possible.

To help people make decisions where appropriate, healthcare professionals should explain organ donation. They should cover possible questions and concerns related to the personal circumstances. People should be given relevant information that is suitable and reflects any religious, ethnic, or cultural needs. It should also take into account whether there is any physical or learning disability, sight or hearing problem or language difficulties. People should have access to an interpreter or advocate (someone who helps people put their views across) if needed.

People should be able to discuss or review the care as time progresses, or circumstances change (although this may not be possible in some emergency situations). This may include changing their mind about organ donation. If the potential donor has made an

'advance decision' (known as a 'living will' in the past) in which they have already given instructions about any treatments that they wish to have or do not wish to have, their healthcare professionals have a legal obligation to take this into account. Healthcare professionals should also consider whether a person has expressed a preference about organ donation, for example by signing the NHS organ donor register.

Healthcare professionals should follow the Department of Health's advice on consent (www.dh.gov.uk/en/DH_103643) and the code of practice for the Mental Capacity Act. Information about the Act and consent issues is available from www.nhs.uk/CarersDirect/moneyandlegal/legal. In Wales healthcare professionals should follow advice on consent from the Welsh Government (www.wales.nhs.uk/consent).

In the NHS, patients and healthcare professionals have rights and responsibilities as set out in the NHS Constitution (www.dh.gov.uk/DH_132961). All NICE guidance is written to reflect these.

Organ donation

Donating an organ can give the gift of life to another person. Organ donation is used to help people with organ failure, including failure of the kidneys, liver, heart and lung.

There is currently a shortage of organs for transplant, which means that people may have to wait a long time to receive an organ. More than 10,000 people in the UK currently need a transplant. Of these, 1000 each year – that's 3 a day – will die waiting as there are not enough organs available.

Questions you might like to ask the patient's healthcare team

- Please can you tell me more about organ donation?
- Are there any support organisations in my local area?
- What can I do to help the patient at this time?
- Will the patient be treated with respect and dignity at all times?

- Is there some written material (like a leaflet) about organ donation that I can have?

Identification

The patient's doctor should identify as early as possible whether the patient is likely to be suitable as an organ donor. Not all patients are suitable as donors but many will be. If the patient is suitable as an organ donor then the doctor will assess which organs may be used for transplantation. All this happens while the patient is in a critical care setting that will ensure they receive continuing care.

Consent

If the patient is able to make their own decisions, the healthcare team should obtain their views on organ donation, and their consent. However, if the patient is close to death and is unable to consent to organ donation, the healthcare team should try to find out what they think about organ donation by asking you or other people close to them, checking whether they are on the donor register, or if they have made a living will. The healthcare team should ask you or other people close to them about the patient's values and preferences.

You should be given time to understand that death is inevitable and to spend time with the patient before a nurse or doctor talks to you about organ donation.

Discussing organ donation

Discussions about organ donation should take place in a setting suitable for private discussion and at a suitable time for you. The patient's healthcare team should explain to you that considering organ donation is a usual part of end-of-life care. They should reassure you that the focus will be on the care and dignity of the patient, and that the standard of care will be the same regardless of whether or not you give consent for organ donation. You should be given enough time to consider any information you are given.

The healthcare team should be aware of whether you and your family need any support (for example, a trained interpreter, a faith representative, family liaison officer or

bereavement service), or if there are any cultural or religious issues that may have an impact on consent.

In some cases organ donation may not take place, even if consent is given. If this happens, your healthcare team should explain the reasons why.

Questions you might like to ask about consent

- When do I need to decide whether or not to give consent?
- What will happen if I refuse to give consent?
- What will happen if I want to change my mind?
- Can I give consent for some organs and not others?
- How old do you have to be before you can give consent for organ donation?

What information can I expect if the patient is a potential donor?

All patients

You should be given information about:

- why life-sustaining treatment will not be given or will be stopped
- what happens during organ donation, including where and when the organs will be removed, and what happens afterwards
- what procedures may have to be carried out after consent has been given
- what current legislation means for the patient if, for example, they are a registered donor or if they have made a living will
- whether anything is needed in terms of referral to the coroner

- what documents you will need to read and sign to give consent.

Brainstem death

The patient's healthcare team should explain how death will be diagnosed and confirmed and what happens next.

Circulatory death

The patient's healthcare team should explain:

- what end-of-life care involved and where it will take place
- how death will be confirmed and what happens next
- what happens if death doesn't occur with a given time period.

Other questions you might like to ask

- Will the doctor tell me how the donation operation went?
- Will I be able to see the body after the donation has taken place?

More information

The organisation below can provide more information and support for parents, families and guardians of people who are potential organ donors. NICE is not responsible for the quality or accuracy of any information or advice provided by this organisation.

- The Donor Family Network, helpline 0845 680 1954, www.donorfamilynetwork.co.uk

You can also go to NHS Choices (www.nhs.uk) for more information.

Accreditation

