

## **Quick reference guide**

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# **Organ donation for transplantation**

Improving donor identification and consent rates for  
deceased organ donation

### About this booklet

This is a quick reference guide that summarises the recommendations NICE has made to the NHS in 'Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation' (NICE clinical guideline 135).

### Who should read this booklet?

This quick reference guide is for healthcare professionals involved in the process of organ donation, including their interactions with potential donors, and parents, partners, family, carers or guardians.

### Who wrote the guideline?

The guideline was developed by the Centre for Clinical Practice at NICE, following the short clinical guidelines process. The Centre worked with an independent group of healthcare professionals, carers, and technical staff, who reviewed the evidence and drafted the recommendations. The recommendations were finalised after public consultation.

For more information on how NICE clinical guidelines are developed, go to [www.nice.org.uk](http://www.nice.org.uk)

### Where can I get more information about the guideline?

The NICE website has the recommendations in full, reviews of the evidence they are based on, a summary of the guideline for patients and carers, and tools to support implementation (see inside back cover for more details).

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NICE clinical guidelines are recommendations about the treatment and care of people with specific diseases and conditions in the NHS in England and Wales.

This guidance represents the view of NICE, which was arrived at after careful consideration of the evidence available. Healthcare professionals are expected to take it fully into account when exercising their clinical judgement. However, the guidance does not override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer, and informed by the summary of product characteristics of any drugs they are considering.

Implementation of this guidance is the responsibility of local commissioners and/or providers. Commissioners and providers are reminded that it is their responsibility to implement the guidance, in their local context, in light of their duties to avoid unlawful discrimination and to have regard to promoting equality of opportunity. Nothing in this guidance should be interpreted in a way that would be inconsistent with compliance with those duties.

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### Introduction

A significant proportion of people in England and Wales would wish to donate their organs after death for the purpose of transplantation. This guideline recognises the complexities that arise owing to the majority of potential organ donors lacking the capacity to be directly involved in decision making at the time of their death. It seeks to promote the identification and fulfilment of these wishes through:

- more effective identification and referral of potential organ donors
- a more informed, considered and timely approach to consent for donation which is based primarily on identifying the wishes of the individual whenever known and however recorded.

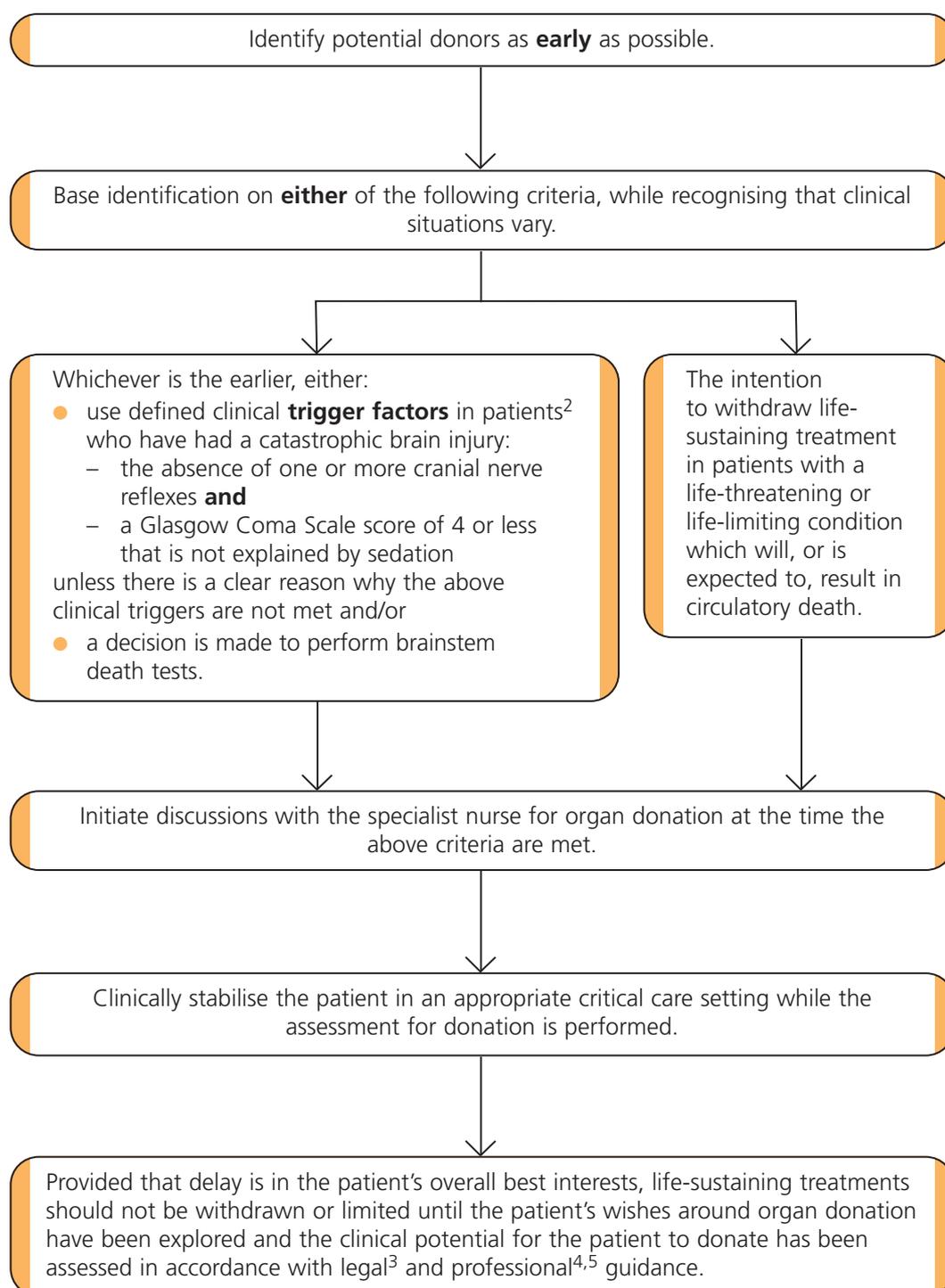
### Person-centred care

Treatment and care should take into account people's individual needs and preferences. Where the person at the end of their life has the capacity to make decisions, they should have the opportunity to make informed decisions about their care, in partnership with their healthcare professionals. In many cases parents, families and guardians are an important part of the consent process and, unless the person has expressed otherwise, should be involved in decisions about consent. If potential donors do not have the capacity to make decisions, follow advice on seeking consent from the Department of Health or Welsh Government. Good communication is essential, supported by evidence-based information tailored to the person's needs.

The Human Tissue Authority has produced codes of practice for consent and for donation of solid organs for transplantation<sup>1</sup>.

<sup>1</sup> Available from: [www.hta.gov.uk/policiesandcodesofpractice/codesofpractice.cfm](http://www.hta.gov.uk/policiesandcodesofpractice/codesofpractice.cfm) and [www.dh.gov.uk](http://www.dh.gov.uk)

## Early identification of potential donors



<sup>2</sup> It is recognised that a proportion of the patients who are identified by these clinical triggers will survive.

<sup>3</sup> [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_108825](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_108825)

<sup>4</sup> DCD consensus meeting report, available from [www.ics.ac.uk/intensive\\_care\\_professional/standards\\_and\\_guidelines/dcd](http://www.ics.ac.uk/intensive_care_professional/standards_and_guidelines/dcd)

<sup>5</sup> [www.gmc-uk.org/guidance/ethical\\_guidance/end\\_of\\_life\\_care.asp](http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp)

## Patients who have capacity

- Where a patient has the capacity to make their own decisions, obtain their views on, and consent to, organ donation<sup>6</sup>.

## Assessing best interests

- If a patient lacks capacity to make decisions about their end-of-life care, seek to establish whether taking steps, before death, to facilitate organ donation would be in the patient's best interests (see box 1).

### Box 1 Assessing the patient's best interests

Consider:

- the patient's known wishes and feelings (in particular any advance statement or registration on the NHS organ donor register<sup>7</sup> and views expressed to those close to the patient)
- the beliefs or values that would be likely to influence the patient's decision
- any other factors the patient would be likely to consider
- the views of the patient's family, friends and anyone involved in their care as to what would be in the patient's best interests
- anyone named by the patient to be consulted about such decisions.

## Seeking consent to organ donation

- If a patient lacks the capacity to consent to organ donation seek to establish the patient's prior consent by:
  - referring to an advance statement if available
  - establishing whether the patient has registered and recorded their consent to donate on the NHS organ donor register<sup>7</sup> and
  - exploring with those close to the patient whether the patient had expressed any views about organ donation.
- If the patient's prior consent has not already been ascertained, and in the absence of a person or persons having been appointed as nominated representative(s), consent for organ donation should be sought from those in a qualifying relationship with the patient. Where a nominated representative has been appointed and the person had not already made a decision about donation prior to their death, then consent should be sought after death from the said nominated representative(s).

<sup>6</sup> If the potential donor is under 16, healthcare professionals should follow the guidelines in 'Seeking consent: working with children' (available from [www.dh.gov.uk](http://www.dh.gov.uk))

<sup>7</sup> [www.uktransplant.org.uk](http://www.uktransplant.org.uk) or [www.organdonation.nhs.uk](http://www.organdonation.nhs.uk)

## Discussions with those close to the patient

### Discussions in all cases

Before approaching those close to the patient:

- identify a patient's potential for donation in consultation with the specialist nurse for organ donation
- check the NHS organ donor register and any advance statements or Lasting Power of Attorney for health and welfare
- clarify coronial, legal and safeguarding issues
- obtain clinical history of the patient
- identify key family members
- identify key family issues, including need for family support
- identify relevant cultural and religious issues.

During the process:

- allow sufficient time for those close to the patient to understand the inevitability of the death or anticipated death and to spend time with the patient
- discuss withdrawal of life-sustaining treatment or neurological death before, and at a different time from, discussing organ donation unless those close to the patient initiate these discussions in the same conversation.

Plan the approach with the multidisciplinary team and approach those close to the patient:

- in a setting suitable for private and compassionate discussion
- at a time that suits the family's circumstances
- in a professional, compassionate and caring manner
- when it is clearly established that they understand that death is inevitable or has occurred.

Discuss with those close to the patient and offer information (see also box 2):

- explain that donation is a usual part of end-of-life care
- use open-ended questions
- use positive ways to describe organ donation
- avoid the use of apologetic or negative language.

Give them sufficient time to consider the information.

**Box 2. Information for those close to the patient**

For all patients who are potential donors, provide those close to them with the following:

- assurance that the primary focus is on the care and dignity of the patient (whether the donation occurs or not)
- explicit confirmation and reassurance that the standard of care received will be the same whether they consider giving consent for organ donation or not
- the rationale behind the decision to withdraw or withhold life-sustaining treatment and how the timing will be coordinated to support organ donation
- a clear explanation of, and information on:
  - the process of organ donation and retrieval, including post-retrieval arrangements
  - what interventions may be required between consent and organ retrieval
  - where and when organ retrieval is likely to occur
  - how current legislation applies to their situation<sup>8</sup>
  - how the requirements for coronial referral apply to their situation
- consent documentation
- reasons why organ donation may not take place, even if consent is granted.

Where circulatory death is anticipated, provide a clear explanation on:

- what end-of-life care involves and where it will take place
- how death is confirmed and what happens next
- what happens if death does not occur within a defined time period.

Where neurological death is anticipated, provide a clear explanation on:

- how death is diagnosed using neurological criteria
- how this is confirmed and what happens next.

<sup>8</sup> Mental Capacity Act (2005) and Human Tissue Act (2004).

## Organisation and policy

### Managing the process

- Each hospital should have a policy and protocol consistent with these recommendations for identifying patients who are potential donors and managing the consent process.
- Each hospital should identify a clinical team to ensure the development, implementation and regular review of their policies.
- Adult and paediatric intensive care units should have a named lead consultant with responsibility for organ donation.
- The multidisciplinary team (MDT) responsible for planning the approach and discussing organ donation with those close to the patient should include:
  - the medical and nursing staff involved in the care of the patient
  - the specialist nurse for organ donation
  - local faith representative(s) where relevant.
- Whenever possible, continuity of care should be provided by team members who have been directly involved in caring for the patient.

### Skills, knowledge and competencies

- The MDT involved in the identification, referral to specialist nurse for organ donation, and consent should have the specialist skills and competencies necessary to deliver the recommended process for organ donation outlined in this guideline.
- The MDT involved in the initial approach should have the necessary skills and knowledge to provide appropriate support and accurate information about organ donation to those close to the patient.
- All healthcare professionals involved in identification, referral to specialist nurse for organ donation, and consent processes should:
  - have knowledge of the basic principles, and the relative benefits, of donation after circulatory death versus donation after brainstem death
  - understand the principles of the diagnosis of death using neurological or cardiorespiratory criteria and how this relates to the organ donation process
  - be able to explain neurological death clearly to families
  - understand the use of clinical triggers to identify patients who may be potential organ donors
  - understand the processes, policies and protocols relating to donor management
  - adhere to relevant professional standards of practice regarding organ donation and end-of-life care.

Consultant staff should have specific knowledge and skills in:

- the law surrounding organ donation
- medical ethics as applied to organ donation
- the diagnosis and confirmation of death using neurological or cardiorespiratory criteria
- the greater potential for transplantation of organs retrieved from donation after brainstem death donors compared with organs from donation after circulatory death donors
- legally and ethically appropriate clinical techniques to secure physiological optimisation in patients who are potential organ donors
- communication skills and knowledge necessary to improve consent ratios for organ donation.

## Further information

### Ordering information

You can download the following documents from [www.nice.org.uk/guidance/CG135](http://www.nice.org.uk/guidance/CG135)

- The NICE guideline – all the recommendations.
- A quick reference guide (this document) – a summary of the recommendations for healthcare professionals.
- ‘Understanding NICE guidance’ – a summary for patients and carers.
- The full guideline – all the recommendations, details of how they were developed, and reviews of the evidence they were based on.

For printed copies of the quick reference guide or ‘Understanding NICE guidance’, phone NICE publications on 0845 003 7783 or email [publications@nice.org.uk](mailto:publications@nice.org.uk) and quote:

- N2680 (quick reference guide)
- N2681 (‘Understanding NICE guidance’).

### NICE pathway

The recommendations from this guideline have been incorporated into a NICE pathway, which is available from <http://pathways.nice.org.uk> (publication expected January 2012)

### Implementation tools

NICE has developed tools to help organisations implement this guidance (see [www.nice.org.uk/guidance/CG135](http://www.nice.org.uk/guidance/CG135)).

### Related NICE guidance

For information about NICE guidance that has been issued or is in development, see [www.nice.org.uk](http://www.nice.org.uk)

### Updating the guideline

This guideline will be updated as needed, and information about the progress of any update will be available at [www.nice.org.uk/guidance/CG135](http://www.nice.org.uk/guidance/CG135)



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