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PRACTICE

GUIDELINES

Donor identification and consent for deceased organ donation: summary of NICE guidance

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This is one of a series of *BMJ* summaries of new guidelines based on the best available evidence; they highlight important recommendations for clinical practice, especially where uncertainty or controversy exists.

Organ donation plays a major role in the management of patients with single organ failure of the kidneys, liver, pancreas, heart, or lung, or with combined organ failure of heart and lung (such as in cystic fibrosis) or of kidney and pancreas (such as in diabetes). A shortage of transplant organs has resulted in long waits for transplantation. Currently about 500 people in the United Kingdom die each year because of a shortage of donated organs,[1] and at 31 March 2011 almost 7000 patients were waiting for a kidney transplant[1] and would be having costly dialysis with serious morbidity and impact on quality of life. This shortage of organs is partly the result of relatively low numbers of road traffic deaths (lower than in many countries) but is also the result of inefficiencies in the donor identification and consent processes. This article summarises the most recent recommendations from the National Institute for Health and Clinical Excellence (NICE) on improving donor identification and consent rates for deceased organ donation.[2]

Recommendations

NICE recommendations are based on systematic reviews of best available evidence and explicit consideration of cost effectiveness. When minimal evidence is available, recommendations are based on the Guideline Development Group's experience and opinion of what constitutes good practice. Evidence levels for the recommendations are given in italic in square brackets.

Identifying patients who are potential donors

- Consider organ donation as a usual part of planning for "end of life care."
- Identify all patients who are potentially suitable donors as early as possible, through a systematic approach. While recognising that clinical situations vary, base this identification on either of the following criteria:
  -Defined clinical trigger factors in patients who have had a catastrophic brain injury (namely *(a)* the absence of one or more cranial nerve reflexes and *(b)* a Glasgow coma scale score of ≤4) unless there is a clear reason why these triggers are not met (for example, because of sedation) and/or a decision has been made to perform brainstem death tests, whichever is the earlier; or
  -The intention to withdraw life sustaining treatment in patients with a life threatening or life limiting condition that will, or is expected to, result in circulatory death.

Assessing best interests

- While assessing the patient's best interests clinically stabilise the patient in an appropriate critical care setting while the assessment for donation is performed—for example, in an adult intensive care unit or discussed with a regional paediatric intensive care unit.
- Provided that delay is in the patient's overall best interests, life sustaining treatments should not be withdrawn or limited until the patient's wishes around organ donation have been explored and the clinical potential for the patient to donate has been assessed in accordance with legal and professional guidance.[3 4]

[*Based on very low to low quality evidence from observational studies and on the experience and opinion of the Guideline Development Group (GDG)*]

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Seeking consent for organ donation

- If a patient lacks the capacity to consent to organ donation, seek to establish whether the patient has given prior consent by:
  -Referring to an advance care statement if available
  -Establishing whether the patient has registered and recorded their consent to donate on the NHS organ donor register, and
  -Exploring with those close to the patient whether the patient had expressed any views about organ donation.
- If it has not been possible to ascertain whether the patient gave prior consent, and in the absence of a person(s) having been appointed as nominated representative(s), seek consent for organ donation from those in a qualifying relationship with the patient (a qualifying relationship ranks those from a spouse or partner (including civil or same sex partner); parent or child; brother or sister and other relatives; through to a friend of long standing). Where a nominated representative has been appointed and the person had not already made a decision about donation before their death, then seek consent after death from the said nominated representative(s).

Approaching those close to the patient

- The multidisciplinary team should be responsible for planning the approach and discussing organ donation with those close to the patient. The multidisciplinary team should include:
  -The medical and nursing staff involved in the care of the patient, led throughout the process by an identifiable consultant and
  -The specialist nurse for organ donation and
  -Local faith representative(s) where relevant.
- Before approaching those close to the patient, try to seek information on all of the following:
  -Knowledge of the clinical history of the patient who is a potential donor
  -Identification of key family members
  -Assessment of whether family support is needed—for example, local faith representative, family liaison officer, bereavement service, trained interpreter, advocate
  -Identification of other key family concerns
  -Identification of cultural and religious concerns that may affect consent.
- Every approach to those close to the patient should be planned with the multidisciplinary team and at a time that suits the family's circumstances.
- When approaching those close to the patient:
  -Discuss with them that donation is a usual part of the end of life care
  -Use open ended questions—for example, "How do you think your relative would feel about organ donation?"
  -Use positive ways to describe organ donation, especially when patients are on the NHS organ donor register or they have expressed a wish to donate during their lifetime—for example, "By becoming a donor, your relative has a chance to save and transform the lives of many others"
  -Avoid using apologetic or negative language such as, "I am asking you because it is policy" or "I am sorry to have to ask you."
- The healthcare team providing care for the patient should provide those close to the patient who is a potential donor with the following, as appropriate:
  -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,[5 6] including the status of being on the NHS organ donor register or any advance care directive; 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.

[*Based on very low to low quality evidence from observational studies and on the experience and opinion of the GDG*]

Organising identification, referral, and consent processes

- The skills and competencies required of the individual members of the team will depend on their role in the process. However, all healthcare professionals involved in identification, referral to a 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. For example, the benefits of donation after brainstem death are that heart and lungs are usable, all retrieved organs are likely to be in a better condition, and failure rates are lower (especially for liver and kidney)
  -Understand the principles of the diagnosis of death using neurological or cardiorespiratory criteria and how this relates to the organ donation process.[3]
  -Be able to explain neurological death clearly to families. For example, they need to be able to explain that death is diagnosed after the brainstem (the part of the brain responsible for maintaining life) stops functioning and is confirmed using specific criteria. This signifies there is no prospect for recovery of brain function and that death is confirmed while the body of the person is attached to an artificial ventilator and the heart is still beating
- -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 for organ donation and end of life care.[3]
- Consultant staff should have specific knowledge and skills in:

-The law surrounding organ donation[7]

-Medical ethics as applied to organ donation[4]

-The diagnosis and confirmation of death using neurological or cardiorespiratory criteria

-The greater potential for transplantation of organs retrieved from donation after brainstem death compared with organs from donation after circulatory death

-Legally and ethically appropriate clinical techniques to secure physiological optimisation in patients who are potential organ donors

-Communication and knowledge necessary to improve consent ratios for organ donation.

[*Based on very low to low quality evidence from observational studies and on the experience and opinion of the GDG*]

Overcoming barriers

The process of identification of potential donors and gaining consent for organ donation, including whether families are asked to consider organ donation, varies widely across the UK (www.organdonation.nhs.uk/ukt/statistics/potential_donor_audit/potential_donor_audit.jsp). This guideline aims to resolve current inequalities by helping to make organ donation a usual part of end of life care, so that families of all potential organ donors are approached and supported, irrespective of factors such as ethnicity and religion. The guidance also aims to overcome barriers through increasing clinicians' skills and competencies in identifying potential organ donors and approaching families for consent, with the support of the specialist nurse for organ donation.

The Guideline Development Group comprised Gary McVeigh (chair), Tim Collins, James Fraser, Karen Morgan, Paul Murphy, Jane Nix, Ronan O'Carroll, Gurch Randhawa, Angus Vincent, Huw Twamley, Barry Williams, and Simon Bramhall (co-opted member). The NICE Short Clinical Guideline Technical Team comprised Mark Baker, Emma Banks, Kathryn Chamberlain, Nicole Elliott, Michael Heath, Prashanth Kandaswamy, Hanna Lewin, Beth Shaw, Faisal Siddiqui, and Sheryl Warttig.

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Further information on the guidance

This guidance was developed by the Short Clinical Guidelines team at NICE in accordance with NICE guideline development method (www.nice.org.uk/aboutnice/howwework/developingniceclinicalguidelines/clinicalguidelinedevelopmentmethods). A Guideline Development Group was established by Short Clinical Guidelines, which incorporated two patient/carer members and healthcare professionals working in clinical areas relating to organ donation for transplantation, including intensive care units, organ donation committees, regional transplant organisations, and ethics and diversity. The group examined five key clinical questions and analysed and appraised the evidence using GRADE methods where appropriate. The draft guideline underwent a rigorous validation process, which included inviting stakeholder organisations to comment. All comments were taken into consideration when producing the final version of the guideline.

NICE produces three versions of its short clinical guidelines: a full version (with all the recommendations plus details of the methods used and the underpinning evidence); a quick reference guide (with recommendations in a suitable format for health professionals); and a version known as “Understanding NICE guidance” (written for people without specialist medical knowledge). All these versions are available on the NICE website (in this case at http://guidance.nice.org.uk/CG135). The guideline will be reviewed for an update in three years as part of the NICE guideline development programme.

Future research

The guideline recommends the following topics for future research:

- Reasons why people join the NHS organ donation register
- Reasons for refusal for consent
- How to improve rates of identification and referral of potential donors
- How to improve consent rates for donation
- Understanding the experience of consenting for organ donation