

United Kingdom Hospital Policy for Organ and Tissue Donation



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1 Introduction

- 1.1 This policy provides universal guidelines on organ and tissue donation in the United Kingdom (UK). It has been produced to reflect existing legislation and amalgamate codes of practices and current policy in the UK. This policy will ensure that, where suitable, the option of organ and/or tissue donation will be offered to the patient's next of kin/significant other¹. It also ensures that healthcare professionals are aware of their role in caring for the potential donor and their family and receive adequate support.
- 1.2 Organ and tissue transplantation is now established practice worldwide. Improvements in surgical techniques, advances in post-operative care, the introduction of effective organ preservation solutions and the development of sophisticated immunosuppression have all contributed to improved outcome for recipients of organ and tissue transplants.
- 1.3 Organ transplantation is often the treatment of choice for end stage organ failure. This has led to an increase in the demand for organs suitable for transplantation. The supply of transplantable organs is however diminishing due to improvements in paramedic care, neurosurgical practice and a simultaneous decrease in the number of deaths from road traffic accidents. These positive advances mean that the number of patients who are confirmed dead by brain stem tests has fallen.
- 1.4 At present the number of people awaiting transplantation greatly exceeds the number of organs available. Currently, there are about 7,000 people waiting for a transplant in the UK. Each year there are approximately 770 cadaveric organ donors and about 2,700 transplants are performed. Organ donation clearly is not keeping pace with the rapidly increasing demand. It is therefore essential to maximise the potential number of organs available from the existing potential donor pool.
- 1.5 A survey conducted by the United Kingdom Transplant Co-ordinators' Association, the British Association of Critical Care Nurses and MORI highlighted that 12% of families of patients in whom death was confirmed by brain stem tests were not approached about organ donation (United Kingdom Transplant Co-ordinators' Association, British Association of Critical Care Nurses, MORI 1995). This policy aims to provide information and support for healthcare professionals to ensure that all families are approached by skilled and experienced personnel, in a sensitive manner and at an appropriate time.



2 Review

- 2.1 This document will be reviewed every three years, or more frequently as need occurs.

¹ The term next of kin/significant other is used to refer to the family or friends who are considered to be the patient's next of kin/significant other.

3 Aim

- 3.1 To identify all potential donors.
- 3.2 To refer all potential organ/tissue donors to the donor transplant co-ordinator/tissue co-ordinator.
- 3.3 To establish whether the potential donor is registered on the NHS Organ Donor Register (ODR) held at UK Transplant (UKT).
- 3.4 To ensure that all potential donor families are approached and informed of the option of organ/tissue donation.
- 3.5 To determine from the next of kin/significant other, whether the potential donor expressed any wishes regarding organ/tissue donation.
- 3.6 To establish the wishes of the next of kin/significant other regarding organ/tissue donation. To ensure that they are given clear and accurate information about organ/tissue donation.
- 3.7 To ensure support and open communication with next of kin/significant other in a sensitive manner.
- 3.8 To ensure that any discussions with the next of kin/significant other are appropriately documented in the potential donor's case notes, including lack of objection to organ/tissue donation in accordance with the national standards.
- 3.9 To maintain optimal management of the potential donor to ensure organs/tissues remain viable for transplant.



4 Rationale

- 4.1 Consulting the ODR to ascertain whether the potential donor is registered may help the next of kin/significant other with their decision making if, in particular, they are not aware of their relative's views and wishes regarding organ and tissue donation. Currently, only 17% of the population are on the ODR. Failure to be on the ODR does not mean that the patient did not want to be a donor. Appropriate healthcare professionals may telephone the duty office at UKT to establish whether a potential donor is registered on the ODR. Alternatively they can ask their local donor transplant co-ordinator/tissue co-ordinator to do this on their behalf.

This should enable families to make an informed decision about organ/tissue donation. Organ/tissue donation is a positive option and can be a comfort at a time of great distress. In not offering the family the option to donate, healthcare professionals may be depriving families of the opportunity to find comfort during their time of grief.

- 4.2 It is essential that the donor transplant co-ordinator/tissue co-ordinator be informed of all potential organ/tissue donors. Donor criteria may change and they are best placed to ascertain suitability of any potential donor. The donor transplant co-ordinator/tissue co-ordinator is able to offer advice to staff on donor identification and suitability, approaching the family and clinical management. They will have access to up-to-date donor criteria including information on donor suitability and will be able to assist with the identification of all donors.

5 Pre donation

- 5.1 The potential donor should be referred to the local donor transplant co-ordinator/ tissue co-ordinator as early as possible for consideration for organ/tissue donation (Department of Health Working Party – *Code of Practice for the Diagnosis of Brain Stem Death* 1998). In cases of organ donation the donor transplant co-ordinator will be present throughout the organ donation process.
- 5.2 The Human Tissue Act (1961) states that only the person lawfully in possession of the body or his/her designated other can authorise the removal of organs or tissues from the body. It states:
- “The person lawfully in possession of the body has powers and duties in connection with removal of organs. The person authorises the removal of any part from the body for the said purposes (therapeutic or medical education, or research) if having made such reasonable enquiry as may be practicable, he has no reason to believe: (a) that the deceased had expressed an objection to his body being so dealt with after his death, and had not withdrawn it: or (b) that the surviving spouse or any surviving relative of the deceased objects to the body being so dealt with.”
- 5.3 Where a deceased person is in an NHS hospital or organisation, the person with control and management of the hospital (usually the chief executive/medical director) is the person lawfully in possession of the body until such time as it is claimed by the person who has right to possession for the purpose of disposal (usually the executor or next of kin of the patient) or, by reason of their statutory obligations, the coroner or procurator fiscal (Department of Health Working Party – *Code of Practice for the Diagnosis of Brain Stem Death* 1998).
- 5.4 In situations where the cause of death was sudden, not due to natural causes or unexpected and/or the doctor has not treated the deceased during his/her last illness, the coroner/procurator fiscal must be informed (Coroner's Act 1988). The medical staff involved in the care of the patient should contact the coroner/procurator fiscal to obtain authorisation for organ/tissue donation or the donor transplant co-ordinator/tissue co-ordinator may do this on behalf of the medical staff.
- 5.5 **Prohibition on payment for organs**
- 5.5.1 The Human Organ Transplants Act (1989) prohibits commercial dealing in organs including non-regenerative tissue. It is a criminal offence to make or receive payment in return for supplying an organ from a dead or living person intended for transplantation. It is also an offence to broker or negotiate an arrangement involving such payment or to advertise for donors who will be paid.
- 5.6 **Conditional offering**
- 5.6.1 No conditions should be attached to the donation of organs/tissues in terms of the potential recipient. This goes against the fundamental principle that organs/tissues are donated altruistically. The only restrictions permitted are with regard to which organs or tissues can be donated.

6 Donor assurances

- 6.1 The donor transplant co-ordinator/tissue co-ordinator will undertake a risk assessment on all potential donors to minimise the transmission of infections and disease. In order to assess the risk of transmission of certain infections, it is important to obtain as much information as possible about the potential donors (Department of Health's Advisory Committee on the Microbiological Safety of Blood and Tissues for Transplantation, *Guidance on the Microbiological Safety of Human Organs, Tissues and Cells used in Transplantation* 2000). This will involve reviewing the potential donor case notes, interviewing the next of kin/significant other, examining the potential donor and contacting the general practitioner. It is the donor transplant co-ordinator/tissue co-ordinator's responsibility after undertaking a thorough assessment of the potential donor to discuss all relevant information with the transplant surgeons/relevant tissue banks. The decision on donor suitability is the responsibility of the transplant surgeon/relevant tissue banks. (British Transplantation Society, United Kingdom Transplant Co-ordinators' Association and United Kingdom Transplant Support Services Authority, *Cadaveric Donor Assurances and Damage Reporting* 1998).

7 Donor family

- 7.1 The donor transplant co-ordinator/tissue co-ordinator should be contacted to establish suitability for donation before approaching the family.
- 7.2 The healthcare professional who raises the subject of donation with the next of kin/significant other should ideally know the patient and the family, have experience of working with bereaved families, have knowledge of organ/tissue donation and believe that donation may be a positive option for some families. Local donor transplant co-ordinator teams organise workshops on approaching families. Please contact your local donor transplant co-ordinator team for further details.
- 7.3 The request for donation should be made when the family has understood that death is imminent or has occurred. For organ/tissue donation, an appropriate time may be after the family has been informed of the result of the first set of brain stem death tests. The request to the family may involve a collaborative approach with the healthcare professionals caring for the patient and the donor transplant co-ordinator. All communication with the family regarding organ/tissue donation should be documented in the patient's notes.
- 7.4 Where a potential donor has lived with someone to whom they are not legally related it is advisable to try to seek their views as well as those of the relatives (Department of Health Working Party, *Code of Practice for the Diagnosis of Brain Stem Death* 1998).

8 Lack of objection to organ/tissue donation (consent)

- 8.1 The UK currently operates an "opting in" system of consent, based on the Human Tissue Act (1961). This means that individuals actively choose to donate organs/tissues after death. While there is no legal requirement to gain consent to donation if the deceased's wishes are known, efforts should be made to establish that the deceased had not expressed objections to donation. Any documentation should be worded in terms of "lack of objection".

- 8.2 “Lack of objection” will be established by the donor transplant co-ordinator/tissue co-ordinator following an interview with the family. This will be documented and the family member will be asked to sign to confirm their “lack of objection”. In situations where the next of kin/significant other are unable to sign a “lack of objection” form (eg living overseas and communicate their decision by telephone) it is acceptable for the person who has taken the “lack of objection” to document the details in the patient’s case notes and obtain a witness signature. In most cases of tissue donation “lack of objection” will be confirmed by a telephone interview where the documentation will be held by the co-ordinators. The local healthcare professional is required to document the discussion regarding organ/tissue donation in the patient’s medical records. In most cases the interview between the tissue co-ordinator and the family will be recorded.
- 8.3 If there is no family available advice should be sought from the donor transplant co-ordinator/tissue co-ordinator.

9 Solid organ donation

- 9.1 Kidney, pancreas, liver, heart, lung and small bowel transplantation are established treatments following the failure of these vital organs. Please contact the local donor transplant co-ordinator via their hospital switchboard for further information.

10 Tissue donation

- 10.1 The quality of life for many people can be improved by the transplantation of tissue, such as eye tissue (to restore sight), bone, tendon, skin (to treat burns) or heart valves (to treat acquired cardiac disorders and congenital malformations). Tissue does not deteriorate immediately following cessation of the heartbeat due to its low metabolic requirements, allowing more time for tissue retrieval. This option of donation can therefore be offered in a variety of clinical settings.

11 Setting of the donor

- 11.1 Typically donation is from a variety of clinical settings.
- Organ donation – usually from the intensive care unit (ICU) or very occasionally from the accident and emergency department (A&E) following confirmation of death by brain stem tests.
 - Tissue donation – from the ICU, the wards, A&E, palliative care units and the community following cardio-respiratory death.
 - Non-heartbeating donation – patients are certified dead following cardio-respiratory arrest. Donation may be from the ICU, the wards or A&E.
- 11.2 Tissue can be donated following either the confirmation of death by brain stem tests or cardio-respiratory death and therefore may be offered to the majority of families following a death.



11.3 Brain stem testing

11.3.1 The Department of Health's Working Party on the *Code of Practice for the Diagnosis of Brain Stem Death* (1998) stipulates:

"Death entails the irreversible loss of those essential characteristics which are necessary to the existence of a living human person. Thus, it is recommended that the definition of death should be regarded as an irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe. The irreversible cessation of brain stem function (brain stem death) whether induced by intra-cranial events or the result of extra-cranial phenomena, such as hypoxia, will produce this clinical state and therefore brain stem death equates with the death of the individual."

11.3.2 The British Paediatric Association and the Council of the Royal College of Physicians reported from a working party the following:

"In children over the age of 2 months, the brain stem death criteria should be the same as those in adults. Between 37 weeks of gestation and 2 months of age, it is rarely possible confidently to diagnose brain stem death and below 37 weeks of gestation, the criteria of brain stem death cannot be applied" (Conference of Medical Royal Colleges 1991, cited in *A Code of Practice for the Diagnosis of Brain Stem Death* 1998).

11.3.3 The patient undergoes two sets of brain stem death tests, as recommended by the *Code of Practice for the Diagnosis of Brain Stem Death* (1998) and the time of death is recorded as the first set of tests. The relatives are fully informed throughout this process by hospital staff and are given time to understand this information before being approached about organ/tissue donation.

11.3.4 The results of the tests should be signed by both clinicians and documented in the patient's medical notes. This documentation must include the date and time the tests were performed and death was certified.

11.3.5 Every case of organ and tissue donation will be managed by the local donor transplant co-ordinator and/or tissue co-ordinator. Other healthcare professionals are however ideally placed to first consider and approach the possibility of organ and tissue donation, if they feel they have the appropriate skills to do so. The donor transplant co-ordinator/tissue co-ordinator is always available to assist where the staff do not have the necessary skills or experience. Donor transplant co-ordinators/tissue co-ordinators encourage a collaborative approach between the hospital staff and themselves in approaching relatives, so are always available to undertake this with the local healthcare professionals.

11.3.6 The local donor transplant co-ordinator/tissue co-ordinator should be contacted at the earliest appropriate opportunity.

11.4 Death outside the Intensive Care Unit

Healthcare professionals should consider the possibility of donation outside the intensive care unit setting. An appropriate time may either be shortly before death (where a willingness has already been demonstrated) or once death has been pronounced, on cessation of cardio-respiratory function.



12 Non-heartbeating donation

- 12.1 There are a number of centres in the UK where it is possible to perform non-heartbeating organ retrieval from the accident and emergency departments (A&E), intensive care units or other wards. Prior to the introduction of confirmation of death by brain stem testing in the late 1970s, all cadaver kidney donors were non-heartbeating donors. This retrieval method has since been revised in an attempt to offer a solution to the ever-increasing disparity between the supply and demand of transplantable organs.
- 12.2 It is possible to retrieve kidneys and livers from non-heartbeating donors, although liver donation is restricted to cases of controlled² non-heartbeating donation. Death is based upon cardiac criteria instead of brain criteria and, following the confirmation of death, the organs need to be cooled as soon as possible by an in situ perfusion technique or retrieved immediately. Please refer to separate and specific non-heartbeating organ donation hospital policies for further information and guidance and/or contact the local donor transplant co-ordinator for further information.

13 Anencephalic donation

- 13.1 Donation is also possible from infants born with ‘anencephaly’ – a malformation not compatible with life. This condition results from the failure of the cranium and scalp to develop. It is usually identified early in the pregnancy by ultrasonography. The infant survives for no more than a few hours/days after birth and a termination may be offered, even in the third trimester of pregnancy. In situations where the pregnancy continues organ/tissue donation may be an option.
- 13.2 The heart is the only organ suitable for donation from anencephalic infants and donation will depend on a suitably matched recipient waiting. The parents would be fully informed of the donation process by the donor transplant co-ordinator/tissue co-ordinator prior to the delivery. If heart donation is not possible the option of heart valve donation will be discussed with the parents. It should be noted that this type of donation is rare.
- 13.3 In a potential anencephalic donation situation, please contact the local donor transplant co-ordinator/tissue co-ordinator for advice.

14 Living donation

- 14.1 The Human Organ Transplants Act (1989) “forbids organs transplanted between living persons who are not genetically related, unless prior permission has been obtained from the Unrelated Regulatory Authority (ULTRA).”
- 14.2 A number of people may wish to donate an organ to a relative or a significant other. These organs may include a kidney, a lobe of lung or a lobe of liver. Some specialist centres carry out this form of donation. Please contact your local transplant co-ordinators for more information on living donation.

² Donors from whom organs are removed after the heart has stopped beating, where the death is expected.

15 Theatre staff

- 15.1 The theatre team are required to be informed at an early stage of a potential donor retrieval. This is to allow for forward planning to aid the donor retrieval process. Following an organ retrieval operation the donor transplant co-ordinator and the theatre team usually perform the last offices as the final act of caring.



16 Follow up

- 16.1 The donor transplant co-ordinator will offer the opportunity to the next of kin/significant other to be informed of the outcome of the transplant operations in writing and give continued support if required (UK Transplant, *Standards of Practice for Donor Transplant Co-ordinators* 2003). In cases of tissue-only donation the tissue co-ordinator will contact the family to confirm which tissues have been retrieved.
- 16.2 The donor transplant co-ordinator/tissue co-ordinator will write to the staff involved with the donation, thanking them for their support and informing them of the donation outcome (UK Transplant, *Standards of Practice for Donor Transplant Co-ordinators* 2003). Donor transplant co-ordinators/tissue co-ordinators will offer a feedback/debrief session as an opportunity to discuss any concerns and ask any questions regarding the donation process.
- 16.3 The involvement of donor liaison sister/charge nurse and link nurses is also a crucial part in the role of organ donation. UK Transplant has funded the introduction of donor liaison sisters/charge nurses in a number of intensive care units in the UK. This is based in part on the Spanish model of organ donation (Matesanz and Miranda *Organ Donation for Transplantation – The Spanish Model* 1996). The donor liaison sister/charge nurse has responsibility for promoting organ and tissue donation from within the ICU initially, but subsequently to the whole hospital. The donor liaison sister/charge nurse works closely with the local donor transplant co-ordinator team in forging closer links between the local donor transplant co-ordinators and the intensive care team and is based on maintaining a collaborative approach to organ and tissue donation.

For further information regarding donor liaison sisters/charge nurses or link nurses please contact your local donor transplant co-ordinator.

17 UK Transplant

- 17.1 UK Transplant is a special health authority covering the United Kingdom. Its responsibilities include maintaining the national transplant waiting list, matching and allocating organs 24 hours per day/365 days per year, the transport of organs to recipient centres and maintaining the ODR. In the year 2000 additional responsibilities were given to UKT, which include improving donation and transplantation rates, establishing a framework for transplant co-ordinator services and a vigorous new national public relations and communications strategy.

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