



UK Transplant

Donor Family Care Policy

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Contents

Introduction

Definitions

Terms of reference

- Aims of the policy.
- Scope of the policy
- Membership of the Working Party

Policy items

- Donation procedure
- Cultural, religious and spiritual considerations
- Bereavement aftercare

Appendices

- | | |
|-----------------------|---|
| Appendix One | Guidelines for Conducting the Donor Family Interview |
| Appendix Two | Information for Donor Families |
| Appendix Three | Guidelines for writing to Donor Families following the Donation of Their Relatives Organs for Transplantation or Research |
| Appendix Four | Guidelines for Communication Between Donor Families and Recipients |
| Appendix Five | Guidelines for Donor families and Recipients who wish to Correspond |

References

Introduction

Transplantation is often the treatment of choice for end stage organ failure. This has led to an increase in the demand for donated organs suitable for transplantation.

This policy has been produced to define best practice that should be integral to the work of donor transplant co-ordinators caring for donors, and families with whom donation was discussed.

The following recommendations constitute the minimum standard that should be achieved to meet the needs of all donor families. This policy is based on the experience of donor transplant co-ordinators across the UK, donor families and is supported by expert opinion and evidence, where it exists.

Definitions

These terms have been defined specifically for the purposes of this document. The Working Party is aware that terms such as 'next-of-kin' are presently currently under review in relation to legislative changes suggested by the *Human Bodies, Human Choices* (Department of Health 2002) consultation document. The Working Party is also aware that the issue of 'consent' for the use of organs and tissues is also under review and this may have implications to the present practice of 'seeking a lack of objection'. This policy will be reviewed and amended in the light of any changes in legislation.

Collaborative Approach - the request for organ/tissue donation is made jointly by the patient's clinician and the donor transplant co-ordinator. A collaborative approach has been shown to demonstrate higher rates of consent.

Death certified by brain stem testing (BST) - '*Death entails the irreversible loss of those essential characteristics, which are necessary to the existence of a living human person*' (Department of Health 1998). The diagnosis of death is regarded as the '*irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe*' (Department of Health 1998). Three phases must be worked through to establish death by BST: 1) a number of preconditions; 2) necessary exclusions; and 3) a set of clinical tests, which assess the functional capability of the brain stem. Death certified by BST is a prerequisite for heartbeating cadaveric organ donation.

Donation - The process or the act of giving organs or tissues for the benefit of others

Donor - A person who makes a donation of tissues or organs for the benefit of others

Donor family - The family, friends and/or significant other/s of the potential donor who is considered to be the patient's next-of-kin for the purposes of decision-making

DTC - A donor transplant co-ordinator. The DTC is normally a registered nurse with significant post- registration experience, normally from within critical care, who is appropriately trained in donor transplant co-ordination.

Lack of objection - The UK currently operates an 'opting in' system, based on the Human Tissue Act (1961). This means that individuals or their family actively choose to donate organs or tissues after death. While there is no legal requirement to gain consent to donation if the deceased had expressed a wish to donate, efforts should be made to establish that the deceased had not expressed objections to donation at a later date. Any documentation should be worded in terms of 'lack of objection'.

Non-Heartbeating Donation

Controlled non-heartbeating donor – Donor, from whom organs are removed where the death is expected and has been certified following asystole.

Uncontrolled non-heartbeating donor - Donor from whom organs are removed where the death is unexpected, and is certified following asystole.

Referral Unit – The hospital/department from which a potential donor is referred to a DTC

Terms of reference

Aims of the policy

- To define best practice for donor transplant Co-ordinators when caring for donor families, recognising their bereavement needs, prior to, during and following donation
- Ensuring that donor families have equity of access to that best practice
- Providing measurable benchmarks for DTCs

Scope of the policy

This policy currently includes all solid organ deceased donors who have been referred to a DTC team.

Membership of the Working Party

Paula Aubrey, Donor Transplant Co-ordinator, North Thames
Steve Bell Donor Transplant Co-ordinator Regional Manager UKT (chairman)
Rachel Clarke, Donor Transplant Co-ordinator, Oxford
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The donation procedure

- 1 The families of all potential donors have the right to discuss the option of organ donation with the DTC

This will be achieved by:

- 1.1 When the initial referral is made the DTC should establish the sequence of events to date. If the option of donation has not yet been discussed with the family the opportunity for a collaborative approach should be explored in areas where a policy has been established.
- 1.2 The NHS organ donor register (ODR) should be consulted to find out if the potential donor has registered his/her wishes. This information should be obtained prior to discussing organ donation with the family. The option of donation should still be discussed regardless of non-registration.
- 1.3 The time of arrival of the DTC on the referral unit should be guided by the needs of the family and the demands of the situation within that unit. A policy of early referral to the DTC team is recommended.
- 1.4 The DTC should provide the referral unit with an expected time of arrival and inform the referral unit of any unforeseen delays that change the time agreed.
- 1.5 On arrival the DTC should ascertain relevant information from the unit staff and make a *preliminary* assessment regarding suitability for donation using the patient's medical notes and other relevant documentation. (This will form part of the formal assessment of the patient if the family have no objection to organ donation).
- 1.6 If the approach to the family has not yet been made the DTC and the referral unit staff should discuss/plan how the approach to the family will be made.
- 1.7 The approach should be carried out at an appropriate time, which is normally when the family has understood that death has occurred or is the expected outcome. The DTC should ascertain what information the family have been given and ensure that referral unit staff have carried out all explanations about the critical injury and the prognosis. The relatives should be informed if the potential donor had registered their wishes on the NHS organ donor register.
- 1.8 The DTC should introduce themselves to the family as the donor transplant co-ordinator who is there to provide information about donation.
- 1.9 When establishing lack of objection the DTC should adhere to 'the guidelines for conducting the donor family interview' and answer any further questions or queries. (**Appendix One**)
- 1.10 The donor family should be offered time and privacy to consider the information they have been given about donation.

- 1.11 The outcome of the discussion should be documented in the patient's notes. If the family does not wish donation to proceed, where possible the reason for this should be documented.
- 1.12 If the family does not wish their relative to become a donor the DTC should acknowledge and support the family's decision. It may be appropriate to write to the family thanking them for considering donation.

Cultural, religious, spiritual beliefs and emotional needs

- 2 All potential donor families have the right to their cultural, religious, spiritual beliefs and emotional needs being acknowledged**

This will be achieved by:

- 2.1 The DTC should discuss the family's religious, cultural and spiritual needs at the time of the family interview. The DTC should aim to facilitate any specific requests.
- 2.2 The donor family should be given the opportunity to spend time alone with the donor prior to donation.
- 2.3 The DTC, in collaboration with the referral unit staff, should ensure the family receives any mementoes they wish to have, such as handprints, footprints and locks of hair.
- 2.4 It is the responsibility of the DTC, in collaboration with the referral unit/theatre staff, to ensure that last offices are carried out according to the wishes of the family and in accordance with the hospital policy.
- 2.5 All donor families should be given the opportunity to spend time with the donor immediately post operatively. This should be facilitated by the DTC in conjunction with local hospital staff as appropriate.
- 2.6 The DTC should liaise with the referral unit staff to ensure the donor family is offered support when leaving the unit/theatre/hospital.

Bereavement aftercare

- 3 Donor families (within the bounds of anonymity and confidentiality) should be offered choices about the nature and timing of the feedback and follow up that will be provided by the DTC**

This will be achieved by:

- 3.1 The DTC should ensure that the donor family has their name and a contact number. Written information about the donation process should be offered to the families if they wish to receive it. If death is certified using brain stem testing criteria written information providing further explanation of this should also be offered. **(Appendix Two)** This information should be offered at the time of donation and in subsequent follow up.
- 3.2 Donor families should be offered the option of receiving a telephone call following the donation procedure. The timing of this call should be discussed and agreed with the family.
- 3.3 Donor families should be offered contact via a letter within two weeks of the donation. The timing and content of this letter should be discussed and agreed with the family. **(Appendix Three)**
- 3.4 Information about the outcome of tissues retrieved for transplant, that was not available when the initial follow up letter was sent, should be forwarded onto families within two weeks of receipt by the DTC, having established the families wishes in relation to this information.
- 3.5 Vulnerable individuals/families should be identified and offered a personal meeting with the DTC. The content, time and place to be discussed with the family and confirmed in writing. This meeting and any other meetings undertaken by a DTC must be undertaken in accordance with the DTC employing Trust's policy particularly if it is necessary for the meeting to take place in the individual's/family's home rather than an alternative venue ie GP surgery.

(Research has identified vulnerable individuals as those without family support, particularly individuals with small children.)

Or

- 3.5.1 If the family prefers, a telephone conversation, this should be facilitated by the DTC.

(This can still give the individual the opportunity to talk freely, ask questions and discuss issues that they still may have).

- 3.6 Donor families should be offered ongoing follow up and support for a time period that will be discussed and agreed with the family. This may include referral to other support agencies.

(The DTC forms a link between the bereaved family and the systems that already exist to support them. The DTC provides information and feedback about the donation and its outcomes, such as information about the recipients. It is important that the donor family is fully aware that this information will always be available to them, for as long as they want it).

- 3.7 Donor families should be offered written contact on the first anniversary of the donor's death and/or at other appropriate times as agreed with individual families.
- 3.8 Accurate records should be kept and maintained regarding the donor families' wishes for long-term bereavement aftercare and the type of recipient information they wish to receive. This will provide the whole DTC team with precise information for future care and/or follow up.

GUIDELINES FOR CONDUCTING THE DONOR FAMILY INTERVIEW

Purpose

- ❑ To ensure that the donor family is given clear and accurate information about organ/tissue donation
- ❑ To establish lack of objection on behalf of the donor to organ and/or tissue donation
- ❑ To collect information relating to the medical and social history of the potential donor to establish suitability for donation
- ❑ To ensure that donor family interviews are conducted in a consistent manner

This document assumes a level of knowledge from the donor transplant co-ordinator. Reference should be made to the document **Rationale for Donor Assessment**.

The interview should be conducted in a quiet, private environment.

Unless there are exceptional circumstances, a face-to-face interview should be conducted. If possible, the interview should be witnessed by another healthcare professional. If the interview is conducted by telephone a witness should also be present.

Terms of Reference

Donor Family The term **Donor Family** will refer to the family or friends of the potential donor who are considered to be the patient's next-of-kin for the purposes of decision-making.

Documentation

Information must be documented on the **Donor Assessment** document and the **Lack of Objection** document. A copy should be placed in the patient's notes. Contact and discussions with the donor family should be documented in the potential donor's notes.

The Interview

Aim	Process
1 To introduce yourself to the donor family	1.1 Introduce yourself. 1.2 Extend sympathy. 1.3 Ascertain that family or friends are the appropriate next-of-kin and that the person who knows most about the potential donor is present. 1.4 If significant family members are not present, the donor transplant co-ordinator should ascertain that they are aware of the situation and that they have no objection to organ/tissue donation. 1.5 Check the donor family's understanding of the current situation. 1.6 Explain the interview and assessment process. 1.7 Inform the donor family of timings and keep them updated throughout. 1.8 Answer any questions that the donor family has at this stage. 1.9 If not already established, the donor family should be informed if the agreement of the Coroner or Procurator Fiscal is required for organ/tissue donation.
2 To obtain lack of objection for organ/tissue donation, on behalf of the potential donor, from the donor family.	2.1 Explain which organs/tissues you believe the potential donor may be able to donate for transplantation. 2.2 Explain that organs/tissues may also be donated for the purposes of research, teaching or validation. 2.3 Discuss with the donor family which organs/tissues they wish to be donated. 2.4 Avoid misleading terminology to ensure that the donor family understand the donation process. In particular they understand that: <ul style="list-style-type: none"> ❑ there will be a large abdominal/thoracic wound that will be sutured and dressed after donation ❑ the whole eye is taken for ocular tissue donation ❑ the whole heart is taken for heart valve donation. In areas of the UK where it is known that a post mortem of the heart is routinely carried out in order to facilitate valve donation, consent must be obtained for this ❑ bone is taken from the hip to below the knee joints. There will be long suture lines down the side of both legs and sometimes some external rotation of the limbs. The legs will be bandaged together to try to avoid this ❑ sometimes bone is also taken from the iliac crest. This will involve an additional suture line higher on the hip

Appendix One

Aim	Process
	<ul style="list-style-type: none"> ❑ skin is usually taken from the back, and the back of the legs down to the ankles ❑ meniscus is taken from the knees as part of the bone retrieval and can be used for transplant if suitable ❑ tendons are taken from the knees and back of the ankles. Where tendons are taken from the ankles additional suture lines from below the heel to mid calf will be necessary. <p>It is important to establish the practice of your local tissue bank to ensure appropriate consent is obtained.</p> <p>2.5 Explain that if organs/tissues are donated for transplantation, there may be circumstances where they cannot be used e.g. if a potential recipient becomes unwell.</p> <p>2.6 Explain that in these circumstances, the organ/tissue may be used for research, teaching or validation. If the donor family does not wish this, the organ/tissue will be disposed of in a safe and legal manner as per hospital policy.</p> <p>2.7 Explain that donated tissues will be preserved and stored until a review of all test results and donor information can be done. This can take several months.</p> <p>2.8 Answer fully any questions the donor family has.</p> <p>2.9 Explain that all efforts will be taken to restore the appearance of the body to normal after donation, but that there may be some signs e.g. bruising around the eyes, fluid leakage after skin donation.</p> <p>2.10 Explain that, in addition to specified organs/tissues, other tissues will be retrieved, stored and used in support of transplantation e.g. lymph nodes and a sample of spleen for tissue typing, and iliac vessels and the gall bladder to assist liver transplantation.</p> <p>2.11 Complete the Statement of Lack of Objection for Organ/Tissue Donation</p>
3 To undertake a medical and social history assessment	<p>3.1 Explain the importance of safety of organ/tissue transplants, that in order to assess which organs/tissues can be donated, it is necessary to ask some questions about the potential donor:</p> <ul style="list-style-type: none"> ❑ that some questions are of an intimate nature ❑ that these questions are not meant to cause offence ❑ that these questions are asked of all potential donors ❑ that the General Practitioner, and any other relevant health professional will be contacted for information about the medical history of the potential donor

Appendix One

Aim	Process
	<ul style="list-style-type: none"> ❑ that a blood sample will be taken to be tested for HIV, HTLV, Hepatitis B and C and Syphilis. ❑ that if any test result is deemed to have significance for the health of the family, they will be contacted and offered the appropriate advice. <p>3.2 Complete the Donor Assessment document.</p>
4 To establish any personal requests by the donor family for after care	<p>4.1 It is the responsibility of the donor transplant co-ordinator to update the donor family throughout the donation process.</p> <p>4.2 Ensure that the donor family understand that tissue donation will take place within the next 24-48 hours. It is important to establish if the donor family have specific requirements for viewing or burial arrangements.</p> <p>4.3 Inquire if there are any religious/spiritual requirements of the donor family.</p> <p>4.4 Ensure that the donor family understands that the potential donor will be treated with respect and dignity.</p> <p>4.5 Establish the donor family's wishes for keepsakes e.g. locks of hair, handprints and photographs.</p> <p>4.6 Offer the donor family the opportunity to see their loved one after donation</p> <p>4.7 Determine whether the donor family wishes to assist with last offices after donation, or wish their loved one to be dressed in certain items of clothing.</p> <p>4.8 Ascertain whether the donor family would like to receive information about the outcome of the donation. This may be in person or in a letter.</p> <p>4.9 Ensure that the donor family has a contact name and number for the donor transplant co-ordinator.</p>
5 To obtain information about medical and social history from the potential donor's General Practitioner, or other relevant health professional, to enable assessment of suitability for donation	<p>5.1 All efforts should be made to contact the potential donor's General Practitioner. Out-of-hours requests should be made to the deputising service. It is sometimes possible to contact the potential donor's own General Practitioner in this way.</p> <p>5.2 Explain the purpose of the enquiry and the need to ensure safety in the donation and transplantation of organs.</p> <p>5.3 Discuss the potential donor's past medical and social history.</p> <p>5.4 Ask specifically, if the General Practitioner is aware of any medical or social history which carried a risk of transmission of HIV, CJD, Hepatitis B or C, or Syphilis.</p> <p>5.5 Ask the GP to complete and return the GP Fax Form.</p>

GUIDELINES FOR WRITING TO DONOR FAMILIES FOLLOWING THE DONATION OF THEIR RELATIVES ORGANS FOR TRANSPLANT OR RESEARCH

Basic principles

The donor family has the right to be informed of the outcome of their relative's donation. This should include information on which organs were retrieved, subsequently transplanted, sent for research or not used. The reason for non-use of donated organs and tissues should also be outlined. The information given to the donor family should include the recipient's age, gender, length of time on the transplant list, and if a renal transplant recipient the length of time spent on dialysis. This information must be anonymous. Other details to be given should include the post-operative condition of the patient and the transplanted organs.

The DTC is responsible for the accuracy of this information, and must obtain the information from the recipient centre concerned for every transplant/recipient update.

If a donor family chooses not to receive any information this should be documented in the donor records. A thank you letter should still be sent, and, the family be made aware that if information is required in the future, the family will be able to receive this at any time. In the cases where the families are explicit that they do not wish to have any further contact this should be respected.

Essential components of the letter:

- 1 A letter should be sent to a donor family within 14 days of the organ/tissue retrieval. Some families may wish to receive some information earlier for specific reasons i.e. to be available for the funeral and this should be facilitated on an individual basis.
- 2 The letter should open offering condolences.
- 3 The donor family should be thanked for the decision they have made regarding organ/tissue donation.
- 4 If a follow up visit is to be offered this should be put forward positively to the donor family with a suggested date and time included. Suggesting a time and date removes the onus from the family to make arrangements at a time when they may be ill equipped to make decisions or feel unable to pick up the telephone. **The safety and vulnerability of the health care professional undertaking this visit is of paramount importance and must be considered in the planning.**
 - 4.1 It should be made clear that the date and time can both be changed if they are inconvenient and that the family can refuse the visit.
 - 4.2 A contact number should be included for the family to decline the offer of a visit or to rearrange the suggested date and/or time of the visit.
 - 4.3 It should also be made clear that the family do not have to make a telephone call to confirm this meeting and that the DTC will ring to confirm that the visit is still required, and that it is convenient, nearer the actual date of the visit.

Appendix Three

- 4.4 It may be prudent to reiterate the purpose of the visit in this letter. The DTC can then suggest that if the family would prefer not to have a follow up visit, the information to be given can then either be discussed over the phone or can be sent in a letter.
- 5 If the family has expressed a wish to receive information about the transplant recipients in this initial letter this information should be enclosed on a separate sheet of paper, within another envelope, which will allow the reader the opportunity to choose when to read the contents. This will provide some warning of the content of the information that is enclosed and will also give the reader some control over the potentially emotional situation.
- 6 If the family is to receive a follow up visit, they should still receive a written copy of the transplant recipient details, which can be provided at the visit.

GUIDELINES FOR COMMUNICATION BETWEEN DONOR FAMILIES AND TRANSPLANT RECIPIENTS

Transplant recipients may wish to convey thanks to the donor family, similarly donor families may wish to communicate with the recipients. Guidelines should be available to assist the sender. (**Appendix Five**) This communication is normally anonymous. However, in some cases the donor family and recipient(s) may wish to meet although this is less common and would normally happen some considerable time after the donation.

Donor transplant co-ordinators have a responsibility to facilitate communication whilst respecting the wishes of both parties.

The following guidance is designed to help donor and recipient transplant co-ordinators ensure that communication between donor families and transplant recipients is facilitated without detriment or upset to either party, and that expectations of both donor families and transplant recipients are realised, if at all possible, within the bounds of confidentiality.

- 1 It should be made clear to the author that letters will be read by the transplant co-ordinators involved (both donor and recipient) to protect both parties. It is for this reason that letters should be sent unsealed, within a sealed envelope. In order to maintain confidentiality identifiable information should not be contained within the letter until such times as there is mutual agreement to share this information. If the author has sealed the letter, it should **not** be **opened** by the DTC until permission has been gained.
- 2 Upon receipt of the letter, the transplant co-ordinator involved should contact the intended recipient directly to determine whether they wish to receive it, unless previous communication has made clear their wishes relating to this. If the letter is to be sent a copy should be made and placed in the donor records.
- 3 The DTC should then send/organise delivery of the letter to the intended recipient.
- 4 If the letter is deemed inappropriate by the DTC, the author should be contacted and the nature of the letter discussed. If suitable amendments are made the letter can then be sent. If the author declines to make the suggested amendments the DTC is not obliged to forward the letter on. If the letter is not sent, a copy should be retained in the donor records with clear documentation supporting the decision. Two DTCs should be involved in this decision.
- 5 Authors of written communication should be informed by the DTC that their correspondence has or has not been forwarded to the intended recipient.
- 6 If members of donor families and transplant recipients wish to disclose their names and addresses to each other in order to communicate directly, that disclosure must be with mutual consent.
- 7 Should both parties wish to meet the DTC should offer to facilitate this initial meeting.
- 8 All evidence of communication should be noted by the DTC and requests to attend any meetings should also be documented

INFORMATION FOR DONOR FAMILIES WHO WISH TO WRITE TO RECIPIENTS

This leaflet is designed to provide you with some information and guidance should you wish at any point to write to any of the people who were transplanted as a result of your relatives donation. It may be that you have received a letter yourself or that you wish to initiate correspondence.

It may be that you do not wish to correspond and this is clearly a personal choice as to whether you write or not, and the timing of the letter is, whenever, and if ever, you feel comfortable and ready to do so.

The following guidelines are to protect the anonymity and confidentiality of both yourself and the individuals who have been transplanted. For this reason the recipients will have very little information about your relative from the health care professionals caring from them.

The letter you send will be read by the transplant co-ordinator involved in the care of the recipient, for this reason please send it unsealed within a sealed envelope.

In order to maintain confidentiality, identifiable information should not be put in the letter until such time as there is mutual agreement to share this information.

Upon receipt of the letter the transplant co-ordinator will contact the recipient to inform them of the letter and, should they wish to receive it the transplant co-ordinator will then organise delivery of the letter

The transplant co-ordinator will let you know if and when the letter was received.

Should you wish to contact the transplant co-ordinators for any further help or guidance please do not hesitate to do so.

Thank you for taking the time to read this leaflet; which we hope will have been of some assistance.

INFORMATION FOR RECIPIENTS WHO WISH TO WRITE TO THEIR DONOR FAMILY

This leaflet is designed to provide you with some information and guidance should you wish at any point to write to the donor family. It may be that you have received a letter yourself or that you wish to initiate correspondence.

It may be that you do not wish to correspond and this is clearly a personal choice as to whether you write or not, and the timing of the letter is whenever, and if ever, you feel comfortable and ready to do so.

The following guidelines are to protect the anonymity and confidentiality of both yourself, and the donor family.

For this reason the donor family will have been given very little information about you as an individual. In the follow up provided for them post donation they may have been told your age and sex and a little about how you are doing post transplant.

We know from speaking to donor families that they often value the personal correspondence they receive from the recipients of their relative's donation, and the information most often put in the letters is an expression of thanks and some idea of how the transplant may have altered your life and the life of those around you.

The local donor transplant coordinators involved in your care will be able to help you if you would like them to in compiling a letter.

The letter you send will be read by the transplant co-ordinator involved with the family, for this reason please send it unsealed within a sealed envelope.

In order to maintain confidentiality, identifiable information should not be put in the letter until such time as there is mutual agreement to share this information.

Upon receipt of the letter the transplant co-ordinator will contact the family members to inform them of the letter and should they wish to receive it the transplant co-ordinator will then organise delivery of the letter

The transplant co-ordinator will let you know if and when the letter was received.

Should you wish to contact the transplant co-ordinators for any further help or guidance please do not hesitate to do so.

Thank you for taking the time to read this leaflet, which we hope, will have been of some assistance.

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