

Family Care

This Management Process Description replaces
MPD845/4.2

Copy Number

Effective

03/01/17

Summary of Significant Changes

Inclusion of DRD and their responsibilities. Removal of letter templates link

Policy

Communicating with the acutely bereaved about the processes of donation after death, and the follow up requirements as determined by patient's families, is a complex area of clinical practice and must only be undertaken by healthcare professionals with the relevant experience and training. Every family should be offered a consistent standard of service in terms of family follow-up following the consent/authorisation for organs and/or tissue donation.

All users of this Management Process Description must act in accordance with the Human Tissue Act 2004/Human Tissue (Scotland) Act 2006, and the guidance laid down in the Human Tissue Authority Codes of Practice/HDL (2006) 46 Scottish Executive Health Department. Appropriate consent/authorisation is the fundamental principle of the legislative framework.

Purpose

The purpose of this document is to define best practice and minimum standards of care that all specially trained healthcare professionals must achieve when caring for patients and their families, with who deceased donation is discussed.

Responsibilities

Specialist Nurse – Organ Donation (SNOD)

To work to this MPD and to seek advice, where required, from the TMs/RMs for additional support and guidance.

Agreement must be made who will be the named contact for ongoing communication.

Donor Records Department (DRD)

To format family letters and send to SNOD for checking prior to sending.

To facilitate ongoing communication between SNOD & families.

Applicable Documents

[POL164](#) - Consent / Authorisation for Organ and/or Tissue Donation

[POL191](#) – Guidance for consent for solid organ transplantation in Adults

[MPD901](#) – Approaching the family regarding organ and tissue donation

[MPD902](#) – Consent conversation for Organ and/or Tissue Donation

[MDP598](#) - Management of the Deceased Donor Family Donation Conversation (Scotland)

[FRM5499](#) – SNOD to DRD handover form

[MPD364](#) – Lone Working

[MPD865](#) – Obtaining Coroner /Procurator Fiscal decision

[MPD953](#) –Service Evaluation

[MPD910](#) - Medical Records Entry

[INF995](#) - Information for families who wish to write to transplant recipients.

[FRM4430](#) – Family Service Evaluation

[FRM4372](#) – Record of Post Donation Family Communications.

[FRM4281](#) – Consent for Solid Organ and Tissue Donation

[FRM1538](#) - Authorisation for Solid Organ and Tissue Donation (Scotland)

[SOP5017](#) –Use of Translation & Interpretation Service

[SOP5049](#) – DRD Process Manual

[DAT2792](#) - Recipient Centre Point of Contact – List of email addresses

[BTS Guidance](#)

<http://www.bts.org.uk/Documents/Consent>

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1 Key Communication With Family Members During The Potential Organ Donation Process

- 1.1 The SNOD should offer & facilitate any specific end of life care requests from the family. These must include the offer of
- Spending time alone with the patient prior to or post donation
 - Receiving keepsakes, such as prints and hair locks
 - Support of any religious, cultural and spiritual needs
 - Liaising with hospital staff to ensure the bereaved family is offered support when leaving the unit/theatre/hospital, regardless of whether donation proceeds.

2 Follow Up For Families

- 2.1 The SNOD must ensure to pass on their name and **the DRD** contact details to the patient's family.
- 2.2 Families must be offered a telephone call at the end of the donation process to inform them of the immediate outcome. The SNOD should agree a convenient time and confirm telephone number.
- 2.3 Families must be offered an outcome information letter, or a letter of thanks, within 15 working days.
- 2.4 If the family has requested no further contact, this must be respected and clearly documented in the **Family contacts – other relevant information section in DonorPath**.
- 2.5 Outcome information letters must be sent to the family within 15 working days. The SNOD must inform the family if the outcome information letter will exceed 15 working days.
- 2.6 Some families may wish to have outcome information available for the funeral and this should be facilitated where possible.
- 2.7 In the cases of tissue only donation, the SNOD must explain to families that the timescale for receiving outcome information in relation to corneal and heart valve transplants can vary. This information should be available from tissue services after 6 months and the family can contact the **DRD** should they wish to receive the information.
- 2.8 Communication relating to donation outcome (initial and ongoing) should be sent either by general mail or e-mail should the family prefer this. If keepsakes are being sent then these must be sent via recorded mail delivery.
- 2.9 Photocopies of **prints** should be taken for the donor file. Keepsakes should be given to the family at the time of donation, however if this is not possible then they should be sent to DRD in the envelopes provided and DRD will then send to families or dispose of them within 15 working days.

3 Process For Writing Initial Family Letters

- 3.1 All initial donor outcome information will be received directly from the Duty Office on the outcome summary reports
- 3.2 **Only** the information given in the outcome summary (excluding geographical location) should be included in the letter to the family in line with **POL191**.
- 3.3 Any personalisation that the SNOD wishes to include should be included on the DRD handover **FRM5499** and in the other relevant information in the family contacts section of DonorPath. The DRD staff will use this information to formulate a paragraph for inclusion in the letter.
- 3.4 All family letters must be written by the DRD and sent to the Lead SNOD for checking prior to sending. It is the SNOD's responsibility to check the content of the letter against the organ outcome summary and DonorPath. DRD will check spelling, grammar and addresses.

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- 3.5 The outcome information letter must be placed in a separate envelope to the covering letter. This gives the family the opportunity to choose when to read the contents. [FRM4430](#) must also be sent in a separate envelope, as per [MPD953](#).
- 3.6 All letters sent out to families must be marked: **Private and Confidential**, both on the letter and on the envelope.
- 3.7 If families request correspondence via e-mail, then the email must be completed by the DRD and sent as a PDF attachment with a covering e-mail. This will allow the family member to read it in their own time.
- 3.8 The e-mail must be composed by a member of DRD staff and forwarded to the Lead SNOD for checking before sending. The e-mail must be sent from the DRD account so that any returning correspondence can be dealt with in a timely manner.
- 3.9 If the primary family member requires the outcome information letter translating in to another language then the DRD staff must facilitate this following [SOP5017](#).

4 Writing To Professionals Following Organ And/Or Tissue Donation

- 4.1 As part of the donation follow up, the SNOD may wish to write a donation outcome letter to department(s) involved in the donation process. SNODs must communicate to the DRD staff that this is required. A member of the DRD team will write the letter and send to the Lead SNOD for checking prior to sending.
- 4.2 Professionals must not receive more information than that contained within the family letter.
- 4.3 Should the family not wish to receive follow up information then professionals **must not** receive the information. The SNOD may ask the DRD to write to professionals to explain the reasons for this.

5 Longer Term Follow Up For Donor Families

- 5.1 Additional follow up will not be routinely sent to families. Should a family request further follow up then this must be facilitated by following the process below:
- 5.2 Reports will be automatically generated at 6 months by information services and put in to the shared folder located at [G:\013 ODT\002 DTC\001 Everyone\ Recipient Reports](#)

After 6 months should further follow up be requested from a family, then the DRD department will facilitate this. An e-mail should be sent from the DRD to the Recipient centre point of Contact (RCPoC) utilising [G:\013 ODT\001 Everyone\Recipient Coordinator Contact List](#) for the appropriate e-mail address.
- 5.3 The SNOD may wish to send a card on the first anniversary of the donor's death as a means of acknowledging the donation. The DRD will generate a list each month of families that have been highlighted as requiring an anniversary card. The SNOD may wish to do this personally or request that the DRD send on their behalf. Clinical or follow up information **must not** be included with the card unless a specific request has been received directly from the donor family.

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6 Donor Family And Recipient Communication

- 6.1 Transplant recipients may wish to convey thanks to a family. Similarly donor families may wish to communicate with transplant recipients. This communication is generally anonymous.
- 6.2 Should a donor family wish to write to a recipient or respond to a letter from a recipient, [INF995](#) should be sent from the DRD to the family with a covering letter.
- 6.3 Any letters that are received from donor families or recipients, should be scanned and a copy placed in the donor files.
- 6.4 Any correspondence must be anonymised and comply with [INF995](#).
- 6.5 If a donor family do not wish to receive any letters then they must be stored in both the paper and electronic donor file, and the DRD must communicate back to the RCPoCs informing them of the reason for not forwarding the letter on. Any correspondence received in the DRD must be forwarded within 15 working days.
- 6.6 The DRD should document in the action log the date of receipt and the date that the family letter was forwarded.
- 6.7 If family members and recipients wish to disclose their contact details to each other in order to communicate directly, that disclosure must be made with mutual agreement. This must be documented within the donor file.
- 6.8 On occasions donor and recipient families may wish to meet. NHSBT staff along with RCPoCs may need to provide support to facilitate the meeting.