

## 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 legislative frameworks in place across all territories of the United Kingdom. For further details around specific legislative frameworks please refer to [POL191](#) - Guidelines for consent for solid organ transplantation in adults.

## Objective

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.

## Changes in this version

Changes made to section 2.5 regarding postage of a donor file to the DRD.

Changes made to 2.3 and 4.1 regarding communication to the DRD via donor path for family and staff letters.

## Roles

### 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.
- To thoroughly complete [FRM5499](#) and DonorPath Family contact section.

### Donor Records Department (DRD)

- To work within [SOP5049](#) – DRD Manual
- To format family letters and send to team leaders for checking. To send any correspondence to the lead SNOD for checking, where necessary, prior to sending.
- To facilitate ongoing communication between SNOD & families.

## 1. Key Communication with Family Members During the Potential Organ Donation Process

1.1. The SNOD should offer and agree specific end of life care requests with 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.
- Discuss with family in regards receiving correspondence including recipient letters.

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## 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 the telephone number.
- 2.3. SNODs must complete all sections of the [family contacts section on donor path](#) thoroughly. Inclusion of the main contact is vital and if other family members would like correspondence their contact details must be included to ensure the DRD have the correct information to write the letters.
- 2.4. [FRM5499](#) must be completed and sent to the DRD within 24 hours of the donation.
- 2.5. [Donor files, whether proceeding or non-proceeding, should be returned to DRD in the Special Delivery envelopes provided within the donor packs via Royal Mail. Once taken to a Post Office the tracking number and date of postage should be emailed to DRD. They should not be sent via local post rooms or internal mail.](#) The donor file must be returned to the DRD within 5 working days following the donation, and the SNOD must e-mail the DRD to confirm posting and include the tracking number of the file.
- 2.6. Families of proceeding donors will be sent a pin badge and certificate of recognition from the Chief Nurse within 2 working days of the donation (sent by the DRD).
- 2.7. The SNOD should clearly indicate on [FRM5499](#) how many pin badges are required, and which family member they are to be sent to.
- 2.8. Families of consented / authorised non-proceeding donors will be sent a pin badge(s) or a personalised letter of thanks from the Chief Nurse within 2 working days (sent by the DRD).
- 2.9. The SNOD must offer the family an outcome information letter, or a letter of thanks. This will be sent within 15 working days of the donation.
- 2.10. 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 and on [FRM5499](#).
- 2.11. If the letter needs translating in to a different language, the SNOD must identify which language the letter needs to be translated into and document this on DonorPath and in the Family Letter section of [FRM5499](#).
- 2.12. Some families may wish to have outcome information available for the funeral and this should be facilitated where possible.
- 2.13. 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 and Eye Services after 6 months and the family can contact the DRD should they wish to receive the information.

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- 2.14. 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 the DRD in the envelopes provided and the DRD will then send to families or dispose of them within 15 working days.
  - 2.15. Hair locks Must be placed in the envelope provided in the donor pack and the information filled in accurately. Prints and copies must have 3 points of PID written on the back.

### **3. Process for Writing Initial Family Letters**

- 3.1. All initial donor outcome information will be received by the DRD directly from Hub Operations on the outcome summary reports.
- 3.2. Only the information given in the outcome summary (excluding geographical location) will 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. Should the SNOD wish to check the letter(s) before sending then they must clearly specify this in the Family Letter section on [FRM5499](#).
- 3.5. A blank greetings card will be included in the donor pack. The SNOD(s) involved in the donation process may wish to write a personalised greeting to the family for inclusion with the outcome letter. The card must not contain any clinical information and should be used as a thank you/ acknowledgement of decision only.
- 3.6. The greetings card must be sent back to the DRD in the returned donor file. The DRD staff will then send on with the outcome letter. The SNOD must indicate on [FRM5499](#) if they have included the card for sending to the family.
- 3.7. It is the SNODs' decision to write a family card to non-English-speaking families. If this is required then it must be clearly documented on [FRM5499](#) and on DonorPath.
- 3.8. All family letters will be written by the DRD and sent to the DRD team leader for checking prior to sending. It is the DRD's responsibility to check spelling, grammar and addresses as well as the content of the letter against the organ outcome summary and DonorPath.
- 3.9. If the DRD are unsure of the detail of the donation e.g. if multivisceral or novel donations, then they will send the letter to the lead SNOD for advice and checking prior to sending. This must be checked and returned to the DRD within 3 working days. If not returned by the deadline this will be escalated to the on call SNOD or Team manager.
- 3.10. If the family stated they wish to receive recipient letters and/or card, these will be sent alongside a cover letter to the agreed family member. No additional correspondence will be sent to the family to confirm if they would like to receive the letters if known wishes are recorded within DonorPath.

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- 3.11. If a recipient letter or card is received to forward to a donor family, the DRD will cross check against the donor file to ensure that the correct family receive the communication. DRD staff will check the donor file to ascertain if the donor family are happy to receive further communication as per [SOP5049](#).
  - 3.12. If a family are happy to receive the letter or card and it is the first recipient correspondence, a letter will be drafted and sent to the SNOD for review along with a copy of the recipient letter as per [SOP5049](#). The lead SNOD will be informed that it has been sent.

## **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 using the [hospital contact section on donor path and state clearly the person's name and department](#). The staff that this is required for. A member of the DRD team will write the letter and send to the Team Leader for checking prior to sending.
- 4.2. Professionals will 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 DRD may write to professionals to explain the reasons for this if requested to do so by the SNOD.

## **5. Longer Term Follow Up for Donor Families**

- 5.1. Additional follow up will not be routinely sent to families. After 6 months, should further follow up be requested from a family, then the DRD department will facilitate this.
- 5.2. The DRD will send a card on the first anniversary of the donor's death as a means of acknowledging the donation. This will not include clinical follow up unless a specific request has been received directly from the donor family.

## **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 will be scanned by the DRD and a copy placed in the donor files.
- 6.4. Any correspondence must be anonymised and comply with [INF995](#).

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- 6.5. If a donor family does not wish to receive any letters then they will be stored in both the paper and electronic donor file, and the DRD will communicate back to the RCPoCs informing them of the reason for not forwarding the letter on. Any correspondence received in the DRD will be forwarded within 15 working days.
  - 6.6. There are occasions when a SNOD/Team Manager (TM) feels a letter from a recipient would be appropriate to share with healthcare colleagues from the donating hospital for training/teaching purposes. It is acceptable for the SNOD/TM to contact the recipient centre and donor family to seek permission to share the information. All conversations and agreement should be added to DonorPath or historic donor file.
  - 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.
  - 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.

## Definitions

- None

## Related Documents / References

- [POL191](#) – Guidance for consent for solid organ transplantation in Adults
- [FRM5499](#) – SNOD to DRD handover form
- [MPD953](#) – Family Service Evaluation
- [INF995](#) - Information for families who wish to write to transplant recipients.
- [FRM4430](#) – Family Service Evaluation
- [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>