

## 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

### 3.5.3 – Escalation to a Team Manager

5.2 – Information regarding writing to health care professionals outside of the donor hospital.

Clarification to the checking of donor family correspondence in section 3.

Availability of bereavement support books for children.

## 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 Family Care Service (DFCS) -

- To work within **SOP5049** – DFCS Manual
- To format family letters and send to SNOD's/SRs for checking.
- To send any correspondence to the lead SNOD for checking, where necessary, prior to sending.
- To facilitate ongoing communication between SNOD/SR & families.
- To facilitate the provision of keepsakes to families in conjunction with the lead SNOD.

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## 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 from NHS Blood & Transplant (NHSBT), including recipient letters, and setting expectations about receiving correspondence from recipients.
  - Discussion with families around the meaning of the gold heart pins sent to consented / authorised families post donation. Families should be offered the option of receiving the pin and notification of that decision sent to the DFCS.
  - [Availability of bereavement support books to support bereaved children.](#)

## 2. Follow Up for Families

- 2.1. The SNOD must ensure to pass on their name and the DFCS 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 DFCS have the correct information to write the letters.
- 2.4. **FRM5499** must be completed and sent to the DFCS within 24 hours of the donation.
- 2.5. Donor files, whether proceeding or non-proceeding, should be returned to the DFCS 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 the DFCS. They should not be sent via local post rooms or internal mail. The donor file must be returned to the DFCS within 5 working days following the donation, and the SNOD must e-mail the DFCS to confirm posting and include the tracking number of the file. Please notify the DFCS via email of any potential delay in returning the donor file.
- 2.6. Families of proceeding donors will be sent a pin badge and certificate of recognition from the OTDT Director within 2 working days of the donation (sent by the DFCS).

- 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. The number of pin badges sent should equate to the number of family members present during consent / authorisation and not exceed 10.
- 2.8. Families of consented / authorised non-proceeding donors will be sent a personalised letter of thanks from the OTDT Director within 2 working days (sent by the DFCS).
- 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 into 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. If requested the DFCS can have letters transcribed into braille. If this is required, this should be noted on DonorPath and in the Family Letter section of **FRM5499**.
- 2.13. Some families may wish to have outcome information available for the funeral and this should be facilitated where possible.
- 2.14. 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 DFCS should they wish to receive the information.

### 3. Process for Writing Initial Family Letters

#### NOTE

Everyone has a responsibility to ensure all correspondence is checked as detailed below to ensure accurate and timely correspondence for our donor families. Please ensure attention is given to checking organ outcome, NOK details, and the name and gender of the donor.

- 3.1. All initial donor outcome information will be received by the DFCS 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 **can** be included in the cover **and outcome** letter from DFCS. Amendments to letters can be made but track changes must be used to allow the DFCS to see where amendments have been made.
- 3.4. The DFCS will forward the first draft of the family letter to the lead SNOD, it is the lead SNODs responsibility to allocate the checking to a colleague if they are unavailable and notify the DFCS.

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- 3.5. On receipt of the drafted letter from the DFCS the SNOD should ensure the following details are checked against DonorPath and the Organ Donor Outcome Summary Form.
- Next of kin name (DonorPath)
  - Next of kin address (DonorPath)
  - Donor Name (DonorPath)
  - Donor Gender (DonorPath)
  - Organs Transplanted (Organ Donor Outcome Summary Form)
  - Recipient gender, age (decade) and time on waiting list (Organ Donor Outcome Summary Form)
  - Organs not transplanted and reason (Organ Donor Outcome Summary Form)
  - Tissue outcome (DonorPath Sequence of Events and Organ Donor Outcome Summary Form)
- 3.5.1. Once the lead SNOD has checked all details and content of the draft letter this should be returned to the DFCS and confirmation should be made in the return email that all details have been checked against DonorPath and the Organ Donor Outcome Summary Form. Track changes should always be used to ensure DFCS can see of any amendments made.
- 3.5.2. Once the letter has been returned to DFCS no further amendments or checks will be made by the SNOD and final checks will be completed by the DFCS and the letter sent to the donor family.
- 3.5.3. The DFCS will allow 48 hours for the checking and amendment of family letters. **If no response is received within the timeframe a Team Manager will be notified for advice.**
- 3.6. 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. There may be occasions when a card is not available, SNOD's may on this occasion write a note to the family in the body of an email and send to the DFCS who will transcribe the SNOD's message into a blank greetings card and send to the family on their behalf.
- 3.7. The greetings card must be sent back to the DFCS in the returned donor file. The DFCS 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 or if they intend to email a message to the family via the DFCS.
- 3.8. 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.
- 3.9. All family letters will be written by the DFCS and sent to the SNOD for checking prior to sending. It is the DFCS's & SNOD's responsibility to check spelling, grammar and addresses as well as the content of the letter against the organ outcome summary and DonorPath.

- 3.10. If the DFCS are unsure of the detail of the donation e.g. if multivisceral or novel donations, then they will contact the lead SNOD for advice.

## 4. Keepsakes

- 4.1. Keepsakes should be routinely offered to all families and materials will be provided in the donor file. Materials provided by the DFCS will consist of: Handprint paper x 2, Inkless wipe x 1, Organsor bag x 5, ribbon x 5, and 1 keepsakes folder.
- 4.2. Photocopies / [Genius Scan](#) 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 DFCS in the A4 envelope provided in the donor file which should be clearly labelled with three points of Donor ID. The DFCS will ensure that keepsakes are sent on to the family or dispose of them within 15 working days if no longer required.
- 4.3. Hair locks must be placed in the envelope provided.

## 5. Writing to Professionals Following Organ and/or Tissue Donation

- 5.1. As part of the donation follow up, the SNOD may wish to write a donation outcome letter to [hospital](#) department(s) involved in the donation process. SNODs must communicate to the DFCS using the hospital contact section on donor path and state clearly the person's name and department. If there are multiple staff members in the department, they will be named in one letter which will be sent to the [hospital](#) department. A member of the DFCS will write the letter and send to the SNOD for checking prior to sending.
- 5.2. [On occasions the SNOD may wish to write to professionals outside of the hospital who has provided support to the family or donation process. On these occasions the SNOD will be required to draft the letter and inform DFCS that a letter has been sent.](#)
- 5.3. Professionals will not receive more information than that contained within the family letter.
- 5.4. Should the family not wish to receive follow up information then professionals must not receive the information. The DFCS may write to professionals to explain the reasons for this if requested to do so by the SNOD.

## 6. Longer Term Follow Up for Donor Families

- 6.1. Additional follow up will not be routinely sent to families. After 6 months, should further follow up be requested from a family, then the DFCS will facilitate this.
- 6.2. The DFCS 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.

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## 7. Donor Family and Recipient Communication

- 7.1. 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.
- 7.2. Should a donor family wish to write to a recipient or respond to a letter from a recipient, **INF995** should be sent from the DFCS to the family with a covering letter.
- 7.3. Any letters that are received from donor families or recipients will be scanned by the DFCS and a copy placed in the donor files.
- 7.4. 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.
- 7.5. Any correspondence must be anonymised and comply with **INF995**.
- 7.6. 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 DFCS will communicate back to the RCPoCs informing them of the reason for not forwarding the letter on. Any correspondence received in the DFCS will be forwarded within 30 working days.
- 7.7. 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.
- 7.8. If family members and recipients wish to disclose their contact details to each other to communicate directly, that disclosure must be made with mutual agreement, and discussion with the lead SNOD and RCPoC.
- 7.9. If a recipient letter or card is received to forward to a donor family, the DFCS will cross check against the donor file and outcome summary to ensure that the correct family receive the communication. DFCS will check the donor file to ascertain if the donor family are happy to receive further communication as per **SOP5049**.
- 7.10. 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.
- 7.11. On occasions donor and recipient families may wish to meet. NHSBT staff, along with RCPoCs will need to provide support to facilitate the meeting.
- 7.12. Recipient correspondence can be received via post directly into the DFCS, sent in via their RCPoC or also sent in directly via [transplant.recipientcare@nhsbt.nhs.uk](mailto:transplant.recipientcare@nhsbt.nhs.uk). The Lead Nurse Family Aftercare and Lead Nurse Recipient Coordination will be responsible for monitoring the transplant inbox for any correspondence received and ensuring it is actioned as appropriate. It is important to note that all members of the multidisciplinary team from both the Donor Family and Recipient perspective

review the appropriateness of correspondence ensuring anonymity, and content (including photographs) to ensure no distress is caused to either party. It is the RCPoC's responsibility to discuss anything contained in the correspondence that is felt inappropriate directly with the recipient and NHSBT will discuss anything inappropriate with the donor family. All communication should be clearly documented within donor path sequence of events or within the historic donor file.

## Definitions

- None

## Related Documents / References

- **POL191** – Guidance for consent for solid organ transplantation in Adults
- **FRM5499** – SNOD to DFCS 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** – DFCS Process Manual
- **DAT2792** - Recipient Centre Point of Contact – List of email addresses
- **BTS Guidance** <http://www.bts.org.uk/Documents/Consent>