

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

Section 2: Interpreter required to communicate to families regarding Organ Donation process added, replacing obsolete SOP5017.

All references to 'SNOD' changed to 'SN', and 'Team Manager (TM)' changed to 'Lead Nurse (LN)' and Wording added to 3.6 and 3.8 to clarify NP family pins and cert/letter process

CR59734 – template letter details in red text

CR58753 – details added re DF bereavement support and DF website

CR58752 – new family feedback process added

CR62023 – update staff letters process

CR57050 – Change of 'Organ Donor Outcome Summary' to 'Organ and Tissue Donor Outcome Summary' throughout document.

CR55843 – Added description of time to correspondence.

Roles

SN – (Specialist Nurse) - for the purposes of this document the terminology 'SN' will apply to Specialist Nurse in Organ Donation, and SR (Specialist Requestor) whom have the relevant knowledge, skills and training in organ donation, working within NHSBT Organ Donation Services Teams (ODST).

- To work to this MPD and to seek advice, where required, from the **Lead Nurse (LN) / Organ Donation Management Team (ODMT) on call** 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 **SNs** for checking.
- To send any correspondence to the lead **SNs** for checking, where necessary, prior to sending.
- To facilitate ongoing communication between **SN** & families.
- To facilitate the provision of keepsakes to families in conjunction with the lead **SN**.

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

- 1.1. The SN 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) **over years, if not months** - 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. Interpreter required to communicate to families regarding Organ Donation

- 2.1. Ascertain if interpretation services are available in the local hospital trust.
N.B. This should be the preferred option to use if available.
- 2.2. If no local interpretation service available, contact Language Empire telephone interpretation service using the number below and refer to the user guide attached.
- 2.3. Voice recording facility **MUST** be used when accessing the telephone interpretation service as per **SOP3649**, if unable to voice record please ensure the conversation is witnessed.
- 2.4. SNs / DFCS can call Language Empire for on demand telephone interpretation by calling 0333 188 3728 and following the operators' instructions and using the NHSBT log in details below:

Account No: NHS88242

User Name (On-Demand PIN): 75909000

Password: MnxJ3497+

- 2.5. To make a translator booking for a later time and date, you must use the Language Empire online booking portal, which can be accessed at www.language-empire.co.uk and follow the points below:

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- Enter all the details of the requested booking time, then press next.
 - Select link 'If you need to access the booking portal, please click here'
 - Log in with Account Number, User Name and Password as detailed above in section 1.4
 - In the left panel of the portal, select the interpretation service you require to book:
 - Face-to-Face Spoken Booking (e.g. Polish, Kurdish, Arabic, Czeck etc.)
 - Face-to-Face Non-Spoken Booking (e.g. BSL, Lip speaking, Sign language)
 - Schedule Telephone booking
 - **(For Schedule telephone booking only)** Select the option to use the Language Empire Telephone Platform – Number to access interpretation booking is 0330 053 2650.
 - The organisation and purchase order number are prepopulated for the NHSBT professional user.
 - Select which ODT region you are requesting the translation service for from the drop-down menu. Enter all your details as required, then press next.
 - **(For Face-to-Face booking only)** Enter the details of the professional who will be involved in the discussions and select what post code region the hospital is within, and select the hospital from the drop-down box for the address, then press next
 - Complete the details of the service user information who will be receiving translation, the language interpretation required and complete all required fields. Detail a summary of the nature of the booking or additional information, then press next.
 - Answer the final questions about the booking preferences, then press Finish and confirm the booking (you will receive a confirmation email with instructions to join the Telephone booking or regarding attending interpreter).
- 2.6. If there are any issues with the Language Empire Online Portal, or you need telephone support in booking, please contact their 24-Hour Customer Services Support Line on 0330 20 20 270 (in the event these numbers are not working, please try 01706 398789).
- 2.7. Document in DonorPath.

3. Follow Up for Families

- 3.1. The SN must ensure to pass on their name and the DFCS contact details to the patient's family.
- 3.2. Families must be offered a telephone call at the end of the donation process to inform them of the immediate outcome. The SN should agree a convenient time and confirm the telephone number.
- 3.3. SNs 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.
- 3.4. **FRM5499** must be completed and sent to the DFCS within 24 hours of the donation.

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- 3.5. 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 SN 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.
 - 3.6. Families of proceeding donors and non-proceeding tissue donors will be sent a gold heart pin badge and certificate of recognition from the OTDT Director within 2 working days of the donation (sent by the DFCS).
 - 3.7. The SN 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.
 - 3.8. Families of consented / authorised non-proceeding donors will be sent a personalised letter of thanks from the OTDT Director within 2 working days, and a gold heart pin badge where requested (sent by the DFCS).
 - 3.9. The SN must offer the family an outcome information letter, or a letter of thanks. This will be sent within 15 working days of the donation.
 - 3.10. 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.
 - 3.11. If the letter needs translating into a different language, the SN must identify which language the letter needs to be translated into and document this on DonorPath and in the Family Letter section of FRM5499.
 - 3.12. 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.
 - 3.13. Some families may wish to have outcome information available for the funeral and this should be facilitated where possible.
 - 3.14. In the cases of tissue only donation, the SN 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.

4. 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.

- 4.1. All initial donor outcome information will be received by the DFCS directly from Hub Operations on the [Organ and Tissue Donor Outcome Summary](#) reports.
- 4.2. Only the information given in the [Organ and Tissue Donor Outcome Summary](#) (excluding geographical location) will be included in the letter to the family in line with **POL191**.
- 4.3. Any personalisation that the SN 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.
- 4.4. The DFCS will forward the first draft of the family letter to the [lead SN and all SNs involved](#), [recorded on the SN to DFCS handover](#), with all variable donor details such as name/relationship [highlighted in red text to prompt the SN to check this detail](#). It is the lead SNs responsibility to allocate the checking to a colleague if they are unavailable and notify the DFCS.
- 4.5. On receipt of the drafted letter from the DFCS the SN should ensure the following details are checked against DonorPath and the [Organ and Tissue Donor Outcome Summary](#).
 - Next of kin name (DonorPath)
 - Next of kin address (DonorPath)
 - Donor Name (DonorPath)
 - Donor Gender (DonorPath)
 - Organs Transplanted ([Organ and Tissue Donor Outcome Summary](#))
 - Recipient gender, age (decade) and time on waiting list ([Organ and Tissue Donor Outcome Summary](#))
 - Organs not transplanted and reason ([Organ and Tissue Donor Outcome Summary](#))
 - Tissue outcome (DonorPath Sequence of Events and [Organ and Tissue Donor Outcome Summary](#))
- 4.5.1. Once the lead SN 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 and Tissue Donor Outcome](#)

Summary. Track changes should always be used to ensure DFCS can see any amendments made and the key populated details must remain in red text for further review and finalising by the DFCS.

- 4.5.2. Once the letter has been returned to DFCS no further amendments or checks will be made by the SN and final checks will be completed by the DFCS and the letter sent to the donor family.
- 4.5.3. The DFCS will allow 48 hours for the checking and amendment of family letters. If no response is received within the timeframe a Lead Nurse (LN) will be notified for advice.
- 4.6. A blank greetings card will be included in the donor pack. The SN(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, SNs 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 SNs message into a blank greetings card and send to the family on their behalf.
- 4.7. 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 SN 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.
- 4.8. It is the SNs' 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.
- 4.9. All family letters will be written by the DFCS and sent to the SN for checking prior to sending. It is the DFCS's & SNs' responsibility to check spelling, grammar and addresses as well as the content of the letter against the Organ and Tissue Donor Outcome Summary and DonorPath.
- 4.10. If the DFCS are unsure of the detail of the donation e.g. if multivisceral or novel donations, then they will contact the lead SN for advice.

5. Keepsakes

- 5.1. 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, Organza bag x 5, ribbon x 5, and 1 keepsakes folder.
- 5.2. 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.
- 5.3. Hair locks must be placed in the envelope provided.

6. Writing to Professionals Following Organ and/or Tissue Donation

- 6.1. As part of the donation follow up, the SN may wish to write a donation outcome letter to the hospital department(s) involved in the donation process. SNs must document staff email address(es) in the hospital contacts section on DonorPath. A member of the DFCS will write one letter addressed to the hospital and send to the SNs for checking prior to sending.
- 6.2. Once finalised, DFCS will send the staff letter as a PDF, via email, to Lead SN, SNs involved in donation and the embedded SN, using covering email template.
- 6.3. It is the embedded SNs responsibility to disseminate the staff letter via email to the donor hospital CLOD and any relevant colleagues identified in the hospital contacts section on DonorPath. This allows each region to share with wider departments and colleagues as appropriate within their hospital.
- 6.4. On occasions the SN may wish to write to professionals outside of the hospital who has provided support to the family or donation process. On these occasions the SN will be required to draft the letter and inform DFCS that a letter has been sent.
- 6.5. Professionals will not receive more information than that contained within the family letter.
- 6.6. Should the family not wish to receive follow up information then professionals must not receive the information. The DFCS will write a limited information letter to explain the reasons for this to healthcare professionals.

7. Longer Term Follow Up for Donor Families

- 7.1. 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.
- 7.2. 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.

8. Donor Family and Recipient Communication

- 8.1. 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.
- 8.2. 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.

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- 8.3. Any letters that are received from donor families or recipients will be scanned by the DFCS and a copy placed in the donor files.
 - 8.4. 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.
 - 8.5. Any correspondence must be anonymised and comply with **INF995**.
 - 8.6. 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.
 - 8.7. There are occasions when a **SN / Lead Nurse (LN)** 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 **SN / Lead Nurse (LN)** 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.
 - 8.8. 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 **SN** and RCPoC.
 - 8.9. If a recipient letter or card is received to forward to a donor family, the DFCS will cross check against the donor file and **Organ and Tissue Donor 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**.
 - 8.10. 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 **SN** for review along with a copy of the recipient letter as per **SOP5049**. The lead **SN** will be informed that it has been sent.
 - 8.11. On occasions donor and recipient families may wish to meet. NHSBT staff, along with RCPoCs will need to provide support to facilitate the meeting.
 - 8.12. 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. 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.

9. Donor Family Feedback

- 9.1. The Specialist Nurses and Donor Family Care Service are committed to providing every family with the best care possible throughout the donation journey; both during and after. All donor families are given the opportunity to share with us what went well, what we could have done differently, and any thoughts they might have about ways we can improve to help families.
- 9.2. **DFCS Process** – SOP5049 DFCS Manual
Timescale – Families will be sent information on how they can feedback within 15 working days of donation/consent or authorisation, along with the initial outcome letters. They will also be advised that they can give feedback on their experience at any time.
Applicable documentation:
 - FRM4430** – Family Feedback form (paper version)
 - INF1659** – DFCS Information Leaflet
 - INF1675** – DFCS Information Leaflet
- 9.3. All proceeding and non-proceeding donor families (who have agreed to correspondence) will be sent a DFCS information leaflet with the initial family outcome letter or pins. Donor families can also be guided to complete the feedback form at any time following donation via either the website (<https://www.nhsbt.nhs.uk/donorfamilycare>), phone or the paper form.
- 9.4. Should a donor family require assistance in completing the family feedback form, electronically, via phone or paper, DFCS will escalate to the DFCS management team for support.
- 9.5. Any donor family feedback received (via telephone, email or letter) highlighting satisfaction or dissatisfaction should be escalated to a Lead Nurse (LN) for awareness and action.
- 9.6. All feedback via the family feedback form will be highlighted, upon receipt, to the Service Lead - Donor Family Care who will share with relevant Lead Nurse (LN) s within 3 working days. Lead Nurse's (LN) s are responsible for review and shared learning with the regional organ donation teams and disseminating any Trust related feedback to donor hospitals as appropriate.
- 9.7. Lead Nurses (LN) are responsible for managing any complaints or compliments (C+C), via the appropriate Clinical Governance process; C+C User Guide (SOP6005) or Incident Investigation User Guide (SOP5778). This must be documented on DonorPath sequence of events.
- 9.8. All family feedback relating to the DFCS will be shared with the DFCS management team who are responsible for sharing with the DFCS team and managing any C+C via the appropriate Clinical Governance process; C+C User Guide (SOP6005) or Incident Investigation User Guide (SOP5778). This must be documented on DonorPath sequence of events.
- 9.9. Feedback will be collated by the Service Lead – Donor Family Care who will review responses, trends and satisfaction rates, providing reports to SMT where requested.

10. Donor Family Post Donation Support

- 10.1. **INF1659** and **INF1675** - DFCS Information Leaflet provides information on the DFCS and post donation family services available. This leaflet will be sent to all families with initial outcome letters or pins when a letter is not required.
- 10.2. **Donor Family Website** - our bespoke donor family website provides a wealth of information about various aspects, from The Order of St John UK Award for Organ Donation, contacting recipients, bereavement support and answers about the donation pathway. Families can be signposted to the website via the link <https://www.nhsbt.nhs.uk/donorfamilycare>
- 10.3. **Sue Ryder Online Bereavement Support** is a bereavement charity UK wide, offering a number of services that donor families can access such as an online bereavement community and qualified counselling sessions. The details of Sue Ryder support, and a number of other signposts can be found via “Further Support and Guidance - Support Services” on the Donor Family Website: <https://www.nhsbt.nhs.uk/987643testarea/987/donor-family-care-service-wip/further-support-and-guidance/>

Definitions

- None

Related Documents / References

- **POL191** – Guidance for consent for solid organ transplantation in Adults
- **FRM5499** – SNOD to DFCS handover form
- **INF995** - Information for families who wish to write to transplant recipients.
- **INF1659** – DFCS Information Leaflet
- **INF1675** – DFCS Information Leaflet
- **FRM4430** – Donor Family Feedback Form (paper version)
- **SOP5049** – DFCS Process Manual
- **DAT2792** - Recipient Centre Point of Contact – List of email addresses
- **BTS Guidance** <http://www.bts.org.uk/Documents/Consent>
- **SOP3649** – Voice Recording of Organ Donor Clinical Conversations
- **SOP6005** – Complaints and Compliments User Guide
- **SOP5778** – ODT – Incident Investigation User Guide