

# MANAGEMENT PROCESS DESCRIPTION MPD598/6

## Management of The Deceased Donor Family Donation Conversation (Scotland)

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This Management Process Description replaces  
MPD598/5

**Copy Number**

Effective

**13/01/2021**

### **Summary of Significant Changes**

Rewrite of the entire document.

### **Policy**

The Quality and Safety of Organs Intended for Transplantation Regulations (2012) state that the procurement of organs and tissue shall be carried out only after all requirements relating to consent, authorisation or absence of any objection in force in the Member State concerned have been met.

### **Purpose**

The purpose of this document is to give guidance on practice when discussing the option of organ, tissue and/or research donation with the patients nearest relative and to ensure valid authorisation for organ and tissue donation (Human Tissue (Scotland) Act 2006). The document aims to ensure that the principles of communicating effectively with families during the donation conversation are consistently applied.

### **Responsibilities**

This MPD is to be utilised by qualified and trained SN-OD/SRs. If the SN-OD/SR is in training, this MPD is to be utilised under supervision.

The SN-OD/SR is responsible for planning the approach with the medical practitioner and nurse responsible for the patient, to offer the option of organ and/or tissue donation and support the nearest relative in making an informed decision.

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#### *Definitions*

**MPD** – Management Process Description

**Nearest relative** – For the purpose of this document ‘nearest relative’ refers to the nearest relative, and significant others of the patient including a friend of longstanding. This may be different to the next of kin the hospital has identified.

**SN-OD** – Specialist Nurse – Organ Donation with the relevant knowledge, skills and training in organ donation, working within NHSBT Organ Donation Services Teams (ODST).

**SR** – Specialist Requestor

**Medical Practitioner** – Clinician responsible for the care of the patient in the critical care area.

**ODT** – Organ Donation & Transplantation, a directorate of NHS Blood and Transplant

**HCP** – Healthcare professional

**DRD** – Donor Records Department

**DNC** (Death by Neurological Criteria) - This term refers to the donor that has been certified dead using neurological criteria

**DCD** (Donation after Circulatory Death) – This term refers to the donor that has been certified dead using cardio-respiratory criteria

**ODR** – Organ Donor Register

**Patient** – This term is used throughout and refers to the donor/potential donor

**In this document the terms ‘must’ and ‘should’ are used in the following ways:**

**‘Must’** is used for an overriding duty or principle.

**‘Should’** is used when we are providing an explanation of how you will meet the overriding duty.

#### *Applicable Documents*

**POL180** - Management of Microbiological Blood Results in Deceased Organ/Tissue Donors

**MPD845** – Family Care

**MPD865** – Obtaining Coroner/Procurator Fiscal Decision

**MPD1131** - Donor microbiology – Role of the SNOD and family contact

**SOP3817** – Access for SNODs and other approved users to the NHS Organ Donor Register (ODR)

**SOP5563** - Authorisation for the Removal and Storage of Specific Organ/Tissue/Samples for Research and Other Purposes

**SOP3632** – General Practitioner Assessment

**SOP3649** – Voice Recording of Organ Donor Clinical Conversations

**FRM1538** – Authorisation – Solid Organ and Tissue Donation

**FRM1602** – General Practitioner Medical Report for Organ/Tissue Donation

**FRM4039** – NHSBT referral for Coroner/Procurator Fiscal

**INF1235** – Research Leaflet (Scotland)

**FRM4154** – Retraction of Patient Authorisation by Nearest Relative

**Human Tissue (Scotland) Act 2006**

<https://www.legislation.gov.uk/asp/2006/4/contents>

**Children (Scotland) Act 1995**

<http://www.legislation.gov.uk/ukpga/1995/36/contents>

**The Human Tissue (Quality and Safety for Human Application) Regulations 2007**

<http://www.legislation.gov.uk/uksi/2007/1523/contents/made>

**The Quality and Safety of Organs Intended for Transplantation Regulations 2012**

<http://www.legislation.gov.uk/uksi/2012/1501/contents/made>

**Adults with Incapacity (Scotland) Act 2000**

<https://www.legislation.gov.uk/asp/2000/4/contents>

**NOTE**

The SN-OD/SR using this MPD must ascertain, prior to undertaking the nearest relative conversation, if the patient has registered a donation decision on the Organ Donor Register (ODR). In the absence of a registered decision the SN-OD/SR must ascertain through discussion with the nearest relative if the patient made a decision known via a donor card/expressed decision/Will. Wherever possible / practicable, any written evidence e.g. the organ donor card or Will should be sought to check specific requests for donation. Oral evidence is equally valid.

If following these discussions, the decision of the patient is not known the SN-OD/SR must establish who the nearest relative of the patient is, in order to discuss the donation information along with information in section 4 below pertaining to issues such as research, disposal and microbiological screening.

If there is no known patient decision and no nearest relative or friend of longstanding exists to provide authorisation, the SN-OD/SR should discuss this with the Team Manager (TM)/geographical Regional Manager (RM)/On-Call RM as donation may not be able to proceed.

The SN-OD/SR needs to balance the full detail contained in this MPD with the needs of the nearest relative, in terms of what level and type of information they require. Best practice information should be discussed with the nearest relative wherever possible.

Where the patient has registered their decision to donate organs / tissue for transplantation and no nearest relative exists, it is lawful for donation to proceed. As it is not possible to obtain authorisation for other purposes other than transplantation, no organ/tissue including samples for tissue typing may be stored for more than 48 hours and the clinicians/laboratories involved need to be made aware of this prior to donation and transplantation.

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#### 1 Organ and Tissue Donation – Nearest Relative Conversation

A face-to-face conversation should be conducted in a quiet and private area. It is recommended best practice to have another healthcare professional witness the conversation where possible. If the conversation is conducted by telephone, refer to **SOP3649**.

- 1.1. The SN-OD/SR must ascertain if the patient is registered on the ODR prior to approaching the nearest relative utilising **SOP3817**, and inform the nearest relative if the patient has registered a decision to donate.
- 1.2. If the patient has registered a decision NOT to donate and the nearest relative states that the patient had changed their mind, the nearest relative must fully discuss any evidence they believe demonstrates the patient would have changed their mind and been willing to be an organ and/or tissue donor. If this information is more recent than the registration, then this will supersede their recorded decision not to donate.
- 1.3. If the patient has registered authorisation for organ/tissue donation on the ODR: Inform the nearest relative specifically which organs / tissue the patient has given authorisation for. Discuss the intention to proceed with the donation for transplantation. If the nearest relative wishes verification of this the SN-OD/SR can provide a copy of the registration. It may be helpful to invite the family to view the short ODT video which helps explain the donation process in a simple animated format.
- 1.4. When the ODR print out displays 'not stated', this is when the registrant has not been presented with all options: for example: the DVLA do not ask for small bowel and tissue authorisation. So, for the individual organ preferences: 'yes' means authorised, 'no' means they have been asked, but did not want to donate that organ/tissue, 'not stated' means they have not been asked/presented with the option. Therefore, 'not stated' does not equate to authorisation, nor is it an indication that they do not wish to donate organ or tissue. 'Not stated' is a discussion point to be explored with relatives.
- 1.5. If patient is not on the ODR: Proceed to seek authorisation from the patient's nearest relative as detailed in section 2.
- 1.6. Introduction to the nearest relative
  - Introduce yourself (or be introduced by clinician) offer hand shake saying you are a specialist nurse caring for families in similar situations and you are there to provide information and offer support.
- 1.7. Extend sympathy.
- 1.8. Offer refreshments / facilities e.g. telephone.
- 1.9. Check the nearest relative understands the current situation and address their questions and needs before proceeding further.
- 1.10. If it is known that a post mortem is required, the nearest relative should be made aware that there will be surgery to the body.

#### Note

**Do not move on with the interview until the nearest relative has a full understanding of what has happened and that their loved one has died or that the decision to withdraw treatment has been made.**

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#### 2 Conversation with nearest relative if patient is not on the ODR

The following conversation aims to ascertain any known decisions of the patient not registered on the ODR, and in the absence of confirmation, establish authorisation from the appropriate individuals.

Section 7 (3) of the Human Tissue (Scotland) Act 2006 allows for the nearest relative to authorise the removal of 'body parts' where not self authorised provided that they have no actual knowledge that the person would have been unwilling for those 'body parts' to be used for transplantation.

- 2.1. Open the conversation, explain that the discussions you are about to have are to explore the opportunity for donation for transplantation and explain that you are going to give them some information about this.
- 2.2. Explain that, following the giving of information, the appropriate individuals may want them to ask questions. It may be helpful to offer the ODT animated video clip.
- 2.3. Explain that after you have given the information and answered their questions, they can tell you if they know of any discussions or decisions the patient made and, in the absence of those, what they would like to do next.
- 2.4. Enquire if there are any specific organs or tissue they or their loved one may have considered for donation.
- 2.5. Explain that this is a private decision and you will support them in whatever decision they make.
- 2.6. Explain that whatever decision they make, the funeral arrangements will not be affected and that they will still be able to see their loved one after donation.
- 2.7. Give information listed in section 3 and 4 below, use section 6 if needed/requested.
- 2.8. Explain that you will get the necessary documents, agree next steps discussing the option of first contacting the patients GP and sending donation bloods prior to completing the paperwork.
- 2.9. Offer refreshments / facilities at this point
- 2.10. Prepare documentation. Initial any organs / tissue that are outside the donation criteria or that the PF has refused permission for (refer to **MPD865**).
- 2.11. Confirm authorisation and ask the appropriate person to sign the authorisation form. SN-OD/SR to complete **FRM1538** and offer a copy to the nearest relative. Ensure family are aware that whoever signs the authorisation form will be the main contact for future communications e.g. St John Scotland, recipient letters.
- 2.12. SN-OD/SR and HCP witness (where applicable) also sign the authorisation form.
- 2.13. Continue to provide reassurance to the nearest relative.
- 2.14. If donation cannot proceed the nearest relative should be thanked for their time. The decision should be documented in the medical records (**MPD845**).
- 2.15. If the donor is found to be medically unsuitable it is necessary to explain to the nearest relative the rationale for the deferral in clear and understandable terms. In the case of a positive microbiological result this situation should be dealt with in accordance with **MPD1131**. Thank the nearest relative for considering the option of donation at such a difficult time.

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- 2.16.** If the patient is an adult Welsh resident and had not lacked capacity for a significant period prior to their death, the donation conversation should be presumptive in favour of donation where a registered donation decision has not been made. Acknowledging that if the patient had died in Wales deemed consent would be applied, but as they had died in Scotland the patient's authorisation could not be deemed.

### **3 Information about organ recovery which may be useful to communicate with the nearest relative**

- 3.1.** Explain that a team of specialists will attend the hospital and that the operation is performed in the same manner as any other procedure.
- 3.2.** Explain that their loved one's body is treated with respect and dignity and any cultural or religious requests can be carried out.
- 3.3.** Explain that yourself or a colleague will be present throughout the procedure.
- 3.4.** Explain that there will be a long body incision that will be closed and dressed after donation.

### **4 Best practice information – to be discussed with all families of solid organ and/or tissue donors**

The following information **should** be given to all families and it is best practice where possible to have a HCP witness present. Whilst this information is listed here together, it is reasonable for the SN-OD/SR to deliver this information throughout the course of their conversation with the nearest relative, according to their cues.

- 4.1.** If the conversation is to be voice recorded, the SN-OD/SR must give a full explanation of the conversation procedure including the order of the process. In the case of "Voice Recording failure", then the SN-OD/SR must have another healthcare professional witness the call in line with **SOP3649** – Voice Recording of Organ Donor Clinical Conversations. The nearest relative must be informed that the conversation is to be recorded or the call witnessed.
- 4.2.** Explain which organs/tissue may be possible for the patient to donate for transplantation. Explain individual benefits.
- 4.3.** If the patient has not registered a decision in life, explain that once authorisation for the purposes of transplantation has been given then it is unlawful to retract that decision.
- 4.4.** If the patient has registered a decision in life to donate, explain that, once authorisation has been given for donation for the purposes of transplantation then it would be unlawful to retract this decision (see Section 7). Withdrawal for research, education and training and audit must be in writing.
- 4.5.** Where tissue donation is being considered explain that tissue will be prepared for transplant and can be stored for a prolonged time in tissue establishments. Where applicable explain to the nearest relative, that the body may be transferred to another NHS facility for the tissue donation procedure to take place. They also need to be told following tissue donation that they will be transferred to the mortuary.
- 4.6.** Explain that if organs/tissue are donated for transplantation, there may be circumstances where they cannot be used e.g. if a potential recipient becomes unwell or because of a significant finding at recovery.

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- 4.7. Explain that in these circumstances, the organ/tissue may be used for research, education, training, and audit. A copy of **INF1235** must be offered. Research restrictions, such as animal testing, DNA testing and commercial research should be discussed with the family and their decision documented on **FRM1538** and on DonorPath. If the nearest relative does not authorise this, the organ/tissue will be disposed of in a safe and lawful manner as per hospital/tissue establishment policy.
- 4.8. Explain that, where appropriate, there may be an opportunity to donate organs/tissue/samples purely for research. Heart, lung and diabetic pancreas may be removed if not suitable for transplant.. (Please refer to **SOP5563** for specific inclusion criteria). If the family agree to this explain that they will be updated as to which organs were placed for research by telephone or in the donation outcome letter.
- 4.9. If appropriate approach for any approved centre specific licensed studies.
- 4.10. Organs/tissue may be removed for specifically approved research projects. A full written description of each research project should be offered to the nearest relative by providing a Relative Information Leaflet (RIL). If authorisation is given for research use, explain that following the completion of research projects, all remaining organs/samples are disposed of in a safe and lawful way in accordance with local hospital/tissue establishment policy. Ensure any research restrictions are noted and documented as per section 4.7.

If the family require more information, the following statement may be useful:

*“NHSBT supports the removal of organs for scheduled purposes, to improve and advance healthcare including transplantation, helping us develop new treatments in the UK and worldwide.*

*Donated organs are treated with the utmost respect by the researchers.*

*With your authorisation, we will approach researchers and tissue/bio banks who wish to receive these organs for their studies. Organs will only be removed if they are accepted for a research study. We won't be able to remove organs if we don't proceed to theatre.*

*There are occasions where we are unable to remove organs for research due to logistical reasons. We will update you of the donation outcome of the organs you have consented for removal for research, either via a telephone call or in the donation outcome letter.”*

- 4.11. Explain that contact details will be stored in the strictest confidence by DRD and that on occasion information may be passed on a need-to-know basis to other healthcare professionals in support of the transplantation process.
- 4.12. Explain that the General Practitioner and any other relevant health professional has been/will be contacted for information about the medical history of the patient.
- 4.13. Explain that blood sample will be taken to test for tissue typing (solid organ donation only), relevant microbiological testing and pregnancy (where appropriate) and that any remaining samples will be stored and may be used for future testing.
- 4.14. In the case of potential paediatric donors, if the patient is under 18 months of age or has been breast-fed in the last 12 months explain that a blood sample will be required from both the mother and child and authorisation for this is required.

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- 4.15. Explain that if any test result is deemed to have significance for the health of the nearest relative/next of kin, they will be contacted and offered the appropriate advice.
- 4.16. Explain that there is a requirement for other tissue to be retrieved, stored and used in support of organ transplantation e.g. lymph nodes and spleen for cross matching, blood vessels and blood.
- 4.17. Specific blood vessels may be required for tissue transplant. Authorisation should be taken from the nearest relative at this time. Any know specific requests for such vessels can be discussed with the nearest relative.
- 4.18. Where applicable explain to the nearest relative that the body may be transferred to another NHS facility for the tissue donation procedure to take place. They also need to be told following tissue donation that they will be transferred to the mortuary.
- 4.19. In the case of DCD explain to the nearest relative the timeframe involved following the withdrawal of active treatment and the beginning of the surgical procedure which impacts on the time they can spend with the patient immediately after death.
- 4.20. Explain that the nearest relative will be able to see their loved one after the donation if they wish. Depending on their wishes, explain the potential appearance of the body. For example, pallor and temperature, and in the case of eye donation possible discolouration/puffiness around the eyes.
- 4.21. Ascertain whether the nearest relative would like to receive information about the outcome of the donation and explain timeframes involved in this.
- 4.22. Ensure that the nearest relative is offered DRD contact information.
- 4.23. If tissue donation has not been authorised on the ODR, explain that it is still possible to remove the heart for donation of the valves where authorisation for heart donation is given.

## 5 Providing Information about the Tissue Donation Process to Families

- 5.1. The SN-OD/SR should provide clear and accurate information about tissue as required by the nearest relative, for example– always starting with the eyes:

### Cornea

*“The cornea is the clear, front part of the eye. It’s just like a contact lens and it’s the part of the eye the contact lens sits on. It sometimes gets so scarred or damaged it needs to be replaced. The cornea is fragile so the whole eye is removed to protect it, and a protective cap is placed under the eyelid and the lid closed restoring appearance. The person doing the removal would be someone who is specially trained, highly skilled and has a lot of experience. It is of course, a sterile procedure like other operations and it only takes a matter of minutes. Occasionally there may be some puffiness or discolouration.”*

### Heart Valves

*“It may not be possible to transplant the heart in its’ entirety, but the valves can be transplanted into two people. The entire heart will be removed from the chest and the chest closed, just like in any other operation.”*

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#### 6 Further information to be shared with families

The information below does not form part of the best practice information that should be given to every nearest relative when establishing authorisation. However, depending on the individual cues and questions they ask, it may be appropriate to explain to them that:

- 6.1 The patient will be examined to ensure the safety of the recipient of the transplant and this may include biopsy.
- 6.2 At this point and throughout the interview process it is vital to answer any questions the nearest relative may have.

#### 7 Confirmation of Authorisation

- 7.1. The SN-OD/SR must check at each stage that the nearest relative has understood the information that has been given to them. If the SN-OD/SR is faced with family discord it is therefore helpful for the SN-OD/SR to correct any misunderstandings.
- 7.2. If the SN-OD/SR speaks it must only be to correct misunderstandings, to emphasise the last decision and to refocus onto the patient. This could be discussed with TM/RM/On Call Regional Manager. All discussions / decisions must be documented on **FRM1538**.

#### 8 Retraction of Authorisation

- 8.1 If the patient had made a decision to donate (written /verbal) in life but the nearest relative does not wish to support this, they must be advised clearly that it is unlawful to retract the decision of the patient in the hope that the nearest relative then upholds the patient's decision. A retraction decision should be documented in **FRM4154** and a copy placed in the medical records. Withdrawal for research, education and training, and audit must also be in writing using **FRM4154**.
- 8.2 Following completion of the authorisation process (whether by patient or nearest relative), the nearest relative should be informed that retraction for transplant is now not legally permissible. Withdrawal for other purposes such as research, education and training and audit would still be possible. The nearest relative would be required to put their retraction in writing, utilising **FRM4154**. If the nearest relatives retracts authorisation for transplantation in the knowledge that this is not supported by law, **FRM4154** should be completed by the SN-OD/SR with the nearest relative ensuring that they understand that this is a legal requirement.

#### 9 Medical and social history assessment of patients being considered for donation – to be discussed with all families of solid organ and/or tissue donors

- 9.2. Explain:
  - In order to assess which organs/tissue can be safely donated, that it is necessary to ask some questions about the patient,
  - Some questions are of an intimate nature and are not meant to cause offence,
  - These questions are asked about all patients where donation is being considered and that they are similar to the questions asked of those donating blood.
- 9.3. The SN-OD/SR must check who the most recent sexual partner is to provide more intimate information. This can be more than one person and, wherever possible, the SN-OD/SR should conduct the interview with each partner. In the case of a positive microbiological result the SN-OD/SR should be guided by **POL180**.

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- 9.4. The SN-OD/SR must complete DonorPath, detailing the relationship to the patient of those persons who provided the information.

#### 10 Establish personal requests of the nearest relative

- 10.1 It is the responsibility of the SN-OD/SR to update the nearest relative throughout the donation process.
- 10.2 Enquire about any religious/spiritual requirements of the patient with the nearest relative.
- 10.3 Establish the nearest relative's wishes for keepsakes e.g. locks of hair, handprints, fingerprints, heart in a bottle etc.
- 10.4 Determine whether the nearest relative wishes to assist with last offices following donation or wish their loved one to be dressed in certain items of clothing.

#### 11 Obtaining medical history from the General Practitioner

- 11.1. To enable assessment of suitability for donation it is necessary to make contact with the GP prior to donation. This process is outlined in **SOP3632**.