Management of The Deceased Donor Family Donation Conversation (Scotland)

This Management Process Description replaces MPD598/3

Copy Number

Effective **01/12/15**

Summary of Significant Changes

Guidance for the donation conversation when a Welsh resident dies in Scotland – section 2.19

Policy

The Quality and Safety 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 and/or tissue donation with the patient's family, 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-ODs. If the SN-OD is in training, this MPD is to be utilised under supervision.

The SN-OD 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 family in making an informed choice.

Definitions

MPD – Management Process Description

Patient Family – For the purpose of this document 'patient family' refers to the family, friends and significant others of the patient.

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

TM – Team Manager.

RM – Regional Manager.

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

MDT – Multi Disciplinary Team includes, the SN-OD/Medical Practitioner/ Nursing staff responsible for the care of the patient/Advocates/Counsellors and Local faith representative/s where relevant.

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

HCP – Healthcare professional

ODST – Organ Donation Service Team

DBD – This term refers to the donor that has been certified dead using neurological criteria

DCD – 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.

'Should' is also used where the duty or principle will not apply in all situations or circumstances, or where there are factors outside your control that affect whether or how you can comply with the document.

Applicable Documents

MPD577 – Management of Positive Microbiological Blood Results in Potential Organ or Tissue Donors

MPD845 – Donor Family Care

MPD865 – Obtaining Coroner/Procurator Fiscal Decision

MPD888 – Access to the Organ Donor Register

SOP3632 – General Practitioner Assessment

SOP3649 – Voice Recording of Organ Donor Clinical Conversations

FRM1538 – Authorisation – Solid Organ and Tissue Donation

FRM1602 – Fax - General Practitioner Medical Report for Organ/Tissue Donation

FRM4039 – NHSBT referral for Coroner/Procurator Fiscal

FRM4154 – Retraction of Patient Authorisation by Nearest Relative

Human Tissue (Scotland) Act 2006
http://www.legislation.gov.uk/asp/2006/4/contents

Human Tissue (Scotland) Act 2006 (Explanatory Notes)
http://www.legislation.gov.uk/asp/2006/4/notes/contents

Adults with Incapacity (Scotland) Act 2000
http://www.legislation.gov.uk/asp/2000/4/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
http://www.legislation.gov.uk/uksi/2012/1501/contents/made

FRM4211 – Patient Assessment Form (Deceased Tissue Donation) version

FRM4228 – Potential Donor Referral

INF953 – Conversation Guides for the Voice Recording of Clinical Information for Organ Donation

Nursing and Midwifery Council Advice Sheet on Record Keeping 2006
http://www.nmc-uk.org/Documents/NMC-Publications/NMC-Record-Keeping-Guidance.pdf

Data Protection Act 1998
http://www.legislation.gov.uk/ukpga/1998/29/contents

Note

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

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

Exceptions to this are documented in the Health Department Letter Scotland 46, as is further guidance.

Where no nearest relative is available to provide authorisation, the SN-OD should discuss this with the TM/geographical RM/On-Call RM as donation will not be able to proceed.

The SN-OD needs to balance the full detail contained in this MPD with the wishes of the family, in terms of what level and type of information they require. A best practice of minimum information should be discussed with the family. This best practice information is contained within the document in section 4.

Where the deceased has registered their wish to donate organs / tissue for transplantation and no family exist, it is lawful for donation to proceed. As it is not possible to obtain authorisation for storage, no organ / tissue including samples for tissue typing may be stored for more than 48 hours and the clinicians involved need to be made aware of this prior to donation and transplantation.

Also within the document there is 'reassuring' information which it is recommended should be discussed with the family should they wish to do so; this information is provided at the discretion of the SN-OD following cues from the family and does not need to be discussed with every family. For some families who request further detail all information within this document can be discussed.

Prior to discussion with the family the SN-OD should ascertain that Procurator's Fiscal (PF) consent, where necessary, has been obtained and clarify any restrictions to donation. This consent requires to be followed up in writing as soon as practically possible to the ICU consultant who has responsibility for the patient and copied to the SN-OD for storing in the donor file.

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1. Organ and Tissue Donation – Donor Family Conversation

Unless there are exceptional circumstances, a face-to-face conversation should be conducted in a quiet and private area. Although not a legal requirement, it is recommended best practice to have another healthcare professional witness the conversation where possible. If the conversation is conducted by telephone, again best practice would be to have a witness present unless the conversation is voice recorded.
If authorisation is obtained over the telephone, use **INF953** and **SOP3649** for best practice.

1.1. Introduction to the family

1.1.1. Introduce yourself (or be introduced by clinician) saying you are a specialist nurse caring for families in similar situations to provide information and offer support. Offer handshake, but refrain from touch.

1.1.2. Posture is important. You should have relaxed muscles; keep your arms down and your palms out. Use slow movements and maintain body position in a slight back tilt.

1.1.3. Reduce eye contact and avoid over focusing on:
- Men
- Tallest man
- Those who agree with you

1.2. Extend sympathy.

1.3. Offer refreshments / facilities e.g. telephone.

1.4. Check the family understands the current situation. For example - where the patient is a potential DBD, check the family's understanding of brain stem death, or in the case of DCD check that the family understand the decision to withdraw treatment.

1.5. Ask if they have any questions about what the clinician has said.

1.6. Address specifically their questions and needs at this time, e.g. registration of the death and collection of the death certificate.

1.7. If it is known that a post mortem is required, the family should be made aware of this.

1.8. Answer any questions that the family has at this stage. Focus on their concerns by using simple probing questions to try and elicit the meaning behind what they say. If needed the SN-OD should offer the family time to reach a consensus.

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

1.9. The SNOD must check if the patient is registered on the ODR and inform the family of the patient's registration decision.

1.10. If the patient has registered an opt out of organ/tissue donation, and the family state that the person had changed their mind, they must provide the evidence they believe proves the person did make a decision to be an organ donor. If this information is more recent than the registration then this will supercede their recorded decision not to donate.

1.11. If the patient has registered authorisation for organ/tissue donation on the ODR: Inform the family specifically which organs / tissue the patient has given authorisation for. Discuss the intention to proceed with the donation for transplantation. If the family wish verification of this the ODT Duty Office can be contacted and a copy of the registration can be faxed to the SN-OD.

1.12. Section 7 (3) of the 2006 Act allows for the nearest relative to authorise removal of 'parts' which are not in the self authorisation, provided that they have no actual knowledge that the person did not wish those 'parts' not to be used for transplantation.

1.13. If patient is not on the ODR: Proceed to seek authorisation from the patient's family as detailed in section 2.

2. Conversation with Family if Patient is not on the ODR

The following conversation aims to ascertain any known wishes of the patient that have not been registered on the ODR and in the absence of confirmation – to establish authorisation from appropriate individuals.

2.1. Open the conversation (using the bridging conversation outlined below). Explain that the discussions you are about to have are to explore the options for donation for transplantation. Explain that you are going to give them some information about this.

2.2. Explain that you want them to ask you any questions they have, about anything you say.

2.3. Explain that after you have given the information and answered their questions they can tell you if they know what the wishes of the patient were and, in the absence of this confirmation, their decision.

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 in the Chapel of Rest.

2.7. Give information listed in section 3 and 4, use section 5 if needed/requested.

2.8. Explain that you will get the necessary authorisation document.

2.9. Offer refreshments / facilities e.g. telephone.

2.10. Leave the room to get the documentation. Initial any organs / tissue that are outside the national age criteria or that the PF has refused permission for. Remember to take something into the room to lean on e.g. a clipboard, but not the medical records. This is to make it easier to pass the papers to the family.

2.11. Take this opportunity to reflect, consolidate thoughts and plan the next stage of the conversation interview. This should take a matter of minutes.

2.12. Give the authorisation form to the nearest relative, thus giving them control of the flow of information.

2.13. Confirm authorisation and ask the appropriate person to sign the authorisation form.

2.14. SN-OD and HCP witness (where applicable) also sign the authorisation form.

2.15. Provide reassurance to the family.

2.16. SN-OD to complete **FRM1538**.

2.17. If donation cannot proceed the family should be thanked for the time they have taken to consider this option and supported in their decision. The decision should be documented in the medical records.

2.18. If the donor is found to be medically unsuitable it is necessary to explain to the family 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 **POL180**, Management of Positive Microbiological Blood Results in Deceased Organ or Tissue Donors. Thank the family for considering the option of donation at such a difficult time.

2.19. 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 the Organ Retrieval Procedure that may be useful to Communicate with the Family

3.1. Explain that a team of specialist doctors comes to 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 their loved one will not feel any pain.

3.4. Explain that the ventilator will be disconnected in theatre where applicable.

3.5. Explain that there will be a SN-OD present throughout the procedure.

3.6. Explain that the organs are removed for transplantation into suitable recipients.

3.7. Explain that there will be a long abdominal / thoracic incision that will be closed and dressed after donation using your hands to describe the incision.

4. Best Practice Information – to be Discussed with ALL Families of Solid Organ and/or Tissue Donors

The following information must 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 to deliver this information throughout the course of their conversation with the family, according to the cues of the family.

4.1. If conversation is to be voice recorded:

4.1.1. Once the SN-OD has established a contact with the family, they must give a full explanation of the conversation process including the order of the process and where the conversation is to be voice recorded or witnessed, the family must be informed of this.

4.1.2. The SN-OD must explain that the recording is covered by the Data Protection Act, is stored and the possible uses of the recording.

4.1.3. Once the recorder is turned on the SN-OD must go back and confirm their name and ask the family members confirm his/her names and relationship to the patient and that they agree to the recording of the conversation.

4.2. Explain which organs / tissue it may be possible for the patient to donate for transplantation. Begin by discussing kidney donation and explain the benefits of renal transplantation. (If the patient is to be referred to the PF the family should have already been made aware of this and it may be necessary at this point to outline any PF directed restrictions to donation).

4.3. Explain that once authorisation has been given for donation for the purposes of transplantation it may not be withdrawn (withdrawal for research, teaching, education, audit and quality assurance must be in writing).

4.4. Where tissue donation is being considered explain that tissue will be stored for extended periods in tissue establishments whilst it is prepared for transplant.

4.5. 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 potential contamination at donation.

4.6. Explain that in these circumstances, the organ / tissue may be used for ethically approved research, education, training, and audit or quality assurance. If the donor family does not authorise this, the organ/tissue will be disposed of in a safe and lawful manner as per hospital / tissue establishment policy.

4.7. In addition to specified organs, other tissue will be retrieved, stored and used in support of organ transplantation e.g. lymph nodes and spleen for cross matching, blood vessels and blood. The specific blood vessels may be used to support other patients requiring transplant surgery. All recipient centres would require to be informed of this decision from the outset however, it remains lawful to proceed with organ donation.

4.8. Organs/tissue may be removed solely for specific ethically approved research projects. A full description of each research project should be given to the family and detailed on the authorisation form. Written information should be provided if available. Where research is offered as the primary purpose of the donation, the authorisation procedure should have been through an independent ethics committee review. If the family have given authorisation to 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.

4.9. Explain that contact details will be stored in the strictest confidence by the SN-OD and that on occasion information may be passed on a need-to-know basis to other healthcare professionals in support of the transplantation process.

4.10. Explain that the General Practitioner and any other relevant health professional will be contacted for information about the medical history of the patient.

4.11. Explain that a blood sample will be taken to test for tissue typing (solid organ donation only), HIV, Hepatitis, HTLV, and Syphilis, and that any remaining sample will be stored and may be used for future testing.

4.12. 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 a blood sample is required from both the mother and child and authorisation for this should be obtained.

4.13. Explain that if any test result is deemed to have significance for the health of the family, they will be contacted and offered the appropriate advice. Without authorisation to this donation cannot proceed.

4.14. Explain that authorisation details will be stored in the strictest confidence by the ODST and occasionally information may be passed on a need-to-know basis to other healthcare professionals in support of the transplantation process.

4.15. Where applicable explain to the family 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 or funeral director of their choice.

4.16. In the case of DCD explain to the family 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.

4.17. Explain that the family will be able to see their loved one after the donation if they wish. Depending on their wishes about viewing the deceased, 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.

4.18. Ascertain whether the donor family would like to receive information about the outcome of the donation and explain timeframes involved in this.

4.19. Ensure that the donor family is offered the contact name and number for the SN-OD and the ODST.

4.20. Tissue donation only:

4.20.1. Authorisation for the donation of each tissue should be ascertained and the family informed that the donated tissue can be stored for extended periods in a tissue establishment whilst it is prepared for transplant

4.20.2. For guidance on how to provide information to the family on different types of Tissue that can be donated, please see section 12.

5. Further Information to be Shared with Families

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

- The deceased patient will be examined to the extent necessary to transplant the organs and Tissue and this may include biopsy.
- It may not be possible to transplant the heart in its entirety, but the valves can be transplanted into two or maybe three people and donated tissue such as heart valves and pericardium / aorta will be held in the tissue establishment sometimes for several years.
- When the liver is donated the gall bladder will be removed
- If the pancreas is donated the duodenum will be removed
- If the small bowel is donated the pancreas, stomach, abdominal wall and duodenum may also be removed
- If the kidneys are donated the adrenal glands will also be removed

5.2. At this point and throughout the interview process it is vital to answer any questions the family may have. Use simple probing questions to elicit the meaning behind what they may say.

5.3. Further Information for families regarding Tissue Donation - when discussing tissue donation with the family depending on the individual cues and questions they ask, please refer to sections 10-14 for advice on this discussion.

6. Retraction of Authorisation

6.1. If the patient had expressed a wish to donate (written /verbal) in life but the family do not wish donation to proceed they should be advised that the law supports the decision of the deceased in the hope of persuading the nearest relative to uphold this decision. The decision should be documented in FRM4154 (Retraction of patient authorisation by nearest relative) and a copy placed in the medical records. Withdrawal for research, teaching, education, audit and quality assurance must also be in writing.

6.2. If during the process of authorisation the family withdraw this authorisation (where it is known the patient had not self authorised in life), as the authorisation process has not been fully completed this should be treated as a family refusal and documented in the medical records.

6.3. Following completion of the authorisation process (whether by patient or family), the family should be informed that withdrawal for transplant is not an option but withdrawal for research, teaching, education, audit and quality assurance is possible. The family are required to put this withdrawal in writing, utilising **FRM4154**, a copy of the form should be sent to the regional ODST office and the original kept in the donor file. If the family retract authorisation for transplant in the knowledge that this is not supported by law, **FRM4154** should be completed by the SN-OD with the family after careful discussion with the family and with the support of the TM/Regional RM/On Call Regional Manager, if necessary.

7. Medical and Behavioural History Assessment of Patients Being Considered for Donation – to be Discussed with ALL Families of Solid Organ and/or Tissue Donors

7.1. Explain:

- The importance of safety of organ / tissue transplants, that in order to assess which organs/tissue can be donated, it is necessary to ask some questions about the patient and also explain that:
- Some questions are of an intimate nature
- These questions are not meant to cause offence
- These questions are asked about all patients where donation is being considered they are similar to the questions asked of those donating blood

7.2. The SN-OD must check that there is no one else that may provide more intimate information and if there is then it will be necessary to carry out the behavioural history assessment with the other person(s). If the SN-OD has any uncertainties regarding the suitability to donate they must explain this to the family and inform them that they will take advice and come back to them with a decision and provide relevant explanations / rationale. In the case of a positive microbiological result the situation should be dealt with in accordance with **POL180**.

7.3. SN-OD must complete **FRM4211** (Patient Assessment).

8. Establish Personal Requests of the Family

8.1. It is the responsibility of the SN-OD to update the family throughout the donation process.

8.2. Enquire if there are any religious / spiritual requirements of the family.

8.3. Establish the family's wishes for keepsakes e.g. locks of hair, handprints and photographs.

8.4. Determine whether the family wishes to assist with last offices following donation, or wish their loved one to be dressed in certain items of clothing.

9. Obtaining Medical / Behavioural History from the General Practitioner

To enable assessment of suitability for donation it is necessary in the case of solid organ donors to attempt to make contact with the GP prior to donation. This process is outlined in **SOP3632**.

9.1. All efforts should be made to contact the patient's GP. Out–of-hours requests should be made to the deputising service. It is sometimes possible to contact the patient's own GP in this way.

9.2. Explain the purpose of the enquiry and the need to ensure safety in the donation and transplantation of organs.

9.3. Discuss the patient's past medical and social history.

9.4. Ask specifically if the GP is aware of any medical or social history, which may carry a risk of transmission of HIV, CJD, Hepatitis B or C, or syphilis.

9.5. Fax the GP Questionnaire **FRM1602** to the GP within 2 working days of donation requesting GP to complete and return it.

9.6. Disseminate information to the relevant SN-OD team/ tissue establishments/ RCPoC/ ODT Duty Office as appropriate.

10. The Tissue Donor Family Conversation – Guidelines

This section must only be used by trained or supervised SN-OD who is dealing with a potential **tissue donor family** and this conversation may be undertaken by voice recording on the telephone, witnessed telephone conversation or witnessed in a face to face interview. The ODR must be checked in every case prior to the donation conversation by the SN-OD (**MPD888**). The ODT Duty Office may be contacted and asked to check whether the patient has registered a wish to either donate or not donate tissue and if so which and if any restrictions have been placed on any Tissue. The outcome of this inquiry must be documented in the SN-OD donor records on **FRM1538**. Where the conversation is undertaken over the telephone, the conversation should wherever possible be voice recorded as evidence of the information that has been given and of ODR registration outcome and or that authorisation that has been given. Where the conversation is undertaken over the telephone and it is not possible to voice record the conversation or where the conversation is undertaken face to face it is best practice to have a HCP witness present where possible. In all cases **FRM1538** should be accurately and fully completed and this form must be kept as part of the SN-OD donor records.

10.1 If the patient is registered on the ODR inform the family of the patient's registration decision**.**

10.2 If the patient has registered an opt out of organ/tissue donation, and the family state that the person had changed their mind, they must provide the evidence they believe proves the person did make a decision to be an organ donor. If this information is more recent than the registration then this will supercede their recorded decision not to donate.

10.3 If patient has registered authorisation on the ODR: Inform the family of this and specifically which tissue the patient has given authorisation to the donation of Tissue. Discuss the intention to proceed with the donation for transplantation.

10.4 If patient is not on the ODR: Proceed to seek authorisation from the patient's family.

10.5 The conversation must take place in a quiet place with no background noise or distractions. The conversation and particularly authorisation is a process and not an event. Where the conversation takes place over the telephone the SN-OD should sit slightly tilted back (avoid sitting forwards at a desk) and the chin should be tucked in (this avoids elongating the neck and thus compresses the vocal cords resulting in a lower pitch voice which sounds more convincing and authoritative). The SN-OD should avoid looking at the line between the ceiling and the wall as research suggests that this is a visual cue for saying something inappropriate.

10.6 The flow can be broken down into the following steps:

- Open the conversation/get past the gatekeeper to the family.
- Serve as a source of help / information.
- Bridge into donation.
- Provide adequate information.
- Surface and respond to core concerns.
- Get medical and behavioural history.
- Get confirmation of authorisation.
- Deal with 'list shock'.
- Extend sympathy and close the conversation.

10.7 Where the conversation is over the **telephone,** utilise **SOP3649** and **INF953** to provide best practice. Open the conversation / get past the gatekeeper - to do this and get to the decision-maker the SN-OD must identify themselves and their contact source and ask for the identity of the speaker to reduce hostility, for example:

"My name is……….. I'm a nurse / SN-OD with the (name of organisation). I was asked to ring you by……. To whom am I speaking? "

The SN-OD must then use the gatekeeper's name, establish authority, ask for the family and acknowledge the loss. For example:

"Mrs Jones, I've been asked to follow up an earlier conversation with Mrs Brown. May I speak to her please? I know this is a difficult time."

If the SN-OD still meets resistance they must tell the gatekeeper:

"I'm sorry but I am only authorised to speak to Mrs Brown."

The SN-OD must keep repeating this message and find an appropriate time to call back.

Note
The following is designed to guide the SN-OD through the conversation. The SN-OD should use the structure below and the suggested phrasing within it to give as much or as little additional information to the family as they require in order to make a decision. If at any stage the SN-OD gets a strong refusal then the choice should be reaffirmed and the family thanked for speaking with them.

10.8 Serve as a source of help / information.

When the SN-OD begins their conversation with the family, they must start by acting as a source of help, by establishing their credibility and gaining rapport. For example:

"I've spoken to …………..about your son's death and have been asked to contact / speak to you. What questions do you have about what the hospital staff told you? "

The SN-OD will then go on to answer those questions and provide any additional information. It is important for the SN-OD to keep their questions open. By asking 'what' questions the SN-OD is meeting the family's needs and establishing a relationship with them.
This step simply serves to demonstrate continuity of care and uses the principle of reciprocity – to give something before you ask for something.

10.9 Bridge into donation.

The SN-OD bridges into donation by informing the family how the conversation will proceed e.g. "I'll give you information, you can ask questions and afterwards I'll do what you decide". An example of how a bridge might go is:

"Due to the circumstances of your son's death, you have the opportunity to donate tissue for transplant or research. I would like to give you some information about that, and I would like you to ask me any questions you might have. After I've answered your questions and given you the information, you can tell me what you want to do and I'll see that it is done. The first thing you should know is that the donation of tissue can enhance the quality of other people's lives. For instance, you could donate your son's eyes so that two other people have the possibility of regaining their sight."

(Always use eyes as an example first)

Later, when giving more information about the donation of tissue the SN-OD should always follow the same order:

- describe the body part
- describe the need/benefit
- describe the procedure

This way the SN-OD gives good news before giving bad news, which the SN-OD should do at all times, including when answering questions.

10.10 Go through the information in section 12 with the family and answer any questions they may have.

10.11 Surface and respond to core concerns.

If the family express concern the SN-OD must ask questions to get to the core concern e.g.

"Do you mean….?"

"Are you saying….?"

"Could you tell me a bit more…?"

The SN-OD can soften this by pausing, calling them by name, and repeating their words e.g.

"Mrs Brown, when you say you are worrying about…."

The SN-OD should also empathise e.g.

"I'm sure this has been tough"

The SN-OD must also affirm feelings and universalise e.g.

"A lot of people ask me the same questions"

The SN-OD must continue until the core concern is covered. When the core concern has been addressed the SN-OD must go back to giving information from the point they left.

If the family responds with a refusal the SN-OD should ask a clarifying question, e.g.

"Are you saying that you object to donation in general or are you saying you aren't interested in donating eyes specifically?"

If the refusal is general the SN-OD should probe, provide information and try to move the family to a strong objection or authorisation. If the SN-OD gets a strong objection, they must reaffirm the choice.

11. Confirmation of Authorisation for Tissue Donation

If the family agree the SN-OD can then proceed to other suitable donations and this includes the various research options. For example:

"Mrs Brown, in order to ensure the safety of our transplanted tissue, I'll need to ask you or someone else some questions about your son's health history. Before I do that and to save us some time, I need you to tell me what, if any, other donations you would like to make. I'm going to name some other possibilities and after each one, I want you to tell me if you want more information on it."

The SN-OD must check at each stage that the family has understood the information that has been given to them. If the SN-OD is faced with disunity, they must listen to what is said but stay out of the discussion. If the SN-OD speaks it must only be to correct misunderstandings, to emphasise the last decision and to refocus onto the patient. If needed the SN-OD should offer to call back, giving the family time to reach consensus. If the family cannot agree then it may be advisable for the donation not to be accepted. This should be discussed with TM/RM/On Call Regional manager. All discussions / decisions must be documented on **FRM1538**.

12. Providing Information about the Tissue Donation Process to Families

The SN-OD should provide clear and accurate information about Tissue as required by the family, and this should be given like this – always starting with the eyes:

Cornea

"The cornea is the clear, front part of the eye. It's the size and shape of a contact lens and it's the part of the eye the contact lens sits on. The cornea is like a watch glass and sometimes, just like glass, it gets so scarred or damaged it needs to be replaced. We can replace damaged corneas with those from someone who has just died and restore the sight of two separate people. It would be possible to see your loved one after the donation, if you'd like to. The shape of the face remains the same whether you donate or not. The cornea is fragile so the entire globe is removed to protect it, but the space is filled. A protective cap is placed under the eyelid and the lid closed. 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, afterwards there is some puffiness or discolouration."

Bone - Not currently retrieved in Scotland but pending

"Long bones and connective tissue can be donated from the legs. Donated bone and tissue is used for surgery for people who have been in accidents or who have conditions like arthritis. A brace will be put inside the leg to maintain its normal shape and the openings are sutured. The incisions are covered by a dressing and will not be visible under by clothing, and you will be able to have a traditional funeral."

Heart Valves

"It may not be possible to transplant the heart it 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."

Blood Vessels Not currently retrieved in Scotland.

Skin

"The skin grafts that are donated are used for burn patients and in plastic and reconstructive surgeries. The grafts are taken form the back, legs and buttock areas that are covered with clothing. The layer donated is just a little thicker than the layer that peels off after sunburn."

13. Obtaining Medical / Behavioural History from the Tissue Donor's Family

13.1. The SN-OD must explain the need for the medical / behavioural history questions. For example:

"I mentioned earlier that we'll need some information about your son's health history. Are you the best person to ask about that? The history may take about 20 minutes. Would you like to do that now or would you like to take a break?"

13.2. The SN-OD must complete the relevant section of the Patient Assessment form (**FRM4211**) relating to past and current medical history by asking the questions and documenting the answers.

13.3. The SN-OD must document all additional relevant medical history and information on the form.

13.4. If there are no medical contraindications, the SN-OD must then complete the behavioural risk assessment explaining that the questions:

- Are of an intimate nature.
- Are not meant to cause offence.
- Are routine.
- Are the same questions asked of all blood donors.

13.5. Finally the SN-OD should check that there is no one else that may provide more intimate information and if there is then it will be necessary to carry out the behavioural history assessment with the other person. If the SN-OD has any uncertainties regarding the suitability to donate they must explain this to the family and inform them that they will take advice and contact them again with the decision and provide relevant explanations/rationale.

13.6. Explain that the patient's General Practitioner will need to be contacted for information about the patient, see guidance in section 9

13.7. Deal with list shock.

The SN-OD must deal with the possibility of list shock by trying to prevent it. The SN-OD must mention that a viewing is possible and group tissue together and maintain empathy and reassurance. For example:

> *"I know that this sounds like a lot but many of the donations are actually very small in size, you should do what you feel comfortable with?"*

13.8. Extend sympathy and close the conversation.

When the SN-OD has obtained and given all necessary information, they can close the conversation. The SN-OD must ask the family if they would like to receive a phone call letting them know that the donation procedure is complete and/or a letter confirming the details of the donation in line with **MPD845** (Donor Family Care) The SN-OD should express reassurance, sympathy and thanks. The SN-OD must also give the family their contact details. SN-ODs using analogue manual voice recorders must switch off the voice recorder and store the recording appropriately labelled with the donor's:

- Name.
- Date of birth.
- Date of death.
- Date and time of interview.
- Is marked as "Confidential".
- Is marked as Property of the NHS Blood and Transplant

The voice recording should be sealed into a wallet, stapled into the donor file and stored in a secure place.

14. Deferring a Tissue Donor

If donation cannot proceed the family should be thanked for the time they have taken to consider this option and supported in their decision. The decision should be documented in the medical records where applicable and in the Potential Donor Referral Form (**FRM4228**)

14.1. If the patient had expressed a wish to donate (written /verbal) in life but the family do not wish donation to proceed they should be advised that the law supports the decision of the deceased in the hope of persuading the nearest relative to uphold this decision. The SN-OD must utilise **FRM4154** (retraction of authorisation) to document any retraction in this circumstance.

14.2. If at any time there is withdrawal of authorisation for research, teaching, education, audit and quality assurance the conversation will be voice recorded as written confirmation is not applicable.

When deferring a deceased patient for donation it is necessary to explain to the family the rationale for the deferral in a clear and understandable manner. Give the family the option of receiving a letter, thanking them for considering donation and explain the reasons for not going ahead with the donation. For SN-ODs using an analogue voice recorder, this can be switched off and the tape removed from the recorder and labelled with the donor's:

- Name
- Date of birth
- Date of death
- Date and time of interview
- Is marked as "Confidential"
- Is marked as Property of the NHS Blood and Transplant

The voice recording should be sealed into a wallet, stapled into the donor file and stored in a secure place.