

Approaching Relatives regarding Organ and Tissue Donation

This Management Process Description replaces
MPD901/5

Copy Number

Effective

02/05/17

Summary of Significant Changes

Changes led by new HTA Codes and to streamline document
Change of terminology from family/family members /friends to relatives
Addition of the Mental Capacity Act (Northern Ireland (2016)
Removal of Assistant Nurse Practitioner

Policy

In England, Wales and Northern Ireland legislation requires consent is ascertained before organ or tissue donation takes place. The fundamental guiding principles of Consent in England, N. Ireland and Wales are Consent - Dignity - Quality - Honesty and openness.

The wishes of the person made during their lifetime may be sufficient to provide this consent. Where no wishes were expressed during lifetime, the Human Tissue Act 2004 (HT Act) and the Human Transplantation (Wales) Act 2013 (HT (W) Act) allows for consent to be provided by certain other people after the person has died or in the case of DCD following the decision to withdraw treatment. In addition, the HT (W) Act allows for consent to be deemed to have been given when a person both lived and died in Wales.

Consent is the fundamental principle of this legislative framework; therefore, the Specialist Nurse-Organ Donation (SNOD)/Tissue Donor Coordinator (TDC)/Nurse Practitioner (NP) must ensure that they understand the requirements of legislation pertinent to their role.

The SNOD/NP/TDC should approach the relatives sensitively and provide enough information to check whether express consent is in place or consent is able to be deemed and where appropriate, to allow a decision regarding organ and/or tissue donation to be reached.

Definitions

HT Act – Human Tissue Act 2004.

HT (W) Act- Human Transplantation (Wales) Act 2013.

Relatives- refers to the spouse, partner and, in cases where there are no relatives, close friends of the deceased person.

SNOD– for the purposes of this document the terminology "SNOD/NP/TDC will apply to the Specialist Nurse/Specialist Requester (SR), Nurse Practitioner with the relevant knowledge, skills and training in organ and tissue donation, working within NHSBT.

Relevant Information- is any information offered by the relatives that might come to light during the donation conversation that suggests the patient changed his or her mind about their decision to donate any or all organs or tissue.

ODR – National Health Service (NHS) Organ Donor Register is a confidential, computerised database recording the decision of people in regard to organ/tissue donation after their death.

HCP – Medical/Nursing Healthcare Professional in critical care, responsible for the patient.

MDT- Multi Disciplinary Team includes, the SNOD/ Medical practitioner/ Nursing staff responsible for the care of the patient/Advocates/Counsellors and local faith representative(s) (where relevant).

Deemed Consent (criteria applies-only in Wales) - means that when there is no record of a person's decision on organ donation, their consent to organ donation will be deemed to have been given, unless a person with a close relationship provides evidence that the person would not have wanted to be an organ donor.

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Applicable Documents

[POL164](#) - Consent / Authorisation for Organ and/or Tissue Donation

[FRM4281](#) - Consent- Solid organ and tissue donation

[MPD902](#) - Consent conversation for organ and/or tissue donation

[FRM4211](#) - Patient Assessment Form (PA1)

[INF947](#) - Rationale document for patient Assessment Form

[MPD845](#) - Donor Relatives Care

[MPD865](#) - Obtaining Coroner/Procurator Fiscal Decision

[SOP3632](#) - General Practitioner Assessment

[MPD942](#) - Management of Microbiological Blood Results in Potential Organ and/or Tissue Donors

[SOP3649](#) - Voice Recording of Telephone Conversations

[MPD888](#) Accessing the ODR

[SOP3817](#) – Access for SNOD/NP/TDCs to the Organ Donor Register (ODR)

[INF1164](#) – Tissue Consent Leaflet

[INF1165](#) – Organ Consent Leaflet

[INF1166](#) – Eye Consent Leaflet

[INF1167](#) – Consent Research Leaflet

NHS Blood and Transplant- Approaching the Families of Potential Organ Donors- Best Practice Guidance

Human Tissue Authority Codes of Practice

<http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice.cfm>

Codes of practice on the Human Transplantation (Wales) Act 2013

<http://www.legislation.gov.uk/anaw/2013/5/contents/enacted>

[http://www.hta.gov.uk/db/documents/HTA_CoP_on_Human_Transplantation_\(Wales\)_Act_2013_-_Final_-_May_2014.pdf](http://www.hta.gov.uk/db/documents/HTA_CoP_on_Human_Transplantation_(Wales)_Act_2013_-_Final_-_May_2014.pdf)

Mental Capacity Act 2005-

<http://www.legislation.gov.uk/ukpga/2005/9/contents>

Mental Capacity Act (NI) 2016.

<http://www.legislation.gov.uk/nia/2016/18/contents>

The Quality and Safety of Organs Intended for Transplantation Regulations 2012

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

The Quality and Safety of Organs Human Tissue Authority Codes of Practice

<http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice.cfm>

Organ donation for transplantation- Improving donor identification and consent rates for deceased organ donation-

<http://www.nice.org.uk/nicemedia/live/13628/57508/57508.pdf>

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

http://www.legislation.gov.uk/uksi/2007/1523/pdfs/uksi_20071523_en.pdf

The Quality and Safety of Organs Intended for Transplantation Regulations 2012

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

The Quality and Safety of Organs Intended for Transplantation – a Documentary Framework

http://www.hta.gov.uk/db/documents/Organs_Intended_for_Transplantation_-_documentary_framework_July_2012.pdf

Intended for Transplantation – a Documentary Framework

http://www.hta.gov.uk/db/documents/Organs_Intended_for_Transplantation_-_documentary_framework_July_2012.pdf

NICE Clinical Guideline - Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation.

HT Act-

<http://www.legislation.gov.uk/ukpga/2004/30/contents>

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1. GUIDING PRINCIPLES

- 1.1. In England, Northern Ireland and Wales the HT and HT (W) Acts set out legal requirements for consent. It is important that the SNOD is aware of the legislation and is competent to work within the principles of the legal frameworks.
- 1.2. Consideration should be made regarding confirming the identity of relatives, especially in Emergency Department referrals when relatives may not have seen the patient.
- 1.3. It is paramount that organ and/or tissue donation is broached with the relatives sensitively and that they are given honest, clear and objective information.

2. CORONER CONSIDERATIONS

- 2.1. The SNOD should ascertain that Coroner permission (where necessary) has been obtained and clarify any coronial restrictions to donation. Please refer to [MPD865](#) for further guidance.

3. NHS ORGAN DONOR REGISTER (ODR) CHECK *PRIOR* TO APPROACHING THE RELATIVES

- 3.1. The Human Tissue Authority has accepted that the Organ Donor Register stands as a record of an expressed decision to organ/tissue donation.
- 3.2. The SNOD must determine whether the patient had given their consent for organ donation, nominated/appointed a representative **OR** opted out of organ/tissue donation by checking the ODR. The relatives should be informed of the patient's decision. Please refer to [MPD888](#) for further guidance.
- 3.3. Evidence of a donor card or known wishes of the patient that may be in place should be obtained where possible.
- 3.4. If the patient is registered on the ODR, the SNOD should obtain evidence of the patient's registration and file a copy in the donor file.
- 3.5. If the patient has registered a decision about organ donation on the ODR but the relatives state, during discussions, that the patient had changed their mind, the relatives must provide the SNOD with 'relevant information' to support this. This evidence must demonstrate to the SNOD, without doubt, that this latest decision was that of the patient and was more recent than the recorded ODR decision.
- 3.6. If 'relevant information' is provided and evidenced, this will supersede any previous recorded decisions made.
- 3.7. If no 'relevant information' is made available to the SNOD indicating the person changed their mind about their decision to donate, the most recent decision recorded on the ODR remains lawful.
- 3.8. The absence of a tick in a box on the ODR operates as a decision by the person not to donate that particular organ/tissue. This decision must be shared with the relatives by the SNOD or another suitably trained member of the MDT. This will allow the relatives an opportunity to share any more recent decisions, known to them, about the person's last known wish.

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- 3.9. A suggested statement the SNOD can use to inform families of a recorded no, for either organs and or tissue is:

“Mrs Smith your husband recorded a decision on the Organ Donor Register to say that he did not want to donate specific organs/tissue / or be an organ donor. This will be the decision I will be relying upon unless you have any other information that you would like to bring to my attention”.

- 3.10. In the absence of a box to tick, where there was no option for organs/tissue available at the time of ODR registration i.e. not listed on the ODR form then consent can be explored with the relatives.
- 3.11. An adult may, during their lifetime, nominate/appoint someone to make the donation decision for them. If in writing, this must be signed by the patient in the presence of a witness who confirms the signature on the document. If verbal, two witnesses are required to have been present at the same time.
- 3.12. The SNOD must approach the nominated/appointed representative to provide consent or refusal to consent. This will not apply if that person cannot be found or if the timeframe needed for the donation is so limited that it is not reasonably practicable to communicate with that person. The nominated/appointed representative is **not** the same as the Power of Attorney.
- 3.13. If established that the patient had not recorded a decision on the ODR or nominated a representative, they should ask relatives whether they are aware of the person’s decision in regards to organ donation after death.
- 3.14. During the donation conversation with the patient’s relatives, if the patient had not made their decision known, then the decision lies with the relatives. Consent should be obtained from the person in the highest ranking ‘qualifying relationship’. If consent is obtained from someone who is not in the highest ranking the SNOD must document the rationale for this on the patient’s consent form and if necessary discuss this with a Team/Regional/On-Call Regional Manager.
- 3.15. For Adult Welsh residents who have ordinarily lived in Wales for longer than 12 months, who have not appointed a representative; recorded or made their decision known and who had not lacked capacity for a significantly period prior to their death deemed consent under the HT (W) Act must be applied. For excepted adults or children (under 18 years) where deemed consent cannot be applied the decision lies with the relatives/friends or person with parental responsibility in the case of a child, about whether to donate or not.

4. FIRST PERSON CONSENT IN THE ABSENCE OF A NOMINATED/APPOINTED REPRESENTATIVE OR PERSON FROM THE ‘QUALIFYING RELATIONSHIP’

If first person consent for organ donation exists and despite reasonable endeavours to find one there is no nominated/appointed representative/or an identifiable person from the ‘qualifying relationship’ with whom to discuss consent for scheduled purposes or medical history, then neither tissue donation or research for scheduled purposes is possible.

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5. PREPARATION PRE-APPROACH CONVERSATION FOR ORGAN AND TISSUE DONATION

- 5.1. Plan the approach and donation conversation with the Multi Disciplinary Team (MDT). The MDT should include:
- The SNOD
 - The Medical Practitioner and Nursing staff responsible for the care of the Patient
 - Advocates/Counsellor/local faith representative (where required)
- 5.2. The SNOD should discuss the clinical history and the patient's cause of death with the Medical Practitioner and Nurse caring for the patient.
- 5.3. The SNOD should also:
- Determine evidence of prior consent such as registration on the ODR
 - Gather information about the relatives of the potential donor
 - Discuss what information the relatives have already been given about the patient's prognosis and their understanding of this.
 - Identify key and appropriate relatives to have the donation conversation with
 - Agree how death will be communicated to the relatives and by whom
 - Make clear that donation should not be broached unless the relatives are understanding/accepting that death is imminent or has occurred
 - Identify any cultural and religious considerations that may have an impact on the donation conversation, recognising the need to involve other parties (e.g. faith representatives)
- 5.4. The SNOD and members of the MDT should discuss and agree their roles and decide '**who**' is going to communicate '**what**' information to the relatives.
- 5.5. The conversation should be conducted in person unless there are logistical reasons why this can not happen.
- 5.6. Depending on what agreements were reached when planning the donation conversation with the relatives, if the Medical Practitioner leaves the room, it is recommended best practice that the SNOD has another professional witness the consent aspect of the conversation where possible.

6. TELEPHONE APPROACH AND CONSENT

- 6.1. If the conversation is conducted by telephone, best practice would be for the SNOD to record the conversation. The SNOD must follow [SOP3649](#) Voice Recording of Telephone Conversations for detailed guidance. If the relative declines voice recording then a second HCP must be present to witness the consent conversation
- 6.2. It is possible to proceed with organ and/or tissue donation on the basis of establishing consent by telephone, as it is not a legal requirement for relatives to sign the consent form.

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COMMUNICATING WITH THE RELATIVES

- 6.3. A maximum time-frame for the donor relatives' conversation should not be pre-established as the variability of information and support required for individual relatives is unique in each situation.
- 6.4. Assessing capacity - assume capacity, unless proven otherwise, The MDT must ensure Individuals can:
- a) Understand the information
 - b) Retain the information long enough to use
 - c) Use and weigh up the information relevant to this decision
 - d) Communicate decisions in some way

Capacity is deemed to be lacking if any one of these is absent it should therefore always be assumed that an adult has the capacity to make a decision unless there is a reason to believe otherwise

7. ASSESSING THE RELATIVES'S UNDERSTANDING OF THE PROGNOSIS AND CONFIRMATION OF DEATH

- 7.1. Cultural requirements and religious beliefs regarding death and the dying process should be considered.
- 7.2. Where the patient is a potential DBD the SNOD must ascertain the relatives' understanding of death confirmed by neurological criteria.
- 7.3. Where the patient is a potential DCD the SNOD should confirm that the relatives understand and accept the decision to WLST.
- 7.4. If there is to be a post mortem, the SNOD should inform the relatives, if this has not been communicated to them already.
- 7.5. Once the relatives understand that there is no hope of survival and that death is inevitable or has occurred, the SNOD should discuss the opportunity of donation.

8. PATIENTS REGISTERED ON THE ORGAN DONOR REGISTER (ODR)

- 8.1. Relatives must be informed of the patient's registration decision. A copy of the ODR registration can be given to the relatives, should this be requested.
- 8.2. If the patient has registered an opt out of organ/tissue donation and the relatives state that the person had changed their mind, they must provide 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 supersede their recorded decision not to donate.
- 8.3. The nominated/appointed representative must be contacted to make a decision on behalf of the patient and inform the relatives of the decision.

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- 8.4. Where express consent is recorded the relatives must be informed of which organs and/or tissue the patient has consented on the ODR to donate.
- 8.5. Where there was no organ/tissue option available at the time of ODR registration i.e. not listed on the ODR form then consent can be explored with the relatives in the same way as if there is no registration.

9. PATIENTS NOT REGISTERED ON THE ORGAN DONOR REGISTER AND WHERE THERE IS NO OTHER CONFIRMATORY EVIDENCE ON WISHES OF CONSENT

- 9.1. The SNOD should discuss the opportunity of donation by considering the option of either the relative providing consent OR in Wales when applicable, applying deemed consent to donating organs and/or tissue for transplantation.