Reference Number: UHB 351 **Version Number:** 1	**Date of Next Review:** 18th Apr 2020 **Previous Trust/LHB Reference Number:** N/A

Deceased Organ and Tissue Donation Procedure

Introduction and Aim

This document supports the UHB Policy on Organ and Tissue Donation after Death. It provides guidance for medical and nursing staff at Cardiff and Vale UHB caring for patients with potential to become organ donors at the end of life. The Human Transplantation Act (Wales) 2013[1] has led to a change in how consent for organ donation can be determined and this procedure supports medical and nursing staff in its application.

The overall aim of the procedure for deceased organ and tissue donation is to ensure best practice is followed in order that at the end of life a patient's decision with respect to organ donation is appropriately explored and their decisions are supported.

Objectives

- All patients are considered for organ donation as a usual part of end of life care.[2]
- All patients at the end of life who meet minimum notification criteria[3] (NICE Guideline) are referred to the specialist nurse for organ donation.
- The family of all patients with the potential to become an organ donor are approached in accordance with the best practice guidelines[4].
- The decisions of all potential patients are determined by accessing the NHS organ donor register[4].
- Consent for organ donation is explored using the criteria set out in the Code of practice[5.]
- Potential organ donors who have consented to proceed are managed according to clinical guidelines.

Scope

This procedure applies to all of our staff in all locations including those with honorary contracts and relates to all patients at the end of life who have the potential to donate solid organs or tissues after death.

Equality and Health Impact Assessment	An Equality Impact Assessment has been completed. The Equality Impact Assessment completed for the policy found there to be negative and positive impacts. The results of this assessment can be reviewed in the Equality and Health Impact Assessment for Donation of Organs and Tissues after Death Policy and Procedure.
Documents to read	Donation of Organs and Tissues after Death Policy

alongside this Procedure	
Approved by	Quality Safety and Experience Committee

Accountable Executive or Clinical Board Director	Organ Donation Committee
Author(s)	Clinical Lead for Organ Donation Specialist Nurse for Organ Donation

Disclaimer

If the review date of this document has passed please ensure that the version you are using is the most up to date either by contacting the document author or the Governance Directorate.

Summary of reviews/amendments			
Version Number	**Date of Review Approved**	**Date Published**	**Summary of Amendments**
1	18/04/2017	02/05/2017	Donation of Organs and Tissues after Death Policy Reference Number 110 is superseded by this document. The main amends reflect changes in Welsh Legislation surrounding consent for deceased donation to take place. The medical treatment and care of the patient by UHB nursing and medical staff remains unchanged.

Contents

1.0 Introduction

1.1 Clinical teams often experience a conflict between providing medical care and compassion to patients at the end of life and their families and society's need to procure donor organs for transplant. This document sets out the guidance for the clinical team to ensure that they work within accepted national professional best practice guidance and the law. [1,2,3,4,5,6,7,8,9]

1.2 It is known that a significant proportion of people in the UK wish to donate their organs after death for the purpose of transplantation[10]. However it is a complex process not least because the majority of potential organ donors do not have the capacity to be directly involved in the decision-making[2].

1.3 It is recognised that the potential donor can be located in any part of the hospital although it is most likely that they are in an intensive care unit or emergency unit. This procedure is relevant to all patients at the end of life irrespective of their location in the hospital.

1.4 This guidance pertains to both donation after cardiac death and donation after brain death. Specific differences between the two processes are clearly stated when necessary.

1.5 This guidance refers to all patients irrespective of age. However there are some specific differences in paediatric practice not least with reference to the HTA Wales 2013 [1] and a paediatric organ donation policy is under development.

2.0 Identification of the potential donor

2.1 Organ donation should be considered as a usual part of end of life care[3,4,8]. It is recognised that the early identification of potential donors will ensure that the patient and their families are given the best level of support and ensure that donation takes place in a timely fashion.

2.2 NICE Clinical Guideline 135 [4] offers detailed guidance regarding the clinical situations that should lead to initial discussions with the specialist nurse for organ donation. This ensures that a systematic approach is followed for referral to the specialist team, enabling earlier referral and reducing the risk of missing a potential donor.

2.3 In line with these recommendations all patients who fulfil the following criteria, known as **minimum notification criteria** should be referred to the specialist nurse. All treatment and interventions should continue at this stage.

- Clinical trigger factors in patients who have had a catastrophic brain injury are:
  - The absence of one or more cranial nerve reflexes
  - Glasgow Coma Score of 4 or less that is not explained by sedation

- The intention to withdraw life-sustaining treatment in patients with life-threatening or life-limiting conditions, which will or is expected to result in circulatory death.

2.4 Decision to withdraw life supporting treatment (WLST): the decision to withdraw treatment in a patient must be made by at least two consultants with knowledge and understanding of the General Medical Council guidance regarding good decision making in treatment and care towards the end of life.[3,8]

3.0 Referral of potential donor to the specialist nurse for organ donation (SNOD)

3.1 This section describes the process for referring patients to the SNOD following identification of the potential to donate as outlined above.

3.2 The consultant in charge of the patient's care or their deputy, including junior doctor or nursing staff, refers the patient to the resident SNOD or the regional SNOD on call.

3.3 The SN-ODs are available 24/7 and are contacted on pager **07659 591889.**

3.4 It is good practice to contact the SN-OD as early as practically possible.[4,7] This allows for early discussion regarding the potential to become a donor, the identification of relative or absolute contraindications and allows transplant surgeons to screen potential organ donors with marginal likelihood to proceed to donation. The SNODs need time to travel to the location of the patient. Furthermore it allows early clinical intervention with donor optimisation bundles enabling clinicians to increase the potential to donate.

3.5 On referral the SNOD will ask for the patient's name, NHS number, date of birth and address in order to be able to check the ODR and ascertain whether the patient had recorded a decision (as indicated in the Human Transplantation (Wales) Act 2013.

4.0 Approach to those close to the patient regarding donation

4.1 Before the approach: There must be a multidisciplinary and collaborative planning meeting between the consultant, nursing staff familiar with the patient and family members and the SN-OD prior to approaching the family.[7]

4.2 Planning meeting: During this planning meeting clinical issues should be clarified, the patient's donation potential assessed and the implications of organ retrieval understood, review of evidence of prior consent for organ donation and a discussion about the key family members involved in the decision making including the need to involve other parties such as faith representatives. A discussion should also take place to decide who will cover each element of the process.[7]

4.2 Timing of the approach: The main emphasis regarding the timing of the approach for donation is to ensure that the relatives have demonstrated an understanding that the patient has died or that death is imminent. The time taken for the relatives to comprehend this can vary considerably but it is crucial they have this understanding before considering approaching the family for donation. If the family do not understand the diagnosis of death or the plan to withdraw treatment an approach for donation **must not** be made.[7]

4.3 Location of the approach: it is important that family members are spoken to in a private room without interruptions and not at the patient's bedside. Best practice should be observed with a planning meeting and SNOD presence irrespective of the location of the patient. The subject of donation must only be raised at a time when families have demonstrated understanding of imminent death and the irreversible nature of the condition. It is important that donation is not raised prematurely prior to the family acceptance or before the medical management has been agreed.[7]

4.3 Roles and responsibilities: Evidence indicates that a collaborative approach between senior medical teams and the SNODs is the standard of best practice. SNODs have received detailed bespoke training in communication and best understand how to support families. They are able to recognise the cues from family and best determine the correct timing with respect to raising the subject of donation.[7]

4.4 Introducing the SNOD: some consultants will have difficulty introducing the specialist nurse, recognising that the subject of organ donation has not yet been raised. Consider introducing them as "a specialist nurse who works on the unit to support families."[7]

4.5 Discussing organ donation: The SNOD will discuss the organ donation process and answer any questions. If it is agreed that the patient's last known decision was that they wanted to donate their organs, consent documentation will then be completed. A medical, behavioural, travel and

social history assessment will also be obtained from the family and other relevant individuals.[7]

4.6 The SNOD will provide information for the family on organ donation and the processes involved in a language of their choice utilising translation services if required. The relatives will be encouraged to ask questions which will be addressed. Where requested the family should be left to discuss donation privately, ensuring appropriate support is available should they require it.[7]

4.7 When families raise organ donation: If the family raise the possibility of organ donation with local staff without being formally asked for donation, the consultant should be informed and a referral to the SNOD should be made. The SNOD will advise staff on how to proceed, if it is clinically appropriate to consider organ donation, the SNOD will facilitate the process in discussion with the family. If there are reasons why donation is not clinically appropriate, the SNOD will explain those reasons in discussion with the family.

4.8 It is possible that out of hours there might be an occasion when the SNOD is delayed in attending due to logistics such as travel delays or multiple donation activity around South Wales. Following detailed discussion and advice from the SNOD the clinical team might consider approaching the family prior to the SNOD arrival. However this should only occur if significant delays are anticipated. It is important to understand the need to decouple the breaking bad news and discussion of futility of further treatment from the approach to organ donation in this conversation. The clinical team should only approach in unusual circumstances with express advice of the SNOD and when delays are going to cause the family greater distress.

5.0 Consent for organ donation

5.1 Consent in the process of deceased organ donation has changed since the implementation of The Human Transplantation (Wales) Act 2013 on 1st December 2015. [1]

5.2 The HTA Wales Code of Practice informs the multidisciplinary team how to use the new transplantation act to determine consent for deceased organ donation.[6]

5.3 It is emphasised that SNODs based in Wales have undergone training and education in the detail of the HTA (Wales) 2013 and therefore are best placed to determine whether a patient has given consent for organ donation. This is a further reason to why it is important to involved SNODs early in the process.

5.4 The HTA Wales 2013 applies to people over the age of 18 who have capacity and who voluntarily live in Wales and then die in Wales. It means that consent to donation can be deemed. [1,6]

5.5. Deemed consent means that if an individual does not register a clear decision either to be an organ donor (opt in) or not to be a donor (opt out), they will be treated as having no objection to being a donor. This choice can be recorded on the NHS Organ Donor Register, carrying a donor card or through conversations with family members. It is the last known wish of the individual that is important. [1,6]

5.6 Patients who have not registered a decision with respect to deceased donation can have their consent deemed provided they are over the age of 18 had capacity to understand the HTA Wales, they lived voluntarily in Wales for one year or longer and they died in Wales. [1,6]

5.7 Patients who do not fit the criteria for deemed consent can become donors after death by seeking consent from families. [1,6]

5.8 Following the introduction of the Human Transplantation (Wales) Act 2013, those patients who have not registered a decision on the Organ Donor Register, may have their consent for donation deemed. The conversation with the family will be presumptive in nature until such time the family disclose that the patient had made a verbal/written decision. This is set out in the codes of practice and NHSBT best practice guidance. [6,7]

5.9 It remains possible for family members to override the individuals expressed or deemed consent decision. SNODs will sensitively but openly explore this decision and guide the family to support the patient's decision, however it is recognised that the impact of proceeding with donation when there is opposition from family would potentially harm the bereaved relatives and is not likely to be in the patients interests or the wider transplant world. [6,7]

5.10 The HTA Wales also stipulates that a patient can nominate a representative to make decisions with respect to organ donation and supersede the family. The SNODs are best placed to support patient's who have nominated a representative and ensure that the legal process is followed.[1,6]

5.11 Qualifying relationships: The code of practice sets out hierarchical qualifying relationships and consent must be sought from the person highest on this list. Refer to the glossary terms for further detail. [6]

5.12 Children Deemed consent does not apply to people under the age of 18 years. However children or their parents on their behalf can register their wishes on the organ donor register. [6]

5.13 Further detail regarding the use of the HTA Wales 2013 should be sought in the Code of Practice. [6]

6.0 Diagnosis of Death

6.1 Donation can take place after brain stem death (DBD) or after circulatory death (DCD) [9,10]

6.2 Brain stem death tests should be conducted on all patients suspected of being brain stem death irrespective of a plan for organ donation. Refer to the Academy of Medical Royal Colleges 2008 Code of Practice for the diagnosis and confirmation of death and UHW guidelines for further detail in how to conduct brain stem death tests. [5]

6.3 In paediatric practice for infants less than 2 months old consult the RCPCH guidelines published in April 2015.[11]

6.4 An explanation of the tests must be offered to family members and in some circumstances family members might wish to observe the tests.

6.5 A patient with a plan to withdraw treatment has the potential to become a donor after circulatory death. The consultant in charge will determine how this withdrawal takes place acting in the best interests of the patient. The process might involve extubation and cessation of haemodynamic support. Deceased donation after cardiac death is more likely to proceed if the patient is extubated as part of their end of life care.

6.6 The patient must be observed by the clinician responsible for confirming death for a minimum of five minutes to establish that irreversible cardio respiratory arrest has occurred. This observation is carried out with the use of an arterial line and arterial pressure trace.[5,9]

6.7 The SNOD is responsible for documenting timings and liaising with transplant surgeons in theatre.

7.0 Donation from patients in areas other than ITU

7.1 It is recognised that patients with the potential to donate organs and tissues after death might be located in areas other than ITU. The principles surrounding decision making in these patients are the same as for patients on the ITU.

7.2 The emergency unit is the most likely area where potential organ donation patients will be located however it is possible that they might be identified on a stroke unit or other wards after emergency critical care interventions. [12]

7.2 Specifically it must be robustly and firmly established that further treatment is not in the patient's best interest. Two consultant clinicians should be directly involved with this decision making. The plan to withdraw treatment must be clearly documented and communicated sensitively to the family. [8]

7.3 The approach of families of potential organ donors must be planned with the SNODs and made collaboratively.[8]

7.4 It is recognised that in order that organ donation can proceed patients will be transferred to the ITU.

8.0 Donation Process Roles and Responsibilities

8.1 The SNOD will:-

- Attend the unit in a timely manner
- Check the Organ Donor Register
- Ascertain eligibility for consent to be deemed
- Ensure that all necessary information pertaining to the potential donor's admission has been obtained and communicated to the coroner to agree cause of death and reporting requirements. This can be done directly or via the responsible healthcare professional in the hospital. The SNOD is responsible for ensuring that the removal of organs and/or tissues for donation occurs only following coroner approval for donation when referral to the coroner is necessary. Occasionally the coroner may place some restrictions on donation dependent upon the circumstances of the patient's death. In this case, the SNOD will inform the family of the coroner's restrictions.
- Plan the approach for donation with the responsible medical practitioner and facilitate a collaborative approach
- Assess suitability for donation potential on an individual basis
- Work with ITU consultants and referring clinicians to ensure that patients not in the ITU at time of referral can be admitted to the ITU in a timely fashion to facilitate donation.
- Take Blood specimens and send for tissue typing and virology testing
- Request further testing as required and review results.
- Support staff through donation process +/- brainstem death testing
- Advise on donor management
    - DBD – NHSBT DBD optimisation extended care bundle
    - DCD – Treatment and intervention in a potential DCD donor is justified if it is thought to be in the patient's best interest and expected to result in a net benefit to the patient rather than burden or harm. The clinician in charge of the patient's care on an individual case-by-case basis must be the judge of their best

interests (12).

- Ensure a full assessment of the patient is made and this information is placed onto the Electronic Offering System (EOS). Recipient transplant centres have access to this system and can make a decision on suitability of potential recipients. It remains the responsibility of the implanting surgeon (and the informed recipient) to decide whether the risks associated with organ donation outweigh the benefits of using that organ.
- Mobilise a transplant team once organs placed
- Liaise with theatre
- Arrange anaesthetic support if required i.e. for DBD patients and for DCD patients donating lungs
- Be present throughout theatre process and be responsible for all explanted organs until they have either left the hospital or been handed over to Cardiff and Vale transplant team (if remaining in Cardiff).
- Will record a clear and precise record of all events in the hospital medical notes.
- Be responsible for (alongside theatre staff) last offices and removal of cannulas, endotracheal tube, catheter etc. before transfer to the mortuary.
- Provide on going contact with family during donation.
- Provide support for the families of eligible and proceeding donors following their death, providing family and relevant parties with outcomes of donation as appropriate.

8.2 For DCDs SNODS will also:

- Pre-arrange the time of withdrawal of treatment with intensive care medical staff.
- The retrieval team must be ready in theatre before withdrawal of treatment. Withdrawal without SNOD being aware/surgical team being ready may stop organ donation proceeding.
- If the patient suffers from a cardiac arrest at any time during donation process, resuscitation should not be attempted.

8.3 Responsible Medical Practitioner will:

- Refer all patients who are suspected brain stem dead and patients who have planned withdrawal of treatment in a timely manner
- Plan approach for donation with bedside nurse and SNOD and facilitate a collaborative approach
- Be responsible for speaking to HM Coroner to discuss the case and confirm the circumstances surrounding the admission of the patient/potential donor, and the decision surrounding the cause of

death to be written on the necessary NHSBT documentation and patient's medical notes.

- Instigate donor management:
    - DBD – Optimise patients using NHSBT DBD optimisation extended care bundle and arrange tests as necessary e.g. chest x-ray, echo, ECG.
    - DCD – Plan on an individual basis introducing new therapies or increasing existing therapies in line with the code of practice.
- Liaise with SNOD about timing of withdrawal of treatment
- Retrieval team MUST be ready in theatre before withdrawal. Withdrawal without SNOD being aware and the surgical team ready may stop organ donation proceeding.
- Be readily available (or nominate a suitable deputy) to certify death 5 minutes after asystole, immediately prior to theatre.
- Plan for treatment withdrawal and document in the medical notes along with Do Not Attempt to Resuscitation Documentation.

8.4 Nursing staff will:

- Continue to provide all care as per normal practice e.g. regular repositioning, oral care, management of ABGs and ventilation, fluid management, electrolyte replacement, temperature control et al.
- Optimise patients using NHSBT DBD optimisation extended care bundle
- Continue pastoral care of family
- Report any changes of patient's condition to SNOD and medical staff
- Report any new family concerns to SNOD and medical staff
- Assist in any further investigations e.g. Xray, ECG, Echo etc.
- Complete pre-op check list as per usual guidelines
- Assist with transfer to theatre

8.5 Theatre staff will jointly:

- Develop with the Organ Donation Team a comprehensive Standard Operating Procedure for patients going to theatre and procedures to be followed. This will include;Support for he retrieval team
- Support for the SNOD
- The procedure will be consistent with "UHW Guidelines for Donor Care During Multi-organ Retrieval"

8.6 In all cases the organ retrieval process will be coordinated by the SNOD who will support all staff involved in the patient's care throughout. Care of the deceased patient's body is performed by the hospital staff and assisted by the SNOD in accordance with the hospital policy. Respect and dignity for the patient, family and friends is maintained at all times

8.7 As per NMC code of conduct, GMC guidance and hospital policy any party involved in the donation process has a responsibility to ensure confidentiality is maintained.

9.0 Tissue Donation

9.1 Tissue donation is often possible after death.

9.2 To determine a patient's eligibility for tissue donation after death nursing staff must contact the National Referral Centre on 0800 432 0559.

9.3 Advice will be offered as to the patient's suitability and staff supported to approach families. Where tissue donation is not contra-indicated, a healthcare professional involved in the patient's care should approach the family about tissue donation. The nearest relative should be offered information regarding tissue donation options.

9.4 Families who wish to consider tissue donation the National Referral Centre will contact the family to complete formal consent process. The National Referral Centre will co-ordinate all tissue-only retrievals.

9.5 For patients who are proceeding organ donors the SNODs will complete the process of referral to the NRC.

Please see Appendix 4 for the flow chart on tissue donation.

10.0 Communication and Education Plan for this document

10.1 Dissemination at the Organ Donation Committee

10.2 Disseminate to Cardiff and Vale University Health Board*;* Medical Director and all Clinical Board Directors and Directors of Nursing.

10.3 Circulation of policy to key areas –Senior Nurse Manager & Lead Clinicians for intensive care unit, emergency department, cardiac intensive care unit and paediatric critical care unit.

10.4 To raise awareness of the policy through internal communication mechanisms.

10.5 Formal programmes of training and education, tailored to the needs of the specific clinical teams and staff, will be delivered and provided by the SNODs and the Clinical Leads for Organ Donation (CLODs). These will be updated on a yearly basis or as necessary, and a record kept of training carried out.

11.0 Monitoring Effectiveness

11.1 The SNOD will continue to audit all deaths occurring within critical care areas using the Potential Donor Audit. This audit will demonstrate rates of eligible donor identification, referral, and approach to relatives and consent to donation.

11.2 Effectiveness of the policy will be monitored using the results of the PDA and benchmarking C+V UHB against other health boards.

11.3 Detailed review of missed potentials will be undertaken and incident forms completed if appropriate. Issues around performance will be discussed at the organ donation committee meeting.

11.4 Variation from the guidelines will be investigated and action taken as necessary to feedback to members of the team.

11.5 Furthermore any concerns raised by the users of the policy or complaints from families of potential donors will also be used to assess the guidance and direct future amendments.

12.0 Review

This document will be reviewed in 2 years time or earlier if there are significant changes to the policy or the national guidance.

END

References

1 Human Tissue Authority (2013)*The Human Transplantation (Wales) Act. Accessed at* http://www.legislation.gov.uk/anaw/2013/5/contents on 04/01/2017

2 Mental Capacity Act 2005 http://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf accessed on 04/01/2017

3 Treatment and care towards the end of life. General Medical Council May 2010 _Accessed at http://www.gmc-uk.org/static/documents/content/Treatment_and_care_towards_the_end_of_life_-_English_1015.pdf on 04/01/2017

4 National Institute for Health and Clinical Excellence (2011) *Organ Donation for transplantation: improving donor identification and consent rates for deceased organ donation.* Accessed at http://www.nice.org.uk/nicemedia/live/13628/57508/57508.pdf on 04/01/2017

5 Academy of Medical Royal Colleges (2008) *Code of Practice for the diagnosis and confirmation of death*. Accessed at http://www.aomrc.org.uk/aomrc/admin/reports/docs/DofD-final.pdf on 04/01/2017

6 Human Tissue Authority (2013)*The Human Transplantation (Wales) Act – Code of Practice.* https://www.hta.gov.uk/guidance-professionals/codes-practice/code-practice-10-human-transplantation-wales-act_ accessed on 04/01/2017

7 NHSBT Best Practice Guidelines Approaching the families of potential organ donors. http://www.odt.nhs.uk/pdf/family_approach_best_practice_guide.pdf accessed on 04/01/2017

8 Royal College of Emergency Medicine Best Practice Guidelines End of Life Care for Adults in the Emergency Department. https://www.rcem.ac.uk/docs/College%20Guidelines/5u.%20End%20of%20Life%20Care%20for%20Adults%20in%20the%20ED%20(March%202015).pdf accessed on 04/01/2017

9 Department of Health (2009) *Legal Issues Relevant to non-heart beating donation.* Accessed at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_109864.pdf on 04/01/2017

10 Department of Health (2008) *Organs for Transplants – A Report from the Organ Donation Taskforce.* Accessed at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_082122 on 04/01/2017

11 Royal College of Paediatrics and Child Health The diagnosis of death by neurological criteria in infants less than two months old. April 2015 http://www.rcpch.ac.uk/system/files/protected/page/DNC%20Guide%20FINAL.pdf last accessed on 09/01/2017

12 NHSBT Organ Donation and the Emergency Department A strategy of Implementation of Best Practice November 2016 http://www.odt.nhs.uk/donation/deceased-donation/donation-from-emergency-department/ last accessed on 09/01/2017

Glossary of Terms used in the Document

Specialist Nurse for Organ Donation
A senior nurse with specialist knowledge in the process of organ donation, who is expert in communication with families and has an important role within the hospital in supporting deceased donation at all levels.

Clinical Lead for organ donation
A consultant in hospital medicine with a special interest in deceased organ donation, who supports the process of donation in the hospital through education, development of policies and providing expert knowledge.

Eligible Donor after Brain Death (DBD)
A patient whose death has been confirmed using neurological criteria, with no absolute contraindications or relative contraindications to solid organ donation.

Eligible Donor after Circulatory Death (DCD)
A ventilated patient, whose imminent death is anticipated, when a decision has been made by a consultant that treatment is to be withdrawn based on medical futility and acting in the patient's best interests or when there is a valid and applicable advance decision to refuse treatment (ADRT).

Non Proceeding Donor
An individual that begins the process towards organ or tissue donation but does not progress through to donation.

Opted in/out
An individual has recorded a positive or negative decision on the organ donor register.

Deemed Consent
Unless a person has made a decision to opt in or opt out of donation then they will be regarded as having no objection and their consent will be deemed to have been given.

Deemed Consent Eligibility

- Over the age of 18
- Who ordinarily live in Wales and have done so for longer than 12 months
- Who have not expressed or recorded a decision
- Who die in Wales
- Who have capacity as per Mental Capacity Act 2005

Nominated/Appointed Representative

One or more people whom the individual has nominated to make decisions solely regarding organ donation. A nominated representative will supersede any other qualifying relationship in relation to organ donation.

Qualifying Relationships

The human tissue act sets out a hierarchy of relationships that in the event that there is disagreement regarding consent for donation allows the opinion of certain relatives to carry greater weight.

A. Spouse or partner
B. Parent or child
C. Brother or sister
D. Grandparent or grandchild
E. Niece or nephew
F. Stepfather or stepmother
G. Half-brother or half-sister
H. Friend of longstanding

From the Human Tissue Act Wales 2013 Code of practice a friend of long standing is not defined in the legislation as having a specified time period attached to the friendship. Whether someone is a friend of long standing will be a question of fact and degree in each case and the SNOD may ask questions and/or request evidence as necessary to establish what degree of friendship existed.

Appendix 1: Flow Chart for the Approach of Family of Potential Donors

Planning

- **Who:** Consultant, SN-OD and nurse
- **Why:**
  - Clarify clinical situation
  - Seek evidence of prior consent/authorisation (eg ODR or other)
  - Identify key family members by name
  - Define key family issues
  - Agree a process of approach and who will be involved
  - Agree timing and setting, ensuring these are appropriate to family needs
  - Involve others as required, eg faith leaders
- **When and where:** in private and before meeting the family to confirm understanding and acceptance of loss

Confirming understanding and acceptance

For a potential DBD donor, ensure the family understand that death has occurred. Spend time with the concept, using diagrams or scans if necessary.

In the DCD setting, ensure the family understand and accept the reasons for treatment withdrawal and the inevitability of death thereafter.

Donation should only be raised at this point if it is clear that a family has understood and accepted their loss. If this is not the case, suggest a break. The key is to ensure that the family have accepted and understood the clinical situation before donation is raised.

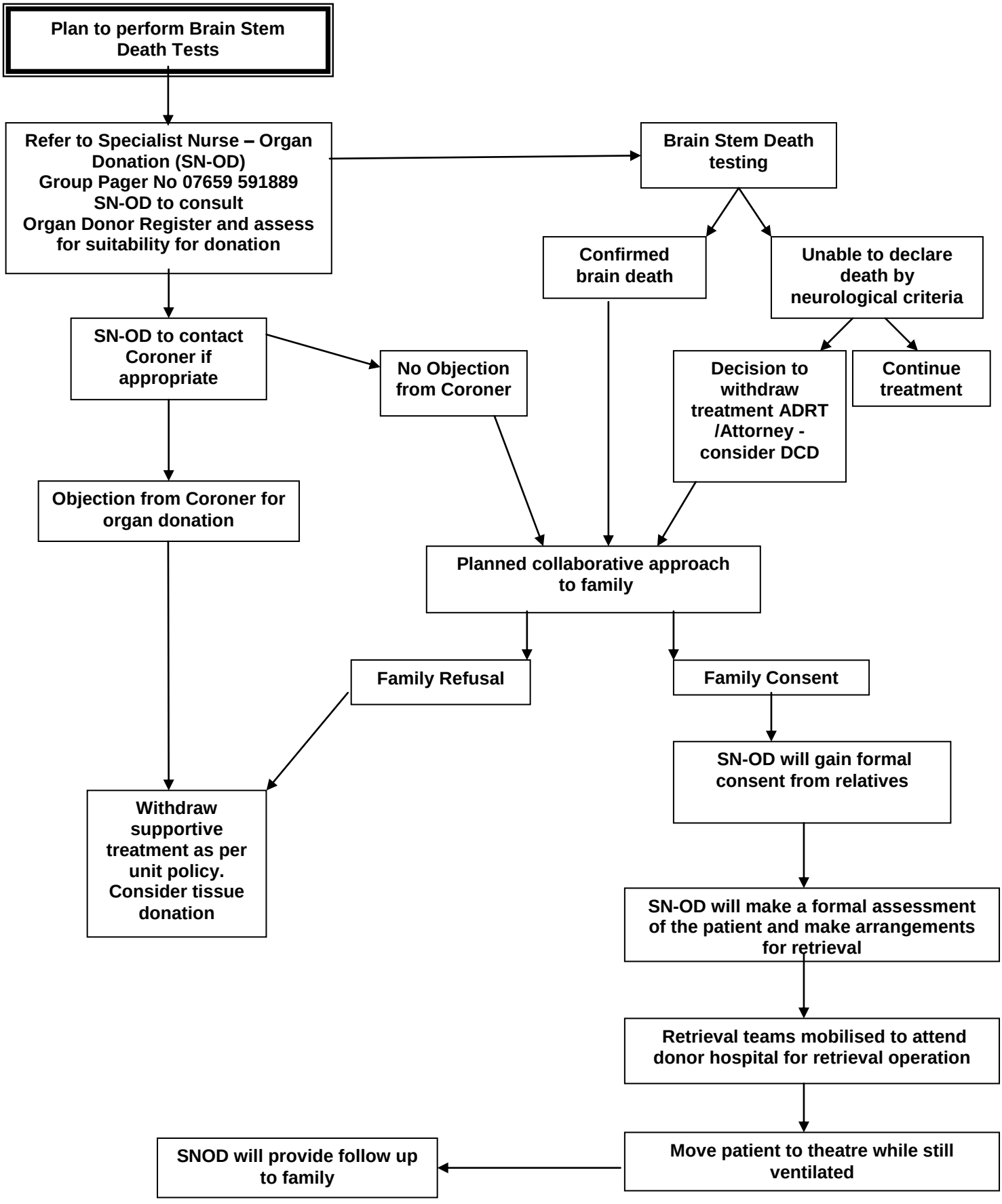
Discussing donation

- Re-confirm the family's understanding of the clinical situation.
- Provide specific information on process before expecting a response
- Avoid negative or apologetic language
- Avoid manipulative or coercive language
- Emphasise the benefits of transplantation – the ability to save and transform several lives
- Sensitively explore an initial 'No', some causes of which can be addressed or are a result of misconceptions about donation.

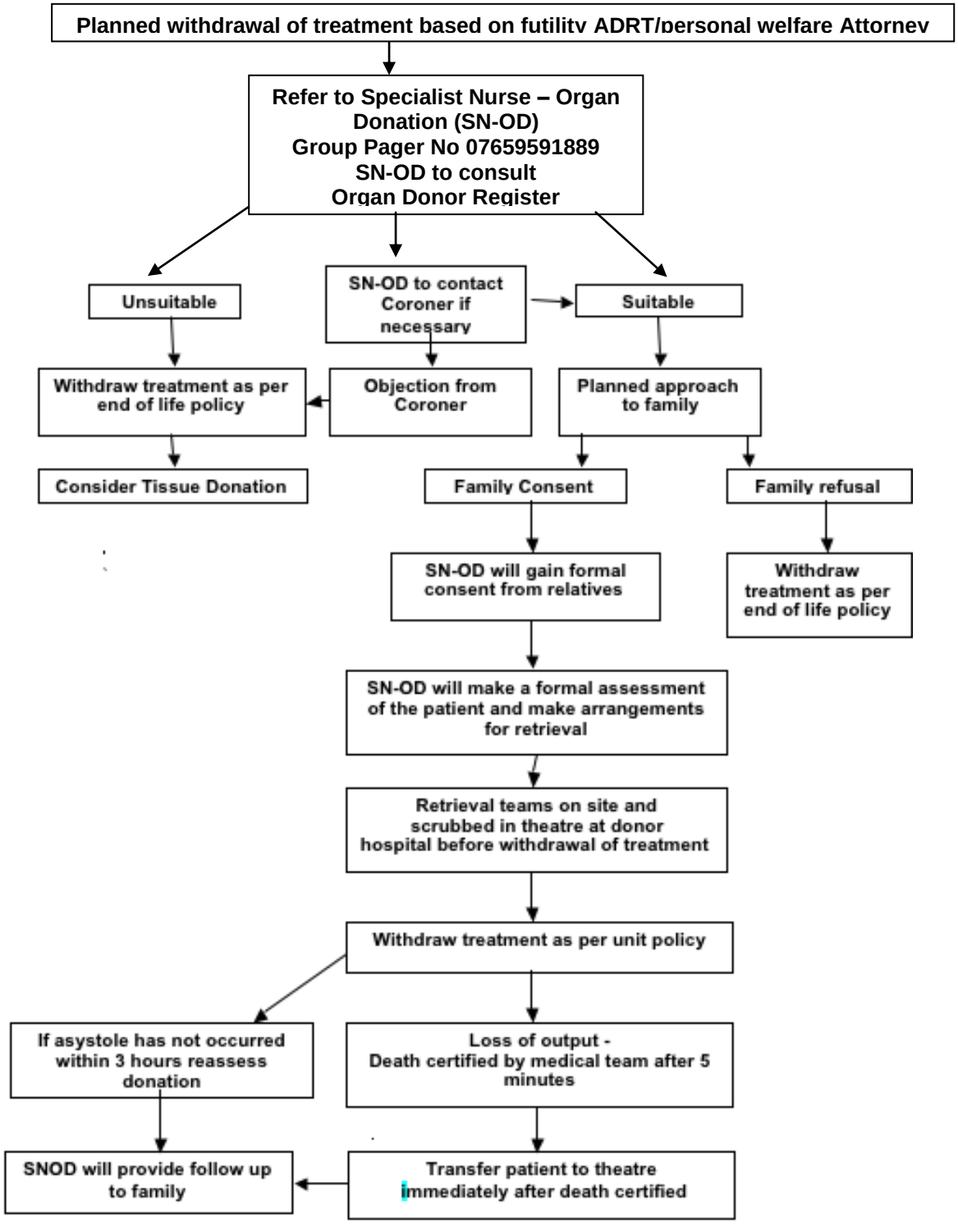
Recognising their training and experience, wherever possible utilise the SN-OD throughout the family approach to:

- Provide knowledge and expertise
- Discuss options
- Help recognise modifiable factors and challenge misconceptions
- Support and spend time with the family.

Appendix 2: Flow Chart for Donation after Brain Stem Death



Appendix 3: Flow chart for Donors Eligible for Donation after Cardiac Death



Appendix 4: Flow Chart for Tissue Donation after Death