

Local Guideline



Health
Hunter New England
Local Health District

Organ and Tissue Donation in the NICU

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| Sites where Local Guideline applies | Neonatal Intensive Care Unit JHCH. |
| This Local Guideline applies to: | |
| 1. Adults | No |
| 2. Children up to 16 years | No |
| 3. Neonates – less than 29 days | Yes. Approval gained by CYPFS 26/09/2017 |
| Target audience | NICU clinical staff, who provide care to neonatal patients |
| Description | Provides information to clinicians about best practice in the care and management of neonates and their families who are being considered for organ and tissue donation following death |
| <div style="border: 2px solid black; padding: 5px; display: inline-block;"> Hyperlink to Guideline </div> | |
| Keywords | neonate, organ donation, procurement, retrieval, brain death, beating-heart-donation, circulatory death, DBD (donation after brain death), DCD (donation after circulatory death) |
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| Related Legislation, Australian Standard, NSW Ministry of Health Policy Directive or Guideline, National Safety and Quality Health Service Standard (NSQHSS) and/or other, HNE Health Document, Professional Guideline, Code of Practice or Ethics: | |
| <ul style="list-style-type: none"> • NHMRC Guidelines for Organ and Tissue Donation after Death 2007 • NSW Health Policy: Donation, Use and Retention of Tissue from Living Persons – PD2016_001 • NSW Organ Donation after Circulatory Death: NSW Guideline GL2014_008 • NSW Health PD: Deceased organ and tissue donation- consent and other procedural requirements PD2013_001 | |
| Prerequisites (if required) | N/A |
| Local Guideline note | This document reflects what is currently regarded as safe and appropriate practice. The guideline section does not replace the need for the application of clinical judgment in respect to each individual patient but the procedure/s requires mandatory compliance . If staff believe that the procedure/s should not apply in a particular clinical situation they must seek advice from their unit manager/delegate and document the variance in the patients' health record. |
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RISK STATEMENT

This local clinical procedure has been developed to provide instruction to the health clinician and to ensure that the risks of harm to the child/family associated with possible organ and tissue donation are prevented, identified and managed.

The risks are:

- *Distress of the families by inadequate communication on subject of organ and tissue donations*
- *Inappropriate timing of organ donation*
- *Missed opportunities of organ and tissue donation*

The risks are minimised by:

- *Clinicians having knowledge of ways to support families when parents request organ and tissue donation*
- *Clinicians seeking assistance when knowledge of organ and tissue donation is outside their scope of practice*
- *Clinician knowledge of information in the local guideline*
- *Contacting the Organ Donation service for support and provision of information*
- *Ensuring consistent information provided to families for each discussion and documented in notes*

Risk Category: *Clinical Care & Patient Safety;*

ABBREVIATIONS & GLOSSARY

| | |
|-----------------|--|
| ABG | Arterial Blood Gas |
| Actual Donor | Operation commenced for organ retrieval. Includes donors deemed medically unsuitable intra-operatively. |
| ANZICS | Australian and New Zealand Intensive Care Society |
| ANZOD | Australian and New Zealand Organ Donor Register |
| AODR | Australian Organ Donor Registry |
| APPT | Activated Partial Thromboplastin Time |
| ARCBS | Australian Red Cross Blood Service |
| ATCA | Australian Transplant Coordinators Association |
| BHD | Beating Heart Donor |
| CK | Creatinine Kinase |
| Conversion Rate | The number of actual donors divided by the number of potential donors, minus the medically unsuitable and represented as a percentage of potential donors progressing to actual organ donation |
| CVA | Cerebrovascular Accident |
| CVP | Central Venous Pressure |
| CXR | Chest X- Ray |
| DBD | Donation after Brain Death |
| DCD | Donation after Circulatory Death |

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| DDAVP | Desmopressin |
| Deceased Refusal/Decline | Person did not wish to be an organ donor, as indicated from family discussion or registration of objection on the AODR or RMS database |
| DI | Diabetes Insipidus |
| CS | Community Services |
| DSC | Donation Specialist Co-ordinator (state office based) |
| DSM | Donation Specialist Medical |
| DSN | Donation Nurse Specialist (hospital based) |
| EAP | Employee Assistance Programme |
| ECG | Electrocardiogram |
| ED | Emergency Department |
| EDR | Electronic Donor Record |
| EUC | Electrolytes, Urea and Creatinine |
| FBC | Full Blood Count |
| FiO2 | Fraction of Inspired Oxygen |
| FP | Forensic Pathologist |
| HNELHD Organ Donation Governance Group | Representation of HNELHD staff (OT, ICU, Social Work, ED, Pastoral Care, Transplant DonateLife representative, & Neurosurgery) discuss and address clinical issues related to organ donation, and management of potential and actual donors |
| ICU | Intensive Care Unit |
| IDAT | Introductory Donor Awareness Training (formerly ADAPT) |
| IDC | Indwelling Urinary Catheter |
| INR | International Normalised Ratio |
| Intended Donor | Consent has been obtained, and blood collection has occurred however, organ donation did not proceed. Includes failed physiological support, contraindication found during process, no suitable recipients, logistical difficulties, and late coronial refusal |
| LFT | Liver Function Test |
| MAP | Mean Arterial Pressure |
| Medically Unsuitable | Organ donation refused due to significant past or current medical history |
| Ministry of Health | NSW Department of Health |
| NICU | Neonatal Intensive Care Unit |
| NHMRC | National Health and Medical Research Council |
| Notification/Referral | Donor Coordinator contacted re: patient potentially suitable for organ / tissue donation |
| NSWOTDS | New South Wales Organ and Tissue Donation Service Otherwise known as Donate Life NSW |
| OT | Operating Theatre |
| PaCO2 | Partial Pressure Arterial Carbon Dioxide |
| PEEP | Positive End Expiratory Pressure |
| Potential Donor | The Australian Organ and Tissue Authority death audit tool - Person(s) with an irreversible brain injury as defined in the DonateLife data audit tool or who meets the clinical trigger. This includes confirmed brain dead (Category A), possibly brain dead but not confirmed (Category B), Potential to progress to brain death within 24 hours (Category C) and not likely to become brain dead |

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| | (Category D). Formal reports from Organ and Tissue Donation Service NSW focus on Category A and B |
| PT | Prothrombin Time |
| RMS | Roads and Maritime Services (previously RTA) |
| SaNOK | Senior available Next of Kin |
| SBP | Systolic Blood Pressure |
| SESAHS | South Eastern Sydney Illawarra Health Service |
| SpO2 | Oxygen Saturation |
| TSANZ | Transplant Society of Australia and New Zealand |
| Unrealised/Missed potential donor | Patients for whom organ donation was not identified as possibility, discussed or requested. These patients are reviewed in death audits by DSN |

OUTCOMES

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| 1 | Early recognition and compassionate management of potential for organ or tissue donation in the neonate |
| 2 | To maintain a safe environment and adherence to OH&S principles |
| 3 | Dignified care of the dying baby and their family |
| 4 | Any decision to donate organs, or not, will be made without undue stress or influence |
| 5 | Any decision by the family to donate, or not, a neonate's organs will not impact on the care of the baby and/or their family provided by all staff involved. |
| 6 | Staff involved in the care of the neonate donating organs will provide supportive and appropriate care to the baby and their family. |
| 7 | Staff involved will receive appropriate support and opportunities to debrief, and further support if requested. |
| 8 | In the event donation is pursued a clinical process will occur, which enables the retrieval of viable organs for transplantation. |

Guideline Title - One Page Summary and Checklist

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GUIDELINE

This Guideline does not replace the need for the application of clinical judgment in respect to each individual patient. This guideline is intended for use within the NICU at JHCH and aims to establish best practice in the care and management of neonates who are being considered for organ and tissue donation following death. Care and support of the family are of equal and utmost importance.

Introduction:

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In Australia, organ and tissue transplantation is a well-established clinical practice. Transplantation is now considered a desirable treatment form, and a cure for many diseases. The health benefits to the community and to the quality of life of individuals and their families are considerable.

Currently, medical, ethical and legal guidelines regulate and monitor the current practice of organ and tissue donation.

To incorporate local philosophy and procedures, a working party representing medicine, nursing, allied health, ethics, and pastoral care considered the medical and ethical aspects of donation after brain death and cardio circulatory death to ensure respect for individuals and for cultural differences. The guideline they developed encourages clinicians to discuss

organ donation and transplantation in a balanced fashion and to provide ongoing end-of-life care for patients and families irrespective of the outcome. The document assists Hunter New England Local Health District (HNELHD) health professionals in this process. This guideline has been regularly updated to remain consistent with state and national practice.

Objective

The opportunity for organ donation is rare, even more so in the neonatal population. All families with a baby who has the potential to be a candidate for organ donation should have access to clear and comprehensive information, provided by staff with experience in discussing and requesting consent for donation. This guideline aims to assist the clinician in the identification of neonates who may be suitable donors and details the clinical pathway from donor identification through to retrieval and donor family follow up.

Background

In the past, donation following brain death (BD) has been the most common pathway for organ donation and still accounts for approximately 75% of all multi-organ donors. However, DCD (Donation post Circulatory Death) numbers are increasing as families are given the option of donating organs and tissue where their loved one is expected to die following withdrawal of ventilator support.

Organs considered for donation include the heart, lungs, liver, kidneys and pancreas, as well as eyes, musculo-skeletal tissue and cardio-vascular tissue. Medical suitability, including age, current and past medical conditions is assessed by the DSN/DSM after referral to the organ donation team.

The demand for donated organs far surpasses supply, with less than 2% of people who die in hospital meeting the criteria for organ donation, (donatelifelife, n.d.). Importantly, the paediatric population has seen “significantly fewer cadaveric donorscompared to adults”, (Brierley and Larcher, 2011). Advances in medical technology have allowed infants through to adults to receive life sustaining treatment on the transplant waiting list. As such these advances have led to “a widening gap between the number of available organs and the need for organs, resulting in a significant number of children continuing to die whilst waiting for transplantation”, (Watts, 2006, 58).

Referrals for potential donors are identified by using the **GIVE** clinical trigger, adapted for the neonatal donor. The National Authority for Organ and Tissue Donation requires a 100% clinical trigger identification and notification to the DSN. This data is audited by the DSN and reported to the National Authority on a monthly basis. Any episodes identified retrospectively as a missed/unrealised potential donor on the monthly death audit are followed up with the appropriate personnel.

1. Principles of Organ & Tissue Donation

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Donation of organs and tissues is recognised as an act of altruism that benefits those in need and society as a whole. The process must respect the patient's dignity as well as the rights and wishes of the family/carers.

Organs and tissues for transplantation must be obtained in ways that:

- Demonstrate respect for all aspects of human dignity, including the worth, welfare, rights, beliefs, perceptions, customs and cultural heritage of all involved
- Respect the family's wishes, where known
- Give priority to the potential donor and their family's needs, over organ procurement
- Protect recipients from harm
- Recognise the needs of the health professionals involved
- Organ and tissue allocation must be governed by just and transparent processes
- Those who choose not to donate should be treated with similar respect and understanding
- HNELHD Health staff must always meet the values of the organisation which are: Collaboration, Openness, Respect, and Empowerment.

2. Identification of potential organ & tissue donors

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Timely notification ensures the best possible opportunity for organ donation. If in doubt, seek advice from DSN.

Currently there is no internationally accepted clinical trigger to identify patients in the neonatal intensive care population. It is recommended that if end of life care is being initiated in a neonatal intensive care situation that medical suitability and the possibility for donation to occur be discussed early with the DSN. The baby will be referred to the NSWOTDS who will liaise directly with state services for paediatric transplantation to ascertain suitability.

The **GIVE** clinical trigger, well known and identified in the adult organ donor population stands for:

- **GCS** of less than 5,
- **I**ntubated,
- **V**entilated and
- **E**nd of Life care has been established and or discussed.

For use in the JHCH NICU, the trigger has been modified for relevance to the neonate:

- **G**estation of 34 weeks or greater,
- **I**ntubated,
- **V**entilated and
- **E**nd of Life Care has been established or discussed.

3. Considerations prior to discussion with families

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- *First and foremost, the family is informed of the baby's end of life care, imminent death or plans for brain death testing.*
- Inform the on-call DSN 24/7 of a potential organ donor or when clinical triggers have been met on mobile 0409 164955 (speed dial 66742) or John Hunter Hospital switchboard (02) 4921 3000.
- If the local DSN is unavailable, you may contact a NSW Organ and Tissue Donation Service (NSW OTDS) Donation Specialist Consultant on 9963 2801
- Check the Donor Selection Criteria, (you may call the DSN to do this) to assess medical suitability, you may also contact the Hospital Medical Director for Organ and Tissue Donation (HMD) to request assistance: All patients must be referred to the NSW OTDS for transplant specialists to decide upon suitability. (*Also see Appendix 4*)
- Family and friends: involve Social Work for support and ascertain if religious support is required
- Family conferences regarding end of life care should always include the nurse and Social Work and Pastoral Care (if desired), caring for the baby
- Check that you are talking to the right people. It is necessary to include the "person responsible" (see later "in who should be present at the consent interview?" section 6.5) and the senior available next of kin in these discussions
- A request for multi-organ donation to the family should **only** be made by the Designated Requestor (senior NICU Staff Specialist or NICU fellow with appropriate training (see appendix), and the DSN)
- Solid organ donation can only occur if the patient is ventilated, 'tissue only' (heart valves and vessels) donation is possible in other cases.
- The family's wishes should be ascertained. This can be done in discussion with family members and senior next of kin.
- If the baby needs to be transferred to another site for donation, the family should be informed that no costs will be associated with the transfer or donation but normal funeral cost (including transfers home) may apply following donation.

4. Principles & Procedures for consent

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The principles and procedures for consent in relation to organ and tissue donation are documented in the NSW Human Tissue Act, 1983, and its amendments (2003).

4.1 Who Can Give Consent (in hierarchical descending order):

- Parent of the child
- Sibling > 18 years
- Guardian of the child at the time of death

4.2 Children in care of the state (Community Services - CS)

If a child is in the care of the state or protective custody, the consent should be obtained as listed below (this will be done by the DSN). If the status of custody or care is unknown, the

police may be contacted and enquires made through CS. The Designated Officer may, after such enquiries with the principal care officer (see below), authorise the removal of tissue from the deceased child's body for the purpose of its transplantation to the body of a living person.

4.3 Principal Care Officer

The principle care officer is the Executive Officer of the designated agency that has responsibility for the baby/child – eg: Community Services.

A principal care officer must not give consent for organ donation or grant an authority before:

- (a) He/she has used reasonable efforts to consult with such persons as the officer considers might be appropriate (for example the parents, grandparents, foster parents, siblings)
- (b) If an objection from any of those consulted arises, the officer must not give consent or grant authority
- (c) The principal care officer may determine that more than one person's approval is required

4.4 Delegation of Senior Next of Kin Responsibilities

The senior next of kin can delegate their responsibility in writing to another nominated person who then, if they agree, becomes the senior next of kin. This should be documented in writing. (Form SMR020031)

4.5 Who Should be Present at the Consent Interview?

It is important to ensure that the right people (that is, those with legal authority) are involved in all discussions about end of life care and the possibility of organ donation. While the baby is alive, the legal authority to give consent lies with the "person responsible" as defined by the Guardianship Act 1987. This person may relinquish this role, in which case the person responsible is the next most senior person. Once a patient is deceased, consent must be obtained from the senior next of kin. The "person responsible" and the "senior next of kin" may or may not be the same person. To avoid confusion, the "person responsible" and "senior available next of kin (NOK)" should be identified clearly as accepting these roles, and both be involved in decision making. Consent for organ donation must be obtained from the senior available next of kin. If the death is being referred to the Coroner the DSN/DSC will liaise with the forensic pathologist and coroner to obtain permission for organ and tissue donation to occur.

4.6 Designated Officer Consent (see local and state policies and procedures relating to Designated Officer role)

- The Designated Officer's role is to authorise the removal of tissue from the deceased, after death, for transplant or other therapeutic, medical or scientific purpose.
- The Designated Officer has discretionary authority. The Designated Officer must be satisfied that the senior available NOK has a clear understanding of consent and process, with no coercion, before giving written authority for a procedure. However, a Designated Officer is not obligated to authorise that procedure.

- Consent from the senior available NOK (and coroner where appropriate) must occur prior to authorisation from the designated officer.
- Consent can be for transplantation and/or research, a list of current research projects is available from the DSN.
- Organ retrieval surgery cannot occur without Designated Officer authorisation
- Designated Officers are available via JHH switchboard.

4.7 Family Refusal

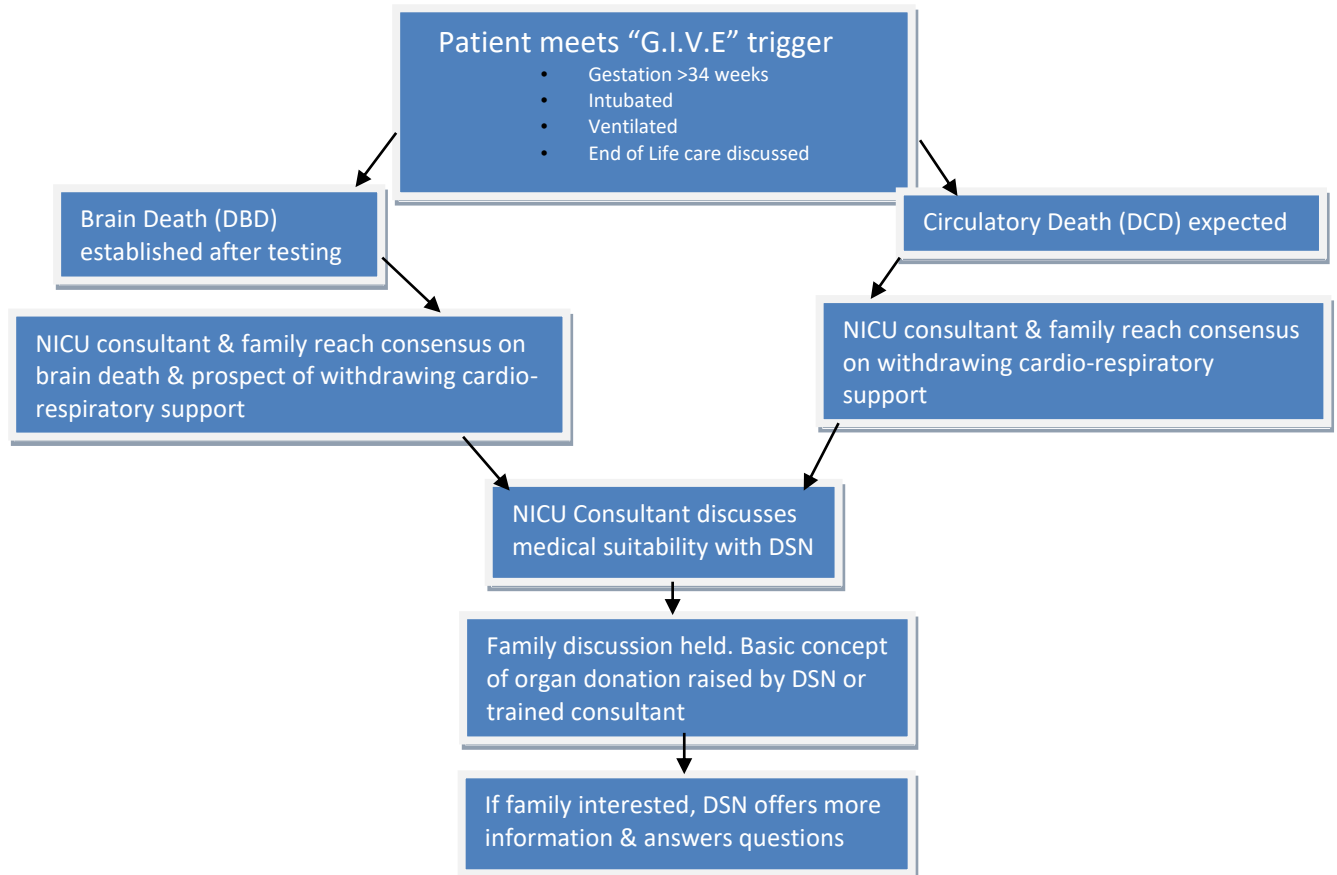
In the event of a refusal to donate organs, staff should offer condolences to the family, and express appreciation for considering donation. All care should continue as per 'Guideline Dying Baby in NICU – Care of.' [*"Dying Baby in NICU-Care of", JHCH NICU 08.01*](#)

All families should be supported regardless of their decision regarding organ donation. Optimal end of life care and family support will continue to be provided as per NSW Health and local guidelines.

5. Process of organ donation

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There are 2 pathways to organ and/or tissue donation: Donation after Circulatory Death (DCD) and Donation after Brain Death (DBD).



DBD has been the most common pathway for organ donation, accounting for approximately 75% of all multi-organ donors in adults. However, clinically confirmed brain death in the neonate is a rare occurrence, thus it is anticipated that DCD will be the more common pathway seen in the NICU

5.1 Donation after circulatory death

Organ and tissue donation should not be discussed until:

- The family and medical staff have reached consensus on withdraw of cardio-respiratory support
- Medical suitability should be discussed with the DSN/DSC and the Donation medical specialist (local or state based). Each case should be case managed and discussed in a team meeting with the NICU specialist, donation specialist staff, NICU bed side nurse, Designated Requestor, and any allied health care staff that are involved.
- Complete the 'Organ Donation Checklist' to assist you in the organ donation process (see Appendix 3)
- Donation may only proceed once the family has had an opportunity to discuss all options and consider possible outcomes.

5.1.1 Family interviews about withdrawal of cardio-respiratory support and DCD

- The NICU Consultant makes the decision to withdraw cardio-respiratory support with the agreement of other consulting specialists and family members (NSW Health guidelines for end of life care and decision making 2005).
 - Circulatory death is assessed by the presence of an arterial line
 - The discussion is clearly documented in the patient's notes.
 - In a separate second conversation, the NICU Consultant, (or designated requestor) and DSN/DSM may introduce the basic concept of Donation after Circulatory Death, and with the family agreement, will arrange for them to receive more information from the DSN, to ensure that an informed decision can be made.
- In the event a family wishes to proceed with DCD, the content of the meeting between the DSN and the family, will involve:
- An assessment of likelihood of death occurring within 60 minutes of WLST is required for DCD suitability
 - Organs that may be considered for donation
 - Reasons that donation may or may not proceed
 - Timelines and expectation for family and DSN during process
 - Provision of information regarding donation and coronial processes
 - Legal requirements for donation to proceed
 - Obtaining written consent for removal of tissue, for transplantation and/or research
 - Completion of a medical and maternal social history questionnaire,
 - Comprehensive assessments of medical history and assessment of organ function to assess suitability for transplantation.
 - Discussion with external health care providers regarding medical history
 - Obtaining consent for blood testing for disease screening, cross matching, tissue typing and transplantation purposes (this may include maternal blood samples)
 - Use of electronic referral systems for provision of information to transplant physicians

- Support for family whilst in the NICU environment
- Location of withdrawal of cardio-respiratory support
- Bereavement follow up and support
- The family will be advised at all times (negotiated with families) regarding updates, operating theatre times and any changes associated with donation.

5.2 Donation after brain death

Organ and tissue donation should **not** be discussed until:

- ***There is medical consensus that death is imminent or actual, and there has been a discussion with the DSN to determine potential recipients and/or if organ and/or tissue donation is possible.***
- Brain death has been established and a Certification of Brain Death SMR010517 is completed. This is to be completed by two doctors who confirmed brain death (see Appendix 2), one of whom must be a designated specialist. Each test should be 24 hours apart.
- Time of death: noted at the completion of the second set of brain death tests and is the legal time of death.
- The family have been informed about the outcomes of brain death testing.
- Inform bed allocations immediately – this ensures that the patient's family is not billed for further tests in the event of organ donation, and also that patient is not prematurely discharged. Patient must have their service category changed to '9 – Organ Procurement Posthumous' one minute prior to the time of brain death being declared.
- Medical suitability should be discussed with the DSN/DSC and/or the Donation medical specialist (local or state based). Each case should be case managed and discussed in a team meeting with the NICU specialist, donation specialist staff, NICU bed side nurse, Designated Requestor, and any allied health care staff that are involved.
- Donation may only proceed once the family has had an opportunity to discuss all options and consider possible outcomes, and gives consent.
 - Consent and Authority for Removal of Tissue after Death SMR020030 – to be completed by the senior available next of kin or delegate and the Designated Officer in the presence of the Staff Specialist and/or DSN
- Electronic Donor Referral to be completed by the DSN as part of the donor assessment and referral. The Clinical Pathway can also be used at this time.
- Donor management and homeostasis is maintained.
- Surgery time to be negotiated with Operating Theatre personnel and retrieval teams via DSN.
- Pre-op checklist attended by nursing staff.
- Organ retrieval surgery.
- Complete the 'Organ Donation Checklist' to assist you in the organ donation process. (see Appendix 3)

6. Donor Management

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6.1 Pre-operative Care

The neonatal donor should be managed according to standard hemodynamic and respiratory strategies for neonates in the intensive care. All vital observations should be within normal target ranges.

- Temperature to be maintained above 36°C, except where therapeutic cooling occurs.
- Heart rate to be stable and appropriate for gestation
- Arterial line in situ for blood sampling and ABP monitoring.
- Blood pressure and MAP to be maintained as appropriate for gestation. Inotropes can be used to maintain blood pressure as per unit policy.
- IV access for medications and hydration.
- Blood gas: aim for pH 7.35-7.45; PCO₂ 35-55; PO₂: 50-70 (term), 45-65 (preterm); HCO₃ 22-26mEq/L; BE -2 to +2 mEd/L, however may be discussed with the DSN.
- Maintain urine output >1ml/kg/hr

In the event of respiratory and/or cardiac failure, an attempt at resuscitation may be undertaken however prolonged resuscitation is not appropriate.

6.1.1 Blood Collection.

- Xmatch
- FBC
- UEC
- serology

Please note: The DSN in collaboration with the pathology services will establish the volume of blood to be removed. The DSN will also liaise with the mother of the baby and obtain serology blood samples for testing.

Collect and send pathology blood samples to local hospital pathology service for: Blood group, and 6/24 FBC, Coags, PT, APTT, INR, EUC, LFT, Glucose, and Troponin should be attended.

6.1.2 Donor Care and Assessment

- Continue antibiotics and other medications
- Obtain chest X-ray, cardiac echo and 3 lead ECG if not already complete
- Maintain hemodynamic stability
- Maintain normal electrolytes: Magnesium (Mg²⁺), Potassium (K⁺) and Sodium (Na⁺)
 - treat arrhythmia
- Contact the DSN at any time re. any questions on donor management or to report any changes in donor's condition
- Regular ABG monitoring of EUCs

6.1.3 Transfer to Operating Theatre (OT)

- Patient collected by operating theatre wards person and anaesthetist. Notes to accompany patient with consent form, brain death certification (if DBD applicable), hard copy of ABO, coronial paperwork (if coroner's case), death certificate and cremation certificate (if DBD applicable)

- A Social Worker, Pastoral Care officer or NICU nurse should be available to support the family once the patient leaves the NICU for transfer to theatre. If requested, the baby can return to NICU to spend time with family.
- A DSC and/or the DSN will be present in the OT to support the OT staff and retrieval teams, as well as to ensure any end of life care wishes and requests can be facilitated on behalf of the family.

6.1.4. Organs That Are Unable To Be Transplanted

The DSN is required to enquire as to the senior next of kin's wishes for any retrieved but non-transplanted organs and tissues. These can be:

- Reunited with the deceased's body (sent to the funeral home or Coroner's mortuary);
- Disposed of as per usual hospital procedure; or,
- Used for research only with specific permission by the donor / donor's family

7. Family Support

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7.1 Bereavement Care

- Ensure Social Work involvement in all cases and ascertain if religious support is required. The DSN is present throughout the donation process and assists with EOL care and transfer to mortuary.
 - Sudden and traumatic incident: shock, grief, reduced cognitive function– requires simple and honest explanations. *Avoid* using terms such as:
 - “life support” (use instead “ventilator”)
 - “harvest” (use instead “surgical removal”, “donation surgery”, “retrieval surgery”)
 - Explain that the appearance of life in babies who are brain dead is due to perfusion from the oxygen provided by the ventilator.
 - Explain the appearance of life is “artificial” in brain dead babies
 - Do not refer to the donor as a “body” in operating suite
 - Family is informed of the donation process, duration/length of the procedure and that organ procurement is a full surgical procedure with considerable respect given to the baby. In brain dead donors, the family will also be informed that the heart will stop beating and the ventilator will be removed during organ retrieval surgery.
 - However, if there is a risk that no organs will be retrieved during surgery, consultation should occur with the OT staff regarding where the extubation will occur.
 - There is no disfigurement to the baby during the donation procedure.

7.2 Post Donation Bereavement Support

Family should always be offered the opportunity to see and spend time with their baby following donation. This may occur:

- in a private room in the NICU (facilitated by DSN, NICU nurse and/or Social Worker)
- in Coroner's Court mortuary (facilitated by Coroner's Court Social Worker in special circumstances)
- in the Funeral home (facilitated by Funeral Director)
- additional support and follow up may be required from Social Worker, Pastoral Care staff and DSN

7.3 Bereavement Aftercare Program

This should include:

- Initial phone call (24-48 hours post-donation) from the DSN and letter (1-2 weeks post-donation) from the Donor Family Support coordinator.
- Follow-up phone call from Bereavement Services 4-6 weeks post-donation.
- Family support coordinators from NSWOTDS provide:
 - a bereavement package that includes a letter, booklets, and relevant contact numbers
 - Toll free number for support and counselling
 - Support groups (either face to face or by teleconference)
 - Liaison with Social Worker and Pastoral Care (and referrals to outside agencies)
 - Information re: annual non-denominational ecumenical service
 - Will pass on, if desired, anonymous recipient communication
 - 1st and 2nd year anniversary cards are sent

8. Care of the Baby Post Donation Surgery

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(As per NICU CPG [“Dying Baby in NICU-Care of”](#), JHCH NICU 08.01).

- Heartfelt photography is offered to the parents and arrangements made at parents request. This is a free service. If Heartfelt Photography service is not available, nursing staff to offer to take photos.
- The family is encouraged to spend as much time as they want with the baby, and can bathe or dress him/her as they desire.
- The family may wish to dress the baby in clothes they have supplied or clothing can be supplied from the NICU store.
- Clothing and wraps can be given to parents as a memento or sent with the baby to the mortuary.
- Parents are informed that they can return later to see the baby again.
- Memory Box – prepared as a memento for the family. This box contains:
 - a memorial card to display a lock of the infants hair (with parents' permission),
 - a hand and foot print card (with parents' permission),
 - identity band, name card,
 - any other memento the parents want from the baby's care in NICU. (E.g. CPAP prongs, cord clamp).
 - Additional memorial cards can be collected if required for separated parents or grandparents.
- Funeral arrangements – Social Worker and DSN will discuss and assist the family with this. The Social Worker will give parents a package of information, (LIGHT Package). In this package is a Centrelink Bereavement Payment Claim Form, the back page of which needs to be completed by a medical officer before giving to parents.
- Other required paperwork will be completed by DSN

Feedback

Any feedback on this document should be sent to the Contact Officer listed on the front page.

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Approved

| | |
|-------------------------------------|------------|
| NICU Executive Management Committee | 07/09/2017 |
| CQ&PCC JHCH | 26/09/2017 |

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[Designated Officers policy and Procedure – PD2013_002](#)

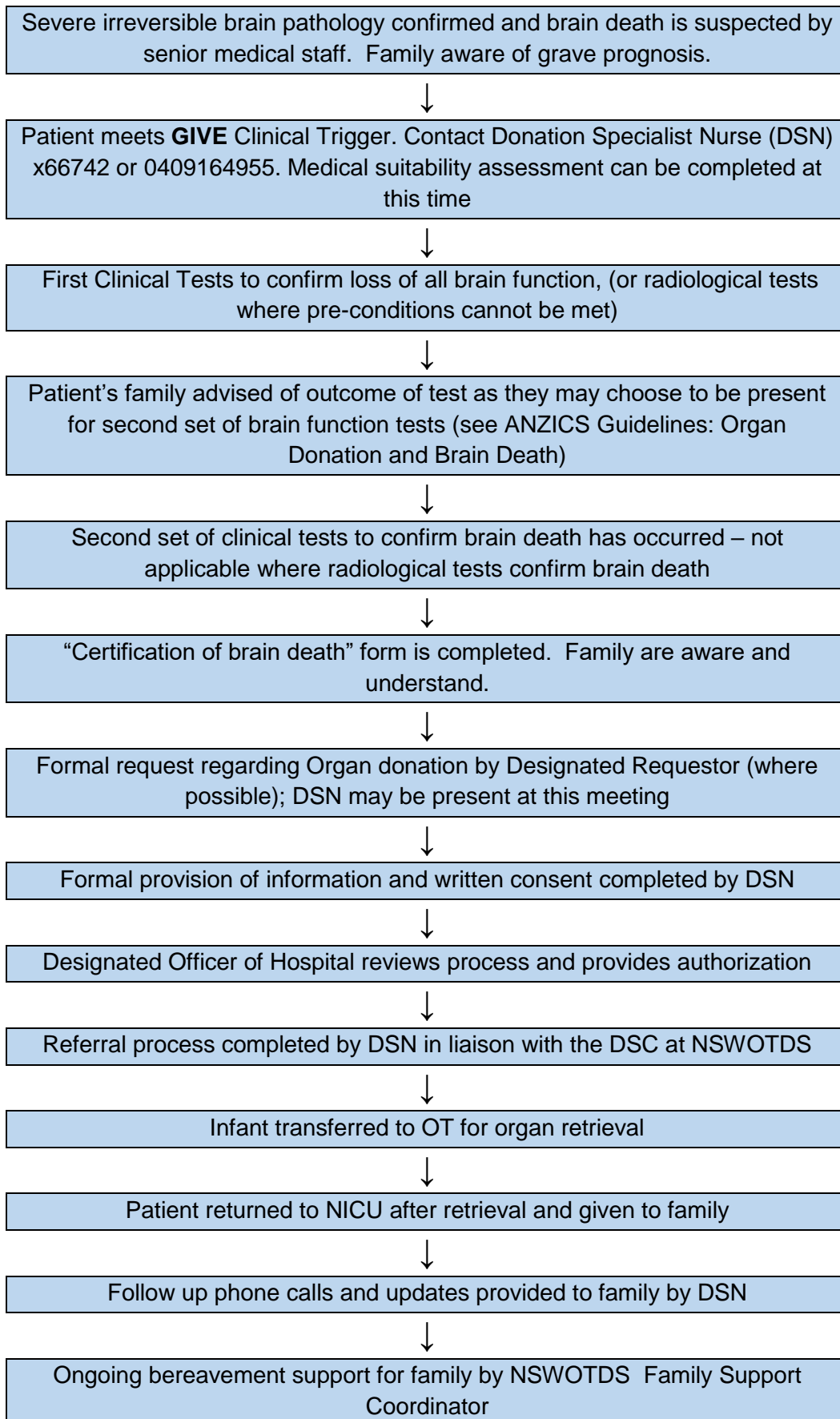
Contacts

| | |
|---|---|
| HNE LHD Donation Specialist Nurse | Office 4921 4464 Mobile 0409 164 955 Speed dial (internal) 66742 Fax: (02) 4921 4177 |
| NSW Organ And Tissue Donation Service Donation Specialist Coordinators | Office: (02) 8566 1700 Fax: (02) 8566 1755 Paging Service: 9963 2801 |
| Coroner's Court | Glebe (02) 8584 7777 |
| Forensic Pathologist - Newcastle | Phone: (02) 4922 3700 |
| Lions NSW Eye Bank | Phone: (02) 9382 7288 Fax: (02) 9382 7274 |
| NSW Bone Bank | Phone: (02) 9382 7855 Fax (02) 9382 7845 |
| Sydney Heart Valve Bank | Phone: (02) 8382 3271 |
| Queensland Heart Valve Bank | Phone (07) 3139 4367 Fax: (07) 3139 4033 |

Appendix 1

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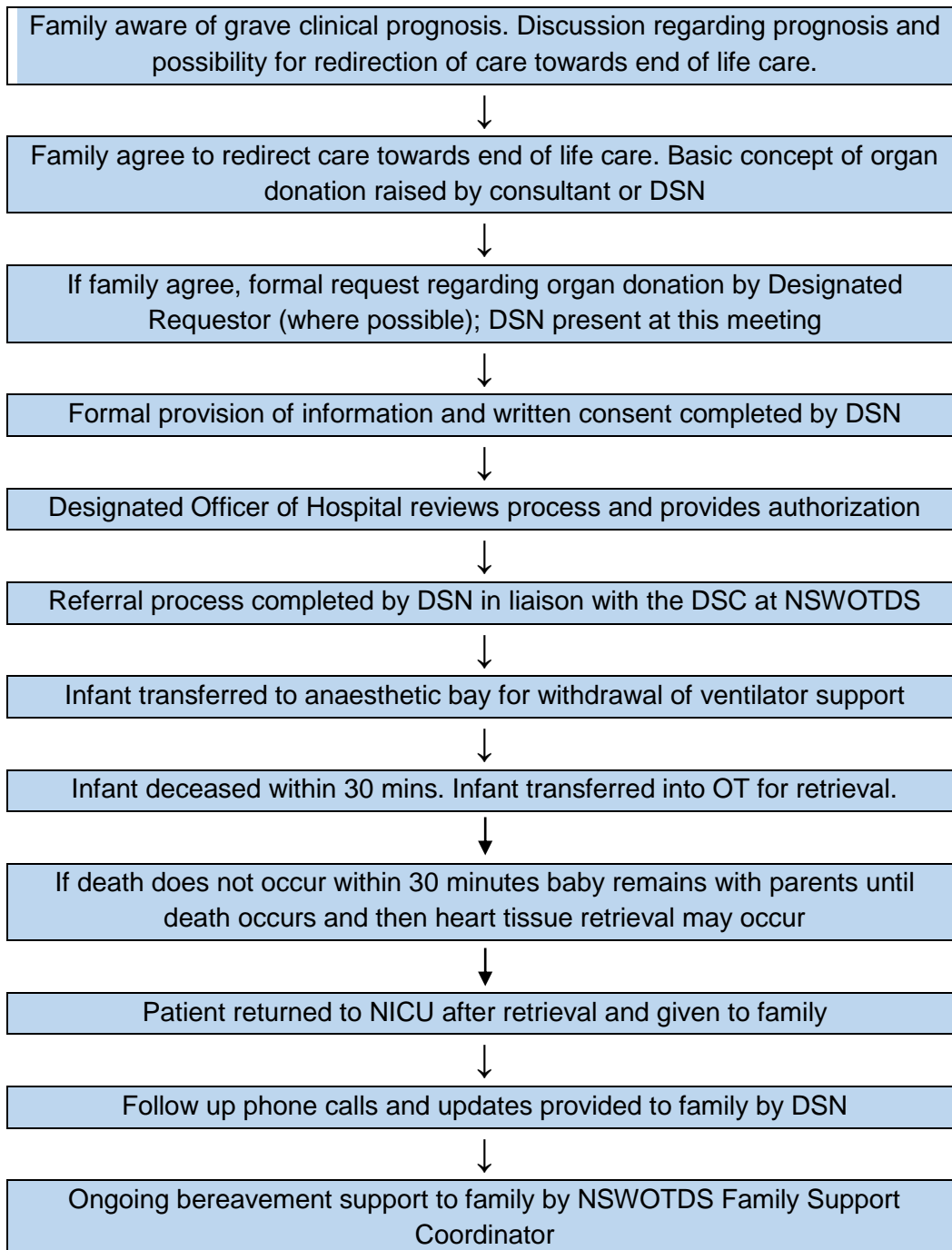
Donation after Brain Death (DBD) Flow Diagram



Appendix 2

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Donation after Circulatory Death (DCD) Flow Diagram



Appendix 3

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Organ & Tissue Donation in NICU Checklist

- Patient suitable candidate for donation (contact DSN) RMS/AODR registry check (if required prior)
- Notify NICU & admitting medical teams
- Contact Social Worker and/or Pastoral Care
- Family agreed to withdrawal of cardio-respiratory support
- Donation offered to family as a possible outcome from end of life care
- “Consent and Authority for Removal of Tissue After Death” completed (Contact Designated Officer via switchboard, to provide authorisation)
- If a refusal, document the reason for refusal (Contact the DSN to inform them about the family refusal, and consider completion of “objection form”)
- Patient converted to non-chargeable patient (where applicable)
- Collect blood (tubes are in a lab mailer in ICU treatment rooms treatment room), send donor blood sample as instructed
- Comprehensive donor and maternal history completed by to be completed by DSN (Contact on-call DSN 0409 164955)
- Does the family wish to have a viewing post-donation?
 - Yes
 - No

Paperwork required

- Certification of death determined by absence of vital signs following circulatory death
- Family informed
- Consent for donation
- Patient Identification
- Death Certificate
- Cremation form
- Post-mortem consent (if required)
- Coronial checklist
- Brain Death Form

Appendix 4

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Exclusions to Organ Donation in the NICU

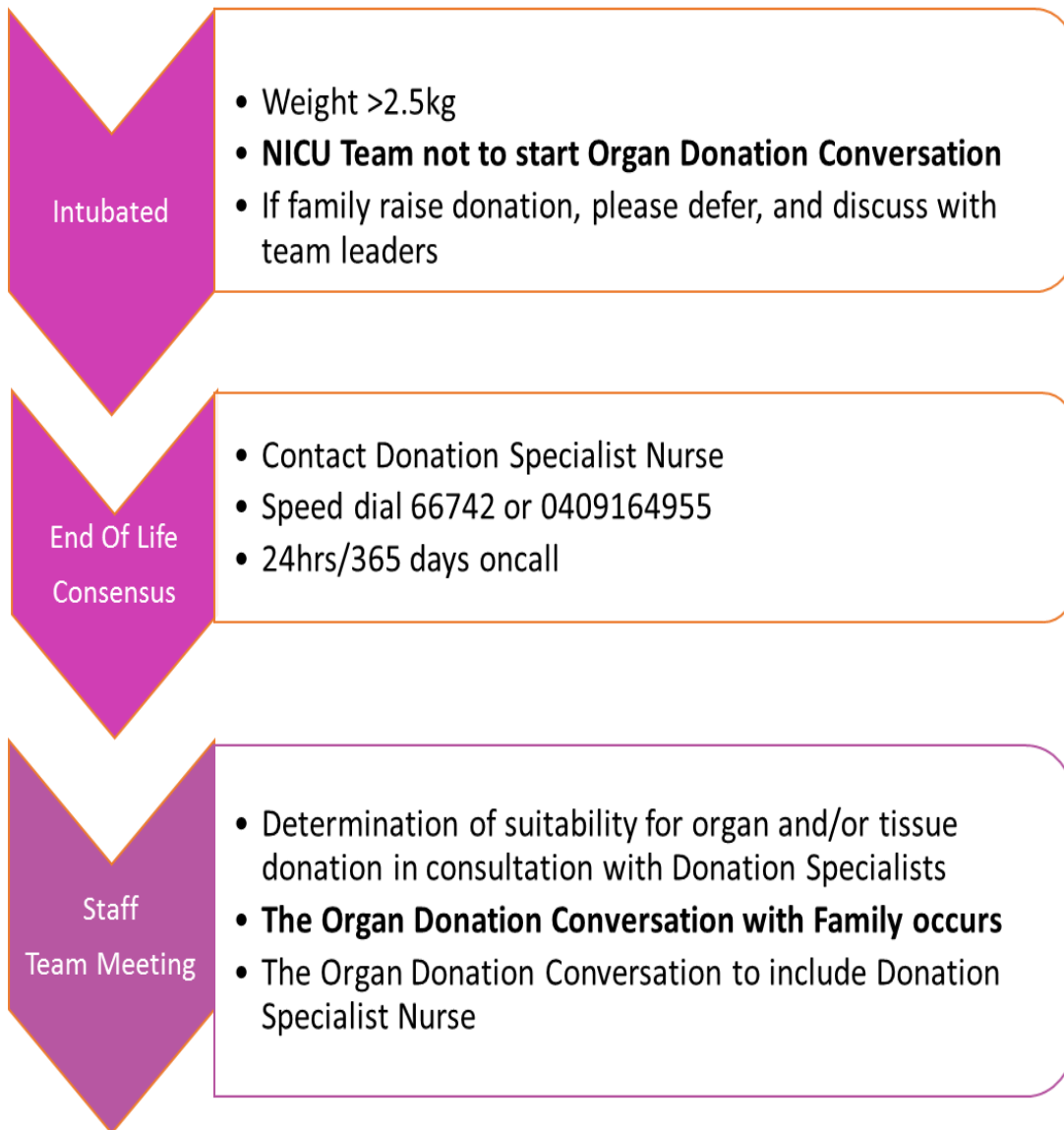
For probable exclusions please confirm with the DSN Organ and Tissue Donation. It is the transplant medical physician, who ultimately decides whether a patient fulfils the criteria and is a suitable candidate for organ donation.

Tissue Donation – General exclusion criteria

- Major untreated sepsis
- Positive serology results to HIV/AIDS (antibody or antigen), Hepatitis A/B/C (antibody or antigen), and syphilis, HTLV-1 - Maternal
- Physical, clinical or laboratory evidence of HIV, AIDS infection

For specific exclusion criteria please contact the relevant tissue bank.

End of Life Care in NICU Organ Donation



Appendix 6 Accepted Training Pathways

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Donate Life provide education and training to health professionals on supporting families in conversations about the opportunity for organ and tissue donation. It is designed to provide participants with the necessary knowledge and skills to sensitively support grieving families to make an informed, proactive and enduring decision about donation that is consistent with the values and beliefs of the donor and their family.

The professional education package consists of –

- Introductory Donation Awareness Training: Introductory information about donation pathways, clinical processes and family communication related to organ and tissue donation.
- Unit 1 - Family Donation Conversation (FDC) – Core Module: focuses on detailed information about grief and family reactions to catastrophic news, and provision of skills for communicating with families to explain death and donation to support informed decision-making.
- Unit 2 - Family Donation Conversation – Practical Module: focuses on practical skills training to build on the cored FDC workshop with opportunity to practice challenging scenarios in targeted role plays.
- Unit 3 - Family Donation Conversation - Advanced Module: provides an advanced level of FDC training offered annually to focus on new and emerging content and specific areas of interest in the sector.
- Unit 4 - FDC E-Learning program: provides material to support the FDC training to reinforce key learnings

Research shows that having a FDC –trained professional lead the conversation was associated with higher consent rates (69% vs 45%) compared with no FDC-trained professional.

A treating clinician should not lead discussions around organ donation until they have completed Unit 1 – FDC as a minimum standard.

For more information on available training, as well as upcoming dates, please visit : <http://www.donatelife.gov.au/professional-education-package>