

# ORGAN DONATION FOLLOWING NEUROLOGICAL DEATH DETERMINATION (DNDD) PRACTICE GUIDELINE<sup>®</sup>

## DOCUMENT SUMMARY/KEY POINTS

- Neurological death was formally known as brain death.
- Organ donation may only occur after the neonate, infant or child has been pronounced dead according to legally recognised criteria (neurological death or circulatory death). In this document we will only be discussing the procedure for organ donation following neurological death.
- We recognised that families require time and assistance to come to terms and understand determination of death via neurological criteria. This assistance may be necessary for some staff members caring for the deceased.
- Exceptional end-of-life care must be the focus for ICU staff, and this is not altered by the decision of a family in regard to organ donation. The respect and dignity of the child and the families' wellbeing will always be our paramount concern.
- A family has the right to withdrawal their consent to the donation process at any time.
- This document provides an operational outline of how organ donation can be facilitated at SCHN.
- Enquiries concerning this Practice Guideline please contact:
  - Medical Specialist (Donation Specialist Medical – “DSM”) or Nursing Specialist (Donation Specialist Nursing – “DSN”) via switch
- See [Glossary](#) for definition of terms

This document reflects what is currently regarded as safe practice. However, as in any clinical situation, there may be factors which cannot be covered by a single set of guidelines. This document does not replace the need for the application of clinical judgement to each individual presentation.

<b>Approved by:</b>	SCHN Policy, Procedure and Guideline Committee	
<b>Date Effective:</b>	1 <sup>st</sup> May 2024	<b>Review Period:</b> 3 years
<b>Team Leader:</b>	Organ & Tissue Donor Co-Ordinator	<b>Area/Dept.:</b> Intensive Care Unit

## CHANGE SUMMARY

- Updates based on the ANZICS “Statement on Death and Organ Donation Edition 4.1 2021. The amendments are to the following topics:
  - Terminology change: brain death to neurological death
  - Collaborative approach for family discussions
- Updated references
- **23/08/24:** Minor review. Updated NSW Health Policy Directives and Guideline links and references.

## READ ACKNOWLEDGEMENT

- Clinical staff working (medical and nursing) in intensive care areas must read and acknowledge they understand the contents of this document.
- Other relevant clinical staff, as identified, should read this document.

This document reflects what is currently regarded as safe practice. However, as in any clinical situation, there may be factors which cannot be covered by a single set of guidelines. This document does not replace the need for the application of clinical judgement to each individual presentation.

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# 1 Organ Donation

## 1.1 Introduction

In accordance with [NSW Ministry of Health](#) and [Australian and New Zealand Intensive Care Society \(ANZICS\)](#) Guidelines, the Intensive Care Units (ICUs) of the Sydney Children's Hospital Network support the donation of organs and tissues following death with informed parental/legal guardian consent.

Staff are sensitive to the extreme stress and grief felt by parents and relatives following the determination of neurological death of a child. This guideline identifies ways to discuss the possibility of organ donation in End-of-Life conversations in the critical care areas, whilst supporting families and respecting their needs, values and decisions.

The SCHN critical care teams recognise and identify the unique spiritual, religious, and cultural needs of each family. They assist in the engagement of culturally appropriate support, including the Aboriginal Health Worker Team for families that identify as Aboriginal or Torres Strait Islander in accordance with the [Aboriginal Health Impact Statement Policy Directive \(PD2017\\_034\)](#).

Organ donation may **ONLY** occur after a neonate, infant or child has died,  
i.e. been lawfully declared dead.

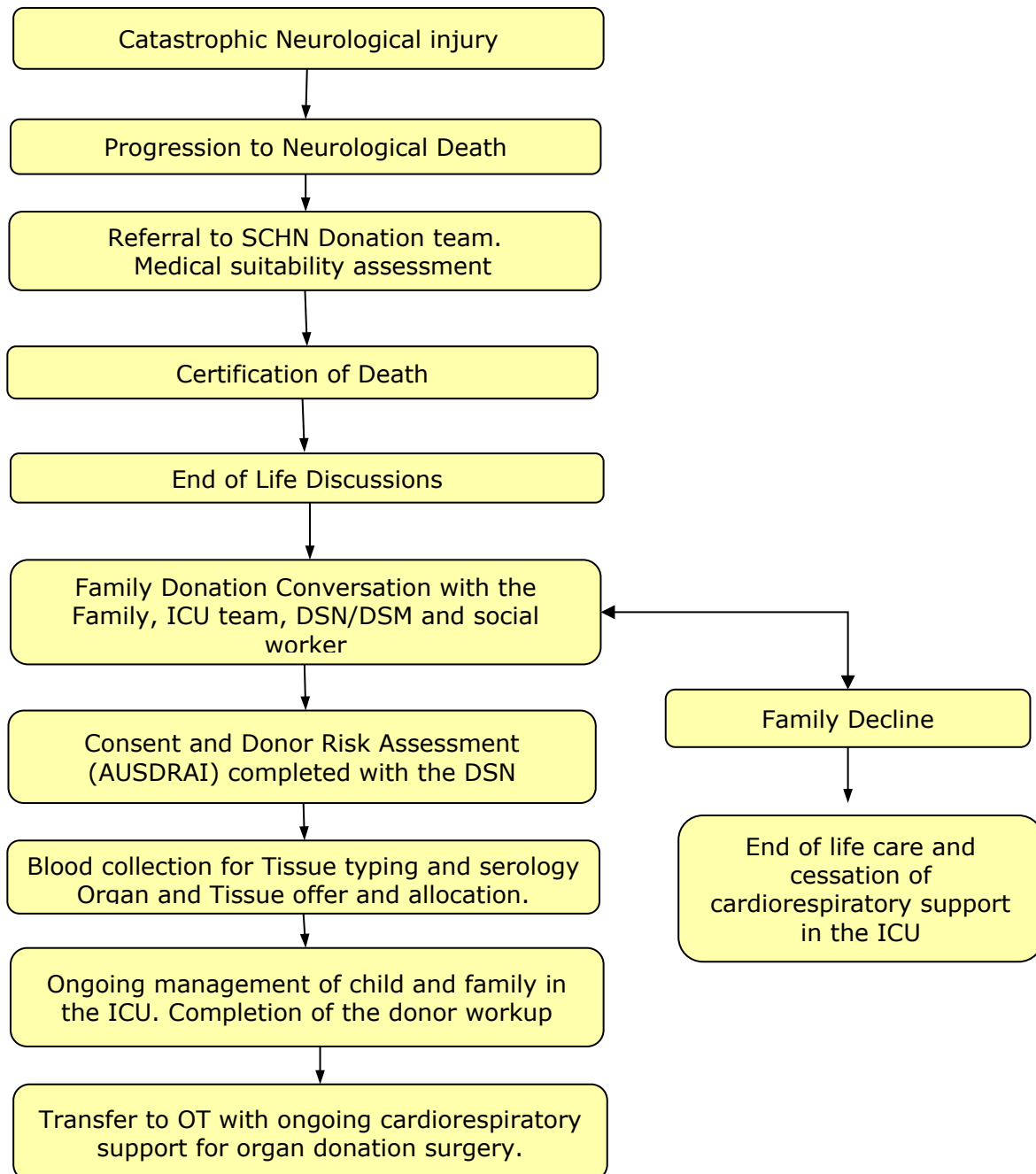
Circumstances where organ donation may be possible in the ICU setting are:

- when death has been declared on the basis of neurological criteria (i.e., the patient has been declared neurologically dead, previously referred to as brain death), or
- when death has been declared on the basis of circulatory standstill following (planned) removal of cardiorespiratory support (inotropes and mechanical ventilation).

Best practise end of life care for the child and family are a priority regardless of their decision regarding organ donation.

## 1.2 Pathway to Organ Donation following Neurological Determination of Death

Flow Diagram outlining the Neurological Death Donation Process



### 1.3 Suitable Donors

Neonates, infants and children who have been certified and documented as neurologically deceased either through clinical testing or imaging ([Determination of Neurological Death Policy](#)) are suitable to be considered as potential organ donors.

When end of life care is being considered, a routine referral to the NSW Organ and Tissue Donation Service (NSWOTDS) can be made. This may be prior to neurological death determination. Notification to the local donation team allows for preliminary discussions and assessment of suitability before donation is discussed with the family. Medical suitability of potential donors is assessed and determined by the NSWOTDS team in conjunction with transplant physicians. There is no expectation that the treating clinician should determine medical suitability.

Optimising end-of-life care for the patient and the family should take precedent at all times.

### 1.4 Family Donation Conversations (FDC)

After determination of neurological death, it is the responsibility for the ICU team to inform the parents/guardians of the death of their child. Time should be allowed for the family to process and understand this information and ask questions. The teams should be guided by the needs of the individual family. This conversation ideally, should be separate from a discussion regarding the possibility of organ donation. If organ donation is raised earlier by the family, it is at the discretion of the intensivist to continue or defer the organ and tissue donation conversation to a later time. A referral should be made as soon as possible to the DSN for consultation. The DSN can be notified of planned end of life discussions and may attend at the request of the treating team where appropriate.

When the family has had time to process the information about the death of their child, a meeting should be arranged to discuss the planning of end-of-life care and the removal of life sustaining therapies.

A multidisciplinary meeting should be convened involving the intensivist, the primary medical / surgical team, DSM/DSN, nursing staff, social worker, pastoral care and other consulting services as relevant. The purpose of the meeting is to discuss and review any possible conflicts of interest and anticipate other clinical / ethical concerns or issues that should be addressed in the family donation conversation. The possibility of organ and tissue donation is part of this planning and is offered to potential donor families. Families should be given the necessary time and space to consider the information and make a decision that is right for their family.

In the SCHN, donation should be raised in a collaborative approach as per the [Best Practise Guidelines for Offering Organ and Tissue Donation in Australia](#) and ANZICS Statement on Death and Organ Donation. There should be involvement of clinicians who have completed the core and practical Family Donation Conversation (FDC) workshops (medical DSM or DSN) in this discussion.

Clear documentation in the medical record of any family donation conversations is required.

## 1.5 Donor Referral and Coordination

Early routine referral of all end-of-life discussions to the Donation Specialist Nurse (DSN) and/or Donation Specialist Medical (DSM) assists in the assessment of medical suitability and provide support and advice to the ICU team. It also enables the involvement of an FDC trained specialist to collaborate with the clinical team in planning the donation conversations. The DSN will be available to meet with the family to provide information regarding the donation process. A referral can be made by anyone involved in the patient care, including medical, nursing, social work etc. Donation specialist staff can be contacted 24/7 via the hospital switch board.

### **The role of the DSN:**

- Consult with the ICU team to obtain accurate information regarding the child's current medical status and medical history. Information can be obtained in accordance with: <https://www.health.nsw.gov.au/patients/privacy/Pages/privacy-leaflet-for-patients.aspx>
- Consultation with the family to provide information about organ and tissue donation and support informed decision making.
- Obtain formal documentation of written consent (with the Designated Officer present) and collect blood for serology, tissue typing and HLA testing.
- Conduct the Donor Risk Assessment Interview (AUSDRAI) to assist in determining medical suitability.
- Completion of the Electronic Data Referral (EDR). The Donor State Coordinator (DSC) will liaise with the surgical retrieval teams, Transplant coordinators, Forensic pathologist and Coroner.
- Ensure all documentation is complete (including determination of death, consent forms ensuring all legal requirements have been met).
- Liaise with ICU staff, Designated Officer, Donor State Coordinator, and theatre staff.
- Ensure confidentiality of both donor and recipients.
- Provides ongoing care to the family including information on available support services and feedback on transplant recipient outcomes.
- Support health professionals and provides feedback to teams involved with the donation process.

## 1.6 Screening

The DSN will require the following information about the potential donor for assessment of medical suitability:

- Name, DOB, Weight, and Height
- Cause of death and current status
- Medical history
- ABO blood group (including A/AB subtypes)
- FBC, EUC, LFT, Calcium, Magnesium, Phosphate, Coagulation Profile, Troponin, CK, Transaminases and microbiology results
- ABG on 100% O<sub>2</sub>, PEEP 5cm for 30mins prior to gas
- Recent chest x-ray and relevant radiology reports
- ECHO and ECG with reports post Certification of Neurological Death if required.
- Medications and fluids

Any specific requests from transplant teams will be discussed with the ICU medical team (i.e. need for additional imaging, bronchoscopy).

## 2 Consent

Consent for deceased organ and tissue donation is governed by the [Human Tissue Act 1983](#) and makes provisions for obtaining consent and authorisation for donation.

Senior available next- of- kin (SANOK) for children:

- Parent of the child (both have equal standing)
- Sibling of the child (18y or over) if parent not available.
- Guardian of the child at the time of death where none of the above is available.

The process involved in organ donation must be explained to the parents in detail by the DSN. Consider using an interpreter when English is a second language to ensure the family understands what is being discussed and provide informed consent. Consent must be given for each organ and/or tissue to be removed.

Parents will be provided with the following information in order to give *informed* consent:

- The possibility that some or even all of the organs may not be suitable for transplantation.
- Anticipated time frames for the donation process (i.e. 18-24 hrs.).
- Donation is an option to consider, and the family can change their mind at any stage and withdraw consent. Support is provided for families regardless of their donation decision.
- The steps in the process, including bloods required, continuation of life sustaining therapies and transfer to the operating theatre on the ventilator with a beating heart,



which will stop during the surgery. Families can return to the ICU following surgery where they can spend time with their child.

- Whether the death requires notification to the Coroner and, the coronial process.
- Organ donation does not have any benefits for their child.
- Prior to retrieval surgery, changes to medical treatment strategies (i.e. alterations in FiO<sub>2</sub>, fluid bolus) may be required to ensure stability and organ function.
- Tissue donation (corneas, heart valves) can be an alternative to organ donation.
- Donation is carried out with respect and dignity for all involved.

Time must be given to a family to consider if organ donation is the right decision for them. Bloods for serology and tissue typing at the SEAL laboratory/ARCBS may be collected following verbal consent due to the length of processing time (6 - 8 hours). The DSN will organise the collection and transportation of these bloods.

If the child is <18months of age or has been breast fed in the last 6 months, maternal bloods and AUSTRAL will need to be completed for screening.

When the family are ready, parents (or SANOK) are required to sign the Consent Form (SMRO20.030 Consent and Authority for Removal of Tissue after Death) with the DSN.

Authorisation from a SCHN [Designated Officer](#) (DO) is required following the certification of death to enable retrieval surgery to proceed. The DO must sign and verify consent has been given by the SANOK and authorise the organ donation and removal of tissue. The DO may want to be present for the consent and speak to the consenting family. The DSN will ensure the DO is informed as soon as possible. The DO for the SCHN campuses can be contacted via the switchboard.

## 2.1 Coroners Cases

If the death is reportable to the Coroner, authorisation from the Forensic Pathologist and Coroner to proceed with donation is required.

This will be obtained by the Donor State Coordinator (DSC) not the treating team. The investigating police and the on call Forensic Pathologist will be contacted regarding possible limitations on organ and tissue retrieval. If there is uncertainty if the death is reportable to the Coroner, the treating intensivist should contact the on call forensic pathologist to discuss referral of the case.

The medical officer will be required to complete Form A (SMR010.510 Report of Death of a Patient to the Coroner) following the determination of neurological death. This can be found in the SCHN death pack.

The local police will be contacted and identify the child with the SANOK/staff before donation surgery when possible. The police identification tag must remain on the child's lower limb throughout the retrieval surgery process.

Following surgery, the Police are notified and will organise the Government Contractor to collect the child's body from the ICU or morgue and transport them to the State Coroner.

## 2.2 Child in the Care of the State

A child under the care of the State immediately prior to their death (i.e. in FACS care/under the care of the Minister for Community Services), must have consent obtained from:

- The Coroner;
- The Principal Care Officer (PCO) of the designated agency which has full case management responsibility of the child, must "...must use reasonable efforts to contact persons who have been significant in the child's or young person's life and who the PCO considers to be appropriate to assist in the decision-making process. These may include: Birth parents; Foster parents; Extended family; if the child/young person is Aboriginal or Torres Strait Islander, appropriate persons from the child's or young person's Aboriginal and/or Torres Strait Islander community; and persons considered relevant by the PCO". NSW Policy Directive PD2022\_035: Organ and Tissue Donation, Use and Retention. 2022
- The Designated Officer must ensure that the above has occurred prior to authorising the retrieval of organs.

Children under the care of the state may only donate organs or tissue for transplantation. It does not allow organs or tissues to be used for research or other medical scientific or therapeutic purposes in these cases.

## 3 Donor Management in ICU

All medical and nursing cares are continued as per ICU to support and maximise the suitability of organs being considered for transplantation. This requires frequent clinical assessment and interventions to maintain and optimise organ function. All general nursing care and infection control principles should continue.

Memory making may be offered to the family unless they are under the jurisdiction of the Coroner. Permission from the forensic pathologist and Coroner is required for memory making in Coronial cases, and clearly documented in the medical records. It may also be facilitated at the Coroners facility following transfer. Respect, dignity and support for the child and their family at end of life, is not compromised at any time.

Any changes in the child's condition or management should be discussed with the DSN.

The focus of treatment changes from neuroprotective to organ protective in neurologically deceased donors.

### 1. Optimisation of respiratory function:

- Ventilate to normocarbida with a mandatory mode of ventilation.
- Supplemental oxygen to maintain  $\text{PaO}_2 > 80 \text{ mm Hg}$  /  $\text{SaO}_2 > 92\%$ .
- Tidal volume 6-8mL/kg.
- Peak pressures  $< 30 \text{ mmHg}$ ,
- Peep 5-10cm  $\text{H}_2\text{O}$ .
- Continue recruitment manoeuvres such as suctioning/physiotherapy/regular repositioning/ Head of bed 30 degrees.
- Four hourly Arterial blood gas (ABG) to optimise ventilation and assess lung function.

## 2. Optimisation of cardiovascular function:

- Maintain age-appropriate normotension: titrate inotropes/ volume to maintain organ perfusion.
- Maintain urine output > 1 mL/kg/hr.
- Arterial & CVP monitoring when possible.

### Management of Hypertension

- Hypertension may be transient, however if prolonged it may require a short acting antihypertensive.
- Sodium Nitroprusside may be used for significant hypertension and lability in blood pressure.
- Beta blockers such as Esmolol may be used for an associate tachycardia.

### Management of Hypotension

- Hypotension maybe multifactorial and is dependent on the clinical examination of the child and management strategy for treatment. These commonly include:
  - Volume expansion
  - Vasopressors / Inotropes
- Volume expansion for hypovolemia:
  - Replace volume to aim for CVP 6-10mmHg and assess fluid balance. Try and avoid hyperchloremia, hyponatremia and using starch-based colloids.
  - The most common fluids used are Hartmann's solution, 0.9% saline (not recommended in hyponatremia) and 5% Glucose. Albumin 5% or 20% may be considered to reduce the volume given however the high sodium content of albumin-based solutions needs to be assessed in regard to the plasma sodium of the donor.
  - Fluid balance needs careful assessment to avoid fluid overload, especially when the lungs are being considered for transplantation.
  - Blood transfusion should aim for Hb >70g/L; unstable donor >90g/L.
  - Maintain urine output >1mL/kg/h.
- Vasopressors/ Inotropes
  - Maybe required to support age-appropriate mean arterial pressure (MAP) / systolic blood pressure once hypovolemia has been excluded.
  - Noradrenaline (NA) is the preferred vasopressor to improve and support organ perfusion for neurologically deceased donors.
  - If Noradrenaline requirements are increasing, a low dose Vasopressin infusion may be considered to reduce the NA requirements.
  - Hydrocortisone, stat dose of 4mg/kg then 1mg/kg 6 hourly may allow reduction of the Noradrenaline infusion. Inotropic agents such as Adrenaline and Dobutamine are used in refractory or deteriorating cardiac function that is not responsive to vasopressors.
  - Some neonates or children with hypotension and bradycardia with low TSH levels, commencement of a T3 infusion may be considered.

### Management of Arrhythmias

- Maintain normal serum electrolytes (optimize K<sup>+</sup>, Mg<sup>+</sup>, Ca<sup>2+</sup>). Optimize fluid status and prevent hyperthermia/ hypothermia.
- Standard arrhythmias management should be initiated if required (i.e. amiodarone, cardioversion).
- Bradyarrhythmia's may be resistant to atropine or glycopyrrolate, due to abnormal vagal response and may require direct acting Beta- sympathomimetics.
- Consider Adrenaline or Isoprenaline titrated to the appropriate heart rate or pacing.
- Prevent hypothermia.

### Management of Coagulation

- Blood products should be used to treat and correct pre-existing or developing coagulopathies.
- INR <1.5.
- Platelets >50.000.
- HB > 70g/L in a stable donor / 90g/L with significant inotropic support.

### Antibiotics

- Microbiology results and clinical signs of infection should guide the use of antibiotics. Antibiotics should not be ceased upon the determination of neurological death and changes should be discussed with the DSN/DSM.

## 3. Optimisation of endocrine and metabolic function

- Aim for normal range for all the following:
  - Temperature (> 36 C and <37.5°C)
  - Urine output (1mL/kg/hr.)
  - Electrolytes (Na<sup>+</sup>, K<sup>+</sup>, Ca<sup>2+</sup>, Mg<sup>+</sup>, PO<sub>4</sub>);
  - Blood sugar (5-8mmol/L)

### Management of Hypothermia

- The inability to generate heat by shivering or conserve it by vasoconstriction increases the risk of neurologically deceased donor to become hypothermic. The effects of hypothermia include an increased risk of arrhythmias, coagulopathy, and a delay in testing for neurological death.
- Active warming to maintain temperature >36.0°C using warming blankets, humidification devices and fluid warmers for large fluid volumes.

### Management of Diabetes Insipidus (DI)

- The loss of Anti Diuretic Hormone secretion from the posterior pituitary gland following neurological death commonly results in the development of DI. This

deficiency can lead to a systemic vasodilatation induced by the loss of sympathetic activity, as well as polyuria, hypernatremia, and hypovolemia. It can be confirmed by a combination of high plasma osmolality and low urine osmolality. The use of a vasopressin infusion is often indicated in neurologically deceased donors with vasopressor requirements.

- As per local guidelines: Vasopressin (arginine vasopressin) infusion or DDAVP (desmopressin, 1-desamino-8-D-arginine vasopressin) should be commenced once the urine output is  $>4\text{mL/kg/hr.}$  for 2h and plasma sodium is rising. Paired urine and plasma electrolytes and osmolality should be sent to confirm diagnosis but DO NOT delay treatment. Vasopressin infusion or DDAVP IV bolus dose every 2-6 hours may be used.
- Fluid replacement for DI, as per local unit policy involves replacement of urinary losses and insensible losses + maintenance fluids. Large urinary volume loss should be replaced with intravenous low-sodium content fluids (i.e. 5% dextrose or sterile water).

### Management of Hypernatremia

- As a consequence of DI or previous treatment for intracranial hypertension, serum sodium can be significantly elevated ( $>155\text{mmol/L}$ ). Hypernatremia (serum sodium  $>155\text{ mmol/L}$ ) in the donor has been associated with poor hepatorenal transplant outcomes, however, does not preclude liver donation.
- Sources of sodium in intravenous solutions should be reviewed and alternative solutions such as 5% dextrose may be utilised. If DI is contributing to hypernatremia, follow DI management guideline.

### Management of Hyperglycaemia

- Maintaining normoglycemia may require a short acting insulin infusion. It may be need due to decreased insulin production, increased insulin resistance post neurological death or the use of 5% glucose solutions.
- Actrapid, as per the unit policy, should be administered to achieve plasma glucose levels 5-8mmol/L.

### The use of Hormone replacement therapy

- The use of thyroid hormone (triiodothyronine: T3) may be considered in the unstable potential heart donor following discussion with the donation and transplantation teams. It is considered for use if there is reversible function impairment on ECHO, low age-appropriate MAP and NA infusion  $>0.2\text{microg/kg/m.}$
- Glucocorticoid therapy: A single high dose of methylprednisolone can be used to suppress the inflammatory response associated with cerebral herniation, in potential heart and lung donors.
- Methylprednisolone: 15mg/kg IV Once only.

### Extra- corporeal membrane oxygenation (ECMO) Considerations

- Neurologically deceased donors will be transferred to OT with ECMO in situ. The cardiothoracic team and Perfusionist will be notified to discuss the case and need for their assistance in OT.

- The skin prep, surgical incision and procedure will proceed as normal with ECMO in situ. At the time of Aortic clamp, the ECMO circuit is also clamped.

### Transport to OT

- The child will be transferred to OT ventilated and supported with ICU and anaesthetic staff.
- The family may wish to accompany them to OT or remain in the ICU. Special requests and needs of the family will be discussed and facilitated by the DSN as possible.

## 4 Post-donation care

At the completion of surgery families may spend time with their child. This can be facilitated in the ICU or mortuary viewing room with assistance of DSN, ICU staff and social workers.

### 4.1 Family follow up.

1. The ICU social worker will provide telephone follow-up with the bereaved family at least once during the first week following the child's death. The family will be contacted by the DSN 48 - 72 hours after the child's death or as negotiated, to provide support to the family, and outline the outcome of the donation process.
2. Parents are offered follow up, including the opportunity to meet with the treating team together with the Social Worker. The DSN/DSM may be also invited to this meeting. This enables parents to ask further questions or discuss unresolved concerns.
3. Telephone follow-up, with the offer of further meetings or counselling, should be continued for at least twelve months.
4. Parents of children who are organ donors are provided with support by the Family Support Coordinator through the NSW Organ & Tissue Donation Service. This program includes bereavement support, regular contact and information regarding donation outcomes, counselling services, support groups and anonymous exchange of letters.

### 4.2 Patient privacy

It is important to maintain the privacy of donor families and transplant recipients. The disclosure of identity or any information that could lead to the identification of the donor or recipient **MUST NOT** be relayed to the family. It is an offence in Australia to disclose information regarding the donor or recipient under The Human Tissue Act 1983 Section 37(2) and 37(3) and the Privacy Act 1988.

The DSN and staff at OTDS will provide families with appropriate information about the transplant recipient outcomes.

### 4.3 Staff Support

The staff involved in the donation process will have the opportunity to receive information about the outcomes of the donation from the DSN in alignment with NSW privacy laws. An



update will be sent to all areas involved in the donation process. The DSN will arrange a case review at an appropriate date and time following each donation. Attendance is voluntary. This provides feedback to all staff involved in the donation process and provide an opportunity to reflect upon the experience and collaborate as a team to discuss and identify areas for improvement for future donations. If further support is required for staff, engagement with the Employee Assistance Program (EAP) is encouraged.

## 4.4 Education

Education is provided by:

- **SCHN DSN (CNC2)** – regular education sessions throughout SCHN (Critical care/ OT/wards/BC/NETS). Replicated on both sites- now face to face. Organised via education teams in units/wards.

Post donation case reviews provided for units involved and OT staff post donation.

Standing item on PICU M&M/ CICU Consultant meeting to provide feedback and discussion. GNN consultant updates as required.

- **NSWOTDS and SCHN DSN:** The Organ and Tissue Donation Awareness Course (IDAT) is held at CHW and SCH 2<sup>nd</sup> yearly for staff (Nationally funded.) Staff can also attend course at other LHD's and information circulated in critical care areas throughout SCHN regarding this.

Peri operative Nursing Donation 1 day course ( Nationally funded) also held at CHW. SCH are covered by the POW OT scheduled course.

## 5 Glossary

Term	Definition
Designated Officer (DO)	<p>The role of the Designated Officer is to authorise:</p> <ul style="list-style-type: none"> <li>• the removal of tissue from a body for transplant or other therapeutic, medical, or scientific purposes.</li> <li>• the performance of non-coronial post mortem examination.</li> <li>• the release of a body for anatomical examination.</li> </ul> <p>The Designated Officer has discretionary authority not simply administrative authority. SCHN has multiple DOs appointed to ensure they are available when required particularly after hours.</p>
Donation Specialist Nurse (DSN)	A Clinical Nurse Consultant who is responsible for the coordination and facilitation of organ and tissue donation.
Donation Specialist Medical (DSM)	A medical professional who is responsible for all processes to optimise organ and tissue donation in their hospitals.
Donation State Coordinator (DSC)	A member of the NSWOTDS service that maintains and coordinates the communication and documentation throughout the retrieval surgery.

Extra Corporeal membrane Oxygenation (ECMO)	A technique providing both cardiac and respiratory support to patients whose heart and lungs are poorly functioning.
Family	Recognising the collaborative nature of end-of-life decision-making, the term 'family' is used to refer to a person or persons who have a close, ongoing, personal relationship with the patient, whom the patient may have expressed a desire to be involved in treatment decisions, and who have indicated a preparedness to be involved in such decisions. This may or may not include biological family. However, it may include relatives, partner (including same sex and de facto), friend, or 'person responsible' according to any express wish of the patient.
Intensive Care Unit (ICU)	Includes Paediatric Intensive Care Unit (PICU), Children's Intensive Care Unit (CICU) and Neonatal Intensive Care Units (NICU).
Intensivist	Refers to Paediatric or Neonatal Intensive Care physicians.
Life-sustaining treatment	Life-sustaining treatment is any medical intervention, technology, procedure, or medication that is administered to forestall the moment of death, whether or not the treatment is intended to ameliorate life-threatening diseases or biological processes.  These treatments may include, but are not limited to, artificial airways, mechanical ventilation, ECMO, artificial hydration and nutrition, cardiopulmonary resuscitation, or drugs to support circulatory function.
Neurological death	Death defined by irreversible cessation of all function of the person's brain. Formally known as Brain death.
Organ and Tissue Donation Service (NSW OTDS)	State service that is responsible to develop, coordinate and maintain clinical and operational protocols for state-wide organ and tissue donation in NSW.
NSW State Coroner	An independent, appointed government official who holds jurisdiction over all reported deaths.
Principal Care Officer (PCO)	In relation to a child in the care of state, the PCO of the designated agency has full case management responsibility for the child. They, automatically become the person with responsibility for consent for organ and tissue donation for transplantation. The PCO will determine whose approval is required and must use reasonable efforts to contact all significant people in the child's life to assist in the decision-making process. They cannot give consent unless all relevant parties have been consulted and provided approval for donation.
Senior Available Next of Kin (SANOK)	The hierarchy of Senior Available Next of Kin is defined in S4 of the Human Tissue Act 1983 (NSW). In relation to a deceased child, it is: <ul style="list-style-type: none"> <li>• Parent of the child (equal standing);</li> <li>• Sibling of child who is 18 years of age or over where a parent is not available; or</li> <li>• Guardian of the child at the time of death where none of the above is available.</li> </ul>



	<ul style="list-style-type: none"> <li>If the child is in the care of the state specific provisions for consent to organ and tissue donation apply.</li> </ul>
Withdrawal of cardio-respiratory support (WCRS)	<p>Withdrawal of cardio-respiratory support is defined as cessation of cardiac and respiratory support. The withdrawal of respiratory support includes removal of the endotracheal or tracheostomy tube.</p> <p>The withdrawal of cardiac support commonly refers to the cessation of inotropes and vasopressors but can also include cessation of ECMO.</p>

## 6 References

1. Australian and New Zealand Intensive Care Society (ANZICS) The Statement on Death and Organ Donation. Edit 4.1 2021: <https://www.anzics.com.au/wp-content/uploads/2022/04/ANZICS-Statement-on-Death-and-Organ-Donation.pdf> (accessed 15/04/24)
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