

# ORGAN DONATION FOLLOWING CIRCULATORY DETERMINATION OF DEATH (DCDD) PRACTICE GUIDELINE<sup>®</sup>

## DOCUMENT SUMMARY/KEY POINTS

- 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 circulatory determination of death.
- 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' well-being 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 (DSM) or Nursing Specialist (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
  - Time frame from loss of pulsatility to declaration of death increased from 3 min to 5 min.
  - Collaborative approach for family discussions
- Updated references

## READ ACKNOWLEDGEMENT

- Clinical staff (medical and nursing) working 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.

<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

# TABLE OF CONTENTS

- 1 Organ Donation .....4**
- 1.1 Introduction .....4
- 1.2 Suitable Donors .....4
- Donation following Circulatory Determination of Death (DCDD) criteria:.....5*
- 2 DCDD Donor categories.....5**
- 2.1 Pathway to Organ Donation after Circulatory Determination of Death (DCDD) .....6
- 2.2 Family Donation Conversations (FDC).....7
- 2.3 Donor Referral and Coordination.....7
- 2.4 Screening .....8
- 3 Consent .....8**
- 3.1 Consent issues specific to DCDD.....8
- 3.2 Coroners Cases.....10
- 3.3 Child in the care of the State .....10
- 3.4 Withdrawal of life-sustaining treatment (WLST) .....11
- Continuation of palliation .....11*
- Pre-Mortem interventions .....11*
- 3.5 Certification of Death .....13
- 4 Post-donation care .....13**
- 4.1 Family follow up.....13
- 4.2 Patient privacy issues.....13
- 4.3 Staff Support.....14
- 4.4 Education.....14
- 5 Glossary .....15**
- 6 References .....17**

# 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 within the Sydney Children's Hospital Network (SCHN) 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 death of a child. This guideline recommends ways to discuss the possibility of organ donation in End of Life (EOL) conversations in 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 based on neurological criteria (i.e. the patient has been declared neurologically dead - formally known as brain dead) or
- when death has been declared based on circulatory standstill following planned removal of cardiorespiratory support (inotropes/ECMO and mechanical ventilation).

Donation following circulatory determination of death (DCDD), formally known as Non-Beating Heart Donation (NBHD) and donation after cardiac death (DCD), enables families of children in critical care units, who do not meet the criteria for neurological death, to consider organ donation.

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

## 1.2 Suitable Donors

Neonates, infants, and children (weight >3 kg) who have a planned removal of cardiorespiratory support (mechanical or non-invasive ventilation / ECMO and inotropes) are suitable to be considered as potential organ donors. The decision to withdraw cardio respiratory support (WCRS) is independent of the consideration of donation.

When there is medical consensus that the child is near end of life and current life sustaining treatments are not in the child's best interest, a referral to the NSW Organ and Tissue Donation Service (NSWOTDS) should be made.

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 SCHN treating clinician should determine medical suitability.

Optimising end-of-life care for the patient and family should always take precedent.

***Donation following Circulatory Determination of Death (DCDD) criteria:***

- Ventilated (invasive or non-invasive) patient from whom life sustaining treatment is to be withdrawn (i.e. severe irreversible brain injury, severe cardiac, respiratory or organ failure, or ventilator-dependent quadriplegia)
- When death is likely to occur within a time frame (30 – 120 minutes) following removal of life-sustaining treatment that permits organ retrieval for transplantation.

It may be difficult to predict the likelihood that circulatory arrest will occur within the 30-120 minutes after removal of life-sustaining treatment. The most influential factor is whether the patient will breathe effectively after extubation or removal of non-invasive ventilation. Prediction may be assisted by observing a patient during a trial of spontaneous ventilation. The test should only be conducted if patient is able to tolerate the test without becoming unstable.

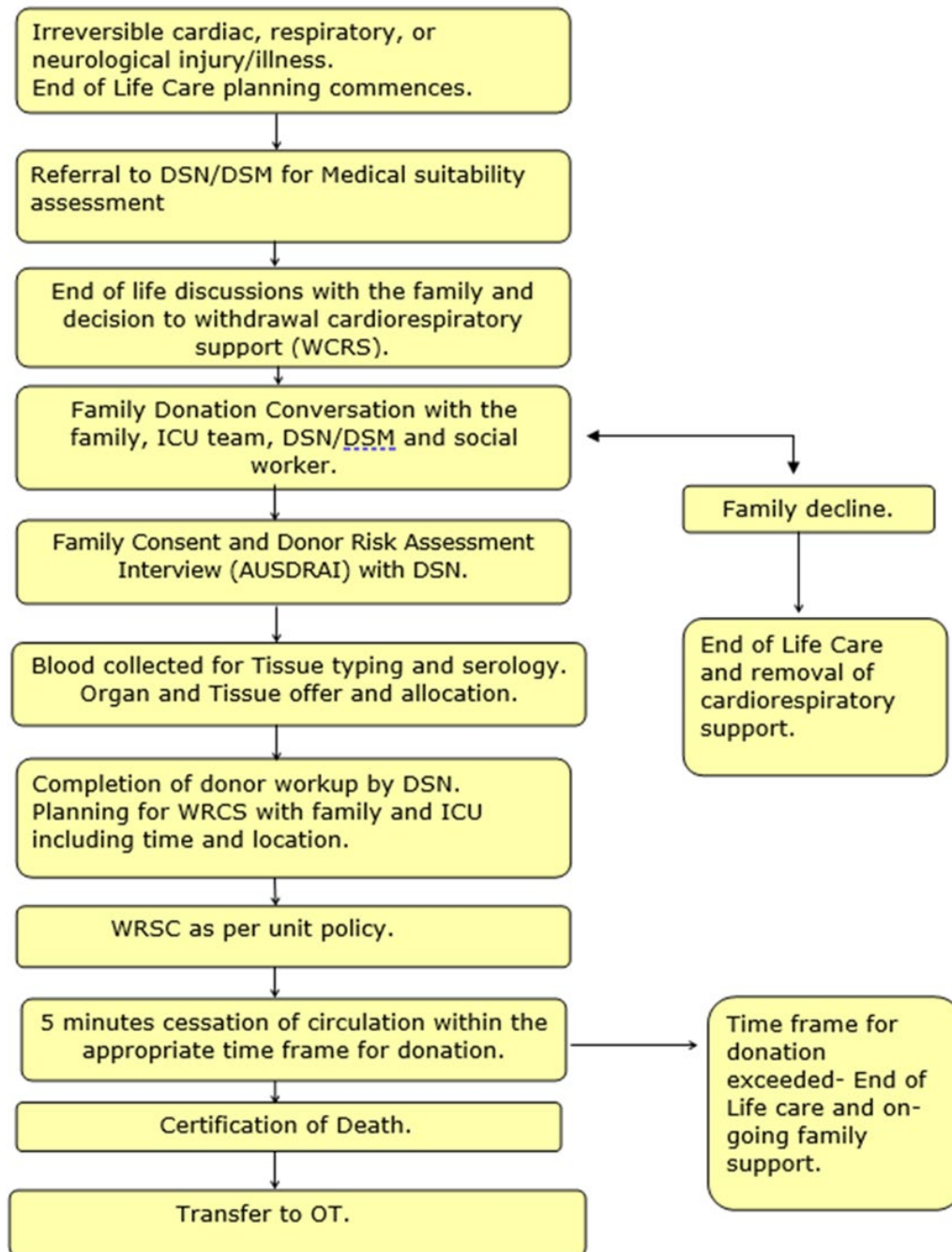
## 2 DCDD Donor categories

The following 'Maastricht' categories for DCDD have been developed and accepted internationally to categorise potential donors on a clinical basis.

- **Category 1:** Deceased on arrival - Unknown warm ischaemic time.
- **Category 2:** Unsuccessful resuscitation- Known warm ischaemic time.
- **Category 3:** Awaiting cardiac arrest following planned treatment withdrawal - Known and limited warm ischaemic time.
- **Category 4:** Cardiac arrest after confirmation of neurological death but before planned organ retrieval - Known and potentially limited warm ischaemic time.
- **Category 5:** Cardiac arrest in a hospital patient.

Only **category 3** and **category 4** are currently permitted to become organ donors in **NSW**.

## 2.1 Pathway to Organ Donation after Circulatory Determination of Death (DCDD)



## 2.2 Family Donation Conversations (FDC)

It is the responsibility of the Intensive care team or primary care team to ensure they have discussed with the family the prognosis and plan for end of life (EOL) care. Teams should be guided by the needs of the individual family and child. The family should be allowed the time they need to process and understand this information and ask questions. The EOL conversation, ideally, should be separate from a discussion regarding the possibility of organ donation. A referral should be made as soon as possible to the Donation Specialist Nurse (DSN) for medical suitability and collaborative discussions regarding the consideration of donation.

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

The possibility of organ and tissue donation is part of this planning and is offered to potential donor families collaboratively with the DSN. Families should be given the necessary time and space to consider the information and make a decision that is right for their family.

All attending medical specialists involved in the patient's care should be informed where DCDD is being considered.

In the SCHN donation should be raised in a collaborative approach as per the [Best Practice Guidelines for Offering Organ and Tissue Donation in Australia](#) and ANZICS Statement on Death and Organ Donation . This enables the involvement of an FDC trained specialist to collaborate with the clinical team in planning and facilitating the donation conversations.

Clear documentation in the medical record of any discussions with the family regarding organ and tissue donation is required.

## 2.3 Donor Referral and Coordination

Early routine referral of all EOL discussions to the Donation Specialist Nurse (DSN) and/or Donation Specialist Medical (DSM) assists in the assessment of medical suitability and provides support to the ICU team. This includes an assessment of the expectation that death may occur within the 30- 120m time frame.

The DSN will be available to meet with the family to provide information regarding organ and tissue donation. 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 includes:**

- 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) 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 and legal requirements have been met (including determination of death and consent forms).
- Liaise with ICU staff, Designated Officer (DO), DSC, 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 provide feedback to teams involved with the donation process.

## 2.4 Screening

Interventions for the benefit of the future organ recipient and of no benefit of the child cannot be administered to optimise organ function. Blood samples for screening and medical suitability are permitted.

- 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 status.
  - Medical history.
  - ABO blood group (including A/AB subtypes).
  - FBC, EUC, LFT, CMP, coags, troponin, transaminases, and microbiology.
  - ABG on 100% O<sub>2</sub>, PEEP 5cm for 30 minutes prior to gas.
  - Current Chest x-ray.
  - Medications and fluids.
- The intensivist remains responsible for the clinical care of the child throughout the process. Changes in the child's condition or care should be discussed with the DSN. Advice regarding medical management of potential donors is always available through the DSN/DSM.

## 3 Consent

### 3.1 Consent issues specific to DCDD

In NSW consent to any pre-mortem intervention, which is not in the best interest of the child, by surrogate decision-makers, such as a child's parents, would not be permitted under the [Children And Young Persons \(Care and Protection\) Act 1998](#) and Part 5 of the [Guardianship Act 1987 \(NSW\)](#). The Act requires that 'the safety, welfare and well-being of the child or



young person must be the paramount consideration' and those providing consent may do so only for treatments that 'promote or maintain the health and well-being' of the person involved.

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.

**Consent regarding DCDD must include:**

- The decision to WCRS is made independently to the consideration of donation with agreement of the family and medical teams.
- Members of the transplant and retrieval teams must NOT participate in the decision for withdrawal of treatment. They cannot participate in the certification of death.

The process involved in organ donation following circulatory death must be explained to the parents in detail by the DSN. Interpreters are available if English is not the family's first language to ensure the family understands the process and provides informed consent. Consent must be given for each organ and/or tissue to be removed.

The withdrawal of life sustaining treatments will be conducted in a compassionate and sensitive fashion that respects the wishes and dignity of the child and family. There is no change in the care of their child in ICU and no hastening of death by the DCD process.

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

- Possibility that some or even all the organs may not be suitable for transplantation.
- Donation is an option to consider, and the family can change their mind at any stage and withdraw consent. Support and care are provided for families regardless of their donation decision.
- Anticipated time frames for the donation process(>24h).
- WCRS and comfort care will be managed by the ICU team with the focus on relieving symptoms and ensuring comfort.
- Donation may proceed if death occurs in a specific timeframe. A longer functional warm ischaemic time may be used at the discretion of the transplant teams. It does not exceed 120m.

Heart/ Liver/ Pancreas: < 30mins from WCRS.

Kidneys: < 60mins from WCRS.

Lungs:< 90mins from WCRS.

- If their child does not die in the designated time frame, comfort care will continue.
- The steps in the process of rapidly transferring the child to the operating theatre for retrieval surgery after death certification without delay, and the duration of retrieval surgery. Families can return to the ICU following surgery to spend time with their child.

- Whether the death requires notification to the Coroner and the coronial process.
- Tissue donation may be an alternative to organ donation.
- Donation is carried out with respect and dignity for all involved.

Bloods for serology and tissue typing at the SEAL laboratory/ARCBS may be collected following verbal consent due to the length of processing time. Pre mortem blood sampling is permissible in NSW for the purpose of organ donation. The DSN will organise the collection and transportation of these bloods.

If the child is **<18 months of age** or has been breast fed in the last 6 months, **maternal bloods** and AUSDRAI 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 and will come into effect upon the child's death to enable retrieval surgery to proceed. The DO may want to be present for the consent and speak to the 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.

## 3.2 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 circulatory death. This can be found in the appropriate SCHN death pack.

The local police will be contacted and identify the child with the SANOK/ staff following organ retrieval surgery. The Police will organise the Government Contractor to collect the child from the ICU or hospital morgue and transport them to the State Coroner, as per local guidelines.

## 3.3 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 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".<sup>9</sup>

- The Designated Officer (DO) must ensure that the above has occurred prior to authorising the retrieval of organs or tissue.<sup>11</sup>
- 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.

### 3.4 Withdrawal of life-sustaining treatment (WLST)

The responsibility for EOL care will remain with the child's treating team. The DSN will coordinate with the ICU team and family with regards to patient condition, OT availability, retrieval team arrival and timing of WLST. Removal of cardiorespiratory support includes discontinuation of mechanical ventilation or Extracorporeal Membrane Oxygenation (ECMO), extubation and cessation of inotropes. Medications for analgesia and sedation should be provided for symptom relief as per unit policy. Intra-arterial blood pressure monitoring, heart rate and oxygen saturations are measured to record the warm ischaemic time and determine cessation of circulation.

A patient on ECMO should have both ECMO and cardio-respiratory support withdrawn.

#### ***Continuation of palliation***

Pain or distressing symptoms following withdrawal of life-sustaining treatment should be managed with analgesia and sedation, as for any palliation of a dying patient. Analgesia and sedation should be provided with the primary goal of relieving pain or other distressing symptoms.

The family should be informed that the comfort of their child is paramount and that all steps will be taken to ensure that is achieved. They must be informed that any drugs given following removal of life-sustaining treatment are to keep the patient comfortable, and do not form any part of the donation process.

#### ***Pre-Mortem interventions***

Pre mortem interventions such as the use of some medications, i.e. Heparin to prevent small vein thrombosis or performing procedures such as bronchoscopes, are not legally permitted in NSW. The consent for such interventions is not within the power of the SANOK.

Acceptable investigations or interventions may include:

- Blood sampling.
- ECG/ ultrasound/ ECHO/ X-rays.
- Non contrast CT.
- Maintenance of ICU support until the agreed plan and timing of WCRS.
- New therapies may be commenced only if they would have been provided regardless of consideration for donation and aimed at palliation goals and symptom management. This includes the administration of antibiotics if indicated.

## Location

The time and place of WCRS and palliation is negotiated with the DSN/DSM, ICU team, the family, Operating Theatre (OT) and retrieval surgeons. The [NSW Ministry of Health DCDD Guidelines](#) recommend that WCRS should occur in the operating theatre area. At SCHN consideration is made of location to minimise warm ischaemic time and balanced the individual family's needs and provision of care.

## ECMO

Regardless of the location, the perfusionist can assist by clamping the ECMO circuit at the same time the child is extubated. If cessation of circulation is within the timeframe for DCDD the child is moved into OT with the clamped ECMO circuit.

The perfusionist may also provide to the abdominal surgeon, details of location/ size of cannulae for assessment of use in OT for organ perfusion.

## **DSN checklist prior to withdrawal of cardio respiratory support (WCRS):**

- Process for certification of death – Medical officer.
- Documentation- including Consent and Declaration of Death form.
- Coordination of staff and family; Medical, nursing staff, social worker, porter and OT staff roles and responsibilities Record keeping, timing and methods of communication with the DSC is established. A group huddle will be held approx. 60m prior to WCRS to discuss roles and expectations.
- ECMO: arrangements for the perfusionist and +/- cardiothoracic surgeon to be in attendance and at huddle.
- Theatre checklist complete and identification bands x 2.
- Family contact details.
- Skin is prepared (including shaving if age appropriate).
- Bed and transfer route are ready for immediate transfer to OT if not in OT area.

The family should be reassured that if the timeframes for DCDD are exceeded, their child will have continual care aimed at symptom control, optimal comfort, and dignity.

The family should be well prepared for the immediate transfer into OT, once death is certified to enable donation to proceed. The family may withdraw consent for donation at any time during the process.

During the WCRS, vital signs will be observed by the DSN and relayed to the DSC to record on the DCDD flow chart, in OT. This may be done discretely via telephone calls or text at regular intervals to update significant events including:

- Withdrawal of cardio respiratory support time.
- Systolic BP <50mmHg.
- Cessation of circulation.
- 5-minute observation period with NO pulsatile waveform on the arterial line due to absence of circulation or electrical asystole if no intra-arterial line.
- Certification of Death.
- Transfer to OT.

### 3.5 Certification of Death

Death is declared when the designated doctor, determines that there is **irreversible cessation of circulation of blood in the person's body**.

Death should be confirmed by clinical examination revealing:

- Absence of spontaneous movement.
- Apnoea.
- Absence of circulation (absence of pulsatile waveform on arterial line / electrical asystole if no arterial line) for a minimum of **5 minutes** and confirmed by clinical examination.

Following determination of death donation surgery can proceed.

**Death is not certified by a member of the organ retrieval or transplant team.**

## 4 Post-donation care

At the completion of surgery, the family 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.

If the death is a Coronial case, formal identification of the child, with the police and family is required post donation surgery in the ICU with ongoing social worker support.

### 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 also be 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, and anonymous exchange of letters.

### 4.2 Patient privacy issues

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 recipients **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 face to face and 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
Circulatory death	Death defined by irreversible cessation of circulation of blood in the person's body. Formally known as cardiac death.
Cold ischaemic time	The period following cooling of the organs until perfusion to the transplanted organ/s is re-established in the recipient.
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	<p>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.</p> <p>These treatments may include, but are not limited to, artificial airways, mechanical ventilation, ECMO, artificial hydration and nutrition,</p>

	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> <li>• If the child is in the care of the state specific provisions for consent to organ and tissue donation apply.</li> </ul>
Warm ischaemic time	Various definitions referring to time from WCRS to commencement of cold perfusion, the time from arrest until cold flush of organs or the time from systolic blood pressure <50mmHg to commencement of cold perfusion.
Withdrawal of cardio-respiratory support (WCRS)	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.  The withdrawal of cardiac support commonly refers to the cessation of inotropes and vasopressors but can also include cessation of ECMO.



## 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)
2. ANZICS Statement on Care and Decision- Making at the End of Life for the Critically Ill. Edition 1.0 2014: <https://www.anzics.com.au/wp-content/uploads/2018/08/ANZICS-Statement-on-Care-and-Decision-Making-at-the-End-of-Life-for-the-Critically-Ill.pdf> (accessed 15/4/24)
3. Australian Government Best Practice Guidelines for Offering Organ and Tissue Donation in Australia. Edit 2 April 2021: [https://www.donatelife.gov.au/sites/default/files/2021-05/final\\_best\\_practice\\_guideline\\_for\\_offering\\_organ\\_and\\_tissue\\_donation\\_apr2021.pdf](https://www.donatelife.gov.au/sites/default/files/2021-05/final_best_practice_guideline_for_offering_organ_and_tissue_donation_apr2021.pdf) (accessed 15/4/24)
4. Human Tissue Act 1983 (NSW): <https://legislation.nsw.gov.au/view/html/inforce/current/act-1983-164> (accessed 15/4/24)
5. Human Tissue Amendment (Children in Care of State) Act No 164 (2008) (NSW): <https://legislation.nsw.gov.au/view/html/inforce/current/act-2008-087> (accessed 15/4/24)
6. NHMRC (2016) Ethical guidelines for organ transplantation from deceased donors: <https://www.nhmrc.gov.au/about-us/publications/ethical-guidelines-organ-transplantation-deceased-donors#block-views-block-file-attachments-content-block-1> (accessed 15/4/24)
7. NSW Health Guideline GL2021\_004: End of Life Care and Decision making (2021): [https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=GL2021\\_004](https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=GL2021_004) (accessed 15/4/24)
8. NSW Health Guideline GL2021\_012: Organ Donation After Circulatory Death (2021): [https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=GL2021\\_012](https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=GL2021_012) (accessed 15/4/24)
9. NSW Health Policy Directive PD2022\_035: Organ and Tissue Donation, Use and Retention (2022): [https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2022\\_035](https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2022_035) (accessed 15/4/24)
10. NSW Health, Policy Directive 2010\_054 Coroners Cases and Coroners Act 2009 (2010): [https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2010\\_054](https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2010_054) (accessed 15/4/24)
11. NSW Health Policy Directive PD2023\_012 Designated Officer (2023): [https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2023\\_012](https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=PD2023_012) (accessed 15/4/24)
12. TSANZ Clinical Guidelines for Organ Transplantation from Deceased Donors 1.12 Dec 2023: [https://tsanz.com.au/storage/documents/TSANZ\\_Clinical\\_Guidelines\\_Version-112\\_March2024Paedheart.pdf](https://tsanz.com.au/storage/documents/TSANZ_Clinical_Guidelines_Version-112_March2024Paedheart.pdf) (accessed 15/4/24) and <https://tsanz.com.au/clinical-guidelines>

### **Copyright notice and disclaimer:**

The use of this document outside Sydney Children's Hospitals Network (SCHN), or its reproduction in whole or in part, is subject to acknowledgement that it is the property of SCHN. SCHN has done everything practicable to make this document accurate, up-to-date and in accordance with accepted legislation and standards at the date of publication. SCHN is not responsible for consequences arising from the use of this document outside SCHN. A current version of this document is only available electronically from the Hospitals. If this document is printed, it is only valid to the date of printing.