

TISSUE DONATION PATHWAY

PRACTICE GUIDELINE[®]

DOCUMENT SUMMARY/KEY POINTS

- Tissue donation may only occur after the neonate, infant or child donor has been pronounced dead according to legally recognised criteria.
- End-of-life care must be the focus for SCHN staff and this is not altered by the decision of a family to consent to tissue donation.
- A family has the right to withdrawal their consent to the donation process at any time
- This document provides an operational outline of how tissue donation can be facilitated at SCHN
- Enquiries concerning this Practice Guidelines please contact:
 - Donation Specialist Medical (DSM) or Donation Specialist Nurse(DSN) via switch

CHANGE SUMMARY

- Process for Automatic Death notification from the SCHN to the NSW Eye and Tissue Bank
- Updated Coronial process for Tissue Donation
- Updated references

READ ACKNOWLEDGEMENT

- Clinical staff working (medical and nursing) in acute 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.

Approved by:	SCHN Policy, Procedure and Guideline Committee	
Date Effective:	1 st September 2020	Review Period: 3 years
Team Leader:	Staff Specialist	Area/Dept.: Emergency

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1 Tissue Donation Following Death

1.1 Introduction

In accordance with NSW Ministry of Health and [ANZICS](#) Guidelines, the intensive care units within the Sydney Children's Hospital Network (SCHN) support the donation of tissue 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 tissue donation in End of Life (EOL) conversations whilst supporting families and respecting their needs, values and decisions.

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

1.2 Types of Tissue Donation

Heart Valve: Newborn >3kg to 65 years of age

Whole Eye/Corneal: >2 years of age

Musculoskeletal: >15 -90 years of age

Bone: > 15-65 years of age

Skin: >17 -70 years of age

1.3 Suitable Donors

Neonates, infants and children who have been lawfully declared dead are suitable to be considered as potential tissue only donors. All SCHN deaths in hospital are automatically notified to the NSW Eye and Tissue Bank for assessment for potential tissue donation in compliance with NSW Policy Directive 2020_012: [Deceased Organ and Tissue Donation – Consent and Other Procedural Requirements](#). They may contact the unit, consultant, nursing staff or social workers involved in the child's care for further information to assist in this assessment. Information can be obtained in accordance with:

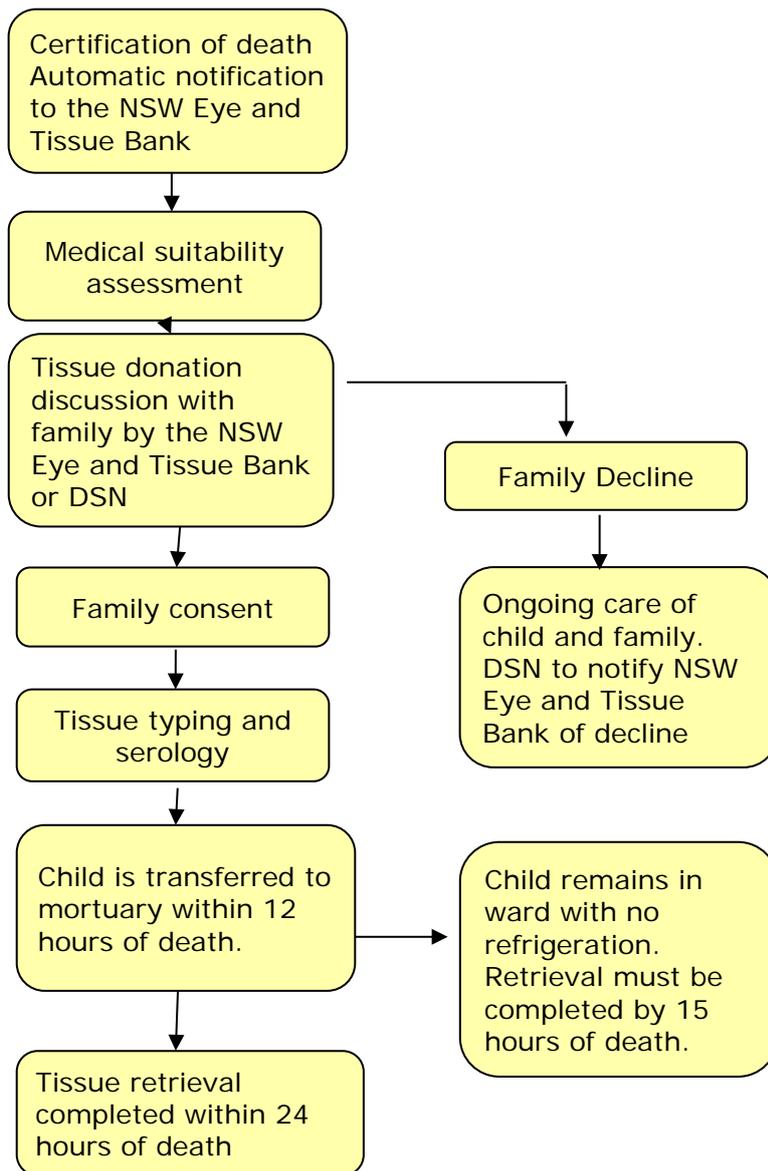
<https://www.health.nsw.gov.au/patients/privacy/Pages/privacy-leaflet-for-patients.aspx> . The NSW Eye and Tissue Bank may contact families to discuss and offer the potential for tissue donation if suitable

Tissue donation can also occur in conjunction with organ donation. The family can meet with the Donation Specialist Nurse (DSN) or Donation Specialist Medical (DSM) for information to make an informed decision. The DSN/DSM can be contacted via switch 24 hours a day. Medical suitability is assessed by the Organ and Tissue Donation Service (OTDS) in conjunction with the NSW Eye and Tissue Bank and Heart Valve Bank.

The exclusion criteria for Tissue Donation is more stringent than for Organ Donation due to license by the Therapeutic Goods Administration (TGA). All potential donors are screened to

exclude any pathology, diseases that may be a risk factor to the recipient. Any potential tissue donor will be discussed with the tissue banks as there may be specific exclusion criteria for each tissue type.

1.4 Pathway to Tissue Donation after Death



1.5 Family Donation Conversations

Deaths within the SCHN are automatically notified to The NSW Eye and Tissue Bank. They will assess and contact appropriate potential tissue donor families to provide information and further discuss the family's wishes.

Medical teams can discuss the possibility of tissue donation if appropriate and should be guided by the needs of the individual family. Families should be given the necessary time and space to consider the information and make a decision that is right for their family.

For assistance in this assessment and discussion:

- The SCHN DSN/ DSM can be contacted via switchboard
- NSW Eye and Tissue Bank can be contacted on 9382 7288

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

2 Consent

The process involved with tissue donation must be explained to the parents in detail by the NSW Eye and Tissue Bank or DSN/DSM. 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 tissue to be removed. The NSW Eye and Tissue Bank will conduct recorded phone consent, Designated Officer authorisation and permission from the Coroner if required.

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

- the possibility some or all of the tissues may not be suitable for transplantation;
- the anticipated time frame for tissue donation process
- that they can change their mind at any stage and withdraw consent
- The steps in the process – e.g. going to the operating theatre or the mortuary for retrieval surgery. Following the procedure the family will be able to spend time with their child.
- Whether the death requires notification to the Coroner and the coronial
- Tissue donation does not have any benefits for their child
- Once processed, tissues can be stored for up to 10 years before use in transplantation
- Non-transplantable tissues will be disposed of if not used after 10 years

Time must be given to a family to consider if tissue donation is the right decision for them. Bloods for serology may be collected.

If circulatory standstill has occurred, a pre mortem sample may be sourced if available. Alternatively the bloods can be taken by the surgeon during heart valve retrievals.

If the child is <18months of age or has been breast fed in the last 6 months, bloods will also need to be taken from the mother for screening.

When the family are ready, the Senior available next of kin (SaNOK) are requested to sign the Consent Form (SMRO20.030 Consent and Authority for Removal of Tissue after Death) with the DSN/DSM or provide taped verbal consent with the NSW Eye and Tissue Bank.

The [Designated Officer](#)(DO) for the SCHN campuses can be contacted via the switchboard. The DO must verify consent has been given by the SANOK and authorise the donation and removal of tissue.

2.1 Coroners Cases

If the death is reportable to the Coroner, authorisation from the Coroner to proceed is required. Consent from the Coroner for tissue donation will be obtained by the Tissue Coordinator. The Coroners Forensic Pathologist is contacted regarding limitations on tissue retrieval.

The medical officer will be required to complete Form A (SMR010.510 Report of Death of a Patient to the Coroner).

The local police will be contacted and identify the child with the senior available next of kin (SANOK) before tissue donation when possible. The police identification tag must remain on the child's limb throughout the retrieval surgery process. Some tissue donation, such as cornea's, may occur following the transfer of the child to the State Coroner's Office.

2.2 Child in the Care of the State

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

- the Coroner;
- the Principal Care Officer 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 Health Policy Directive (PD2020_012) "Deceased organ and Tissue Donation-Consent and other Procedural Requirements
- the DO must ensure that the above has occurred prior to authorising the retrieval of tissues for the purpose of transplantation

3 Heart Valve Retrieval

Medical suitability for heart valve donation is assessed by the NSW Eye and Tissue Bank and Sydney Heart Valve Bank. It is important to have a complete history of any cardiac surgery the child may have had to assist in determining suitability.

Retrieval surgery for Heart Valves usually occurs in the Operating Theatres.

4 Corneal Retrieval

Whole eye and corneal donation may only occur in children over the age of 2y, who meet the criteria for donation. This is determined by the NSW Eye and Tissue Bank. In NSW the whole eye is removed and a prosthetic disc placed to prevent any disfigurement to the child. Tissue donation of the cornea (whole eye) can occur in the hospital mortuary or at the coroners, if appropriate, within the discussed time frames.

IMPORTANT NOTE ON EYE CARE: any patient >2y *may* be considered for eye donation; hence eye care is paramount to ensure the corneas are kept moist and minimize infection and ulceration. If a patient is unresponsive or unconscious, please ensure eye care is performed by applying sterile normal saline every 2-4 hours, and/or lubricant eye ointment once overnight. In the event of a deceased patient (once the family has left the ward), please irrigate the eyes with sterile normal saline, or apply a sterile gauze (moisten with saline) over the eyes. Close the eyes (secure with tape if necessary) and arrange for transportation to the mortuary.

NSW Eye and Tissue Bank

5 Post-donation care

At the completion of surgery the family have the option of seeing their child. A viewing can be arranged at the hospital, Coroner's facility or funeral directors with assistance from the social workers.

5.1 Follow-up of the family

- Parents from the SCHN will be followed up by the Social Worker by telephone communication at least once during the first week following the death and more often as required. They are also contacted by the DSN to outline the outcome of the donation.
- Parents of children who are tissue only donors are provided with support through NSW Eye and Tissue Bank. They will receive a support package following the donation. Families are able to contact the DSN to receive updates regarding the transplant outcomes.

5.2 Patient privacy

It is important to maintain the privacy of the transplant recipients and donor families. 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 Tissue coordinators will provide families with appropriate information about the transplant recipient outcomes.

5.3 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.

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6 Glossary

Designated Officer (DO)

The role of the Designated Officer is to authorise:

1. the removal of tissue from a body for transplant or other therapeutic, medical or scientific purposes;
2. the performance of non-coronial post mortem examination;
3. the release of a body for anatomical examination

The Designated Officer has discretionary authority not simply administrative authority. *Source: NSW Human Tissue Act 1983 No. 164 (includes amendments up to Act 2003 No. 45 and NSW Health Circular 2004/1).*

Donation Specialist Nurse (DSN)

A Clinical Nurse Consultant who is a member of the organ and tissue donation service

Donation Specialist Medical (DSM)

Specialised doctor trained in the management of potential organ and tissue donors who is a member of the Organ and Tissue Donation Service.

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.

Organ and Tissue Donation Service (OTDS)

State service that is responsible for the coordination and management of potential organ and tissue donors.

NSW Eye and Tissue Bank

State service that is responsible for the coordination and management of potential tissue donors.

NSW State Coroner

An independent, appointed government official whom holds jurisdiction over all reported deaths.

Principal Care Officer (PCO)

PCO of the designated agency has full case management responsibility for the child, automatically becomes 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. In relation to a deceased child it is:

- Parent of the child (equal standing);
- Sibling of child who is 18 years of age or over where a parent is not available; or
- Guardian of the child at the time of death where none of the above is available.
- If the child is in the care of the state specific provisions for consent to organ and tissue donation apply.

Sydney Heart Valve Bank

State service that is responsible for the coordination, assessment and management of potential heart valve donors.

7 References

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3. 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>
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