

NSW Perinatal Post-mortem Service

Post-mortem consent guide

(June 2023)

Consent requirements

- Access the NSW Perinatal Postmortem Service [internet page](#) to view all consent documentation and guidelines <http://www.pathology.health.nsw.gov.au/clinical-services/perinatal-post-mortem-service>
- Where possible, the senior treating clinician who has an established rapport with the family should obtain consent.
- Informed consent for postmortem examination **must** be obtained in writing from a parent of the deceased baby regardless of weight or gestation
- Complete consent form (See Consent Form page 1)
- Arrange authorisation for postmortem examination (See Consent Form page 2) to be completed by the hospital Designated Officer for any registered births
- Where there are specific cultural practices affecting who can give consent for postmortem, this needs to be discussed with the family and an alternative person clearly appointed. A parent or legal guardian can authorise another adult to consent. Ideally, this delegation would be in writing. If a written delegation exists, place a copy in the medical record.
- Following the verbal discussion, provide the family with written information on postmortem examination. This can be found online at <http://www.pathology.health.nsw.gov.au/clinical-services/perinatal-post-mortem-service>

The role of senior treating clinician

- The clinician must understand the post-mortem process. If you would like any education around perinatal post-mortem, please get in touch with the PPMS
- Reassure the family that their baby will be treated with respect and dignity
- Explain the benefit of completing a postmortem and discuss the possibility that the postmortem will not identify a cause of death
- Be prepared to answer questions about the postmortem examination and how the baby will look after reconstruction. Inform families that arrangements can be made to view and hold their baby following the examination
- Discuss postmortem options, including external, full, and limited
- Discuss the need for collection of tissue samples and organ retention (if applicable), clarifying that tissue sampling is routine but organ retention is not
- Discuss options for disposal of retained organs. Document the parental preference on the consent form
- Discuss the collection of bone and muscle samples, when indicated, and need for a third suture line. Document this on the consent form

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- Discuss the use of tissue for research
- Discuss options for cremation, burial or funeral arrangements. Non registerable birth include option of hospital respectful care of baby's remains or return to parents. Document the parental preference on the consent form
- Advise the family how long their baby will be with the perinatal pathologist (5 to 7 days but be aware of adding time for transport, dependent on your hospital) and when the results of the examination will be available to them
- Advise on timing for funeral arrangement, transportation and be aware of what is available in your LHD

The role of the Designated Officer

- **The Designated Officer cannot be the consenting doctor**
- Designated Officers must be appointed in accordance with section 5 of the Human Tissue Act 1983 (NSW) by the governing body of a hospital or NSW Health pathology departments and forensic institutes.
- Designated Officers must complete mandatory training to become accredited and appointed. To remain eligible for reappointment, Designated Officers are required to successfully complete reaccreditation training every two years.
- The Designated Officer has discretionary authority. They are not obligated to authorise a procedure
- The Designated Officer's authority must be in writing, Designated Officers are required to authorise the removal and use of organs and tissue from a deceased's body in non-coronial post-mortem examinations

Note

- Consent is not required for placental examination, but the placenta must be accompanied by a pathology request form
- Where a death is expected, a preliminary discussion prior to baby's birth can give the parents more time to consider their options
- Parents can delay their decision where the baby is kept refrigerated. However, parents should be made aware that time delays can influence the quality of post-mortem results
- The NSW Perinatal Postmortem Service Care Coordinator is available to discuss any specific questions with the family and can also facilitate family discussion with a perinatal pathologist. Please share our contact details with any family considering a perinatal post-mortem

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Further information

Burial, cremation, and funeral arrangements

Families need to indicate their preferred option for burial or cremation at the time of consent.

- Options for **unregistered** babies:
 - Burial via a registered funeral director
 - Cremation arranged by the laboratory undertaking the postmortem
 - Written consent for cremation must accompany the baby to Pathology (SMR020.037)
 - Written information relating to the specific laboratory cremation arrangements to be given to parents. Contact the Perinatal Postmortem Service Coordinator for pamphlets if required
 - Cremation by the hospital does not occur immediately. Families can change their mind and request baby be returned to them. Baby will be kept for approximately 3 months depending on the hospital.
 - Unregistered babies can be returned to the referral hospital for cremation. Indicate parental preferences on the consent form
 - Unregistered babies can be returned to the family (collect in person) for burial/cremation. Discuss this option with the Care Coordinator.
- Options for **Registered** babies:
 - Burial or cremation via a registered funeral director
 - The Perinatal Postmortem Care Coordinator will liaise with the funeral director, hospital, and the family to ensure this process is individualised to the family's cultural and religious needs. They will also help streamline the safe return of the baby to the family/hospital/funeral director

Retained tissue and organs

- It is routine practice to replace a baby's organs once they are examined. Small tissue samples are retained and converted to a slide for histological analysis under a microscope. Small samples may also be taken for Microbiology and/or DNA extraction to enable future genetic testing as required
- If organs are required to be retained for specialist examination and not able to be replaced at the time of the postmortem, the PPMS team will consult with the family. No organs will be retained unless parental consent is obtained
- Slides are retained by NSW Health Pathology for a period of at least 25 years in case a review is required in line with requirements.

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- Some organs (such as the brain) require fixation with a solution so the perinatal pathologist can adequately examine the structure. This will impact the length of time a postmortem will take
- Very small tissue samples will be stored frozen for up to 25 years in case:
 - There is a need to investigate the molecular basis for a baby death
 - Malformation syndromes of unknown cause at the time of postmortem are later shown to have a genetic basis.

Disposal or return of retained organs

If organs are retained and not reunited with the baby at the time of postmortem the following options for disposal should be discussed with the family and their preferred option included on the consent form. In these cases, the PPMS will be in touch with the family

1. Delay burial or cremation of baby until the organs can be reunited with baby
2. Go ahead with burial or cremation of baby. The family can organise to cremate or bury the retained organs at a later stage
3. The laboratory conducting the postmortem cremates the retained organs.

Resource documents

NSWHP	NSW Statewide Perinatal Post-Mortem Service - An explanation for families
IB2020_010	Consent to Medical and Healthcare Treatment Manual Information Bulletin
PD2023_012	Designated Officer Policy and Procedures
PD2007_025	Stillbirth – Management and Investigation
GL2006_021	Human Tissue – Requirements of the Human Tissue Act 1983 in relation to research & use of tissue
GL2013_015	Retention of Bodies - Approval to Retain Bodies for Longer than Permitted
PD2013_051	Non-Coronial Postmortems
Perinatal Society of Australia and New Zealand <i>Clinical Practice Guideline for Perinatal Mortality</i> ; Third Edition, Version 3 2014 Section 3: Psychological and social aspects of perinatal bereavement	