Consent requirements


☐ 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

☐ 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.


The role of senior treating clinician

- The clinician must understand the postmortem process
- 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
- 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 tissue or organs. Document the parental preference on the consent form
- Discuss the use of tissue for research (if applicable)
- Discuss options for cremation, burial or funeral arrangements. Document the parental preference on the consent form
- Discuss what to expect following reconstruction and advise that arrangements can be made to view and hold their baby following the examination
Advise the family how long their baby will be with the perinatal pathologist (usually two to three days depending on clinical circumstances) and when the results of the examination will be available to them.

Advise on timing for funeral arrangement, transportation and which facility baby is being transported to for examination.

Note

- Consent is not required for placental examination, but the placenta must be accompanied by a pathology request form.
- Allocate sufficient time with the family to discuss the options for postmortem examination and answer any questions. Parents should not be rushed to decide. 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 for up to three days. However, parents should be made aware that time delays can influence the quality of postmortem 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.

Resource documents

<table>
<thead>
<tr>
<th>Document Code</th>
<th>Description</th>
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<tbody>
<tr>
<td>PD2005_406</td>
<td>Consent to Medical Treatment – Patient Information</td>
</tr>
<tr>
<td>PD2013_002</td>
<td>Designated Officer Policy and Procedures</td>
</tr>
<tr>
<td>PD2007_025</td>
<td>Stillbirth – Management and Investigation</td>
</tr>
<tr>
<td>GL2006_021</td>
<td>Human Tissue – Requirements of the Human Tissue Act 1983 in relation to research &amp; use of tissue</td>
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<tr>
<td>GL2013_015</td>
<td>Retention of Bodies - Approval to Retain Bodies for Longer than Permitted</td>
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<tr>
<td>PD2013_051</td>
<td>Non-Coronial Postmortems</td>
</tr>
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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
  - 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

- **Deceased neonates** are returned to families for burial or cremation via their nominated funeral director
  - Families who decline responsibility for neonate disposal, should be managed as per [PD2008_012 Destitute Persons - Cremation or Burial](#)

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 Service Care Coordinator will consult with the referring clinician. 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.
• 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 five years in case:
  - There is a need to investigate the molecular basis for a baby death
  - Or
  - 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.

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.

**Research and use of Human Tissue**

Requirements of the *Human Tissue Act 2003*

• In no circumstances is tissue to be removed from the body of a deceased child who is, or was, a ward of the state for research purposes, either with or without consent from any person.

**Child in the care of the State**

Requirements of the *Human Tissue Act 2003*. A person must not:

• Authorise the removal of tissue from the body of a deceased child for any purpose (other than for the purpose of its transplantation to the body of a living person) if the child was, immediately before his or her death, in the care of the State.

• Authorise the postmortem examination of the body of a deceased child if the child was, immediately before his or her death, in the care of the State.

• Authorise the use of tissue removed during the postmortem examination of the body of a deceased child for any purpose (other than the purposes of the postmortem examination) if the child was, immediately before his or her death, in the care of the State.