Consent requirements


2. Where possible, consent to be obtained by the senior treating clinician who has an established rapport with the family

3. Informed consent for post mortem examination must be obtained in writing from a parent of the deceased baby regardless of weight or gestation

4. Complete consent form (Consent Form page 1)

5. Arrange authorisation for post mortem examination (Consent Form page 2) to be completed by the hospital Designated Officer

6. Where there are specific cultural practices affecting who can give consent for post mortem, 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, a copy of it should be placed in the medical record

7. Role of senior treating clinician:
   a. The clinician must have an understanding of the post mortem process
   b. Explain the benefit of completing an post mortem, and discuss the possible situation where the post mortem does not identify a cause of death
   c. Be prepared to answer questions about what actually happens in an post mortem examination and how the baby will look after reconstruction
   d. Understand and discuss post mortem options including; external, full and limited
   e. Discuss the need for collection of tissue samples and organ retention, if applicable, clarifying that tissue sampling is routine but organ retention is not
   f. Discuss options for disposal of retained tissue or organs. Document parental preference
   g. Discuss issue of use of tissue for research (if applicable)
   h. Discuss options for cremation, burial or funeral arrangements. Document parental preference
   i. Discuss what to expect following reconstruction of baby and that arrangements can be made to view and hold their baby following the examination
   j. Advise family how long their baby will be with the Pathologist (usually 2-3 days depending on clinical circumstances)
   k. Advise on timing for funeral arrangement and transportation
1. Reassure family; baby will be treated with respect and dignity
   m. Advise family on when the results of the examination will be available to them


Note:

- Consent is not required for placental examination, but placenta must be accompanied by a pathology request form
- Sufficient time should be allocated to discuss with families the options for post mortem examination and answer questions; parents should not be rushed to decide. Where a death is expected, a preliminary discussion prior to delivery may give the parents more time for consideration
- Where baby is kept refrigerated for up to three days, parents can delay making a decision until they are ready, parents should be made aware that time delays can influence quality of post mortem results
- If there are specific questions, the Perinatal Post Mortem Service Coordinator is available to discuss these with the family and can also facilitate family discussion with a Perinatal Pathologist

Resource documents

<table>
<thead>
<tr>
<th>Document ID</th>
<th>Description</th>
</tr>
</thead>
<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>
</tr>
<tr>
<td>GL2013_015</td>
<td>Retention of Bodies - Approval to Retain Bodies for Longer than Permitted</td>
</tr>
<tr>
<td>PD2013_051</td>
<td>Non-Coronial Post Mortems</td>
</tr>
</tbody>
</table>

Further information

Burial, cremation and funeral arrangements

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

- **Options for unregistered** babies:
  - Burial via a registered Funeral Director
  - Cremation arranged by the laboratory undertaking the post mortem
    - 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 Post Mortem Service Coordinator for pamphlets if required
  - Unregistered babies can be returned to the referral hospital for cremation, indicate on consent form parental preferences
  - Unregistered babies can be returned to the family (collect in person) for burial/cremation, a discussion with the Care Coordinator should take place to discuss this option

- **Options for Registered** babies:
  - Burial/cremation via a registered Funeral Director
  - The Perinatal Post Mortem 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 and streamline the safe return of the baby to the family/hospital/Funeral Director

- **Deceased neonates** are returned to families for burial/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

- In routine practice, once a baby’s organs are examined they are replaced. 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 post mortem, the service Coordinator will consult with the referring clinician. No organs will be retained unless parental consent is obtained
NSW Perinatal Post Mortem Service
Post mortem consent guide
(June 2018)

- Slides are retained by Pathology for a period of at least 25 years in case a review is required
- Some organs such as the brain require fixation with a solution so the Pathologist can adequately examine the structure, this will impact the length of time a post mortem will take
- Very small tissue samples will be stored frozen for five years in case the need to investigate the molecular basis for a baby death or where by malformation syndromes of uncertain aetiology at the time of post mortem may later be 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 post mortem the following options for disposal should be discussed with the family and their preferred option included on the consent.

1. Burial or cremation of baby is delayed until such time as the organs can be reunited with baby
2. Burial or cremation of the baby occurs and retained organs are cremated/buried at a later stage to be organised by the family
3. Retained organs are cremated by the laboratory conducting the post mortem

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
- Small tissue samples which have been lawfully removed from living or deceased persons to be used without consent for the purposes of carrying out analyses or tests:
  - that are part of a program (including any quality assurance program, quality control program, audit or evaluation) to ensure, or improve, the quality of services carried out at or by a hospital, a forensic institution, a laboratory, an educational or research institution or a supplier of blood or blood products
  - That are necessary for the delivery of services carried out at or by a hospital, a forensic institution, a laboratory, an educational or research institution or a supplier of blood or blood products or for the accreditation under any Act of a hospital, a forensic institution, a laboratory, an educational or research institution or a supplier of blood or blood products
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 post-mortem 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 post-mortem examination of the body of a deceased child for any purpose (other than the purposes of the post-mortem examination) if the child was, immediately before his or her death, in the care of the State.