

# STANDARD OPERATING PROCEDURE

## PERINATAL POST MORTEM CONSENT

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<b>RATIFIED BY:</b> Perinatal Governance Group	<b>DATE:</b>
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### PURPOSE

- Seeking or taking of consent for a post mortem is a very sensitive issue for both the consent giver and staff.
- This procedural document details the process involved, the required documentation and discussion and training required to ensure that consent for a post-mortem is sought and taken as sensitively, effectively and accurately as possible from fully informed individuals, in accordance with the law and legal requirement of the Human Tissue Act 2004 and Human Tissue Authority codes of practice.

### OBJECTIVE

- To ensure that factual information regarding the post mortem procedure is provided sensitively and appropriately to those who will need to give consent, according to the guidelines issued by the Human Tissue Authority.
- To ensure that consent is given based upon fully informed choice.
- To ensure that the consent form is fully and accurately completed.
- To ensure that consent is sought and completed by sufficiently trained individuals.

### SCOPE

- All staff involved in taking Post Mortem consent within the Maternity and Neonatal setting.
- Consent may be taken by senior medical staff, the Bereavement Midwifery Team and any other Senior Midwife or member of nursing staff who has received post-mortem consent training.

Standard Operating Procedure	<b>Current Version is held on the Intranet September 2023</b>	First ratified: September 2023	Review date: September 2026	Version 1	Page 1 of 8
------------------------------	---	-----------------------------------	--------------------------------	--------------	-------------

## COMPETENCIES

Professionals taking consent must know the legal requirements:

- The circumstances in which a death must be referred to the coroner and/or medical examiner.
- The consent that is required for a hospital post mortem.
- The consent that is required to use and store human tissue.
- Who can give consent when a baby dies in circumstances of neonatal death, stillbirth or early pregnancy loss)

All staff taking Post mortem consent must feel confident to make parents aware of their choices and decision making.

All staff taking PM Consent must have completed appropriate training in PM consent.

Consent seekers should understand:

- The shock, confusion and distress that newly bereaved parents are experiencing, and how this may impair their ability to take in information, understand it and make decisions
- Consent seekers should be mindful not to overwhelm parents and should check that parents are happy to discuss the post mortem at that point in time
- The importance of ensuring privacy and uninterrupted time to discuss post mortem consent
- Staff should aim to foster a culturally sensitive care approach in accordance with the religious and cultural beliefs of the parents and families in our care.

Consent takers should be able to:

- Communicate clearly and sensitively with the parents.
- Outline the post mortem process and the different options sensitively and in language that the parents can understand; using interpretation services if required.
- Tailor the amount of information he/she gives according to the needs and wishes of the parents and the requirements of the consent/authorisation form.
- Help the parents to reach decisions that they will not later regret.
- Explain that a PM may not provide the reason why a baby has died. If it is not possible to identify the cause of death a PM may help to eliminate certain potential causes and may help with planning care for future pregnancies.

### Essential information about local arrangements for post mortems

Consent seekers must be fully conversant with the local procedures regarding post mortem examinations. Prior to seeking consent they should therefore have been trained in:

Standard Operating Procedure	<b>Current Version is held on the Intranet September 2023</b>	First ratified: September 2023	Review date: September 2026	Version 1	Page 2 of 8
------------------------------	---	--------------------------------	-----------------------------	-----------	-------------

- How the baby's body would be cared for and kept safe in the hospital mortuary.
- Where the PM will be carried out, which is at St Thomas's Hospital and that the baby will be transferred respectfully and with dignity by the Trust's contract Funeral Director. Following post-mortem baby will be returned to St Peter's Hospital in the same way
- The policy on organ retention and storage of tissue samples
- When the baby can be visited by the family and how they arrange this.
- The choices that parents have about a funeral for their baby.
- When the baby's body is likely to be returned for the funeral (usually 2 weeks but on occasion may be longer).
- Who will give parents the results of the post mortem and when and where this is likely to happen.

### INDICATIONS

All deceased babies delivered on Labour ward from 14 weeks gestation or babies who die in NICU. This includes miscarriages from 14 weeks gestation, stillbirths and neonatal deaths.

### PROCESS

All Parent's should be offered the opportunity for a post mortem for their baby from 14+0 weeks gestation.

Except in circumstances where the Coroner requires a PM, parents may decline a PM.

Where the baby has been born with signs of life and subsequently died (neonatal death), the independent Medical Examiner will be informed and will scrutinize the cause of death.

Where the cause of death cannot be determined by the medical team or where the death is considered to be unnatural (eg Termination of pregnancy resulting in a live born infant) or where the circumstances are suspicious, referral will be made to the Coroner. The Medical Examiner and Coroner do not have any jurisdiction for still born babies and babies who miscarry.

#### Coroner's Post Mortem

- If a referral to the Coroner is deemed to be required, depending on the circumstances, the Coroner may require a Post Mortem to be carried out.
- The parents cannot decline a post-mortem in these circumstances and their consent is not required.
- If there is to be a Coroner's Post Mortem it will generally be necessary to leave any medical equipment, such as tubes, IV access in situ.

Standard Operating Procedure	<b>Current Version is held on the Intranet September 2023</b>	First ratified: September 2023	Review date: September 2026	Version 1	Page 3 of 8
------------------------------	---	--------------------------------	-----------------------------	-----------	-------------

- Where there is to be a Coroner's PM, the parents will not be permitted to take their baby home prior to the PM. It may be possible for them to do so after completion of the PM. (Refer to Taking Baby Home Standard Operating Procedure)
- If the coronial referral has been made and the coroner has not instructed a Post Mortem examination to go ahead then the Parents must be offered a post mortem for their baby and have the right to consent or decline a post mortem.

**Procedure For Hospital Post Mortem:**

1. The person taking consent is required to be an appropriately trained individual
2. The consent seeker must be able to verify that:
  - a They have completed consent training.
  - b They have ideally attended or observed a post mortem examination or equivalent;
  - c They understand what blocks and slides are in the context of a post mortem examination.
3. If the consent seeker is not appropriately trained they must be accompanied by an appropriately trained and competency assessed individual.
4. Ensure the parents have been given the SANDS guidance on "Deciding about a Post Mortem – Information for Parents" or equivalent and ensure that they are given sufficient time to read and digest this information so that they can reach a decision that is appropriate to them.
5. If the parents do not wish to proceed with consenting for a hospital post mortem examination this should be discussed with them and documented in the patient notes. The parent's wishes must be respected.
6. A suitable location that ensures privacy and uninterrupted time to discuss post mortem consent should be located. On Labour Ward this is usually the Daffodil Room Bereavement Suite or Birthing Room. If the baby has died in NICU, this may be a counselling room.
7. Consent should only be obtained at an appropriate time following the death of the baby. Unless the parents raise this themselves, consent for post-mortem should not be obtained immediately before induction, during labour or just following delivery.
8. If an interpreter or information in a different format is required then these should be sought prior to the completion of the consent form. If an interpreter is declined this should be documented in the notes.

Standard Operating Procedure	<b>Current Version is held on the Intranet September 2023</b>	First ratified: September 2023	Review date: September 2026	Version 1	Page 4 of 8
------------------------------	---	--------------------------------	-----------------------------	-----------	-------------

In accordance with Trust Guidelines, family members should not be used to interpret. Interpreter services can either be via language line or face to face. Guidance for interpreter services can be found on the Trust Intranet.

9. Provide a full explanation of the post mortem procedure, tailored to the needs of the individual, using language the family can understand and ensure that appropriate choices are offered. Any questions should be answered accurately to ensure fully informed consent.

The consent seeker must have received sufficient training to allow them to explain what histopathological blocks and slides are along with their relation to the post mortem examination procedure.

The parents should be informed that the results may provide useful information relating to the cause of death of their baby but also that there may on occasions be no cause of death identified.

If the post mortem is to be a limited or external examination the limitations of these examinations should be explained to ensure that they are fully informed

10. The SANDS consent form must be used and completed fully and accurately. This includes writing the words 'yes' or 'no' to each of the questions on the consent form. Ticks or crosses in the boxes on the consent form will **not** be accepted.

11. The consent form must be signed by the person giving consent and the consent taker. If the child has not had a separate existence from the mother (i.e. miscarriage or stillbirth) then **only** the mother will be able to consent to the post mortem examination, although the Partner can join in giving consent. The Partner cannot give consent alone in these circumstances. (There are exceptional circumstances where the Partner will be able to consent, such as if the mother is incapacitated or has died)

Where possible both parents should join in giving consent and sign the consent form.

Where there is a disagreement between the parents and the mother wishes a post-mortem., then her wishes need to be respected as the results may benefit her in any future pregnancy.

Document any difficulties that have arisen and how these were resolved.

A teenage mother can give consent if she has capacity to understand what is involved in the decision and can comprehend the information being discussed.

A learning disability does not automatically exclude the mother from giving consent.

Standard Operating Procedure	<b>Current Version is held on the Intranet September 2023</b>	First ratified: September 2023	Review date: September 2026	Version 1	Page 5 of 8
------------------------------	---	--------------------------------	-----------------------------	-----------	-------------

Each case should be thoroughly assessed to ascertain whether the individual lacks competence to make a decision. This involves being unable to understand, retain and process the information in order to make a decision or is unable to communicate her decision in any way.

12. The cooling off period (usually 24 -48 hours) must be explained along with a contact procedure should they wish to change their mind regarding the post mortem examination procedure. Parents should be names and contact details of who they should contact if they change their mind.

Labour Ward Midwife in Charge: on 01932 722864  
 Bereavement Officer: 01932 722319/2516

In the event of withdrawal of consent and a decision by the Parent(s) not to go ahead within the cooling off period, the procedure to ensure this is cascaded to appropriate areas/staff must be followed.

The procedure is:

To notify the Midwife in Charge of the LW or Bereavement Midwife or The Bereavement Officer

The Midwife in Charge or Bereavement Midwife will notify the Bereavement Officer.

13. Three copies of the consent form will be made:

- a. The original will accompany the deceased's body to the mortuary along with the required medical notes
- b. One copy will be filed with the patient notes
- c. One copy will be provided to the person giving consent, if they wish.

14. A PM Referral Form with detailed background information must be completed and accompanying medical information such as USS reports must accompany the PM Consent and Referral Form.

15. The PM Consent, Referral Form and accompanying medical information must be emailed to St Thomas's Hospital for checking and acceptance before Baby can be received by them.

16. Consent for placental examination only may be verbal rather than written and should be documented in the maternal record. If consent is not given, this should be documented.

17. Parents must be informed that the post-mortem examination of the baby is likely to take two weeks but can be longer on occasion. Following the return of their baby to St Peter's Hospital the Bereavement Team will contact the parents and they may then proceed with the chosen funeral arrangements.

Standard Operating Procedure	<b>Current Version is held on the Intranet September 2023</b>	First ratified: September 2023	Review date: September 2026	Version 1	Page 6 of 8
------------------------------	---	--------------------------------	-----------------------------	-----------	-------------

18. Parents must also be informed that the results of the post-mortem will often take up to twelve weeks . A follow up appointment with the Consultant will be offered and may take approximately 16 weeks.

**TERMINATIONS OF PREGNANCY FOR FETAL ABNORMALITIES**

In cases of termination of pregnancy for fetal abnormalities, parents should be counselled about the possibility of a post-mortem examination, as this may have implications for their decisions about method of termination. i.e not possible where there is surgical management.

**Communication and documentation**

People with learning disabilities, visual or hearing impairments or those whose first language is not English must be offered assistance to help them to understand the information. Interpretation services should be used where applicable, and where appropriate a telephone interpreter must be used.

It is paramount that clear channels of communication are maintained at all times between all staff, the women and their families. Once any decisions have been made/agreed, comprehensive and clear details must be given to the woman thereby confirming the wishes of the women and their families.

All communication difficulties (including learning difficulties) and language barriers must be addressed as outlined in the previous paragraph at the time any leaflet, such as the SANDS leaflet, is issued.

Details of any discussion together with explicit details of proposed management must be documented contemporaneously, as appropriate (NMC, 2016).

**TRAINING FOR POST\_MORTEM CONSENT TAKERS**

1. All consent takers must have completed either in person post-mortem consent training or completed the e-learning for health on line training package, every three years.
2. If they do not have previous PM Consent experience ideally they should observe the PM consent process and be observed once by a person who is competent in obtaining consent.
3. It is beneficial to observe a perinatal post-mortem examination. This can be arranged directly by contacting St Thomas’s Hospital Mortuary on 02027 188 3928
4. The Consent Taker must be aware of the Human Tissue Act (HTA) Standards relating to consent for post-mortem examination. HTA Code of Practice and Standards; B; Post-mortem examination 2017

**RESPONSIBILITES**

Standard Operating Procedure	<b>Current Version is held on the Intranet September 2023</b>	First ratified: September 2023	Review date: September 2026	Version 1	Page 7 of 8
------------------------------	---	--------------------------------	-----------------------------	-----------	-------------

The Bereavement Midwives will provide support and guidance to staff and parents

All professionals taking PM Consent are responsible for ensuring they have been appropriately trained.

**AUDIT**

Bereavement Midwives

Standard Operating Procedure	<b>Current Version is held on the Intranet September 2023</b>	First ratified: September 2023	Review date: September 2026	Version 1	Page 8 of 8
------------------------------	---	-----------------------------------	--------------------------------	--------------	-------------