

Obtaining Consent for a Perinatal Post Mortem

VERSION	v1.4
AUTHORISED BY	L. Luscombe, Designated Individual
AUTHOR	E Seymour
COPY	2
LOCATION OF COPIES	<ol style="list-style-type: none">1. Mortuary / Bereavement Office2. Q-Pulse3. Perinatal post mortem consent file – CDS

CONTENTS

0	INTRODUCTION.....	3
0.1	SCOPE AND PURPOSE	3
0.2	RESPONSIBILITY.....	3
0.3	TRAINING.....	5
0.4	STAFF INVOLVED.....	5
0.5	REFERENCES.....	5
0.6	DEFINITIONS.....	6
0.7	DOCUMENTATION.....	6
0.8	REFERENCE DOCUMENTS FOR INFORMATION AND GUIDANCE	6
1	OBTAINING CONSENT FOR A PERINATAL POST MORTEM	6
1.1	FIRST STEPS	7
1.2	WHO CAN GIVE CONSENT.....	8
1.3	PROCESS OF FORMALLY OBTAINING CONSENT FOR HOSPITAL POST MORTEM	8
1.4	WHAT HAPPENS NEXT.....	10
1.5	PLACENTA ONLY.....	11

0 INTRODUCTION

0.1 Scope and purpose

To ensure correct consent procedures are followed before a perinatal hospital post mortem is conducted.

It will ensure that the person giving consent is an appropriate person, as defined by the Human Tissue Act, 2004 to give consent. They are aware of the benefits and limitations of the examination and the nature of the procedures undertaken during a hospital post mortem examination. For valid consent it must be a positive act. To be valid it must be given voluntarily by an appropriately informed person who has the capacity to agree to a post mortem.

0.2 Responsibility

For hospital post mortem following a perinatal death it is the responsibility of the consultant clinician or delegated team member caring for the mother to raise the possibility of a post mortem examination and follow this procedure to obtain consent. Where possible the Bereavement Support Office is contacted in advance to arrange for someone to be available to support the consent taking procedure. The person taking the consent must be an approved consent taker i.e. having satisfied the conditions set out in 0.2.1 and be on the current list of approved consent takers. This can be found in the perinatal post mortem consent file on CDS and in the Bereavement Support Office.

Ideally the midwife involved in the mother's care will have attended a training session on taking consent for post mortem.

0.2.1 Clinician seeking consent

Anyone seeking consent to a perinatal post mortem must be on the current list of approved consent takers. The requirements for this are:

- Attend NDHT Training session on taking perinatal post mortem consent
- Read SANDS *Guide for consent takers*
- Read the "Understanding why your baby died" chapter in the *SANDS Bereavement Support book* for parents
- Read SANDS *Guide for consent takers: Local practices and arrangements*
- Read NDHT Policy: *Post Mortem, Sensitive Disposal and Tissue Policy*
- Read this Policy in full
- Read the NDHT booklet for parents appropriate to the gestation of the loss
- Be familiar with the post mortem consent form
- Advised but not essential: Observe a perinatal post mortem

This list can be found in the Perinatal Post Mortem file on CDS and in the Bereavement Support Office. Annual refresher training will be required.

In the case of a neo-natal death you should first ensure whether HM Coroner has been informed of the death and whether there may be a Coroners post mortem. If there is to be a Coroners post mortem there is no need for parental consent and there is not usually any need for a hospital post mortem. **Clinicians should ensure parents have been offered consented post mortem in cases which have been reported to HM Coroner but no Coroners PM is ordered.**

The mother's consultant or member of their team should sensitively raise the possibility of a post mortem examination with the parents. As a clinician you will know the medical problems and what might be useful to investigate further. You will be responsible for establishing the parents' willingness to discuss consent. All parents with pregnancy losses over 12 weeks must be offered a post mortem. If the loss is at an earlier gestation but the parents request a post mortem you should discuss this with the Perinatal Histopathologist.

If parents do not consent to a post mortem, ask them if they will consent to the placenta being sent to Bristol for specialist examination.

The Bereavement Support Officers will have a sound knowledge of perinatal post mortem procedures and therefore will be able to explain to the parents about the post mortem examination and be able to answer any questions they may have.

The clinician and the bereavement support team are responsible for following this procedure and working together when seeking consent to a perinatal hospital post mortem examination.

0.2.2 All persons seeking consent

Persons seeking consent are responsible for ensuring consent is valid, i.e. given voluntarily, by an appropriately informed person who has the capacity to agree to a post mortem examination. They are responsible for following this procedure.

0.2.3 Designated Individual

This is the person at the Trust required for the Post Mortem establishment licence issued by the regulatory body, the Human Tissue Authority.

At Northern Devon Healthcare Trust Lee Luscombe, the Pathology Service Manager is DI.

Lee can be contacted on 01271 311754 (ext 3754) or at lee.luscombe@nhs.net for advice, guidance and information in regard to Post Mortems

Designated Individuals have a key role to play in implementing the requirements of the Human Tissue Act. They are the person under whose supervision the licensed activity, post mortems, is authorised to be carried out. They have the primary (legal) responsibility under Section 18 of the Human Tissue Act to secure:

- that suitable practices are used in undertaking the licensed activity;
- that other persons working under the licence are suitable and;
- that the conditions of the licence are complied with.

The Designated Individual is responsible for ensuring there is a suitable consent procedure in place that meets the requirement of the Human Tissue Act and the standards and codes of practice issued by the Human Tissue Authority.

0.2.3.1 Persons Designated

An establishment can designate particular individuals in a Notice to the HTA. They will then be regarded as Persons Designated (PD) as a person to whom the licence applies: to whom the authority conferred by the licence extends. Typically they are individuals carrying out duties licensed by the HTA. i.e. post mortem consent takers

Persons Designated do not have a legal duty comparable with those set out for the DI under Section 18 of the HT Act (i.e. to ensure that suitable practices are used and that there is compliance with licence conditions). However the role of Person Designated carries with it the ability to “direct” others in relation to the HT Act.

At NDHT Mortuary and Bereavement Support Officers are PD’s and can provide advice and guidance.

It is good practice to have named PD’s in each area where licensed activities may be taking place and therefore those trained to take consent may be asked to be a PD, with their names provided to the HTA in a notice.

0.3 Training

A Bereavement Support officer will provide training for all doctors and midwives who wish to be approved perinatal post mortem consent takers in line with HTA guidelines. A thorough knowledge of the associated documents is also a requirement – see 0.2.1

0.4 Staff involved

- The consultant clinician caring for the mother and other team members
- Midwife
- Perinatal Histopathologist
- NDDH Mortuary and Bereavement Support staff
- Perinatal Anatomical Pathology Technicians at St Michael’s Hospital, Bristol

0.5 References

- Human Tissue Authority Codes of Practice – PM sector, MOR-EXT-7
- D.O.H. Families & Post Mortems
- D.O.H. Consent to a Hospital Post Mortem / Human Tissue Act 2004 – consent form templates.
- SANDS Post Mortem consent package 2017

0.6 Definitions

Perinatal: Foetuses from approx. 11/40 weeks gestation to full term and up to 4 weeks post-delivery.

0.7 Documentation

- **Form:** NDHT Perinatal post mortem consent
- **Form:** NDHT Consent to further examination of organs for diagnostic purposes (if appropriate)
- **Form:** NDHT Sands Optional section on retaining organs for the PM consent form (if appropriate)
- **Form:** Bristol Perinatal Post Mortem Request

These can be found in the Perinatal Post Mortem Consent file on CDS and in the Bereavement Support Office.

For a paediatric post mortem for a child age up to 2 years – use perinatal form

For a paediatric post mortem for a child age 2-16 – use paediatric form (ask BSO)

For age 17 and over – use adult form (ask BSO)

0.8 Reference documents for information and guidance

- SANDS Guide for consent takers
- SANDS Information for consent takers: Local practices and arrangements
- “Understanding why your baby died” chapter in the *SANDS Bereavement Support book* for parents
- Information for consent takers: local practices and arrangements
- NDHT Post Mortem, Sensitive Disposal and Tissue Policy

These can be found in the Perinatal Post Mortem Consent file on CDS and in the Bereavement Support Office.

1 OBTAINING CONSENT FOR A PERINATAL POST MORTEM

Clinicians should ensure parents have been offered consented post mortem in cases which have been reported to HM Coroner but no Coroners PM is ordered.

For consent to be valid it must be given voluntarily by an appropriately informed person, who has the capacity to agree to a post mortem examination. This procedure will ensure that you provide the person giving consent with sufficient information for this to be the case.

It is **essential** that a post mortem consent form **and** post mortem request form are both completed fully. A perinatal post mortem cannot be performed until these forms are completed. All scan reports will also need to be copied and sent with the consent and request forms..

1.1 First Steps

1. The consultant caring for the mother must first establish that a post mortem examination is appropriate. They can discuss the case with a Perinatal Histopathologist at St Michael's Hospital if necessary.
2. The consent taker will then establish a willingness of the parents to discuss consent to a post mortem, setting out clearly with objective information why a post mortem might be helpful. Ensure that you acknowledge the parents' loss and express your sympathy. Always refer to the baby by name if the parents have chosen one, use 'he' or 'she' – never 'it'. Take your cue from the parents as to whether to use the term baby or foetus. Perinatal post mortems are performed at St Michael's Hospital, Bristol so ensure that the parents are fully aware of the implications this will have on funeral arrangements given that we will not be able to say with certainty when the baby will be returned to NDDH. Give them assurances that the Bereavement Support Office will keep them informed, make arrangements to keep in contact and let them know they can contact the bereavement support office at any time if they have any questions.
3. Ensure they have the *SANDS Bereavement Support book* and allow them an opportunity to read the chapter "Understanding why your baby died"; allow time for them to ask more questions before you discuss the consent form with them.
4. Consider their cultural or religious beliefs and be sensitive to the needs of the family. Allow families to make a personal decision about a post mortem and be aware that cultural and religious beliefs may forbid post mortems.
5. Consent is only valid if proper communication has taken place. Consider the need for translation services if English is not the first language of those who will be giving consent. Make arrangements as appropriate following Northern Devon Healthcare Trust Interpreting and Translation policy. Consider the use of communication aids if the next of kin have any sensory impairment.
6. Be prepared for the parents to refuse to give consent. They may do this immediately when approached or they may refuse during the formal process as they understand more about the examination they are being asked to give consent for. At all times respect their wishes and do not try and influence their decision. Your role is to support them, providing objective information.

1.2 Who can give consent

This would usually be the mother. The father can give consent jointly. In exceptional circumstances - e.g. if the mother is too ill to give consent and is likely to remain so for some days - the father's consent may be accepted.

1.3 Process of formally obtaining consent for hospital post mortem

1. Consent will be documented on the NDHT perinatal post mortem consent form. This form sets out all the aspects of the examination that must be consented and must be completed in full. A post mortem will not be performed until the Perinatal Histopathologist is satisfied that the correct consent is in place.
2. Check that you are on the current list of approved perinatal post mortem consent takers; this can be found in the Perinatal Post Mortem Consent file on CDS and in the Bereavement Support Office.
3. Where possible contact the Bereavement Support Office in advance to arrange for someone to come and support the consent taking. The midwife caring for the parents should also be present so that they know exactly what has been discussed; they will then be able to answer any questions the parents have at a later time.
4. Throughout the process allow the parents time to reflect and to discuss any issues. Allow them some privacy if they require it and where possible facilitate discussions with other people they feel may help them in making a decision.
5. If at any time you believe the mother may not fully understand what is being explained to her, may not be giving consent voluntarily or does not have the capacity to consent you must stop the process as the consent given may not be valid. You must sensitively explain why you do not think they are able to give consent. You must act in their best interest.
6. Explain the benefits of the examination and the medical problems that would be investigated further. Using clear objective information explain the limitations and that it may not provide the answers you are looking for. Give them every opportunity to ask questions and answer these honestly.
7. **Section 1** deals with the choice of a full or a limited post mortem. It may be the case that a limited post mortem will be sufficient. Explain what needs to be examined and allow them to ask questions to make a decision on a full or limited post mortem.
8. You will need to talk about the actual post mortem examination procedure explaining what happens, what will be removed, what may need to be retained for further examination and how the baby will be reconstructed afterwards. Give as much information as they require. You must ensure they are offered sufficient information to make an informed choice to

make the consent valid. It is acceptable for them to decline such information but still give consent.

9. If they decide on a limited post mortem when ideally a full examination is appropriate you must explain that this will limit the information obtained. You may think at this time that it is no longer of value to carry out the examination. If this is the case explain this but do not pressure them to consent to a full examination if they do not want to.
10. **Section 2** deals with tissue samples being kept as part of the medical record once a full or limited post mortem is complete. Explain exactly what these samples will consist of i.e. histology tissue blocks and the slides made from them. Show them an example of a tissue block and slide.
11. If consent is **not** given for tissue samples to be retained in this way, the options for disposal should be explained – see Section 8 Item 6 of the consent form. Record the parents' wishes on the form.
12. **Section 3** deals with tissue samples being taken for genetic testing. The options for their retention or disposal are detailed in Section 8 Item 6 as above.
13. **Section 4** covers additional separate consent that parents may wish to give regarding tissue samples being kept for professional training, audit and research. It will not affect what they have already agreed to or the information they get about their baby's condition. They can withdraw consent for this at any time in the future.
14. **Section 5** gives the parents an opportunity to state any other requests or concerns.
15. Complete **Sections 6 and 7** of the consent form ensuring that everyone involved has signed it in all the appropriate places.
16. Make sure the parents are aware that they are able to withdraw consent anytime up until the post mortem is scheduled to take place and can change their minds about any other aspect of the consent they have given.
17. Explain that we will comply with the consent given in the consent form at all times. Then **give them a copy of the completed consent form** which will have on it the Bereavement Support Office contact details and a time by which they will need to contact the Bereavement Support Office if they change their mind (usually 24 hours).
18. Explain that following the examination they may, if they wish still see the baby. Describe sensitively how they will appear after the post mortem and that great care is taken so that once dressed and presented in the viewing suite they should not see evidence of the examination having taken place.

19. It is important to let them know that they can make provisional funeral arrangements but they should not fix a date until baby has returned from Bristol.
20. Inform them that when the results of the examination are available they will be contacted to come in to discuss them with their consultant.
21. Make sure they have all the information they require and the contact details of the Bereavement Support Office should they wish to ask further questions or withdraw consent.
22. **Possible further examination of one or more organs:** Very rarely, it may be recommended by the Paediatric Histopathologist that an organ is kept for more detailed examination after the baby is released from the mortuary. In this case, the form *Consent to further examination of organs for diagnostic purposes* and/or *Sands Optional section on retaining organs for the PM consent form* should be completed, as well as the post mortem consent form. See Item 9 Section 8 for full details

1.4 What happens next

- You must complete the request form for a perinatal hospital post mortem: send the original to Bereavement Support and file a copy in the notes.
- Send the original consent form to Bereavement Support, give one copy to the parents and file one copy in the notes.
- Take copies of all scan reports and send to Bereavement Support.
- Email ndht.bereavementsupport@nhs.net to let them know that a post mortem is required and whether this is on a baby or placenta.
- The Bereavement Support staff will arrange for the baby and/or placenta to be transported to Bristol with the completed forms.
- The Bereavement Support staff will keep in touch with the parents throughout the process until the baby has returned from Bristol. They will support them with making funeral arrangements and arrange for them to see the baby again if they wish.
- The Bereavement Support staff will arrange for the release the baby to the family's nominated funeral director or arrange a hospital funeral if requested to do so by the parents.
- The Bereavement Support staff will inform the Obs and Gynae secretary that a post mortem has taken place so that they can check when the post mortem results have been received from Bristol.

- The Bereavement Support staff will keep the file open until they have confirmed that parents have met with a consultant to discuss the results and have been offered/given a written copy.

1.5 Placenta only: If the parents do not consent to a post mortem on the baby, they may be willing for the placenta to be sent to Bristol for specialist examination. In this case:

- Do not complete a consent form
- Gain verbal consent from the parents and document this in the case notes
- Complete a request form and take copies of all scans
- Contact Bereavement Support as in section 1.4