

Post Mortem Examination Consent Form

Your wishes about the post mortem examination of your
baby/child

All sections MUST be completed to prevent delay.

The examination of your baby/child will take place at

Great Ormond Street Hospital NHS Foundation Trust.

London WC1N 3JH

0207 829 7906.

Version 2.1

Reviewed: 2019

Review due: Two Years

Your wishes about the post mortem examination of your baby/child

Mother	Baby/Child
Last name	Last name
First name(s)	First name(s)
Address	Date of birth
	Date of death (if liveborn)
Hospital no.	Hospital no.
NHS no.	NHS no.
Date of birth	Gender (if known)
Consultant	Consultant
Father/Partner	Address (if different from the mother's)
Last name	
First name(s)	
Preferred parent to contact, tel. no.:	
Religion:.....	
Other notes: language, interpreter	

How to fill in this form:

- Please show what you agree to by writing **YES** in the relevant boxes.
 Write **NO**
 - where you do not agree.
 - Record any variations, exceptions and special concerns in the Notes to the relevant section or in Section 5.
 - Sign and date the form. The person taking consent will also sign and date it.

Changing your mind

After you sign this form, there is a short time (*Up to 48 Hours*) in which you can change your mind about anything you have agreed to. If you want to change your mind you must contact:

[Name] **[tel.]**

before [time] **on [day]** **[date]**

Please be assured that your baby/child will always be treated with care and respect. Any investigations listed below are only undertaken according to your specific wishes.

Section 1: Your decisions about a post mortem examination *Select one of these 4 options.*

The extent of examination that is carried out is up to you according to the options below. Each option describes all of the tests that will take place. However, for some patients, if it is felt that a more limited examination can adequately answer the questions raised, the examination may not include some of the components. This depends on the specific features and history for each patient and is therefore at the discretion of the Consultant Pathologist responsible. However, we will NEVER perform more extensive investigations than you have agreed to.

A complete / full post mortem. This is the standard approach and may provide the most information in some cases. It includes an external examination, then via two or more incisions, examining all of the internal organs, examining small samples of tissue under a microscope, a range of imaging techniques as appropriate (E.g. X-rays, CT, Micro CT, MRI, ultrasound) and medical photographs. Tests may also be done for infection and other problems. The placenta where relevant will also be examined.

I/We agree to a complete / full post mortem examination.

with Micro CT examination (This involves using a contrast solution which may cause discolouration)

OR

A minimally invasive post mortem examination. This includes an external examination, a range of imaging techniques as appropriate (E.g. X-rays, CT, Micro CT, MRI, ultrasound), medical photographs and examination of the internal organs of the body that you agree to, usually via a “key-hole surgery” approach. This will only involve a small incision for the endoscope; no large incisions will be made. The placenta will also be examined. In some cases it may be possible to take small tissue biopsies under imaging guidance alone to answer certain specific questions.

I/We agree to a minimally invasive post mortem examination.

with Micro CT examination (This involves using a contrast solution which may cause discolouration)

OR

A limited post mortem. This may give less information than a complete/full or minimally invasive post mortem examination but depending on the circumstances can often adequately answer specific questions. A limited post mortem includes an external examination, examining the internal organs in the area(s) of the body that you agree to, examining small samples of tissue under a microscope, and imaging and medical photographs. Tests may also be done for infection and other problems and the placenta will also be examined where relevant.

I/We agree to a limited post mortem examination.

Please indicate what **can** be examined: head chest and neck

abdomen placenta Only other

OR

An external / imaging post mortem. This may give less information than a complete/full or minimally invasive post mortem examination but depending on the circumstances can often adequately answer specific questions. An external post mortem includes an examination of the outside of your baby/childs body plus a range of imaging techniques as appropriate (E.g. X-rays, CT, Micro CT, MRI, ultrasound) and medical photographs but no incisions will be made or biopsies taken. The placenta will also be examined.

- I/We agree to an external post mortem examination with / without MRI
- With MicroCT examination (This involves using a contrast solution which may cause discolouration)

Whatever type of post mortem examination you have chosen above, you can also choose to agree to additional imaging tests, over and above those required for the PM report, to help teaching and research that may improve post mortem examinations in the future:

There is a separate information sheet which will give you more information about this.

- I/We agree to additional imaging tests for use in teaching, quality control and research (E.g. X-rays, CT, Micro CT, MRI, ultrasound).

Section 2: Tissue samples

Only if you consent to a complete, minimally invasive, limited post mortem or placenta only examination

With your agreement, the tissue samples taken for examination under a microscope will be kept as part of the medical record (in small wax blocks and on glass slides). This is so that they can be re-examined to try to find out more if new tests or new information become available. This could be especially useful if you would like further tests in the future.

- I/We agree to the tissue samples being kept as part of the medical record for possible re-examination. *If consent is **not** given, you must note below what should be done with the tissue samples. See page 8 Item 7 for more information.*
- Dispose of all tissue samples respectfully
- Return to Hospital for a later burial / cremation / collection

Notes to Sections 1 and 2 if required

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Section 3: Keeping tissue samples for training professionals and for research

Section 3 covers additional separate consent that you may decide to give. It will not affect what you have already agreed to above, what is done during the post mortem, or the information you get about your baby's condition, but it may be helpful for others in the future.

With your agreement, the tissue samples may also be examined for quality assurance and audit of pathology services to ensure that high standards are maintained.

I/We agree to the tissue samples being kept and used for quality assurance and audit.

Tissue samples, medical images and other information from the post mortem can be important for training health professionals. Identifying details are always removed when items are used for training.

I/We agree to anonymised tissue samples, images and other relevant information from the post mortem being kept and used for professional training.

Tissue samples, medical images and other relevant information from the post mortem can also be useful in research into different conditions and to try to prevent more deaths in the future. All research must be approved by a Research Ethics Committee.

I/We agree to tissue samples, images and other relevant information from the post mortem being kept and used for ethically approved medical research.

Occasionally extra tissue samples may be useful for research to help other parents and professionals in the future. These small extra samples are taken at the same time as the routine postmortem samples and are not identifiable when used.

I/We agree to additional tissue samples being taken for teaching, quality control, audit and research.

Section 4: Genetic testing

To examine the baby/childs chromosomes or DNA for a possible genetic disorder or condition, the pathologist takes small samples of skin, other tissue and/or samples from the placenta (afterbirth). With your agreement, this material will be kept as part of the medical record so that it can be re-examined to try to find out more if new tests or new information become available. This will be done on a request only basis.

I/We agree to the genetic material being stored as part of the medical record for possible examination. See Section 8 Item 6 for more information.

I/We agree to genetic testing of samples of skin, other tissue and/or the placenta. If samples should not be taken from any of these, please note this below. This will mean we will not contact you if the material is requested by a geneticist.

Section 5: Keeping one or more organs for diagnostic purposes

In most cases, all the organs will be returned to your baby's/child's body after the post mortem examination. But occasionally the doctors may recommend keeping one or more organs for longer, to carry out further detailed examination to try to find out more about why your baby/child died. This might take some weeks and so could affect the timing of your baby/child's funeral. The person who discusses the post mortem with you will tell you if it is likely.

- I/We agree to further detailed examination of the organ(s) specified below:**
 - Any organ**
 - The following organ(s)**

If you agree to further detailed examination, you also need to decide what should be done with the organs after the examination.

- I/We agree to donate the organ(s) to be used to train health professionals.**
- I/We agree to donate the organ(s) to be used for ethically approved medical research.**
- I/We want the hospital to dispose of the organ(s) respectfully as required by law.**
- I/We want the organ(s) returned to the funeral director we appoint for separate cremation or burial.**
- I/We want to delay the funeral until the organ(s) have been returned to my/our baby's body.**

If you agree to donate one or more organ(s), any residual tissue will be sensitively disposed when they are no longer needed. This will be carried out in accordance with the HTA standards (usually after a minimum of one year).

If you change your mind about this donation at any time in the future, and want to withdraw your consent, please contact the hospital and ask for the mortuary department.

Notes to Section 5 if required

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You can withdraw consent for any of the options in section 3 at any time in the future. To do so, please contact the hospital and ask for the person who has signed the consent takers statement. Alternatively you can ask for the mortuary manager who can document any changes in your consent.

Section 6: Consent from person(s) with Parental Responsibility

- I/We have been offered written information about post mortem examinations.
- I/We understand the possible benefits of a post mortem examination.
- My/Our questions about post mortem examinations have been answered.

Mother's name (Print): **Signature**

Other person with Parental Responsibility: name (Print).....

Signature

Date **Time**

Section 7: Consent taker's statements *To be completed and signed at the time of consenting.*

- I have read the written information offered to the parents/those with Parental Responsibility.
- I believe that the parent(s)/those with Parental Responsibility has/have sufficient understanding of a post mortem and (if applicable) the options for what should be done with tissue and organs to give valid consent.
- I have recorded any variations, exceptions and special concerns.
- I have checked the form and made sure that there is no missing or conflicting information.
- I have explained the time period within which parents can withdraw or change consent, and have entered the necessary information at the beginning of this form.

Name **Position/Grade**

Department **Contact details (Ext/Bleep)**

Signature **Date** **Time**

Interpreter's statement (if relevant)

- I have interpreted the information about the post mortem for the parent(s)/those with Parental Responsibility to the best of my ability and I believe that they understand it.

Name **Contact details**

Signature **Date** **Time**

Section 8: Notes for the consent taker

1. "Responsibility for obtaining consent should not be delegated to untrained or inexperienced staff. Anyone seeking consent for hospital post-mortem examinations, should have relevant experience and a good understanding of the consent procedure. They should have been trained in dealing with bereavement and in the purpose and procedures of post-mortem examinations. Ideally, they should have also witnessed a post-mortem examination." (Human Tissue Authority, Code of Practice B, 2017).
2. Consent must be given by those with Parental Responsibility.
3. Written information about post mortems should be offered to all Parents/those with Parental Responsibility before you discuss the form with them.
4. If the parents/those with Parental Responsibility have a specific request that you are not sure about, contact the pathologist **before the form is completed**.
5. Make sure that an appropriate time and date are entered in the *Changing your mind* section at the beginning of the form, and the parent(s)/those with Parental Responsibility understand what to do if they change their minds. The post mortem should not begin unless this section is completed. **It is your responsibility to ensure that, if the parent(s)/ those with Parental Responsibility change their minds, they will be able to contact the person or department entered on this form.** If the parents do not want a copy of the form, they should still be given written information about changing their minds.
6. Write the mother's or the baby/childs hospital number in the box at the foot of each page of the form. For a baby who was born dead at any gestation use the mother's hospital number; for a baby who was born alive use the baby's hospital number.
7. **Sections 2, 3 and 4 : Tissue samples and genetic material** If the parents/those with Parental Responsibility do not want tissue samples or genetic material kept as part of the medical record, explain the different options for disposal (below) and note their decisions in the relevant section.

If disposal is requested, it will usually take place a year later. This is to ensure that the family have the opportunity to ask for further testing. Our experience shows that this often happens 6-8months later. The options are: disposal by a specialist hospital contractor; Returned to Hospital for a later burial / cremation / collection by chosen funeral director; or release to the parents themselves. They can't be returned to the body but can accompany in a small box, this option may delay collection of their baby/child.

8. Send the completed form to the relevant pathology department, offer a copy to the parent(s)/those with Parental Responsibility, and put a copy into the mother's (for a stillbirth or miscarriage) or the baby/childs medical record.
9. Record in the clinical notes that a discussion about the post mortem examination has taken place, the outcome, and any additional important information.
 - **Possible further examination of one or more organs.** If the organ is donated for research, after research sampling is completed the residual tissue will be sensitively disposed of unless specific instructions from the family are documented. **If you already know that this is recommended**, discuss this and also explain how it might affect funeral arrangements.
 - **If the pathologist recommends further examination after the post mortem has begun**, they will contact you or the unit. The parents/those with Parental Responsibility should then be contacted as soon as possible to discuss their wishes and to explain how keeping the organ might affect funeral arrangements.