

A guide to the post-mortem examination procedure involving a baby/child

Information for
recently bereaved
family members

On behalf of our staff at Leeds Teaching Hospitals NHS Trust (LTHT), we would like to express our sympathy to you and your family following the loss of your baby/child.

We understand that this is a difficult time for you to consider a post-mortem examination and you may find it hard to ask any questions. This booklet has been written with the assistance of other bereaved families to give you clear information about the post-mortem examination and its potential value. We hope that it will help you decide what is right for you and your family.

Please take the time to read this booklet and discuss it with other members of your family if you wish.

People vary as to how much information they want about what happens during a post-mortem examination. If you would rather not know about certain aspects, then please say so; however, it is important that you understand what your choices are and what you are agreeing to.

The person discussing the post-mortem examination with you should make sure you know enough about the process of a post-mortem examination to decide if you wish to give your consent. Although they may recommend a particular course of action, it is important that you come to your own decision. They will make sure you have understood the information you have been given.

If you require support with communication; for example, you are hard of hearing, please inform the person providing you with this leaflet so arrangements can be made.

The Human Tissue Authority, established by the Human Tissue Act 2004 is the regulator for human organs, tissues & cells, and they ensure post-mortem examinations are performed with appropriate and valid consent on suitable premises. You may find it useful to visit the Human Tissue Authority website at: www.hta.gov.uk.

Please do not hesitate to ask if anything is unclear, you have any questions or you would like more information.

The Nurse Specialist for Post-mortem Consent is usually available Monday to Friday, 9.00 am - 3.00 pm.
Tel. **07900 433617** if you would like to discuss any aspect of the post-mortem examination.

Member of staff name:
Job title:
can be contacted on:
between (times available):

What is a post-mortem examination?

A post-mortem is an examination of a body after death. It may also be called an autopsy. Post-mortem examinations are performed by pathologists (these are doctors who specialise in the diagnosis of disease and identification of the cause of death). They work to standards set out by The Royal College of Pathologists.

Is a post-mortem examination useful?

A post-mortem examination can help to:

- Identify/verify the cause of death;
- Confirm the nature of any illness and/or the extent of any disease;
- Identify conditions that may not have been diagnosed in life.
- Assess the effects of treatments & drugs, and identify any complications or side-effects;
- Answer any additional/outstanding questions the doctors or family may have about the baby's/child's death;
- Help plan future pregnancies and care in pregnancies;
- Highlight potential familial diseases affecting other family members;
- Advance medical knowledge and help in the training of doctors.

However, please note that even though a post-mortem examination cannot always provide a reason for the death, it can exclude certain important causes of death or illness; therefore, providing valuable information for you and the treating medical staff.

Who decides whether a post-mortem examination should take place?

There are two types of post-mortem examination; a coronial post-mortem and a consented post-mortem examination.

For liveborn babies and children, by law, His Majesty's Coroner can order that a post-mortem examination be performed to determine the cause of death. There are three main reasons why a death is referred to HM Coroner:

- A death has been sudden and unexpected;
- A patient has been ill but the doctor confirming the death is not certain why they have died at that particular time;
- A death has been the result of an accident or unusual circumstances (including deaths following a medical procedure such as surgery).

If it is not necessary to refer your baby's/child's death to HM Coroner, the medical team may offer you the opportunity for a consented post-mortem examination. Alternatively, you can approach them and request that a consented post-mortem examination be performed.

This can only be done with written consent. For stillborn babies regardless of gestational age, the mother must give this consent (although both parents should be involved, if possible). For a child, a person with parental responsibility can give consent or a child with the capacity to make the decision can give their consent before death.

What if I don't want a post-mortem examination to take place?

HM Coroner does not require your consent to have a post-mortem examination performed. If HM Coroner is not involved and you do not wish for a post-mortem examination to be performed, you are under no obligation to consent to one. It is important that you feel able to make an informed decision that is right for you and your family.

What happens if I change my mind about the post-mortem examination?

The pathologist needs your permission before a consented post-mortem examination can take place. The post-mortem examination consent form acts as a written record of your decisions, making it clear to everyone what you have and have not agreed to. If you change your mind before the post-mortem examination has taken place, you can modify or withdraw your consent (even after signing). The doctor or other health professional who discusses the post-mortem examination with you will tell you how much time you have in which to do this and they will record it on the post-mortem examination consent form. You will be provided with a copy of this consent form.

What types of post-mortem examination are available?

Full post-mortem examination:

This has the potential to provide the most information. X-rays will usually be taken before starting the post-mortem examination. The pathologist will examine the outside of your baby's/child's body and take various measurements. The pathologist will make careful skin incision(s) to be able to carefully remove and examine all of your baby's/child's major organs. Occasionally, it may be necessary for the pathologist to extend or make additional skin incision(s) to allow for further examination of your baby's/child's body as a result of their initial findings during the post-mortem examination, or based on certain information in the clinical history. The mortuary technicians will always carefully sew any incision(s) and your baby/child will be treated with care and respect at all times.

Small samples of tissue from the organs will be obtained for a more detailed examination using a microscope to investigate diseases which cannot be detected by the naked eye only.

Occasionally, the pathologist may recommend keeping one or more whole organ(s) for several days to facilitate a more detailed examination or to obtain another specialist's opinion. Rarely, this may involve sending the whole organ(s) to a specialist centre for examination. The pathologist will also examine the placenta, if available.

Fluids (such as blood, approximately 1-2 mls) and very small tissue samples (less than a quarter of a £1 coin) may be sent to microbiology to look for infection. The entire sample is often required for these tests. In the few cases where there is some sample left, it is disposed of according to laboratory protocols.

Photographs of part(s) of your baby's/child's body or organ(s) will be taken, including, on occasions, photographs of the tissue sections examined under the microscope. These photographs form part of the medical record and may also be used for ethically-approved medical research, professional training, clinical audit and quality assurance, in which case, any information which would allow your baby/child to be identifiable will be removed. If you object to images being used in this way, you can say so and it will be noted on the post-mortem examination consent form.

It may be helpful to examine your baby's/child's chromosomes and/or DNA to investigate the cause of your baby's/child's condition. This may have particular relevance for future pregnancies. Genetic tests can be performed on blood or skin, or other tissue samples; the entire sample is often required for these tests.

In the few cases where there is some sample left (and DNA extraction is not required), it is disposed of according to laboratory protocols.

Once the examination is completed, the organ(s) will be returned to your baby's/child's body (although they cannot be returned to their original positions within the body).

In some babies/children, the skin can be very thin and fragile, and (very occasionally), this can lead to some tearing during the course of the examination; however, the mortuary technician will always carefully sew any incision(s) and tears, then wash your baby/child and redress them. Your baby/child will be treated with care and respect at all times.

Limited post-mortem examination:

A limited post-mortem allows you to restrict the extent of the internal examination, which means only certain parts of your baby's/child's body are examined. This will provide less information than a full post-mortem examination but can potentially still provide useful information. The person discussing the post mortem examination with you will explain what your options are and the value of this type of post-mortem examination for your baby/child.

X-rays will usually be taken before starting the post-mortem examination. The pathologist will examine the outside of your baby's/child's body and take various measurements.

The pathologist will make a careful skin incision(s) to be able to carefully remove and examine the organ(s) in the area(s) of the body that you agreed to beforehand.

Small samples of tissue from these organ(s) will be obtained for more detailed examination using a microscope to investigate diseases, which cannot be detected by the naked eye only.

Occasionally, the pathologist may recommend keeping one or more whole organ(s) for several days to facilitate a more detailed examination, or to get another specialist's opinion which (rarely) may involve sending the whole organ(s) to a specialist centre for examination. The pathologist will also examine the placenta, if available.

Fluids (such as blood, approximately 1-2 mls) and very small tissue samples (less than a quarter of a £1 coin) may be sent to microbiology to look for infection. The entire sample is often required for these tests. In the few cases where there is some sample left, it is disposed of according to laboratory protocols.

Photographs of part(s) of your baby's/child's body or organ(s) will also be taken, including, on occasions, photographs of the tissue sections examined under the microscope. These photographs form part of the medical record and may also be used for ethically-approved medical research, professional training, clinical audit and quality assurance, in which case, any information which would allow your baby/child to be identifiable will be removed. If you object to images being used in this way, you can say so and it will be noted on the post-mortem examination consent form.

It may be helpful to examine your baby's/child's chromosomes and/or DNA to investigate the cause of your baby's/child's condition; this may have particular relevance for future pregnancies. Genetic tests can be performed on blood or skin, or other tissue samples; the entire sample is often required for these tests. In the few cases where there is some sample left (and DNA extraction is not required), it is disposed of according to laboratory protocols.

Once the examination is complete, the organ(s) will be returned to your baby's/child's body (although they cannot be returned to their original positions within the body).

In some babies/children, the skin can be very thin and fragile, and (very occasionally), this can lead to some tearing during the course of the examination ; however, the mortuary technician will always carefully sew any incision(s) and tears, then wash your baby/child and redress them. Your baby/child will be treated with care and respect at all times.

External post-mortem examination:

Of the three post-mortems available, this will provide the least amount of information as it involves no internal examination. X-rays will usually be taken before starting the post-mortem examination. The pathologist will examine the outside of your baby's/child's body and take various measurements.

Photographs of part(s) of your baby's/child's body or organ(s) will also be taken. These photographs form part of the medical record and may also be used for ethically-approved medical research, professional training, clinical audit and quality assurance, in which case, any information which would allow your baby/child to be identifiable will be removed. If you object to images being used in this way, you can say so and it will be noted on the post-mortem examination consent form.

The pathologist will also examine the placenta, if available. Your baby/child will be treated with care and respect at all times.

It may be helpful to examine your baby's/child's chromosomes and/or DNA to investigate the cause of your baby's/child's condition. This may have particular relevance for future pregnancies. Genetic tests can be performed on a skin sample, the entire sample is often required for these tests.

In the few cases where there is some sample left (and DNA extraction is not required), it is disposed of according to laboratory protocols.

Post-mortem examination imaging:

Full post-mortem examination remains the gold standard examination for stillbirths and miscarriages. Non-invasive post-mortem examination of a baby or child after death using Computerised Tomography (CT) or Magnetic Resonance Imaging (MRI) can give useful information where there are certain congenital malformations; however, this type of examination cannot detect infection or hypoxia (low oxygen), two of the major conditions found during full post-mortem examinations and would be unlikely to provide any additional information over an external post-mortem.

Non-invasive post-mortem imaging for babies and children using CT or MRI is not currently offered at LTHT for consented post-mortem examinations.

The doctor or other health professional who discusses the post-mortem examination with you will explain all of the above options to you. If you have any questions or do not understand what is being discussed, please do not hesitate to say so.

When will a post-mortem examination take place?

The pathologists aim to perform the post-mortem examination as soon as possible because the earlier this examination takes place, the more likely it is to yield useful information. The doctor or other health professional discussing the post-mortem examination with you will be able to advise you on a timescale.

The post-mortem examination will take place at St. James's Hospital mortuary. If your baby/child is at Leeds General Infirmary, they will be respectfully transferred to St. James's Hospital mortuary by the LTHT nominated funeral directors, at our expense.

If, because of your religion, it is necessary to have the funeral within a certain time, please inform the doctor or other health professional discussing the post-mortem examination with you and the pathologist will try to accommodate this, where possible.

Is anyone but the pathologist present during the post-mortem examination?

The pathologists are always helped by other members of staff, usually at least one mortuary technician. LTHT is a teaching hospital and sometimes, medical students, doctors and other health care professionals may attend a post-mortem examination for training purposes. If you object to non-pathology medical professionals being present, inform the doctor or other health professional who discusses the post-mortem examination with you. This should be noted on the post-mortem examination consent form.

Will a post-mortem examination delay the funeral?

The doctor who has cared for your baby/child will issue a medical certificate of death (if required) before the post-mortem examination is performed, to allow you to proceed with the funeral arrangements.

If you are arranging a private funeral, your baby/child can usually be collected by your nominated funeral director within 24 hours of the post-mortem examination being completed; however, if you have requested that tissue blocks and slides (see page 14) are to be returned to be with your baby/child on completion of the post-mortem examination report, this will delay the funeral. This will be discussed with you when completing the post-mortem examination consent form.

If it is important to you that your baby/child is collected by your nominated funeral director as soon as possible, please discuss this with your funeral director as they may not intend to collect your baby/child from the hospital until just before the funeral.

Can I see my baby/child after the post-mortem examination?

Yes. After the post-mortem examination, the mortuary staff will make sure your baby/child is ready and you can see & hold them again, if you wish. There are Mortuary viewing suite facilities at both Leeds General Infirmary and St. James's hospital mortuaries. You will need to ring to arrange an appointment time (the phone numbers are at the end of this leaflet).

You may also be able to see your baby/child again at your funeral director's premises. It is important that you are aware that there will be natural changes to your baby's/child's body after death and you might want to discuss this with the mortuary staff or your funeral director before your visit.

What happens to tissue samples obtained from organ(s) during a full or limited post-mortem examination?

The small pieces of organ tissue that are removed at post-mortem examination are placed in plastic cassettes. These samples are no bigger than a pound coin in size and up to 5 mm thick (although often they are much smaller).



The tissue is chemically treated to remove water which is replaced with wax. These tissue blocks become hard so that very thin sections - ten times thinner than a human hair - can be made. The sections are stained and placed on glass slides so that they can be examined using a microscope. More than one section can be cut from one tissue block to perform different tests.

These slides may be digitally scanned and stored on a secure database to facilitate the pathologist to write the post-mortem report. These scanned images form part of the medical record and may also be used for ethically-approved medical research, professional training, clinical audit and quality assurance. Any information which would allow your baby/child to be identifiable will be removed.

If you object to images being used in this way, you can say so and this will be noted on the post-mortem examination consent form.

What happens to the tissue blocks and slides, once they have been examined and the post-mortem examination report is complete?

As the person providing consent for the post-mortem examination, you must decide what you want to happen to the tissue blocks and slides, once the post-mortem examination report is complete. Whatever your decision, it will not affect any aspect of care that you or your baby/child receives, or the information you get about your baby's/child's condition but it may be helpful for your family or others in the future.

- You may agree that the tissue blocks and slides can be donated and could be used for ethically-approved medical research, professional training, clinical audit and quality assurance. This may benefit other patients in the future and help doctors learn about disease and maintain high standards of care.

Please note, it is not always possible to make use of donated tissue blocks and slides but they will be stored according to national guidelines.

- You may also agree that the tissue blocks and slides can be stored on behalf of your family for future investigation, if required.
- You may decide that you do not want the tissue blocks and slides to be donated or stored for potential future use after the post-mortem examination report is complete. Further diagnosis on the tissues will then not be possible and you should choose from the following options:
 - You can request that LTHT respectfully and lawfully dispose of the tissue blocks & slides by clinical incineration. This process will begin within 3 months from the date of the initial appointment offered to you to discuss your baby's/child's post-mortem examination results;
 - You can have the tissue blocks and slides returned to yourself, once the post-mortem examination report is complete. Your proposed method of disposal must be lawful and safe, this may mean you need to arrange for a separate funeral at your expense. If the tissue blocks and slides are not collected, it is not possible for LTHT to store them without your permission and the process to respectfully and lawfully dispose of them will begin, 3 months from the date of the letter informing you they are ready for collection;
 - You can ask LTHT to return the tissue blocks and slides to be with your baby/child, once the post-mortem examination report is complete; this **will** delay the funeral. The tissue blocks and slides are placed in a suitable container and are transported with your baby/child, they are not placed inside your baby's/child's body;

- You can have the tissue blocks and slides returned to your nominated funeral director, once the post-mortem examination report is complete to arrange lawful disposal. This may mean that you need to arrange a separate funeral at your expense. If the tissue blocks and slides are not collected, it is not possible for LTHT to store them without your permission and the process to respectfully and lawfully dispose of them will begin 3 months from the date of the letter informing you that they are ready for collection;
- As the person providing consent, you **must** choose from one of these options. The Nurse Specialist for Post-mortem Consent or clinical team is available to provide support and advice if you feel unsure about which option to choose. If you are not able/willing to make a decision, it is not possible for LTHT to store the tissue blocks and slides without your permission and the process to respectfully and lawfully dispose of them will begin, 3 months from the date of the initial appointment offered to you to meet with the clinician to discuss your baby's/child's post-mortem examination results.

What if I change my mind about what happens to tissue blocks and slides donated for future use?

Your consent will remain in place for 30 years, following which, the tissue blocks and slides will be respectfully and lawfully disposed of. If you wish to change your consent within that period of time, please contact the Nurse Specialist for Post-mortem Consent on mobile number: **07900 433617** or the Histopathology department on: **0113 2068855**.

Please note the tissue blocks and slides may have already been used for one of your agreed purposes and may no longer be available.

What happens after the post-mortem examination has been completed?

Tests on tissue blocks and slides, obtained for further examination take several weeks. The pathologist will do their best to complete all investigations as soon as possible and consented post-mortem examination reports are usually available to the medical team within 6 - 8 weeks from the date of the post-mortem examination. You may wish to have your baby's/child's funeral during this time.

How do I find out the results of the post-mortem examination?

A copy of the post-mortem examination report will be sent to the doctor in charge of your baby's/child's care at the hospital. You will then be contacted and offered an appointment to come back to the hospital and discuss the results.

You can request a copy of the post-mortem examination report after it has been explained to you by the doctor in charge of your baby's /child's care.

Useful telephone numbers:

Nurse Specialist, Post-mortem Consent

Telephone:	0113 2067027
Mobile:	07900 433617

St James's University Hospital

Main line:	0113 2433144
Chaplaincy:	0113 2064365
Bereavement Liaison Office:	0113 2064162
Mortuary:	0113 2064312

Leeds General Infirmary

Main line:	0113 2432799
Chaplaincy:	0113 3923547
Bereavement Liaison Office:	0113 3923560
Mortuary:	0113 3923313

Useful web sites:

Leeds Teaching Hospitals NHS Trust:	www.leadsth.nhs.uk
Royal College of Pathologists:	www.rcpath.org
Human Tissue Authority:	www.hta.gov.uk
Child Bereavement UK:	www.childbereavementuk.org
Cruse Bereavement Care:	www.crusebereavementcare.org.uk
Stillbirth and Neonatal Death Society:	www.uk-sands.org/helpline@uk-sands.org
Charlies-Angel-Centre Foundation:	www.Charlies-Angel-Centre.org.uk
Leeds Bereavement Forum:	www.lbforum.org.uk
Mindwell	www.mindwell-leeds.org.uk



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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