



York and Scarborough
Teaching Hospitals
NHS Foundation Trust

Deciding About A Post-Mortem Examination

Information for patients, relatives and carers

① For more information, please contact:

Bereavement services

York Hospital

Wigginton road

York, YO31 8HE

Telephone: 01904 725445

Scarborough Hospital

Woodlands Drive, Scarborough, YO12 6QL

Telephone: 01723385178

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Introduction

On behalf of our staff at York and Scarborough Teaching Hospitals NHS Foundation Trust, we would like to express our sympathy to you and your family following the loss of your baby.

We understand that this is a very difficult time for you to consider a post-mortem examination and you may find it hard to ask 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.

The Human Tissue Authority established by the Human Tissue Act 2004, is the regulator for human organs, tissues and 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.

What is a post-mortem examination?

A post-mortem (also called an autopsy) is the medical examination of a body after death. Your baby would be examined by a paediatric pathologist (these are doctors who specialise in identifying conditions that affect babies/children and to determine the cause of death). They work to standards set out by The Royal College of Pathologists.

Does a post-mortem include DNA paternity testing?

No this is a private test that needs to be organized and paid for by the family concerned prior to burial/cremation of the baby's body. The hospital Trust does not take any responsibility for this to occur.

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 and drugs and identify any complications or side effects.
- Answer any additional/outstanding questions the doctors or family may have about the baby'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 a post-mortem examination cannot always provide a reason for the death, but it can exclude certain important causes of death or illness.

Can I change my mind and withdraw consent after signing to have a post mortem?

As part of the process for taking consent the staff member taking consent will explain that you can withdraw your consent within 24 working hours of completing the form. If consent is taken over a weekend, then you will be given an additional 24 hours (usually till Tuesday at 9:00) This time will be extended further if there is a bank holiday following the weekend. The date and time this period ends will be documented on the consent form along with the telephone number and the details of the person you need to contact if you would like to withdraw your consent. Bereavement services is the usual contact number given. (Please see useful numbers at the back of this booklet)

Only when this period has been passed will a funeral director be contacted to arrange transport of your baby to Leeds for the post mortem to proceed.

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 prior to starting the post-mortem examination. The pathologist will examine the outside of your baby's body and take various measurements and photographs. The pathologist will carefully remove and examine all of your baby's major organs and will obtain small samples of tissue from these organs for more detailed examination using a microscope. Fluids (such as blood) and tissue samples may be sent to microbiology to look for infection. The pathologist will also examine the placenta, if available.

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.

Once the examination is completed, the organ(s) will be returned to your baby's body (although they cannot be returned to their original positions within the body). The mortuary technician will then carefully sew the incisions, wash your baby, and redress them. It is important that you are aware that your baby will be treated with care and respect at all times.

It may be helpful to examine your baby's chromosomes and/or DNA to investigate the cause of your baby'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.

Limited post-mortem examination:

A limited post-mortem examination allows you to restrict the extent of the internal examinations; this will provide less information than a full post-mortem examination and it would be worth discussing the value of this with your medical team.

X-rays will usually be taken prior to starting the post-mortem examination. The pathologist will examine the outside of your baby's body and take various measurements and photographs. The pathologist will carefully remove and examine the internal organ(s) in the area(s) that you agreed beforehand. They will obtain small samples of tissue from the organ(s) for more detailed examination using a microscope. Fluids (such as blood) and tissue samples may be sent to microbiology to look for infection. The pathologist will also examine the placenta, if available.

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.

Once the examination is complete the organ(s) will be returned to your baby's body (although they cannot be returned to their original positions within the body). The mortuary technician will then carefully sew the incisions, wash your baby and redress them. It is important that you are aware that your baby will be treated with care and respect at all times.

It may be helpful to examine your baby's chromosomes and/or DNA to investigate the cause of your baby'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.

External post-mortem examination:

Of the three post-mortem examinations available, this will provide you with the least amount of information, as it involves no internal examination. X-rays will usually be taken prior to starting the post-mortem examination. The pathologist will examine the outside of your baby's body and take various measurements and photographs. The pathologist will also examine the placenta, if available. It is important that you are aware that your baby will be treated with care and respect at all times.

It may be helpful to examine your baby's chromosomes and/or DNA to investigate the cause of your baby'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.

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' Hospital mortuary in Leeds. Your baby will be respectfully and carefully transferred to St James' Hospital by our nominated funeral directors.

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.

Who will be present during the post-mortem examination?

The pathologists are always helped by other members of staff, usually at least one mortuary technician. As St James' Hospital is a teaching hospital sometimes medical students, doctors and other healthcare 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 with you. This should be noted on the post-mortem examination consent form.

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 size and up to 5mm thick (although they are often 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.

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 receives, or the information you get about your baby's condition, but it may be useful 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 the national guidelines.

Alternatively, you may wish for the tissue blocks and slides to 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 and used 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 the tissue **blocks**, and slides are respectfully and lawfully disposed of. The blocks and slides will be returned from Leeds and sent to the histology department at York Hospital with the consent form where they will arrange for them to be disposed of sensitively.
- 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 them to be stored without your permission and therefore the process to dispose of them respectfully and lawfully will begin, three months from the date you are informed that they are ready for collection.
- You can ask that the blocks and slides are returned with your baby 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. They are not placed inside your baby's body.
- You can have the tissue blocks and slides returned to the 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 them to be stored without your permission. Therefore, the process to dispose of them respectfully and lawfully will begin three months from the date you are informed they are ready to be collected.

As the person providing consent, you **must** choose from one of these options. The person taking consent from you 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 the tissue blocks and slides to be stored without your permission.

Therefore, the process to dispose of them respectfully and lawfully will begin three months from the date of the initial appointment offered to you to meet with the clinician to discuss your baby's post-mortem examination results.

What happens 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 bereavement team on:

York: **01904 725 445**

Scarborough: **01723 385 178**

Please note that 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 20 weeks of the post-mortem examination, but some may take longer than this.

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 care at the hospital. You will then be contacted by their secretary either by letter or telephone 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 care.

Will a post-mortem examination delay the funeral?

Parents are advised that their baby can be in the care of the mortuary team at St James' Hospital for a period of up to three weeks (sometimes longer during holiday periods).

However, it is still possible for you to liaise with the bereavement team, during the time your baby is in Leeds, to start to make arrangements for the funeral of your baby. The time your baby is in Leeds gives you the time to think about your wishes for the funeral and to start to make the difficult decisions around this with the support of the bereavement team.

You will be informed by the bereavement team as soon as your baby arrives back in the care of the mortuary team at York or Scarborough Hospital as we understand the importance to you of knowing exactly where your baby is at all times.

Please note that if you have requested that tissue blocks and slides are to be returned to be with your baby on completion of the post-mortem examination report, this will delay the funeral. This is because it can take up to twelve weeks for the report to be completed and returned to your hospital consultant. This will be discussed with you when completing the post-mortem examination consent form.

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

Yes. If you wish you can arrange an appointment to view your baby at the chapel of rest at St James' Hospital, Leeds.

You may wish to wait until your baby is back in the care of the mortuary team at York or Scarborough Hospital and arrange an appointment to view your baby.

You will also be able to arrange an appointment to view your baby at the Chapel of Rest at the funeral director who will be taking care of the funeral arrangements for your baby.

It is important that you are aware that there will be natural changes to your baby's body after death and you might want to discuss this with the bereavement team, mortuary staff or the funeral director prior to your visit.

Useful telephone numbers:

York Hospital

Bereavement Services: 01904 725445

Mortuary: 01904 726803

Chaplaincy: 01904 725579

Scarborough Hospital

Bereavement Services: 01723 385178

Mortuary: 01723 342213

Chaplaincy: 01723 342500

St James' Hospital

Mortuary: 0113 206 4312

Useful websites:

**York and Scarborough Teaching Hospitals NHS
Foundation Trust:** <https://www.yorkhospitals.nhs.uk/>

Department of Health
www.dh.gov.uk

Royal College of Pathologists
www.rcpath.org

Human Tissue Authority
www.hta.gov.uk

Stillbirth and Neonatal Death Society (SANDS)
<https://www.sands.org.uk/>

York Stillbirth and Neonatal Death Society (SANDS)
<https://yorksands.wordpress.com/>

Tell us what you think of this leaflet

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact:

Bereavement midwife at Bereavement Services
York Hospital, Wigginton road, York, YO31 8HE,
telephone 01904 725445 or
email yhs-tr.bereavement.midwives@nhs.net

Teaching, training and research

Our Trust is committed to teaching, training and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

Patient Advice and Liaison Service (PALS)

PALS offers impartial advice and assistance to patients, their relatives, friends and carers. We can listen to feedback (positive or negative), answer questions and help resolve any concerns about Trust services.

PALS can be contacted on 01904 726262, or email yhs-tr.patientexperienceteam@nhs.net.

An answer phone is available out of hours.

Leaflets in alternative languages or formats

If you would like this information in a different format, including braille or easy read, or translated into a different language, please speak to a member of staff in the ward or department providing your care.

Patient Information Leaflets can be accessed via the Trust's Patient Information Leaflet website:
www.yorkhospitals.nhs.uk/your-visit/patient-information-leaflets/

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