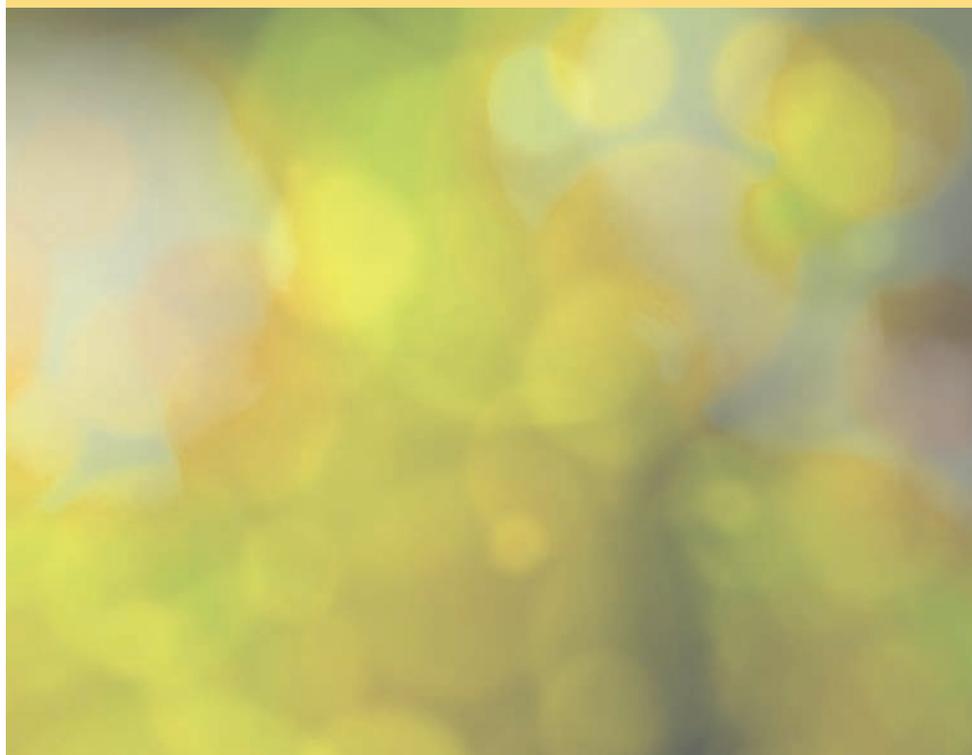


Hospital postmortem examination of a baby

Information for parents



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Introduction

You have been given this booklet because your baby has died and a member of staff has spoken to you about your baby's death and the value of a post-mortem (PM) examination. We would like to express our sympathy to you and your family at this sad time.

We understand that this is a difficult time for you to consider the issue of a PM examination. Our staff will give you the information you need to help you make the decisions that are right for you and your family. The amount of information people require regarding PM examination does vary. If you need further explanation please ask or, if you would rather not know about certain aspects please say so.

We hope this booklet will help you understand the reasons for undertaking a PM examination, what it involves and why it may be important, so you may wish to take time to read it before you complete the consent form. It may also be helpful to discuss the contents of the guide with your family. We encourage you to ask us if anything is unclear or if you have any questions.

What is a PM examination?

A PM examination is an external and internal examination of the body after death. It is also called an autopsy. It is carried out by a paediatric pathologist who is a doctor specialising in the diagnosis of disease in babies and identification of the cause of death. Paediatric pathologists work to standards of the Royal College of Pathologists and relevant codes of practice from the Human Tissue Authority.

There are two types of PM examination:

- A hospital PM examination, which is not required by law, and can only be carried out with your consent; and

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- A coroner's PM examination, which is required by law and consent is not necessary.

Why carry out a hospital PM examination?

We appreciate that it will be painful for you to consider a PM examination so soon after the death of your baby, however it is important to realise that it may help to:

- Confirm why your baby died by identifying an illness, if present, or a previously undiagnosed condition, if present
- Identify congenital abnormalities such as heart or kidney defects
- Identify a condition that may be present in your other or future children
- Plan future pregnancies and care in pregnancy
- Provide information that may benefit other people who suffer from similar problems
- Identify the effects of treatments and drugs.

The PM examination will provide additional information which may help the doctor explain to you in more detail why your baby died. Unfortunately, in a small number of cases, a PM examination does not provide the reason for a baby's death.

Who can consent to a hospital PM examination?

A decision to consent to or refuse a hospital PM examination may be made by the person(s) with parental responsibility. When a baby is not born alive, the mother must provide consent.

Parental responsibility: *The person(s) with parental responsibility will usually, but not invariably, be the child's birth parents. People with parental responsibility for a*

child include: the child's mother; the child's father (if married to the mother at the child's conception, birth or later; or if unmarried if he is named on the child's birth certificate with effect from 15 April 2002); a legally appointed guardian; the Health and Social Services Trust if the child is the subject of a care order; or a person named in a residence order in respect of the child.

A father who has never been married to the child's mother or, after 15 April 2002, whose name has not been included on the child's birth certificate, will only have parental responsibility if he has acquired it through a court order or parental responsibility agreement with the child's mother. (Good Practice in Consent, DHSSPS March 2003)

If you cannot come to an agreement about the PM examination as a couple, you may seek further help from the doctor. If you still cannot agree, it is probably better that the PM examination does not take place. You are under no obligation to agree to a hospital PM examination; the choice is entirely yours.

What does consent to a hospital PM examination involve?

A consent form will be completed as a written record of your decisions and this will make your wishes clear to everyone. The health care professional who has requested the PM examination will take you through the consent process, ask you to indicate your choices at each section of the form and sign it.

If you have any special requests or conditions regarding the PM examination you will have an opportunity to record them. You will be given a copy of the completed consent form, a copy will be filed in the hospital records and a copy will be sent to the Paediatric Pathologist. This ensures that everyone knows your decisions.

If you change your mind before the examination has taken place, you can modify or withdraw your consent, even after signing the form.

When and where is a hospital PM examination carried out?

All PM examinations of babies are carried out in the mortuary at the Royal Hospitals in Belfast, 1-2 working days after death. If your religion requires the funeral to take place within 24 hours, please inform the person obtaining consent - it may be possible to carry out the examination within this time.

Who is present during the PM examination?

A paediatric pathologist is responsible for the entire examination but is often helped by other staff including anatomical pathology technicians and trainee pathologists. Occasionally medical students and other health care professionals may attend a PM examination for educational purposes. If you do not wish them to be present please say whilst completing the consent form.

What happens during the hospital PM examination?

A hospital PM examination can be full, limited or external only:

A full PM examination begins with a very careful external examination of the body. After this, an incision is made down the front of the body to remove the major internal organs and a further one along the back of the head at the hairline to remove the brain. The organs will be examined visually and small tissue samples and fluid (such as blood) will be taken. Tissue blocks and tissue slides will be made for examination under the microscope.

Photographs or other images (including X-rays) of your baby, parts of their body or an organ may be taken to be studied later. These images will become part of the medical record. With your consent they may also be used for education and training or research (all identification will be removed).

In some cases analysis of chromosomes and other genetic tests will help diagnose an inherited disease. Looking at your baby's tissues or fluids (such as blood) may help answer questions regarding illnesses of other family members in the future. Genetic testing of tissue samples requires your consent. You will also be asked whether you consent to them being used for education and training or research.

A full PM examination will provide you with the most information.

A limited PM examination combines an external examination with a partial internal examination. The internal examination will be limited to whatever parents are willing to consent to, for example, a single organ such as heart or brain, a body system such as the respiratory system, or one area of the body such as the chest or abdomen. Tissue blocks and tissue slides will be made in the same way as for a full PM examination.

A limited PM examination may still be useful but it is possible that something important may be missed. The person explaining the procedure will discuss the limitations and implications with you.

An external examination only - if you choose this option your baby's body will be visually examined and measurements taken. The body will not be opened or organs removed. Photographs and x-rays may be taken. Other tests including analysis of chromosomes can be carried out with your consent.

This examination will provide limited information. The person explaining the procedure will discuss the limitations and implications with you.

Following a full or limited PM examination most organs will be returned to the body, though they cannot be placed in their original position. Sometimes the brain or the heart will require a longer time for detailed examination and if you consent

to their retention for that purpose, they will not be returned to the body on the day of the PM examination. You will be asked what your wishes are for them when detailed examination is complete.

After the PM examination the mortuary staff will prepare your baby's body for you to see and hold again. The incisions will not be visible when your baby is dressed.

What happens to tissue samples removed during the hospital PM examination?

Tissue samples in the form of blocks and slides can be very useful and it is strongly recommended that they are kept at the hospital. Having slides as a permanent record means that any diagnosis made can be checked by another pathologist, if required. They may be of value to your family as new tests are always being developed and examining the tissue samples in the future may help make a diagnosis in living family members.

Tissue samples may be used in the training of doctors and other health care professionals. They are also helpful for public health monitoring, quality assurance and audit purposes, for example, they can be used to check on standards in a hospital pathology service. These will only be kept if you have given your consent and will be securely stored in conditions that preserve them.

If you decide that you do not wish tissue samples to be kept after their examination is completed, you can arrange for their collection.

What happens to organs retained for detailed examination?

If organs have been retained, the Royal Hospitals, Belfast will dispose of them lawfully by cremation at Roselawn. Alternatively they can be returned to you

when the examination has been completed - usually via your funeral director. If you choose to have your baby's organs returned, you can proceed with the funeral prior to return of the organs and arrange their cremation/burial at a later date, or you may wish to delay the funeral for several weeks so that the organs can be reunited with your baby.

What happens to my baby after the hospital PM examination?

When the PM examination is over, you will be able to see and hold your baby again if you wish. You can arrange to have your baby collected by a funeral director for a family funeral or the hospital will arrange to have your baby buried or cremated. You can discuss the options available to you with the health care professional taking consent.

If you choose to have a family burial/cremation, you can contact a funeral director either before or after the PM examination but the date and time of the funeral should not be finalised until the time of your baby's release has been confirmed.

How will I find out the results of the hospital PM examination?

A report of the findings will be sent to your hospital consultant and general practitioner when all the tests are complete. This will take a minimum of three months and in some cases considerably longer. You will be contacted when the report has been sent and can then make arrangements to have the results explained to you.

Explanation of some of the words used in this book

Microscope

A piece of equipment with special lenses that allows the pathologist to look at tissue on a glass slide and see the cells magnified.

Mortuary

A department which includes a room where bodies are kept in refrigerators until collection by the funeral director. It may also have a post-mortem examination room and a viewing room.

Organ(s)

Important parts of the body, for example, brain, heart, kidneys, lungs and liver.

Paediatric Pathologist

A medical doctor trained in the diagnosis and study of baby diseases who performs laboratory tests for live babies as well as post-mortem examinations.

Tissue

The collection of cells that make up organs and give them their special functions.

Tissue blocks

Small samples of tissue (less than the size of a postage stamp and up to 5 mm thick) which are placed in plastic containers and treated to remove water then hardened with wax.

Tissue slides

Very thin sections (approximately a tenth of the thickness of a human hair) of hardened tissue which have been cut from tissue blocks and placed on glass slides for examination under the microscope.

If you are unhappy about any aspect of the communication, information or support you received during the consent for post-mortem examination process and wish to make a complaint please contact your Trust's Complaints/Patient Liaison Department. You can obtain the contact address and telephone number from ward staff.

