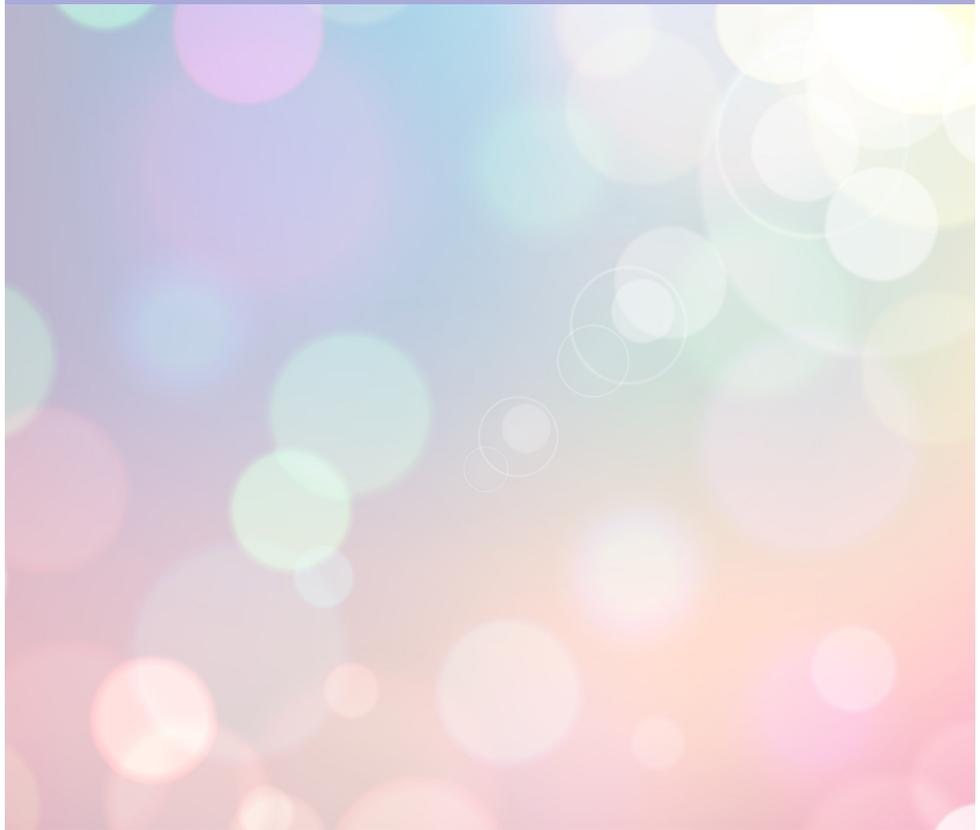


# Hospital Consented Post-Mortem Examination

Following the death of a baby or child in Northern Ireland

Information for parents



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## Introduction

We would like to begin by offering our deepest condolences following the death of your baby or child. We understand that this is a very distressing and difficult time and that it is not easy to decide about a Post-Mortem (PM) examination.

We hope that you will find this booklet helpful. It explains what a PM examination is and the possible benefits of having one.

Our staff will also 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 would like 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.

This booklet explains the reasons why it might be important for you to consider a PM examination and what it involves, so it may be helpful to read it before you complete the consent form. You may also wish to discuss the contents of the booklet with those important to you.

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 children, and in the identification of the cause of death.

Paediatric pathologists work to guidelines set by the Royal College of Pathologists and relevant codes of practice from the Human Tissue Authority.

There are two types of PM examination:

- A hospital consented PM examination, which is not required by law, and can only be carried out with your consent and
- A coroner's PM examination, which is required by law and consent is not required.

### Why carry out a hospital consented PM examination?

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

- Confirm the cause of death by identifying an illness, or a previously undiagnosed condition, and/or the extent of the illness or condition
- 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 during those pregnancies
- Provide information that may benefit other people who have similar problems
- Identify the effects of any medical treatments.

The hospital PM examination may provide additional information to help the doctor explain to you in more detail why your baby or child died.

Unfortunately, in some cases, a hospital PM examination does not provide a reason for the death.

### Who can consent to a hospital consented 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 Care 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 hospital PM examination as a couple, you may seek further information from the doctor. If agreement is not possible, the hospital PM examination will 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 consented 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 hospital 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 hospital PM examination, they will be documented. 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 what you have consented to.

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 consented PM examination carried out?

All babies and children undergoing a hospital consented PM examination will be transferred from Belfast Health and Social Care Trust Mortuary (in Belfast), to Alder Hey Children's NHS Foundation Trust in Liverpool where the examination will take place. For this reason, it will not be possible to arrange a hospital PM examination in time to allow a funeral to take place within 24 hours of death, if your beliefs require this. The health care professional who discusses the hospital PM examination with you will be able to advise you as to when it will take place and when your baby or child is likely to leave and return to the Belfast Health and Social Care Trust Mortuary.

### Who is present during the hospital consented 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 hospital PM examination for educational purposes. If you do not wish them to be present, please state while completing the consent form.

### What happens during the hospital consented PM examination?

A hospital PM examination can be full, limited or external only. In each case, the examination will be carried out with the utmost respect for your baby or child.

**A full hospital PM examination** - this begins with a very careful external examination of the body. An incision is then made down the front of the body (chest and abdomen) and a further one along the back of the head at the hairline in order for the organs to be examined. The internal organs will be removed and examined visually. Small tissue samples and fluid (such as blood) will be taken. Tissue blocks and tissue slides will be prepared for examination under the microscope.

X-rays or other images will be taken of your baby or child, and possibly of parts of their body. These images will be studied and 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 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 hospital PM examination** - this combines an external examination with a partial internal examination, using an incision to examine the relevant area of the body. The internal examination will be limited to whatever parents have consented 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 hospital PM examination.

A limited hospital 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 or child's body will be visually examined and measurements taken. The body will not be opened or organs removed. X-rays or other images 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 hospital PM examination, most organs will be returned to the body. 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 hospital PM examination.

You will be asked what your wishes are for the organs when the detailed examination is complete as part of the consent process.

After the hospital PM examination the mortuary staff will prepare your baby or child's body for you to see again. Your child will be dressed and the incisions will not be visible. Your baby or child will be treated with the utmost respect, dignity and sensitivity throughout the hospital PM process.

### [What happens to tissue samples removed during the hospital consented PM examination?](#)

Tissue samples in the form of blocks and slides can be very useful and it

is strongly recommended that they are held at Alder Hey Children's NHS Foundation Trust. Having slides as a permanent record means that the diagnosis 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, you can request to have these returned to the Belfast Health and Social Care Trust Mortuary and these will be handled in line with parent's wishes.

### [What happens to organs retained for detailed examination?](#)

If you consent to organs being retained, they will be returned to the Belfast Health and Social Care Trust Mortuary once the final pathology report has been completed. They will then be disposed of lawfully by cremation at Roselawn Crematorium, and, in the case of babies their ashes will be scattered in the Baby Garden of Remembrance. Alternatively, you can choose to have a funeral director collect them for you. If you choose to have your baby or child's organs returned, you can proceed with the funeral prior to this and arrange their cremation/burial at a later date, or you may wish to delay the funeral so that the organs can be reunited with your baby or child, although this may take several weeks.

## What happens to my baby or child after the hospital consented PM examination?

When the hospital PM examination is over, your baby or child will be brought back to the Belfast Health and Social Care Trust Mortuary. You can choose to have your baby or child returned to you from there by a funeral director for a family funeral or, in the case of babies, you may prefer your Trust to arrange burial or cremation. You can discuss the options available to you with the health care professional taking consent.

If you choose to have a family burial/cremation, the date and time of the funeral should not be finalised until you have been informed that your baby or child has returned to Belfast Health and Social Care Trust Mortuary.

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

A report of the findings will be made available to your hospital consultant and general practitioner when all the tests are complete. The majority of reports will be available within two months, but some may take longer. You will be contacted when the report is available 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 and child diseases who performs laboratory tests for live babies and children 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 wish to provide feedback about any aspect of the consent for hospital Post-Mortem examination process, please contact ward staff.

If you are unhappy about any aspect of the consent for hospital Post-Mortem examination process and wish to make a complaint please contact your Trust's Complaints Department. You can obtain the contact address and telephone number from ward staff.

