

Department of
**Health, Social Services
and Public Safety**

An Roinn

**Sláinte, Seirbhísí Sóisialta
agus Sábháilteachta Poiblí**

www.dhsspsni.gov.uk

Information for Parents:
Hospital Post Mortem
Examination of a Baby

A post mortem examination

There are two types of post mortem examination. A hospital post mortem which is not required by law and can only be carried out with your consent and a Coroner's post mortem examination, which is legally required and for which consent is not required.

A post mortem is the examination of a body after death. It is also called an autopsy.

Post mortem examinations are carried out by pathologists.

Pathologists are doctors who specialise in the diagnosis of disease and the identification of the cause of disease.

The importance of a post mortem examination

A post mortem examination can provide information which will help you and the doctors understand why your baby died.

An examination can only be carried out with the permission of the parents or legal guardians, unless the Coroner has ordered it.

Post mortem examinations can provide information about illness and health that would not be discovered in any other way. Much of what we know about illness today came from such examinations.

They help to:

- Identify the nature of a disease, if this is not already known.
- Identify other conditions that may not have been diagnosed.
- Identify congenital abnormalities such as heart or kidney defects.
- Help plan future pregnancies and care in pregnancies.
- Diagnose and treat conditions in your other children or future children.
- Provide information that may benefit other families in the future who suffer from similar problems.

Unfortunately, it is possible that a post mortem examination may not provide a reason for the death.

Different options

The doctor or other health professional who discusses the post mortem examination with you will be able to explain what these are:

- Full post mortem examination.
- Limited post mortem examination.
- No post mortem examination.

If you do not agree to a full post mortem examination, you might consider a limited examination. This means that only certain parts of your baby's body are examined.

It may however only provide limited information about your baby's cause of death or illness. Because of this, the doctor may advise you that it would be better not to proceed with a limited post mortem examination.

If you do not agree to a full or limited post mortem examination, you may choose to consent for an external examination only. This means that the organs are not examined as the body is not opened. This will only provide limited information.

Tissue samples will be retained from the organs you consented to be examined. From these, blocks and slides will be made in the same way as for a full post mortem examination.

However, you may chose not to have a post mortem examination carried out on your baby.

Timing of a post mortem examination

Post mortem examinations are usually performed 1-2 working days after death, and are carried out in the mortuary. If, because of your religion, the funeral must take place within 24 hours, please let us know; we will try to do the post mortem examination within this time.

About a post mortem examination

The pathologist works to standards set by the Royal College of Pathologists. Sometimes it is necessary for a body to be moved to another hospital for the post mortem examination where there are special facilities and pathologists skilled in dealing with particular cases (for example deaths in infancy and babyhood and diseases of the brain).

During the post mortem, a very careful external examination of your baby is carried out. The pathologist then makes an incision (cut) down the front of the body and the internal organs (or those agreed beforehand with you) are removed and examined. All organs are usually returned to the body afterwards but they cannot be placed in their original position.

Occasionally, it is important to retain whole organs for further examination, as this can provide more detailed understanding of the disease. This can only be done with your consent.

If the brain needs to be examined, an incision is made in the back of the head around the hairline. It takes six to eight weeks to properly examine the brain because special processes (fixation) need to be carried out.

Small samples of tissue will be retained from each organ for examination under the microscope. Sometimes tissue samples or fluid (such as blood) will be retained for further tests such as looking at the baby's chromosomes or genes or to search for infections due to bacteria or viruses.

The samples of tissue retained for testing are usually retained as part of your baby's medical records in case they are needed to answer further questions about the cause of death. They may also help answer questions regarding illnesses of other family members in the future (see section below on tissue samples, blocks and slides).

In some cases the post mortem examination findings suggest a gene abnormality for which genetic testing is not available at present. This may become available in the future and so it may be helpful to store a small sample of tissue or extracted DNA for possible future investigation. This will not be done without your consent.

Tissue samples, blocks and slides

Although some information can be obtained from looking directly at organs in a post mortem examination, often the only way to understand properly what has happened is to look at part of an organ under the microscope.

- Small **samples** of tissue are removed from the organs and placed in little plastic containers (cassettes).
- These samples measure approximately 1.5 x 1.5 cm (less than the size of a postage stamp) and up to 5mm thick.
- Samples from tiny organs are much smaller and those from the brain are larger, usually 2 x 2 cms.
- The tissue is chemically treated to remove water, which is replaced with wax.

These **tissue blocks** become hard. Very thin slices (sections), a tenth of the thickness of a human hair, are then cut off the surface.

- The sections are placed on glass **slides** so that they can be examined under a microscope.
- More than one slide can be cut from one block.
- These techniques are the same as those used to examine tissue from living patients.

Blocks and slides are kept in special cabinets designed for this purpose, which are kept securely in hospitals or research laboratories.

Methods of examining tissues are improving each year, and new tests become available. In the case of genetic disorders, looking back to stored tissue, blocks or slides of deceased family members may help to make a diagnosis in living members of the family. They can then receive the appropriate treatment.

If you give your consent, your baby's tissue blocks and slides can also be used in medical research, which may benefit other patients in the future. When a new disease or health problem emerges, examination of tissue samples on a wide scale may provide clues about how and why the disease emerged - and how this may be treated.

Residual tissue

After the blocks have been prepared there may be small amounts of unused or "residual" tissue remaining. The hospital will need to know how you want this tissue to be disposed of by cremation or incineration or returned to you.

X-rays and other images

Often the pathologist will take X-rays and photographs of the body or an organ during the examination.

These images are retained as part of your baby's medical records and can be re-examined if new knowledge becomes available.

Organ retention/disposal

If you have consented for an organ to be retained, the consent form gives you several options. You can choose:

- For the organs to be used in medical education, or research, or both.
- For the organs to be returned to you, through your funeral director, once tests are completed. You will then need to arrange a separate cremation or burial service for these.
- For the organs to be returned to your baby's body for burial or cremation, but this will significantly delay the funeral.
- For the hospital to arrange disposal of the organs through cremation, incineration or burial. Staff will let you know what options are available in the hospital.

Further use of blocks, slides, photographs, x-rays

Tissue blocks and slides, photographs, X-rays and other images are part of your baby's medical records. You can choose:

- To give these for use in medical education, or research, or both. You may wish only to give some of them.
- For the blocks and slides to be returned to you for cremation or burial. This means it will not be possible to have the case reviewed or seek a second opinion at a later date.

Your baby's body after the post mortem examination

When the post mortem examination is over, you will be able to see and hold your baby again in a private room in the mortuary.

The incision on the body from the post mortem examination is bandaged once the post mortem is finished and is not seen when your baby has been dressed. A little hat can be used to cover the mark over the back of the head.

Funeral arrangements

You can contact the undertaker about funeral arrangements either before or after the post mortem examination has taken place. Alternatively you may request the hospital to make arrangements for the burial or cremation. If you chose a hospital arranged cremation the ashes cannot be returned to you.

The results of the post mortem examination

Following a miscarriage or stillbirth the post mortem report will be sent to your hospital consultant and general practitioner. Following a baby's death before the 28th day of life the post mortem report will be sent to your baby's hospital consultant and their general practitioner. This takes a minimum of 6 weeks to complete and may be considerably longer in some cases. A letter will also be sent to you informing you that the doctors have received the report. You can arrange an appointment with them to discuss the findings, if you wish.

The consent form

Unless it has been ordered by the Coroner, the doctors need the consent of parents or those having parental authority before they can carry out the post mortem examination.

The form is a written record of your decision and makes 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 withdraw your consent, even after signing.

You will be given a copy of the consent form and a copy will be filed in your baby's hospital notes. A copy will also be sent to the pathologist. This ensures that everyone knows your decisions.

Medical education/research and quality standards

The consent form asks you about whether you want to give blocks and slides, images, samples for genetic testing or organs for use in medical education and/or research.

- *Medical education:* this includes teaching, training and educating all types of doctors, nurses and health professionals.

- *Research:* examining tissue, organs and images is one of the most important ways in which doctors learn about illness and how to treat it. Tissue blocks and slides are used to teach medical students and new doctors, to help experienced doctors continue to learn about new conditions or treatments, and to teach specialist knowledge.

Sharing information between doctors is important in maintaining high standards of care.

Doctors training to be pathologists need to watch and learn from post mortem examinations, and discuss the findings with an

experienced pathologist. Sharing information between doctors and hospitals is also very important for public health surveillance. This can make sure that infectious diseases do not spread throughout the population.

A separate copy of the consent form will be kept, if you agree that blocks and slides, images, samples for genetic testing or organs may be used for medical education and research.

- *Checking quality standards*: includes audit, quality assurance, public health, and performance management.

Questions

You can ask as many questions as you like. You may also wish to discuss the decision about a post mortem examination with other family members.

People vary as to how much information they want about what will happen during a post mortem examination.

If you would like more details or want to discuss the matter with another health professional, please ask.

Before giving your consent

It is important that you understand all the information and come to your own decision.

Hospital staff are available to give further help, if you wish. They can also discuss your options. They will ask you to say whether you have understood the information you have been given. If you are not sure, say so.

What some of the words mean

Archiving

Archiving is the long-term preservation of tissue or organs.

Archives are important and useful because:

- The tissue/organ can be examined if new techniques or knowledge become available.
- The education and training of medical students and doctors is easier if they can see for themselves what happens inside the body in disease.

- Research using archived tissues and organs can help in the diagnosis and treatment of future patients.

Tissue and Organ Banks

Rare diseases can be investigated properly only when a number of cases have been studied. This means that tissues/organs from post mortem examinations may be stored safely and securely until enough cases have been collected and then the research can begin. Tissues/organs are only stored with the family's permission.

Body Parts

Body parts are groups of organs, a limb or part of a limb.

Cassette

A small plastic container, usually measuring 2.5 x 1.5 x 0.5 cms, in which tissue samples are placed at post mortem examination. Each cassette is marked with the patient's identifying number. The tissue samples remain in the cassettes from the time of the post mortem examination, through processing and slide cutting, and are stored in them.

Consented post mortem examination

A post mortem examination carried out with the agreement of relatives, not one required by law.

Coroner

The Coroner is an independent lawyer who investigates deaths due to unnatural, suspicious or unknown causes. The Coroner may hold an inquest in a small number of cases.

Coroner's post mortem examination

This is a post mortem examination that has been asked for by a Coroner. The agreement of relatives is not needed as the examination is required by law but the tissue or organs cannot be used for other purposes without your consent and the agreement of the Coroner.

Death Certificate

A death certificate is required to allow the death of the person to be registered, along with the cause of death. It lets the Registrar of Deaths issue the form allowing the funeral to take place. In the case of a still birth, defined as “The complete expulsion from its mother, after the 24th week of pregnancy of a child which did not at any time after being completely expelled or extracted breathe or show any other evidence of life”. (The Stillbirth Definition (NI) Order, 1992), the stillbirth needs to be notified and the hospital staff will provide a stillbirth certificate to allow burial/cremation.

Fixation

Before organs or tissues can be examined in detail, they have to be hardened by soaking them in a chemical, usually formaldehyde. This is known as fixation or fixing. The complete process may take several weeks, especially for the brain.

Full post mortem examination

The full post mortem involves examination of all the organs in the chest and abdomen, and the brain.

Inquest

A Coroner may hold an inquest into any death that is reported to him. This may be when a death is known or suspected to be due to anything other than natural disease. Sometimes it is held in the presence of a jury. An inquest considers all the evidence about the death and gives relatives or their legal representative an opportunity to question witnesses.

Incision

An incision is a cut in the skin to allow the internal organs to be examined. It is made in the same way as for a surgical operation. The incision is closed with stitches at the end of the post mortem examination and may then be bandaged.

Limited post mortem examination

This is a post mortem where only some organs are examined. This may only provide a part of the possible information about the illness

Microscope

This is a machine with special lenses that allows the pathologist to look at the tissue on a glass slide, and see the cells magnified. Changes in the tissue that are not normal indicate the type of disease.

Mortuary

The mortuary is a group of rooms where bodies are kept in refrigerators before being collected by the funeral directors. The mortuary also includes the post mortem room where the examinations are performed.

Organ(s)

The body contains many organs such as the brain, heart, kidneys, lungs and liver. Each organ carries out different functions. The organs are connected in the body by nerves, blood vessels and fibres.

Pathologist

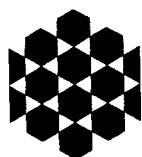
A pathologist is a medical doctor trained in the diagnosis and study of disease. Pathologists who perform post mortem examinations usually work in hospitals, and are also involved in the diagnosis of disease in live patients.

Some pathologists have further specialist training:

- Neuropathologists study diseases of the brain.
 - Paediatric pathologists study diseases of babies and children.
 - Forensic pathologists study sudden, suspicious or unnatural deaths.
- Pathologists work to standards laid down by the Royal College of Pathologists.

Tissue

Organs are made up of tissue, which is a collection of cells that give organs their special functions. For example, the heart contains muscle tissue composed of cells that contract to pump the blood.



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