

# The post-mortem examination for a baby or child

Information and advice for parents

## Pathology

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This leaflet explains why you may be being asked to give your consent to a post-mortem examination. Please take the time to read it and discuss it with your family if you wish, before you complete the consent form. If you have any questions or anything is unclear, please let us know. We are aware that this is a difficult time for you and that this is not an easy subject for people to deal with and want to help you make the decision that is right for you and your family.

### What is a post-mortem?

A post-mortem, also known as an autopsy, is an important medical examination of a person's body after death. It aims to find out more about their last illness and the cause of their death.

### Why are post-mortem examinations carried out?

Post-mortem examinations are usually carried out to find out exactly how or why a baby/child died. Sometimes families ask questions that can only be answered with information from a post-mortem examination.

Post-mortems help to:

- Identify the cause of death
- Confirm the nature and extent of an illness
- Identify other conditions that may not have been diagnosed
- Assess the effects of treatments and drugs, and identify any complications or side-effects
- Help plan future pregnancies and care during pregnancy
- Diagnose and treat conditions in other children in the family

Post-mortem examinations also provide information about illness and health that would not be discovered any other way. It is also possible that the information gained may benefit other children/families who suffer similar problems.

In very small babies, a post-mortem is less successful than in adults or older babies/children. In these babies, the examination is successful in three to five out of ten babies.

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### How are post-mortem examinations carried out?

#### Who performs the examination?

Post-mortems are carried out by pathologists – doctors who specialise in the diagnosis of disease and identifying causes of death. The pathologist is helped by other staff, usually at least one mortuary technician.

Sometimes medical students, doctors and other health care professionals may attend a post-mortem for educational purposes or to act as a quality check on standards of care.

If the coroner has ordered the post-mortem, you can be represented at the examination by a medical practitioner.

#### How is it performed?

The pathologist will remove and examine your child's major internal organs (or those agreed beforehand with you) and will take samples of tissue and fluid (such as blood) for later inspection in detail. 'Tissue' is a collection of human cells that perform a particular function; organs contain tissues.

Sometimes the pathologist may need to examine a part of an affected organ in more detail under a microscope. To do this, small samples of tissue are taken from the organ (usually about 1 cm across and about 5 mm thick). These samples are made into hard blocks using wax. From these, very thin sections, 10 times thinner than a human hair, can be cut off. They are placed on glass slides so that they can be examined under a microscope. These techniques are the same as those used to examine tissue from living patients. Most blocks and slides are kept in special cabinets designed for this purpose, which are kept securely.

In babies and very young children, because some of their organs are so small, sometimes a tiny organ may unavoidably be taken along with a tissue sample and be prepared with the tissue blocks and slides.

In some cases, whole organs may be retained for closer examination. Sometimes these organs need to be 'fixed' (preserved with chemicals) before samples can be taken. In these cases, it may be some weeks before the organs can be returned to the body. You should be aware that if the organ cannot be retained it might be difficult or impossible to diagnose why your child died.

Often the pathologist will take X-rays or other images (including photographs and CT scans) of part of your child's body or one of their organs during the examination, to be studied again later.

If your baby has died during pregnancy or childbirth they may also have genetic tests

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performed to find out if the cause of their death is hereditary and if there is a chance of this happening again during a subsequent pregnancy.

If your child has a congenital abnormality (a condition that they have had from birth as a result of hereditary or environmental influences) they may require more extensive investigation.

### Where is the examination carried out?

Post-mortem examinations take place in a mortuary. Most post-mortem examinations on babies and children are performed at other hospitals where there is a specialist paediatric (children's) pathologist. If your child needs to be taken to another hospital for their post-mortem staff, will tell you about this.

### When is the examination carried out?

The post-mortem will be carried out as soon as possible, usually within two to three working days of death because the earlier the examination is held, the more likely it is to provide useful information. It may be possible to arrange the examination within 24 hours for religious reasons if necessary, please let the hospital or coroner's officer know and the pathologist will try to do the post-mortem within this time limit.

The coroner's officer will normally be able to let you know the date, time and place of a post-mortem ordered by the coroner.

### How long does it take?

The examination itself may take several hours, but some tests may take several days or weeks. Hospital staff or the coroner's officer will be able to give you a better idea of the timescale.

### What happens after the post-mortem?

After examination your child's organs will be returned to their body, but cannot be put back in their original positions. Because some tests take several weeks, some organs may not be able to be returned for several weeks. You may wish to have the funeral during this time and bury or cremate your child without these organs.

### What happens to tissue or organs kept for further examination?

Once the coroner's duties have been completed, you decide what happens to the tissue or organs kept for further examination, apart from the tissue samples that were prepared for

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examination under microscope.

Your options are:

- You can ask for any organs and tissues that have been retained to be returned to the funeral director (or direct to you) once the tests are complete. You can either delay the funeral so that they can be returned to the body for burial or cremation, or can arrange a separate cremation or burial.
- You can donate tissue samples or organs for use in medical education or research.
- You can ask the hospital to dispose of the organs and tissue in a lawful way. This is usually by incineration.

Donating organs for transplant is handled separately from the post-mortem procedure. Please ask the bereavement team if you want to know more.

Samples of tissue prepared for examination under a microscope are usually kept as part of the child's medical records in case they are needed to answer further questions about the cause of death, or to help answer questions regarding illnesses of other family members in the future. Small blocks of tissue and corresponding microscope slides can be kept in the hospital pathology laboratory if you wish, or they will be respectfully disposed of.

Any images taken are usually kept indefinitely as part of the child's medical records and may be used for education, audit, or research. In this case any information which would allow the child to be identified would be removed. If you object to images being used in this way, you must say so.

### **What happens to any tissue removed during the post-mortem but not prepared for further examination?**

When a tissue sample is taken, it is often larger than the piece needed for making into a block. This is necessary because to trim unfixed or fresh tissue to the exact smaller size needed for processing may damage it. Any tissue left over will be respectfully disposed of by the laboratory.

### **Can I see my child after the post-mortem?**

After the post-mortem the mortuary staff will prepare your baby or child's body for you to see and hold again if you wish, and for the undertaker to prepare him/her for the funeral. You may also like to see your baby/child at the funeral director's premises. You should be

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aware that the appearance of your child's body may have changed, and you may wish to discuss this with your funeral director, so you know what to expect.

### How do I get the results?

Some weeks later, after all the tests are complete, a copy of the post-mortem report will usually be sent to your child's GP, and you may be able to get a copy from them. You can also arrange to discuss the findings of the post-mortem with the doctor in charge of their care at the hospital.

If your baby was stillborn or was a neonatal death you should be offered an appointment with the consultant obstetrician about six weeks later to discuss the results.

If the post-mortem was ordered by the coroner, you should be able to obtain a copy of the report from the coroner's office, although, there is generally a fee for this, unless an inquest has been ordered following the post-mortem. You should be informed as soon as the coroner's report is available.

### Giving consent for a post-mortem

**If the coroner has ordered the post-mortem examination**, they do not need consent for this. There are three main reasons why a death is referred to the coroner:

- A death has been sudden and unexpected.
- A person has been ill but the doctor confirming the death is not certain why it happened 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).

The coroner is an independent judicial officer responsible for investigating deaths. He/she is either an experienced lawyer, or an experienced doctor who has also had legal training.

**If a hospital has requested a post-mortem examination**, this can only be done with your consent.

If the hospital requests a post-mortem and you do not want to agree to a full post-mortem examination, you do not have to agree to one. You might, however, consider a limited examination. A limited post-mortem examination means that the post-mortem can be limited to certain parts of the body. However, this is likely to only provide limited information about the illness or cause of death. Because of this the doctor may advise you

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that a limited examination would not be of enough benefit to be worth doing.

**If you have asked for a post-mortem to be done**, you will still need to complete a consent form.

It is important that you know enough about the examination to decide whether or not you want to give your consent for it. If you do not understand any of the information, please say so. You can also ask as many questions as you like.

If you would rather not know about certain aspects of the post-mortem, or if you would like more detail or would like to discuss the matter further with a health professional please let us know.

The consent form acts as a written record of your decision, making it clear to everyone what you have, and have not, agreed to. If you change your mind before the post-mortem has taken place you can modify or withdraw your consent – even after signing. The hospital or coroner's office will tell you how much time you have in which to do this.

## Medical research and education

With your consent, tissue blocks and slides can be used in research which may benefit other people in future. When a new disease or health problem emerges, examination of tissue on a wide scale may provide clues about how and why the disease emerged, and how to respond. If there is any particular type of research you are worried about, you should discuss this with a member of hospital staff. You do not have to give overall consent but can exclude certain types of medical research.

With your permission, an organ (or part of an organ) might also be retained for use in medical research or education. If the organ shows a particularly clear example of a specific illness, it may play an important role in the education of medical students, doctors and nurses.

Examining tissue is one of the most important ways in which doctors learn about illness and how to treat it. Tissue from post-mortems can be used to train medical students and new doctors, to help experienced doctors continue to learn about new conditions or treatments, or to teach specialist knowledge.

New medical conditions are recognised all the time. If tissue samples have been retained, it is sometimes possible at a later date to diagnose these new conditions in cases in which they were previously undiagnosed, or given a different diagnosis.

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### What happens to organs or tissue donated for medical research, education or audit?

They cannot usually be returned to you. After they have been used, they will normally be disposed of by incineration. In some cases they may be used for many years before disposal.

## Contact details

If you have any more questions you can contact:

**Bereavement Team on 0121 507 4638**

## Sources used for the information in this leaflet:

- Human Tissue Authority, Codes of Practice, July 2014
- Human Tissue Authority, Policies and Position Statements, 2007–2011

If you would like to suggest any amendments or improvements to this leaflet please contact the communications department on 0121 507 5303 or email: [swb-tr.swbh-gm-patient-information@nhs.net](mailto:swb-tr.swbh-gm-patient-information@nhs.net)



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