





Introduction

You have been asked to read this booklet because your baby has died and you have been asked to consider giving consent for a post mortem examination or a coroner's post mortem is required. On behalf of our staff, we would like to express our sympathy to you and your family on the death of your baby.

We know that parents suffer distress and a deep sense of loss when their baby dies. Having a post mortem examination performed will hopefully give some answers to the questions you will have in relation to why your baby died. We hope the information in this booklet will help you to understand more about the post mortem examination and why it is important. Some of the answers to the questions go into significant detail which some people may find upsetting. We do not intend to upset you but we do want to give you as much information as possible. The booklet is based on feedback we have received from parents about what they want to know about post mortems.

What is a post mortem examination?

A post mortem examination or autopsy is the examination of a person's body after death. If your baby has died before or after birth and you wish to have a post mortem examination performed on your baby, this will be carried out by a pathologist. A pathologist is a specialist doctor who diagnoses disease and identifies what causes death.

What are the benefits of a post mortem examination?

A post mortem examination can give you extra information about your baby's illness or why they died. A post mortem can:

- help confirm why your baby died;
- reveal other diseases or conditions (including birth defects) that your baby may have had, but were not obvious at the time;
- assess how effective any treatment and medication was;
- help answer questions about possible health problems that may run in your family that could affect other children or pregnancies;
- help answer questions that you may have in the future; and
- help the medical staff to plan your care in a subsequent pregnancy.

However, a post mortem may not answer every question and does not always find the cause of death. We know this would be upsetting for you, but it may reassure you that your baby did not have a potentially treatable illness, or that your baby did not have any previously undetected birth defects.

There are two types of post mortem examination:

'Hospital post mortem'

You can ask for your baby to have a post mortem examination or the doctor caring for you or your baby may ask you to think about having one. We can only do a hospital post mortem with the consent of the baby's parent(s) or next of kin.

'Coroner's post mortem' By law, a coroner must investigate a death in certain circumstances. These include when a baby dies:

- suddenly and unexpectedly around the time of birth;
- soon after an operation; or
- suddenly at home.

As part of the investigation a coroner can order a post mortem even if you do not want one. Your consent is not required for this examination. When this happens, the pathologist performs the post mortem on the instructions of the coroner. When the post mortem report is completed, the coroner will decide whether or not there should be an inquest into the death (a coroner's inquiry). For further information about deaths reported to the coroner and specific information about a coroner's post mortem, please go to page 6.

When will the post mortem be performed?

Post mortems are performed Monday to Friday. Ideally, the post mortem examination should be performed as soon as possible after death, usually within 24 to 48 hours. The analysis of the examination, and test results usually take at least ten weeks, and may take up to twelve weeks.

When can you see your baby?

You can spend some time with your baby after death, but we recommend that your baby is moved to the mortuary after a few hours, so that they can be kept cool before the post mortem examination. You can see and hold your baby, if you wish both before the post mortem examination and after the initial examination is completed. We can dress your baby in clothes that you give us or, if you prefer, we can provide the clothes.

What happens to your baby during a post mortem examination?

In order to get the most information from a post mortem examination a 'full' examination is preferable but there are a number of choices that you can make about the extent of the post mortem examination. Firstly, we will explain what a post mortem usually involves. The post mortem is carried out in the mortuary, in a special room like an operating theatre. The pathologist performs the post mortem and is assisted by an 'anatomical pathology technician'. The pathologist performs the post mortem with the same level of care as if your baby was having an operation. The pathologist makes two openings, one down the front of your baby's body and another along the back of the head and down the back. This allows the pathologist to take out and examine all the organs and look for anything unusual which may have contributed to your baby's death.

The pathologist measures and weighs your baby. X-rays and medical photographs are usually taken to help us find out why your baby died. Samples of tissue are taken so we can examine them under a microscope. These small samples of tissue are kept in paraffin wax blocks and on microscopic glass slides in the hospital pathology archive. We keep these indefinitely as part of your baby's healthcare record. Some samples may be tested for infection and small amounts of body fluids may be taken for other tests.

Most of the tissue samples are taken during the initial examination of the body. However, for some tests to be successful, it may be necessary to remove an organ temporarily from the body for a couple of days. A special fluid is added to the organ before it is placed in a special incubator. After a couple of days small samples of tissue are taken and then the organ is returned to the baby's body before the funeral. This is known as 'rapid fixation' and is often used to examine a baby's brain.

Once the post mortem examination is completed, all the organs are returned to the body, which is closed with stitches. A bandage is placed over the scar on the baby's head and

around the body. You will not be able to see the scars when you hold and look at your baby after the post mortem.

Are there any options other than a 'full' post mortem?

A 'limited' post mortem examination is a partial examination of your baby's body. As parents you decide on the limits of the examination and what organs or parts of the body are examined and what tests we can do. We will record your instructions on the consent form, which we will ask you to sign. We usually take x-rays and medical photographs and collect small samples of tissues.

Genetic testing involves the testing of a skin sample or tissue to try and find out if the cause of death is hereditary (passes from one generation to the next) and if there is a chance of it happening again during another pregnancy. Genetic testing can be performed on its own or as part of a full post mortem. If you have any specific request in relation to genetic testing, you must write this on the consent form under the 'limitation' option.

An 'external' examination is a type of limited post mortem where the pathologist looks at the baby to see if there are any obvious abnormalities on the outside of the body, but your baby is not examined on the inside and no incisions of the body cavities are made. The baby will be weighed and measured and x-rays and medical photographs will be taken.

It is important to know that a limited post mortem will reduce the chance of us identifying why your baby died or identifying medical conditions that affected more than one of their organs. However, a limited post mortem is worthwhile as it may help identify the cause of death.

Is an organ ever retained at post mortem?

In the vast majority of cases all organs are returned to the baby's body before release of the body for the funeral. In exceptional circumstances, the pathologist may request that an organ is retained, so that further tests can be carried out. You will be told why it is considered important to do so. However, the organ cannot be retained without your consent. Once all the tests are completed and the post mortem report is finalised, the bereavement support midwife will talk to you about burial or cremation of the retained organ.

Will any of the information from a post mortem help future pregnancies?

Having information from a post mortem may help you. Some conditions may happen again in future pregnancies. With some genetic conditions the risk of recurrence can be as high as one in two babies. Identifying these conditions can help us to estimate the risk of another child being affected, which we will then discuss with you. This is also why we check to see if there was any infection or abnormality in the placenta (the afterbirth).

Will a post mortem delay the funeral arrangements?

We recommend that you wait a few days after the baby's death before arranging the funeral. This usually gives the pathologist enough time to complete the tests on your baby so that the funeral can take place with all your baby's organs in the body. The bereavement support midwife will tell you when the post mortem will take place and about when your baby will be released for the funeral. She will also help you to make the funeral arrangements.

What does 'medical audit' mean?

We must have our post mortem practices reviewed regularly to make sure that we comply with best practice guidelines. This is called 'medical audit'.

Why is 'education' mentioned on the consent form?

The results of the post mortem examination may be shared with other healthcare workers for educational purposes. Through this sharing of information, the staff will try to ensure that other patients get the best care possible. Your baby's identity will not be revealed during these educational sessions.

What does 'research' mean?

The initial tests performed on the tissue and body fluid samples are to diagnose the cause of death. The tissue samples are kept as part of the healthcare record of your baby in the hospital pathology archive in the form of blocks and slides. Future developments in medical research may involve studying these tissue samples to try and understand causes of death. You may wish to allow the blocks and slides retained from your baby's post mortem to be reviewed for this purpose in the future. This can only happen if you give consent to have your baby's samples included in research projects. All research projects require approval from the Research Ethics Committee of the hospital before the research project starts.

When will the results of the post mortem be available?

80% of reports are usually ready around 8 - 12 weeks after the pathologist has completed the post mortem examination. Sometimes the pathologist may need to do more detailed analysis and then the report will take longer to complete.

The pathologist will send the report to the consultant obstetrician and the bereavement midwife who was responsible for caring for you. The consultant paediatrician will also get a copy, if one was involved in the care of your baby.

You have a number of options in relation to communication of the post mortem results:

- A copy of the report is given to you at your follow-up appointment;
- The findings can be sent to your GP so that he or she can discuss the findings with you; or
- No communication whatsoever about the results if you do not want to be given details
 of the results.

We recommend that you attend a meeting with hospital staff so that the doctor can discuss the post mortem report with you and explain the results of the tests to you. We will offer you a copy of the report but it can be difficult to read because it is written using medical terminology. We will also send the report to your family doctor, if you wish. The bereavement support midwife will let you know if the report will be delayed and she will arrange an appointment for you to receive the results as soon as they are available.

CORONER'S POST MORTEM

Why is the coroner notified of some deaths?

Under Irish law, the coroner must inquire into the circumstances of sudden, unexplained, violent and unnatural deaths. This may require a post mortem examination, which is sometimes followed by an inquest. The fact that a death is reported to the coroner or that the doctor wishes to seek the advice of a coroner does not mean that a post mortem will always be required. There are guidelines on the types of death in a maternity hospital which must be reported to the coroner.

If the coroner decides that a post mortem is necessary, the Garda Síochána assist the coroner by arranging a formal identification of the body with a member of the hospital staff or with the next of kin. The bereavement midwife will keep you informed of what is happening in the event of a coroner's case.

What is different about the coroner's post mortem?

This is a compulsory post mortem under the law, and so the next of kin's consent is not required.

The post mortem is carried out by the pathologist, who acts as the coroner's agent. Usually the examination will take place in our hospital mortuary, but it may not do so. The post mortem procedure is similar to the full hospital post mortem as outlined above. Rarely, it may be necessary to retain an organ and we will inform you if this happens. Consent is not required for the retention of an organ during a coroner's post mortem when the purpose is to identify the cause of death. Once the coroner allows for the release of the organ, the bereavement support midwife will talk to you about burial or cremation of the retained organ.

Will the coroner's post mortem delay the funeral?

When a death is reported to the coroner, funeral arrangements should not be finalised until your baby's body is released or the coroner has indicated when release will occur. Cremation cannot take place until the appropriate coroner's certificate is issued. The coroner must give permission for your baby's body to be released for the funeral. Therefore, you should not make any funeral arrangements until we know exactly when your baby's body will be released for the funeral. The bereavement midwife will you informed of when you can start planning your funeral the event of a coroner's case.

When will the results of the coroner's post mortem be available?

It is usually at least six months, and often longer after the baby's death before the results are available and the report is finalised. As some laboratory tests can take a long time to complete and an inquest may be required, final conclusion and a death certificate may not be available for a significant period of time.

The bereavement support midwife will initiate contact with the coroner's office about three months after the death, and can update you on whether the results are available or not. She will be in regular contact with the coroner's office until the case is certified. Once the death is certified by the coroner or with her approval, the bereavement support midwife will organise a meeting for you with hospital staff to discuss the findings of the post mortem examination.

If you do not wish to attend a meeting with the hospital staff but would still like specific information about the post mortem findings, you can:

- Request a copy of the post mortem report from the coroner (once all the investigations are completed) or
- · We can send the report to your GP, who can explain the findings to you

Parents may contact the coroner's office directly if they wish to ask for updates on the case and to request a copy of the post mortem report, once death has been certified by the coroner.

Dublin City Coroner's Office, Store Street, Dublin 1. Tel **01 - 874 6684 www.coronerdublincity.ie**

How is the death registered?

When a death is reported to the coroner and a post mortem examination or inquest is required, the coroner will complete the death certificate, which is sent to the Civil Registration Office for registration of the death. The death certificate can then be obtained by you from your local Civil Registration Office.

Dublin Area

The Civil Registration Service, Ground Floor, Lucia House, 12 – 14 Lombard Street East, Dublin 2.

Tel 01 - 863 8200

What is an inquest?

An inquest is an inquiry in public by a coroner, with or without a jury, into the circumstances surrounding a death. The purpose of the inquest is to establish the facts surrounding the death, to place those facts on the public record and to make findings on the cause of death. The range of verdicts open to a coroner or jury include accidental death, misadventure, suicide, open verdict, natural causes and in certain circumstances, unlawful killing.

You will be informed of the date and place of the inquest. The coroner will decide on the witnesses to be called. If you have information which may be helpful at an inquest you should communicate this to the coroner (or gardaí) as soon as possible.

Your questions and comments

If you are unclear about any of this information, please let us know and we will explain it to you. You may like to write down some questions or comments of your own. This will help you remember them when the doctor comes to complete the consent form with you.

Acknowledgement

We wish to acknowledge the assistance and feedback received from A Little Lifetime Foundation in compiling this information booklet and to members of other bereavement support groups for providing feedback. We are committed to ensuring that we continue to work closely together to ensure we provide a high quality service to bereaved parents.

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