GOVERNMENT OF WESTERN AUSTRALIA

PathWest LABORATORY MEDICINE WA

Information for families

# Having a post-mortem after the loss of your baby

*Please be aware that the following information may be distressing to some readers.*

We offer our heartfelt condolences if you, or someone close to you, has suffered the loss of a baby. We understand that the loss of your baby is painful, so we are committed to supporting and caring for you and your family as you navigate this difficult experience.

The loss of your baby may raise important questions that can affect your grieving process. One of the ways to try and answer these questions, is through a post-mortem examination of your baby.

The aim of this brochure is to provide you with some more information and answer some frequently asked questions. Your healthcare provider will approach you about performing a post-mortem examination of your baby. You can choose to proceed with a post-mortem, or refuse/decline. The decision is entirely yours. You will have the opportunity to ask your healthcare provider about the process to help inform your decision.

## Frequently asked questions

### What is meant by consent?

Your permission, or consent, is needed before a post-mortem can proceed; a senior clinician will discuss this with you. If you consent to a post-mortem, you will be asked to consider what type of post-mortem you are providing permission for, and to specify how tissue and organs removed for examination during a post-mortem will be looked after. For example, it is sometimes helpful to retain an organ to allow a more detailed examination.

You can determine how long an organ can be retained, and how it will be taken care of at the end of the examination. These matters will be discussed with you by the doctor helping you with the consent process. It is important to know that whatever your decision, your baby is always treated with the utmost of care. The post-mortem is performed in such a way that you will be able to see and hold your baby after the procedure.

## What is a post-mortem examination?

This is an examination performed after death to provide as much information as possible to explain what happened to your baby. The examination is performed by a medical specialist called a Paediatric and Perinatal Pathologist who is experienced and trained specifically in this area.

There are three types of examination: **external**, **full** and **limited**. The consent form contains separate options for each type of examination. For an external examination, Part 2a should be completed, for a full examination Part 2b, and for a limited examination, Part 2c.

A more complete examination (such as a full examination) allows a pathologist to provide a more informative final report. This in turn allows your doctor or counsellor to better explain what happened to your baby.

Each examination, including an external examination, includes the following steps:

- Clinical photographs (these are very useful to detect and record congenital abnormalities)
- A standard set of measurements (to determine how a baby has grown)
- A babygram (a type of x-ray which allows assessment of the skeleton)
- An external examination of the body (to look at how body structures and limbs have developed)
- A detailed examination of the placenta (afterbirth).

Although a post-mortem is a very specialised examination, it is not always possible to determine the cause of death or explain all the findings.

Please also be aware that the pathologist may share clinical photographs, x-rays, and the report with other clinicians particularly when the case is very complicated and extra information is required, or a second opinion is being sought.

### External post-mortem examination (PART 2a)

We recognise that you may not wish for any incision to be made on your baby's body, and this is okay. We can still get a lot of information from the clinical photographs, the measurements, the babygram, and examination of the placenta.

### Full post-mortem examination (PART 2b)

A full post-mortem is the most complex and detailed type of post-mortem. This will allow the pathologist to examine all the organs, to obtain the most information possible. To perform the autopsy, incisions are made along the chest, abdomen (tummy) and to the scalp.

After the post-mortem these incisions will be delicately repaired and will not be visible when your child is returned to you, carefully dressed.

### Limited post-mortem examination (PART 2c)

Whilst it is best practice to perform a full post-mortem, we recognise that you may wish to have the least possible testing performed. This may be especially true if your baby is known to have a specific problem, for example with the heart or the brain.

There may also be times when your medical practitioner has advised that genetic studies be performed after your baby has died. In these instances, a limited post-mortem can be performed such as:

- Examination of the abdominal and chest organs with no head incisions
- Examination of chest organs only
- Examination of abdominal organs only
  Examination of head only
- Examination to sample tissue for genetic investigation only.

The decision is entirely up to you. To perform a limited autopsy, an incision is made as determined by the pathologist. This will be delicately repaired and will not be visible when your baby is returned to you, carefully dressed and wrapped in a blanket. Your healthcare professional can provide more information about the process.

## Do I have to make any decisions right now?

No, you don't. It's important to reach decisions you are comfortable with, and we understand that this may take some time. No examination of your baby will be performed without your consent.

## What tissue is taken?

For a full or limited post-mortem examination, small specimens (about the size of a pea) are routinely taken from every major organ for microscopy to detect disease. This is like a biopsy taken during life. Similar sized samples may be taken for testing by other departments (e.g. genetics, microbiology, and virology). A small piece of tissue is also taken for storage for further testing (such as genetics). The decision of what tissue is taken is determined by the pathologist at the time of the post-mortem.

The results of these additional tests are included in the final report.

## How long is tissue kept?

Unless permission is granted all tissues not used for further testing, or tissue that is stored (such as frozen tissue), are returned to the body at completion of the post-mortem.

## What happens to the tissue that is taken for microscopy?

This tissue is processed into a paraffin block from which a microscope slide is produced. The pathologist will study the slide under the microscope to determine if there is any disease. The blocks and slides are kept indefinitely as part of your baby's record and can be referred to at a later stage.

## Why is tissue taken for storage and what happens to this tissue?

There are several reasons tissue is taken for storage. Firstly, the pathologist may not be sure what extra testing to do (such as genetic testing) on the day the post-mortem is performed. This is especially true when the examination is complex. It is very useful to have frozen tissue available to send for additional testing once the pathologist has a clear understanding of what the underlying disease process may be.

Secondly, medical science (and especially the field of genetics) is growing rapidly, and it is very helpful to have tissue available for advanced testing. The tissue that is taken is frozen at -80 degrees in a special process and is kept at a PathWest laboratory for up to 20 years. This tissue may be used for later for testing, especially genetic testing.

## Do you keep the organs?

No. Unless you provide your consent for an organ to be retained, all organs are returned to the body. However, as some organs such as the brain cannot be examined satisfactorily without chemical treatment (this is called fixation), you may be asked by your healthcare professional before the postmortem begins, to give PathWest permission to keep the organ a little longer and to complete part 3 of the consent form.

If permission is granted and an organ is retained for fixation, the options for cremation and burial include:

1. Delay cremation or burial until examination is complete (this may take up to two weeks) or;
2. Proceed with cremation or burial and have a separate interment later.

## What about genetic testing?

Over the past decade, there has been a tremendous growth in the understanding of the genetic basis for disease and congenital disorders. Genetic testing is a very complicated process and needs to be performed in a specialised laboratory. The testing can be done at the time of the postmortem, or after, or both, depending on the underlying disease process. It is usual practice to remove a small pea-sized piece of tissue (for example from the muscle in a full or limited post-mortem, or from the umbilical cord in an external post-mortem) which is then taken and frozen in a special process. The tissue is then either sent to the genetics laboratory, or stored, or both. You can give or decline consent for genetic testing to be performed by ticking the" yes" or " no" box in Part 2a or 2b or 2c of the consent form.

Whilst genetic testing is very sophisticated, it may not always provide an answer. Sometimes a genetic test may indicate that other family members could be a carrier of disease and should be tested. Your doctor can discuss the implications of genetic testing with you; this is a separate consenting process to the post-mortem examination.

## Can tissues be used for other purposes such as research?

The law allows the use of tissue for other purposes such as research, training and education, and quality assurance purposes.

For example, researchers may wish to study post-mortem tissue. Consent to allow tissue to be available for ethical research, or other purposes, can be given with the post-mortem consent process. It is important to note that all research must be consistent with the National Health and Medical Research Council National Statement on ethical conduct in research involving humans and approved by the hospital ethics team. All tissue will be de-identified, ensuring protection of you and your baby's identity.

If you do not want your baby's tissue to be used for research, quality assurance or education you can strike out the applicable words in the relevant section of Part 2a, 2b or 2c.

## What information does the post-mortem examination report contain?

Following the examination, the pathologist will write a report for the doctor who cared for you and your baby, detailing their findings. This takes 6-8 weeks to complete.

The information contained in this report allows your healthcare professional to discuss with you why your baby died, and the risks for future pregnancies. You can also ask for a report in non-technical language (called the Plain Language Report) when signing the consent form.

Please note that both the technical and nontechnical post-mortem report can only be sent to the doctor nominated on the consent form.

## Where does the examination take place?

Your baby is kept in the PathWest Perinatal Pathology Department at King Edward Memorial Hospital (KEMH). If you request an examination of your baby, he/she will be transferred to the PathWest Paediatric & Perinatal Pathology department at Perth Children's Hospital (PCH) where the facilities for examination are located.

Your baby is kept in Perinatal Pathology (PathWest) at King Edward Memorial Hospital (KEMH)/Women and Newborn Health Service (WNHS). If you request an examination of your baby, he/she will be transferred by PathWest approved transport personnel to the PathWest Paediatric & Perinatal Pathology department at Perth Children's Hospital (PCH), where the facilities for examination are located. Your baby will be returned to the Perinatal Pathology department at KEMH the same day, after the examination has been performed.

## Who else is present during an examination?

During a post-mortem examination, a training doctor, midwife, nurse, laboratory technician or specialist may be present as part of their training or to review findings.

## Who can I speak to for advice?

The post-mortem coordinator or your doctor will be able to discuss all your questions about the post-mortem examination with you to review the findings.

## Comfort, support, and more information

Information about other services provided by Paediatric Mortuary can be accessed on our website, including:

- Arranging viewings
- Grief support
- Funerals.

## Contact PathWest

**Office hours**
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