

Deciding if your baby should have a post-mortem examination

We are so sorry for your loss.

The decisions you make following the death of your baby will be some of the most difficult you will ever have to make.

You have been given this information to help you think about whether or not you will decide to have a post-mortem examination (also known as an autopsy) of your baby. Our aim is to give you clear and accurate information to help you make an informed decision that is right for you, your family and your baby.

This information sheet explains our services, details of the different post-mortem options available, where they take place and how we ensure your baby arrives safely.

If there is anything you are not sure about, or would like explained in more detail, please don't hesitate to ask the person who gave you this information sheet. It is important that you have all the information you need before deciding about a post-mortem. You may want to discuss this with your family. You may also wish to seek spiritual or cultural guidance and support, or even speak with a parent who has lived experience (see bereavement resources QR code on page 4).

Who is the Victorian Perinatal Autopsy Service?

The Victorian Perinatal Autopsy Service (VPAS) provides autopsy services for perinatal deaths in the Victorian community. Perinatal deaths consist of stillbirths and neonatal deaths. A stillbirth is when a baby is born without signs of life after 20 weeks of pregnancy or weighs more than 400g if the length of the pregnancy is unknown. Neonatal death is when a baby dies within the first 28 days of life.

VPAS was created by the Victorian Government and is a collaboration between The Royal Women's Hospital, Monash Health, Mercy Hospital for Women and their pathology providers.

We work closely with Victorian hospitals to support families experiencing the loss of a baby. We provide information and guidance to hospital staff and coordinate requests for post-mortem examinations following the death of a baby.

What is a post-mortem?

A post-mortem is a medical examination of a body after death by a medical specialist.

All perinatal post-mortem examinations are attended by a perinatal pathologist. They are highly skilled and experienced doctors who have trained specifically in post-mortems for babies.

A post-mortem examination of any type will not be done without your consent. Your decision must be recorded on the *VPAS consent for perinatal post-mortem examination* form.

The examination happens as soon as possible after your baby's death. This is usually within a few business days.

Your baby will always be treated with care and respect from the time they are transported to the specialist site, during the examination and as they are returned to the funeral director of your choice.

The post-mortem examination and any additional tests follow the guidelines of the Perinatal Society of Australia and New Zealand (PSANZ).

In certain circumstances, a baby's death must be referred to the coroner. In this situation it is the coroner's responsibility to arrange the post-mortem investigation. This is uncommon and would be discussed with you by the staff caring for you and your baby.

Why do we offer post-mortems?

When a baby dies, we offer a post-mortem to understand what happened.

Depending on the circumstances of your pregnancy, a post-mortem may help to find further important information about any conditions diagnosed before birth and the cause of death.

It also provides valuable information for future pregnancies and supports research to prevent stillbirths and neonatal deaths.

What are the different types of post-mortems?

Different types of post-mortems are available, each providing varying levels of detail. The more thorough the examination, the more accurate the information we can get.

All post-mortems include taking clinical photographs and examining the placenta. They may also include other tests like x-rays, MRI scans (which give detailed internal images), and tests for infections and genetic conditions.

Full post-mortem

A full post-mortem involves a thorough external and internal examination of your baby's body. During the internal examination, the pathologist will usually make two openings (incisions) and carefully remove and inspect the organs and brain. Small samples of tissue (like a biopsy) will be taken for analysis and stored. Any tissue or organs, including the brain, not needed for diagnosis will be returned to your baby's body unless you request otherwise.

After the examination, the incisions will be carefully closed, and your baby can be dressed. Once dressed in an outfit and beanie, the stitches will not be visible.

Limited post-mortem

In a limited post-mortem, only some parts of a full post-mortem are done.

The pathologist will thoroughly examine the outside of your baby's body. They will then do a limited internal examination of specific organs or areas decided by you and your doctor.

For example, you might choose to only have the outside examined and just the organs in the abdomen (tummy) checked internally. Or, you might agree to only have skin samples taken for genetic testing.

The small tissue samples will be taken for analysis and stored.

External post-mortem

An external post-mortem involves a thorough examination of the outside of your baby's body. There will be no internal examination, no incisions and no tissue samples taken.

DOCUMENT NUMBER FAM-GUI-01 DECIDING IF YOUR BABY SHOULD HAVE A POST-MORTEM EXAMINATION

What happens to the tissue and organs after a post-mortem?

After a post-mortem, the perinatal pathologist will examine small pieces of tissue taken under a microscope. These samples are usually preserved in wax blocks. Once examined, these blocks are stored in the pathology department.

Hospitals are required by law to keep any tissue (wax blocks) taken during a post-mortem for at least 25 years. A small sample of tissue may also be frozen and stored for future tests that you and your doctor decide are necessary.

All remaining tissue or organs will be returned to your baby's body. However, sometimes in small babies with very small organs, we might need the entire organ to get enough sample for testing.

If you have given permission for the hospital to use any remaining tissue or organs for research and teaching, please know this may include tissue in wax blocks, fresh tissue and clinical photographs. Your baby will not be identifiable from these items.

If you wish, your placenta can be returned to you after the examination. The placental examination involves taking a small sample for examination and the use of formalin (a chemical to assist in preserving the placenta).

What are the advantages and disadvantages of a post-mortem?

Advantages

A post mortem may help to:

- Provide information on the cause of death or what to exclude as a cause of death.
- Confirm the gestational age of your baby.
- Confirm the sex of your baby.
- Provide an approximate time of death.
- Explain the significance of genetic or physical problems.
- Provide information about possible considerations for future pregnancies.
- Provide data and information to guide research around perinatal loss and help other families and babies in the future.

Disadvantages

- A post mortem may not always provide a specific cause of death.
- Occasionally complex tests at the time of post mortem may mean that your baby needs to stay longer, and lead to a delay in funeral arrangements. You will be able to decide whether to proceed with these tests, and your healthcare team can clarify how long they might take.
- After an internal examination, your baby will have stitches, but these will not be visible when your baby is dressed.
- Some families notice a difference in how their baby feels after a full post mortem.

Where will the post-mortem take place?

In Victoria post-mortem examinations are performed at one of three specialist sites, depending on where your baby died. These sites are all located in Melbourne. They are:

- The Royal Women's Hospital, Parkville (Royal Children's Hospital Pathology)
- The Mercy Hospital for Women, Heidelberg (Austin Pathology)
- Monash Health, Clayton (Monash Pathology)

The staff caring for you will let you know which hospital will examine your baby.

Who will take my baby for the examination?

We have a dedicated transport team who are experienced and trained in caring for babies.

If you decide to have a post-mortem for your baby, we will send our team to the hospital where your baby is located. They will make sure your baby is ready for travel and arrives safely for the examination.

If you live in a regional area of Victoria, we will also arrange for your baby to be returned after the examination to your funeral director you have chosen to assist you with the funeral.

This service is free.

How long does the post-mortem take?

The post-mortem examination starts with external tests like x-rays or MRI's. These tests will be done as soon as possible but it might take a few days, depending on when those services become available. After these tests are finished, the internal examination, which involves surgery, can occur. The internal examination will take approximately three hours.

We understand it's important for you to know how long your baby will be in our care, as this may affect your plans for your baby's funeral. Another thing to consider is where you and your baby are located. If you are in a regional area of Victoria, we'll also need to factor in the time it takes to transport your baby to the perinatal pathologist in Melbourne.

The staff caring for you can contact the VPAS coordinator to get a more accurate idea of when your baby will be returned to you.

What happens after the post-mortem?

When the post-mortem examination is complete we contact the funeral director that you have selected to assist you with the funeral arrangements.

We will coordinate your baby being safely and respectfully transferred from our care to theirs.

Can you see your baby after the post-mortem?

Yes. Some parents choose to spend time with their baby after the post-mortem examination, either while their baby is in the care of the funeral director or, in some cases, at home.

When will you get the results of the post-mortem?

After the post-mortem examination, the perinatal pathologist will write a detailed report explaining what they found. The report is usually completed within 10 to 12 weeks, depending on the tests needed and how long it takes to get the results.

The report will be sent to the doctor who cared for you and your baby. They will arrange a follow-up appointment with you to discuss what was found during your baby's post-mortem examination.

What costs are involved?

There is no cost for the post-mortem examination. This is covered by VPAS.

We will also cover the cost of transporting your baby to the specialist site for examination and bringing babies from regional locations home.

When do you need to decide?

Your healthcare team will talk with you about having a post-mortem soon after your baby's death. It's important to make this decision as soon as you can as waiting may affect the accuracy of the examination results.

Take your time with your baby and your family to choose what feels right for you.

More information

You can scan these QR codes for information on:

Perinatal autopsy







Contact the VPAS coordinator if you need more details

T 1800 841 024

E <u>VPAC@thewomens.org.au</u>

Hours

Monday-Friday 9:00am to 5:00pm.