

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.

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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



Bereavement resources



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.

SECTION 1

UR number	
Surname	
Given name/s	
Date of birth	Gender
	(Affix baby's label)

Baby's label

Victorian VPAS Perinatal Autopsy

Consent for perinatal post-mortem examination

Interpreter required:		
If Yes, requested language:		
Interpreter's name (print)/ID reference :		
Interpreter's translation provided:		
Date: / /		
SECTION 2 The following checklist is provided to ensure that you (parent/legal guardian)	n/s)	
have received adequate information.		
The post-mortem will only proceed if YES has been answered to all questions		
 I have received and/or read the VPAS Deciding if your baby should have a post-mortem examination information sheet 	Yes	☐ No
 I understand the options and reasons for performing the post-mortem. 	☐ Yes	☐ No
· I have received satisfactory answers to my questions.	☐ Yes	☐ No
 I understand that as part of a thorough post-mortem examination, sometimes specific organs may need to be temporarily kept for further testing which may delay the burial or cremation. 	Yes	☐ No
 I understand that full and limited post-mortem examinations involve taking and keeping small tissue samples and bodily fluids for diagnostic testing. These tissue samples may be requested for research; however tissue samples cannot be used without approval by the hospital's Ethics Committee. 	☐ Yes	□ No
• In accordance with the law, tissue taken for diagnostic testing must be kept by the hospital		

Service

Victorian Perinatal Autopsy Service

for at least 25 years.

Yes No

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UR number	
Surname	
Given name/s	
Date of birth	Gender
	(Affix baby's label)

UR number	
Surname	
Given name/s	
Date of birth	Gender
(Affix mother's label)	

Baby	s label	N	Nother's label
SECTION 3			
Decision regarding post-m	ortem examinat	ion (please tick only on	e box)
☐ I consent to a full post-mortem e☐ I consent to a limited post-morte like to set. For example: - Is the examination limited to a consent to a consent to a limited to a consent to a co	m examination. Specif a particular organ syst eg. no brain examinatio	y what limitations you would tem or part of the body. on.	Full, limited and external examinations may include imaging and clinical photography that assist in assessment of physical abnormalities.
(go to section 4), or I consent to an External Post-mo I do not consent to any type of Po			
SECTION 4 Decision following the example of the property of the example of the property of the example of the	organs to be returned what you would like tal: lawful cremation or	d to the body prior to release for the hospital to do when the exa disposal of the remaining tissu	or burial or cremation? amination is completed e/organs
SECTION 5 Parent/legal guardian sign I/we have been given adequate time		ion to make an informed decision	on (only one signature required).
Parent/legal guardian name:		Parent/legal guardian nam	e:
Relationship to baby: Signature: Date: / /		Relationship to baby: Signature: Date: / /	
SECTION 6 Witness statement I have explained the nature and ext making the decision has understood	·	em examination and believe that	
Doctor's name (print):		Doctor's provider nur	nber:
Doctor's signature:		Date: / /	

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Your baby's post-mortem examination

We are so sorry for your loss.

You have been given this information sheet because you have consented to a post-mortem examination of your baby. This examination will help us learn as much as we can about why your baby died.

Your healthcare team will have discussed your options for further investigations with you.

You should have also been given other written information, including Deciding if your baby should have a post-mortem examination. If not, you can ask for a copy. Or you can scan the QR code at the end of this information sheet to read it.

This information sheet explains what happens next, where the examination will take place and who to contact for more information.

What happens after you agree to a post-mortem?

After you have spent some time with your baby, your healthcare team will let the Victorian Perinatal Autopsy Service (VPAS) coordinator know your baby is ready for the post-mortem examination. The VPAS coordinator will arrange the transfer of your baby to the specialist site for the examination.

You can contact the VPAS coordinator from the time your baby leaves your care. They are there to answer your questions and keep you informed with as much information as you want. You will find their details at the end of this information sheet.

Where will the post-mortem take place?

Your baby's post-mortem examination will take place at:

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

How long does the post-mortem take?

The post-mortem examination will begin with external tests, such as x-rays or MRIs. These tests will be done as soon as possible, but it might take a few days, depending on when those services are available. After these tests are complete, the internal examination (surgical procedure) 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.

Once your baby is at the specialist site, the VPAS coordinator can give you a more accurate idea of when your baby will be returned to you.

What happens after the post-mortem?

When we finish the post-mortem, we will work with your funeral director to safely and respectfully transfer your baby 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.

This is a personal decision for your family.

If your baby has a full or limited post-mortem, the perinatal pathologist (doctor) will make surgical openings (incisions) to examine their tissue and organs. After the examination, they will carefully close these incisions. Once your baby is dressed, the incisions will not be visible.

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.

Bereavement support and information

If you need more information and support, please speak with your healthcare team.

You can scan these QR codes for information on:

Bereavement resources



VPAS Family information



Contact the VPAS coordinator if you need more details

T 1800 841 024

E VPAC@thewomens.org.au

Hours

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

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UR number		
<u>Ort Harriber</u>		
Surname		
Given name/s		
Date of birth	Gender	
	(Affix baby's label)	

UR number	
Surname	
Given name/s	
Date of birth	Gender
	(Affix mother's label)

Baby's label

Mother's label



Family's instructions

This form is to be completed by hospital staff caring for the bereaved family before their baby is transferred for a post mortem examination. Please complete this while consulting directly with the family.

ioi a post mortem examination. Ptease complete ti	is write consutting an ecity with the family.
Staff person name (print):	Date: / /
Baby's belongings	
If there are belongings with the baby that the family wish for the post mortem examination.	nes to keep, we recommend that these are not sent with the baby
Will the baby be transferred to VPAS with any belo	ngings: 🗌 Yes 🔲 No
If yes , all items such as valuables, clothing, blankets and described and listed below:	mementos that are remaining with the baby must be clearly
e.g. white knitted beanie	
Funeral director selected by the family	
It is the family's responsibility to select a funeral direct their baby.	or to assist them with making the funeral arrangements for
for the baby to be transferred into their care. If the famil	Il contact the family's nominated funeral director to arrange y lives in metropolitan Melbourne the funeral director will attend egional Victoria, VPAS will arrange transferring the baby to the etails of the funeral director the family have selected.
Name of Funeral Director:	
Address:	
Phone Number:	Email:
Signed by parent	
Print name:	Relationship to baby:
Signature:	Date: / /

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VPAS: FAMILY'S INSTRUCTIONS



UR number	
Surname	
Given name/s	
Date of birth	Gender
	(Affix baby's label)

UR number		
Surname		
Given name/s		
Date of birth	Gender	
(Affix mother's label)		

Baby's label

Mother's label



Checklist for arranging a perinatal post-mortem

This checklist is for registered births. If you are making a referral from RWH, the Mercy Hospital for Women, or Monash Health (Clayton), please call your hospital lab and request a copy of their checklist for internal referrals.

Action	Send to VPAS	Send with baby	Initial when done
Consult your hospital bereavement procedure.			
Complete the Medical Certificate of Cause of Perinatal Death (death certificate).	~	~	
Discuss the option of perinatal post-mortem with the family. Provide a copy of VPAS Deciding if your baby should have a post-mortem examination (VPAS/01) information sheet. Contact VPAS if you would like assistance or support T 1800 841 024.			
Complete VPAS Consent for perinatal post-mortem examination (VPAS/02) form with the parents/ guardians of the baby. If they decide against a post-mortem, please complete VPAS Consent form (VPAS/02) and select 'I do not consent to any type of post mortem'.	*	~	
Complete VPAS Family's instructions (VPAS/04) form and ensure all belongings travelling with the baby are clearly listed.	~	~	
Provide the family with VPAS Your baby's post-mortem examination (VPAS/03) information sheet.			
Call VPAS to begin the referral T 1800 841 024.			
Complete VPAS Clinical information before placental and post-mortem examination (VPAS/06) form.	*		
Send all relevant antenatal, intrapartum and postnatal clinical info. to VPAS perinatal autopsy coordinators: • The Victorian Maternity Record or antenatal record, notes and relevant referrals. • Birth summary. • Discharge summary (if available). • Relevant medical, midwifery and/or nursing notes. • All relevant pathology results for mother and baby. • All relevant imaging results/reports.	*		
Secure patient identification labels on the baby, as per VPAS <i>Patient identification for perinatal post-mortem examination</i> flowchart. The identification labels need to match the details on the consent form.			
Place the placenta in a watertight container (not in formalin). The placenta needs to be labelled with the maternal patient identifiers.		~	
The placental pathology request form needs to specify clinical scenario and request: I placental histopathology placental MC&S, and molecular karyotype/microarray.	~	~	
For transfer, please ensure that the baby is wrapped (consider using a bluey for infection control, or if the baby has delicate skin).			
Once these items are complete, and the family knows when they will be ready for their baby to be transferred to the VPAS pathology laboratory, please call VPAS coordinators (T 1800 841 024) so they can book the transport.			

All forms, information sheets, and guides are available on the VPAS website: thewomens.org.au/VPAS

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UR number		
Surname		
Given name/s		
Date of birth	Gender	
(Affix mother's label)		

Baby's label

Mother's label

Victorian Perinatal Autopsy Service

Clinical information before placental and post-mortem examination

therapeutic interventions, if applicable. (e.g. unexpected fetal death in utero at 38 week's gestation, extreme prematurity

Describe the clinical circumstances leading up to the perinatal death including the gestation and any

following preterm labour at 21 week's gestation, termination of pregnancy for fetal anomalies at 23 week's gestation). What clinical questions need to be answered by the post-mortem and placental examination? (e.g. cause of unexpected fetal death, evidence of suspected chorioamnionitis and fetal infection, characterisation of anomalies diagnosed on antenatal imaging, assess if there are any complications of neonatal resuscitation, etc). Describe any clinical issues during in the antenatal period. (e.g. IVF/assisted conception, gestational diabetes, multiple pregnancy, suspected IUGR, recurrent bleeding, evolving pre-eclampsia, prelabour premature rupture of membranes, etc). Were there any significant findings in the antenatal investigations - maternal antenatal serology, genetic screening/diagnostic testing, fetal imaging and perinatal blood tests? (e.g. maternal antiphospholipid antibodies, suspected fetal structural abnormalities on scan, high risk first trimester combined screening, etc)

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UR number	
Surname	
Given name/s	
Date of birth	Gender
	(Affix baby's label)

UR number	
Surname	
Given name/s	
Date of birth	Gender
	(Affix mother's label)

Baby's label	Mother's label
Maternal obstetric history	
Please indicate the mode of delivery and describe any significate. (e.g. cord entanglement, manual removal of the placenta, emergency suspected chorioamnionitis, instrumental delivery, difficult breech extends to the control of the placenta of the placen	Caesarean section for fetal distress,
Please add any further details if available/necessary:	
Please ensure copies of the following are available to forward	to the VPAS autopsy coordinator:
☐ Maternal antenatal serology ☐ Maternal perinatal blood tests	
$\ \square$ Genetic screening and diagnostic test results $\ \square$ Fetal imaging (ultrasounds, MRI if applicable)
Antenatal care record Birth summary Maternal admission	on clinical notes
Neonatal resuscitation and admission clinical notes, if applicable	
Autopsy report:	
Name (referring Dr to receive autopsy report):	
Phone: E	mail:
Address:	
Additional copies to:	

Victorian Perinatal Autopsy Service

Name:

Designation:

Contact details:

Signature:

Date: