

Stillbirth Investigations: Information for Parents

The stillbirth of your baby is a very distressing time for families and we are sorry for your loss. It is important to us that we provide you with the care and support you need during this time.

Parents who have experienced stillbirth told us what information they wanted to know about tests available and autopsy. We have put the information in this fact sheet to help you during discussions about autopsy and other types of investigations that will be offered to you. These will give you the best chance of finding out why this has happened. The staff caring for you will also give you the opportunity to ask any questions and help you to understand your options.

We understand these discussions and decisions are difficult. There is no “right or wrong” choice and you will be supported, whatever you decide. We also understand that the information below is very confronting and you may require additional support as you read. Please never hesitate to ask any questions or speak your concerns.

Stillbirth Investigations

What sorts of tests will the staff offer us?

The mother will generally be offered different blood tests depending on the pregnancy and how your baby and placenta look after birth. These might include checking for any problems with blood sugar levels, blood clotting, liver function, infections and to see if any blood mixed between mother and her baby. You will be offered a range of tests for your baby, from a general visual examination to an autopsy, along with genetic testing to gain additional important information. The placenta is also examined as part of the tests and can provide valuable information.

Why will tests and an autopsy be offered to us after our baby was stillborn?

All investigations are done to try to find a reason why your baby died. Many parents say the main reason they chose to have an autopsy was to help identify any conditions that might affect future pregnancies or children. Having an autopsy can also help with your grief and worry in another pregnancy. If a reason is found, your care in future pregnancies may be altered to prevent the loss of another baby. Even if a cause isn't found, this can be reassuring as it may rule out some possibilities.

Autopsy

An autopsy is one part of the investigations offered in evaluating the loss of your baby. It always involves careful examination of the body to look for any signs of abnormality.

Are there different types of autopsy?

Yes, there are 3 different types of autopsy; full, limited or external examination

- Full autopsy, which is similar to a surgical procedure. All the body's organs are examined and a variety of tests are done.
- Limited autopsy, where only certain areas of the body are examined.
- External examination by a pathologist +/- imaging, like X-rays or a MRI.



What is a full autopsy and what happens during an autopsy?

A full autopsy is a thorough examination of the body and internal organs performed by a pathologist. A pathologist is a specialist doctor that is highly trained in stillbirth investigations who will treat your baby with dignity and respect throughout the examination.

Like an operation, an incision is made along the chest and abdomen and behind the ears to look at the internal organs. Small tissue samples are taken from the organs. They will be examined under a microscope by the pathologist. Tissue samples are taken for genetic testing to check the baby's chromosomes and genes. If infection is suspected, swabs of the organs will be sent for bacterial testing. Clinical photographs are also taken during the examination.

After the examination, all organs are replaced in the body except for the tissue samples. Occasionally, an organ may need to be removed for closer examination and extra testing, which may take more time.

A full autopsy will give you the best chance of finding out why your baby passed away.

In a limited autopsy, can we say what is and what is not looked at?

Yes, in a limited autopsy, you can state what you do and do not want examined. You can be very specific. On the form you sign to consent for autopsy, there is a space for you to put any restrictions or check that they have been listed. The pathologist ALWAYS follows these instructions.

What is involved in an external examination?

The most limited form of autopsy is an external examination, so there are no incisions and the internal organs are not examined. The body is studied in detail by the pathologist. Clinical photographs and growth measurements are taken. Sometimes an X-ray or MRI are also performed. There is also the option of taking a small skin sample for genetic testing. If you would like this test, it is recorded on the consent form.

What will our baby look like after an autopsy?

After an internal examination your baby will have some stitches, similar to after an operation. They may be behind their ear and on the chest and abdomen, depending on the type of autopsy you choose. The stitches will not be noticeable once your baby is dressed.

Will an autopsy always find a reason why our baby was stillborn?

The main reason to do an autopsy is to determine an accurate cause of death and in the case of stillborn babies, to estimate when the baby passed. Even if your doctor is confident of the cause of death, confirmation with an autopsy can be very reassuring. In many cases, autopsy discovered new findings that changed or modified the suspected cause of death or gave additional information. The autopsy may not find a reason, but this is still helpful as it can rule out some causes.

Would an autopsy give us information about whether this could happen again and whether anything could be done to help prevent it?

An autopsy may identify a condition that could happen again in another pregnancy. Some examples include a genetic abnormality, a problem with the placenta or a medical condition in the mother. Knowing about these conditions may help us to prevent stillbirth from happening again.

What happens to your baby before and after the examination?

Who conducts the autopsy and where will the autopsy occur?

The autopsy will be conducted by a pathologist from the South Australian Perinatal Autopsy Service in the mortuary at the Women's and Children's Hospital (WCH) in North Adelaide.

How would my baby get there?

If your baby is at the WCH, a midwife will carry your baby down to the mortuary. If your baby was born elsewhere, the hospital will organise transport for your baby. You can also arrange your own funeral director to provide transport for your baby to the WCH.

How is my baby cared for when they are in the mortuary and during the autopsy process?

The mortuary staff and pathology team will treat your baby with gentleness, respect, care and kindness at all times.

How long does my baby need to stay in the hospital mortuary to perform an autopsy?

Usually your baby will be in the mortuary for 2 – 3 days. Sometimes the examination may take longer depending on some of the tests performed.

Can I spend time with my baby before the autopsy?

Your baby can remain with you while you are still in hospital. There is also a room where you can sit to spend time with / hold your baby near the mortuary before the autopsy.

Can I spend time with my baby after the autopsy?

If you are still in the hospital after your baby's autopsy is complete, you may be able to have your baby in the room with you following the examination, depending on where the hospital is, transport arrangements and funeral preparations. If you are at home, you can come in and spend time with / hold your baby in the room near the mortuary. You can also arrange to spend time with your baby at the funeral home, or at home.

Can I still take my baby home for a while before or after an autopsy?

Wherever possible we will work to ensure your wishes are supported. Please ask the staff caring for you if you wish to spend time with your baby at home.

Will an autopsy or other tests cost me anything?

There are no fees for an autopsy or any testing done during the examination if you have a Medicare card. Please ask the staff if you are at all unsure.

Cultural considerations

What if our culture or religion has certain practices or ways of dealing with a body after death that I need to follow?

It is important that the staff understand what is important to you so that they can support you in your cultural or religious practice. The staff may also be able to speak to your religious or community leader if you require.

The timing of autopsies can usually be organised to accommodate religious or cultural requirements. Please talk with your midwife, doctor or social worker or pastoral care worker and they will be able to help arrange this with the pathologist.

Aboriginal families may want their baby and placenta to return to Country. We will support you with this.

Making memories

Will we still have time to make memories with our baby? Do the mortuary staff create mementos?

Yes, we encourage you to make memories with your baby whilst in hospital. You may want to take photos or hand/foot prints, read stories, introduce your baby to family or friends etc. It is an individual choice for you to make as parents or with other important people in your life. The staff can support you with this if you would like them to.

If you choose to have an autopsy performed by the SA Perinatal Autopsy Service, they can also produce a memento package. This includes high quality digital photos of your baby dressed and wrapped, hand and foot prints, the name band and a lock of hair (if possible). The photographs taken at the time of autopsy are special memories, but your baby will look different as time passes.

If you wish to have a memento package, you will need to sign the consent form or provide consent over the phone. Nothing is done to your baby without your consent. There is no charge for the memento package.

If your baby was born in a hospital other than WCH, the completed package will be forwarded to the maternity unit at that hospital. A midwife will be in touch to arrange collection, or have the mementos sent to you. If your baby was born at the WCH, someone from the social work department will contact you to arrange collection or have the package sent to you. If you have any queries, you can contact Women's Social Work via switchboard on 81617000 using the mother's name.

Placenta

Why is the placenta needed as part of the examination?

A problem with the placenta may have led to your baby dying, which is why having the placenta examined is so important. Examination and testing of the placenta identifies the cause of death in many cases. The placenta pathology report will be sent to the requesting doctor and GP (if requested). It is also included as part of the final autopsy report.

Can I get my placenta back after the examination?

Yes, you can request to have your placenta returned to you following the examination. You are able to bury it but as chemicals have been added to the placenta, you will not be able to eat it or consume it in capsule form. If you want the placenta returned to you, please request this on the consent form.

Consent

Will tests and the autopsy happen without my consent?

No investigations will be performed without your consent. You have full control of what happens in most situations.

However, in some circumstances, the Coroner may be involved and request a full autopsy for legal reasons. This does not happen very often, and you would be informed.

Can other people that are important to me be involved in the decision-making?

The mother of a stillborn baby is the only person who can legally consent to an autopsy. However, with your agreement other people who are important to you can be involved in discussions to help you decide whether to give consent or not. You can ask the staff to involve them in these discussions. If the mother is unwell, and unable to consent, the father or senior member of the family can consent.

When do I need to decide?

The doctors, midwives and social workers involved in your care are there to help you with the decisions you are making. You can take up to a week to decide (or prior to burial or cremation), but the results will generally be of higher quality if the autopsy is undertaken within 4-5 days.

Autopsy report

What kind of information would be in an autopsy report?

The report is a medical document. It will detail clinical information from the pregnancy and link this to findings from the post-mortem examination. It will give a cause of death if one is found. It will be sent to the doctor who signed the autopsy consent form with you.

Will we be able to understand the medical autopsy report?

Medical language is used in the report. You can get a copy of the full report or it may be more useful to get a plain language report. We can organise this for you.

How long will it take to get the results of an autopsy or other investigations?

The time for results to be available can vary, but is likely to be between 8 and 10 weeks. You will be given an appointment for 8 - 10 weeks in your hospital after the birth to go through the results.

Would our GP or local health care organisation be sent a copy of the autopsy report?

You can ask for a copy of the autopsy report to be sent to a GP or healthcare organisation of your choice.

Other questions

Can an autopsy help with research?

If permitted on the consent form, tissue samples taken in the autopsy and the information in the autopsy report may be used for research. This research may in time help to reduce the number of stillborn babies in the future.

Can we ask for an interpreter, even if one of us speaks English?

Yes. It is important that you both fully understand why you are being offered the tests, what information can be obtained from the tests and what is involved. Please speak to the staff so that they can arrange an interpreter to assist with these important discussions.

What if I have more questions? Who do I ask?

You can ask any of the staff looking after you and your baby.

For more information

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