

Tests and investigations after stillbirth

Trying to find answers when your baby has died

This information sheet is for parents who have experienced a stillbirth. It provides information on the tests and clinical investigations that should be offered when a stillbirth is diagnosed, and how results should be recorded.



What is stillbirth?

Stillbirth is when a baby dies before birth. In Australia, it is defined as the death of a baby after 20 weeks of pregnancy, or that weighs 400 grams or more.

Six babies are stillborn in Australia every day, meaning that one in every 140 pregnancies ends with stillbirth.

Some of the common causes of stillbirth in Australia include abnormalities with the developing baby, premature birth and health conditions of the mother.

After a stillbirth, there are several clinical investigations that can be performed to help identify what may have contributed to the loss.

For many parents, this information can be an important and helpful part of living with the death of their baby. It may also assist with decisions about care for future pregnancies.

Discussing stillbirth tests and investigations

Experiencing a stillbirth is a devastating and difficult experience for parents, their families and support people.

For many parents, understanding what may have contributed to the stillbirth can be an important part of living with the death of their baby.

There are a number of clinical investigations (tests and examinations) that may help identify potential causes of your baby's death. Your clinician will speak with you and your support people about the tests that are available.

As this can be a challenging subject to discuss, your clinician will try to have this discussion when you are ready, taking into account your emotional and personal needs during this difficult time. This often involves more than one conversation, so that you and your support people have time to consider your options and ask any questions you might have.

Your clinician will ask you about your personal wishes, including any cultural or religious preferences or needs that may affect your decisions, and about any concerns you might have.

You can involve family members or other support people in these discussions if you want to, including people who provide spiritual or religious support.

Your clinician will only arrange clinical investigations – for you or your baby – with your permission. For some investigations (such as autopsy) written permission

is required; for other investigations (such as blood tests) your clinician will seek your verbal permission. You should be given the time you need to consider, and make decisions about any investigations that are discussed with you. Some investigations will need to be completed within a certain time, which will be discussed with you.

Your clinician should explain:

- What time you can spend with your baby before and after the investigations
- What the investigations may find
- What the investigations involve and where they will take place
- How long the results will take
- How you will be informed about the progress and results of the investigations
- Who you should contact if you have any questions
- That you can change your mind about proceeding with any investigation you have agreed to, up until the time it takes place.

Clinical investigations for mother and baby

After a stillbirth, your clinician may recommend some clinical investigations for the mother, such as taking a detailed history of the pregnancy and blood samples.

They will also recommend examining the placenta and umbilical cord. Some families may have particular preferences about what happens to the placenta – for example, some may wish to bury the placenta. Let your clinician know what you would prefer – they should accept your decisions.

Your clinician will also discuss clinical investigations for your baby. Your baby will always be treated with care and respect during any investigations. You will also be able to spend time with your baby before and after any investigations are completed, if you would like to do so.

Investigations for your baby may include one or more of the following:

- Completing an external (outside) examination, and taking photographs of your baby
- Performing an autopsy (also known as a *post-mortem examination*), where a pathologist who specialises in babies and children will complete an external and internal (inside) examination of your baby's body
- Examining or taking small samples from only certain parts of your baby's body (also known as a *limited* or *minimally invasive* autopsy)
- Taking scans of your baby using imaging such as X-ray, ultrasound or magnetic resonance imaging (MRI, which gives detailed internal images of your baby).

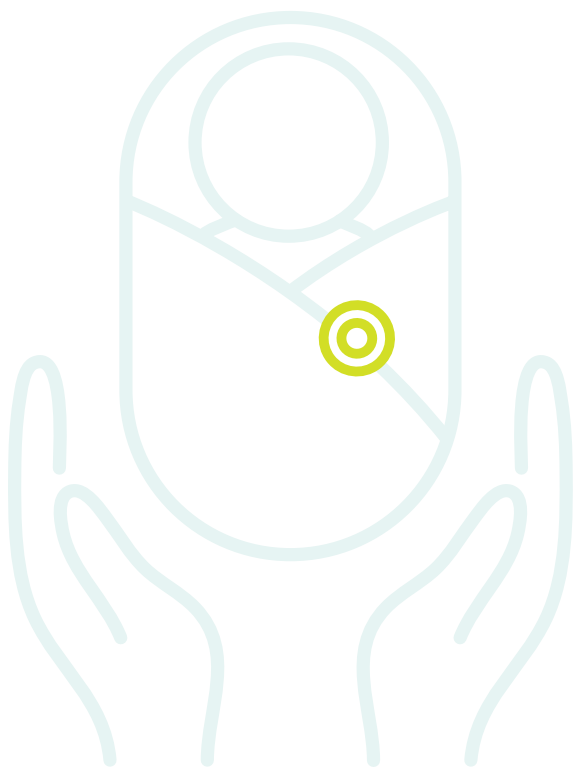
Your clinician will provide further information about these investigations and support you to make decisions that you feel are best for you and your baby. You may choose to proceed with all of the recommended investigations; some investigations, but not others; or no investigations at all.

Sharing your perspective

You should also be offered an opportunity to discuss anything that you think may have contributed to the stillbirth of your baby, including any aspects of your pregnancy care.

Your clinician will explain that this discussion can occur whenever you feel ready, and that the information you provide will be discussed with sensitivity and respect at all times. You can choose to have this conversation with another clinician, if you do not feel comfortable sharing this information with the clinicians who were directly involved in your care. The support people of your choosing can also be involved in these discussions.

The information you provide should be taken into account along with the results of any clinical investigations you choose to have. Your perspective should also be considered as part of standard review processes conducted within the hospital to identify factors that may have contributed to the death of your baby (sometimes called *mortality audits*, or *incident investigations*).



Stillbirth investigation results

Clinical investigations that you have agreed to following the death of your baby will be carried out by specialist clinicians. These clinicians will also review and interpret the results. In most cases, a pathologist who specialises in causes of death for babies and children will write a detailed report on the results.

Discussing clinical investigation results

When the results are available, a clinician who understands your case will arrange a follow-up meeting with you and your support people to discuss the results.

Some clinical investigations can take longer than others, so your clinician may not have all the results available at the first meeting, and further meetings may be required.

You should expect that your clinician will discuss clinical investigation results with you in a caring, sensitive and culturally safe way. If you would like to have a support worker or interpreter with you during this discussion, this can often be arranged. This may be an Aboriginal and Torres Strait Islander health worker or liaison officer, a cross-cultural health worker and/or an interpreter, depending on your needs.

During this discussion, your clinician will also consider any information that you and your support people have shared about factors you think may have contributed to the death of your baby. Your clinician will discuss the information you have provided, with sensitivity and respect at all times.

If more specialist clinical expertise is needed to explain what the results mean, or if more tests are needed, your clinician will discuss this with you and arrange relevant referrals.

Where appropriate, this should include the option of discussing the results via telehealth, especially if you live in a rural or remote area or cannot easily access the necessary clinical expertise.

Information you should expect to receive

Your clinician will provide you with a summary of information about your pregnancy and the death of your baby. This should include a record of the results of the investigations (including whether a cause for your baby's death was found), and any recommendations that might affect your plans to become pregnant again. They should also let you know how this information has been documented in your healthcare record.

It is important to be aware that reasons for the baby's death cannot always be found. Clinical investigations can sometimes provide information about what may have contributed to the death, or can rule out some causes.

Sharing investigation results

With your permission, your clinician should share information about the death of your baby with other clinicians involved in your care, including your GP and/or your Aboriginal Community Controlled Health Organisation or Aboriginal Medical Service. This should include information about your pregnancy, the findings of the autopsy or any other investigations completed and recommendations for your future care.

Hospital review process

After a stillbirth occurs, many hospitals will complete a formal review of the care provided to the mother and baby, to help understand the events leading up to the death of the baby. This process is called a *perinatal mortality audit* or *perinatal mortality and morbidity review*. This is a standard process.

As part of this process, the results of any clinical investigations you have agreed to, and any information you have provided about potential contributors to the loss, are carefully considered by the clinicians involved in your care. Because the results of investigations will not be available straight away, it may take some time for this process to be fully completed.

Stillbirth cannot always be prevented, and reasons may not be found. However, if the review finds that any aspects of the care provided to you may have contributed to the death of your baby, you will be informed. You should expect to receive an apology, be offered an opportunity to share your views on what happened, and an explanation of how the incident happened and the steps being taken to prevent it from happening again. This process is known as *open disclosure*, and may involve more than one meeting.

What is the Stillbirth Clinical Care Standard?

The *Stillbirth Clinical Care Standard* describes the health care that should be provided to women who are pregnant or planning a pregnancy, from before pregnancy to after a stillbirth occurs.

It also addresses bereavement care for parents (and their support people) who have experienced any perinatal loss, including stillbirth, miscarriage, termination of pregnancy and neonatal death.

For more information or to read the full clinical care standard visit: safetyandquality.gov.au/stillbirth-ccs

Questions?



Find out more about the *Stillbirth Clinical Care Standard* and other resources. Scan the QR code or use the link safetyandquality.gov.au/stillbirth-ccs

Where to get more information

- Centre for Research Excellence in Stillbirth:
 - [Autopsy: Trying to find answers when your baby has died](#)
 - [Guiding Conversations with Your Health Care Team When your Baby Dies](#) (in partnership with Stillbirth Foundation Australia)
- Red Nose Grief and Loss:
 - [Born still or died soon after birth](#)
 - [Finding out the cause of a stillbirth or neonatal death](#)
 - [After the autopsy](#)

State and territory resources

- ACT Health – [What is a post mortem?](#)
- NSW Health – [Perinatal post-mortem service: Information for families](#)
- Queensland Health – [Autopsy examination of a baby](#)
- The Royal Women's Hospital, Victoria – [Learning why a baby has died](#)

The Australian Commission on Safety and Quality in Health Care has produced this clinical care standard to support the delivery of appropriate care for a defined condition. The clinical care standard is based on the best evidence available at the time of development. Healthcare professionals are advised to use clinical discretion and consideration of the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian, when applying information contained within the clinical care standard. Consumers should use the information in the clinical care standard as a guide to inform discussions with their healthcare professional about the applicability of the clinical care standard to their individual condition.