

Information for healthcare professionals seeking parental consent for postmortem investigations of a baby

Discussing postmortem investigations with parents

The death of a baby is devastating for parents and their family. Often the death is unexpected, and the parents are confronted with the shock of losing their baby, as well as the overwhelming emotions that follow. Sensitivity and compassion are critically important when providing information to parents around the death of a baby. This resource aims to provide guidance to healthcare professionals when approaching bereaved parents to discuss postmortem investigations. Each hospital should have its own policy and procedures regarding parental consent for autopsy and other investigations. This policy should initially be consulted.

Why is it important to offer bereaved parents postmortem examinations?

Provision of information on why postmortem investigations are performed will help parents make the right decision for their baby. The primary reason for postmortem investigations is to understand why the baby has died. The investigations may confirm suspected reasons for the death or uncover new information, which may help parents to understand what happened and may be useful in planning care for future pregnancies. Information from investigations after a perinatal death can also help healthcare services and researchers understand why babies sometimes die. A full investigation does not always provide an answer as to why a baby died, but it does offer the best opportunity to get this information, and may rule out some possible causes.



Parents should be given time to consider the information before making their decision

What are the options?

Explain to the parents that a full work-up following stillbirth or neonatal death and a full autopsy provides the highest likelihood of finding a cause of death along with placental examination.

As soon as possible after diagnosis of a fetal death in utero, a **fetal postmortem ultrasound** should be performed by a skilled healthcare professional; this may help to identify selected abnormalities.

Placental examination is one of the most important investigations. Parents should be offered the option of taking the placenta home after examination.

Full autopsy is where a perinatal pathologist makes surgical incisions and examines the baby's internal organs. Samples may be taken for examination under a microscope and medical photographs and X-rays may be taken. Examination of the placenta is included.

Less invasive options may be offered if parents decline a full autopsy. It is helpful to discuss these options with a perinatal pathologist to ensure the most appropriate investigation is undertaken. Less invasive options include **limited autopsy** which includes targeted examination of organs or tissues (also known as minimally invasive tissue sampling) by the pathologists based on clinical suspicion of case (e.g. the chest organs only, if a cardiac anomaly is suspected).

Noninvasive options include **external examination** of the baby by a specialist doctor or pathologist without surgical incisions. **Medical photographs** may help to identify possible causes of death and enable consultation with specialist expertise. **Full body Xray** imaging of the baby (also known as a 'babygram'), helpful where skeletal abnormalities may be suspected.

A postmortem MRI, where appropriate MRI services are available, can be helpful as an adjunct or, where parents decline an autopsy, in place of autopsy. Consultation between the obstetric and /or neonatal team, perinatal pathologist, and radiologists will help to inform specific situations where postmortem MRI is likely to be most helpful.

Barriers to autopsy

The most common reason for parents to decline a full autopsy is concern about the invasiveness of the procedure. In addition, there are common misunderstandings around autopsy that may lead parents to decline. For example, parents may have concerns that they will not get to see their baby following the examination or that organs will not be returned. Sometimes autopsy is at odds with religious or cultural practices around death. It is important to acknowledge parents' protective instincts towards their baby, address any unfounded concerns, and respond honestly to questions. Other important barriers are belief that the cause is already known. A lack of understanding by healthcare professionals about the value of autopsy can also be a barrier.

When is the best time to discuss options?

The best time to discuss postmortem investigations varies. When a baby dies in utero, the parents should be given time to begin processing the information that their baby has died before discussing postmortem investigations. Discussing postmortem investigations prior to birth may be appropriate, particularly if parents are asking for information about why baby has died. However, some parents can't comprehend that their unborn baby has really died until the baby is born, so mentioning postmortem investigations prior to the birth can be difficult in this circumstance. In addition, many parents are too distressed immediately following the birth to discuss autopsy and require time before initiating this conversation. Each situation is different. The decision to have a postmortem investigation is time-sensitive in that it is ideally performed within 72 hours of birth. However, the timing for initiating the discussion needs to be as sensitive as possible.

Who should ask?

Due to the sensitive nature of the issue, the person most appropriate to initiate a discussion about postmortem investigations is the consultant obstetrician or paediatrician, or the healthcare professional, such as lead midwife or specialist bereavement care midwife, who has an established relationship with the parents. In all cases, the healthcare professional must be familiar with the process of discussing postmortem investigation options with parents' and be competent in answering questions relating to the procedures and

processes in a sensitive and informative manner. The IMPROVE course is recommended for all healthcare professionals providing care for families around the time of a perinatal death. <https://stillbirthcre.org.au/researchers-clinicians/education-and-workshops/>.

Where should the discussion be held?

The most appropriate environment is a quiet, private room away from other patients, relatives, and hospital staff. It is not appropriate to have this discussion in a corridor, shared room, or public waiting room. Some parents may prefer that discussions about postmortem investigations not take place in the presence of their baby.

How do I discuss postmortem investigations with parents?

The healthcare professional should approach the discussion with honesty, integrity, and respect. They should explain all the investigation options, their clinical indications, and why they recommend certain options.

Generally, terms such as fetus, products of conception or termination, should be avoided. Although healthcare professionals should take their cues from the parents in terms of preferred language. If the baby has been given a name, refer to them using their name because this helps to validate the importance of the baby to the parents, as well as the significance of their loss.

Parents should be given time to consider the information before making their decision, and encouraged to discuss with others in their decision-making circle. It is important to understand that parents are likely to have questions and/or concerns about the autopsy process. Parents should be encouraged to express these concerns openly.

Some parents may require information several times as shock and grief may limit the ability to take in and process new and unfamiliar information. Parents should be offered written and/or audiovisual information to refer to following the discussion. However, some may prefer not to have detailed autopsy information, so check before presenting this.

Ask all parents about any cultural, spiritual or religious needs around death and dying that are relevant to the discussion of autopsy. It is important not to make

assumptions about religious or cultural practices based on the parent stated or apparent religion or ethnicity. Cultural and religious requests should be accommodated where possible.

Information you need to have

- Types of postmortem investigations available and the advantages and disadvantages of these.
- Where the baby will go for the autopsy, when it is likely to occur, and when the baby will be returned to the parents.
- Information regarding the presentation of the baby after autopsy, for example, where the incisions will be made, and that they will be delicately repaired and covered with a dressing. Baby will be carefully redressed and wrapped afterwards.
- Confirmation that the baby will be returned to the parents for burial or cremation according to their wishes.
- Confirmation that they will be able to see and hold their baby after the autopsy.
- If any organ, including the placenta, is to be retained for longer, the parents can either delay the funeral, or have a separate burial or cremation of the organs later.
- Process for communicating the results, including contact details of who will arrange an appointment to discuss the results.
- Any associated costs for the autopsy or investigations.

Reporting results

Explain to parents that the final report may not be available for several weeks or months. Although, provisional results are likely to be available sooner. Advise parents of how the results will be communicated to them (e.g. never by text message or by phone with no preparation). This will help to reduce anxiety in the parents as they wait for the final report. Ensure parents understand that sometimes no explanation is found for the cause of death.

Important things to keep in mind when counselling parents

- Treat parents with respect.
- Always be honest.
- Use the baby's name if this is the parents' preference.
- Use a quiet, private place to conduct discussions.
- Introduce details at the individual's pace and use language that parents understand.
- Give parents time to make their decision.
- Offer written and audiovisual material.
- Make a note of what you say and what the parents say.
- Avoid terms such as 'fetus', 'products of conception', and 'termination' to refer to the baby unless parents use these terms first.
- Be prepared for strong emotions. Do not get defensive. Parents may be looking to blame healthcare professionals and may be feeling hostile and angry. These are real emotions that may help bereaved parents maintain a sense of control in an uncontrollable situation. These emotions must be acknowledged by you in an understanding and supportive manner.



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Stillbirth Foundation Australia

Research, education and advocacy to reduce the incidence and impact of stillbirth.

(02) 9557 9070

stillbirthfoundation.org.au

Stillbirth Centre of Research Excellence

Research, resources and information to reduce the number of stillborn babies and provide best possible support for parents and families when a baby dies.

stillbirthcre.org.au

Red Nose

Supporting families whose babies have died through peer support and professional counselling services.

1300 308 307 (Available 24 hours)

rednose.org.au

Bears of Hope

Leading support and exceptional care for families who experience the loss of a baby.

1300 11 HOPE

bearsofhope.org.au

Still Aware

Supporting a safer pregnancy through education and awareness programs nation-wide.

stillaware.org

Pink Elephants Support Network

Providing the latest resources, information, and peer support for anyone impacted by early pregnancy loss.

pinkelephants.org.au