

This information sheet is designed to assist health care professionals with the difficult task of discussing the subject of autopsy with parents who have experienced the death of their baby from causes relating to stillbirth or neonatal death.

Each hospital will have its own policy regarding the process of obtaining autopsy consent and the policy should be consulted.

In some instances state legislation may require an autopsy of a child, such as in the case of unexplained death of an apparently healthy child. When law does not require an autopsy there are still many valid reasons for its conduct.

These include -

- To ascertain cause of death of a stillborn baby or of a neonate.
- To study the effects of treatment during pregnancy, perinatal or neonatal period.
- For research purposes, including genetic studies.
- To ascertain whether there are any implications in respect of future pregnancies.

Parents may find it easier to consent to an autopsy on their baby if they are given information on the value and benefit of the procedure.

When is the best time to talk to parents?

Each parents' individual circumstances need to be considered when broaching the subject of autopsy.

If their baby was stillborn, discussion of autopsy may be appropriate before labour commences. Giving parents written and verbal information whilst encouraging them to ask questions is often helpful. If the mother has had pain relief or anaesthetic, ensure that she is fully aware of the discussion. It may be appropriate to delay this discussion until both parents are fully able to understand and contribute.

Who should talk to parents?

The health care professional who has had the optimum relationship with the parents should discuss the autopsy. This may be the obstetrician, doctor, midwife or social worker. Whoever begins the discussion should have excellent communication and interpersonal skills and should be familiar with the process of obtaining consent and be able to answer questions parents may have concerning the autopsy. It may also be appropriate for the pathologist to speak to the parents.

Where should the discussion take place?

A quiet private room away from other patients and interruptions is the most appropriate environment. Many parents quickly develop strong parental instincts and you need to take into consideration the presence of the baby when conducting the discussion.

Which is the best way to ask for consent?

In seeking consent for an autopsy, the health care professional should approach the parent consultation as a meeting where all are involved.

Honesty, integrity and respect need to be maintained at all times. Some parents may appreciate the support of a family member or friend when the discussion takes place. Being direct and ascertaining the level of information they require will allow for an open discussion without misunderstanding.

Ask parents what they understand about autopsy. Unfortunately many people have seen television programmes which do not always give an accurate portrayal of the procedure. Describing the autopsy as an operation and examination may help alleviate their fears. Explain in plain language the reason for the autopsy and possible benefits for future pregnancies.

Some parents may be altruistic and appreciate the scientific and research benefits of an autopsy for other parents and babies. Others may not consider this relevant to their situation. Parents should be given an opportunity to ask questions and if none are forthcoming, they may be prompted as some parents may feel their questions are trivial or may make them appear ignorant.

It can be helpful to give parents time to discuss the issue between themselves. Further discussion with them may be necessary. Parents may appreciate knowing that they do not have to make an immediate decision. Written information can often be valuable – parents may be able to refer to this when discussing the issue with each other.

Information you need to be aware of

Parents will need to know where in the hospital the autopsy will be conducted and when their baby will be returned to them. Inform them that they will be able to see and hold their baby after the autopsy. Explain changes to the baby's body – balance, colour and temperature. You will need to advise them how and where the incisions will be made.

Ensure the pathologist understands that the parents may wish to see and hold their baby after the autopsy.

Parents will need to know when the results of the autopsy will be available and who they can speak to regarding the results. They will need to understand that interim result may be available at the postnatal appointment but the final report may not be available for many months.

Some parents may wish to speak to other parents who have had similar experience. If so, you may wish to contact SANDS for details.

Things to consider -

- Allow adequate time to talk to parents.
- Answer questions honestly.
- Use the baby's name.
- Do not use the terms foetus, products of conception, termination or other words that detract from the individuality or humanity of their baby.
- Use a quiet, private place to talk to the parents.
- Introduce details at the parents pace and use language they will understand.
- Make a note of what you say and what the parents' responses are.
- Give the parents adequate time to make their decision.
- Treat the parents with respect and as intelligent people.
- Don't become defensive – parents may be angry and looking to blame someone for the death of their baby.
- Ask if they would like a family member or friend with them when discussing the question of autopsy.
- Understand that the parents may need more than one meeting to make a decision.

For further information please visit

www.sandsqld.org.au

or contact the state office
(07) 3254 3422



This information sheet was written in consultation between medical students of the Graduate Medical Course, University of Queensland and bereaved parents of the Stillbirth and Newborn Death Support group.