





Information for parents about the Post-mortem Examination of a stillborn baby

Contact numbers

Post-mortem Coordinator	
	
Doctor	
	
Social Worker	
	
Chaplain	
	

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When your baby is stillborn, expectations, hopes and dreams are shattered and lives are changed. Many parents have initial feelings of shock and confusion when told that their baby has died. Babies are not supposed to die. When they do, it can be devastating, overwhelming, and painful. It is a great sadness that your baby has died.

You may have a lot of questions and there will be decisions to make over the coming days and weeks. Help is available to you; your caregiver(s) will be able to advise you.

This leaflet has been prepared to help you make a decision about a post-mortem examination.

Deciding about a post-mortem can be very difficult. It is important that you make the decision that is right for you and your family. Consider how you and your family will feel in the future. In particular, think about whether a post-mortem would help you and your family to understand why your baby died. Hospital staff will respect and support whatever decision you make about a post-mortem examination.

A post-mortem examination of a stillborn baby can only be undertaken with the parent/s consent.

After reading this information, you may find it helpful to discuss the examination with a doctor or midwife who has cared for you during your pregnancy or a counsellor or hospital social worker. You may also ask for more time to think about it and speak with your partner, family, friends or religious leaders.

What is a post-mortem?

A post-mortem, also known as an autopsy, is a medical examination of a body after death. A doctor undertakes the examination (usually a pathologist or a doctor undertaking specialised training in pathology, under the supervision of a pathologist). Pathologists are doctors who specialise in the study of disease. The post-mortem is carried out with utmost respect and care for the baby's body.

What information can a post-mortem provide?

A post-mortem examination can be a full or a limited post-mortem. These two options will be explained in further detail.

A full post-mortem may:

- Help you to find out more information about medical conditions that may have caused or led to your baby's death.
- Provide information that may confirm or rule out a suspected or unsuspected medical condition. This may be important for you or other members of your family, particularly if the condition is likely to be inherited.

- Provide information to health professionals that may be important in the management of your future pregnancies.
- Indicate conditions that may affect other children within the family or future pregnancies.
- Contribute to the understanding of those who cared for you and provide knowledge that can be used to help other mothers and babies in the future.

A post-mortem examination does not always provide all the answers about a cause of death.

What is a limited post-mortem?

A limited post-mortem may involve either an external examination only; an external examination and some testing on small samples of tissue or blood; or an external examination with an internal examination limited to one particular area.

A limited post-mortem will not provide the same amount of information as a full post-mortem examination and there is always the possibility that something unexpected will be missed. However, a limited post-mortem can provide valuable information.

What happens to your baby at a post-mortem?

A doctor, who is usually a specialist pathologist, performs the post-mortem. The doctor will carefully review the medical record and then undertake a thorough examination of your baby. A full post-mortem examination includes a careful external examination, with measurements, as well as an examination of internal organs. X-rays and photographs may also be taken to further assist in making a diagnosis or to determine the cause/s of death.

A full post-mortem examination is undertaken as though the baby was having an operation. The Pathologist usually makes two openings, one across the back of the head, and another on the front of the body. This allows the pathologist to examine all the major organs and look for anything unusual or any clues to the cause of death. Small samples of tissues and fluids will usually be taken for microscopic examination and other tests, such as looking for an infection, or in special cases for genetic testing.

Sometimes it is necessary for the pathologist to retain an entire organ (usually the brain or heart) for further examination in order to test for signs of disease or injury that are not

immediately apparent. The importance of retaining a particular organ may not be known until the post-mortem is under way. In some cases, a short delay in the funeral arrangements may be enough to have these organs returned to the body before it is released for burial or cremation. If this is not possible, you can decide whether you would like the baby's organs returned to you or a person nominated by you for separate burial or cremation or disposed of in a lawful manner by the public health organisation (usually by cremation). Your doctor will explain in further detail what these processes are.

What happens after the post-mortem?

Once the examination is complete, the baby is washed and the incisions are closed. In most cases, once the baby has been dressed, the effects of the post-mortem are not very noticeable. Normally, after the post-mortem examination you and your family can see and hold your baby again. The appearance and colour of your baby's skin will change after death and the body will feel different to touch. These changes occur naturally after death and are not related to the post-mortem.

Will I have to pay for a post-mortem examination?

There are usually no costs associated with the post-mortem examination. However, it is important that you discuss any potential costs with your doctor or hospital representative before you give consent. If you and not the hospital request the post-mortem, these costs may be related to transport of your baby to a hospital that provides post-mortem examinations for babies. Financial assistance with the funeral costs associated with burial of your baby or of the retained organs may be available through the hospital or Area Health Service.

Why is consent needed for a post-mortem?

Written consent is required from you before a post-mortem of your stillborn baby is carried out. This is a legal requirement. You will be approached by a health professional and asked for your consent to the post-mortem examination. You are free to choose whether or not to give your consent for the post-mortem examination. Your consent must be given in writing.

Because a post-mortem examination may reveal potential genetic information relating to either biological

parent, consent also includes a requirement to find out whether the other parent has no objections.

Alternatively, you may prefer someone else to make the decisions on your behalf, regarding consent for the post-mortem and for the use of tissue removed for the purposes of the post-mortem. There is a form you will be asked to complete if you wish to have someone else to make these decisions on your behalf. You must understand that by doing this, you are allowing another person to make decisions about your baby in this regard.

What happens after consent is given for a post-mortem?

The post-mortem will be carried out as soon as possible after consent has been given. Occasionally, when certain conditions are suspected, samples need to be taken soon after death to enable the appropriate tests to be done. If this is the case your doctor will discuss this with you. If you wish to see your baby prior to the post-mortem, let your doctor or midwife know and arrangements will be made to delay the post-mortem. The post-mortem can be delayed for a short period, but it is recommended within 48 hours.

When will I know the results of the post-mortem?

A preliminary post-mortem report will be available within a few days of the examination but the results of some tests may not be available for twelve weeks, after which the final report will be prepared.

You should consider whether it is best for you to receive the post-mortem report directly from your primary carer, or to receive a copy through your family doctor, or another doctor who can discuss the report with you. It is suggested that you make a time with one of these doctors to discuss the report and any implications it may have for you or your family, as it may contain technical language.

Retaining and using organs and tissue for use for therapeutic, medical and scientific purposes

When your health professional approaches you to give consent for a post-mortem, you may also be asked to consider allowing the use of your baby's organs or tissue for other purposes (such as research, medical or therapeutic purposes) that are not part of the post-mortem examination.

If you consent for your baby's organs and/or tissue being retained for research, medical or therapeutic purposes, the organ or tissue will usually be retained for the period for which it is considered needed. The period of retention of retained organs or tissue for research may be outlined in the specific information on the research project or you can ask for more information.

You do not have to consent to the use of organs or tissue for therapeutic, medical or scientific purposes. A post-mortem can still be carried out, even if you do not consent to the use of tissue for these purposes. If you do give such consent, it applies only to the tissue that was removed for the purposes of the post-mortem examination. It does not mean that any extra organs or tissue will be removed.

Information and bereavement support

If you have any questions, your doctor, midwife, post-mortem coordinator or social worker will try to answer them for you. Health professionals can provide you with contact details of support groups to help you through this sad time.

SIDS and Kids NSW (incorporating SANDS) provide bereavement support services to families who have experienced the death of their baby, for support and information phone 02 9818 8400, toll free 1800 651 186 or information can be accessed via the website www.sidsandkids.org

Summary

- A post-mortem is an important medical examination to help find answers as to why your baby died and to exclude treatable or inherited conditions for future pregnancies.
- It may help to talk to your doctor, midwife, social worker or religious leader or other members of your family, if you have more questions about the post-mortem.
- If you do not want your baby to have a full post-mortem, talk to your doctor about other possible tests, which may give you more information about the cause of the death.
- A post-mortem cannot take place without your written consent.
- The hospital post-mortem will be carried out as soon as possible after consent. Usually this is within 48 hours after death.
- If you wish, you can see and hold your baby again after the post-mortem.
- Results of the post-mortem are usually sent to the doctor within 6-12 weeks