

This pānui is for whānau, families, parents, kaitiaki and caregivers who are trying to decide whether or not to consent to a post mortem to be undertaken on their baby who has died during the perinatal period.

Perinatal deaths are those of a baby of at least 20 weeks gestation. Both stillborn babies and babies who die within the first month of life are included.

Asking a grieving family or whānau to consent to a post mortem of their baby is difficult as it is a time of stress and grief. However, a post mortem can provide additional information as to the cause of death and may assist in preventing future deaths.

What is a post mortem?

A post mortem (also known as an autopsy) is a surgical procedure for gathering information about why your baby died. A pathologist will examine your baby's body to look for signs of infection, disease or something unusual that may explain the cause of death. The placenta will also be examined as it is a very important part of the pregnancy and can often provide useful information about why your baby has died.

You will be asked to give written consent for a full or unrestricted post mortem or a limited post mortem. The difference between full and limited examinations should be explained to you.

The full post mortem involves the following procedures:

- an external examination and general description of the body including measurements and photographs
- an internal examination, general description and weighing of all major organs
- examination of the placenta, membranes and umbilical cord
- small tissue samples taken from the major organs (e.g., the lungs and heart or bones), brain and placenta for examination under a microscope before the organs are returned to the body

- an X-ray to look for bone abnormalities
- blood tests as well as bacterial and viral swabs to look for infection
- storage of tissue/fibroblasts/DNA samples and a karyotype if genetic diseases are suspected.

A limited post mortem may involve any but not all of the above procedures. Usually the term is used to describe the examination of one particular organ such as the heart or the kidneys. A limited post mortem still requires a surgical operation.

If a baby is suspected of having a genetic metabolic disorder, investigations may also include:

- the collection and storage of blood, urine and skin samples before the baby dies
- the collection of liver, muscle and cerebro-spinal fluid samples as soon as the baby dies
- family history, clinical photographs, skeletal surveys and parental investigations.

What is the value of a post mortem?

On most occasions, the post mortem will help to answer questions such as:

- Why did your baby die?
- Is a death like this likely to happen again?
- Would different care or treatment be beneficial during a future pregnancy?

For you, and your whānau or family, the post mortem examination may help to:

- gather new information about your baby's death
- confirm an antenatal diagnosis or suspected disorder
- identify disorders that may benefit from treatment in future pregnancies
- dispel fear and uncertainty.

Your baby's post mortem examination may also help health professionals and researchers to identify other babies who may be at risk of dying from the same disorder, identify and gain a better understanding of some conditions, improve maternity services and in some cases assist in the training of pathologists.

Sometimes, when a perinatal death is sudden and unexpected, or there are questions about events around the time of death the baby's death may be reported to a coroner. Once this happens, the coroner is legally obliged to establish the cause of death and has the authority to order a post mortem. If this happens, the post mortem must occur. The coroner, usually through the Police, will contact you and your whānau/family to explain the process, findings and implications of their examination. If your baby is stillborn, it is unlikely the coroner will be involved. In certain circumstances, the immediate whānau/family can object to a coroner's request for post-mortem but such objections must be lodged within 24 hours of receiving the Coroner's notification. For further information see *When Someone Dies: A guide to the Coronial Services of New Zealand* (www.justice.govt.nz/coroners).

When and where does a post mortem happen?

The post mortem examination itself usually takes between two and three hours. Every effort will be made to find a time that is convenient for both the whānau/family and pathologist. Sometimes the pathologist will travel from a main centre to do a perinatal post mortem examination but, if the baby dies outside a main centre, it is usually the baby who has to travel. Please be aware that when your baby travels on a plane, it will be in the hold in a secure container. You can negotiate the travel details of your baby with the airline, but you will need to contact the Cargo Division.

The health system covers the travel costs of babies and pathologists but not whānau or family members.

A perinatal post mortem should be performed by a perinatal or paediatric pathologist but this is not always possible. Some tissue samples also need to be collected within 4 to 12 hours of death. This is particularly necessary if the cause of death is thought to be an inherited metabolic disease. In these cases, it is important to do the post mortem as soon as possible after the death.

The baby is usually returned to their whānau/family on the day of post mortem. Although whānau/family members are not allowed to be present at the post mortem itself, they can accompany their baby to and from the examination and a nearby room is usually available to wait in.

What happens to the samples that are taken?

Any tissue samples taken at post mortem cannot be used for research purposes unless you give your consent and there is ethical approval. Indefinite storage means that cause of baby's death can be reviewed years later, particularly if there are similar deaths in the whānau or family.

If you signed the consent form and agreed to storage of samples, these will be stored by the hospital and could be re-examined if you or someone in your whānau or family has problems with another pregnancy. In some cases, the samples could be used for the training and education of students, hospital staff and pathologists or used in research projects (with ethical approval) to learn more about the nature of some diseases.

There are strict rules for protecting a donor's identity when tissue samples are used for teaching or research purposes. In most cases, it is photographs of the actual samples, or microscope reports that are used. It is also very rare for tissue samples to be used in research. Consultation is required for ethics committee approval to access post mortem data and tissues for any research use (even if individuals have consented to future research use).

If you do not want your baby's tissue stored or used for later diagnostic purposes, you can ask for the all samples including slides to be cremated or returned to you after they have been fully assessed by the pathologist and a report finalised, or at some later stage. If cremation takes place, you can also ask for copy of the cremation certificate.

Alternatives to post mortem

If you decide against post mortem, other types of examinations can help to gather information about the reasons why your baby died. For example, you may prefer to give consent for:

- an external examination by a perinatal pathologist, geneticist, obstetrician, midwife, paediatrician, neonatal nurse practitioner or other health professional
- clinical photographs
- full body X-ray or babygram
- magnetic resonance imaging (MRI)
- needle biopsy of a particular organ or tissue
- ultrasound of specific organs.

None of these investigations will provide information that is as accurate as that obtained by a post mortem examination but they provide more information than no examination at all. Some of these procedures may not, however, be available in your hospital.

Informed consent

The perinatal post mortem examination is not compulsory. Kei a koe te tikanga! The choice is yours. Many health professionals encourage whānau/families to give consent for a perinatal post mortem examination because of the additional information it can provide. Sometimes the information obtained changes the final diagnosis. This is true for both stillborn babies and babies who die after a few days or weeks of life.

The health professional who asked you for permission

to undertake a post mortem on your baby should fully explain the examination process and the options or alternatives for consent. They must obtain written consent from you unless it is a coroner's case.

Most clinicians will ask you to sign two forms for:

- consent for post mortem which usually includes consent for photographs to be taken
- consent for storage and use of tissue samples for training and/or research purposes.

Organ retention rarely happens in New Zealand and should only occur with your written consent unless ordered by the coroner.

As parents, family or whānau considering or consenting to a post mortem, you are entitled to:

- information about the process and procedures for dealing with perinatal deaths
- a full explanation and written information about the post mortem examination and options for consent
- an opportunity for personal discussion with a senior clinician and/or the coroner (if involved)
- information about what will happen to your baby and how your baby will look following the examination
- a copy of the post mortem report
- a consultation with a clinician to discuss with you the implications of the post mortem report for and answer any questions you may have
- a letter from the clinician summarising the consultation in plain language
- request the return or disposal of all samples, scan reports and clinical photographs.

Making your decision

Giving permission for your baby to have a post-mortem may challenge cultural beliefs and interfere with the process of tangihanga. Whānau, for example, may be reluctant to consent to an autopsy especially when baby is stillborn. For some whānau, there maybe concerns that perinatal post mortem is becoming a routine medical procedure, rather than only performed when absolutely necessary.

Talk to your family/whānau or with someone who can provide advice on tikanga. You do not have to make this decision on your own. The health professional talking with you about consent can also provide advice on how to access support.

Further information

If you would like more information or background reading, see the PMMRC website: www.pmmrc.health.govt.nz.

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