

The post-mortem examination for babies less than 20 weeks gestation

**Welcome to the National Women's
Tena Koe Noho Ora Mai**

Introduction

This leaflet is to help parents having to make a decision about whether their baby should have a post-mortem examination. We recommend parents consider a post-mortem. We realise this is a difficult decision for many parents. However, a post-mortem could help you, and also provide useful information for the health professionals caring for you during any future pregnancies.

After reading this leaflet you may find it helpful to discuss the post-mortem examination or other questions you have with the doctor, midwife or nurse caring for you and/or your baby. Others who are also available for you to meet with include the chaplains, social worker, genetic counsellor and Maori Health Advisor.

Why is a post-mortem recommended?

It can be important to parents to find out more information regarding their baby's death. A post-mortem examination may determine why the baby died. It could also exclude diseases or conditions which the doctor or parents suspect may have contributed to a baby's death. Knowing more about your baby's death can help in the grieving process, although there is no guarantee of a diagnosis.

Certain tests performed during the post-mortem examination can provide information that may confirm or rule out a genetic condition.

As well as being important for parents, this information may also be important to other family members, particularly if the condition is likely to be inherited. The post-mortem may identify problems which could influence the way care and monitoring is provided if you have any future pregnancies.

In some cases, a post mortem may not provide all the information necessary to make a diagnosis or understand all the factors contributing to the death of your baby. However, it may be able to help eliminate or lessen some of the questions and 'whys' that you have. Sometimes, even when a cause of death is identified, the doctor may not be able to tell you why your baby had that particular medical condition.

At all times your baby will be treated with dignity and respect. Personal items such as clothing, jewellery and toys will be kept with your baby.

Giving Consent for a post-mortem

In most circumstances a post-mortem is not legally required. However, a doctor will usually recommend a post-mortem be carried out to obtain extra information. You can choose whether or not to give your consent to the post-mortem examination. Your consent needs to be given in writing.

It can be difficult for parents to think about whether or not to give their consent. While the post-mortem does not usually have to be done immediately, some tests, which are carried out during the post-mortem, may need to be done within 48 hours of your baby's death.

What happens if I don't give consent?

If you do not consent to your baby having a post-mortem you may be asked if you will consent to an external examination by the Pathologist. This does not involve an incision (cut) and can sometimes provide helpful information. Scan and/or x-ray and clinical photographs of the baby are recommended. You will sometimes be asked to consent to an examination of the placenta/whenua. This can produce helpful information. Your written consent is required.

The post-mortem procedure

A doctor who is a Perinatal Pathologist specialising in the post-mortem examination of babies and children usually carries out the procedure at the Auckland City Hospital mortuary. You will be informed if the post-mortem is to be carried out by another pathologist, or at a different location. In that case the mortuary assistant will accompany the baby.

The doctor who carries out the post-mortem will undertake a thorough examination of the baby. A full post-mortem includes an external examination as well as an examination of internal organs. During a partial post-mortem only part of the examination or some of the tests are undertaken. A clinical geneticist may examine the baby to look for features, which can suggest an underlying diagnosis. This may be of help when counselling you about future pregnancies.

Full post-mortem

A full post-mortem includes a surgical procedure like an operation. Small samples of tissue and fluids are removed and sent to the laboratory for microscopic examination and further tests. These samples are particularly important in the investigation of infection and genetic conditions but may not be able to

be returned to the body. You may be asked if you consent to tissues being kept for possible testing in the future. As with any operation, after the procedure the incisions are carefully closed.

Partial post-mortem

Some parents choose to consent to a partial post-mortem. This may involve:

- an external examination with an internal examination limited to the site of an operation if the baby has had surgery, or limited to a part of the body such as the heart if a heart abnormality has been seen
- an external examination and some tissue samples
- an external examination only
- X-rays, scans and photos may also be useful in making a diagnosis.

Consenting to a partial post-mortem provides some information that may be helpful but may not be complete.

The post-mortem report

Findings from the examination are recorded in the post-mortem report. A summary verbal report may be available within 24 hours of the post-mortem examination, although sometimes it can take longer. Depending on the type of tissues examined and the tests ordered by the doctor, the final results of the post-mortem may take up to twelve weeks. This means the full report may take from eight to twelve weeks to complete.

At National Women's follow up appointments are made to discuss the results with you when they are available. If you come from out of Auckland arrangements can be made for you to return to National Women's to discuss the results or if you prefer, they can be sent to your GP or LMC (Lead Maternity Carer). It may be helpful to write down questions that you would like to ask during this appointment.

Funeral Arrangements

There is a legal requirement for burial or cremation arrangements for babies born over 20 weeks. Babies under 20 weeks may have a funeral, but there is no legal requirement for one. Social workers are available to advise and assist parents with funeral arrangements.

Information for Maori families/whanau

You are able to have access to pepe at any time until you leave the hospital. Whanau can arrange to stay to keep pepe warm while the post-mortem takes place. The mortuary is blessed (karakia) on a regular basis by a Chaplain. Most whanau like to conduct their own karakia in their room in private once pepe's post-mortem is finished. If whanau are waiting for Tangihanga to proceed, arrangements can also be made to release pepe as quickly and smoothly as possible.

Useful Contacts

- **National Women's Allied Health (Social Work and Counselling Service)**
ph (09) 307 4967 x 25967 or fax (09) 631 0792
- **Northern Region Genetic Service**
Based at Auckland Hospital (covers Auckland and Waikato areas)
ph (09) 307 4949 ext 25870 or 0800 476 123 fax (09) 307 4978
- **National Women's Health Information Unit**
Based on Level 9 Atrium, the Unit provides free information on health matters. Phone (09) 307 4949 ext 25678 or email hiws@adhb.govt.nz if you want information posted to you.

Support Groups

(Contact your local Citizens Advice Bureaux for local support groups if you come from out of Auckland).

- **Stillbirth and Neonatal Death Support Groups (SANDS)**
SANDS offers an excellent range of information and support services for bereaved parents.
<http://www.sands.org.nz/>
- **Twin and Multiple Birth Loss**
Please see the Twin and Multiple Birth loss website:
<https://twinlossnz.wordpress.com/>