

Stillbirth - Management and Investigation

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Functional Sub group Corporate Administration - Information and data
Clinical/ Patient Services - Maternity
Clinical/ Patient Services - Baby and child
Clinical/ Patient Services - Human Tissue

Summary Area Health Services (AHSs) are required to have a local policy for the management and investigation of stillbirth based upon the Clinical Practice Guideline for Perinatal Mortality Audit produced by the Perinatal Society of Australia and New Zealand.

Replaces Doc. No. Stillbirth Investigation - Guidelines [GL2005_013]

Author Branch NSW Kids and Families

Branch contact NSW Kids & Families 9391 9503

Applies to Area Health Services/Chief Executive Governed Statutory Health Corporation, Board Governed Statutory Health Corporations, Ministry of Health, Public Hospitals

Audience Maternity clinical staff, obstetricians, midwives, nurses, pathology, paediatricians, GPs

Distributed to Public Health System, Divisions of General Practice, Ministry of Health, Public Hospitals, Private Hospitals and Day Procedure Centres, Tertiary Education Institutes

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Status Active

Director-General

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THE MANAGEMENT AND INVESTIGATION OF A STILLBIRTH

This Policy Directive replaces GL2005_013.

This Policy Directive should be read in conjunction with:

- PD2006_006 Deaths- Perinatal – Hospital procedures for review and reporting of perinatal deaths
- PD2005_138 Deaths Register
- PD2005_341 Human Tissue - Use/Retention Including Organ Donation, Post-Mortem Examination and Coronial Mat
- PD2005_406 Consent to Medical Treatment – Patient Information
- PD2007_017 - Deceased Persons In Health Facility Mortuaries & Management of Health Facility Mortuaries
- The Australian Health Ministers Advisory Council The National Code of Ethical Autopsy Practice 2002.

This Policy Directive is based on the *Clinical Practice Guideline for Perinatal Mortality Audit* produced by the Perinatal Society of Australia and New Zealand. The complete guideline can be found at

<http://www.psanzpnmsig.org/guideline.asp>

A stillbirth¹ is the complete expulsion or extraction from the mother of a product of conception of at least 20 weeks gestation or 400grams birth weight that did not, at any time after delivery, breathe or show any evidence of life such as a heartbeat (see Glossary Appendix 1).

In the case of a stillbirth where it is unclear whether the gestational age is less than 20 weeks at the time of delivery the fetus is to be weighed. If the weight is 400 grams or greater the fetus must be registered as a stillbirth.

1. General considerations

- 1.1 Every hospital must have a local policy for the management of the family, care of the stillborn baby and the investigation of the stillbirth.
- 1.2 The local policy must clearly articulate the processes for the distinct identification of the body of the stillborn baby and comply with PD2005_138 Deaths Register.
- 1.3 The local policy must include procedures for the transfer of the stillborn baby between and within maternity services and the mortuary. This must be documented in the baby's medical record.

2. Documentation

- 2.1 There must be full documentation of the clinical circumstances of the stillbirth.

¹ NSW Health NSW Mothers and Babies 2005 NSW Public Health Bulletin Volume 18 Number S-1 2007

2.2 Clinicians must undertake and document a comprehensive maternal and family history.

2.3 All clinical examinations of the mother, baby, placenta, membranes and cord must be documented.

3. Consent

3.1 Clinicians must comply with PD2005_403 Consent to Medical Treatment – Patient Information

3.2 Consent for all investigations must be documented in the maternal record. This includes the histological examination of the placenta and membranes.

3.3 Consent for the post-mortem examination, which clearly outlines the extent of the investigation, must be recorded on an approved consent form.

3.4 Clinicians are also required to ascertain that the other parent has no objections and this must be documented in the maternal record.

4. Respect

4.1 The deceased baby must be treated with the same respect as a live baby.

4.2 The different cultural and religious practices and rituals associated with death must be respected.

4.3 Parents must be given time to make decisions and be informed about how much time can be spent with the baby in keeping with hospital policies and procedures.

5. Information

5.1 Parents must be given:

5.1.1 Written information using parent friendly language (for example to not use terms such as fetus)

5.1.2 Verbal and written information about birth registration

5.1.3 The leaflet *Information for Parents about the Post-mortem Examination of a Stillborn Baby*. (Appendix 2). This leaflet is available in print and can be downloaded from the Department of Health website in English and several other languages.

5.1.4 Written information regarding available support services

- Up-to-date information on genetic counseling services availability, locations, access and educational resources is available from:

NSW Genetics Education Program
PO Box 317
St Leonards NSW 2065
Ph (02) 9926 7324
(02) 9906 7529

- Information and support is available from SIDS& Kids NSW
Phone (02) 9818 8400
- 24 hour bereavement line 1800 651 186 or
http://www.sidsandkids.org/nsw/bereavement_support.html

5.1.5 Information about expectations for their grief. Mothers with mental illness or risk factors for psychological disturbance must have an appropriate mental health referral

5.1.6 Expectations for a 6 week check up and that there may be other babies present

6. Birth options

6.1 Caesarean section must only be considered in the presence of compelling maternal risk factors.

7. Creating memories

7.1 Parents must be informed that:

7.1.1 They can hold, undress and bath their baby

7.1.2 Mementos are helpful for long-term grief outcome

7.1.3 Baptism or blessing can be arranged through the hospital

8. Investigation of stillbirths

8.1 The following Investigations must be undertaken where parental consent has been granted, for all stillbirths where there is no obvious cause. Consideration should be given to omitting screening tests when the cause of death is absolutely clear.

8.1.1 At diagnosis of a fetal death:

- Ultrasound scan to detect possible fetal abnormalities and to assess amniotic fluid volume
- Amniocentesis (where available and warranted) for cytogenetic and infection investigations
- A low vaginal and peri-anal swab, to culture for anaerobic and aerobic organisms
- Maternal blood must be collected for:
 - Full blood examination

- Serology for cytomegalovirus, toxoplasmosis parvovirus B19
- Rubella and syphilis if not already undertaken in the pregnancy
- Blood group determination and antibody screen if not already undertaken in this pregnancy
- Kleihauer –Betke test
- Renal function tests including uric acid
- Liver function tests
- Bile acids
- HbA_{1c}
- Anticardiolipin antibodies
- Lupus Anticoagulant; and
- Activated protein C (APC) resistance

8.1.2 Following birth

- External examination of the baby (by a Perinatal pathologist, neonatologist or a paediatrician where possible)
- Clinical photographs
- Surface swabs (ear and throat) for microbiological cultures
- Babygram or ultrasound (where an post-mortem is refused)
- Post-mortem examination
- Blood samples from the cord or cardiac puncture for investigations of infection
- Blood samples for chromosomal analysis
- Detailed macroscopic examination of the placenta and cord
- Placental microbiological cultures
- Placental and amnion biopsy for chromosomal analysis
- Placental histopathology

8.2 Further investigation for thrombophilia must be undertaken 8-12 weeks after the birth where:

8.2.1 fetal death is associated with:

- fetal growth restriction,
- preclampsia,
- maternal thrombosis and/or there is maternal family history of thrombosis

8.2.2 the stillbirth remains unexplained following the standard investigations or

8.2.3 tests for thrombophilia were positive at the time of the intrauterine fetal death (IUFD) as follows:

- Anticardiolipin antibodies; and Lupus anticoagulant repeated if positive at the time of the intrauterine fetal death or initial testing if not previously undertaken
- APC resistance if it was not undertaken at birth

- Factor V Leiden mutation if APC resistance was positive at birth
- Fasting Homocysteine and if there is a positive test for MTHFR gene mutation
- Protein C and S deficiency
- Prothrombin gene mutation 20210A

9. Post-mortem

- 9.1 Clinicians must discuss the value of a post-mortem examination with the parents in all cases of a perinatal death and seek consent for the procedure. Where possible, this must be a senior clinician who has established a rapport and understanding with the parents.
- 9.2 The clinician approaching for post-mortem consent must discuss:
- 9.2.1 the value of the post-mortem examination
 - 9.2.2 options for a full, limited or stepwise post-mortem examination
 - 9.2.3 the issue of retained tissues
 - 9.2.4 the possibility that the information gained may not benefit them but may be of benefit to others.
- 9.3 When consent has been obtained for specific organ/s to be retained for further examination, the parents must be offered the choice between delaying the funeral until the organs can be returned to the body or specifying their preferred method of organ disposal.
- 9.4 There must be no charge to a parent where the hospital requests the post-mortem.
- 9.5 The Guidelines on Autopsy Practice produced by the Royal College of Pathologists² should be used for guidance on minimum standards until guidelines for Australia and New Zealand are developed.
- 9.6 Guidelines for post-mortem reports produced by the Royal College of Pathologists must be used as a guide for reporting of perinatal post-mortem examinations.
- 9.7 A request for the General Practitioner to receive a copy of the report (including the PLR if available) must be explicit on the request form, as they are the main care provider on discharge.
- 9.8 The parents are not to be unduly rushed into making a decision for post-mortem, but should be advised that ideally a post-mortem should take place within 48 hours of birth.

² The Royal College of Pathologists. Guidelines on Autopsy Practice: report of a working group of the Royal College of Pathologists. In. London: Royal College of Pathologists; 2002

10. Placenta, membrane and umbilical cord

- 10.1 The placenta, membranes and cord must be examined thoroughly following the birth and findings documented in the mother's notes.
- 10.2 Clinicians must discuss the value of pathological examination of the placenta, membranes and cord.
- 10.3 Where parental consent has been granted, the placenta, membrane and cord must be sent as soon as possible, fresh and unfixed, for pathological examination by the perinatal/paediatric pathologist, once samples have been taken for cytogenetics and microbiology
- 10.4 Where parents are ambivalent about pathological examination, the placenta, membrane and cord should not be disposed of immediately in anticipation that they may change their minds.

11. Funeral arrangements

- 11.1 Parents must be advised that there is no urgency to organise a funeral and that they have continued access to baby prior to the funeral, depending on requested investigations such as post mortem

12. Health professionals

- 12.1 Clinical leaders must promote formal and informal educational opportunities for clinicians on: post-mortem examination procedures; the potential benefits of an post-mortem examination; compassionate counseling and obtaining parental consent; and address specific local barriers to the conduct of perinatal post-mortem examination
- 12.2 Area Health Services should provide all clinicians with specific training in bereavement counselling.
- 12.3 Area Health Services should make debriefing/support services available to staff working with perinatal death.

Appendix 1

Glossary of Terms

AMNION

A thin but tough extraembryonic membrane of reptiles, birds and mammals that lines the chorion and contains the fetus and the amniotic fluid around it, in mammals it is derived from trophoblast by folding or splitting

AMNIOTIC FLUID

The fluid that surrounds the developing fetus within the amniotic sac. This environment cushions the baby from injury and plays an important role in fetal development

APC RESISTANCE

Activated protein C resistance.

AUTOPSY

A surgical procedure post-mortem, which involves the examination of body tissues (including internal organs), often to determine cause of death

CHORION

Extraembryonic membrane surrounding the embryo of amniote vertebrates. The outer epithelial layer of the chorion is derived from the trophoblast

CHROMOSOME ANALYSIS (KARYOTYPE)

A picture of the chromosomes of an individual arranged in a standard manner so that abnormalities of chromosome number or form can be identified

*Perinatal Society of Australia and New Zealand Perinatal Mortality Audit Guideline
Section 1: Overview and summary of recommendations; Appendix 2*

CONFIDENTIAL ENQUIRY

Enquiry by peer groups, including experts in the field, into the cause of, and the factors surrounding, a death, where strict confidentiality is observed at all stages of the process. It is a form of clinical audit, with the important difference that the feedback or 'closing of the audit loop' is via reports on the general findings, and not direct feedback to those involved with the individual cases subjected to enquiry.

CESDI

Confidential Enquiry into Stillbirths and Deaths in Infancy

CMV

Cytomegalovirus.

CONGENITAL ANOMALY

A physical malformation, chromosomal disorder or metabolic abnormality which is present at birth.

CYTOGENETICS

The study of the structure of chromosomes; cytogenetic tests are carried out to detect any chromosomal abnormalities associated with a disease; these help in the diagnosis and selection of optimal treatment

Title: The Management and Investigation of a Stillbirth

DIC

Disseminated intravascular coagulation is an acquired disorder of clotting characterised by intravascular fibrin formation which occurs in the course of a variety of conditions including sepsis and pre-eclampsia.

DCT

Direct Coombs Test

FETAL DEATH

See Stillbirth

HAEMOGLOBIN A1C

The substance of red blood cells that carries oxygen to the cells and sometimes joins with glucose. Because the glucose stays attached for the life of the cell (about 4 months), a test to measure haemoglobin A1C shows what the person's average blood glucose level was for that period of time

HISTOLOGY

The study of cells and tissue on the microscopic level

HISTOPATHOLOGY

This is the science concerned with the study of microscopic changes in diseased tissues

INTRAUTERINE FETAL DEATH (IUFD)

Death of a fetus in utero after 20 weeks gestation or at birth weighing at least 400gms. See STILLBIRTH

IUFD

See INTRAUTERINE FETAL DEATH

KARYOTYPE

The complete set of chromosomes of a cell or organism; used especially for the display prepared from photographs of mitotic chromosomes arranged in homologous pairs

KLEIHAUER-BETKE

A blood test performed on the mother's blood to identify whether substantial bleeding has occurred from the fetus into the mother's circulation

METHYLENETETRAHYDROFOLATE REDUCTASE (MTHFR) GENE

The MTHFR gene provides instructions for making an enzyme called methylenetetrahydrofolate reductase. This enzyme plays a role in processing amino acids (the building blocks of proteins)

MTHFR

Methylenetetrahydrofolate reductase.

PATHOLOGY

The branch of medicine concerned with disease, especially its structure and its functional effects on the body

PCR

Polymerase Chain Reaction.

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POST-MORTEM

After death. Hence a post-mortem examination may not include an autopsy.

PSANZ

Perinatal Society of Australia and New Zealand.

PSANZ-PDC

Perinatal Society of Australia and New Zealand – Perinatal Death Classification.

PSANZ-NDC

Perinatal Society of Australia and New Zealand – Neonatal Death Classification.

RANZCOG

Royal Australian and New Zealand College of Obstetricians and Gynaecologists.

RCP

Royal College of Pathologists.

RCPA

Royal College of Pathologists of Australasia.

SADFA

Support After Fetal Diagnosis of Abnormality.

SANDS

Stillbirth And Neonatal Death Support Group.

SLE

Systemic lupus erythematosus.

STILLBIRTH (Fetal Death)

Death prior to the complete expulsion or extraction from its mother of a product of conception of 20 or more completed weeks of gestation or of 400 g or more birthweight. The death is indicated by the fact that after such separation the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles.

Appendix 2

INFORMATION FOR PARENTS ABOUT THE POST-MORTEM EXAMINATION OF A STILLBORN BABY

When your baby is stillborn, expectations, hopes and dreams are shattered and lives are changed. any 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?

The purpose of a post-mortem examination is to find any medical condition which may have contributed to or led to your baby's death.

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 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 will usually make 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 usually 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 in so doing 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.

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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 <http://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

Contact numbers

Post-mortem Coordinator _____

Phone _____

Doctor _____

Phone _____

Social Worker _____

Phone _____

Chaplain _____

Phone _____