



the women's
the royal women's hospital

*P*ost mortem
*F*amily information booklet

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This booklet was produced by both medical and community staff at the Royal Children's Hospital and The Royal Women's Hospital, in partnership with parents and families at both hospitals, and representatives from the Miscarriage Stillbirth and Newborn Death Support (SANDS), and SIDS and Kids Victoria.

We are very grateful to these people who volunteered their time and worked very hard to produce this publication.

The booklet will be evaluated. If you have any comments that you would like to make about the booklet, please contact:

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*P*ost mortem examination of babies and children

The decisions following the death of your child are some of the most difficult you will ever have to make. The choices you make will affect you and your family very deeply both now and in years to come. We understand that the decision about a post mortem may not be an easy one. Some parents will find it helpful to know as much as possible about why their child died while others may prefer not to know any more than they already do.

You have a right to any of the information that a post mortem can provide.

We hope this booklet will help you decide whether or not to give your permission for a post mortem examination (also called a post mortem, autopsy or necropsy) on your baby or child. This booklet should be read together with the post mortem consent form.

If your child's death has been referred to the Coroner some aspects of this booklet will not relate to you. There is specific information that has been produced by the Coroner that you may find helpful.

If there is anything you are not sure about, or would like explained in more detail, please ask the person who gave you this booklet. It is important that you have enough information before deciding about a post mortem and are given enough time to decide.

You may want to talk to your close family, your friends or your religious representative. There are also people at the hospital you can talk to, such as your doctor, nurse or midwife, a social worker or pastoral worker.

The doctor who will carry out the post mortem can also give you more information if you wish. This doctor is called a pathologist.

In this booklet we will refer to 'your child' even if your child is a very small baby.

It is important that you have enough information before deciding about a post mortem and are given enough time to decide. You may want to talk to your close family, your friends or your religious representative. There are also people at the hospital you can talk to.

*W*hy a post mortem?

The examination may:

- Help to explain your child's illness or why they died. This may make it easier for you to come to terms with your child's death.
- Help to explain problems that happened during the pregnancy. This can be important to assist in preventing problems in future pregnancies.
- Find problems that may happen again to another child. Some illnesses in children may be genetic and you or other members of your family may want to know about these.
- Rule out diseases or problems that you may be worried about.
- Provide vital information about new investigations or treatments and help doctors to treat other patients with the same kind of illness.

The most important reason for doing a post mortem is to give more information to you and your family.

Sometimes though, even the most detailed post mortem does not show the cause of death or answer all your questions.

*W*hat is a post mortem?

A post mortem examination includes a range of tests that are done when a person has died to try and understand what may have caused their death.

The examination is usually performed within days of the person dying. If it is important to you or your family that the funeral happens quickly, you should talk about it with the person who gave you this booklet.

Post mortems have been carried out for centuries and are one of the most important ways we have to learn about disease and to improve treatments. Even today, post mortems give us information about a person or a disease that wasn't known about before. With this information we can improve medical care for future patients.

A more detailed explanation of post mortems can be found later in this booklet.

*W*hat if my child is to be examined by the Coroner?

A child's death may need to be referred to the Coroner for a variety of reasons. If your child's death is referred to the Coroner and you do not want the Coroner to do a post mortem, you will need to lodge an objection. If you wish to object, talk to your doctor about what you need to do. The doctor can give you the forms that you will need and a booklet about the Coroner.

The Coroner will take your concerns very seriously and be respectful of your feelings. Finally though it is the Coroner's decision if the post mortem is to go ahead.

The Coroner's details can be found in the contacts section of this booklet on page 21 .

The information in the rest of this booklet does not refer to post mortems that have been referred to the Coroner.

*W*hat are my options?

Giving your permission

Your doctor will ask for your permission to do a post mortem. If you agree to this your doctor will give you a Medical Certificate of Death before the post mortem so that you can make arrangements for the funeral. The post mortem can only go ahead with your written agreement.

You should give your agreement only after the purpose of the post mortem has been explained to you.

You should be given the chance to ask questions and be given enough time to make your decision.

Saying No

You do not have to agree to a post mortem. Even without a post mortem, your doctor will still try to answer all your questions as best as possible. You may decide not to know any more about the reasons for your child's death and to proceed with the funeral arrangements.

What if I change my mind?

You may have already agreed to a post mortem or you may have said you do not want a post mortem.

If you feel that you would like to change your decision, you may be able to do so within a certain amount of time. It's OK for you to feel undecided at this time but if you have any doubts you should speak to your doctor as soon as possible.

Things to remember

- The post mortem can only go ahead with your permission.
- You don't have to agree to anything until you feel that all of your questions have been answered.
- You can ask your doctor how long you have to think about it.
- If you change your mind either way, talk to your doctor as soon as possible.

The post mortem can only go ahead with your permission. You can change your mind either way, but it is important to speak to your doctor as soon as possible.

*I*f I agree what will happen then?

You and your doctor will make a decision about how detailed the examination should be. You will decide on one of the following options:

- a full examination of all of your child's organs, tissues and body fluids, this is called a full post mortem
- a limited examination that will focus only on very specific areas of your child's body, this is called a limited post mortem
- an external examination only.

A **paediatric pathologist**, who is a doctor that specialises in diseases in babies and children, will do the examination. Sometimes the examination will be done by a pathologist in-training, but only under close supervision.

The following section will explain what the different procedures are and what your options are once you have made a particular decision.

Full post mortem

In a full post mortem, the pathologist will remove all of the organs and examine them very thoroughly. The pathologist will also take specimens of body fluids and tissue samples. This type of post mortem can provide the most detailed information. A full post mortem is described in more detail later in this booklet.

You may decide not to proceed with a full post mortem. If that is the case you may be asked to think about a limited post mortem.

Limited post mortem

In a limited post mortem, the pathologist will only remove and examine specimens of body fluids, tissues and organs in the areas that you specify. A limited post mortem cannot give as much information as a full post mortem because:

- stillborn and newborn babies can have problems in many organs or tissues, and any or all of these could have caused your child's death.
- in children with malformations or birth defects it is very important to know if there are other problems present, as this can help decide if other children in the family might be affected.

External examination

In some cases it won't be necessary to do a post mortem that involves surgery. Or it may be your decision that you do not want your child's body to be operated on. In that case a very limited post mortem can be done that involves careful observation of the body, including x-rays and photographs. No specimens of body fluids, tissues or organs are taken in this examination.

Things to remember

- If you agree to a post mortem it is still up to you how detailed the examination will be.
- You can talk to your doctor about what kind of post mortem is necessary to find the cause of your child's death.
- Your doctor can explain all of your options and help you with your decision but the doctor will always respect what you decide.
- If there is anything you still don't understand you can ask your doctor to explain it again.

*T*reatment of tissues and organs after a post mortem

In this booklet the word ‘tissue’ refers to a small sample that is taken from the body. It might be a sample of an organ or a sample of a body fluid like blood. The word ‘organ’ refers to a whole organ such as the brain or heart.

*W*hat happens to the tissue that is taken after a post mortem is completed?

When a full or limited post mortem is done, small samples of tissue must be taken for examination under the microscope. The samples are small blocks of tissue and are usually preserved in wax. Afterwards the wax blocks are stored in the pathology department. We are required by law (the national accreditation standards) to keep such ‘blocks’ and ‘slides’ for 23 years. Storing tissue samples is also important and useful because:

- the tissue can be looked at again if your child’s illness is later questioned or if there is new knowledge about the disease that might help to further explain your child’s illness
- the education and training of medical students and doctors is helped if they can see for themselves what happens inside the body when there is disease
- research using stored tissues and organs can help in the diagnosis and treatment of future patients.

*W*hat happens to the organs that are taken after a post mortem is completed?

Usually all organs are returned to the body before the funeral. Sometimes though, if you and the doctor agree to certain examinations, it may be necessary to keep the organs for a longer time. There may also be other reasons that the doctor might ask you about keeping a particular organ. The following information should help you understand when that might happen and why.

1. Examining the brain

Because the brain is very soft it is very difficult to examine. If a pathologist wants to examine the brain it will need to be treated or 'fixed'. It can take up to two weeks before the brain is ready to be tested.

2. Investigating certain conditions

Other organs with certain conditions may require a prolonged examination. This is very rare.

3. Congenital abnormality

If your child had a specific congenital abnormality such as congenital heart disease, there may be teaching or training benefits in keeping the organ.

You may tell us exactly which organs we may or may not keep or you can let the pathologist decide. You may also decide what should happen to them afterwards. If you agree to the pathologist keeping any organs, you need to tell us what to do with them when the examination is completed. Your choices are:

- organs may be returned to your child's body before the funeral (this may delay the funeral for two to four weeks)
- if your child is buried or cremated before the organs are restored to the body, you can give the organs to your funeral director who will cremate or bury the organs according to your wishes. You will incur additional fees for the cremation of the organs as it is considered a separate cremation
- the hospital may dispose of the organs in a lawful and respectful manner. This means the hospital will organise for the specimens to be cremated at a cemetery and for the ashes to be scattered in the cemetery's memorial garden. As the specimens are cremated together, it will not be possible for you to collect the ashes. This service is free of charge
- if you choose to bury the organs in the same grave as your child's body, you will be charged additional costs of several hundreds of dollars to have the grave reopened. You will need to discuss this with your funeral director
- if you wish to make your own arrangements the organs can be returned to you. To ensure that you are going to comply with health regulations, a funeral director will facilitate the return of the organs.

Your options can be discussed with a funeral director, a bereavement support worker at the hospital or your religious representative.

Organs that are kept by the hospital

With your permission the hospital may retain the organs in the long-term. Any retained organs are kept in safe and secure conditions in the hospital. Organs kept by the hospital are stored in a teaching collection (museum) or archive.

The identity of the organ and the diagnosis is treated in the same confidential manner as all hospital medical records.

No whole organs can be kept for research without your specific consent. All research projects need to be approved first by the Ethics in Human Research Committee before you can be asked permission for the organs to be used.

No whole organs can be kept for research without your specific consent. Your doctor or the hospital pathologist will answer any further questions that you may have in relation to the treatment of organs after a post mortem.

Things to remember

- Whenever a full or limited post mortem is performed tissue samples are taken.
- The hospital is legally required to keep tissue samples for 23 years.
- To do a thorough examination it might be necessary for the pathologist to keep certain organs for longer. Your doctor should explain the reasons for this.
- If you don't want an organ to be kept for any reason you should tell your doctor.

*W*ill my child be treated with care?

A full post mortem is a careful external and internal examination of your child and is done with the same care as if your child were having an operation. The post mortem will be done by a paediatric pathologist, who is a doctor specialising in the study of diseases in unborn babies, newborn babies or older children. Sometimes, a pathologist in-training will do the examination, but only under close supervision. It will be done in special facilities provided in the mortuary at the hospital caring for your child.

The post mortem will be done to standards set by the Royal Australasian College of Pathologists. These standards include treating your child's body with dignity and respect and carrying out the examination with regard for the feelings of bereaved parents.

*H*ow is the examination performed?

First, the pathologist carries out a careful external examination of your child's body. In many cases x-rays and photographs are taken. Then an incision is made down the front of the body and internal organs are taken out for a detailed examination. To examine the brain, an incision is made in the scalp over the crown of the head. Afterwards, thin tissue samples are taken from all organs for later examination and the organs are returned to the body. The tissue samples are processed into blocks of wax and after being examined these blocks are stored in the pathology department.

Your doctor or the hospital pathologist will answer any further questions that you may have in relation to the full post mortem.

Sometimes body fluids may be sent for laboratory tests to look for certain things such as infection. Sometimes it may be necessary to keep your child's brain for several weeks to allow for special preparation and full examination. In some cases we may suggest that other organs, particularly the heart, are kept for further examination. We will not keep any organs without your permission. However, this may limit the information we can get from the examination.

How are tissue samples used for education and research?

The use of stored tissue samples for education and research usually involves further detailed examination of microscope slides, often using different techniques. It does not affect anything else about the post mortem. It is anonymous (that is, your child will not be identifiable from any published results of research). It will not change the results of the post mortem on your child, or lead to any need for us to contact you again.

How do research projects get approved?

Any requests for research to be performed on archived tissue samples must be approved by Ethics in Human Research Committee before commencing. The Ethics in Human Research Committee carefully considers each proposal and in particular the need for specific consent. If the research projects are known at the time of your child's death, you will be asked for specific permission prior to the post mortem.

If you have any concerns or questions about research and education issues or you would like anything clarified please talk with your doctor or the hospital pathologist.

When will the post mortem be carried out?

The initial post mortem is carried out as soon as possible after death, usually within two to three working days. When religious observance requires a funeral within 24 hours, every effort is made to carry out the post mortem within this time. The actual examination can take up to three hours. However, sometimes tissues or organs are kept for detailed examination. This could delay the funeral if you wanted the tissues or organs to be reunited with your child's body. Laboratory investigation of tissue or fluid samples may take several weeks, and the complete report is usually available after six weeks.

How do we receive the results of the post mortem examination?

A report on the post mortem examination will be sent to the consultant who looked after you or your child or to the Coroner in the case of a Coroner's post mortem. We aim to send the full report within six weeks of the date of the post mortem. A report may also be sent to your general practitioner. As these reports are usually written in medical terminology it may be helpful to have the results explained to you.

You will be offered an appointment with the consultant who looked after you or your child, or with your general practitioner, to discuss the results. This doctor should be able to provide you with an explanation of the report in non-medical language. You will also be given a copy of the autopsy report if you want one.

If at any time in the future you would like a copy of the report, you will be able to access it through the hospital. If you wish you can talk to the pathologist who did the post mortem.

The pathologist cannot discuss the results of a Coroner's post mortem with you unless the Coroner has given permission.

Will a post mortem delay the funeral?

Your child's body is usually released to the funeral director on the day of the post mortem. If the post mortem has been carried out late in the afternoon, this may happen the following morning.

However, sometimes the investigations are complex, requiring a detailed examination of the organs. This may take several days or even weeks and there may be a delay to the funeral if you wish to have any retained tissue or organs reunited with your child's body.

For further information about this see page 12.

Will the post mortem change my child's appearance?

Due to natural events that occur after death, your child's body will look slightly different. After the post mortem a technician will take great care to prepare the body so that your child's appearance looks the same and your child will feel the same to touch and hold. There will be evidence of an incision on the back of the head and another down the front of the body that won't be noticeable after your child is dressed. If you have questions or concerns about the way your child looks or feels to touch and hold, you can discuss them with your doctor or the pathologist.

What are the costs involved?

You will not be expected to contribute financially towards the cost of the examination. If you choose to have retained organs buried or cremated separately after examination, there may be extra funeral expenses.

Hospital contacts

The Royal Women's Hospital

<i>General Enquiries</i>	 (03) 8345 2000
<i>Genetic Counsellors</i>	 (03) 8345 2180
<i>Pastoral Care</i>	 (03) 8345 3016
<i>Women's Health Information Centre</i>	 (03) 8345 3045
<i>Women's Social Support Services</i>	 (03) 8345 3050

Royal Children's Hospital

General Enquiries  (03) 9345 5522

Family Bereavement Support Program
Social Work Department

 (03) 9345 6111

Chaplaincy

 (03) 9345 5522

(ask the operator to page)

The Coroner's Office

Enquiries

 (03) 9684 4380

1300 309 519

Grief Support Organisations

National Association for Loss and Grief

Enquiries ☎ (03) 9650 3000

SANDS (Vic). (Miscarriage, Stillbirth and Newborn Death Support Inc)

Support line ☎ (03) 9899 0218 or administration ☎ (03) 9899 0217

SIDS and Kids Victoria (Sudden Infant Death Research Foundation)

☎ (03) 9822 9611 or free call ☎ 1800 240 400 ☎ 1300 308 307

AFAR: Trauma Counselling Service

Enquiries ☎ (03) 9813 3400

Bonnie Babes Foundation Inc

Enquiries ☎ (03) 9803 2699 or email enquiries@bbf.org.au

Centre for Grief Education – Counselling Services

Enquiries ☎ (03) 9265 2111

The Compassionate Friends Vic Inc

Enquiries ☎ (03) 9888 4944 or toll free ☎ 1800 641 091

Grief line

Enquiries ☎ (03) 9596 7799

Mercy Western Grief Services

Enquiries ☎ (03) 9364 9777

Adults

After the Death of a Child, Living with Loss through the Years

A.K. Finkbeiner, The Tree Press, 1996.

Coping with Grief, Mal McKissock, Australia, 2001.

Grief in Children – A Handbook of Adults

A. Dyregrov, Jessica Kingsley Publishers Ltd, London, England, 1991.

Stillbirth and Newborn Death are the Same Mysteries

Peter Barr and Deborah de Wilde, Sydney, Australia, 1987.

The Bereaved Parent, Harriet Schiff-Sarnoft

Penguin, New York, 1978.

The Forgotten Mourners, Guidelines for Working with Bereaved Children

M. Pennells and S.C. Smith, 1995.

The Grief of Our Children

D. McKissock, ABC Books, Sydney, Australia, 1998.

The Worst Loss: How Families Heal from the Death of a Child

B.D. Rosof, Henry and Holt and Co., New York, USA, 1995.

Your Baby has Died

Rosemary Crowther and Penny Brabin, SANDS (Vic), Australia, 2002.

Always a Part of Me, Surviving Childbearing Loss

Amanda Collinge, Sue Danial, Heather Grace Jones
ABC Books, Sydney, Australia 2002.

Good Grief: A constructive approach to the problem of loss

Granger E. Westberg. JBCE, Melbourne 1992

Living With Grief

Tony Lake, Sheldon Press, London 1998.

Always a Part of Me

Amanda Collinge, Sue Daniel, Heather Grace Jones, ABC Books, Sydney 2001.

Stillborn: The Invisible death

John Defrain, The Free Press, 1991

Empty Arms: coping with miscarriage, stillbirth and infant death

Sherokee Ilse, Wintergreen Press, Minesota 2001.

Children

Talking About Death: A dialogue between parent and child

Earl A Grollman, Beacon Press, Massachusetts, 1990

Helping Children Cope with Grief:

Facing a death in the family, Rosemary Wells

Sheldon Press, London, 1988



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