# When a person dies The hospital post-mortem examination process

Information for family and friends



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#### Introduction

This booklet has been prepared to provide information about hospital post-mortems (also known as autopsies). It explains what a post-mortem involves, why it is considered important and the choices the relevant family member of the deceased can make.

You have been given a copy of this booklet if you, or your family, have requested a post-mortem, or if the treating doctor requests that you consider a post-mortem. Please note, that you have the right to request, or refuse, a hospital post-mortem and you are not required to read this booklet.

If you **do** wish for a hospital post-mortem examination to be carried out, you and your doctor will need to complete a request and consent form. You can request a full examination or place limitations on the extent of the examination. If you **do not** wish for a hospital post-mortem examination to be carried out, your doctor will provide you with the request form on which you can document your objection. Your decision will be respected by the hospital. Under exceptional circumstances, the Minister for Health may determine that a post-mortem is required to identify or deal with a risk to the health to the community (this is rare and would be discussed further with the family).

Many people find this a difficult time to make decisions. Your doctor and/or any relevant hospital staff will discuss the postmortem with you and answer any questions. You can also request to speak to a pathologist, the specialist doctor who performs the post-mortem, or a geneticist, social worker or any other specialist to answer specific questions. It often helps if you also discuss it with your family, your doctor or someone close to you.

## Cultural and religious beliefs

It is acknowledged that in many communities there are strong connections to cultural aspects and the body (and body parts), which may have an impact on whether a hospital mortem can take place, as well as any practices or beliefs that should be respected during the process. It is important for you to know that you and your family, your spiritual leader and/or community elder/leader, are encouraged to discuss any issues with your doctor.

If you have any cultural or religious considerations that you want respected during the post-mortem examination you can note these in part 4 of the Post-Mortem Authority and Consent form that the doctor will give you.

#### **Definitions**

The following is a list of definitions of terms used throughout this booklet. If anything is not clear, please ask your doctor.

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Chromosomes (and DNA)

Threadlike material made from DNA (deoxyribonucleic acid) that carry the genetic information (genes). Humans have 22 pairs of chromosomes plus two sex chromosomes for a total of 46. One chromosome from each pair is inherited from each pair is

inherited from each parent.

Designated Officer A medical practitioner appointed by the Minister for Health to act as an independent medical authoriser for certain activities (e.g. organ donation, hospital post-mortems).

Genes

Genes contain the information that determines a person's traits – everything from height to hair colour. Genes are found on chromosomes.

Genetic testing

Scientific testing of a person's DNA in their genes and chromosomes.

Organ

A body organ is made of specialised cells and tissues that form a particular structure and perform a particular function (eg heart, lungs, brain, liver, kidney).

**Pathologist** 

A medical specialist who is expert in the diagnosis of diseases and conditions by examining tissues and organs.

#### Post-mortem

Also known as an autopsy. A step-by-step examination of the outside of the body and of the internal organs by a pathologist.

#### Relevant family member

The person who will be asked to give permission for a hospital post-mortem to be performed.

In the case of pregnancy loss/stillbirth, this is the mother or the person responsible for the mother if the mother is unable to consent.

For other cases it is the senior available next of kin (see below).

# next of kin

**Senior available** The closest adult relative to the deceased. The term 'senior' is used as there is an order of priority for who will be asked, which is based on their relationship to the deceased (not age). Page seven of this booklet outlines how this term is defined within the relevant SA legislation.

#### Tissue

Any piece of the body including cells and their products from organs and supporting components.

#### Tissue sample

A small piece of tissue taken from the body (typically about 0.5cm thick). It is usually taken for further testing e.g. for examination under a microscope, (a list of Designated Officers is held by the hospital's General Manager or equivalent) to detect infection or for genetic tests.

## What is a post-mortem?

A post-mortem (or autopsy) is a detailed examination of the body outside and of the internal organs by a medical specialist – a pathologist who is trained in this work. The post-mortem examination is carried out in a mortuary with absolute respect to the deceased and the wishes of the family.

The body is opened by making incisions in the chest, abdomen and head so that organs can be removed and examined. Small tissue samples are taken for detailed examination under a microscope. Other small samples are taken to send to other laboratories to identify infections, to test biochemistry, blood tests or to test for genetic abnormalities.

Sometimes, to make an accurate diagnosis, it is best to take an entire organ for a more detailed examination that might take a few additional days or weeks. You can discuss the likelihood of this with your doctor or the pathologist, and indicate on the form whether you consent. You can request that all organs are returned before the funeral.

Once the post-mortem examination is completed, the incisions are carefully closed but can be seen if the body is uncovered. A normal viewing of the body can be held after a post-mortem.

You may want to give permission only for a limited post-mortem. You will need to indicate on the Post-Mortem Authority Form the part or areas of the body that you do, or do not want, to have examined or specify limitations on the post-mortem process. This will limit the information gained but can still be a valuable procedure. Talk to your doctor or the pathologist to discuss how this might influence the examination.

Small tissue samples (typically about 0.5cm thick) are normally retained in wax blocks and glass slides by the laboratory and according to national pathology standards. They occasionally form part of laboratory reviews and quality assurance to ensure laboratory standards are maintained. Sometimes new diagnostic methods become available or the family requests new information or testing and these samples can be used to provide the family with this new information. The relevant family member can also consent for organ or tissue sample use for research and/or other therapeutic, medical or scientific purposes. When the tissue samples, blocks and slides are no longer needed, the hospital will respectfully dispose of them by incineration in the same way as other test samples and organs removed during surgical operations.

#### Time frame for a post-mortem

The post-mortem is performed as soon as possible after permission has been given by the relevant family member and authorised by the Designated Officer who is an independent doctor. This is usually within two working days after death.

#### What are the benefits of a post-mortem?

A post-mortem can provide detailed information about what caused the person's death and medical conditions present. Even if the cause of death seems clear, the person may have had a medical problem that was not recognised during life.

The post-mortem may identify an undiagnosed problem such as an infection, cancer, blockage in a blood vessel, a genetic disorder or a complication of treatment. This information can be important to help the family and doctors understand why the death occurred. The results can also provide information to help manage other family members' health.

The future health of the general community may also benefit from the findings of a post-mortem. Post-mortems provide valuable information to improve the quality and standard of medical care, by advancing knowledge of health and medicine, and helping educate and teach health professionals.

#### Who decides if there should be a post-mortem?

Who may request a post-mortem depends on the type of post-mortem to be conducted. There are three types – coronial, ministerial or hospital.

#### Coronial post-mortem

Some deaths must be reported to the Coroner, who may direct a post-mortem examination be performed. A death is reportable to the Coroner if it has occurred in certain ways, including:

- > within 24 hours of leaving hospital (unless it was medically planned that death could occur naturally at home)
- > during an anaesthetic procedure or within 24 hours of having an anaesthetic
- > if a person is certified by a doctor as "Dead on Arrival" at a hospital
- > death from unusual, suspicious or unknown causes, or unexpectedly. These may include assault, accident and suicide. Deaths in custody and some in institutions, must also be reported.

There does not have to be anything suspicious about the death for the Coroner to be involved. The Coroner's role is to establish the cause and circumstances of death. If the Coroner directs a post-mortem to be performed, permission from the family is not required but it is still important that the family is kept informed. The doctor notifying the Coroner will also inform the family of the notification.

This booklet provides information about hospital (non-coronial) post-mortems only. For more information about coronial post-mortems please contact the Social Worker at the State Coroner's Office by phoning (08) 8204 0600.

#### Ministerial post-mortem

In rare cases, it may be necessary or desirable for a post-mortem examination to occur in order to identify or deal with any risk (actual or perceived) to the health of the public. In cases where the senior available next of kin objects to a post-mortem examination but where the Minister believes that in the interests of public health a post-mortem examination should occur, the Minister can consent to a post-mortem examination. Before the Minister consents to a post-mortem examination, he/she will contact the senior available next of kin to discuss the matter. This override provision does not apply in the case of pregnancy loss or stillbirth.

#### Hospital post-mortem

A hospital post-mortem may be requested by someone before they die; the family may ask for a post-mortem; or a doctor may ask the family for permission to carry out a post-mortem to help find out why the person died or to better understand their condition or illness.

A hospital post-mortem is not performed without seeking the permission of the relevant family member. Hospital staff will respect and support any decision the relevant family member makes about a hospital post-mortem.

#### Who gives permission for a hospital post-mortem?

The deceased can consent or object to a post-mortem during his/her lifetime. This information may be contained in an Advanced Care Directive, the Will or some other legal document, or may have been conveyed verbally to one or more family members.

The relevant family member is the next person who will be asked to give permission for a hospital post-mortem to be performed. He or she will be required to sign the Post-Mortem Authority Form.

Finally, the Designated Officer is responsible for the final sign-off approving that the post-mortem can proceed. Part of the Designated Officer's role is to make reasonable enquiries to ensure that neither the deceased nor the relevant family member have raised any objections, prior to authorisation being given. This does not apply in the case of pregnancy loss or stillbirth. In this case, the Designated Officer acts solely as an independent medical witness to certify that the mother, or the person responsible for the mother if the mother is unable to consent, has given consent and the post-mortem can proceed.

If you have any questions about this process you should discuss these with the doctor helping with the post-mortem request and consent process.

#### Senior available next of kin – order of priority

Where an adult has died, the senior available next of kin, in order of priority is:

- > the spouse (including a domestic partner)
- > a son or daughter over 18 years
- > a parent
- > a brother or sister over 18 years.

If a child has died, the senior available next of kin, in order of priority, is:

- > a parent
- > a sister or brother over 18 years
- > a guardian of the child.

#### Pregnancy loss or stillbirth

In the case of pregnancy loss or stillbirth, the mother is the only person who can legally consent to a post-mortem. If the mother is unable to consent, the person responsible for the mother can act on her behalf, according to what her wishes would have been.

#### **Cultural considerations**

In some communities it may not be culturally appropriate for the relevant family member to either consent to a post-mortem or be involved in discussions around donation of organs and/or tissues for medical, scientific or research purposes. You may delegate the authority to consent to another person, however, this person must be listed in the order of priority list above. Ideally an Advanced Care Directive will spell this out.

# Is it possible to donate organs or tissues for transplantation?

Many people have indicated their desire to be an organ donor after their death either by registering on the Australian Organ Donor Registry, by indicating their wish on their driver's license, or simply telling a family member. Not all deaths provide the right conditions for organs to be donated. It is important to honour these wishes when possible. Even if it is not possible for the person to be an organ donor, it may be possible to donate tissues such as bone, corneas, skin and heart valves. This needs to happen within 24 hours of death. The Tissue Bank Coordinator can assist and advise about tissue donation.

A staff member from DonateLife SA,phone: (08) 8207 7117, is available to discuss all aspects of organ donation and transplantation with families. The hospital can also arrange for a counsellor to discuss any issues that you may have.

#### What happens to the organs after a post-mortem?

Once the post-mortem is completed, organs are usually returned to the body. In some cases organs may need to be removed for a more detailed examination which may take place over the next few days or weeks. The likelihood of organs being needed for more detailed examination can be discussed with your doctor or the pathologist and the relevant family member needs to give consent for this. Organs may be of value for research and/or education and may be retained for these purposes – but again, only with consent by the relevant family member.

You will be given a number of choices as to what happens to any retained organs – whether the organs should be:

- > respectfully disposed of by the hospital (this is usually by incineration), or
- > returned to the body before the funeral (this may delay and add costs to the funeral), or
- > given to the funeral director for burial or cremation after the funeral. This needs to be discussed and prearranged with the funeral director with agreement from the relevant family member and may also incur additional costs.

#### Donating for research and education

The relevant family member will be asked if tissue samples and organs may be retained and used for research or education and training purposes. If permission is given to retain organs and/ or tissues for research or future education purposes, it can be withdrawn at any time by contacting the doctor who spoke to you about the post-mortem or by writing to the Chief Executive Officer of the hospital.

All research undertaken by the hospital is approved by the Hospital Ethics Committee. Research using donated tissue samples and/or organs is only approved if the privacy of the deceased is respected and any identifying information is treated as confidential. Whether donated tissue samples and/or organs are actually used depends on the research projects undertaken at any given time.

The decision to allow, or not allow, tissues and organs to be used for future training and education purposes and/or research will not affect the way in which the post-mortem is performed.

#### Genetic testing

A genetic test examines the genetic information contained inside a person's cells, called DNA, which are inherited from the person's parents. The purpose of this in post-mortems is to help diagnose diseases that are caused by DNA abnormalities, which may help to provide an explanation for the death. This is done most commonly when the death involves a baby or child. Currently this testing is routinely performed as part of a perinatal/paediatric post-mortem. A genetic sample taken for testing can be from any tissue. A blood sample is the most commonly used.

Genetic studies do not guarantee detection of all genetic conditions and some genetic changes that are detected are of uncertain significance. Some findings might raise concerns for other family members if further tests identify them as inherited. If genetics studies identify any findings of any concern, or further testing is required, the relevant family member(s) would be referred to the Medical Genetics Service where the test results and possible further testing would be discussed.

If you have further questions or wish to discuss genetics testing in more detail please ask your doctor and/or ask to speak to the hospital geneticist.

# How do I find out about the results of a post-mortem?

The post-mortem examination findings and report take some weeks to be generated as test results need to be determined and then considered together. The relevant family member may then choose to discuss the post-mortem results with the doctor responsible for the care of the deceased and/or they can also choose a general practitioner (GP) to receive a copy of the post-mortem results and discuss the findings with them.

A plain language version of the post-mortem report is also available if requested and this will be sent to the referring doctor or GP who can provide it to the relevant family member.

If the post-mortem was performed for the State Coroner, the relevant family member will need to contact the Coroner's Office on (08) 8204 0600 for more information about the post-mortem report.

#### When can funeral arrangements be made?

A funeral director should be contacted as soon as possible after death and they will contact the hospital regarding the release of the body.

If you decide that a hospital post-mortem can be performed, the person's body will be released to the funeral director, usually two or three days after death (although it may be later if the death occurs on a weekend or public holiday). Also, if the decision has been made to return organs to the body after more detailed examination then the release of the body and the funeral may need to be delayed. It may be difficult to predict in advance how long this will take but the pathologist and the funeral director can guide you with this information.

Funeral directors are used to working with mortuary departments to meet the needs of bereaved families. Do not hesitate to discuss any issues and ask any questions you might have.

#### What support is available to you?

#### Cultural and religious beliefs

If you have any needs, you are encouraged to talk with someone who can give you cultural or religious support. Please advise your doctor who can arrange for hospital staff to help you contact an appropriate person.

#### **Mementos**

When a post-mortem is carried out on a baby, if requested, hospital staff will prepare a memento pack. This may include photographs, foot and hand prints, name-band and hair if possible. The memento pack is available through the hospital social work department.

Families are encouraged to contact Social Work and collect the memento pack as soon as possible after it is available.

If you do not want a post-mortem examination but wish to have a memento pack for your baby, this can be arranged.

Please speak to your doctor for more information.

#### Information and bereavement support

If you have any questions your doctor, other hospital staff or staff in the pathology department will try to answer them for you. The hospital can help you access bereavement support when requests for post-mortems are made. This service will be able to help you with a variety of personal and practical problems.

The hospital staff can also provide you with literature and contact details of a wide range of support groups who are available to assist you to cope with your grief.

#### For more information

www.sahealth.sa.gov.au

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