

# MODEL VICTORIAN GUIDELINES ON REQUESTING CONSENT FOR NON-CORONIAL POST-MORTEM EXAMINATION

# Introduction

These guidelines deal with hospital-based (non-coronial) post-mortem examinations and have been developed by a Department of Human Services Victoria Working Party. The guidelines cover the key issues with respect to obtaining consent, including the consent for the retention, use and disposal of human tissue.

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## **Background**

The practice of performing non-coronial post-mortem examinations, and of retaining both whole and portions of body parts removed for further pathological study, quality control and research or scientific purposes has been accepted for many years. This is lawful under the *Human Tissue Act 1982*, which also specifies the requirements for obtaining consent for this purpose. Contemporary standards, however, require that there be full disclosure with regard to the retention, use and disposal of tissue and body parts at post-mortem examination.

There has been public concern expressed in Australia and overseas regarding the retention of human tissue and organs without what the community believes to be informed consent. This concern was sparked by inquiries into incidents in the United Kingdom at Alder Hey Hospital, Liverpool and the Royal Bristol Infirmary. It is, therefore, important that the consent policies and practices relating to post-mortem examination in Victorian hospitals are reviewed and standardised. These draft guidelines lay the foundations for this uniformity and their preparation has been informed by a Working Party of key stakeholders and relevant experts established in January 2001 by the Victorian Department of Human Services. The assistance provided by the New South Wales Health Department in the preparation of these guidelines is also acknowledged.

Policies and practices developed by health services relating to consent for post-mortem examination and for the retention, use and disposal of tissue obtained during this process should incorporate the recommendations provided in this document.

By following these recommendations, health service consent policies and procedures should be acceptably transparent and fulfil community expectations of fully informed consent.

## **The benefits of a post-mortem examination**

Post-mortem examinations provide valuable information for the family of the deceased, medical professionals, the institution in which the death occurred and the wider community. Non-coronial post-mortems are undertaken primarily to identify factors contributing to the death and can prove or disprove previous clinical hypotheses.

Further uses of the information obtained from a post-mortem examination include:

- **Provision of information for families**

Information obtained from the post-mortem can be used to discuss the cause of death and contributory factors with the next-of-kin. This information can be incorporated into the counselling of relatives after the death, and assist in allaying guilt. It may also be of use in counselling families where a genetic or hereditary disease has been found. Importantly, post-mortem examinations in which no specific cause of death or treatable illness can be found may still provide helpful information for relatives.

- **Provision of information for clinicians**

As well as providing information on the likely specific terminal pathologies of the deceased, information derived from post-mortems can increase our understanding of disease, including poorly understood diseases, and may assist in the detection of emerging diseases.

- **Clinical audit purposes**

A post-mortem examination provides evidence that may confirm or refute the reported cause of death. This gives valuable feedback to treating clinicians and is information relevant to improving and maintaining clinical care. The information can also be used in the calculation of mortality and morbidity statistics and to inform government policy.

- **Evaluation of new therapies and procedures**

Information obtained in a post-mortem can contribute to an assessment of the clinical benefits or complications of various therapies.

- **Research and Training**

The sharing of information provided by post-mortem examination is a valuable tool for the education of medical students, doctors and other health-care personnel in the disciplines of anatomy and pathology.

## **Communication in requesting a post-mortem**

It is the responsibility of the institution to ensure procedures are in place so that fully informed consent is obtained sensitively and by appropriately skilled staff.

Although the request for consent to a post-mortem from the bereaved next-of-kin is a sensitive and difficult task, experience has shown that relatives respond best if they are provided with a full explanation of the value of the post mortem and potential organ retention. Conversely, distress can be caused by later discovery that organs and tissues have been retained and used without the knowledge of the next-of-kin. The attributes and skills of the individual who approaches the next-of kin for consent should include:

- A relationship with the deceased and/or next-of-kin (where possible)
- An understanding of the role of post-mortem examination with a good knowledge of the post-mortem process and the options available to the next-of-kin
- An understanding of, and respect for, the rights of the dead
- An understanding of grief counselling requirements
- Time to be available for questions

The needs of relatives from culturally and linguistically diverse (CALD) backgrounds require special consideration, in terms of requirements for interpreter services, written resources and an understanding of their cultural attitudes and behaviours.

Hospitals may wish to designate a named individual or individuals who have these skills to assist the clinician requesting consent and to provide support and information to families of the deceased when a post-mortem examination is contemplated.

Counselling should be offered to bereaved relatives, irrespective of whether there is consent for an autopsy. The development of a directory of appropriate support groups may be useful also.

## **An overview of the post-mortem procedure**

Systems should be in place for the detailed recording of all post-mortem examinations including which organs, body parts or tissues were retained and how the retained organs and tissues were archived and/or disposed of.

The procedure itself usually involves an initial incision made in a “Y” shape, starting at the lateral end of each clavicle, and meeting in the midline at the sternal notch. From there the incision runs inferiorly over the sternum past the umbilicus to the pubis. All thoracic and abdominal organs are removed for individual examination and are then returned to the body. A second incision is made over the back of the head to examine the brain. A post-mortem requires a wide range of tissue samples to be taken for histological examination, as well as some tissue and fluid taken for other tests. These tests may include microbiological examination, genetic examination or examination for metabolic disease.

Sometimes a whole organ, such as the brain or heart, may be retained for later detailed examination. It is, therefore, important to discuss with the pathologist the need for retention of organs prior to obtaining consent for post-mortem from the next-of-kin.

## **Retention of body parts and tissue**

It must be emphasised that all post-mortems require the retention of small tissue samples and bodily fluids for histological and other testing purposes. There is little value in a post-mortem examination without such samples being obtained for testing. These samples will always need to be retained by the hospital and cannot be returned. Retention of these tissue samples is usually not an issue.

An issue may arise, however, over the retention of whole organs or other parts of the body. If it is proposed that whole organs or other parts of the body be kept after the post-mortem examination for testing, this needs to be explained to the next-of-kin and informed consent obtained.

## **Disposal of body parts**

There are a number of possible options regarding the disposal of organs, should they be retained during the post-mortem examination. The hospital needs to develop a policy that enables them to offer legally appropriate options for disposal of retained body parts and should ensure that disposal of retained organs is undertaken according to this policy and in line with the legitimate prior wishes of the deceased individual and the wishes of the next-of-kin. The hospital’s legal advisers can provide further

information regarding the legislation that must be taken into account when offering these options to the next-of-kin.

Possible options for the disposal of retained body parts are:

1. Disposal of body parts as clinical waste once testing is completed, in accordance with NHMRC National Guidelines for Waste Management in the Health Industry (1999) and the relevant legislation (Environment Protection Act 1970 and the Environment Protection (Prescribed Waste) Regulations 1998).
2. Reunion of the body parts with the body of the deceased, prior to burial or cremation.
3. A separate burial or cremation using an undertaker, after the burial or cremation of the body.

## **The consent process**

### **1. Requesting consent for autopsy**

Consent to a post-mortem examination is obtained either by the prior instructions of the deceased or by the next-of-kin.

It is up to the doctor obtaining consent for post-mortem to ensure that:

- The deceased was mentally competent at the time of giving prior instructions
- The next-of-kin approached is the appropriate person to consent under the *Human Tissue Act 1982* (See table below)
- The consent is fully informed

#### **Order of senior available next-of-kin is as follows:**

##### **In relation to deceased adults:**

1. Spouse
2. Child (18 years or older) where spouse is not available
3. Parent where no spouse or child (18 years or older) is available
4. Sibling (18 years or older) where no spouse, child (aged 18 years or older) or parent is available

##### **In relation to a deceased child:**

1. Parent of the child
2. Sibling (18 years or older) where a parent is not available
3. Guardian of the child at the time of death where a parent of the child or sibling (18 years or older) is not available.

## **2. The consent interview**

The discussions with the senior next-of-kin (or the deceased when obtaining ante-mortem consent) should include:

- Information on why the examination is indicated.
- Information on what a post-mortem entails, including the long-term storage of multiple tissue samples. A limited post-mortem may be of value if the next-of-kin does not wish to give consent for a full post-mortem. However, such a post-mortem limits the information obtained.
- Information on the retaining of organs for further diagnostic tests (eg. the brain) or for research, teaching, medical and scientific purposes.
- The disposal of organs or body parts upon completion of detailed examination. Reunion of the body part with the body after the funeral may be an option.
- The possible impact of a post-mortem on the preparation of the deceased and the timing of funeral arrangements.
- The timing and method of relatives receiving information after a post-mortem.

The needs of people from CALD backgrounds should be addressed with respect to information provision and sensitivity to cultural practices. Cultural practices concerning death must be reconciled with any delay resulting from the post-mortem examination. eg. Muslim washing rites.

If, for any reason, the body will not be available for viewing after the post-mortem examination, the next-of-kin must be informed of this prior to giving consent and an opportunity to view the deceased before the post-mortem should be arranged.

## **3. Provision of written information to next-of-kin**

In addition to verbally discussing the post-mortem process with the next-of-kin, written information should be provided. Written information should cover the following points:

- What the examination involves (including the retention of tissue samples).
- Which organs may be retained and why.
- How a post-mortem may affect preparation of the body and funeral arrangements.
- Whether retaining organs/tissues for research or legal reasons is desired.
- Where any retained organs may be stored, why they are stored, for how long they are stored and arrangements/options for reuniting retained organs with the body or disposal of retained organs.
- Any costs associated with the autopsy process.
- Follow-up procedures for autopsy results.

#### **4. Consent forms**

Consent forms that are used to document the consent of the senior available next-of-kin to a non-coronial post-mortem should include the following:

- The name of the next-of-kin and their relationship to the deceased.
- The date of the consent.
- Consent to post-mortem examination, including retention of tissue samples or body fluids for laboratory investigation, to establish cause of death.
- Consent to the retention of organs or body parts for the purposes of further detailed post-mortem examination and for research and education purposes.
- Consent to a form of disposal of any retained organs.
- Details of the medical officer obtaining the consent.
- The person to whom information/results should be sent.

A model consent form accompanies these guidelines. The consent form has three options for consent. Option 1 is suitable for individuals wishing to give consent for a full post-mortem and who give consent to the retention of parts of the body, and their use for research, education and other medical and scientific purposes approved by the hospital, with disposal to be arranged by the hospital. Option 2 contains choices that enable the consenting individual to limit the post-mortem and stipulate their wishes in relation to retention, use and disposal of body parts. Option 3 serves as a written record for individuals who do not wish to give to consent to a post-mortem.

The completed original consent form should be kept in the Department of Pathology, together with the interim and final autopsy report. Copies of the consent form and reports should then be:

- Placed with the deceased's medical records.
- Forwarded to the deceased's general practitioner or other medical officer requested by the next of kin.

#### **5. Other consent issues**

Specific consent needs to be obtained for the retention of tissue for transplantation into a living person. Further information about appropriate protocols can be obtained from the Donor Tissue Bank of Victoria (ph. 9684 4444).

### **Authorisation to conduct a post-mortem examination**

Under the *Human Tissue Act 1982*, the designated officer for the hospital must authorise the performance of non-coronial post-mortem examinations in writing. Where the body of a deceased person is in a place other than a hospital, a registered medical practitioner can give authority for post-mortem examination.

The designated officer must be satisfied that the deceased had consented to a post-mortem examination and had not revoked this consent. If no consent had been

expressed by the deceased, the designated officer can authorise a post-mortem examination if the person had not expressed an objection to a post-mortem during their lifetime and consent has been given by the senior next-of-kin (this latter requirement is removed if there is no next-of-kin available).

**A post-mortem can be authorised by a designated officer where:**

- the deceased had, at any time, in writing, expressed the wish for, or consented to, a post-mortem; OR
- the deceased had, during his/her last illness, orally in the presence of two witnesses expressed the wish for, or consented to, a post-mortem; OR
- the senior next-of-kin gives consent for the post-mortem unless the deceased had expressed an objection to a post-mortem at any time in writing or at any time during his/her last illness, orally in the presence of two witnesses; OR
- the designated officer if, after making such inquiries as are reasonable under the circumstances, is unable to ascertain the existence or whereabouts of the next-of-kin and has no reason to believe the deceased had expressed an objection to a post-mortem examination of his/her body.

## **Reporting the findings of a post-mortem examination**

Processes should be in place to inform appropriate bereaved family members of the cause of death as noted in the autopsy, if they wish to know, taking full account of patient confidentiality.

A preliminary report is usually available within a few days of the examination. A full report may take 6-12 weeks. A copy of the post-mortem report should be placed in the patient's medical record and the post-mortem record.

The method of reporting of the post-mortem findings to the relatives should be discussed. Some relatives may not want to know the findings, however most will appreciate the explanation of the deceased's death that a post-mortem can provide.

Procedures should be in place so that a suitable person can discuss the findings of the report with the relatives. This may be a general practitioner, a specialist or the pathologist performing the post-mortem. Any issues arising from the post-mortem will need to be addressed.

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**\*Denotes member of the working party on the retention, use and disposal of tissue obtained at post-mortem**

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