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HUMAN TISSUE AND TRANSPLANT ACT 1982

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NON-CORONIAL POST-MORTEM EXAMINATIONS CODE OF PRACTICE 2002

Issued by the Executive Director, Public Health, with the approval of the Minister for Health, under Section 32A (1) of the *Human Tissue and Transplant Act 1982*.

This code is to be read in conjunction with the Principles set out in Schedule 1 and the Guidelines set out in Schedule 2. The Principles and Guidelines are based on the "Code of Ethical Autopsy Practice" which is a national code of practice endorsed by Health Ministers in April 2002 as reflecting "best practice" in post-mortem examinations.

Citation

1. This code may be cited as the *Non-Coronial Post-Mortem Examinations Code of Practice 2002*.

Commencement

2. The Code will come into operation on 1 August 2002.

Application

3. The Code applies to any non-coronial post-mortem examination.

Definitions

4. In the Code, the following words have the following meanings—

"approved consent form" means a consent form which has been approved by the Deputy Director General, Health Care;

"approved information document" means an information document which has been approved by the Deputy Director General, Health Care;

"consent form" means a document used by a hospital carrying out non-coronial post-mortem examinations to record the informed decisions of the senior available next of kin and other matters relevant to the authorisation of such a post-mortem examination;

"Deputy Director General, Health Care" means the person who holds, or acts in, the position of Deputy Director General, Health Care in the Department of Health;

"designated officer" has the same meaning as set out in the *Human Tissue and Transplant Act 1982*;

"diagnostic purpose" means for the purpose of arriving at a diagnosis in relation to the cause or extent of any pathological condition which may be present in the body of the deceased;

"disposal" and **"disposed of"** in relation to tissue includes incineration by the hospital or contractors, and release to funeral directors for cremation or burial;

"Executive Director, Public Health" has the same meaning as set out in section 3 (1) of the *Health Act 1911*;

"information document" means a document used by a hospital carrying out non-coronial post-mortem examinations to provide relevant information to the senior available next of kin about post-mortem examination practices and procedures;

"informed decision" means a decision by the senior available next of kin which has been made after that person has been provided with relevant information about post-mortem examination practices and procedures;

"non-coronial post-mortem examination" means any post-mortem examination carried out on the body of a deceased person which is not carried out at the direction of a coroner made under the *Coroners Act 1996*;

"non-diagnostic purpose" means any purpose other than a diagnostic purpose, and includes—

(a) the purpose of medical research;

(b) the purpose of teaching;

(c) the purpose of therapeutic or medical use;

"post-mortem co-ordinator" means, in relation to a hospital, the person (or persons) appointed by a hospital in accordance with clause 6 of the Code;

"senior available next of kin" has the same meaning as set out in the *Human Tissue and Transplant Act 1982*;

"the Code" means, the *Non-Coronial Post-Mortem Examinations Code of Practice 2002*;

"tissue" has the same meaning as set out in the *Human Tissue and Transplant Act 1982*.

General guidelines

5. Each hospital in the State which carries out non-coronial post-mortem examinations shall take all reasonable steps to ensure that—

(a) its practices and procedures allow the senior available next of kin of a deceased person to make informed decisions about—

(i) whether or not to agree to a non-coronial post-mortem examination being carried out on the body of the deceased person;

(ii) whether or not to agree to a full post-mortem examination or some more limited form of post-mortem examination;

(iii) whether or not to agree to any tissue being retained at the completion of the internal examination (whether for diagnostic and/or non-diagnostic purposes);

(iv) how and when any tissue retained at the completion of the internal examination should be disposed of by the hospital;

(b) its practices and procedures will enable the senior available next of kin (and any other relatives of the deceased person) to be treated with appropriate sensitivity and due respect, and in particular—

(i) so that the senior available next of kin is able to make any necessary decisions within a timeframe and setting, and with the emotional support, which will minimise any undue distress;

(ii) so that there is no pressure placed on the senior available next of kin to make any necessary decisions in a particular way;

(c) the informed decisions of the senior available next of kin about any such matters are respected and implemented by the hospital.

Post-mortem co-ordinator

6. Each hospital in the State which carries out non-coronial post-mortem examinations shall have a person, or persons, appointed to be a post-mortem co-ordinator.

General responsibilities of post-mortem co-ordinator

7. A post-mortem co-ordinator shall have the following general responsibilities—

(a) arranging for the senior available next of kin to be provided with the information which will enable that person to reach informed decisions about the matters referred to in clause 5 (a) of the Code;

(b) ensuring that a non-coronial post-mortem examination is not authorised by a designated officer unless and until the senior available next of kin has had the opportunity to reach informed decisions about the matters referred to in clause 5 (a) of the Code;

(c) ensuring that appropriate records are kept, in each case, of the decisions made by the senior available next of kin in relation to the matters referred to in clause 5 (a) of the Code, and of the implementation of those decisions by the hospital;

(d) being an ongoing point of contact for the senior available next of kin (or other relatives) in relation to any requests for further information about any matter relating to a non-coronial post-mortem examination carried out on the deceased person.

Notification to be given to the post-mortem co-ordinator

8. A post-mortem co-ordinator shall be notified, as soon as is practicable, whenever a non-coronial post-mortem examination is being considered.

Preliminary action by post-mortem co-ordinator

9. When a post-mortem co-ordinator is notified that a non-coronial post-mortem examination is being considered, that person shall take steps to ensure that—

(a) the senior available next of kin of the deceased person is identified;

(b) the senior available next of kin is provided with an approved information document and approved consent form;

(c) the senior available next of kin is given an adequate opportunity to read and consider the approved information document and approved consent form and to discuss their contents with any other relatives;

(d) the senior available next of kin is given an adequate opportunity to have any questions answered about the contents of the approved information document and approved consent form, or about any other aspects of the non-coronial post-mortem examination.

Subsequent action by post-mortem co-ordinator

10. When the post-mortem co-ordinator is satisfied that the senior available next of kin has had the opportunities referred to in clause 9 (c) and (d) of the Code, that person shall—

(a) ascertain from the senior available next of kin whether the deceased person had given any indication during his or her lifetime of his or her attitude to the possibility of a post-mortem examination after death;

(b) ascertain from the senior available next of kin whether he or she agrees to a post-mortem examination being carried out on the body of the deceased person.

No further action when objection expressed

11. If the post-mortem co-ordinator is informed by the senior available next of kin that the deceased person had expressed an objection during his or her lifetime to a post-mortem examination after death, no further action shall be taken by the hospital.

Consent form procedure

12. Where the senior available next of kin agrees to a post-mortem examination being carried out on the body of the deceased person, the post-mortem co-ordinator shall ensure that—

(a) an approved consent form is completed and signed by the senior available next of kin;

(b) the approved consent form includes a record of all relevant decisions made by the senior available next of kin (including any limitations or conditions which may be placed by the senior available next of kin on the post-mortem examination and/or any retention of tissue following the internal examination);

(c) the approved consent form includes certification from the post-mortem co-ordinator that all relevant information has been provided to the senior available next of kin so that informed decisions could be made (and that the approved consent form is not submitted to the designated officer until that has been certified);

(d) a copy of the approved consent form is provided to the senior available next of kin if and when it has been endorsed with the authorisation to perform a post-mortem examination by the designated officer.

Action by designated officer

13. Subject to section 25(3) of the *Human Tissue and Transplant Act 1982*, a designated officer shall not authorise the carrying out of any non-coronial post-mortem examination unless he or she has been provided with a completed approved consent form (which includes the certification from the post-mortem co-ordinator referred to in clause 12 (c) of the Code).

Feedback to relatives

14. The post-mortem co-ordinator shall ensure that the senior available next of kin has an opportunity to receive appropriate feedback on the findings of any post-mortem examination which has been carried out on the body of that deceased person.

Records to be kept

15. The post-mortem co-ordinator shall ensure that, in relation to each case where a non-coronial post-mortem examination is considered, an adequate record is kept of—

(a) who was identified as the senior available next of kin;

(b) when an approved information document and approved consent form was given to the senior available next of kin;

(c) any questions raised by the senior available next of kin about the contents of the approved information document, approved consent form or about any other aspects of the non-coronial post-mortem examination, and the answers given to those questions;

(d) any information provided by the senior available next of kin about the attitude of the deceased, prior to death, to the possibility of a post-mortem examination;

(e) any decisions made by the senior available next of kin in relation to the matters referred to in clause 5 (a) of the Code;

(f) the implementation by the hospital of any decisions made by the senior available next of kin in relation to the matters referred to in clause 5 (a) of the Code.

Register to be kept

16. The post-mortem co-ordinator shall ensure that there is maintained at the hospital, and kept up to date, in relation to any non-coronial post-mortem examination which is carried out after the date on which the Code comes into operation, a register which includes the following information—

(a) a description of any tissue retained;

(b) an indication of when the non-coronial post-mortem examination to which the tissue relates was carried out and the deceased person on whom it was carried out;

(c) an indication of when the approved consent form was signed, and any limitations placed by the senior available next of kin on that retention;

(d) an indication of any use of that retained tissue (ie for diagnostic purposes and/or non-diagnostic purposes as may have been authorised by the senior available next of kin) and when any such use was completed;

(e) an indication of how and when any retained tissue was disposed of by the hospital.

Access to register by senior available next of kin

17. An extract from the register maintained in accordance with clause 16 of the Code, containing the details which relate to any retained tissue from a particular deceased person, shall be provided by the hospital on request to any senior available next of kin of that deceased person (or other person authorised by the senior available next of kin).

Access to register by authorised officers

18. The register maintained in accordance with clause 16 of the Code shall be open to inspection at any time by the Deputy Director General, Health Care or any officer of the Department of Health who is authorised in writing by the Deputy Director General, Health Care.

Reporting

19. The post-mortem co-ordinator shall ensure that on or before the 31st day of July 2003 and, thereafter, on or before the 31st day of July in each following year, a report is provided to the Deputy Director General, Health Care which includes the following information—

(a) the number of non-coronial post-mortem examinations which were carried out at the hospital during the period from the 1st day of July of the preceding year to the 30th day of June of that current year, other than for the initial report, which will cover the period from 1st day of August 2002 to the 30th day of June 2003;

(b) the number of non-coronial post-mortem examinations during that period in which tissue was retained at the completion of the internal examination;

(c) the number of non-coronial post-mortem examinations during that period in which tissue was retained for diagnostic purposes;

(d) the number of non-coronial post-mortem examinations during that period in which tissue was retained for non-diagnostic purposes (and a percentage breakdown of the types of non-diagnostic purposes for which tissue was retained);

(e) the total number of tissue samples retained from non-coronial post-mortem examinations carried out at the hospital during that period;

(f) the number of tissue samples from non-coronial post-mortem examinations carried out at the hospital since the commencement of the Code which were disposed of during that period (and a percentage breakdown of the method of disposal which was used);

(g) the total number of tissue samples which are still retained at the hospital from non-coronial post-mortem examinations carried out at the hospital since the commencement of the Code.

Copies of reports to be provided to EDPH

20. The Deputy Director General, Health Care shall provide copies of any reports received in accordance with clause 19 of the Code to the Executive Director, Public Health on or before the 1st day of September in the year in which the reports are received, together with any comments which the Deputy Director General, Health Care considers should be made on those reports and on the operation and effectiveness of the Code generally.

Review

21. The Deputy Director General, Health Care shall review the operation and effectiveness of the Code after it has been in operation for a period of 18 months, and report to the Executive Director, Public Health on the findings of that review within a further 3 months.

Report on review to be provided to Minister

22. The Executive Director, Public Health shall provide a report to the Minister for Health on the review referred to in clause 21, which shall include any recommendations for improving the operation and effectiveness of the Code.

Dr VIRGINIA McLAUGHLIN, Acting Executive Director,
Public Health.

SCHEDULE 1

PRINCIPLES

The following Principles are based on the "Code of Ethical Autopsy Practice" which is a national code of practice endorsed by Health Ministers in April 2002 as reflecting "best practice" in post-mortem examinations.

The following principles underpin the Code and govern for the conduct of non-coronial post-mortems —

- It should be clear to families that a non-coronial post-mortem can only be carried out in accordance with the requirements set out in the *Human Tissue and Transplant Act 1982* and the Code.
- Respect must be shown towards the deceased and their families at all times.
- Full, open and attentive communication is fundamental to effectively involving families.
- Processes must be transparent and accountable and able to be assessed and reported.
- The public benefit of post-mortems needs to be recognised.

In addition, post-mortem practice must be governed by the following principles—

- The family must be consulted and given the opportunity to be involved to whatever extent they wish to be.
- The wishes of the deceased and the family in regard to the post-mortem examination should be accommodated as far as possible.

- Information must be provided in a timely, understandable and sensitive fashion and answers to questions must be open and honest.
- Only appropriately trained persons (post-mortem co-ordinators) should provide information to families.
- Family members must be consulted and their agreement obtained about organ retention and disposal, (in person wherever possible) unless they have made it clear they do not want to be consulted.
- Appropriate bereavement support should be provided to families in acknowledgment of their loss.
- An appropriately qualified and authorised person should take responsibility for the performance of each and every post-mortem.
- There must be a clear delineation between the uses to which retained tissues/organs can be put such as diagnosis, research or education.
- All research using organs or tissues derived from post-mortems must have the approval of a properly constituted ethics committee.

SCHEDULE 2

GUIDELINES

The following Guidelines are based on the "Code of Ethical Autopsy Practice" which is a national code of practice endorsed by Health Ministers in April 2002 as reflecting "best practice" in post-mortem examinations.

(i) BEST PRACTICE GUIDELINES FOR INFORMING AND INVOLVING FAMILIES

Traditionally professionals have sought to protect families from information that they may find distressing. However, experience has shown that timely information provided in a sensitive manner can empower families and is far less distressing than later disclosure.

Bereaved families have the right to clear, factual and sensitive communication from a skilled professional. Institutions have a responsibility to ensure that in each case there is a specifically trained staff member (the post-mortem co-ordinator) whose role is to engage with the bereaved family and provide clear, factual information in a sensitive manner following the death of a patient.

The approach to the family regarding post-mortem is most appropriately made by the senior clinician treating the patient. This is not a duty to be delegated to a junior medical officer or untrained interviewing officer. Requesting a post-mortem and discussing organ retention and use and other sensitive information should be conducted face to face wherever possible. Whilst an approach by telephone may be allowable and in some cases unavoidable, it is not ideal.

The appropriately trained person whose priority is the needs of the bereaved family should support the clinician in this role.

The capabilities of such persons in providing assistance to the bereaved family should include—

- an understanding of the dynamics of the grief process,
- counselling and communication skills to convey information at a pace and using language the family are able to understand,
- the capacity to recognise the needs of families where English is not the first language (including Torres Strait Islander and Aboriginal families), and the potential for diminishing fluency and comprehension or reversion to original language,
- communication and advocacy skills to ensure the wishes of the family are conveyed and respected,
- a good understanding of the non-coronial post-mortem examination process and the legal and ethical issues related to agreement to that process,
- a good understanding of the post-mortem process relative to the need for tissue/organ retention and options available for future use, release or disposal of the retained tissue/organ,
- knowledge of all aspects of funeral arrangements.

Institutions involved with the bereaved family must recognise and provide for the following needs—

- a quiet, private area to undertake these discussions,
- time to assimilate the impact of the death before being approached to discuss post-mortem. Whilst it is acknowledged in certain situations the treating clinician may have had extensive discussions about the prognosis of the patient and the benefit of post-mortem may have already been raised with the family, in most situations it is inappropriate to raise the issue until the family has had time to take in the death of the patient,
- information about events leading to the death, treatment attempts etc before feeling ready to discuss other issues,
- support to facilitate their "goodbye" to their relative,
- any special religious or cultural rituals which must be acknowledged and met where possible,
- clear honest information,

- specifically families must be clearly informed of their rights—
  - to refuse the performance of a post-mortem,
  - to limit the extent of the examination and retention of tissue and organs, understanding that such limitations may compromise the information obtained from the post-mortem,
  - in regard to disposal options for retained tissues and organs,
  - to be advised about uses other than diagnosis to which retained tissues/organs can be put.
- access to interpreters and appropriate health workers where necessary,
- information and assistance to make funeral arrangements,
- assessment and referral for ongoing counselling if required,
- provision of post-mortem results in an understandable form. They may prefer to meet with the clinical team who cared for their relative or with their own GP. In some situations discussion with the pathologist may be appropriate.

(ii) GUIDELINES FOR POST-MORTEM REQUEST AND CONSENT FORMS

THE REQUEST BY PRACTITIONER

The form should include—

- name of medical practitioner requesting post-mortem,
- name of deceased,
- the family member consulted, by whom and their relationship to the deceased,
- clinical report and reason for seeking post-mortem,
- information on hazards presented to mortuary staff—infectious, radioactive etc,
- mode of request—in writing, in person or by telephone.

Every reasonable effort must be made to contact the next of kin, recognising different kinship arrangements in some cultures (eg. Aboriginal).

The role of the post-mortem co-ordinator is to check and sign that the documentation reflects compliance with the *Human Tissue and Transplant Act 1982* and the Code.

THE CONSENT FORM

The approved consent form should be simple and refer to the approved information document, and include a statement that the approved information document has been read and understood, with a copy provided to the family. The approved consent form should also include—

- the name of the key person who discussed the issues with the family,
- the name of the person seeking the family's authorisation,
- that there was adequate explanation of the reason for and process of post-mortem,
- options for both broad and conditional agreement. Both a general and specific agreement should be offered. Families should be offered the option to agree to a post-mortem without specifying conditions, but also to agree individually to research, teaching and return of organs. It is recognised that while many families want to be very informed and be provided with an opportunity to determine what organs are retained, what they can be used for and how they will be disposed of, not all families are comfortable considering these aspects.
- whether the deceased had previously agreed or objected to post-mortem,
- whether any other next of kin had previously objected to post-mortem,
- options for full or limited post-mortem, specifying limitations,
- options for retention of organs, specifying limitations,
- agreement that specimens will be retained - the need for indefinite retention of blocks and slides must be explained to the family,
- whether retained organs or tissues can be used for education,
- whether retained organs or tissues can be used for approved research consistent with the National Health and Medical Research Council National Statement on ethical conduct in research involving humans,
- options for disposal of retained organs including return to body, later return to funeral director nominated by the family or respectful disposal by the hospital,
- the date and time of planned funeral arrangements,
- name of doctor(s) to whom the post-mortem report should be provided.

(iii) GUIDELINES FOR WRITTEN MATERIAL PROVIDED TO FAMILIES

THE INFORMATION DOCUMENT

Families should be provided with a copy of the consent form that they have completed. Explanatory information (the approved information document) should be available to give to the family to supplement the discussions. The approved information document should include an explanation of the post-mortem including what retention of tissues and organs means. It may be necessary to include a glossary to explain samples, tissues, organs and other terms. This information should be provided in relevant languages if no member of the family is literate in English.

Information about non-coronial post-mortems should include the choices about—

- the rights to refuse permission for a post-mortem,
- the extent of the post-mortem,
- retention of organs,
- the limitations on the information available if they choose to limit the post-mortem,
- their right to choose whether retained samples can be used for other purposes such as research, education and quality control,
- who the post-mortem report is provided to,
- disposal of retained samples, eg. return to the body before release, subsequent release to funeral director or respectful disposal by the institution.

Families affected by non-coronial post-mortems may also benefit from information about—

- obtaining the death certificate,
- procedures for reporting complaints and concerns,
- sources of further assistance including interpreters and counselling.


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