

Interviewing families to seek consent for hospital autopsies – Explanatory Information

Introduction

http://www.health.qld.gov.au/consent/html/sub_specialties/autopsy.asp

This explanatory information supports the attached Procedure for seeking consent and aims to help those involved to reverse the long-standing decline in hospital autopsies¹. Causes of the decline include a shortage of pathologists to provide a timely service, and the mistaken belief that modern imaging obviates the need for autopsy. Despite some limitations, however, autopsies remain the diagnostic gold standard².

Seeking consent for autopsy – interviewing families^{3 4 5 6}

The decline is also attributable to twin myths – that seeking informed consent is difficult and time-consuming and that families generally refuse. In fact, the medical literature shows that experienced doctors with knowledge of the patient, a belief in the value of autopsies, training in the consent process and good communication skills can achieve high consent rates. The task should not be delegated to a junior doctor untrained in autopsy consent.

Social workers, nurses⁷ and “Interviewing Officers” can also play important parts in seeking consent and may choose to interview families jointly with an experienced doctor. While face to face interviews are preferable, Coronial Counsellors have found that, with training, consent can also be readily sought by telephone. To be valid, consent must be informed and comply with legislation and codes of ethics. Staff must therefore be trained in autopsy consent, understand autopsy practices, and, before seeking consent, discuss the proposed autopsy with a pathologist. The Chief Forensic Pathologist (or delegate) can provide training.

Queensland legislation governing autopsies (see www.legislation.qld.gov.au)

<i>Transplantation and Anatomy Act 1979</i> (abbreviated as “The Act”)	Part 1, sect 4 & 6 Part 3 Part 4 Section 48	Definitions of Designated Officer, etc Donations of tissue after death Post-mortem examinations Offences in relation to removal of tissue
<i>Coroners Act 2003</i>	Part 2 Sections 12 & 26	Reporting deaths Deaths not to be investigated, Control of body
<i>Births, Deaths and Marriages Registration Act 2003</i>	Section 30	Cause of death certificate (Form 9)
<i>Criminal Code Act 1899</i>	Section 236	Misconduct with regard to corpses

¹ Burton, JL and J Underwood, Clinical, educational, and epidemiological value of autopsy. *Lancet* 2007; 369: 1471–80

² Shojania KG, Burton EC, McDonald KM, Goldman L. The autopsy as an outcome and performance measure. *Evid Rep Technol Assess* 2002; 58: 1–5.

³ RCPA Policy. Autopsies and the use of tissues removed from autopsies. 1993 and revisions

⁴ Lugli A, Anabitarte M, Beer JH. Effect of simple interventions on necropsy rate when active informed consent is required. *Lancet* 1999; 354:1391-2

⁵ Burton EC, et al. The relation of autopsy rate to physicians’ beliefs and recommendations regarding autopsy. *Am J Med* 2004; 117: 255-61

⁶ Tsitsikas DA, et al. The attitudes of relatives to autopsy: a misconception. *J Clin Pathol* 2011; 64: 412-414

⁷ Limacher E, et al. Reversing the slow death of the clinical necropsy: developing the post of the Pathology Liaison Nurse. *J Clin Pathol*. 2007 Oct; 60(10):1129-34

Definitions under the *Transplantation and Anatomy Act 1979* (the *Act*)

Senior available next of kin (SANOK) – Section 4 of the *Act* defines SANOK based on a ranked hierarchy of family members. Unless the deceased gave written consent to autopsy while alive, the consent of the SANOK is required. The consent of other family members who are not the SANOK is insufficient.

Designated Officer (DO) – Section 6 of the *Act* defines how DOs are appointed. DOs may be medical practitioners or other staff, and must be appointed in writing, apart from a Medical Superintendent (or equivalent), who is a DO *ex officio*. The DO must undertake the checks set out in sections 22 and 26 of the *Act*. Signature of a consent form by a person who is not a DO under section 6 does not authorise an autopsy (or tissue donation).

Authority – Parts 3 and 4 of the *Act* define how tissue donation after death and autopsies can be authorised. Usually this requires both consent by the SANOK and the approval and signature of a DO. (Also, a Coroner may order an autopsy under the *Coroners Act 2003*.)

Offences – Section 48 of the *Act* defines offences and penalties for removing tissue or performing an autopsy without authority (see also *Criminal Code Act 1899*, section 236).

Tissue – Section 4 of the *Act* defines tissue widely as an organ, blood, or an extract or part of a human body or foetus. Anything taken from a body is therefore tissue, except for foreign items inserted into the body, such as prostheses, implants or canulae.

Specimen tissue – Section 29 of the *Act* defines “specimen tissue” counter-intuitively as “tissue kept in the form of a tissue block [in wax] or ... [microscope] slide”.

Codes of ethics governing autopsies

The first modern Australian standard on autopsy practices and ethics was the 1993 Policy of the Royal College of Pathologists of Australasia⁸. WHO published practice guidelines for mortuaries in 1999⁹. Australian Health Ministers adopted a National Code of Ethical Autopsy Practice¹⁰ in 2002 to address problems with autopsies in the UK and Australia.

The National Code includes a duty to seek consent from next of kin, to give clear information, and to engage a skilled professional in the approach for consent. The Code was referenced in Australian mortuary standards (2004, updated 2009)¹¹. Of special importance to autopsy practices is the emphasis which health-related codes place on informed consent and awareness of new ethical issues¹²; and respect for people and for the law¹³.

Research involving cadaveric human tissues must follow the NHMRC National Statement which requires consent from the next of kin and discussion of disposal arrangements¹⁴.

⁸ RCPA Policy. Autopsies and the use of tissues removed from autopsies. 1993 and revisions

⁹ Ethical Practice in Laboratory Medicine and Forensic Pathology”, WHO, 1999

¹⁰ <http://www.dh.sa.gov.au/autopsy-organs/documents/National%20Code%20of%20Autopsy%20Practice.pdf>

¹¹ National Pathology Accreditation Advisory Council. Requirements for the facilities and operation of mortuaries. 2004 and second edition 2009

¹² Australian Medical Association Code of Ethics, 2004, revised 2006

¹³ Queensland Public Service Code of Conduct, January 2011

¹⁴ National Statement on Ethical Conduct in Human Research, NHMRC, 2007

Frequently asked questions (FAQs)

The following FAQs are based on questions asked by those completing autopsy consent forms and those receiving them in mortuaries.

What autopsy consent form should I use if the death has occurred in a private hospital?

If a pathologist has agreed to do an autopsy in a Queensland Health facility, then you should ask the pathologist to send you a copy of the current Queensland Health consent form. In general, other autopsy consent forms are not acceptable in Queensland Health facilities.

What should I do if the body is not in a hospital?

You should follow the procedures in section 27 of the *Act (Authority for post-mortem where body of deceased not in hospital)*. In brief, section 27 enables the deceased while alive, or the SANOK after death, to consent to autopsy in writing and thereby authorise an autopsy (without the need for a DO) – providing that the Coroner's consent is obtained if the death is reportable. Also, the SANOK must not authorise an autopsy if the deceased has revoked consent, or if a SANOK of similar or higher rank has objected to autopsy.

What if the hospital where I work does not appear to have a Designated Officer (DO)?

Under section 6 of the *Act*, the Medical Superintendent (or equivalent) is automatically a DO. Alternatively, section 6 allows a hospital manager to appoint a DO in writing.

Can an autopsy be authorised in one facility and performed in another?

The *Act* appears not to prohibit this arrangement, which for obvious practical reasons must have been a common – and growing – practice ever since the *Act* commenced.

Can an autopsy be authorised prior to death?

Yes – but only by the deceased person in writing while alive (and mentally competent) under sections 26(5) and 27(3) of the *Act*. Also, section 26(3) of the *Act* permits the SANOK to inform a DO prior to death that there are no known objections to autopsy. In all other situations, the process of authorising an autopsy can only begin after the person has died.

Can a hospital autopsy be done to help a doctor determine the cause of death?

No – section 30 of the *Births, Deaths and Marriages Registration Act 2003* requires the doctors involved to decide whether any of them “is able to form an opinion as to the probable cause of death”. Such a doctor “must complete” a Cause of Death Certificate (Form 9) within two working days, unless the death is reportable or under investigation by a Coroner. Section 30 makes it clear that the opinion may be based on treating the person while alive, examining the body after death, or considering information about the medical history and circumstances of death. The process is thus exactly the same as making any clinical diagnosis. In many cases, a good history is a sufficient basis.

What if the hospital autopsy shows a cause that differs from the Form 9?

This will occur in about 20-30% of cases. It is acceptable to issue an amended Form 9.

Does a Form 9 need to be issued before seeking consent to an autopsy?

Yes – it must. Under the *Coroners Act 2003*, a death is reportable (to a Coroner) if “a Cause of Death Certificate [Form 9] has not been issued, and is not likely to be issued”. If a death is reportable, the Coroner is unlikely to consent to a hospital autopsy.

If there is a risk that the family may refuse a medically desirable autopsy, should a Cause of Death Certificate (Form 9) be withheld in order to prompt a coronial autopsy?

No – the law is explained above. A doctor who can form an opinion as to the probable cause of death must complete a Cause of Death Certificate (Form 9), unless the death is reportable to the Coroner. Imposing an autopsy on a reluctant family in this way would be contrary to the National Code of Ethical Autopsy Practice and the Queensland Health Code of Conduct. Also, it is unlikely to lead to an autopsy. A Coroner who considers a death does not merit coronial investigation is likely either to encourage issue of a Cause of Death Certificate, or to order an external examination of the body only, particularly if the family objects to autopsy.

Does an authority for autopsy allow a pathologist to take tissue samples or organs for teaching and research?

No – under section 29 of the *Act*, the authority only allows the autopsy, removing tissue for the autopsy, and using such tissue for “medical purposes or scientific purposes” if it is “specimen tissue” (i.e. slides and blocks). Taking additional tissue samples or organs for purposes other than the autopsy requires an authority under Part 3 (Donations of tissue).

Can a medical practitioner who is not a specialist pathologist perform an autopsy?

Section 30 of the *Act* requires an autopsy to “be made ... by a medical practitioner”. Moreover, Queensland Health endorses the Policy of the Royal College of Pathologists of Australasia¹⁵: “An autopsy is a specialised medical procedure and therefore should only be performed by a pathologist ...”, or a pathology registrar in a training program.

Is it permissible for a medical practitioner to both authorise and perform an autopsy?

No – section 29 (1) of the *Act* prohibits a medical practitioner who has acted as DO from performing the autopsy.

What should I do if I am a pathologist or mortuary assistant and am not sure if the appropriate consent form has been used and correctly completed?

If in doubt, you must not proceed with the autopsy until you have had the form checked. Performing an autopsy without valid authority is an offence. You can seek advice from a lawyer retained by your facility, and can ask for training to help with future cases.

¹⁵ RCPA Policy. Autopsies and the use of tissues removed from autopsies. 1993 and revisions

Procedure for seeking consent to hospital autopsy

This Procedure sets out the steps required to seek consent for, and authorise, an autopsy, summarises the documents to be provided to the pathologist before an autopsy can be performed, and provides a check-list for the person interviewing the family. It is strongly recommended that this person be trained in the process and should have read the Explanatory Information about legislation and codes of ethics. The Explanatory Information is accessible at: http://www.health.qld.gov.au/consent/html/sub_specialties/autopsy.asp

Steps required

1. Legislation and codes of ethics must be followed, especially the *Transplantation and Anatomy Act 1979* (the *Act*), Parts 3 and 4 and the definitions in sections 4 and 6 of Senior Available Next of Kin (SANOK) and Designated Officer (DO).
2. The person interviewing the family must check that the family member from whom consent is to be sought fulfils the definition of SANOK.
3. The person must also discuss the proposed autopsy with the pathologist. This will allow sufficient details to be explained to the SANOK, including the scope of the autopsy, the samples to be tested, whether whole organs are to be kept, options as to their disposal, etc. The consent form must record the responses and also include details relevant to the mortuary (e.g. name of the funeral firm, time of funeral). Judgement is required to avoid unnecessarily confronting details and yet provide sufficient information to allow informed consent.
4. Generally, the Autopsy Consent Form may only be completed after the patient has died – and forms completed prior to death are invalid.
5. If the death is reportable under the *Coroners Act 2003*, the Autopsy Consent Form *must not* be used unless one of the following applies:
 - A Coroner consents to a hospital (non-coronial) autopsy under section 28 of the *Transplantation and Anatomy Act 1979*.
 - A Coroner stops having control of the body, e.g. by authorising issue of a Cause of Death Certificate (*Coroners Act 2003*, sections 12(2)(b) and 26).
6. If a person signs a written consent to autopsy during life, and has not changed his/her mind, this authorises an autopsy under the *Act* (without involvement of a DO). The written consent *must be attached* to the form, completed in relevant sections.
7. If the person did not give written consent, the *Act* requires one of the following to authorise an autopsy:
 - *Body in hospital*: written consent of the SANOK and authorisation by a DO. If the consent is obtained orally by telephone, the DO must ensure that the telephone conversation is documented and that reasonable attempts are subsequently made to have the SANOK confirm the consent in writing.
 - *Body not in hospital*: written consent by the SANOK
8. The DO must meet the definition in section 6 of the *Act*, make the checks required by section 26 before signing the authority, and ensure that all documents recording consent are placed in the deceased person's hospital records as soon as practicable.
9. Removing additional tissue for a purpose that is *not part of the autopsy* requires separate authorisation under Part 3 of the *Transplantation and Anatomy Act 1979*.

Essential documents required by the pathologist prior to autopsy

The person interviewing the family must ensure the following documents are forwarded promptly to the pathologist, who should not perform the autopsy until they are all available:

1. A copy of the completed consent form, or a written record of the consent having been obtained by telephone (with the original placed in the medical records)
2. Any written consent to autopsy signed by the deceased person during life
3. A copy of the Cause of Death Certificate (Form 9) (with the original sent to the Registrar General)
4. The clinician's request to the pathologist listing issues to be addressed at autopsy
5. The patient's original medical records – a photocopy or fax may be acceptable at the pathologist's discretion

Responsibilities of the person interviewing the family – a check list

It is recommended that the person interviewing the family complete this check-list in every case to satisfy him/herself that all the key requirements have been met.

<input type="checkbox"/>	I am familiar with the process of seeking consent for autopsy, including the relevant legislation and codes of ethics.
<input type="checkbox"/>	I am confident that the death is not reportable under the <i>Coroners Act 2003</i> .
<input type="checkbox"/>	I have checked that the family member interviewed is the SANOK under the <i>Act</i> .
<input type="checkbox"/>	I have arranged an interpreter or cultural support person where necessary.
<input type="checkbox"/>	I have explained the cause of death and shown the Form 9 to the SANOK.
<input type="checkbox"/>	I have made sure that hospital autopsy consent form is the most up-to-date version in use by Queensland Health and that all sections have been completed.
<input type="checkbox"/>	I have discussed the proposed autopsy with the pathologist, including its scope, likely benefits, samples to be tested, whether whole organs are to be kept, and options as to their disposal. I have explained the autopsy to the SANOK, answered any questions, and documented the outcome on the consent form.
<input type="checkbox"/>	I have given my contact details to the SANOK.
<input type="checkbox"/>	I have ensured that, where applicable, a DO, who complies with the <i>Act</i> (and is not conducting the autopsy), has signed the form and authorised the autopsy.
<input type="checkbox"/>	I have, if consent was obtained by telephone, posted a copy of the completed form (and information sheet) to the SANOK for signature confirming consent, asking that it be returned in the prepaid envelope to the DO.
<input type="checkbox"/>	I have, on behalf of the DO, ensured that all original consent documentation has been placed in the deceased's medical records in compliance with the <i>Act</i> .
<input type="checkbox"/>	I have forwarded a copy of the consent form and other essential documents to the pathologist, and understand that the autopsy cannot proceed without these.