

## **DO YOU HAVE PATIENTS OR CLIENTS WITH QUESTIONS ABOUT ORGANS OR BONE SAMPLES KEPT AT AN AUTOPSY PERFORMED IN THE PAST ON A FAMILY MEMBER?**

This information has been produced by the Australian Health Ministers' Advisory Council Sub-committee on Autopsy Practice as part of the National Communication Strategy being implemented from 30<sup>th</sup> October 2002. This gives individuals the opportunity to seek information from information lines in every state or territory should they be concerned that a family member may have been involved.

### **INFORMATION FOR HEALTH PROFESSIONALS**

*It is recognised that there may still be families who have questions about organs and bone samples retained from an autopsy that was performed some time ago. In the past there was a reluctance to tell family members about the processes of an autopsy for fear of increasing their distress at an already very difficult time. It is now understood that families have a right to information and need to determine for themselves what information they would like to know. Two national reports have addressed this and their recommendations implemented.*

*An information pamphlet and a poster have been prepared to alert families to telephone information lines aimed at allowing them to make inquiries when and if they are ready. This approach was adopted so that individuals could choose if and when they obtained information about past autopsies. Next of kin will not be directly contacted.*

*The information available will depend on what records can be accessed and usually can only be released to the senior available next of kin of the person who died. The information, including translated versions of the pamphlet, is also available at [www.dhs.sa.gov.au/autopsy-organs](http://www.dhs.sa.gov.au/autopsy-organs).*

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#### **Background**

Retention of tissues and organs following autopsy first attracted public attention following events in the UK. The Bristol Inquiry into paediatric cardiac surgery practices went on to investigate organ and tissue retention issues (<http://www.bristol-inquiry.org.uk>) Subsequent information revealed at the Royal Liverpool Children's Hospital (Alder Hey) (<http://www.rlcinquiry.org.uk>) and a report of the Chief Health Officer, "The Removal, Retention and Use of Human Organs and Tissue from Post-Mortem Examination" (<http://www.doh.gov.uk>) increased community concern.

In response to these international concerns and to address local issues, the Australian Health Ministers set up a subcommittee (AHMAC Autopsy Subcommittee) to produce policy and guidelines for future autopsy practice. This subcommittee produced the National Code of Ethical Autopsy Practice that was released in April 2002.

The Australian Health Ministers subsequently referred two reports produced by the Australian Health Ethics Committee (AHEC) to the AHMAC Autopsy Subcommittee. The two reports,

entitled " *Organs Retained at Autopsy - The Ethical and Practical Issues*" and "*Ethical and Practical Issues concerning ashed bones from the Commonwealth of Australia's Strontium 90 Program, 1957-1978*" tasked the AHMAC Autopsy Subcommittee to oversee the implementation of the reports' recommendations (<http://www.nhmrc.gov.au>) The recommendations required institutions to conduct audits of retained organs and ashed bones, and for a public information campaign to be conducted.

### **Why have a public information campaign?**

Media coverage of the issues resulted in many people whose family member had died and undergone autopsy contacting the institutions concerned seeking information about whether organs had been retained. It is recognised that there may still be families who have questions in relation to an autopsy that was performed some time ago.

A key recommendation in both reports was that institutions holding organs removed at autopsy, or those holding samples or records relating to use of samples in the Strontium 90 testing program should not initiate contact with next of kin about this. Rather it was decided that a public information campaign should be designed to inform the public and invite their questions. This approach was adopted so that individuals could choose if and when they obtained information about past autopsies rather than having this information forced on them.

As part of this information strategy, this background material has been prepared to assist you if a patient/dient asks you questions. An information pamphlet and a poster are available that outline further information and provide contact details for those who wish to inquire.

### **What are the different reasons for autopsy?**

In Australia, there are two reasons for autopsies:

#### *Hospital Autopsies*

The family may ask the doctor to arrange for an autopsy to be performed, or a doctor may ask the family for permission to carry out an autopsy. A hospital autopsy is not performed without the permission of the family or the person before they died. An autopsy can give valuable information about the illness and treatment. It may also help families and doctors to better understand the reason for illness and death.

#### *Coronial Autopsies*

Some deaths (e.g. where the cause of death is unknown or where the person has died of unnatural causes such as an accident or suicide) must be reported to the Coroner. The permission of the next of kin is not required for a coronial autopsy.

### **What samples may have been kept after the autopsy?**

Most autopsies would involve the taking of small samples of tissue for subsequent examination and this is generally understood and accepted by families. However, of far greater concern to most bereaved families is the thought of whole organs being retained. Some autopsies may have involved whole organs, such as the heart or brain, being retained for further diagnosis; teaching or research and the family may not have known this occurred. While some of these organs will have been disposed of, some organs will still be in existence. In other cases, samples of bone may have been provided to the Commonwealth for inclusion in the Strontium 90 program, which was looking at the effects of nuclear testing by measuring the take up rate in the bones of people who had died and underwent autopsy from 1957 to 1978 (see <http://www.arpana.gov.au> ).Whilst a small number of ashed bone samples still exist, the majority have been used up in the testing process. Records however may indicate that samples were taken from a particular person, even if the samples no longer exist.

### **Would the family have known about the whole organ retention or participation in Strontium 90?**

If the family gave consent for a hospital autopsy, varying degrees of information may have been given to them depending on where the autopsy occurred. Consent for the autopsy in

most cases in the past was considered consent for other uses of the samples, which were removed at autopsy. Some families may not have fully understood what they were giving permission for, or that whole organs or bone samples may have been removed and kept.

In Coronial autopsies, the permission of the family is not required and in years gone by, they would have received very little information about what happened at the autopsy. They might have been given a general brochure that explained the autopsy process, but may be quite surprised to learn that whole organs and or bone samples had been removed and kept.

### **Sort of information that may be available**

The information available will depend on the records that can be accessed and usually can only be released to the senior next of kin of the person who died. Requests from other family members will need to be considered on a case by case basis.

After carefully checking all available records, the type of information that may be provided to the inquirer includes:

- whether any organs or ashed bone samples were retained;
- if material was retained but subsequently disposed of;
- whether any of this retained material still exists;
- where material still exists, options for disposal or continued use.

### **Issues that may arise for your patient/client**

Thinking about the issues associated with the autopsy may raise many questions for your patient/client and may also bring up feelings of grief, anger, and distress. Discovering that material was retained at the autopsy without their knowledge will for some people be a shock.

In the past there has been a reluctance to tell family members about the processes of an autopsy for fear of increasing their distress at an already very difficult time. It is now understood that families need information and need to determine for themselves what information they would like to know. The national communication strategy and information lines are aimed at allowing families to make inquiries when and if they are ready.

### **What about the future**

A National Code of Ethical Autopsy Practice was released in May 2002. This strives to ensure that families are as involved as they wish to be in the decision making process about autopsies. It also includes guidelines for what should be covered on hospital autopsy request forms and best practice for caring for bereaved families. Copies of the Code can be obtained from (<http://www.dhs.sa.gov.au/documents/publications/autopsy-practice.pdf>)

### **Where to obtain further information**

Please contact the information line in your state. Contact details are listed on the pamphlet and poster. The information, including translated versions of the pamphlet, is also available at [www.dhs.sa.gov.au/autopsy-organs](http://www.dhs.sa.gov.au/autopsy-organs).

