

the discretion of the coroner to notify any person of the date, hour and place at which a post-mortem examination will be made and to permit him to attend the examination." Coroners are thus empowered to decide who may attend; this may be on an individual case basis or according to a general agreement between the pathologist and coroner.

Those attending autopsies must, of course, respect the medical confidentiality of the deceased and his or her family. They should also understand that information gleaned from the autopsy about the case is, in a sense, owned and controlled by the coroner. Furthermore, although students can attend as observers, pathologists can make examinations only that will contribute to determination of the cause of death. They cannot extend the autopsy dissection and examination solely to serve the learning needs of medical students.

### Public concerns

The New Zealand situation has arisen because of legitimate public concerns about organ retention. However, banning students from autopsies ultimately risks worsening the discomfort of bereaved families. Relatives naturally turn to doctors and other healthcare professionals for help and advice when they are asked to consent to an autopsy or one is required by law. With coroner's autopsies now being the main opportunity for learning about the medical examination of the

body after death, the new generation of doctors will find themselves struggling to explain a procedure they have rarely or never witnessed.

I share O'Grady's enthusiasm for the autopsy as a teaching medium. Zealous overinterpretation of coroner's legislation is not the only factor contributing to the moribund state of the teaching autopsy. Many mortuaries are dilapidated or poorly designed with inadequate viewing facilities. In the United Kingdom, perhaps autopsy education should feature in the training of preregistration and junior house officers, thus remedying the deficiencies of the undergraduate experience.

The root cause of the New Zealand situation is apparently a belief that bereaved relatives might resent students witnessing the autopsy. My experience of families deeply affected by organ retention is that their objection is not necessarily to what was done but that it had been done without their knowledge or, where required, their agreement. There will be exceptions, but bereaved people generally want some good to come from their grief. If medical students can learn from the death, it may be some consolation that future patients could benefit.

Competing interests: I am President of the Royal College of Pathologists and led the production of the college's guidelines on organ retention (2000). I am an observer on the Retained Organs Commission and am paid to do coroner's autopsies.

## Obtaining consent for autopsy

Michael B McDermott

Consent for autopsy is usually obtained by the consultant in charge of the case. Given the detailed information now required, should pathologists take on this role?

The recent controversy about organ retention has led to big changes in the information given to bereaved families. Professional bodies continue to advocate that the clinical consultant in charge of the case has the primary role in the hospital's interaction with relatives at this time.<sup>1</sup> However, their unfamiliarity with autopsy procedures could lead to discrepancies between what is discussed and what the pathologist actually does. As the only pathologist at my hospital, I have taken on responsibility for giving information to relatives and completing autopsy documentation. Although not without its difficulties, this meeting leads to a transparency beneficial to both parents and the pathologist.

### Public disquiet changes practice

The Bristol Royal Infirmary inquiry into deaths of babies having heart surgery caused widespread public concern about the quality of information delivered to families about postmortem examinations.<sup>2</sup> There was particular disquiet that parents had not been specifically informed that this procedure would entail the retention of whole organs for detailed laboratory examination. Similar revelations at other hospitals and in other countries, including Ireland and Australia, prompted a series of public and private inquiries and



Bereaved parents need a full understanding of postmortem proceedings

have resulted in radical changes to the procedures used for conveying information and obtaining consent for postmortem examinations (box 1).<sup>1 3 4</sup>

See also *Papers* p 781  
*Education and debate*  
p 802

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## Experience with new guidelines

One of the main indications for retaining a whole organ, as opposed to a tissue fragment, is the investigation of congenital heart disease. As the national centre for the treatment of children with congenital heart disease, my hospital has been at the centre of this public debate since it began in Ireland in September 1999. The hospital introduced revised postmortem consent and information procedures, including the provision of information booklets for families. Nevertheless, delivery of this sensitive information presented problems.

In common with many hospitals, we found the logistics of informing families about the retention of organs and arranging their return when requested difficult. Professional bodies recommend that the consultant treating the patient should discuss a postmortem examination with relatives. However, staff often felt uncomfortable discussing the details of the procedure with parents, many of whom they had developed long standing relationships with. Furthermore, clinical staff's lack of familiarity with some of the practicalities of postmortem examinations meant that what was proposed in conversation with the family could differ from what was done by the pathologist.

Some paediatric pathologists, particularly in the United States and Australia, hold next of kin clinics a few weeks after the postmortem examination to discuss their findings.<sup>5</sup> As the pathologist is in the best position to describe the procedure, I saw no reason why a pathologist could not take on a similar role before the postmortem examination. I therefore undertook to meet families wherever possible. This meeting has now become standard practice at the hospital. In the 32 months since its introduction, I have been able to meet 78% (65 of 83) of families before the postmortem examination. In the past six months, the figure is 100% (18/18), reflecting improved familiarity with the system.

## How the pre-autopsy consultation works

Before the postmortem examination, I meet parents with or without other members of the family in accordance with the parents' wishes. The meeting is also attended by a social worker, nursing staff who have

cared for the child, and a chaplain if appropriate. A member of the medical staff usually introduces me to the family. I explain the role of the coroner, give a detailed description of what is involved in a full postmortem examination, and explain how long it will take and why I need to retain tissue or organs. If organs are to be removed, families are given the option to have them returned and, when possible, to defer the funeral until the examination of organs is completed. The families are also given the opportunity to ask any questions they may have about the procedure.

Although this meeting is the main conduit of information on the autopsy procedure, many or most of the families will have had some discussion with clinical staff beforehand. They also receive a postmortem information booklet.

## Challenge of providing more information

The principal motivation for the change in practice was anxiety about the potential gap between families' understanding of what was proposed as part of a postmortem examination and the examination itself. A direct discussion between the pathologist and families seemed the best way to overcome this problem. I was conscious that delivering such information to recently bereaved families would be distressing to them. Many clinicians had also expressed their concern about the insensitivity of delivering this information at this time. Some commentators have argued that families should be given the opportunity to opt out of this information process before any discussion of the postmortem procedure.<sup>6</sup> In my experience, only two parents have asked to leave the room before or during the discussion, deferring the task to their spouse.

Some parents, however, have obviously been angered by the discussion, particularly when the coroner has directed a postmortem examination and parental consent is not a determining factor. In such cases, the discussion is often protracted and uncomfortable as I seek a compromise that satisfies both my responsibility to the coroner to perform a full postmortem examination and the expressed desire of the family to limit it. So far, I have always reached an agreement with the family.

## Dialogue about organ retention and return

Discussion about the return of retained organs forms another important part of the meeting. In all cases, having read the hospital chart and discussed the case with clinical staff, I have been able to predict what organs I may need to retain for further examination before I meet the family. This enables me to discuss the issue openly with parents and present their choices for dealing with retained organs practically rather than hypothetically.

Interestingly, in the early months of the process, nearly all the families asked for organs to be returned for subsequent burial on completion of the autopsy. Over the past 18 months, however, families have been increasingly opting to delay burial or cremation until detailed examination is completed. This deferral of funeral arrangements represents a radical change from

### Box 1: Some of the new guidelines for consent to autopsy

- Relatives must be given sufficient information about the postmortem examination to ensure that their perception of the procedure unambiguously matches the procedure performed, particularly regarding tissue retention
- Relatives should be informed that processed, wax embedded tissue from the examination will be stored in the hospital archive
- Specific written agreement must be obtained for the retention of any whole organ
- Specific written consent must be obtained for use of tissue for educational or research purposes
- Relatives should be given the opportunity to direct the ultimate disposal of any organs or tissues retained as part of the autopsy

### Summary points

Public criticism has prompted review of consent procedures for postmortem examinations

Professional bodies recommend that the principal clinician discusses the autopsy with relatives

Pathologists are in a better position to ensure that relatives are aware of everything that may be required in the postmortem examination

Pre-autopsy consultations between the pathologist and relatives have been successfully established in a children's hospital

Although they increase workload, the meetings result in clearer understanding for both the family and the pathologist

the previous experience in Ireland, where many families sought to leave the hospital with the remains of the child as quickly as possible, often within hours of the child's death.

### Resource implications for pathology

In the past, examination of a congenitally abnormal heart or central nervous system was done after prolonged fixation and at a time suitable to the pathologist and the relevant clinical staff. However, I am now committed to completing the examination within two or three days, irrespective of other demands within the department, in order to accommodate parents' wishes. Of the 83 postmortem examinations under the new system, 38 (46%) took place at weekends or public holidays. Additional procedures initiated on Thursday or Friday were often completed over weekends. An important problem with this accelerated process is that it has not always been possible to include clinical staff in the examination.

### Benefits for parents and hospital

The changes in practice described above are radical but have undoubtedly benefited both the hospital and parents (box 2). The hospital has removed a potential information deficit, which might be the subject of future criticism. It now has clear instructions for the ultimate disposal of all retained organs before the postmortem examination is started. Parents have had an opportunity to ask detailed questions about the

#### Box 2: Benefits and difficulties of pre-autopsy meetings

##### Benefits

Clarity and consistency of information for relatives  
Greater parental choices in the nature and extent of autopsy and timing of funeral

##### Difficulties

Difficult information to parents delivered at a difficult time  
Additional workload in pathology before autopsy  
Additional workload in pathology during autopsy process, often out of hours

examination. They can be certain that the pathologist has heard and documented any limitations they have imposed and their instructions about the return of retained organs. Even in the circumstances of a coroner's autopsy, this discussion gives the family an opportunity to participate in the decision making process—for example, influencing the time scale and directing the return of retained organs.

### Change in nature of interaction

Changes to the procedure and documentation have been accompanied by changes in the nature of the discussion between hospital staff and families about postmortem examinations, particularly in non-coroner's autopsies. The discussion is no longer the simple delivery of information by the hospital and the documentation of a family's consent in the form of a signature. Rather, the family and I present our requirements, limitations, expectations, and hopes for the procedure. After negotiation, we agree a set of terms under which the autopsy will be performed. I then offer to perform the procedure within the agreed terms and the family decides whether to request that I proceed. We may now need to change the documentation associated with postmortem examinations to reflect this evolution, with families being offered the opportunity to sign a postmortem request form rather than a consent form.

Further discussion of the effect of this strategy is obviously required. In many hospitals, the large numbers of postmortem examinations may preclude such meetings. Even when they are feasible, the strategy imposes large burdens on limited pathology resources. Pathologists have not been trained for such an interaction with families, and many think it is inappropriate to meet the families before the examination. Some have privately argued that such a meeting leaves pathologists open to the accusation that they are attempting to influence unduly the family's decision about an autopsy. Given the change in the nature of the discussion I have described above, I do not think the meetings are susceptible to any such interpretation. If postmortem examinations are to survive the current controversy and continue to have a role in professional audit, such changes must be given further consideration.<sup>7</sup>

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