EDITORIAL

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Since 2000 the hospital post mortem rate has been in free fall and is now less than 5% of deaths in many hospitals in the UK. A major factor in this decline has been the turmoil following events in Bristol and in Alder Hey Hospital, Liverpool where organs were retained apparently without the knowledge or consent of the bereaved. There is now a real danger of hospital post mortem examinations (PMEs) disappearing altogether, with the associated loss of the necessary skills amongst consultant pathologists. Does this matter?

To answer the question we need to focus on what has been achieved through examination of post mortem human brains in the past, specifically for neurological disorders. Firstly, collections of diseased and normal cases in Brain Banks have facilitated the discovery of new diseases such as Dementia with Lewy Bodies and variant CJD. Secondly, the cellular and molecular mechanisms underlying long recognized diseases like Alzheimer's disease are being worked out, leading to more appropriate therapy. And thirdly, the potential for future re-

Is post mortem practice in terminal decline and should we care?

Professor Jeanne E Bell

Professor of Neuropathology, University of Edinburgh, UK; E-mail: jeanne.bell@ed.ac.uk
Practical Neurology, 2004, 4, 257–259

search in proteomics and genotypic/phenotypic correlation is exciting and will certainly require human brain tissue. However, resources of brain tissue, including vital normal control cases, require regular replacement as they are used up in research studies. Where is such tissue to come from in the future and how is the necessary cadre of future neuropathologists to be trained?

In the UK, hospital post mortem activities have been regulated by the Human Tissue Act (1961) and the Anatomy Act (1984). Both are now deemed unsatisfactory for providing a properly consented framework for hospital PME. It is worth noting that forensic PMEs greatly outnumber hospital PMEs but gaining consent for anything other than diagnostic activities in this setting would require Herculean efforts. The authority of Coroners and Procurators Fiscal who instruct pathologists to undertake forensic PMEs in the UK extends only to determining the cause of death. In order to take tissue samples or organs for research, or to undertake teaching activities in the context of a

forensic PME, the consent both of relatives and of the legal authorities is needed. It is unlikely that Coroners or Procurator Fiscals will feel it appropriate to *tell* families that a PME is taking place and in the next breath *ask* whether they will allow tissues or organs to be removed for research purposes. Who then can explain the issues to families and seek the necessary consent? This thorny question remains unresolved in most forensic settings. The situation is further complicated by the likely impact of planned changes in legislation. The complex Human Tissue Bill 2004 has been unveiled for England, Wales and Northern Ireland. Plans for new legislation in Scotland are currently out for public consultation.

Legislative plans across the UK take as their foundation the principle of consent, which has been heartily endorsed by all sides. Outside Scotland, compliance with every aspect of pathology practice will be under the control of a Human Tissue Authority, constituted in law under the new Bill, which covers not only post

mortem tissues but also tissues removed from living patients. What is surprising is that the Bill pays little or no attention to organ retention, or to research activities (or the lack of them), two issues that lay at the heart of the organ retention crisis. Not surprisingly, many professional and research organizations in the UK have expressed grave concerns about the impact of this complex legislation on future training and research. Even diagnostic practice will be made more difficult as a result of the burgeoning bureaucracy. Promised Codes of Practice from the Human Tissue Authority do not inspire confidence if the membership of the Authority changes on a three yearly cycle. Each and every pathologist is likely to be nervous about incurring a penalty of 3 years imprisonment for defaulting on the new Act. It is particularly frustrating that the all-important issue of using archival samples for research remains unresolved until a suitable Code of Practice is drawn up. In Scotland, it is hoped that consultation will lead to a clearer outcome, and in the meantime a proper framework for the research use of archival tissue has already been established. Courageous decisions have been taken by the Scottish Executive in balancing the public good against the views of the minority who seek to curtail the use of post mortem tissue.

The role of Ethics Committees in overseeing research projects that use post mortem tissue is crucial. Increasing requirements for ethical approval of every aspect of pathology practice are frustrating if the research poses no possible threat to the deceased, nor to their family. Most of all, consistency in Ethics Committee decision making is required, from members of those committees who thoroughly understand the issues and who are prepared to take difficult decisions for the public good.

Pathologists committed to the value of PME are fighting their corner on several fronts. We need to lobby for clear and sensible legislation which will provide a workable framework for PMEs in the future. Neuropathologists strive to provide a good service for clinical colleagues who need to understand why a neuropathology report takes several weeks to prepare. However, neuropathologists can help their colleagues by displaying flexibility. While advocating whole-brain fixation as the optimal approach to reach a diagnosis, it is possible to briefly fix the brain and remove appropriate blocks for histology before the brain is returned to the body, if for

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example parents are adamant in their opposition to brain retention. Most important of all, pathologists need to be seen outside their laboratory cloisters, engaging with the public about what is involved in PME, and what will be lost if this disappears. All too often the public perception of research is far removed from what actually happens in pathology departments.

It is clear from surveys across Europe, and further afield, that there is considerable variation in the legal and ethical constraints that govern hospital and forensic PMEs in different countries. Colleagues outside the UK have noted the recent developments in Britain and are taking steps to avoid a similar crisis in their own countries. Closer alignment of working practices will facilitate ongoing collaboration across frontiers to maximize the benefits of PME-related research.

COMPETING INTEREST

I undertake autopsies for the NHS and for the legal authorities. I maintain MRC funded brain banks for HIV/AIDS with drug abuse, and for Alzheimer's disease. The views expressed here are personal.