

Sebastian Lucas and Richard Cook reflect on a public scandal.

# Alder Hey



Alder Hey is the latest in a series of high-profile ‘scandals’ involving the NHS in general and doctors in particular. The stockpiling of organs without consent highlighted in the 600-page Redfern Report, and especially Health Secretary Alan Milburn’s criticisms of the NHS, which followed, have provoked a huge variety of reactions. *Triple Helix* invited comment from a pathologist and a paediatric surgeon on the practical and spiritual lessons we should learn.

## Lessons need learning, but autopsies remain fundamental

‘Arrogant’ and ‘paternalistic’ pathologists, deeply wounded parents angry because they did not bury the entire bodies of their dead fetuses and children and a no-regrets, foreign professor to demonise. Images of baby hearts and other organs stacked in cellars, a 1961 Human Tissue Act that is woefully outdated and a health secretary promising radical changes in medical practice and law – all wrapped up in a media frenzy. The Royal Liverpool Children’s Inquiry was the latest defining episode in the relationship between the public, hospitals and autopsy pathologists. The problems arose because what went on in the autopsy room was, by tradition of sparing unpleasant details, not described to relatives when permission for autopsy was being sought or being ordered by a Coroner.

Since 1970, according to the Chief Medical Officer’s census of organ retention, over 50,000 organs of adults, fetuses and children have been retained; mostly without fully informed consent from relatives. A small proportion were held technically unlawfully in that they came from Coronial autopsies where material is only retained in order to make a diagnosis and for inquest. The fetal/paediatric organ collection at Alder Hey is the largest, but by no means the only such, in the UK.

No one disputes the value of retaining material from autopsies - for getting the diagnosis right, undergraduate and post-graduate education, and research. The management of congenital heart disease has improved greatly, in part through having archived sets of heart-lungs for surgical review. Our knowledge of

dementia depends on having well catalogued brains (for Alzheimer’s, not just the hopefully rare vCJD). The parents of the children whose organs were kept reinforce that, had they been asked properly, they would usually have consented. But the process of obtaining consent for autopsy takes place at the worst possible time emotionally both for them and for doctors; and the standard consent forms did not necessarily distinguish ‘tissue samples’ (for histopathology) from whole ‘organs’ such as heart, brain and lung.

We move forward, but pathology has taken a large knock in morale; with few exceptions the tissue retention was done with the best of medical intentions. We need to apologise where distress has resulted and draw a line to say that what was done is history. The autopsy consent process now involves full participation by the next of kin. I worry that rapid drafting of laws and amendments leads to unmanageable outcomes, and prefer guidelines that can be modified with practice. We need a Human Tissue Authority to oversee research and ethical aspects of tissue archives (and that includes material from surgical operations – another area of historical ignorance). But the autopsy will continue to be a fundamental part of clinical governance and medical education.

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## We need a Christian perspective on death and the body

‘Great Organ Scandal’ may sound like the title of a Roald Dahl children’s story. Yet this has been the language of press and parliament, often intemperate and extravagant, and, even if not trivialising the problems, has diverted thought and action from the fundamental issue of how we treat our dead. One doctor’s excesses have brought to light the widespread and long-standing practice of collecting and preserving human organs and tissues. Is this now seen as a ‘scandal’ because of a shift in society’s attitude to death and to our bodies?

The Bible says less than we might expect about the human body. It is material - made from ‘the dust of the ground’, but made a living being by ‘the breath of God’.<sup>1</sup> It is a ‘tent’, or ‘clothes’,<sup>2</sup> allowing expression of the real person who is ‘at home’ in the body, then absent from it after death.<sup>3</sup> It is mortal and will decay. However, there are examples of careful and loving treatment of the body after death (the burial of Sarah, Abraham, and other Patriarchs), and even of embalming (Jacob and Joseph - and this, of course, would have involved removal of the viscera). Jesus healed physical diseases, and his own body was treated with care and respect by two secret disciples.

The overall picture is one where both the limitations of the physical body (mortality, decay and disintegration) and also its uniqueness and value are recognised. Above all else it is clear that after death, the body is only a shell. The destiny of the person is elsewhere; either to be with Christ, clothed with a resurrected body like his or to face eternal separation from God.<sup>5</sup> Thomas Sydenham’s advice to his students, as

## References

- 1 [www.rlcinqury.org.uk](http://www.rlcinqury.org.uk) (published 30 January 2001)
- 2 The CMO’s report and census on organ retention are on [www.doh.gov.uk](http://www.doh.gov.uk) (published 30 January 2001)



Photo: PA photos

‘WE NEED TO REDISCOVER THE TRUTH THAT THE BODY, ALTHOUGH A PRICELESS AND UNIQUE MASTERPIECE, IS NOT THE TOTALITY OF THE PERSON. RATHER IT IS A DYING SEED, A MERE FORETASTE OF THE RESURRECTION BODY..!’

published in ‘Medical observations concerning the History and Cure of Acute Diseases’ in 1688, crystallises what should be our attitude:

‘Whoever applies himself to medicine should seriously weigh the following considerations...he must remember that it is no mean or ignoble creature that he deals with. We may ascertain the worth of the human race since for its sake God’s only begotten Son became man and thereby ennobled the nature that he took upon him.’

All of us, as doctors, learnt from, were taught on and even examined on, dead bodies and preserved specimens. Much essential morphological research was dependent on the study of whole organs or parts, and much current microscopic and genetic research depends on ‘tissues’, using biopsies, aspirates and blood - but still human tissue. Obtaining, handling and examining this is never pleasant, and where the material has come from is never far from the consciousness of most of us who are involved. The great successes of much of today’s medicine rest to a considerable extent on the careful examination of yesterday’s failures - and we have heard little of the huge improvements achieved in recent years. This method of working has been controlled (perhaps not tightly enough) by the law, and by the mores of society - in so far as society at large has wanted to know or to be involved. Our public mores, and especially the religious philosophy of most, has changed. Consequently the perception of the nature of death, and the significance of the body, and the rites and rituals that help have also changed.

The doctor has two, often conflicting, duties. Clearly there is a duty of care for the bereaved. Attention to this usually led

me, for one, to limit the information offered when asking for an autopsy. Yes, I was paternalistic - in a desire to protect relatives (and especially parents) from explicit and unpleasant details. I was perhaps failing to recognise their autonomy, but my motive was not to aggravate their grief, rather to bear some of it for them. I wonder if I would have the courage (or the callousness) to get ‘fully informed’ consent for an autopsy. Yet it is also caring (as well as a legal obligation) to be accurate in certifying the cause of death. Shirking the duty of obtaining an autopsy easily leads to dishonesty, and to a failure to advance medical science for the sake of future patients.

Other aspects of pastoral care have been sadly mismanaged in the current affair. Parents claim to have been told of their children’s retained organs sometimes callously and occasionally erroneously, and with little help to understand why they were kept, or how they should be decently disposed of. They are understandably aggrieved as well as still grieving.

But doctors too are hurt, not only by the deaths of their patients, but also by the misunderstandings fostered by inept publicity and by misinterpretations of motives. It cannot be denied that the wholesale and, as far as is known, fruitless accumulation of organs by one academic

pathologist was indeed a scandal. If the public (and press and parliament) are indeed ‘scandalised’ by usually respectful, valuable and life saving studies by the medical profession as a whole, what is required is not ill considered and draconian changes in the law, nor a witch hunt to identify culprits. What we all need is to rediscover the truth that the body (whether our own or that of our nearest and dearest), although a priceless and unique masterpiece, is not the totality of the person. Rather it is a dying seed, a mere foretaste of the resurrected body the person could enjoy for eternity through the grace and power of God.<sup>6</sup>

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## KEY POINTS

**T**he stockpiling of children’s organs at Alder Hey without parental consent or apparent purpose was wrong. While insisting that autopsies must remain an essential part of medical practice, for diagnosis, audit, teaching and research, we also need to hear the cry for more honesty and sensitivity when seeking permission to perform them. But the public reaction to this issue is also a symptom that society has lost its way. The increasingly accepted materialist worldview, which equates the person with the physical body, is inadequate. What is really needed is a rediscovery of Christian beliefs about the body, death and eternity.

### References

- 1 Genesis 2:7
- 2 2 Corinthians 5:1-5
- 3 Philippians 1:22-24
- 4 1 Corinthians 15:12-58; 2 Corinthians 5:1-10; Philippians 3:20-21
- 5 Matthew 25:41; Revelation 21:7,8
- 6 Matthew 10:28; Revelation 20:14, 21:1-4