

Increasing the organ transplant rate: some recent UK initiatives

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Series Editor

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In both Australia and the UK, the recent revelations about organ retention without consent after postmortem have made their governments anxious to radically increase organ donor rates. Ideas for doing this are given here.

'I don't carry a donor card myself because it got nicked along with the rest of the contents of my wallet... It's possible that the thief... has himself fallen under a bus and his kidneys are sitting beneath a grateful third party's ribs masquerading as my own. In any case, I'll let this column serve as carte blanche for my organs to be used, post mortem, for any purpose the surgeons see fit – feeding the hospital cat included.'

Thus wrote the newspaper columnist, John Diamond, shortly before his death earlier this year after a long battle with cancer which he documented weekly in *The Times* and also in his best selling book, *Because cowards get cancer too*.¹ (Apparently he was delighted when this book was adopted as required reading for trainee doctors on how it feels to have cancer.)

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Bristol and Alder Hey

It is a pity that Diamond's generosity concerning the posthumous use of his body is not more widespread. In the UK, as in Australia, the demand for organs for transplant far exceeds supply. In fact, the Australian donor rate was the lowest on a comparative table in the UK Department of Health's recent *Draft Consultation Document for Comment*.² In the wake of the revelations from 1999 to the present time of human organ retention at Bristol Royal Infirmary and the Alder Hey Children's Hospital in Liverpool, and the consequent loss of trust in the medical profession, there are concerns that the gap between supply and demand may widen.

For weeks after the Alder Hey report was released, the newspapers reported the retention of children's organs after postmortem, often without the knowledge or consent of the parents. Not surprisingly, the grief and anger of these parents struck a national chord and doctors also were distressed as the details were published. The President of the British Paediatric Cardiac Association said in a letter to *The Times* that he had learnt only during the Bristol Inquiry that 'organs had been retained without the full knowledge of the parents ... or subsequent to removal during autopsies ordered by the Coroner', and that 'loss of public trust was inevitable'.³ *The Times* reported that the Health Secretary, Alan Milburn, had warned that the report on organ retention at Alder Hey Hospital was

‘the most shocking he [had] read’, that ‘one incident given in the report is believed to concern the discovery of a child’s head stored in a jar’, and that ‘thymus glands taken from living children during heart operations [were given] to a drug company for research, in exchange for financial donations’.⁴

Some doctors wrote to the press about the importance of postmortem examination in determining cause of death, clinical audit, teaching and research, and for advising parents of what had happened to their child.^{5,6} They explained why it is necessary to retain organs for later examination – to check by retesting that the initial diagnosis was correct, to have a wide range of organs available for comparison, especially with variations of disease, and so on. But the words ‘scandal’ and ‘loss of trust’ hang in the air. What effect will these revelations have on the number of organs available for transplant? Are there lessons for Australia?

Effect on the organ donor rate

Since I arrived in the UK in January this year, I have seen few reports of Australian news in *The Times*. There was Pauline Hanson’s resurgence in politics, the death of Sir Donald Bradman, and concern about hospitals holding deceased children’s organs and tissue without their parents’ knowledge.⁷ The Australian public’s response to doctors’ practices seems similar to that in the UK. If press reports affect the donation rate in the UK, it is likely that the same will occur in Australia.

In the UK, a flurry of press articles suggested that the organ donor rate would decline after the publicity concerning Alder Hey. The North Bristol Healthcare Trust reported ‘a sharp fall in organs for transplant’.⁸ However, Sir Peter Morris, Nuffield Professor of Surgery at Oxford University and Vice-President of the Royal College of Surgeons, reportedly said that, although the rate increased in 2000, it had been in decline for most of the previous decade.⁸

A renal transplant surgeon in South London reportedly said that people were tearing up their donor cards.⁹ There were photographs of baby Margaux Bride, dying from congenital cardiac disease and urgently needing a heart transplant.⁹ Her mother pleaded poignantly in the national press for a donor.¹⁰ Fortunately, one was found on the Continent and Margaux is now ‘all smiles’.¹¹ The parents of another baby, Maebh Bradley, also appealed for a kidney at the same time.⁸ Other people may still be waiting for organs, or they may have died in the meantime.

On the other hand, some commentators have said that the donor rate has not declined. John Evans of the Organ Donor Society, reportedly said that ‘Organ donation for the whole of [the year 2000] showed a 5% increase over 1999. And if we compare January 2001 with January 2000, statistics show that while there were 58 donors in that month in 2000, this year there were 74’.⁸

Recent suggestions in the UK to increase the organ donor rate

- Change the law to an ‘opt out’ system, so that everyone is presumed to consent unless they have earlier expressed an objection. Doctors have apparently shown ‘little appetite’ for this proposal. UK Health Secretary Alan Milburn reportedly said that this option was ‘touched on’ but ‘in practice wouldn’t change anything’. ‘Even if you had an opt out law, you would never operate it but would always want to discuss donation with relatives.’¹³ The opt out proposal has some popular support, however. A telephone phone-in on a BBC One television program showed an overwhelming majority of respondents were in favour.
- Issue donor forms to employees in their pay packets. Mr Milburn reportedly met with surgeons, transplant organisations and the British Medical Association to discuss this idea.¹³
- Send out donor forms with electoral information. This suggestion was reportedly made by Dr Liam Fox, the UK Shadow Health Secretary.⁹
- Distribute donor information at doctors’ surgeries and with applications for drivers’ licences and passports (doctors’ surgeries and drivers’ licence applications are the principal source of registrations for organ donations in the UK).¹⁴
- Provide for donor forms to be downloaded from the internet. The website of the UK Department of Health allows this, and people may register electronically as donors (the UK National Health Service Organ Donor Register).¹⁴
- Co-ordinate transplant services better throughout the UK.¹⁴
- Advertise on buses, radio and television, and in the popular media.¹⁴ For example, an organ donor form was recently distributed in *The Times*, so that readers could complete it and send it to the office for the Organ Donor Register.
- Work with retailers.¹⁴ The UK Department of Health is considering approaches to Boots (the pharmacy), other private organisations, high street retailers and supermarkets, credit card companies, local authorities, Rotary clubs, and employer and trade union organisations to promote donation.
- Inform MPs, employees in Civil Service, National Health Service staff, police, fire officers, including through their professional magazines.¹⁴
- Campaign to increase awareness concerning organ donation in the south Asian, African, African/Caribbean populations.¹⁴

Initiatives to increase donor rates

Whatever the effect of the adverse publicity concerning the medical profession and the practice of retaining organs without consent after postmortem, the UK government has been anxious to increase radically the organ donor rate. It organised a national summit to discuss new ideas.¹² Some of the suggestions discussed at this summit and elsewhere are listed in the box on page 104. These provide new ideas for consideration in Australia.

Series Editor's comment

It seems there will always be a shortage of organs for donation. Even if we, as a community, embrace in increasing numbers the concept of organ donation – as one bumper sticker I saw put it, 'Don't take your organs to heaven, heaven knows we need them here!' – the number of people requiring vital organ replacement will rise at a faster rate. Allografts or artificial organs are likely to be a more sustainable resource. In the short term, however, human organs plus immunosuppressive therapy remain the best available treatment for liver, renal, cardiac or pulmonary failure. Further, a pitifully small percentage of organs that could be used for transplantation are made available.

Interestingly, as a matter of law your body is not 'property'. Thus when you die, your body is not an 'asset' of your estate. It has been settled law for over a century in Australia that there is no property in a corpse (*Doodeward v. Spence* [1908] 6 CLR 406 [HCA]). No one owns a corpse, although the next of kin are entitled to possession of it for the purpose of burial or cremation. Similarly, although the Supreme Court of Western Australia recently held that brain tissue stored in paraffin wax was property, it did not find that it was 'owned' by the next of kin (or anyone else) (*Roche v. Douglas* [2000] WASC 146). (A woman claiming to be the daughter of a deceased man wanted to access his stored brain tissue for testing to prove she was his daughter.¹⁵)

There has been much negative press recently about retention of organs for teaching or research, without permission – raising centuries-old fears about body and body parts' snatching. 'Was my dad/son/mother/daughter really dead when they turned off the respirator, or did they have a patient waiting for his/her heart?' Robin Cook's book, *Coma* and the subsequent film, played on this fear of what could happen if 'big business' and ambitious 'modern medicine' get together.¹⁶ Earlier, Aldous Huxley

portrayed, in his book *Brave new world*, a world in which age was itself an indication for involuntary euthanasia.¹⁷ Attitudinally, the community's fear of death translates to undue reverence for, and superstition about, dead bodies.

In the past there may have been valid reasons for retaining organs. For example, fixing a brain in formalin to allow microscopic assessment took about a week; hence, any autopsy that required histological examination of brain tissue usually required retaining the brain after burial of the rest of the body.

Using body parts after death for transplantation, teaching or research can be done respectfully, and is frankly of far more use to the community than just letting organs rot in the earth or be burned to ash. But how should the community be encouraged to focus more on the benefits and less on irrational fear?

Doctors should take the lead. Do you have leaflets and Universal Donor Card information in your waiting room? It would be better to have them actually on your desk, so patients can talk to you about them. You can obtain pamphlets from the Australian Organ Donor Registry (telephone 1800 777 203). **MT**

The list of references is available from the editorial office.

Medicine and the Law

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