\Professor Emeritus L R Humphreys

25 August 2008

Ms Karen Struthers MLA
Chair, Parliamentary Committee on Organ Transplants
Parliament House
George St Brisbane 4000.

Dear Ms Struthers,

I was most impressed by your excellent presentation on ABC TV last week about 'presumed consent' for organ transplants. I strongly support the introduction of 'presumed consent'. No doubt your Committee has all the latest dismal figures on the rate of organ donation in Australia and the great benefit to longevity following kidney transplant. I write in two connections:

1. I should like to put the late Sir Raymond Hoffenberg's views to your Committee, if imperfectly, through an extract from my forthcoming biography: 'Hoffenberg: Physician and Scientist, Humanist and Academic' which the Royal College of Physicians in London is publishing.

Hoffenberg was President of the College (1983-89), Professor of Medical Ethics at University of Queensland (1993-95) and late in life was much involved in the International Forum for Transplant Ethics.

With warmest wishes for the success of your Committee,
Yours sincerely,
Ross Humphreys
Ross Humphreys.

'Hoffenberg: Physician as Scientist, Humanist as Academic',
L Ross Humphreys 2008 (in press)

anguish. The Institute of Medical Ethics, of which he became president, favoured medical euthanasia if the patient continually sought death. Legal euthanasia brought many problems; court disputes, division of relatives and caused suffering. He was 'in favour of letting doctors get on with it - quietly, unobtrusively, in the peculiarly British way, unwritten, unacknowledged, and, in a rather pious hope, unchallenged'.

The Ethics of Transplanting Organs

Hoffenberg's interest in transplanting organs from person to person, which had been stimulated by his involvement with Christian Barnard's group at Groote Schuur in 1967, revived in the 1980s with his awareness of the considerable shortage of organs available for donation. He chaired a working party of the Medical Royal Colleges which reported in 1987 about approaches to increasing the supply of donor organs. At this time:

> Successful transplantation of heart, liver, pancreas and lung requires their removal from a dead but heart-beating donor. Kidneys should be taken from a donor before or immediately after the heart stops beating. Corneas may be taken up to twelve hours after cessation of heart beat.

These considerations evoked the reservations of some doctors about brain stem death and its criteria, and the fears of the general public generated by slanted media coverage. Hoffenberg wrote in *The Times* that

> the lives of many patients are being jeopardized by 'irrational and unfounded' allegations about the conduct of transplant teams ... which could lead to a severe cutback in the public response to the need for donor organs for adults and

children who would otherwise die … There is no possibility of organs being taken from a patient who is still alive.[19]

The shortage of kidneys was especially acute for patients suffering endstage renal disease (ESRD). Transplantation led to a longer and better quality life than the alternative of renal dialysis, but some hospitals regarded kidney removal as an unwarranted expense; in fact when the costs of renal dialysis were taken into account, each kidney operation saved the National Health Service c. £30,000. Hoffenberg sought wider public education on these issues, but the manner in which organ transplantation had become institutionalized raised many ethical questions needing re-examination.

These were addressed from the mid-1990s by a distinguished group Hoffenberg helped to form: the International Forum for Transplant Ethics (IFTE). There were 'representatives of philosophy, anthropology and law as well as transplant surgeons and physicians, drawn from Boston and Montreal, from London, Liverpool and Oxford, as well as Oman. The *modus operandi* of the group was to investigate designated transplant issues and to meet for open-ended discussion until a consensus emerged which might be published. Their starting point was 'the premise that any procedure that increased the supply of organs would be doing good by saving lives or improving the quality of life for the recipient, unless it is inherently and incorrigibly associated with consequences that outweigh its benefits'.[20]

Hoffenberg and the group believed that ethical questions of what is right, good or just in human conduct should be examined *de novo* and not initially conflated with

social, religious or professional tradition, or justified by an immediate response such as human revulsion. Some legislation restricting organ donation had been introduced on the basis of intuitive responses after little reasoned debate.

Consenting to the Donation of Organs

The procedures which are adopted before organs are removed from a dead person vary greatly between countries. In the UK the system is one of 'contracting in', where the patient is known to have consented to future donation of organs and there is no express objection by relatives. In Belgium consent is presumed unless the patient has expressly declared an objection to organ removal, but in practice the relatives are consulted, a 'soft' form of 'contracting out'. The primary role of relatives is to corroborate that the dead person did not actually register an objection. In Austria there is a 'hard' form of presumed consent and organ removal is carried out irrespective of the relatives' views.[21]

Hoffenberg believed the UK, which had a low kidney donation rate (13 per million persons per year), should legislate to change to the presumed consent model. There are grounds for believing this would increase the rate of kidney donation, since this occurred in Spain, Austria and Belgium (34, 26 and 25 per million persons respectively), after legislation for presumed consent was introduced. This increase may have been confounded with better transplant arrangements in hospitals and public education campaigns. However in Belgium there was an 'internal control': Antwerp did not adopt the change, its organ donation rate remained static, whereas in Leuven where the change was implemented organ donations over a 3-year period rose from 15 to 40

per year. In Belgium objections to organ donation are registered at the Town Hall and constitute less than two per cent of the population. It is argued that in most Western countries presumed consent more accurately reflects public attitudes to the use of organs. It also relieves hospital staff and bereaved families of some of the burden of active decision making at a time of great emotional stress; simple, expected acquiescence is a less demanding option. Hoffenberg wrote:

> The Conference of European Health Ministers and the World Health Organization have supported the Belgian model in which the views of relatives are not ignored. Experience with 'contracting out' legislation has shown that by and large the public is comfortable with it. There seems no reason any longer not to adopt it.[22]

The gap between supply and demand for kidneys is an acute, world-wide phenomenon, increasing by c. 5 per cent each year. In Australia and New Zealand in 2002 c. 6,800 persons required dialysis, but only c. 200 kidneys were donated each year. In 1997 there were over 260,000 patients with ESRD in the USA, whilst between 1988 and 1995 the overall waiting list trebled and the deaths of those waiting increased by 45 per cent.[23]

The Sale of Organs

The statistics quoted above suggest that some new radical approaches to the supply of kidney donations should be considered. The gift of kidneys from living persons is feasible, since the human body has two kidneys and is able to function with one. However in most countries both the sale of kidneys and the donation of a kidney from an unrelated person are banned. Despite this, there is a significant international trade in

organs and many Westerners travel abroad to obtain a kidney transplant. Hoffenberg believed the forms of restrictive legislation should be revised and the arguments advanced for their retention subjected to ethical scrutiny. These were:[24]

- 'Poor people driven to the extreme of having to offer a kidney for sale may be unable fully to comprehend the situation, and their consent cannot therefore be properly informed.'

Comprehension is not necessarily linked to wealth, and 'good medical practice demands proper counselling and explanation'.

- 'The donor is exposed to untoward risk.'

The risk associated with kidney removal is low; one estimate is less than 0.03 per cent. 'Society appears to tolerate the exposure of paid workers to [greater] occupational risk.'

- 'Less scrupulous donors might be induced by the promise of money to lie about their health ... that might place recipients in jeopardy.'

This hazard is more likely to emerge in illegal trade; in properly regulated circumstances donors would be screened for HIV and other necessary tests carried out.

- 'Donation is a gift, an expression of altruism, and this important attribute should be preserved without contamination by the passage of money.'

Altruism can take many forms and its lack is not necessarily grounds for prohibition, especially in an increasingly commercialized society.

> In the London trial of doctors involved in the sale of organs, it emerged that one of the donors was a Turkish man who offered his kidney for sale in order to be able to buy medicines for his daughter, who was suffering from tuberculosis; he had no employment and no other saleable assets. By prohibiting him from

selling his kidney, he was deprived of the only opportunity of saving his daughter. In doing so ... are we really helping him from being exploited by denying him this option?[25]

- 'The slippery slope argument is frequently adduced: if kidney sales from living donors are allowed, soon it will be a vital organ such as a heart or a liver.'

This argument defies logic. Removal of a kidney is an acceptable procedure, removal of a heart would kill the subject and not be countenanced in a civilized society.

- 'The sale of kidneys will deter donation of cadaver kidneys.'

This assumption lacks any credibility.

- 'Trade in organs will attract criminal activity.'

The persistent rumours of the abduction of people to provide a source of body parts do not yet have foundation. The extensive medical facilities involved in such a practice make it almost inconceivable.

- 'The rich would benefit unfairly from trade in organs.'

Trade would only disadvantage the poor if the purchase came from a limited pool. It should also be recognized that wealth is relative: someone with ESRD might well direct resources to a kidney purchase than, for example, a new car, which would probably cost more. The image of the rich gold-plating their bathrooms has little in common with an ESRD sufferer attempting to save his or her life.

- 'It is degrading to have to sell an organ in order to get badly needed money.'

Poverty is the primary degradation to be attacked, rather than the autonomy of the donor. 'These arguments seem more designed to protect Western sensibilities from distress in contemplating the fate of the would-be paid donor in the developing world,

rather than to solve his or her problems.'

Hoffenberg suggested that the establishment of an intermediate agency between purchaser and vendor might maintain health standards and promote equity of allocation.

Prisoners as Donors

The use of prisoners in medical research was mentioned in an earlier chapter where Hoffenberg's working party on research on volunteers expressed reservations about possible coercion; prisoners were placed in the same vulnerable category as the students and staff of a research worker, where power relations might invalidate consent.[26] Some prisoners would be prepared to donate a kidney if this led to some remission of sentence and the vexed question is whether this opportunity should be denied them, especially in a social climate where payment is made to volunteers who participate in clinical trials. Hoffenberg also raised the possibility of prisoners seeking some expiation of their crime through kidney donation; should this avenue be closed to them?

The removal of organs from executed prisoners is widely practised in China and has been discussed with great repugnance in Western countries. Hoffenberg insisted that two ethical questions should not be conflated: the death penalty, which he opposed and which is now prohibited in most European countries, and the issue of whether after an execution organs might be removed to alleviate the suffering of other persons. The death penalty is still available in more than 100 countries, and in about 37 States of the USA, so the question has relevance.

Hoffenberg summarized the main arguments against organ donation from executed prisoners. (1) Prisoners may be executed to provide a source of organs. He believed that the range of offences attracting the death penalty in China was so wide and the supply of executed persons so great that this scenario was improbable. (2) The process of execution may be modified to facilitate the supply of effective transplants. In China this is usually a bullet through the back of the neck; the question is whether this is less humane than hanging or electrocution? (3) The autonomy of the prisoner in consenting to organ removal is unlikely to apply in the circumstances that surround executions. However this is an ethical question of much smaller moment than that of killing the person and should also be viewed in the context of the lesser weight given to the rights of the individual in Chinese culture. (4) Organs taken from executed prisoners may be sold for profit. It is the abuse of the system which should attract opprobrium rather than the legitimate and controlled removal of organs. (5) The role of doctors in the removal of organs is unacceptable to some professional bodies.[27]

These issues need to be viewed in the context that countries of ancient civilization such as China, Japan and India have evolved their own ethical codes; these should engender respect if a charge of cultural imperialism is to be avoided.

Donations from Unrelated Persons

Although donation of kidneys from unrelated persons has a higher success rate than cadaver donation, there are in many countries substantial restrictions about their use. Hoffenberg[28] pointed out that this could not be justified by their failure rate, especially

when the growth of immunosuppressor technology had lessened the significance of tissue matching. 'Kidney transplantation between living, unrelated donors is just as successful as between blood relatives matched for a single haplotype.'

In the UK Mrs Thatcher's government in 1989 enacted the Human Organ Transplant Act, which prohibited commercial dealings in human organs intended for transplanting, and established a policing arm, the Unrelated Living Transplant Regulatory Authority to which donors must apply for approval of **transplants** between genetically unrelated persons. This appears to have had a dampening effect on donations; only 25 were approved in 1997/1998 in the UK.

The argument that restricting donations to family members will avoid commercialism and coercion is unrealistic; one cannot assume that altruistic, unselfish love of the kind which leads to organ donation exists only within the family, or that the consent of family members is always freely given and never involves an unequal exchange of presents. 'Blood relations may be just as corruptible or open to pressure as non-relations.'

In most countries donations are permitted between spouses. It may be argued that close and dear friends and others should have the same opportunity to display their altruism freely. Hoffenberg wrote:

> A person who dives into the sea to rescue a drowning person or runs into a burning house to save a threatened child does not first check whether it is a

blood relative. In both cases the risk to the rescuer is greater, but saving a life in this way is not banned by law or limited to those with genetic links. The fact that one action takes place in the heat of the moment, the other planned in cold blood, does not detract from the heroism, or altruism of both.

The Organization and Allocation of Donated Organs

The issue of allocating organs across ethnic boundaries was raised by Hoffenberg in 2003 in response to an article praising this bridging. He indicated that the 1967 second heart transplant at Groote Schuur Hospital, given to the white dentist, Dr Phillip Blaiberg, came from a young black man of mixed race.

> This transracial exchange was quite remarkable in a country that at the time kept separate blood banks for white and non-white blood and in which an occasional white patient was allowed to die rather than be transfused with 'black' blood or, for that matter, transported to hospital in a 'black' ambulance. How sad it is that transplants across ethnic or religious barriers are still regarded as remarkable ...[29]

Hoffenberg's group was concerned that many studies of minority attitudes towards organ donation repeat conceptual and methodological errors that undermine their scientific value; race, ethnicity or culture may be conflated with biological variation. 'The commonly held view that minorities donate dramatically less than their representation in the population is in fact mistaken' with respect to Afro-Americans in the USA, but their greater representation on the waiting list for kidneys suggests

inequity and discrimination.[30]

Other issues explored by Hoffenberg include the use of organs from anencephalic babies, which in these days are rarely born full-term, the negative availability of organs from patients in a permanent vegetative state after legal permission for termination is granted, and the low prospects for xenotransplantation (transplants from non-human animals) or artificial kidneys.

Many organizational factors influence the availability of organs. Increased appointment in hospitals of specifically designated, paid transplant coordinators increases the identification of potential donors; perhaps part-time or limited term appointments are needed to avoid 'burn-out'. Many hospitals not actually carrying out transplants need to be incorporated in the donor system, and a shortage of intensive care unit beds for donors is a further constraint.

The family interview process requires that staff have special training; often a transplant coordinator is most appropriate. It is desirable to have information about the circumstances of the family before the approach is made, and to have a quiet, private setting for the conversation when the family's understanding and acceptance of the diagnosis of brain death may be confirmed. The issue of organ donation may then be raised, with a series of counter-arguments available as appropriate to the family response. Often the family is then left to discuss the issue, the interviewer returning to respond to further queries.[31]

Hoffenberg stated that in each country central processing units are needed which are responsible for payment (where required), for checking the provenance of the organ and providing storage under proper conditions, for testing (for example, for HIV), and for transport to authorized transplant units according to need and established priority. R. A. Sells, a leading transplant surgeon in the IFTE, raised the issue of kidney allocation according to the conflicting values of equal opportunity or 'best medical benefit'. Medical factors in allocation include tissue matching, waiting time and graft ischaemic time, whilst patients with cardiovascular complications might be avoided. The very sick patient has the highest rate of graft failure and death, and the points system for kidney allocation in the UK favours the young, the longest waiting and the less sensitized patients, and avoids large age differences between donor and recipient.[32]

Over many years Hoffenberg took a keen interest in the ethics of organ transplants and activated some radical protocols designed to reduce the shortages in organ supply, which he presented in both the general and the scientific medical community.

Medicine and Torture

Hoffenberg did not avoid the hard issue of torture in human societies, and sought to turn the medical profession's involvement to its traditional emphasis of the alleviation of human suffering. He recognized that

even in recent years there have been innumerable accounts of torture from much

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[7] RCP, 1984 Annals p. 67; 1985 Annual Report; *The Times*, 17 December 1984; RH to LRH, 7 August and 2 December 2003; R. Mahler to LRH, 18 September 2003.

[8] *The Times*, 10 August 1983; RCP 1983 Annals, pp. 60, 70; RH, 'Modern Medicine: prospects and problems' in *New Prospects for Medicine*, ed. J.M. Austin, Oxford University Press, Oxford, 1988, pp. 8-22.

[9] RH to LRH, 12 August 2003.

[10] RH, *Clinical Freedom*, The Nuffield Provincial Hospitals Trust, London, 1987, pp. 13, 18, 25-26, 32, 35; J. Cubbon, 'The Principle of QALY maximisation as the basis for allocating health care resources', *Journal of Medical Ethics*, 17, 1991, 181-184.

[11] Report of a Working Party, *Recruitment and Training of Doctors: The Prison Medical Service in England*, Home Office and Department of Health, London, 1990; Margaret Turner-Warwick to LRH, 4 October 2003.

[12] RCP, RH, Annual Address, 16 April 1984.

[13] RH, *The Science and Cunning of Physick*; Royal College of Physicians, *A Great and Growing Evil: The Medical Consequences of Alcohol Abuse*, Tavistock, London, 1987; *The Times*, 31 March 1987.

[14] HFP, RH, unpublished autobiography, p. 9.

[15] *The Times*, 15 June 1984; RH, 'Modern medicine: prospects and problems'.

[16] HFP, RH, 'Inequalities in health – a comment', 13 January 1983.

[17] RH, 'Modern medicine: prospects and problems'.

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[1] RH, *Clinical Freedom*, The Rock Carling Fellowship, Nuffield Provincial Hospitals Trust, London, 1987, pp. 37-8.

[2] RH to LRH, 6 June 2003.

[3] WCA, RH, 'Live and let die', lecture 10 June 1993.

[4] Conference of Medical Royal Colleges and their Faculties in the United Kingdom, 'Diagnosis of brain death', *British Medical Journal*, 2, 1976, pp. 1187-8; C. Pallis, 'Prognostic significance of a dead brain stem', *British Medical Journal*, 286, 8 January 1983, pp. 123-4.

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[7] C. Pallis, 'Prognostic significance of a dead brain stem', *British Medical Journal*, 286, 8 January 1983, pp. 123-4.

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[9] *HFP, M. Lock, R. H. et al, 'Taking the brain out of death', draft ms; Z. Meradi.

[10] WCA, RH, 'Live and let die', lecture 10 June 1993.

[11] B. A. Brody, *Life and Decision Making*, Oxford University Press, Oxford, 1988.

[12] Royal College of Physicians, *Resuscitation from Cardiopulmonary Arrest*, Report of a Working Party, Royal College of Physicians, London, 1987, p. 7.

[13] *RH, *Clinical Freedom*, p. ?

[14] WCA, RH, 'Live and let die'.

[15] B. R. Ferguson, 'Causing death or allowing to die. Developments in the law', *Journal of Medical Ethics*, 23, 1997, pp. 368-372.

[16] RH to LRH, 15 December 2003.

[17] G. R. Dunstan, 'Conversations overheard', in *Consent in Medicine*, (eds) G. R. Dunstan and M. J. Seller, Oxford University Press, Oxford, 1983, pp. 9-25; P. Baume, E. O'Malley and A. Bauman, 'Professed religious affiliation and the practice of euthanasia', *Journal of Medical Ethics*, 21, 1995, pp. 49-54.

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[24] RH, 'Acquisition of kidneys for transplantation', pp. 131-4.

[25] J. S. Cameron and RH, 'The ethics of organ transplantation reconsidered: Paid organ donation and the use of executed prisoners as donors', *Kidney International*, 55, 1999.

[26] Royal College of Physicians, *Research on Healthy Volunteers*, Report of a Working Party, Royal College of Physicians, London, 1986.

[27] RH, 'Acquisition of kidneys for transplantation', pp. 139-142.

[28] Ibid., pp. 136-7.

[29] RH, 'Commentary on "A bridge between hearts"', *Transplantation*, 76 (11), 15 December 2003.

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[34] RH, 'Medical involvement in torture', *Journal of Medical Ethics*, 19, 1993, pp. 133-4.

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[36] RH to LRH, 17 March 2003.

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[2] HFP, UKCCCR/20 February 1992.

[3] *Sunday Times*, 27 May 1990; RH to LRH, 2 December 2003 and 28 May 2004.

[4] RH to LRH, 12 August 2003.

[5] *The Mental Health Foundation Spring Newsletter*, 1990; RH to LRH, 10 August 2003.

[6] M.A. Lehmann to LRH, 24 May 2004; The Nuffield Provincial Hospitals Trust, Thirteenth Report 1991-1993, London, 1993 and Report and Accounts for the year ended 31 March 1994, p. 1.

[7] RH to LRH, 12 August 2003; *The Times*, 25 November 1991.

[8] Wolfson Foundation Papers, RH to Lord Wolfson, 26 July 1991.

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