

## **The 11th Gordon Arthur Ransome Oration: Ethical and Legal Issues Arising from New Frontiers in Medicine**

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I am honoured by the invitation to deliver the Gordon Arthur Ransome Oration at this twenty-sixth Singapore-Malaysian Congress of Medicine. This is the eleventh such Oration, and the occasion recognises the contribution to the practice and teaching of medicine of the man we honour. The first oration was delivered by Dr Seah Cheng Siang in 1971, and he took as his subject the life and times of Gordon Arthur Ransome. He spoke of his skills and commitment as a physician and as a medical teacher; particularly he made reference to the initiative which in 1957 led to the establishment of the Academy of Medicine of Singapore of which Sir Gordon was the first Master. He delineated the man and his cultural and more general interests. For my part, I am pleased to be in Singapore once again and for this purpose.

I have chosen to speak of ethical and legal issues arising from new frontiers in medicine. We live at a time when science and technology present many challenges to laws developed in earlier times, and the changes they bring to society frequently call for the reconsideration of existing rules. Indeed it is in the fields of medicine, the life sciences and biotechnology that some of the great contemporary challenges of science and technology have presented themselves, raising great social, ethical, religious and legal questions. In its final report, the United States President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research, which over the period from 1980-1983 undertook a wide exploration of these issues, said that the awesome powers of medicine that are continually expanded by developments in the life sciences have sparked growing public interest in what we now termed "bio-ethical issues". To the traditional matters of personal conscience for scientific workers and for physicians and other health care workers have been added the increasingly difficult questions that face courts and legislators, among others, as biomedical and behavioural scientists explore new ways to conquer illness, to sustain organ function, to generate human life in many ways and even to manipulate the genetic basis of life itself. It is an awesome agenda and such investigations perform an important service as contributions to public education and understanding, through their reports on problems whose value components are at least as important as their technical aspects. New developments and techniques pose problems of great difficulty and complexity for the law. As an Australian judge aptly put it, while the law marches with medicine, it does so in the rear and limping a little.

Over recent years, there have been many such enquiries and investigations in many places, as particular developments and issues have been examined by a variety of bodies. My own interest in such issues was stimulated by an invitation to participate in a symposium on organ and tissue transplants in the immediate aftermath of Dr Christiaan Barnard's widely publicised heart transplant in South Africa in 1967. My assigned task was to explore the legal and ethical issues in transplantation; I accepted readily soon to discover that the issues posed an array of questions which I had at least imperfectly considered. In the aftermath, I joined committees, I spoke and wrote, and as a member of the Australian Law Reform Commission in the mid 1970s participated in a comprehensive exploration of the legal issues involved in the regulation of human tissue transplants. That was a very special experience; the Commission under the Chairmanship of Justice Michael Kirby, who is one of the major world figures in law reform in this generation, made **what** I believe is regarded as a major contribution to the study and identification of the legal and associated problems which arise in this area of medical science and technology. It was clear that, as it stood, the law did not furnish adequate direction on the many issues involved in human tissue transplantation. If, then, transplantation was to proceed with assurance, legislative action was necessary, and, in advance of that, careful consideration and resolution of various issues of principle. Because of their complexity, effective law reform called for special procedures on the part of the Commission in conducting its investigation. It was necessarily an interdisciplinary exercise; the Commission sought the advice and participation of medical doctors, scientists and technologists with a wide range of relevant knowledge and skills, of philosophers, ethicists and theologians. I was

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an active participant in that work as a member of the Commission, and I recall the experience with great appreciation; I remember particularly a day long meeting of the Commission with a group of doctors with diverse specialist knowledge and experience. That session was devoted to the definition of death, a matter of central importance in transplantation, though its significance extends beyond that. As the President's Commission rightly observed, the need for viable organs to transplant does not account fully for the concern with the definition of death; that concern rests more broadly on the need both to render appropriate care to patients and to replace artificial support with more fitting and respectful behaviour when a patient becomes a dead body. The need to update the criteria for determining death stems from the realisation that the dedication of scarce and expensive care facilities to bodies without brain function may not only prolong the uncertainty and suffering of grieving families, but also preclude access to facilities for patients with reversible conditions.

There was another interesting element in the activities of the Australian Law Reform Commission in its consideration of this matter: the ascertainment, as best it could be achieved, of the sense of the community. In the exploration of issues arising in the case of transplantation and in vitro fertilisation would be another obvious case community views and attitudes, so far as they could be ascertained, are of importance. So in the case of human tissue transplants, laymen's discussion papers were prepared and widely circulated; public hearings were arranged in various parts of Australia at which people were afforded opportunity to present their views. The media, and specially television, were used quite effectively to publicise the issues and to generate debate.

Sometimes - this is a conspicuous case - regular law reform agencies, equipped in these ways and using such procedures, may serve the needs of adaptation of the law to biotechnological change very well; it may be that specially constituted commissions of enquiry are used for the purpose. So in the areas of reproductive technology, artificial insemination and in vitro fertilisation, a Committee of Inquiry was established under the chairmanship of Baroness Warnock in the United Kingdom which reported in 1984. Lady Warnock is a professional philosopher and educator, and the clearly and elegantly written report of her broadly based committee, bears evidence of her hand and style. So too in 'Australia, where the Australian Law Reform Commission had made reference in its tissue transplant report to reproduction and in vitro issues, the decision was taken to leave these issues for consideration by specialist committees. The Australian work on assisted reproduction is of special interest, because scientific and technological work in the field has been very active and advanced there. There the work of the Waller Committee, appointed to consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilisation, (and named for its chairman, a distinguished academic lawyer) has been extremely productive. As with Dr Barnard's heart transplant, so too the birth of Louise Brown in 1978, as an outcome of research and techniques developed by the obstetrician Patrick Steptoe and the scientist Robert Edwards, generated worldwide interest and active debate. The American journalist George Will, in a review of the major events of that year, 1978, wrote that, leaving aside the little Mozarts who had not yet made themselves known, the most important birth was that of Louise Brown, conceived in a laboratory dish. That fertilisation, he said, was less important as an achievement than as an omen; in biology as in politics, power is expanding faster than our ethical understanding. In this area, there is striking testimony to the fact that the pace of development is such that the time cushion, which used to exist, within which lawmakers could prepare legal regulations to state society's needs and desired rules, has virtually disappeared. The point may be illustrated in this way: the writers of a book "The Reproduction Revolution" published in 1984 asked: How do we handle these issues? and observed that in this field future possibilities had the habit of turning into present realities before anyone is ready for them. So they noted that when they began writing the book, pregnancies from donated and from frozen embryos were both mere future prospects; as they brought the book to a close, both were realities. Their conclusion was that, though we are learning to expect the unexpected, it is not easy to predict what the next breakthrough will be, nor when it will come, let alone know how to respond to it.

In such an area as this, it is demonstrably the case that science and technology have outstripped the law, and that the time cushion between the advent of scientific and technological changes and the need for governmental and social reaction is now greatly diminished. Yet while scientists are in a hurry and are hustling society, that society, for its part, is understandably, slow to evolve its attitudes, particularly in cases which raise issues going to the core of human being. These biotechnological achievements and inventions often confront an unprepared and largely inchoate public opinion. Scientists argue that we should beware of premature legal regulation which will not serve the public interest. So it is said that the pace of biotechnological advance is so rapid that, if we have a commission or introduce legislation about recombinant DNA or in vitro fertilisation or anything else of this nature, the ground will have shifted before we have gone through the mechanics, and the action will have shifted to the next level. Specifically, there are powerful scientific voices arguing that it is preferable to use "soft edged measures" depending upon judgment, such as strong hospital and ethics committees (which include lay members) to monitor research and treatment. In any case, it is said that the genie is out of the bottle and cannot be put back.

It is clear however, that a comprehensive “hands off” claim will not be acceptable. The Warnock Report said this quite clearly in 1984,

“It would be idle to pretend that there is not a wide diversity in moral feelings, whether these arise from religious, philosophical or humanist beliefs. What is common . . . is that people generally want some principles or other to govern the development and use of the new techniques. There must be some barriers that are not to be crossed, some limits fixed beyond which people must not be allowed to go. Nor is such a wish for containment a mere whim or fancy. The very existence of morality depends on it. A society which has no inhibiting limits especially in the areas with which we have been concerned, questions of birth and death, of the setting up of families and the valuing of human life would be a society without moral scruples. And this nobody wants.”

In amplification, while cautioning against too fast and too extensive a regime of legal intervention, the Committee stated its view that “new laws will be necessary to cope with the new techniques for alleviating infertility and their consequences, and to deal with the developments in research in the field of embryology”. This was reinforced in the debates in the British parliament on the issues raised by the Warnock report. The point was put characteristically and passionately by the most famous of living English judges, Lord Denning, in that debate. “On one of the most important questions of our time,” he said, “there is no law and no restriction whatever. Medical scientists and medical men can do as they like with what I believe are human beings. Buy or sell, kill or freeze and the like without any control. They are dangers to our society.” It is vintage Denning; it overstates, but it makes a point. On such matters as experimentation on early embryos, he was emphatic that there must be an absolute prohibition: from the moment of conception there is a living human being. On this issue, preeminently, it has taken a comparatively long time to reach agreement on a regime of law; what prevails is the wise, but necessarily imprecise formulation of the Archbishop of York in the debate. “We are all struggling to do the best we can in using the new powers and insights which science, medicine and technology are continually providing . . . (human lives) . . . begin with chemistry and they reach their fulfilment in mystery. There is no doubt about the depth, wonder, moral worth and religious significance of personhood, but the transitions on the way to it are not clean, clear and decisive despite the tremendous significance attached by some persons to the moment of fertilisation. Biologically speaking, we are looking at a continuous process.” This led the Archbishop to support controlled experimentation on early embryos, and this is the way the law has settled after protracted debate in the United Kingdom and in Australian jurisdictions.

Almost two years ago, I spoke in Singapore at the first international scientific meeting of the Royal College of Obstetricians on a variety of issues relating to assisted reproduction and associated matters and I shall not traverse them again beyond saying that in this area there are divisions and disagreements all along the line, not many, to be sure, at the first point of take off which is the “couple centred paradigm”, illustrated by the conception and birth of Louise Brown, though even at this point, questions about the propriety of the whole regime of in vitro fertilisation are raised. The doubts grow as we move into the area of donation, whether of sperm, ova or embryos. The problems can become more spectacular, or at least dramatic with frozen embryos. The use of this technique, and its legal recognition, is supported as avoiding wastage of surplus embryos. World wide attention was given to the case where a wealthy foreign couple who banked frozen embryos in Australia were killed in an air crash, and the issue of the disposal and use of the ‘Rios’ embryos was the subject of protracted and passionate debate, and produced legislation. Very recently under the title “The Heat is On for Frozen Babies”, an English newspaper highlighted an American case involving the permissibility of the use of frozen embryos where the former husband donor would not agree to their implantation in any person including his former wife. The husband’s claim to prevent this use was upheld.

Then there is the case of surrogacy, the bearing of a child for another with an agreement to give it up to that other to be raised as the child of the rearing parents. It has been debated at length in the Warnock, in Australian and in other reports. Generally it is disapproved and prohibited, in some cases with criminal penalties; there are however some narrow compassionate cases where a minority in the Warnock Committee would have kept the door ajar.

As with reproduction technology, so too in the field of human tissue transplants there are matters which give rise to ethical and legal concern; and these turn on the character of consents which may be required. In the case of cadaver organs, it is most widely accepted that consent may be properly indicated by reference to what is styled a “contracting in” formula, that the deceased during his lifetime has signified his assent to the use of tissue and organs or, if he has been silent, that his representatives, as defined, may furnish assent. There is, however, in the law of some countries, a notion of “contracting out”; that is to say, that tissue may be taken unless the deceased in his lifetime has expressly prohibited it. “Contracting out” facilitates transplants and has growing support. A more radical notion is that the law should move to a point at which all dead bodies are available for such purposes; this views society as having a claim on human bodies for useful human tissue after death, as a matter of public entitlement. I believe that this is unacceptable; that donation must rest upon consent. In terms of social utility it seems to me that there is a persuasive

case for the adoption of the principle of contracting out, though in the Australian Law Reform Commission we judged that even that was in advance of contemporary public opinion, as best we could assess it.

The more difficult problem of consent arises in the case of living donors of non-regenerative tissue in particular, and notably of kidneys. Here a requirement of effective or informed consent applied, and the difficulties arose in the case of persons lacking full capacity, notably minors (persons under full legal age) and mental incompetents. Russell Scott, in his excellent book "The Body as Property" (1981), draws attention to a body of American cases in which courts have approved the transplantation of kidneys from young children and mental incompetents into the bodies of seriously ill siblings who urgently require such organs, in a regime of scarcity. It is a characteristic pattern that the tissues of sibling donors and recipients are compatible, and the parents have actively supported the giving of the organs on which the life of the recipient may depend. In some cases the courts have used the language of "substituted judgment" in giving approval to such transplants; they have regarded it as open to them to furnish the consent which the minor or incompetent lacks capacity to give. Sometimes the Court has found a psychological benefit to the donor in the gift of life to a seriously ill sibling. It is obviously an area of great emotional difficulty, but my own view is that the only valid principle on which a donation of tissue, certainly non regenerative tissue, can be supported is one which establishes effective consent, and that a minor or an incompetent cannot give that.

What then of the use of non-human organs or tissue for transplant into human? There is a recent widely publicised report of the transplant of a baboon liver in the United States into the body of an adult male. An Australian newspaper report of this bore the headline "Living With the Animal Within", with a subtitle which announced an Australian project to breed genetically engineered pigs for use for transplants into humans. Russell Scott gives an account of earlier attempted transplants, including operations done by Dr Christiaan Barnard with chimpanzee and baboon hearts without success. A well known case, the Baby Fae case, involved the transplant of a baboon heart into the body of an infant which was also a failure. There is a report of the use of a chimpanzee kidney where the patient survived for nine months. Scott reports on operative success with the use of ox bone and pig and ape valves; in England pig skin is effectively used for the treatment of severe burns. On the broader ethical, potentially legal issues involved, Scott observes that "man has practised the domestication of livestock, and the control and breeding of animal prey for his own consumption for more than ten thousand years. In principle, the introduction of similar practices aimed at producing organs and tissues for therapeutic purposes should be acceptable. Whether this would be so in fact is another matter. It is possible that there could be resistance not only from animal lovers, but also from those who believe that animal organs should not be implanted into the human body, no matter how scientifically justifiable the operation may be." As a footnote, the newspaper reports of the recent baboon liver transplant told of a placard outside the hospital which carried the words "did the baboon consent?" As well as practical medical issues (which may return different answers for different procedures), we have ethical and religious issues to take into account. I do not have a clear answer.

Time allows me to take only one other case. The US President's Commission in one of its reports, "Deciding to Forego Life Sustaining Treatment", noted that between 1970 and 1980, the death rate in the first 28 days of life had been almost halved in the United States. Medicine's capacity to forestall death (achieved at immense cost) had magnified the difficulties for doctors and parents alike in assessing which infants would benefit from interventions and this, as the Commission said, raised "profound ethical issues". While cases of Down's syndrome and spina bifida had attracted great public attention, the predominant problem in the newborn nursery was prematurity. The Commission warned further of the consequences of intervention. "These children, once rescued, are not (to be) left to drown in a sea of indifference and unresponsiveness . . . to the extent that society fails to ensure that seriously ill newborns have the opportunity for an adequate level of continuing care, its moral authority to intervene on behalf of a newborn whose life is in jeopardy is compromised." The issues raised by this difficult debate are not novel; the difference between an earlier time and now is that, while they had then largely remained a private episode between parents and doctors and nurses who attended, they have now been propelled into public notice, in part anyway, as a consequence of the action of whistleblowers who include "right to life" organisations.

Let me illustrate the problem by reference to cases which have arisen since the early 1980s. There were two English cases which attracted wide attention. In the case of the baby Alexandra, a child was born with Down's syndrome and with a life threatening, but surgically correctable intestinal blockage. The parents refused consent to the operation) judging that in all the circumstances it was better that the child be allowed to die. Action was then taken to have the child made a ward of court and thereafter the doctors declined to operate for want of parental consent. There followed speedy recourse to the courts which yielded a decision in the Court of Appeal that the best interests of the child were the decisive consideration, and that these were not necessarily expressed in the agreed judgment of doctors and parents. There was a very strong presumption in favour of maintaining life, though this might be

overcome in a case where "the life of the child is going demonstrably to be so awful" that it should be allowed to die. This was not such a case; the operation was accordingly ordered and performed. There were obvious and ominous implications for doctors, and later in 1981, Dr Leonard Arthur, a respected paediatrician, stood trial for attempted murder; he had ordered a regime of very simple care and sedation for a child born with Down's syndrome; the intended outcome was that the child's passage to death should be facilitated. Dr Arthur's action was reported and he stood trial. There was powerful medical testimony to support Dr Arthur and the course he had adopted; the judge in summing up to the jury said that they would want to think long and hard before concluding that such eminent doctors had evolved standards of conduct which constituted criminal behaviour. Dr Arthur was acquitted amid widespread public approval. How this is reconciled with the court's approach in the Baby Alexandra case is unclear; the jury gives no reason for its decision. There are Canadian and Australian decisions which follow the Alexandra case in adopting the tests and criteria formulated in that case. In the United States, federal administrative intervention which purported to protect the lives of children in such cases has been opposed by the American College of Obstetricians and Gynaecologists, and other professional bodies, on the ground that it is not appropriate for the federal government to involve itself in decisions about the medical treatment of severely handicapped newborn children.

How do we go forward? The *cri du coeur* of a journalist mother in the aftermath of the Baby Alexandra case, that the law and the courts should keep out of this, cannot be answered as she would wish. There is an interest which is separate from that of doctors and parents; it is the independent interest of the child, and it is asserted by the right to life interveners. The Courts are now deeply involved in such matters; in very recent cases they have given answers to doctors seeking to know whether in the case of seriously ill children they must use particular technology, specifically mechanical ventilators, and the courts have given what seem to me to be good answers that the doctors may make the medical decisions for themselves.

How we go forward still remains unclear. I do not think that the hard edged answer that in all cases the obligation must be to preserve life is acceptable; it is extreme and, as I believe, intolerable in its implications. At the other end there is the view expressed by Singer and Kuhse in their book "Shall the Baby Live?" which starts with the proposition that some handicapped children would be better off dead than living seriously impaired lives. This leads them to argue that "it is better and more humane to intervene actively to terminate their lives quickly and painlessly rather than to achieve the end result at the cost of stretching out the grim and, it may be, painful process of slow death". The English Court of Appeal has stated quite unequivocally that this cannot be countenanced. To quote the words of the present Lord Chief Justice of England, "it cannot be too strongly emphasised that the court never sanctions steps to terminate life. There is no question of approving, even in a case of the most horrendous disability a course aimed at terminating life or accelerating death. The court is concerned only with the circumstances in which steps should not be taken to prolong life."

This prompts the difficult question: what then was Dr Arthur doing? He was certainly not moving to kill his infant patient in the sense that the authors of "Shall the Baby Live?" would argue for. But he was on a course, and an intended course, in respect of a person totally dependent on him, which was intended to expedite death. We do not and we cannot know what lay behind the jury's acquittal of Dr Arthur, and I do not find it easy to reconcile the decision in the criminal process with the decision of the court in the Baby Alexandra case. We are in an area in which the law and the ethics are not clear, at least to me.

I fear that I have been an unconscionable time talking, and I thank you for the opportunity to speak on this acutely difficult topic. I say at the end, as at the beginning, that I am honoured by the invitation to deliver this Oration.