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The Hon Justice Michael Kirby CMG*

THE SPAN OF LIFE REDEFINED

Professor Max Charlesworth is one of the most prominent and thoughtful of the commentators on bioethical questions now living. His Boyer Lectures show the range of his interests, the penetration of his insights and the delicacy of his judgments on very hard questions. As the pages of this book show, the subject matter of those question is varied and complex. Bioethics also present problems of great urgency.

The subject matter of these lectures spans the whole of human life. They begin at a point before human life has commenced. The revolutionary developments of biology as they affect conception and the use and limits of reproductive and genetic techniques are by now matters of widespread public debate. The rationing of health care as it is made available

to patients and the community, is a new focus of attention. The standards of informed consent for medical care and the subject of medical malpractice are matters of community concern.

The new challenge of AIDS must now be faced. It presents many problems: medical, legal and ethical. It underlines once again the unpredictability of human existence. Who would have thought, but a decade ago, that the world would today be facing such a major global epidemic whose consequences insist, out of self-protection, that we think radically about our laws and policies on drug control and human sexuality?

Death, in Shakespeare's words, is the "necessary end". "It will come, when it will come". But the coming of it as Professor Charlesworth points out, may not always nowadays depend upon chance, or "nature's changing course untrimm'd". Life-sustaining treatment may be withheld or withdrawn. Heroic surgery may be denied to a deformed or retarded neonate. The patient may be found to be "brain dead" or in such a vegetative state that the law will not call it "life" and require its sustenance. In many lands, calls are now made for laws on euthanasia. In some, they will only reflect the medical practices which occasionally already reserve to the knowing patient facing a painful end, the right to be done with it.

So there we have the subjects of Professor Charlesworth's concern. From the moment of conception to the

hour of death. Life and death. The termini may once have seemed so clear in their definition. Life, when the baby begins its squarking - receiving the first of life's blows. Death, when the breathing stops and like Lear's desperate gesture the glass is held up but does not fog. But now we know better. Upon the precise moment of the commencement of a human life philosophers, doctors and lawyers may debate. About the moment at which the law should provide its protective shield, the debate becomes ever more vigorous, impassioned, even strident.[1] Death too, we now discover is not an instant but a process: that remarkable machine, the body, gradually ceasing its extraordinarily integrated process of living. The head may stop but the hair and the nails continue to live after the other organs have finished their journey.

GOOD ETHICS AND GOOD DATA

We are not necessarily wiser than the ancients in tackling the ethical issues which arise between the commencement of a human life and its end. But thanks to people like Professor Charlesworth we are better informed. The primary rule for good policy, law and ethics - whether on artificial conception, AIDS, rationing of health care, informed consent or fixing life's end - is, as he constantly emphasises, a sound understanding of the scientific data. Good law and good ethics must be grounded in good data. Let others indulge in preconceptions, prejudice, emotion and dogma. Life and death - and the slings and arrows in

between - are things of emotion. We should not be surprised that our fellow citizens react in that way. But experts need to approach the difficult problems dealt with here with an affirmation of the scientist's first obligation: to get the data right. Out of that approach, the answers to ethical questions and to the design of legal policy may not readily come. But when they come, the answers are more likely to be sound and lasting if they are based on good science.

There is little point in designing complex laws and policies on the control of the AIDS epidemic, for example, if we ignore the rudimentary data which is now available concerning the limited ways in which the HIV virus is transmitted. We do not advance our understanding of "informed consent", if we ignore the empirical data of how patients actually make their decisions, of the information supplied to them, of their understanding of the choices available and of the meaning of forms presented for signature at a critical moment of stress or pain. We do not frame good policies or laws on the inevitable rationing of health care in this technological age if we are ignorant of the basic rules by which the triage actually takes place.[2] Similarly, in our understanding of the end of life, we do well to wrench ourselves from speculation and to get down there into the intensive care wards or the old people's facilities where the only "life" being maintained may lack the rudimentary qualities of sentience and appreciation. In such circumstances, to condemn a fellow human being to a

vegetative existence may itself be an offence to respect for humanness. To insist upon the prolongation of life, as nothing more than the coursing of blood and bodily functions, and to do so in circumstances of intractable and irremedial pain, is so offensive to the very purpose of human life, that it calls out for relief. The law hesitates on the brink of sanctioning this decision only because of its fear of the misuse of the power to terminate life. This is a fear reinforced by the events of this melancholy century, now dragging itself to its close.

THE HUMAN DIMENSION

The topics which Professor Charlesworth discusses lend themselves to anecdote, sentiment and passion. We cannot avoid these entirely. Nor should we try. At life's end, it was the eerie spectacle of Karen Quinlan, clinging to a form of life that captured the attention of millions and caused them to reflect upon her predicament and its significance for their own faltering existence. The risks and dangers of in vitro fertilisation and surrogate parenting seem manageable when we depersonalise them and look upon them as issues for legal or ethical debate. But when, from anecdotal material, we affix to them the faces of a childless couple burdened with a dream of children - the fulfilment of their concept of a full life - the debates may take on another, more human complexion.

So too with the rationing of health care. Our rational economic sense acknowledges that we cannot have nuclear

magnetic resonance or CT scanners in every village hospital. Nor can we yet offer AZT to every unfortunate villager in Africa with the slim disease. But if it is our loved one who suffers, the ethical questions assume an entirely new perspective. For them - or for ourselves - we might consider, in the words of the jingle, that only the best will do - all of the time.

So we must have our anecdotes, our case histories and the human interest, without which ethical speculation would be idle. In this, we will simply acknowledge that we are human beings first and experts a long way after. In matters of life and death, emotion is inescapable. We will not be exempt from it. Laws made by Parliament - and to a lesser extent by judges - will reflect, even where they do not mirror, public opinion in the communities governed by those laws. So, popular reactions to the subjects of birth, life and death are not at all irrelevant to the questions raised in these Lectures. But it behoves an informed mind to accept the rigorous discipline of getting the primary data right - or as right as modern knowledge and reasonable inquiry permit.

LAW IN THE REAR - LIMPING

Increasingly, the problems prescribed by Professor Charlesworth are arising for decision in courts of law. An Australian judge (Justice Windeyer), once said here that the law marches with medicine, "but in the rear and limping a little".[3] In a sense, that relationship is

inevitable. New technology presents entirely new problems. Are the hospital staff who terminate the respirator responsible for the death of the patient already "brain dead"?[4] With the advance of sophisticated surgery which would without hesitation be used for a normal neonate, should a court require the self-same surgery for a deformed or retarded neonate? Or is the baby's life so "demonstrably awful" that it should be allowed peacefully and naturally to cease?[5] Is a surrogate birth arrangement pernicious and void so that the courts will not enforce it?[6] And if a child is born to such an arrangement, will a court enforce it against the mother who has carried the child to full term?[7] Where an operation is complicated, will the law require a detailed exposition of the risks to an extent that was unnecessary in the earlier, obvious days of pre-anaesthetic brutal surgery?[8] How will the courts approach decisions at the end of life?

With new technology, novel advances in biology and entirely new problems (such as AIDS), it is little wonder that the law limps behind. Parliaments, with their busy agendas, can more readily find time for the political controversies from which votes may be extracted. Out of a consideration of bioethical questions, there are few votes to be had. Indeed, in an age of increasing attention to single issue electoral campaigns, that territory often marks out danger. There may actually be votes to be lost in striking a positive position.

For example, at the end of life, Parliament might prefer to leave things alone so that decisions are made quietly - in hospitals; not noisily in courtrooms. And as for the status of the foetus, from that topic most politicians will run a mile. The powerful, polarised opinions of the community about abortion and the procedures of reproductive technology frighten many of our otherwise valiant leaders. In a democracy, this is understandable. Their object is to be re-elected. True, it is to serve and to strive for certain ideals. But if one is not re-elected, the opposing camp may secure the spoils of office or the legislature may even be deprived of the inestimable benefit of one's own presence there. In these circumstances, survival is the first rule of politics. Little wonder, then, that the first reaction of politicians to the subjects reviewed by Professor Charlesworth is one of the most extreme caution. Nimbly they tiptoe through the minefield of the topics upon which Professor Charlesworth ventures with almost foolhardy determination. The strong feelings which may be engendered amongst minorities about any one of the topics dealt with here could tip the balance. And, in the process, could tip them right out of office.

This is one of the reasons why the problems of bioethics present a unique challenge to the democratic form of government at the close of the 20th century. When so many other portents are full of promise for democracy, a fundamental question is presented by these topics. It is the

question which looms up from this Series. It is whether, in the interface of law, medicine and ethics the Parliamentary institution - the democratic system of government - can cope? This is the fundamental issue which weaves its way, like the thread of Ariadne, through Professor Charlesworth's Boyer Lectures.

A DEATHLY SILENCE ON AIDS

The surest indication of a breakdown in the democratic process on one of those issues is found in the treatment of AIDS in its epicentre, in the United States of America. For four and a half years of his long Presidency, the avuncular leader of that great democracy, Mr Ronald Reagan, could not bring himself on a single public occasion to utter the acronym "AIDS". Whilst an estimated one or one and a half million of his fellow countrymen became infected with a terrible virus, a deathly silence fell upon the White House. Leadership in a struggle for containment of the epidemic was just not there. Furthermore, the free press of the United States, caseated and protected under the shield of the First Amendment, failed to ask a single public question of their national leader on this topic for four long years. Not a single interrogatory was pressed upon the Chief Executive - neither in press conferences, nor on other formal occasions, not even in those smiling walks to the noisy helicopters. It is a grim tale of institutional failure. Mr Reagan's silence is a symptom of the failure of a democracy to come to terms with one of the hard questions, so much more readily

consigned to the bottom drawer - to someone else, anyone else.

Other democracies, including Australia, have done better in this and other bioethical concerns. But even then, there are stumbling blocks. The question recurs, whether our democratic leaders and institutions - and indeed our people - will have the strength and wisdom to make the hard decisions. The point must be made that to fail to make decisions is often, in effect, to make a positive decision. Doing nothing may be easy. But doing nothing and allowing events to drift is sometimes to lose control of these events. Upon some subjects, that may be the correct decision. Upon others, such as AIDS, it may be fearsomely risky.

In common law countries at least, there is never, ultimately, a legal vacuum. By procedures of logical reasoning, old precedents on different cases in earlier times considering quite different problems may be stretched and adapted to meet the problems of today. So it has happened upon several of the issues which Professor Charlesworth explores.

But the process of deciding what is, and what is not, permissible in a courtroom has obvious limitations. Usually, the decision must be made quickly, in the midst of more conventional problems. The desperate urgency of decisions concerning the withdrawal of life support or the authorisation of an operation on an intellectually handicapped neonate necessarily restricts the time for

judicial reflection and philosophising. The judge and the lawyers may have little insight into the ethical questions raised. There is no Max Charlesworth to lean on. Judges and lawyers may have still less knowledge of the intricacies of the medical procedures. Unlike law reform bodies and committees of inquiry, the courts cannot consult widely for expressions of public opinion as they develop the law. The rules of evidence may positively forbid the receipt of opinion polls. In a time of shifting moral values, deriving the rule for today from the precedent of yesterday may be perilous indeed.

Yet, haunted by the concern that inactivity carries in its train its own decisions, governments and legislatures are now beginning to act. The resolution of the problem of human tissue transplantation blazed the trail.[9] And then came the transplantation of the tissue of life itself - with in vitro fertilisation opening up new hope to infertile couples. Had this simply remained a hurdle-jump over the impediment of infertility in married couples, it is possible that the call for controlling legislation would have been muted. But soon other possibilities - and other problems - sprang up. The very procedure invited new experiments. The difficulties of achieving success produced the demand for multiple embryos to increase the prospects of achieving pregnancy by multiple attempts. Even today only 6.9% of IVF treatment cycles in Australia actually produce a live-born baby. And the question is presented: what is to happen to

the frozen embryos no longer needed? Are they not human lives in potential? The answers to these questions tend to reveal where each of us stands on the spectrum between the ethical absolutists and the ethical consequences referred to by Charlesworth.

The higher levels of deformity and the defects discovered in the IVF embryos quite naturally turned the minds of the scientists to consideration of how they could reduce that factor of risk by genetic screening. Yet the idea of scientists experimenting on embryos after syngamy (when the sperm and egg fuse) greatly distressed some ethical absolutists. They were concerned about where this might lead - to gender pre -selection or other forms of experimentation on embryos which signalled an erosion of respect for each precious, unique human life.

Because of early advances on the medical side of IVF in Australia - and early success in the regulation of human tissue transplantation - the call was soon made for legislation to cover the issues raised by artificial conception. Where the scientists pleaded for flexibility and to be left to guidelines developed by their peers, lawyers declared that the creation of human life in the laboratory "should not be left to the ethical determinations of scientists or medical practitioners, nor to private conscience, nor to the chances of a forensic lottery in the superior courts".[10]

The result was the passage of the Infertility (Medical

Procedures) Act 1984. This was one of the first attempts in the world to regulate, by law, the procedures of artificial conception. It sanctioned IVF, the freezing of embryos, the use of donor sperm, ova and embryos. But it prohibited cloning, animal - human hybridisation, surrogate motherhood and experiments on embryos. The last-mentioned prohibition, however, could be waived on the recommendation of an Advisory Committee. At first human embryo research was limited to the 22 hour old pre-syngamous embryo. Later, however, the State's law officers advised that under the wording of the Act, experiments could be performed on embryos older than 22 hours if they were "spare". The scientists argued that to tackle the still low success rates and the high levels of defective embryos, experimentation on such "spare" embryos was essential. To many it seemed logical. Was this not simply science working for the benefit of human kind on profligate nature's excessive production of life? If such experiments were not allowed in Victoria, they would surely soon be taking place elsewhere. The possibility of technological leadership, financial rewards, not to say help to the patients, would be lost or delayed. The Advisory Committee decided to approve genetic experiments on human embryos up to 2 days old. The purpose was to test the safety and accuracy of a new technique designed to help identify healthy embryos from those with growth chromosomal defects.

But a by-election was looming. The health portfolio changed. The new Health Minister became concerned. The

earlier decision to permit the research - which would admittedly have involved the destruction of the embryos - was suddenly reversed. The government imposed a moratorium. Two members of the Advisory Committee resigned. The State Premier (Mr Cain) declared: "I want to make it very clear that there will not be brave new world stuff in this State so far as I am concerned ... We will not allow genetic engineering, cloning and that kind of thing".[11] Then, as if to distance himself from the outspoken opinions of the Roman Catholic Archbishop of Melbourne the Premier said that experiments beyond 22 hours designed to test a particular embryo for implantation in a particular woman might be permitted. That was similar to amniocenthesis. But experiments on "spare" embryos for basic research of widespread significance would not be condoned.

Needless to say, this outcome pleased nobody. The scientists condemned it as ineffective and some the leaders have packed their microscopes and left Australia. The members of the cautious Advisory Committee wondered about the utility of giving their reasoned advice, only to be ignored. The fundamentalists expressed alarm at any further slippage beyond 22 hour syngamy. The humanists are still wondering what all the fuss is about. The childless couples saw yet another obstacle on the path to their dream. The community turned to the sporting pages to escape these puzzling dilemmas. And the good electors of the Victorian constituency of Greensborough dutifully returned the

government's candidate.

This is a little story which illustrates just how difficult it is for the democratic process to grapple successfully with the issues of bioethics described in these Lectures.

BRAVE NEW WORLD, INDEED

The Victorian Premier's reference to Brave New World takes us back to 1931 when Aldus Huxley penned his remarkable book of prophesy. Looking back at the famous novel, in 1958, Huxley wrote:

> "In 1931, when Brave New World was being written, I was convinced that there was still plenty of time ... Twenty-seven years later ... I feel a good deal less optimistic ... The prophesies made in 1931 are coming true much sooner than I thought they would ... and why has the nightmare, which I had projected into the 7th century AF (after four) made so swift an advance in our direction? The answer to these questions must begin where the life of even the most highly civilized society has its beginnings - on the level of biology."[12]

One wonders what Huxley would say today in conversation with Charlesworth, a further quarter century on. The lesson is plain. Time has been telescoped. Advances in this, as in other technologies, bombard us. Puny human minds and even more puny human institutions - find it hard to cope.

The language of Shakespeare and Milton binds us together. The ideas of liberty and of a government of laws, not of men bind us together. The ideal of democracy, and of an informed popular voice in the government of our

communities bind us loosely together. Democratic institutions, neutral courts, the rule of law, the honourable practice of the healing arts, vigilant science, thoughtful ethics and creative technology will all go on in harmony, in the future as in the past. But will they? What will be the informed democracy if the science has gone beyond human understanding? What will the courts do if the laws are silent and the past precedents irrelevant? What does the rule of law mean if the legislators - fearful of a chance by-election - react hastily or, even worse, look the other way? Will we have the wisdom to provide the institutional answers to the questions which are posed by Professor Charlesworth in these Lectures? Can democracy cope in the age of science and technology? These are the fundamental question which is suggested by the multitude of issues dealt with here. A rational contemplation of their variety, difficulty and sensitivity will make us profoundly pessimistic. Only the talents of the sensitive, thoughtful human intellect, performing the hard work of thinking gives a glimmer of hope. And that is why we must be grateful to Professor Charlesworth.

FOOTNOTES

1. See discussion by Heilbron J in C v S & Anor [1987] 2 Weekly Law Reports 1109, 1117. At the time of writing the Supreme Court of the United States has reserved its

decision in the challenge to Roe v Wade 410 US 113 (1973), the leading case on abortion in that country. See Webster v Reproductive Health Sources et al New York Times 17 April 1989 B12.

2. For example,in England the availability of renal dialysis depended largely on whether the patient was under 45 years of age. The Times (London) 10 January, 1985, 12.

3. Mount Isa Mines Pty Limited v Pusey (1970) 125 Commonwealth Law Reports, 383, 395.

4. The Queen v Malcherek and Steel [1981] 1 Weekly Law Reports 690 (Court of Appeal).

5. In re B (A Minor) (Wardship: Medical Treatment) [1981] 1 Weekly Law Reports 1421 (Court of Appeal).

6. Re AVC, Commyn J, Family Law, vol 8 no 6 1978, 170-1.

7. In re A Baby, Times Law Report, 15 January 1985, 8 (Mr Justice Latey).

8. Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital [1985] Appeal Cases 871 (House of Lords).

9. Australian Law Reform Commission, Human Tissue Transplants, (ALRC 7) 1977, Australian Government Publishing Service, Canberra.

10. L Waller, La Trobe Memorial Lecture, La Trobe University, 1988.

11. See report The Age (Melbourne) 21 January 1989, 1.

12. A Huxley, Brave New World Revisited, 1959; 11-15. See R Scott, "Legal Implications and Lawmaking in Bioethics and Experimental Medicine", 1 Journal of Contemporary Health Law and Policy, 47 (1985).