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SECOND INTERNATIONAL CONFERENCE ON HEALTH LAW AND ETHICS

LONDON, SUNDAY 16 JULY 1989

BIOETHICS, '89: CAN DEMOCRACY COPE?
THE SPAN OF LIFE

This conference comes together at a critical time for law, ethics and medicine. As displayed in the programme, the issues which will come under attention are of the greatest variety, complexity, sensitivity and urgency.

The topics span 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 will arrest our thoughts on Thursday. The rationing of health care as it is made available to patients and the community will be the
focus of attention on Tuesday. The standards of informed consent for medical care will be considered on Monday. So will the subject of medical malpractice and the litigation which attends it where the patient or the family claim that things have gone wrong.

On Monday too the new challenge of AIDS will be discussed with its many faceted problems: medical, legal and ethical. It is difficult now to remember the world before AIDS. Yet is is less than a decade since the fearsome acronym became a household word on every continent. This simply 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? AIDS generally strikes young people in the prime of their lives. But the virus is so intractable, and impervious to cure or ready treatment, that it brings the cycle in all too many cases to its premature end in death.

Death, in Shakespeare's words, is the "necessary end". "It will come, when it will come". But the coming of it 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 Life sustaining treatment may be withheld or withdrawn.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. These vexed issues will be addressed on Wednesday.

And in the final session Justice Bhagwati, former Chief Justice of India, will address the death penalty in the context of coercion, medicine and the State. So there we have our conference. 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. Death too, we now discovers 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 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 a sound understanding of the scientific data. Good law and good ethics must be grounded in good data. Let those be the watchwords for this week in London. 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 let us, as experts in our various disciplines, approach the difficult problems which lie ahead this week 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. Yet when we enquire into the criteria for the provision of kidney dialysis, for example, we may find that some of the indicia seem less than convincing. Shortly after my own 45th birthday, when I still considered myself robustly young, I read to my alarm a report that in this country a decision about a patient's unsuitability to receive dialysis "may reside principally in the intractable symptoms of having passed his 45th birthday".2

Similarly, in our understanding of the end of life, we do well to wrench ourselves from philosophical 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 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. Yet in some jurisdictions, the State still reserves that power to itself and goes about the painstaking process of extermination by planned execution.

The Human Dimension

My first point has been sufficiently made. The topics we will discuss lend themselves to anecdote, sentiment and passion. We cannot avoid these entirely. Nor should we try. The common law itself - the great legal system nurtured over the centuries and spread from this city to the four corners of the world - moves from precedent to precedent. From the solution of human problems in individual cases it stumbles sometimes upon principles. It rises, on occasion, reluctantly to concepts as if by accident and then only over a long time. But cases are the stuff of the law. They add flesh to the bare bones of theory. In matters such as AIDS, they remind us of the pain and despair of young people and their families - with so much to offer, deprived of the chance of a full and normal life.

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.

Had I the heavens' embroidered cloths, Enwrought with golden and silver light, The blue and the dim and the dark cloths Of night and light and the half-light I would spread the cloths under your feet: But I, being poor, have only my dreams; I have spread my dreams under your feet; Tread softly because you tread on my dreams".

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 will have our anecdotes, our cases 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, which are on the agenda of this conference, are not at all irrelevant to the questions that are before us. But it
behoves a trained 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

An Australian soldier, turned judge (Justice Windeyer), once said of the relationship between the principal disciplines represented here that the law marches with medicine, "but in the rear and limping a little". 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"? 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 its life so "demonstrably awful" that it should be allowed peacefully and naturally to cease? Is a surrogate birth arrangement pernicious and void so that the courts will not enforce it? 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? 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? How will the courts approach decisions at the end of life? According to what principles will the law step in before birth and offer wardship protection to a "child", not yet born, against the
wishes of the mother? Is the wilful persistence by a person who knows that he is infected with the AIDS virus in having unprotected sex tantamount to a criminal offence - of murder (if the receiver dies) or assault occasioning grievous bodily harm (if the receiver is infected but has not died)?

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. This is the age of the ultimate triumph of the dismal science of economics. Whereas a British Cabinet of the past might solve the world's problems by reference to the histories of Thucydides, today the focus of attention is more likely to be upon Milton Friedmann, GDP, the balance of payments and the latest terms of trade.

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. The containment of AIDS, if we are really serious about it, may require radical changes to our laws on narcotic drugs and to laws and policies on human sexuality. But such changes run headlong into the lobbies that speak for the self-proclaimed "moral majority". Attention to the problems of medical mistakes, as for example by adopting a system of national compensation for
all accidents such as they have done in New Zealand, runs into the vociferous and influential lobby of the legal profession: determined to protect its bailiwick of personal injury actions. Any attempt by the legislature to assert and uphold the patient's right to fully informed consent to medical procedures may bring down the thunder of the organised medical profession and its associations. They will point, with some justification, to the explosion of malpractice litigation in the United States and its consequence for increased insurance costs, defensive medicine and little, if any, improvement in the standard of medical care for parents. The issues of medical rationing should, in all conscience, come out into the open. We should know the bases upon which the decisions are made on a community and individual footing, so that we can be sure that it is not mere age, gender or some other arbitrary criterion that has determined a person's life or death. Yet, brought out into the open, these are controversial subjects for the reason already mentioned. To a person whose life is at stake - or their family - the cruelty of denying the most up to date and available resources that medical science can offer will seem intolerable. The wise arguments about the expenditure of the medical dollar on a macro level melt before the flame of the anger of individual citizens or groups who insist upon this or that new therapy or facility for them or for their community.

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 - horrors - the legislature may 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 we will be discussing is one of the most extreme caution. Nimblly they tiptoe through the minefield of the topics upon we will venture with foolhardy determination. For the strong feelings which may be engendered amongst minorities about any one of the topics of our conference 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 mode 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 the subject matter of our conference. It is, whether in the interface of law, medicine and ethics the Parliamentary institution - the
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 an epidemic which had a global significance was just not there. Furthermore, the free press of the United States, cosseted and protected under the shield of the stirring words 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. And as the United States, and other countries, reap the sad burden of suffering and death which results over the next decade or so from this pitiful neglect, we should reflect upon its lessons for our
democratic institutions of that failure. Mr Reagan, personally, is not to blame for all of this. His silence is simply 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 have done better, including in the painful decisions to try to contain the AIDS epidemic by very candid public discussion of things so recently regarded, in modesty, as sacrosanct and private. And by the provision of needle exchange to halt the coming second wave of AIDS, spread through the vectors of the intravenous drug users who mirror the sexual orientation of the whole community. But even in such democracies, like my own, there are stumbling blocks. The provision of condoms and the supply of cleaning material for sterile needles in prisons is one of these. In the end, in AIDS, we have to make very hard choices. And the question recurs, whether our democratic leaders and institutions - and indeed our people - will have the strength and wisdom to make them. The point recurs that to fail to make them 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. Whether stimulated by the
general principles of a Bill of Rights or simply
past-precedents of the common law on analogous problems, the
judiciary is the ultimate fall-back. 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.

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 like landlord and tenant or the Statute
of Limitations. 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. They 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. 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 likely 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. Yet 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 higher levels of deformity and 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 observers. 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 in my country for legislation to cover the issues raised by artificial conception. The arguments for such regulation were voiced by Professor Louis Waller, who was appointed Chairman of the Victorian State Committee on Infertility. Legislation, he declared, would ensure "that Parliament, and hence the community, knows of and has the opportunity to consider and comment upon, developments in the challenging field of novel birth technologies". Where the scientists pleaded for flexibility and to be left to guidelines developed by their peers, Professor Waller 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".

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 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". But then, as if to distance himself from the outspoken opinions of the Roman Catholic Archbishop of Melbourne (Sir Frank Little) 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
amniosynthesis. But experiments on "spare" embryos for basic
research of widespread significance would not be condoned.

Needless to say, this flare-up pleased nobody. The
scientists condemned it as ineffective and some the leaders
packed their microscopes and left Australia. The members of
the cautious Advisory Committee wondered about the utility of
giving their reasoned advice. 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
constituency of Greensborough dutifully returned the
government's candidate.

This is a little story from a far-away corner of the
world which illustrates just how difficult it is for the
democratic process to grapple successfully with the issues
presented by bioethics. No doubt you could tell your own
stories.

SECOND GAUNTLET OF WESTMINSTER

These, then, are some of the common themes of this
conference. The problems presented by the interactions of
law and technology are pressing. They are numerous. They
are more complicated than ever. There are no easy solutions
for them. They require sensitive treatment. No jurisdiction can effectively tackle them alone. Yet to wait for all jurisdictions to act is a pipe dream. The World Health Organization, as in AIDS, can stimulate, provoke and guide our communities in the four corners of the world in the responses which we offer to the social implications of the new biology. But because the societies themselves are so different - and have profoundly differing cultural perspectives and moral values - universal solutions will be almost impossible to come by. Between the universal nature of the problems and the infinite variation of the societies that must offer the solutions - we have one of the fundamental dilemmas of the legal treatment of biomedical questions today.

The Victorian Premier's reference to *Brave New World* takes us back to 1931 when Aldus Huxley penned his remarkable prophecy. 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."

One wonders what Huxley would say today, 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.

Yet cope we must. Between the sessions of this conference we will walk out into this splendid, ancient city. We will behold its familiar landmarks. We will walk up its historic streets. We will behold the Mother of Parliaments. On the Strand we will visit the Royal Courts of Justice - successors to an unbroken chain of legal regulation reaching back almost a millennium. These signs of continuity will be reassuring to us. So will the sights of the ordinary men and women of this cosmopolitan city: scurrying here and there, many of them living illustrations of the international character of London, even after the sun has set on its Empire. 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. These sights will reassure us that we will be able to cope. Democratic institutions, neutral courts, the rule of law, the honourable practice of the healing arts, vigilant science 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?

In 1264 a Norman nobleman, Simon De Montfort led the Barons of England in rebellion against King Henry III. It was the first assertion by the English since Magna Carta of the right to limit the power of the Crown. It was by no means the last. The challenge by De Montfort was ultimately delivered when he rode on horseback into Westminster Abbey. He threw down his gauntlet - literally - on the floor of the Abbey where so much English history is written.

Australians are a somewhat rebellious lot. Remembering the brave Simon, I wish to throw down a gauntlet of my own. We should reflect upon it during the week. We should especially reflect upon it tomorrow night at the Evensong Service at Westminster Abbey in the presence of De Montfort's spirit. Now the challenge is not to the Crown - nor even to its successor - the Executive Government. It is not to the legislature or to the elected leaders of our professions or of our communities. It is to ourselves.

Will we have the wisdom to provide the institutional answers to the questions that will be asked this week at this conference? Can democracy cope in the age of science and technology? That is the fundamental question which is suggested by the multitude of issues which we will face. A rational contemplation of their variety, difficulty and sensitivity will make us profoundly pessimistic. Only the talents of human intellect here assembled and the London
sites of stable continuity provide reasons for optimism. Each one of us will draw our own conclusion when Friday comes.
FOOTNOTES


"Abortion itself is a very controversial subject. It has been; it still is. Many people feel genuinely and sincerely for and against its operation. It involves sociological, moral and profound religious aspects which arouse anxieties. Parliament itself has been much exercised over this subject for many years. None of these matters concern or affect my considerations or my ultimate decision. The court endeavours, to the best of its ability, to interpret the law and, as Sir George Baker P said: 'My task is to apply the law free of emotion or predilection. See Paton v British Pregnancy Advisory Service Trustees [1979] QB 276, 278.

Since the enactment of the Infant Life (Preservation) Act 1929 there have undoubtedly been rapid, extensive and truly remarkable developments in medical science, not least in the field of obstetrics. Some matters have become much clearer, some have remained obscure and difficult to determine; so it is perhaps understandable that the question as to when life begins, as to when a foetus is capable of being born alive, as to when a child is actually alive, are all problems of complexity to even the greatest medical minds. The determination of when life ends is now also a matter of concern and dispute."

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). See Webster v Reproductive Health Sources et al N. Y. Times 17 April 1989 B12.
2. The Times (London) 10 January, 1985, 12.
4. The Queen v Malcherek and Steel (1981) 1 WLR 690 (CA).
9. Re a Child (Wardship).
11. L Waller, La Trobe Memorial Lecture, La Trobe University, 1988.
12. Ibid.