CLINICAL ONCOLOGICAL SOCIETY OF AUSTRALIA

ANNUAL DINNER

THE NATIONAL GALLERY OF VICTORIA, MELBOURNE

THURSDAY, 29 NOVEMBER 1979, 8.00 P.M.

THE RIGHTS OF THE LIVING AND THE RIGHTS OF THE DYING

The Hon. Mr. Justice M.D. Kirby
Chairman of the Australian Law Reform Commission

November 1979

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THE LAW REFORM COMMISSION

The task of the Law Reform Commission is to advise Parliament on the reform, modernisation and simplification of the federal laws of our country. The Commission is established in Sydney. There are eleven Commissioners, four of whom are full-time. The Commissioners are assisted by a staff of 20 and by teams of consultants chosen, with the approval of the Attorney-General, to work on particular projects. The Commission engages in public debate about the law, its purposes and its reform. It does this by the use of the media and by publishing papers setting out tentative proposals for change. The Commission holds public hearings in which experts and ordinary citizens have their say, directed at identifying the defects and omissions in current law and proposing ways in which our legal system can be improved. Reform does not imply change for its own sake. It suggests change for the better. When the Commission has formulated its proposals for legal change for the better, it presents a report to the Attorney-General and Parliament. The proposals in several reports have already been adopted as part of the law of the land.[1]

Great forces are at work for change in Australian society. They include the impact of a changing population and changing social and moral values. One could scarcely expect that a society that is better educated and better informed would conform to a legal system laid down in earlier times when the law was there to be obeyed and that was that.

Many of the problems facing the medical and legal professions today reflect, in part, this phenomenon. People nowadays are more conscious of their rights. They are also better informed of where things have gone wrong. They ask why this or that should be the law. They are more prone to assert their rights. I believe we will see more rather than less of this. There will be no turning back the clock to universal blind acceptance of the professional wisdom of the doctor, any more than of the lawyer.

The second force for change is science and technology itself. Science affects the law as it does medicine. The law tends to speak to the society of today in the language of a previous time. Uncomfortably for the law, society and its technology do not stand conveniently still. Whether it is the impact of computers on our privacy, telecommunications on the repetition of a defamation, the breathalyzer on intoxicated driving or transplant surgery on the legal definition of death, technological and scientific developments are occurring at a rapid rate and may require adjustment and accommodation by the legal system which, ultimately, states the standards by which we live peacefully together.

LAW AND MEDICINE

In a number of the tasks that have been given to the Law Reform Commission by successive Attorneys-General, we have been thrown into close contact with the medical profession, working in an interdisciplinary way to improve the law by a thorough understanding of relevant medical data and an appreciation of the proper relationship between medical practitioners and the law. Thus, in an early project designed to reform the laws of criminal investigation, we suggested that persons subject to an intimate police or customs search of their bodies should have such a search performed, at their option at least, by a medical practitioner not a law officer.[2] Already, this proposal has been substantially adopted in the customs area.

In a task on alcohol, drugs and driving, we had to address the different means available to establish sufficient alcohol or drug intoxication to impair driving efficiency.[3] This is a case of technology coming to the aid of the law. Certainly, the law and the courts could not have coped with the

tremendous expansion of the social problem of intoxicated driving, without the aid of breathalyzer and like equipment. The old procedures of oral testimony, of the impression of witnesses concerning intoxication, would have seriously impeded an effective social response to the phenomenon of the drinking driver. As it is, our legal remedies seem puny and ineffective against this endemic anti-social activity.

Two later projects, one completed and one still proceeding, have thrown the Law Reform Commission into the closest contact with the medical profession. I believe it has been a bracing experience for both of us.

In 1976 we were asked by Attorney-General Ellicott to advise on the law that should govern human tissue transplants and associated matters.[5] The Commission was led in the project by Mr. Commissioner Russell Scott. It numbered amongst the Commissioners Sir Zelman Cowen and Mr. Justice Brennan of the Federal Court of Australia. Sir Zelman, before joining the Commission, had written on the subject of transplantation over many years and had drawn attention to the legal and ethical problems which human transplantation brought in its train.

To ensure that the lawyers of the Commission fully understood the medical, moral and other issues raised, we assembled, as is our usual practice, a team of honorary consultants who numbered some of the finest medical practitioners in the country. From all States, and from the varied relevant disciplines of your profession, busy practitioners, at the height of their powers, gave their time to contribute with the Commissioners of Law Reform to the preparation of an advice to the national Parliament. In addition to lawyers and doctors, we included in our team Professors of Philosophy and Divinity and representatives of major religious faiths.[6] We published a consultative document. We held public hearings in all parts of the country. We listened to patients who told us of the predicament of transplantation and the grievous stresses which the pressures for donations placed upon the family group. We then confronted many sensitive legal and moral questions :

* Should consent be required for donations or was it enough to infer consent, unless in his or her lifetime a person recorded an objection to donating a vital organ?

* Should the same regime of transplantation cover transplantation of spermatozoa and ova or was the transplantation of life itself in a special class, suitable for legal treatment separate from a transfer of kidney, cornea and so on?
* Should coroners be empowered to give a pre-death consent to tissue removal?
* Should a child, in any circumstances, be permitted to donate a non-regenerative paired organ to a sibling, say, or should the law forbid this to protect the family from facing such a dilemma?
* Should a new definition of death for legal purposes be introduced, in terms of irreversible loss of all function of the brain, to cope with people sustained on hospital ventilators : often suitable as donors of transplant material?
* Should the retention of cadaver pituitary glands from autopsies be legitimised, in the name of the great social benefit derived from the hormone extract so procured?

I think you will agree that these questions (not the full catalogue of the issues we had to confront) represent intensely sensitive issues. All of them are issues urgently posed by the advent of transplant surgery. As in so many areas of scientific and technological advance the "time cushion" to permit society's lawmakers the opportunity of reflection and the gathering of a community consensus, is not now always available. The advances in immunology occurred so quickly and the benefit to the patient was so manifest and dramatic that medical science advanced. The law, which is supposed to state society's standards, was left behind. There are few votes in the resolution of these issues. On the contary, because they are sensitive, complex, even distressing questions, lay politicians tend to put them to one side in a busy world in which there are headier and less intractable issues to be addressed. But if the law is to be relevant to doctors, patients and society : a living and protective instrument that prevents conflicts and resolves disputes where they occur (and even facilitates beneficial advances where current law provides an impediment) issues such as this cannot indefinitely be put into the legislator's "too hard basket".

We produced our report. We agreed on most things. On one issue the Commission divided, namely on the issue of consent by minors to transplant donations. Our report was well received. The British Medical Journal, in a leader, provided a detailed and favourable review, describing the report as "the latest of an outstanding series".

> The publicity which the Commission's activities attracted in the course of preparing and publishing its report did a lot in Australia to remedy the ignorance of the public and apathy of the medical profession towards this important subject.[7]

The British Medical Journal picked up an important suggestion in the report :

> Of particular interest is the Commission's warning that the difficulties and distress experienced by medical staff in dealing with dying patients are likely to increase rather than diminish as medical advances add to the patient's prospect of survival, and the report concluded 'careful instruction in medical ethics and behaviour and related subjects are ... likely to benefit both the student and the community'.[8]

The B.M.J. summed up our approach, describing the report as :

> A carefully researched and well reasoned case for legal sanction of current practices ... in favour of cautious liberalisation of laws (as relating to the use of cadaveric tissue).

Similarly sympathetic reviews appeared in the Lancet and the Medical Journal of Australia. More recently we have given permission for the translation of the report into Spanish for use throughout South America, where governments are facing like issues. I cannot remember Australia's last legal transplant to Hispanic America.

If it ended there, it would doubtless be a satisfying academic exercise but scarcely one which had improved the law of our country. Fortunately, more has happened. In the Commonwealth's sphere the report has been implemented in the Capital Territory. Sir Zelman Cowen presided at the meeting of the Federal Executive Council when the law was brought into operation. He has described the special satisfaction of seeing this project through from the conception, as it were, to its legal birth. In Queensland, the Deputy Premier, Dr. Edwards, has announced the intention of the government to implement the report. In Victoria the Minister of Health has told Parliament that his Ministry "is to a large extent favourably disposed towards the proposed legislation" included in the report.

A working party has been set up chaired by Mr. H.W. Pascoe S.M. and is examining the proposals. The Standing Committee of Commonwealth and State Attorneys-General decided to refer the report to all State Ministers of Health. It has been discussed at the national meeting of Health Ministers. It is understood that the report is also under study in the other States.

For a country which can boast very few achievements of uniform law, there does appear to be a distinct movement toward uniform adoption of the Law Reform Commission's legislative package. This is the more remarkable, I believe, because of the intensely controversial nature of some of the issues involved. I say this not out of idle boastfulness but because it is a signal to this audience that we may be optimistic. Given the right methodology, an interdisciplinary means may have been found to capture the attention of distracted lawmakers. If this optimism proves well placed, we may yet look to the development of a legal regime in such vexed matters as :

* In vitro ferilisation
* Artificial insemination
* Transplantation of foetal material
* Genetic engineering
* Clinical trials in the treatment of cancer and other diseases.

If my optimism is ill-founded, and political leaders cannot be engaged in consideration of these sensitive issues, there is nothing surer than that they will not go away. They will remain, lying in wait to cause uncertainties for the medical profession, confusion among the laity, distress to some of the patients involved and their families and sporadic, intermittent injustice as outdated laws operate with their unexpected results upon new, unforeseen circumstances.

PRIVACY AND MEDICAL RECORDS

I said that the other current task was one upon which we were still working and had not yet reported. I refer to the reference to the Law Reform Commission on the issue of privacy protection. In Australian medical and hospital practice, it has been tradition rather than the law that has protected privacy and confidentiality up to now. A number of pressures have diminished the security of medical and hospital information.

First, there is the growing perception of competing moral principles, not least at a time when medical care is passing from being almost exclusively a private responsibility to, substantially, a community responsibility. In any system of subsidised health care, some form of audit and control may be necessary.

Secondly, since the War the focus of epidemiological research has been on chronic non-infectious diseases such as emphysema and cancer. But these require intensive medical surveillance of a substantial population over a long period of time. Among the many moral issues raised is the resolution of the tension between the individual's right to the privacy of intimate information about his medical condition and the just requirements of others, even of the international community, for knowledge that will promote the greater good of mankind. I know of one such trial in cancer research where the trial secretariat is in Lausanne, Switzerland and the statistical centre is in Boston, U.S.A. Personal data from Australia is sent by identification number. In other countries they have not apparently troubled to de-identify the data as we have. In part this may be because of differing cultural factors. In part it may be to preserve the rigour of the test and to prevent patients who move from hospital to hospital ending up in the data twice.

Thirdly, the very size of hospitals, the impersonal form of some medical records and the new technology of computerisation all add to the dangers to medical privacy. The great bulk of information which is now kept contrasts notably with the medical card at the turn of this century where the ailments, personal habits and social relationships of the patient were typically locked in the safe crevices of the physician's mind. That there is a vast increase in the demand for access to medical data seems beyond question. A recent report by a Presidential Study Commission in the United States put it thus :

> ...[Requests] for medical record information that are not directly related to the delivery of medical care [are many]. For example, the director of the medical records department of a 600-bed university teaching hospital testified that he receives an estimated 2,700 requests for medical record information each month, some 34% of them from third-party payers, 37% from other

> physicians, 8% in the form of subpoenas and 21% from other hospitals, attorneys and miscellaneous sources. The attorneys for the [Mayo Clinic] testified that the clinic receives an estimated 300,000 requests for medical record information a year, some 88% of them patient-initiated requests relating to claims for reimbursement by health insurers.[10]

Privacy is an attribute of individualism. In days gone by, the only privacy which hospital patients were concerned about was the bodily privacy of the environmental surroundings: the screen around the bed, the private room and so on. Now, a new kind of privacy is upon us. Just as people can be perceived directly in their physical circumstances (and can be intruded upon in that way, unexpectedly and against their will), so, nowadays, important invasions of privacy can occur through information systems. Such an expansion in the quantity of medical data and the equal ease with which, technically, it may be transmitted across the ward or across the world, have led to demands for new means by which the data subject can control the perceptions which others have of them or at least know how others are evaluating them on their filed information.

The advent of computerisation, in particular, has led to the development of legislation in Europe and North America designed to reassert the right of the individual in relation to personal data about himself. A remarkable feature of this legislation is that, despite the differing legal systems of France, Germany, Sweden, Canada and the United States, Luxembourg, Denmark and Austria, a "golden thread" runs through the privacy laws so far developed. This is the right of the subject of personal data generally, with few exceptions, to have access to that data, to see how others see him. In the United States (though not yet universally in Europe) this right of access has been in force in relation to the patient's entitlement to inspect his own hospital and medical records. Under the United States Privacy Act, federally funded hospitals have come under the obligation to grant access by patients to their files. No access, no federal funds. Some State legislation excludes psychiatric records. Some cover only hospital records. In some cases, intermediate access is provided. In others, medical authorities can determine how much of a medical record the patient may see.

The predicted flood of access claims has not eventuated. At a federal level, with a total estimated patient population of 5 million, requests to the Bureau of Medical Services for patient access to records have so far numbered about 3,000 in three years.

I fully realise the resistance in some medical quarters, particularly in Australia, to the notion of patient access. But I think it is a symptom of something more pervasive and dynamic. I refer to the pressures for a more equal relationship between physician and patient: one in which there is a greater lay knowledge of the physician's activities and an increased disinclination to leave everything up to the doctor.

There are other principles of information privacy which may or may not have application in the context of medical records and research. One is that there should be limits on the collection of personal data and that such data should only be obtained by lawful and fair means with the knowledge and consent of the data subject. Another is that the purposes for which personal data are collected should be specified at the time of the data collection. A moments reflection will show that these rules are designed to uphold individual integrity. Until now, the law has concentrated most of its attention on the protection of bodily integrity of the individual. Assaults, trespass and similar invasions have been effectively redressed. With the advent of new technology: telephone tapping, surveillance devices, computers and telecommunications generally, new forms of privacy invasion are created, where the law's standards are often ill-stated, if stated at all. The lesson of other countries is clear: to defend the individual (his autonomy and his integrity) against new invasions of his privacy, new rights must be created, ultimately enforced in the law.

Medical records are a small but vital area of private information. They may well require special, discreet treatment. The Law Reform Commission has widely circulated a research paper, which embraces, as an application of the "golden rule", a general principle of patient access. Needless to say, it has engendered much heat. I hope that before we are done, it will promote some light as well.

CLINICAL TRIALS

At the heart of the privacy issue is a tension between the old and the new approach to medicine. The old was a kind of professional paternalism. It was sometimes described as a "therapeutic privilege" not to impart information to the patient. The formal position of the common law of England, which we have inherited in Australia, has always been clear. It upholds the integrity of the will of the patient:

> Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent, commits an assault for which he is liable in damages. 12

Like principles govern non-surgical therapy. Put shortly, in the eye of the law, the patient calls the shots.

In practical terms, as we all know, it is not so straight forward. A resourceful, paternalistic, powerful and sometimes overbearing profession may nominally favour the patient or the client with a choice or a right not to consent. But often there is little real choice, inconvenient options or alternatives considered unsuitable are not fully discussed. The consent of the patient is not free, knowing and informed. In cosmetic surgery there may be a choice. After a diagnosis of cancer, most patients, abetted by their families, are only too prepared to surrender their will to the medical profession. This is entirely understandable. But it imposes special responsibilities which become most acute where there is no clear cure and experimental efforts are essayed in the attempt to save the patient or, at least, prolong life and reduce pain.

The agony about experimental clinical trials is, so far, a crisis of the medical profession rather than of the law. In part this is because of the general public confidence for integrity and skill which the medical profession in Australia enjoys. In part, it is because the subjects, the patients, are often ignorant of their rights, frightened about their condition and even confused and ill-informed about the treatment they are receiving. In some cases, too, the potential complainant dies, effectively terminating any community or legal review.

As the treatment of cancer diversifies from radio therapy and surgery to new forms of chemotherapy, extensive experimentation must take place. This imposes still greater responsibilities. The chances of loss of effective patient control over the course of treatment become more remote where the patient is part of an experimental group.

Society seems undecided on the question of experimental trials. On the one hand, it triumphantly embraces the success that followed a medical breakthrough in treatment of this or that disease. On the other hand, it is not willing to countenance the treatment of human beings as an object which, like goods in a storm, can be thrown overboard, in part, to save the residue.[13] Lord Smith of Marlow in the Telford Memorial Lecture 1978 stated the problem:

> Let us admit, one of the major difficulties in treating cancer is the unreliability of the means available to measure the significance of our achievement or even, at times, to prove beyond doubt that they are achievements.[14]

The great need in the treatment of cancer is for more data, reliable statistical data, based upon differential application of therapy to large groups of patient subjects in all parts of the world. This need runs headlong into ethical, professional and legal problems. The doctor's problem, Lord Smith described thus:

> As is the case with the whole of medicine, when a doctor has a patient with cancer, at the heart of the matter is a one-to-one relationship ... The doctor should not, in my view, decide how to treat a patient on the basis that a high priority should be given to fitting him into a trial designed to acquire knowledge that might help future patients ... I believe that one can accept ... and co-operate in clinical research without ethical qualms of any kind, provided that this does not lead you to treat a patient less well than your judgment would dictate.[15]

Some will criticise this as unduly conservative. Within the medical profession, there appears to an ambivalence which, amongst the judiciary, Lord Denning has described as dividing the "timorous souls" from the "brave spirits". These are emotive words which imply a judgment. The late Sir John Loewenthal who, amongst his many contributions to public service acted as a consultant to the Law Reform Commission on Tissue Transplants, wrote shortly before he died:

> The spectacular progress of medicine in this century has provided many examples of advances achieved in uncontrolled and random fashion. Penicillin, anti-T.B. drugs, anti-poliomyelitis vaccine and other treatments were so obvious in their beneficial effect that their evaluation was comparatively simple. On the other hand, the surgeons who proceeded with cadaver donor renal transplantation at a time when the majority of the world's greatest biologists and immunologists assured them that it could not possibly succeed were unable to await for the approval of the basic scientist. A gigantic clinical experiment was carried out and its history is now being written month by month ... The results have been clearly and objectively reported and the value of the procedures has been determined as progressive evidence has become available. 16

In John Loewenthal's view, it was important to defend the courage and skills of the surgeons who went ahead. An over-restrictive attitude to clinical trials might be good conservative professionalism. But it would be folly, and costly in terms of life and human pain, to wait for the major breakthrough in cancer treatment and to desist from experiments which may just help the patient, and many after him or her in a like predicament.

There are various reasons why those, within and outside the medical profession who know about it, are anxious about experimental therapy. The Nazi euthanasia programme began as a means of "relieving" the severely and chronically sick. It was advanced by the medical profession and recent studies show just how many doctors who presided over killings viewed themselves as idealists. Interviewed today, they talk compulsively about technical matters seeking to avoid confrontation with the reality of the horrors that surrounded them.[17] Some still describe themselves as parties in a "vast revolutionary biological therapy":[18]

> It started with the acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as life not worthy to be lived. This attitude in its early stages concerned itself merely with the severely and chronically sick. Gradually the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, the racially unwanted and finally all non-Germans. But it is important to realise that the infinitely small wedged-in lever from which this entire trend of mind received its impetus was the attitude towards the non-rehabilitatable sick. 19

The horrors of the revelations which followed the War made succeeding generations extremely cautious about any deviation from the physician's concentrated duty to heal the patient in his care.

On the other hand, the tragedy of Thalidomide would undoubtedly be replicated if careful trials were not common place before new drugs are introduced. In the United States, the appalling damage done to human beings in other countries was limited by the Federal Drug Authority's controlled test release of thalidomide. Over 2 1/2 million tablets were distributed by August 1962 to more than a thousand doctors who prescribed the drug to almost 20,000 patients, including 3,760 women of childbearing age. Fortunately, the F.D.A. stopped general distribution and prevented the frightful damage done elsewhere.

But whilst hindsight shows the wisdom of restraint in this case, two intractable problems are identified by it. The first is the bad results that may flow from the denial of useful and valuable drugs or the restraint on possibly useful treatment that has not yet been conclusively proved. The second is that any controlled attempt to spare the whole of society from similar disasters requires, at the initial stages of therapy, an imposition on the control group of fellow citizens. The 3,760 women of childbearing age who submitted, in all likelihood unknowingly, to the Thalidomide control, did so for the benefit of society. If all goes well, and particularly if there is an advance, we applaud yet another medical triumph. But if things go wrong, what is the moral and legal position of the doctor?

There are, as you would all know, numerous international statements of limitations on human experimentation. The Nuremburg code,[20] the Declaration of Geneva,[21] the International Code of Medical Ethics,[22] the Declaration of Helsinki[23] and most recently the Covenant on Civil and Political Rights all place limitations on what should be done. The last mentioned document, the Covenant, is a United Nations instrument which Australia has signed but not yet ratified. The Commonwealth has announced its intention to proceed to ratification and the Human Rights Commission which is to be established in Australia contemplates national machinery to ensure that we comply with the terms of the Covenant. Article 7 reads as follows:

> No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one should be subjected without his free consent to medical or scientific examination involving risk where such is not required by his state of physical or mental health. 24

There are few legal decisions on the practical translation of these broad principles to actual cases. If therapy is beneficial, or at least does no harm, nothing will generally eventuate. In cancer treatment, even if the therapy is not beneficial, the patient will generally understand that experimental, even desperate measures are required. We have not yet become fascinated with medical mal-practice litigation. If the patient does not know of or fully understand the experimental nature of the therapy, he or she will rarely be in a position to take a complaint further. It does seem, however, that a higher standard of care may be required where a medical practitioner is carrying out therapeutic research on a patient. Canadian cases suggest that the test goes beyond the normal principles (viz. what a reasonable doctor would have done under the circumstances) and imposes on the practitioner the duty to exercise "very great care, if not the greatest care possible" in experimenting with new treatment.[25] English authority, furthermore, suggest that a physician is under a strict duty to read all relevant medical literature, in his or her specialty at least, before using a new therapeutic measure on their patients.[26] These are onerous, some will think insupportable, obligations. But they are the counterpoise to the law's recognition of the very great confidence and trust which the medical practitioner enjoys.

So far as the amount of information that must be imparted to a patient before he or she can legally consent to new or experimental therapeutic treatment is concerned there is little specific domestic law on the subject. It is not ordinarily necessary for a patient to be informed about every conceivable risk.[27] But as the treatment used becomes more experimental and the potential risks are consequently increased a duty to tell the patient and secure informed consent correspondingly increases.[28]

The law cannot be expected to yield precise answers to the moral problems posed by the technological advances in medicine.[29] The time cushion has gone. Events are moving faster than the law or indeed our powers of ethical understanding. But though society is ambivalent and inclined to justify the means, (when all goes well), by the ends, I do not imagine that the law will embrace, unreservedly, this point of view. On the contrary, I believe that the future legal regime will reinforce, in Australian law, the principle of informed consent. As recent research suggests,[30] the overriding duty to heal is not incompatible with py experimentation. Some of this research points to the improved understanding of forms and the greater perceptions of treatment options when the patient is allowed to take a brief written explanation home, to consider it in solitude or with his or her family.[31] We who are so close to problems, medical or legal, often assume comprehension in speed and quality that goes beyond the citizen in a stressful situation. To allay fears and promote the ultimate control by individual human beings over their own destiny. I am sure that we will see even greater efforts in the future towards frankness with the patient. We are dealing with a better educated and better informed community. I have confidence that there is an understanding of the need for medical experimentation. But whether there is or is not, it is for the individual to decide his or her destiny, however foolish that decision may seem to others.

THE RIGHT TO DIE:

Does this principle extend to a right to die? The horrors of the Nazi camps and the fear of the "thin wedge" of euthanasia promote resistance to this concept. The Judeo-Christian tradition resists both active and passive euthanasia. The official teaching of the Roman Catholic Church, however, stresses that human life continues "for so long as its vital functions, distinguished from simple life of the organs, manifest themselves without the help of artificial processes".[32] The Papal view was reflected in a statement written in the name of Pope Paul VI

> The duty of a doctor consists principally in applying means at his disposal to lessen the suffering of a sick person instead of concentrating on prolonging for the longest time possible - using any methods and under any circumstances - a life which is no longer fully human and which is drawing naturally to its end.[33]

Under Jewish doctrine although any form of active euthanasia is strictly prohibited, the "artificial prolongation" of the life of a terminal patient is not generally thought to be required.[34]

Because of the distinction draw by much moral and religious teaching between the issue of euthanasia and the right of a terminal patient to refuse "extra-ordinary care", moves have developed in the United States of America to provide a legally enforceable right to die. This is not, as some would misunderstand it, a right to commit suicide or to prematurely terminate a healthy life. It is rather the right of an adult person of sound mind to execute a declaration which directs the withholding or withdrawing of extra-ordinary life-sustaining procedures once he or she is adjudged to have a terminal condition.[35]

Statutes have been passed in the United States preserving this perceived ultimate right of the individual. They would not appear to conflict with Christian and Jewish religious teaching. They provide exceptions in the case of minors or pregnant women and people who are not of full legal capacity. They protect the medical profession against the charge of aiding and abetting the death of another. They pay great attention to the patient's capacity to comprehend his or her situation, the risks and the alternatives. They respond, I believe, to the genuine horror felt by many American citizens about the well publicised predicament of Karen Quinlan.[36]

There appears to be little present agitation for similar legislation in Australia. But I believe that the time will come when law makers here will have to face this issue too.

CONCLUSIONS:

As people become more assertive of their rights, better informed about what those rights are, the problems for the medical profession will expand. In cancer treatment the dependence of the patient is so overwhelming and uncritical that additional duties are cast on the medical profession, as the price of the trust it enjoys.

That this is realized can be seen from a scrutiny of the literature which shows a keen sense of obligation felt in many quarters about the primacy of the duty to heal and the importance of the obligation of frankness. It was doubtless easier in the days when paternalistic professionalism insulated the doctor from these pressures, whether from within the profession, from patients or from the law. But the genie will not be put back into the bottle. And in the resulting controversy there will be underlined, I believe, a principle from which the common law has never deviated : namely that society and its laws should defend the right of the patient to make knowing decisions that may effect his person, so that he is upheld as an individual and never treated as a mere object.

I am honoured to have been invited to join you for this occasion. I applaud the honourable way in which you are facing the stressful task of your discipline and also some of the acutest moral issues of our times. The distinguishing feature of professionalism which is certainly worth preserving is its concern with higher principles. I know of no professionals who enjoy greater respect in the community than you do. As I look at your literature and speak with you individually, I am convinced that the confidence of the community is well placed.

FOOTNOTES

1. For a review of the implementation of reports see The Law Reform Commission (Cth) Annual Report, 1979 (ALRC 13), 23.

2. The Law Reform Commission, Criminal Investigation, 1975 (ALRC 2), 57.

3. The Law Reform Commission, Alcohol Drugs and Driving, 1976 (ALRC 4).

5. The Law Reform Commission, Human Tissue Transplants, 1977 (ALRC 7).

6. id., vii to viii.

7. British Medical Journal 28 January, 1978, 195.

8. ibid.

9. id. 196.

10. United States Privacy Protection Study Commission Personal Privacy in an Information Society 1977, 280

11. The Law Reform Commission Privacy Research Paper vii, Medical Records and Privacy, 1979.

12. Justice Cardozo in Schloendorff v Society of New York Hospital 211 NY 125, 129, (1914).

13. The analogy is suggested in B.M. Dickens, "Information for Consent in Human Experimentation" (1974) 24 Uni Toronto Law Journal 381, 410.

14. Sir Rodney Smith (now Lord Smith of Marlow) "The Patient with Cancer and his Doctor", Telford Memorial Lecture, 1978. Annals of the Royal College of Surgeons of England (1978), vol. 68. No. 5, 384.

15. ibid.

16. J. Loewenthal, open letter "Surgical Trials" Aust NZ J Med (1979) Vol, 9, No. 2, 118, 120.

17. R.J. Lifton, Death in Life, reviewed, Time, 25 June 1979, 38.

18. Ibid.

19. Kamisar, "Some Non Religious View Against Proposed "Mercy-Killing" Legislation" 42 Minn L. Rev 969, 1031-32 (1958) (quoting Alexander, "Medical Science under Dictatorship", 241 New Eng J. Med 59, 44 (1949).

20. Dickens, 381.

21. The full text of the Declaration of Geneva (1948) [The Hippocratic Oath] is found in Katz, Experimentation with Human Beings 312 (1972).

22. De Moerloose "A Survey of International and National Codes and Legislation in Selected Areas", in Council for International Organisations of Medical Sciences, Round Table Conference on the Protection of Human Rights, 329, 331 (Geneva, 1974).

23. Declaration of Helsinki (1975).

24. The International Covenant on Civil and Political Rights is the Schedule to the Human Rights Commission Bill, 1979 (Cth).

25. Ballis v Boulanger (1924) 2 DLR 1083 (Canada). For a useful discussion on authorities and international law see L.W. Stanridge, "Experimentation on Humans : Controls at the International Levels and in Foreign Nations" (1979) 3 Legal Medical Quarterly, 3

26. Roe v Minister of Health [1954] 2 QB 66, 83-4.

27. See e.g., Richter v Estate of Hamman (1976) 3 S.A. Law Reports 226, 232 (South Africa).

28. L.E. Rozovsky, "Medical Experimentation and the Law" 52 (7) Dimensions in Health Service 8, 9 (1975).

29. Professor Paul Freund cited in Sir Zelman Cowen, "Law and Society", the Listerian Oration, 19 May 1979, Mimeo, 21.

30. See for example "Randomised Clinical Trials" British Medical Journal, 14 May 1977, 1238; R. Peto and Ors, "Design and Analysis of Randomised Clinical Trials Requiring Prolonged Observation of Each Patient", Br. J Cancer (1976) Vol 34, 585; R. Burkhardt and G. Kienle, "Controlled Clinical Trials and Medical Ethics" The Lancet, December 23, 1978, 1356.

31. See G. Morrow, J. Gootnick and A. Schmale, "A Simple Technique for Increasing Cancer Patients' Knowledge of Informed Consent to Treatment", Cancer, August 1978, Vol 42, 793; Compare W. P. Jazvac, "Informed Consent: Risk Disclosure and the Canadian Approach, (1978) 36 Uni of Toronto Law Journal, 191; M. Brazier, "Informed Consent to Surgery" Med Sci. Law (1979), 19, 49; S.A. Shapiro, "Limiting Physician Freedom to Prescribe a Drug for any Purpose: the Need for FDA regulation" 73 North Western University Law Review, 801, 831 (1979).

32. Filbey, "Some Overtones of Euthanasia", Hospital Topics, September 1965, 55, 57 cited in "Rejection of Extraordinary Medical Care by a Terminal Patient: A Proposed Living Will Statute", Note, 64 Iowa Law Review 573, 583 (1979).

33. McCormick, "The Moral Right To Privacy", Hospital Progress, August 1976, 38 cited Iowa Law Review, 584.

34. Rosner, "Jewish Attitude Towards Euthanasia", 67 N.Y. St.J Med 2499, 2504 (1967) cited Iowa Law Review op.cit.

35. Iowa Law Review, 649.

36. ibid. 575.