

ROYAL NORTH SHORE MEDICAL ASSOCIATION

MALCOLM GILLIES ORATION

SYDNEY, 22 SEPTEMBER 1980

NEW DILEMMAS FOR LAW AND MEDICINE

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

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MALCOLM GILLIES AND R.N.S.

*ὅν οἱ θεοὶ φιλοῦσιν ἀποθνήσκει νεός<sup>1</sup>*

Malcolm Gillies, who is honoured by this oration series, was a young medical practitioner of outstanding ability. In 1958 he died, tragically, from cancer. He was then a resident at the Royal North Shore Hospital in Sydney. Just before his death, he suffered a specially unkind blow, in the loss of his young son, also from cancer.

To commemorate the life of Malcolm Gillies and to encourage the ongoing professionals of this hospital, and people beyond, to reflect upon the loss of such a man, this oration was established. But it is also designed as a continuing tribute to all promising, young professionals who, for one reason or another, are denied the opportunity of fulfilling their potential in life. It is the only oration which has been held in the history of this famous hospital. I am preceded to this stage by many distinguished Australians. Earlier this month, the Governor-General (Sir Zelman Cowen) and the Chancellor of the University of Sydney (Sir Herman Black) told me of their contributions to this series. In delivering it, I am conscious of the special loss which occurs when a young man or woman of promise dies before the full flowering of their talents.

Even such is Time, which takes in trust  
Our youth, our joys and all we have,  
And pays us back with age and dust.<sup>2</sup>

The poet tells us that death takes away all lovely things. Of course, it is not only death which deprives people of the chance to reach their prime, extend their abilities and otherwise flourish in this world. Every physician and surgeon knows of the curious operation of chance, accident, fate. We may puzzle over these things and seek to find an explanation and a reason.

It is reassuring to see that my predecessors in this oration have generally been chosen from outside the special discipline of medicine. Though the passage of time and different areas of experience will inevitably reduce the numbers who knew Malcolm Gillies, we all experience the particular loss which occurs in death. Members of the healing professions know death as a daily companion. In part, it is about death that I wish to speak.

Before I turn to my theme, however, can I say how delighted I am to be in this hospital. Quite apart from its dedication to the relief of suffering and the treatment and cure of disease, Royal North Shore Hospital has played a particular part in the public affairs of our country. I am told that six Members of the outgoing Australian Parliament at one time served on the staff here. Dr Doug Everingham was certainly one. So was Dr. Moss Cass and Dr. R.E. Klugman. So was Senator Peter Baume, the Government Whip in the Senate. Senator Don Grimes, an Opposition Shadow Minister, was at school with me. When we recently met in that great Australian federal democratizer: the first class section of an aircraft, he told me of his time at North Shore. Outside Parliament, Professor Peter Wilenski (my predecessor in this series) served for a time here before he took his great intellectual gifts into the public arena. There is a long tradition in this hospital of public service, both within and outside the medical profession. We live in a time when close attention is needed, within the medical profession and beyond, to some of the acutest problems facing our society and its lawmakers today. I refer to the problems posed by the development of new medical technologies and of the community more questioning of the role of the professional and more demanding in its relationship with him.

#### THE AUSTRALIAN LAW REFORM COMMISSION

By what right do I claim your attention to my views on these subjects? As you have heard, I am the Chairman of the Australian federal law reform commission. In the Australian federation, the constitutional arrangements between the Commonwealth and the States leave it to the States to design most of the laws affecting medicine and the medical profession. It might therefore seem to be a curious thing that the Commonwealth's law reform agency has become directly involved in a number of topics which evidence the growing interface between law and medicine today.

The Commission is established to advise the Attorney-General and Parliament on the reform, modernisation and simplification of federal laws in Australia. There are 11 Commissioners, 4 of whom are full-time. Sir Zelman Cowen, who has long interested himself in the relationship between law and medicine was, until his appointment as Governor-General, a part-time Commissioner. In its early days the Commission had the participation of Mr. Justice Brennan, a most thoughtful Federal judge and one who has written specifically about law, ethics and medicine.<sup>3</sup> Last weekend, the Attorney-General announced the appointment of Mr. Justice Neasey of the Supreme Court of Tasmania as a part-time Member. The Commission is a body of lawyers, from different branches of that profession and different parts of the country working on tasks assigned to it, to improve our legal system.

The Commission prepares reports, many of which have been picked up and implemented both at a Federal and State level.<sup>4</sup> Before doing so, however, it engages in a debate with the expert and lay community about the defects in the current law and the ways in which those defects can be cured.

One of the greatest forces that is at work for change in Australian society today is indubitably the impact upon it of science and technology. There has never been a time when technological change occurred at today's pace. The machinery of legal change moves slowly. Technological developments (including in the area of medicine) sometimes occur quite rapidly. The 'time cushion' within which our society and its lawmakers can adjust to change is frequently removed. Events move quickly and new medical developments are upon us. Often the laws remain unchanged. Acute ethical and moral values are put in question. The result is a quandary of uncertainty and even controversy within the law, within medicine and within society at large.

Most of the tasks given to the Law Reform Commission by successive Attorneys-General have raised, one way or another, the adjustment of the law to the dynamic of technological change. Several projects have required us to consider implications of legal reform for members of the medical profession. For example, our first reference required the Commission to propose laws to govern criminal investigation by federal police. The result was a report<sup>5</sup> which led on to the Criminal Investigation Bill 1977. Among the proposals for reform contained in that Bill was the suggestion that intimate police or customs searches of the body of suspects should, at the option of the suspect, be carried out not by law enforcement officers but, as until then, by a medical practitioner.<sup>6</sup> In a report on Alcohol, Drugs and Driving<sup>7</sup> proposals were made for the identification of intoxicants in suspected drivers which, whilst involving the medical profession, respected the importance of the distinction between the doctor's duty to heal and his duty to society where there is a suspected crime.

Our current project on the reform of child welfare laws raises the issue of the effectiveness and desirability of imposing upon medical practitioners and others the compulsion of reporting cases of suspected child abuse.<sup>8</sup> Our current task on the reform of the law of evidence in federal courts takes us into a consideration of the definition of the privilege of the medical profession not to disclose patient communications, even to a court of law. Such a privilege is recognised in few of the jurisdictions of Australia.<sup>9</sup> Our work on the protection of privacy raises the whole question of patient access to medical and hospital records. With the growing computerisation of records, including health records, fears are generated that important decisions will be made about the individual on the basis of information over which he has no control. These fears have led American investigations to suggest that there is a need to enforce, as a general principle of privacy protection, the right of the individual to have access to personal data about himself.<sup>10</sup> Such a suggestion, however palatable in the area of government files, strikes resistance in the medical profession, accustomed to keeping its files to itself. Medical and hospital records are a small but vital area of the individual's private information. They may require special discrete treatment by the law so that frankness as between practitioner and the patient is not inhibited.<sup>11</sup>

#### HUMAN TISSUE TRANSPLANTS

Any of these topics would be the fruitful subject for consideration before this audience. But in 1976, the Commission received a reference from the Attorney-General which was specific to the relationship between law and medicine and symptomatic of the problems which are waiting in the wings for joint resolution by our two professions. I refer to the Commission's project on the law that should govern human tissue transplants and associated matters. In terms, the report was limited to legal change in the Australian Capital Territory. However, as the federal commission has special responsibilities to consider uniformity of law<sup>12</sup>, and as this was a subject upon which uniform legislation was considered warranted<sup>13</sup>, we proceeded to work on the basis that the proposals put forward by us would be available for consideration throughout Australia. So it has proved.

Mr. Justice Windeyer of the High Court of Australia once said that the law marched with medicine 'but in the rear and limping a little'.<sup>14</sup> Nowadays his Honour's observation seems positively charitable. The common law of England, inherited in Australia, offers no rule or principle for dealing with such difficult modern problems as transplantation of human organs and tissues, in vitro fertilisation of the human ovum, artificial insemination generally, genetic engineering and so on. There is a simple reason for this. Until recently, the legal problems posed by these developments did not have to

be confronted. Indeed they were not thought of or, if contemplated, they were regarded as impossible. In the case of transplants, the body's immunology rejected the process. In these circumstances, it is not a matter of criticism that the law gave no thought to the question of operations on donors for the positive removal of healthy, non-regenerative tissue. The law gave no thought to the conduct of intrusive surgery, not for the cure of the donor but for the relief of some other, third person. Likewise, the taking of organs from a dead human body was scarcely considered. At most, the law recognised only a limited right to property in a dead body. It offered few rules about the rights and obligations of the legal personal representative, relatives or others with respect to it.

In the course of the Commission's inquiry it emerged that suitable 'donors' of viable organs and tissues (such as kidneys) were often young, otherwise healthy patients brought into hospitals such as this, frequently after motor car accidents and with massive brain damage. In these cases, blood circulation is maintained for a time by the use of artificial, mechanical means, until a decision is made to terminate this external support. The law tends to conceptualise 'death' as an instantaneous phenomenon. Medical science shows that death is a process.<sup>15</sup>

Before artificial ventilators were developed, the classical criterion for determining death was the cessation of respiration and circulation of the blood. Interpose a mechanical device and this definition of 'death' is not only outmoded. It is positively mischievous. In The Queen v. Potter<sup>16</sup> a man stopped breathing 14 hours after his admission to hospital with head injuries sustained in a fight with Potter. He was then connected to an artificial respirator for 24 hours. The respirator was disconnected. There was no spontaneous breathing and heart beat. He was pronounced dead. A kidney was removed and transplanted. At the Coroner's inquest the question arose as to whether the accused had caused the victim's death. It was suggested to the Coroner that the proximate cause of death was the removal of the ventilator support and transplant operation. Medical evidence was called to show that the patient had no hope of recovery from the brain injury he sustained in the fight. The Coroner's jury found that the removal of the kidney had not caused the patient's death. It returned a verdict of manslaughter against the assailant, who was then committed for trial. But he was subsequently charged not with murder nor with manslaughter but with the lesser offence of common assault. He was found guilty. The case is in many ways unsatisfactory. It demonstrates the doubts, confusions and potential risks of the law in its present state.

The Law Reform Commission presented its report. It proposed that the law should recognise a definition of 'death' for all purposes of the law (not just transplants). This definition would have regard not only to irreversible cessation of circulation of the blood but also to 'irreversible cessation of all functions of the brain of the person'.<sup>17</sup>

A large number of other contentious questions had to be faced by the Commission. I list some of them to indicate the sensitive and difficult issues which law reform must address in the medico-legal area:

- . Should consent be required for donations at death or is it appropriate, in today's society, to infer consent to remove organs at death, unless a person has, in his lifetime, registered an objection? The law of France and of some other countries has recently adopted the latter approach.
- . Should the same legal regime cover transplantation of human spermatozoa and ova or is the transplantation of human life itself in a special class requiring legal treatment separate from the transfer of a kidney, cornea and so on?
- . Should a child, in any circumstances, be permitted to donate a non-regenerative, paired organ to a sibling or should the law absolutely forbid this to protect the family and a young person from facing such a dilemma, even though the consequences of such an absolutist stand may be the death of a member of the family for non-availability of an organ suitable for transplant?
- . Should Coroners be empowered to give pre-death consent to tissue removal?
- . Should the present retention of pituitary glands, removed from bodies at autopsy, be legitimised, because of the great social benefit that ensues in the treatment of dwarfism and other conditions from the use of the hormone extracted from such removed discarded tissue?

These are some only of the sensitive, controversial questions forced upon our society by the sudden advent of transplant surgery. The law, which is supposed to state society's standards, has been left behind. In confronting these questions, the Law Reform Commission adopted its usual processing of exhaustive consultation. It turned to a team of consultants drawn from the medical profession in all parts of Australia. It added to this team moral philosophers and theologians of different traditions. Public hearings were held in all parts of the country. A consultative document was issued and widely discussed. The media was engaged in the debate. Millions of Australians heard the issues thoroughly and soberly explored before television and radio.

In the end, the Commission delivered a report<sup>18</sup> with draft legislation. The British Medical Journal, not frequently given to commenting on Australian legal developments, declared it 'the latest of an outstanding series'.

The publicity which the Commission's activities attracted in the course of preparing and publishing the report did a lot in Australia to remedy the ignorance of the public and the apathy of the medical profession towards this important subject.<sup>19</sup>

Requests for the report have come from all over the world. Authority has been given for its translation into Spanish for use by governments throughout South America. I cannot recall to mind another case of a legal transplant from Australia to Hispanic America. Although Australian achievements on the international stage of medical research have been numerous, our equivalent achievements in legal theory and jurisprudence have been fewer. Times change.

Nor has the project been simply a scholarly exercise. Already governments throughout Australia are adopting the Commission's report. The Commonwealth has adopted it for the Australian Capital Territory in 1978.<sup>20</sup> In Queensland<sup>21</sup> and in the Northern Territory of Australia<sup>22</sup> legislation substantially based on the Commission's report is now in force. In Victoria, within the last fortnight, a report of a committee chaired by the former Coroner, Mr. H.W. Pascoe, has recommended adoption of the legislation in Victoria.<sup>23</sup> Progress in New South Wales is not known but the report is under consideration in the other States. In a country which cannot boast many uniform laws, here is an area where uniformity of legislation is both desirable and urgent. It is desirable because there are no reasons of local conditions which promote the merits of diversity. The biology involved, the medical techniques, the human and ethical problems are all the same. The use of organs removed in one part of the country for transplantation in another part of the country, cannot be ruled out. For the clear instruction of medical and other staff, a simple modern regime is required. Above all, it is desirable that a single definition of 'death' for all legal purposes should be adopted throughout the country, giving recognition to the advance of human knowledge of 'death' and the understanding of its processes. The urgency of attention to this subject arises from the large numbers of persons awaiting transplantation, the desirability that the law should not unduly stand in the way of this medical advance and the need to avoid the mischief, uncertainty and unfairness which arises where the law is silent, obscure or obstructive in modern conditions.



### THE RIGHT TO DIE

I realise that to many transplants and the law may seem an exotic area of particular, limited concern. I also realise that the medical profession itself is divided about the utility of some transplants and the prognosis for this particular procedure.<sup>24</sup> Though it is a subject that creates great public fascination, captures headlines and agitates vocal groups, there are many more 'low key' developments which are occurring in the treatment of disease and distress which, in the numbers affected, far outweigh the contribution to human happiness which transplants cause. What is special about this procedure is that it is a species of the modern genus of medical developments which challenge the ethical, professional and legal boundaries governing the healing professions. There are others in the genus. To some of them I now turn.

Death, which we sought to define in our report, has lately been the subject of an unusual amount of community interest and debate. Sir Macfarlane Burnet has described the development thus:

There is a nearly universal taboo against the discussion of death; even the word is avoided in favour of some acceptable alternative wherever possible. As many have said in recent years, the time seems almost ready for that taboo to be lifted in the same way as the taboo against the public discussion of sexual matters has been over the past two decades.<sup>25</sup>

Sir Macfarlane takes a firm geneticist's view that it is 'absurd to continue to believe that all human life must be conserved at any cost'.<sup>26</sup> He argues vigorously the right to die, and in some circumstances, to let die. He asserts, as a fact, that this already happens in Australia:

[C]ompassionate infanticide is already standard practice where the product of birth is such as to justify the term 'monstrous', i.e. where there is a gross and physically disgusting malformation such as anen cephalo (complete absence of brain). Severe spina bifida, where there is no possibility of effective surgery, is also not infrequently dealt with by allowing the infant to die under sedation. Evenly balanced controversy persists in regard to spina bifida generally, the results of surgery being so unhappy that many paediatricians prefer to allow the child to die in comfort. ... Most physicians will agree that compassionate infanticide ... is no less morally defensible than the accepted routine in a suspected pregnancy of waiting three months until a cell test of foetal fluid (amniocentesis) can be carried out and, if positive, the foetus

destroyed by a late abortion. ... Nowadays an intelligent woman desires, and usually achieves, a two-child family; she would appreciate, rather than resent, anything that could help ensure that the two children she rears are genetically sound.<sup>27</sup>

If these views lead the fearless Sir Macfarlane into controversy with the Churches and with some members of his own profession, his call for the painless and private killing of psychopathic criminals 'rather than [requiring them to] rot out life in a prison asylum'<sup>28</sup> raise doubts in the minds of many of the legal profession.

But these are extreme and unusual cases. Much more frequent is the daily moral and ethical problem posed by the so-called 'right to die'. Quite apart from the need in any society to face squarely the costs and benefits of extreme measures in maintaining life, there is an even more fundamental question which perplexes modern man: whether the individual has a right to die or whether countenancing such a 'right' amounts to a form of 'passive euthanasia'.

In the United States, in the wake of the Karen Quinlan tragedy and the controversy this case<sup>29</sup> aroused a number of States have moved to provide for an enforceable 'living will' by which a person of full capacity can, in his lifetime, direct that 'extraordinary means' will not be used to keep him or her 'alive'.<sup>31</sup> Such legislation proposes the right of an adult person of sound mind to execute a declaration which directs the withholding or withdrawing of 'extraordinary life sustaining procedures' once he or she is adjudged to have a terminal condition. On this subject too, Sir Macfarlane has few doubts.

When a person is diagnosed as suffering from a condition which, in the opinion of two or more competent physicians, will be lethal with greater than 90% probability within two years, the quality of the rest of his life should be clearly visualised for the patient, so that he can consider the available alternatives. The typical example of such a situation arises when the patient is diagnosed as suffering from some form of cancer. ... I believe that if [the] alternatives were carefully and honestly presented, most elderly people would opt for what comfort they can have rather than face mutilating surgery or other 'heroic' measures. ... If the patient chooses what the doctor regards as essential passive euthanasia, he must be allowed his way. ... Eventually it could become an admired and even expected action that an old person should deliberately sign off from life when he realised that he had become a burden to his kinsfolk and the community.<sup>31</sup>

Without embracing all of Sir Macfarlane Burnet's views, it is probably fair to say that the right to elect against extraordinary medical procedures would be supported by most Australians today. Certainly the teachings of the Catholic, Protestant and Jewish religions, whilst in no way supporting active forms of euthanasia or mercy killing, do not require artificial sustenance of a life which is naturally ebbing away. Pope Paul VI put it thus:

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.<sup>32</sup>

Within the medical profession, it is a widely held opinion that where a patient with a terminal illness who suffers great pain or disability has formed a firm, irrevocable and informed wish to die, that wish should be respected. Although a medical practitioner may not deliberately terminate such a life, he should do what is in his power to ensure for his patient a painless and dignified death. This will be so, even if measures he adopted may slightly accelerate the extinction of life or at least measures he fails to adopt may, if they had been adopted, have slightly prolonged it.<sup>33</sup>

A most eminent English judge, summing up to the jury in the case of Dr. J. Bodkin Adams, put it thus:

If the first purpose of medicine — the restoration of health — can no longer be achieved, there is still much for the doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life.<sup>34</sup>

In Othello Shakespeare reflected upon the 'right to die' when a person reaches a tormented and intolerable state:

It is silliness to live when to live is torment;  
And then we have a prescription to die when death is our physician;<sup>35</sup>

The position under Australian law of the practitioner terminating the life even of a 'monstrous', 'deformed' and 'retarded' child is, to say the least, dubious. The act and the intent to kill may not be excused by high social or personal motives. Description of infanticide as 'compassionate' is question-begging. Though our dependence on medical skills and the urgency of many procedures require a very great deal of latitude in the

professional decisions of practitioners it is just not the way of our legal system to countenance (without due, lawful criteria and standards) the practitioner's becoming judge, jury and executioner in the determination of whether even a deformed child will live. Of course, I realise that if Sir Macfarlane is right, few of these cases will come to notice, presumably even notice of the parents. Even if it came to the notice of parents, few would seek a prosecution. Few would be the State prosecutions of doctors in these circumstances. Fewer still would be the convictions of a jury. The fact remains that we are muddling along here in a shady world, in which the law says one thing with relative clarity and medical practice (probably countenanced by many in society) may be following another course. In decisions so vital as life and death, and where value judgments of what is 'monstrous' and 'unacceptable' life are matters of high controversy, the law is pointing one way. Modern ethics and some medical practice would seem to be pointing another.

I can see a great difference between positive steps to terminate a life (inherent in any talk of 'infanticide') and the passive acceptance of the inevitability of death naturally occurring if there is no 'officious' medical intervention. It is a fine line between the positive acts which constitute euthanasia and the passive acceptance of nature's normal course. But it is an important distinction. The embrace by many members of Germany's medical profession of the euthanasia programme of the Nazi administration, stands as a warning to us of the slippery slope we are on when termination of life depends on the value judgment of somebody, however educated and apparently civilised, as to the 'worth', 'value', 'monstrous' or 'retarded' quality of the life proposed to be extinguished.<sup>36</sup>

The controversy about a legal 'right to die' has now reached Australia. A Bill has been introduced into the South Australian Parliament by the Honourable Frank Blevins M.L.C. for an Act to be titled the 'Natural Death Act 1980'. The long title declares that the purpose of the Act will be:

To enable persons to make declarations of their desire not to be subjected to extraordinary measures designed artificially to prolong life in the event of a terminal illness.

In the Bill, 'extraordinary measures' are defined to mean:

medical or surgical measures that prolong life by maintaining the operation of bodily functions that are temporarily or permanently incapable of independent operation.

The Bill would permit a person who desires not to be subjected to extraordinary measures in the event of his suffering from a terminal illness, to make a declaration in the form of the schedule to the Act<sup>38</sup> It goes on to provide for the duty of the medical profession:

Where a person who is suffering from a terminal illness has made a declaration under this Act, and the medical practitioner responsible for his treatment has notice of that declaration, it shall be the duty of that medical practitioner to act in accordance with the wishes of the patient as expressed in the declaration unless there is ground to believe that the patient has revoked or intended to revoke, the declaration.<sup>39</sup>

The necessity of informed consent for medical procedures is underlined by another provision:

This section does not derogate from the duty of a medical practitioner to inform a patient who is conscious, and capable of exercising a rational judgment, of all the various forms of treatment that may be available in his particular case so that the patient may make an informed judgment as to whether a particular form of treatment should or should not be undertaken.

It is specifically provided that the Act will not affect the right of a person to refuse medical treatment or the legal consequences (if any) of taking or refraining from taking extraordinary measures in the case of a patient who has not made a declaration.<sup>40</sup>

This South Australian Bill has been referred to a Select Committee of the Legislative Council. The committee is taking evidence upon it. Whether it will be enacted, remains to be seen. I predict that we will see much more in this issue in Australia. I am sure that an audience of medical practitioners knows better than I of the anxiety of some patients at least to be spared what they consider as the indignities and (possibly) prolonged pain to themselves and their family of 'extraordinary measures'. The growing proportions of the aged in our community, the advances in medical technology and the dedication of the Australian medical profession ensure that this will be an issue of increased controversy in the decades ahead.

#### UNITED STATES DEVELOPMENTS

Quite apart from the enactment of statutes, similar to the South Australian Bill, on the 'right to die' an increasing body of case law is developing in the United States. This may, in time, come to have parallels in our country.

The Supreme Court of the United States has spelt out of the Constitution a constitutional 'right of privacy' to which it has given content relevant to treatment of the patient. For example, the resolution in the United States of the debate about abortion occurred not in the Legislature nor in the Executive Government but in the Judicial arm of government.<sup>41</sup> Whatever one may think of this or the particular decisions, it is clear in the United States that the constitutional right to privacy encompasses some matters of personal health. This comes about because the United States Supreme Court has characterised the individual's interest in privacy as protecting 'the interest in independence in making certain kinds of important decisions'.<sup>42</sup> Commentators have now begun to examine the implications of this line of authority for particular forms of treatment. One, for example, has examined whether the denial of the use of heroin for painkilling purposes in the case of a terminally ill cancer patient is 'an abridgement of his constitutional right of privacy'.<sup>43</sup> The author puts his case thus:

Although the court has only begun to explore its parameters, few personal decisions can be imagined that possess the intimacy or importance of the decision to alleviate chronic pain during the final weeks or months of one's life.<sup>44</sup>

In the United States, in pursuance of World Health Organisation Resolutions<sup>45</sup> the possession, manufacture and importation of heroin remains criminally punishable under Federal and State law and is civilly prohibited, even for therapeutic use. It may seem to us to be a curious approach to the argument for the therapeutic use of heroin, to call in aid the courts and the 'right to privacy'. The resolution of the debate about the 'compelling state interest' in absolutely forbidding heroin use and its alleged properties in alleviating pain would seem more appropriate for a medical conference or administrative resolution than decision in a courtroom. That the case is argued indicates the developing American jurisprudence about the rights of patients as against the doctor and as against the state. It is a jurisprudence which I am sure a self-confident, ancient and sometimes paternalistic medical profession will fear and even resist. We have no such constitutional rights as can give rise to an argument on the ground of a 'constitutional right to privacy'. But I have no doubt that in Australia, with a population better educated and better informed, with high expectations of itself and of the medical profession, analagous challenges to the unreviewed professional decision may be expected in the future.

Apart from learned speculation, cases are actually coming before the United States courts for judicial control of the profoundly important decisions of life and death. In November 1977, the Supreme Court of Massachusetts delivered its judgment in the case

of Joseph Saikewicz.<sup>46</sup> He was a severely retarded resident of a State institution who had developed an acute form of leukemia. He died in September 1976. According to medical testimony, chemotherapy would have involved considerable suffering and at best would have prolonged the patient's life for approximately one year. A court refused to order the chemotherapy. Prior to his death, the State Supreme Court affirmed this decision and later published its reasons. In the reasons it sought to establish:

procedures appropriate for reaching a decision where a person allegedly incompetent [and terminally ill] is in a position in which a decision as the giving or withholding of life-prolonging treatment must be made.<sup>47</sup>

The court held that the proper tribunal for making such decisions in cases of this kind was the court, based on the court's determination of what the patient would have wanted. This aspect of the decision provoked a great deal of controversy. Leaders of the medical profession responded with 'shock and indignation', arguing that the decision 'encroaches unjustifiably on medical practice and requires decision-making machinery that is both impractical and inhumane'.<sup>48</sup> It was contended that the decision conflicts with the approach to decision-making for incompetents laid down by the Supreme Court of New Jersey in the Karen Quinlan case.<sup>49</sup> It was said that the latter was more humane and more consonant with sound medical practice.

On the other hand, law professors have now sprung into the fray, supporting the Saikewicz approach. They contend that the 'rule of law' requires clear and public pre-existing rules, openly applied and ultimately upheld and scrutinised in the courts.<sup>50</sup> A third course is now being argued by a professor of philosophy. He is equal in his condemnation of the 'medical paternalism' of his medical colleagues and what he calls the 'legal imperialism' of those in the law.<sup>51</sup>

Whether crucial moral decisions are routinely made in closed medical committees or in open court rooms, it is unlikely that the results will be understandable, much less acceptable, to the general public, which must live with them. Concentrating such responsibility in the hands of one or other professional group is not likely to encourage a much needed responsible public consensus. Nor is it likely to aid in the development of the public's powers of moral reasoning or its sensitivity to complex issues.<sup>52</sup>

THE PATIENT'S RIGHT TO KNOW

This tension between so-called 'medical paternalism' and 'legal imperialism' is equally evident in consideration of the issue of truth-telling in the doctor/patient relationship. Let me start by stating that I approach this issue with, I hope, an understanding of the problem that must often confront a doctor, looking across the desk at the anxious eyes of a patient, or his family, for whom the only truthful news can be bad. In a piece titled 'Should Doctors Tell the Truth?' Joseph Collins, an experienced medical practitioner, put it this way:

To tell the whole truth is often to perpetuate a cruelty of which many are incapable. This is particularly true of physicians. Those of them who are not compassionate by nature are made so by experience. They come to realise that they owe their fellow-men justice, and graciousness, and benignity, and it becomes one of the real satisfactions of life to discharge that obligation. To do so successfully they must frequently withhold the truth from their patients, which is tantamount to telling them a lie.<sup>53</sup>

The same author contends that the 'art of medicine' consists largely in skilfully mixing falsehood and truth:

In order to provide the patient with an amalgam which will make the mettle of life wear and keep men from being poor shrunken things, full of melancholy and indisposition, unpleasing to themselves and to those who love them.<sup>54</sup>

Collins says that in his experience, though patients have often asked for the truth, they fall into four types of individuals:

Those who honestly and courageously want to know so that they make as ready as possible to face [life] while there is still time; those who do not want to know, and who if they were told would be injured by it; those who are wholly incapable of receiving the truth. Finally, those whose health is neither seriously disordered nor threatened.<sup>55</sup>

Collins asserts:

It may seem an exaggeration to say that in 40 years of contact with the sick, the patients I have met who are in the first category could be counted on the fingers of one hand. The vast majority of who demand the truth really belong in the fourth category. But there are sufficient in the second to justify consideration of their case.<sup>56</sup>



In a study of medical attitudes in the United States on what to tell cancer patients, Dr. Donald Oken contends that 'no area in which we work makes heavier claims than the treatment of cancer patients, with the suffering, and death which are its frequent attendants'.<sup>57</sup> Oken reports upon a number of surveys that preceded his in the United States. One conducted among Philadelphia physicians, based on a mail survey of 442 physicians, indicated the following response<sup>58</sup>

Always tell	3%
Usually tell	28%
Usually do not tell	57%
Never tell	12%

A nationwide survey of nearly 5,000 physicians indicated the following answers to a question about telling patients with an 'established diagnosis of incurable cancer':

Never tell	22%
Always tell	16%
Sometimes tell	62%

Oken's questionnaire was administered differentially to interns, surgeons and general practitioners. Respondents were asked to assume that the diagnosis is certain cancer and that though treatment may be possible, the eventual prognosis was grave. Responding to that survey, the aggregate results of his detailed questionnaire sent to all members of the staff of a busy teaching hospital in Chicago were<sup>59</sup>:

<u>Usual Policy</u>	<u>Exceptions Made</u>	<u>Percentage Response</u>
Do not tell	Never	9
	Very rarely	47
	Occasionally	29
	Often	3
	<u>Sub-Total</u>	<u>88</u>
Tell	Often	4
	Occasionally	5
	Very rarely	3
	Never	0
	<u>Sub-Total</u>	<u>12</u>
Total		100

I am not aware of similar research in Australia though it may exist. The research by Oken was conducted in 1961. It took place in another country. It was confined to one hospital. The relationship between society and its medical profession have changed in significant ways in the past two decades. Yet the problem of the doctor telling the truth to a patient and his family surely remains the same today. One doctor responds to this problem as follows:

The longer I practise medicine the more I am convinced that every physician should cultivate lying as a fine art. [Some] lies ... contribute enormously to the success of the physician's mission of mercy and salvation.<sup>60</sup>

Oken, however, is very critical of the failure of his brethren to inform patients of suspicion of cancer:

Many studies have revealed a significant proportion [of delay in diagnosis and treatment] which is ascribable to physicians. A recently published critical survey of this literature documents the importance of attitudinal factors such as pessimism and insensitivity. ... When doctors lose hope their patients know it. If doctors communicate the feeling that cancer is dreadful and irremediable, how can patients fail to despair? And, frightened and despairing, how can they deal with the possibility that they have cancer? Their only course is to keep the possibility hidden -- from themselves as well as their doctors. Thus, they court the very fate which they most fear. No physician, no matter how skilful, can treat the patient who stays away. Unfortunately, our own feelings reinforce the anxieties which keep them away; the very opposite of our intent.<sup>62</sup>

An English Law Lord, Lord Edmund-Davies, has pointed to the dearth of judicial authority in British countries on the 'patient's right to know the truth'.<sup>63</sup> The difficulties of mounting and proving a case of complaint obviously stand in the way of a successful prosecution or suit. In the case of patients with a fatal disease, who is there, after a time, to complain? But when the hard question is asked of the lawyer, Lord Edmund-Davies cites with approbation the view of Professor John Hinton in saying that:

Most doctors will bear in mind how far a person needs to set his affairs in order, when considering what they should tell a dying patient. Imparting advice to a man that it might be a wise precaution to tidy up business arrangements serves more than that single function. Conveyed with tact, it is a hint that an ill man can discuss further with his doctor, if he is of a mind to know more, or it is advice he can just accept on its face value.<sup>64</sup>

Where a patient's consent to procedures or further procedures is required or where things have gone wrong in an earlier operation, decisions of the courts suggest the necessity of frankness so that consent to treatment can be truly informed.<sup>65</sup> You will all be aware of recent litigation in New South Wales in which, in the case of psychiatric attention it was claimed that informed consent was neither sought nor given.<sup>66</sup> Recommendations were made on the subject of psycho-surgery by a New South Wales Committee of Inquiry in 1977 which some columnists have recently contended that they provide the model for legislation on informed consent to 'all medical treatment'.<sup>67</sup> This 'model' would require in every case free and voluntary consent following:

- . a full explanation of the procedures
- . a full description of the discomfort and risks
- . a full description of the benefits
- . a full disclosure of appropriate alternative treatment
- . an offer to answer any inquiries about the procedures
- . notice that he or she is free to refuse or withdraw consent at any time
- . full disclosure of any financial relationship with other medical practitioners, institutions or hospitals
- . notice that he or she has the right to legal advice and representation<sup>68</sup>

Many members of the medical profession, both within and outside the psychiatric discipline, will doubtless feel that such procedures amount to the early symptoms of 'legal imperialism' the law forcing its way into activities long regarded as the exclusive preserve of the medical profession. Many lawyers, on the other hand, will regard the claim of the medical profession to a discretion to depart from frankness and full disclosure to the patient as an arrogant paternalism, unsuited to today's world. Typically, the law seeks to uphold the integrity of the individual human being and his right, if he is competent to do so, to make the vital decisions that affect his life and person. Typically, the law asserts for itself the right to step in to speak for the person where he is, by reason of age, incarceration, mental, social or other infirmity unable to speak for himself. Until lately, a great deal has been left to the judgment and discretion of the medical practitioner on the spot. Though obviously much discretion and room for professional judgment must remain, I predict that the decades which close this century will see attempts from both within the medical profession and from without to provide clear and publicly available criteria for action and procedures for review in at least some vital medical decisions.

If I can join with the American philosopher, whose message to the 'medical paternalists' and 'legal imperialists' was essentially 'a plague on both your houses' I would say that the one thing that is plain is that frank

public debate and discussion about the dilemmas of modern medical practice is vitally necessary and increasingly urgent. Otherwise, we run the risk of building medical practice and regulating laws on shifting sands which lack a public consensus on the moral issues at stake.<sup>69</sup> I also agree with Oken that, however difficult it may be, new attention must be given within the medical profession to means of communication with patients so that, as far as possible, frankness and honesty are observed. It is not a lawyer's fancy to say that anything less is a negation of the individualism, integrity and right of self-determination of the patient

### CONCLUSIONS

What I have said about transplants, the right to die and truth telling could be expanded into an essay of much greater length on the other medico-legal issues that confront us today. Developments in modern medicine stretch the boundaries of the law and of medical ethics. They also test our notions of morality. Test tube fertilisation, the conduct of clinical trials, genetic manipulation, the use of foetal material, the treatment of the intellectually handicapped, the whole issue of abortion, patenting medical techniques and biological developments the problems of artificial insemination by donor, sterilisation, castration, psycho-surgery, the compulsory measures for health protection, human cloning and so on lie before us. Each of these developments poses issues for medical practitioners. But each also poses complex problems for the law and for society governed by the law. It is undesirable for the law to get too far ahead of community understanding and moral consensus in such things. But there is an equal danger, as it seems to me, in an ostrich-like refusal to face up to the legal consequences of medical therapy that is already occurring. According to Sir Macfarlane Burnet, 'infanticide' on compassionate grounds already occurs in 'monstrous' cases. Artificial insemination is occurring in Australia on an increased scale because of the fall-off in the availability of children for adoption. In vitro fertilisation recently proved successful in a Melbourne hospital. Various forms of experimentation in genetic engineering already take place in Australia. Hospital ventilators are turned off. Transplant surgery is a daily reality.

Moral, ethical and legal problems will not conveniently go away because the law is silent upon them. Unless the law can keep pace with these changes, there will be inadequate guidance for the medical profession when guidance is most needed. Laws of a general kind, developed in an earlier age to address different problems, will lie in wait for their chance, unexpected operation upon new unforeseen circumstances.

I hope that our society will be courageous and open-minded enough to face up to these problems and not to sweep them under the medical and legal carpet. Truth-telling extends from our professions to society as a whole. What we need are doctors and lawyers (and I should say philosophers, churchmen, patients and clients) who will be prepared to debate publicly the dilemmas forced on us by the advances of science and technology. Procedures of law reform bodies can be adapted as a medium for this interchange between expert and citizen. What is needed is effective machinery to find Australian solutions for the guidance of conscientious doctors and distracted (and often timorous) lawmakers.

There are no easy solutions to any of the problems I have mentioned. But until we start to ask the questions, and face the dilemmas, our society will continue to shuffle along in directions in which we would not choose to travel and to destinations at which we would not choose to arrive.

FOOTNOTES

1. Menander, Dys Exapaton, fr. 4 (He whom the gods love, dies young).
2. Sir Walter Raleigh, Poem written night before his death.
3. See F.G. Brennan, Law Ethics and Medicine (1978) 2 Medical Journal of Australia 577.
4. See The Law Reform Commission, Annual Report 1979 (ALRC 3), 23.
5. ibid, Criminal Investigation, 1975 (ALRC 2), 57.
6. Criminal Investigation Bill 1977 (Cwlth), cl.42.
7. The Law Reform Commission, Alcohol, Drugs & Driving, 1976 (ALRC 4).
8. ibid, Child Welfare: Child Abuse and Day Care (Discussion Paper No. 12), 1980, 25.
9. In Victoria, Tasmania and the Northern Territory, a communication by a person to his doctor cannot be revealed in evidence without that person's consent. In all other States and Territories, there is no statutory provision conferring such protection.
10. United States Privacy Protection Study Commission, Personal Privacy in an Information Society, 1977, 280.
11. The Law Reform Commission, Privacy and Personal Information (Discussion Paper No. 14), 1980, 43.
12. The Law Reform Commission Act 1973 (Cwlth), s.6(1)(d).
13. The Law Reform Commission, Human Tissue Transplants, 1977 (ALRC 7), 2.
14. Mt. Isa Mines Limited v. Pusey (1971) 45 ALJR 88.
15. ALRC 7, 52.
16. Unreported, The Times, 26 July 1963. See also (1963) 31 Medico Legal Journal 193.
17. ALRC 7, 163 (cl.42(a)).

18. ALRC 7. See note 13.
19. British Medical Journal, 28 January 1978, 195.
20. Anatomy & Transplantation Ordinance 1978 (A.C.T.).
21. The Transplantation and Anatomy Act 1979 (Qld.).
22. The Human Tissue Transplant Act 1979 (N.T.).
23. Victoria, Report of the Working Party established to consider the Draft ordinance attached to the Australian Law Reform Commission's report, Human Tissue Transplants (Mr. H.W. Pascoe S.M., Convenor), 1980. The report recommended, as in the Queensland and Northern Territory legislation, that inter-sibling donations of non-regenerative organs and tissues should be forbidden. See T. Gerber, 'Some Medico-Legal Implications of the Human Tissue Transplant Act' (1979) 2 Medical Journal of Australia 533 and M. Kirby, 'Human Tissue Transplants — a Riposte', loc cit.
24. For example, see the current controversy on heart transplants in The Times, 3 September 1980, 1 ('Transplants not the way to conquer heart diseases'); ibid, 5 September 1980 3 ('Heart transplants defended after another operation').
25. M. Burnet, 'Endurance of Life: The Implications of Genetics to Human Life', 1978, 94.
26. ibid, 95.
27. id, 96.
28. id, 98.
29. In Re Quinlan, 70 N.J. 10, 355A. 2d 647 (1976).
30. Note, 'Rejection of Extraordinary Medical Care by a Terminal Patient: a Proposed Living Will Statute', 64 Iowa Law Review 573 [1979].
31. Burnet, 97—8.

32. Cited in Iowa Law Review 584 (n.67).
33. World Health Organisation, 'Health Aspects of Human Rights: With Special Reference to Developments in Biology and Medicine', 1976, 34.
34. Sir Patrick (now Lord) Devlin, cited in S. Bedford, 'The Trial of Dr. Adams', 1962, 245.
35. Shakespeare, Othello.
36. A.C. Ivy, 'Nazi War Crimes of a Medical Nature' in S.J. Reiser, A.J. Dyck and W.J. Curran (Eds), 'Ethics in Medicine: Historical Perspectives and Contemporary Concerns', 1977 (hereafter 'Ethics'), 267. See also Z. Cowen, 'Law and Society', the Listerian Oration, mimeo, 19 May 1979, 21ff.
37. Natural Death Bill 1980 (S.A.).
38. ibid, sub-cl.3(1).
39. id, sub-cl.3(2).
40. id, sub-cl.4(1) and (2).
41. Roe v. Wade 410 U.S. 113, 165 (1973); Doe v. Bolton 410 U.S. 179, 198 (1973). See also discussion in Sir Roger Ormrod, 'A Lawyer Looks at Medical Ethics' (1978) 46 Medico-Legal Journal 18, 22.
42. Whalen v. Roe, 429 U.S. 589, 599 (1977).
43. E.L. Shapiro, 'The Right of Privacy and Heroin Use for Painkilling Purposes by the Terminally Ill Cancer Patient', 21 Arizona Law Review, 41 (1979).
44. ibid, 42.
45. 48 U.N., W.H.O. (9th plen. mtg), 22 U.N. Doc. WH.A6.14 (1953)
46. Superintendent of Belchertown State School v. Saikewicz (1977) Mass. Adv. Sh. 2461, 2495; 370 N.E. 2d 417, 432.
47. ibid, 432.



48. As explained in A. Buchanan, 'Medical Paternalism or Legal Imperialism: Not the only Alternatives for Handling Saikewicz-type Cases', 5 American Journal of Law and Medicine 97 (1979).
49. Quinlan above n.29.
50. C.H. Baron, 'Medical Paternalism and the Rule of Law', 4 American Journal of Law and Medicine 337 (1979).
51. Buchanan, 98.
52. *ibid*, 114.
53. J. Collins, 'Should Doctors Tell the Truth?' in Ethics 220.
54. *ibid*.
55. *loc cit*.
56. *ibid*.
57. D. Oken, 'What to Tell the Cancer Patients: A Study of Medical Attitudes' in Ethics 224.
58. Described in Oken, 225.
59. Oken, 226
60. Collins, 221.
61. Oken, 231.
62. *ibid*, 231—2.
63. Lord Edmund-Davies, 'The Patient's Right to Know the Truth' in Ethics 235.
64. Hinton cited in Edmund-Davies, 236.
65. See e.g. Gerber v. Pines (1935) 79 Sol.J. 13; Daniels v. Heskin [1953] Ir.L.T. 189.

66. The reference is to a civil case in Sydney in which Mr. B. Hart recovered \$560,000 against a doctor and a hospital in a 77-day case concerning psychiatric treatment.
67. T. Eatts, 'Patient's Consent Issue Raised by Malpractice Case' in The National Times, 27 July -- 2 August 1980, 20.
68. *ibid.*
69. Cf. Brennan, 577.