1005

WOMEN'S AND CHILDREN'S HOSPITAL

QUEEN VICTORIA HOSPITAL

ADELAIDE, SOUTH AUSTRALIA

Friday 21 May 1993

PATIENTS' RIGHTS - HAVE WE GONE TOO FAR?

THE QUEEN VICTORIA HOSPITAL ORATION, 1993

WOMEN'S AND CHILDREN'S HOSPITAL

QUEEN VICTORIA HOSPITAL

ADELAIDE, SOUTH AUSTRALIA

Friday 21 May 1993

PATIENTS' RIGHTS - HAVE WE GONE TOO FAR?

THE QUEEN VICTORIA HOSPITAL ORATION, 1993

The Hon Justice Michael Kirby AC CMG*

A TIME OF CHANGE

It is trite to say that we live in a time of rapid change. Sometimes changes seem to happen with frightening speed. It seems only yesterday that my parents were buying the Empire Day fireworks to celebrate, on Queen Victoria's birthday, the "great imperial family"¹ of which we, in Australia, were senior members. In my school, the faded yellow map of the world was enlivened by the crimson colours of the Empire. There was Canada. There was Australia and New Zealand. India and Burma were almost linked to Malaysia. Irritating, that small section of Thailand which broke the chain. However could that break in railway access have been tolerated? And in Africa from Cape to Cairo the red colours marked out the comfortable world of British dominance. Much of this was achieved during the reign of Queen Victoria. Indeed it is surprising to realise how short was the period of British rule in many parts of the Empire, particularly Africa. But in India, where Victoria became Empress, it dated back hundreds of years. And the whole modern history of Australia has been marked by the symbols of the British. Safe, secure and stable these symbols appeared. And no-one epitomized the stability and propriety of it all more clearly than Queen Victoria herself, for whom this hospital in Adelaide was named.

In his famous biography of the great Queen, Lytton Stratchey² recounts, rather movingly, the domestic circumstances in which Victoria and Albert reared their many children. On his arrival in England, the German Prince was looked upon with great suspicion. His influence did not really come to be acknowledged until the children appeared.³ The early discords of the Royal couple's married life then passed away, completely resolved, according to Stratchey, in "the absolute harmony of married life":⁴

"Victoria, overcome by a new, and unimagined revelation, had surrendered her whole soul to her husband. The beauty and the charm which so suddenly had made her his at first were, she now saw, no more than the outward manifestation of the true Albert. There was an inward beauty, an inward glory which, blind that she was, she had but dimly apprehended, but of which now she was aware in every fibre of her being - he was good - he was great!"⁵

Surrounded by such personal contentment, Victoria built the modern English constitutional monarchy. Stratchey again:

"It was indeed a model court. Not only were its central personages the patterns of propriety, but no breath of scandal, no shadow of indecorum, might approach its utmost boundaries. For Victoria, with all the zeal of a convert, upheld now the standard of moral purity with an inflexibility surpassing, if that were possible, Albert's own. She blushed to think how she had once believed -

- 2 -

how she had once actually told him - that one might be too strict and particular in such matters and that one ought to be indulgent towards other peoples' dreadful sins. She was no longer Lord Melbourne's pupil: she was Albert's wife. She was more - the embodiment, the living apex of a new era in the generations of mankind. ... The Victorian Age was in full swing."⁶

With few and brief exceptions, the pattern of the great Queen's life has marked the expectations of service, devotion to duty and personal propriety which have been such a feature of the Sovereigns of her line ever since. The Edwards may not have always conformed to the rôle. But George V, George VI and Elizabeth II have certainly done so.

This is not the occasion to speak of the present challenge to this stable and enduring system of government in Australia. But 24 May - the old Empire Day - approaches. Even into the present Queen's reign we celebrated this day which was Queen Victoria's birthday. In Sydney, on 24 May every year, an unknown person places a posy of marigolds at the foot of the bronze statue of Victoria which stands in Queen's Square where it was first raised on the 100th Anniversary of the establishment of the Australian colonies in Sydney. In Adelaide and in most of the cities of the Empire such statues of Victoria stand, or stood, to symbolise constitutional history and order.

Now, like a sudden storm in the tropics, this order is under challenge. But the challenge to such fundamentals is but an aspect of the challenge to other stable rules and long accepted conventions. If we are to preserve the form of civilisation which we value in this country, the trick in the years ahead is going to be to respond to the challenges of change whilst keeping the best of the old. Which challenges we should respond to and which is the "best" are controversial matters upon which legitimate differences of opinion exist. It is one of the blessings of our civilisation that

- 3 -

we can dispute the necessity of change. As free people we can control our own destiny. Our law is not like that of the Medes and Persians, unchangeable even to the slightest particular. On the contrary, it is in a constant state of change to keep it in harmony with the society we have. That society is itself very different today in Australia from the English society over which Queen Victoria reigned. It is therefore scarcely surprising that the law which governs us - including in the particular relationships between medical practitioners and their patients - should change and develop to conform to changing social expectations.

It is a great privilege for me to be invited to deliver this Oration named in recollection of a remarkable woman who was Australia's Queen for the longest reign of any Sovereign to date. It allows me to pay a tribute to a hospital in this great city which took her name and carries it proudly to this day. She was a woman of many children whose life was privileged but, as we know, struck by profound unhappiness at a relatively early age. She became the mother of the greatest Empire the world has seen, of which we were part. The influence of her conception of constitutional monarchy remains with us to this day. It is faithfully acted out by her great great grand-daughter. Much of the legacy of that Empire was doubtless condescending, racist and even wicked, at least to those who were not themselves of British stock. But in Australia, we inherited Parliamentary democracy, independent courts, the great legacy of the common law and jury trial, fundamental freedoms, trusted professions, the English language and its treasure-house of literature, English sports and recreations. We do well, at a time when it has become temporarily fashionable to decry this legacy, to reflect soberly upon its many enduring blessings.

- 4 -

CIRCUMCISION, BIRTH PREDICTION AND GENOMES

When I was asked to deliver this oration my mind rushed ahead to the wealth of topics with which I could address you.

For a time I served as a Commissioner of the Global Commission on AIDS of the World Health Organisation. My first association with that body began, ironically enough, in a study of legal responses to the sale of breast milk substitutes in developing countries, particularly in Africa. Many of the colleagues whom I met working on that topic were later to join the Global Programme on AIDS. Because of the risks of neonatal infection by breast feeding it became necessary for WHO completely to reverse engines. From preaching the value of breast feeding and the rejection of formula, in many parts of Africa today the lesson is that formula may be safer as a means of avoiding neonatal cross-infection with HIV. My essay on breast milk substitutes and the law caused one of my colleagues to suggest, at the time, that there was nothing I would not speak about. But it is rather sombre to consider the unpredictably of human life when, in little more than a decade, the scourge of AIDS has come upon us with its devastating consequences - particularly in Africa, the Caribbean and Latin America - for women and children as well as men.

In the course of my work on the Global Commission on AIDS, I learned some remarkable data concerning the apparently increased risk of HIV acquisition amongst men who are not circumcised. WHO has for some time been conducting a study of the available evidence of the effect of male circumcision as a risk-factor in reducing HIV infection. Dramatic published figures show the apparent correlation between areas of Africa where circumcision is not practised and the high incidence of HIV infection. Other co-factors may explain the apparent correlation. The suggested relevance of genital sores as vectors for the acquisition of the virus has led some writers to urge a return to routine neo-natal circumcision in men. Circumcision in women has absolutely no medical benefits as WHO made plain in a statement this week. Having expressed an interest in exploring this subject, I soon discovered how controversial it was within your profession. It is a bold person who, out of his or her discipline, ventures upon such controversies. A lack of fortitude would not have restrained me. But the thought of speaking for half an hour on circumcision to the steadily growing rage of half of my audience did not seem an appropriate way with which to reward the honour of the invitation to deliver this oration.

Just the same, the crucial point which I learned during my service on the Global Commission on AIDS is that pre-conceptions which antedated the commencement of this major global challenge to public health must be set to one side. We must base our strategies and laws strictly upon good science. Notions of what was right, developed in pre-AIDS days, must now, where relevant, be entirely reconsidered. Those who resisted, as unnecessary, the circumcision operation for male neonates must examine with strict scientific impartiality the body of evidence which now suggests a heightened risk of infection in uncircumcised men. To refuse to do this would be to fall into the error which I so often see in my own profession: clinging blindly to rules fashioned in the past in different places for different circumstances and failing to adapt practices to meet entirely new challenges which were unpredictable at the time the earlier rules were developed. All of us, in the face of HIV/AIDS must be humble. Lawyers and law-makers, medical practitioners and citizens must base urgent new strategies upon good scientific data not upon religious tradition, blind prejudice or ignorant adherence to policies adopted before HIV and AIDS came along.7

When I turned from circumcision as my theme, my eyes fell upon

· 6 –

the latest reports from England concerning the growing availability of infant sex selection techniques. An article in the London Times on 23 January 1993 reported a laser technique for choosing the sex of the baby wanted by the parent(s). According to the report, the London Gender Clinic, which opened in London in January, now offers to arrange for customers to have a baby of the desired sex for a fee of £650. The clinic, in default of legal rules, has drawn up its own code of conduct. Only married couples who already have a child can use the service. The sex of the child selected has to be opposite that of the existing child or children. According to the report, the practitioners are being inundated by parents seeking to use the service. The sperm sorting technique used was claimed to have a success rate of up to 80%. However, an editorial in The Times⁸ questioned the ethical acceptability of the availability of such a choice:

"The notion of designer babies chosen for inappropriate reasons of vanity is repugnant. But there may be more serious reasons why families may wish to conceive a child of a particular sex. As a way of dealing with the problem of congenital illnesses like haemophilia which are only transmitted to males, it may seem to be a less objectionable solution than the present one. This is to offer a termination to a woman who is a known carrier of the defective gene when she is discovered to be carried a boy."

The editorialist concluded:

"When a technological innovation threatens the most far-reaching social and cultural effects, it must be debated in the most knowledgeable and rational way."

Doubtless this topic would also reward exploration. But it opens up a subject broader than the scrutiny of sperm, ova and embryos for genetically inherited diseases. Tomorrow I depart for Bilbao in Spain for an international conference on the legal and social implications of the Human Genome Project. As you are aware, a programme is underway to map and sequence the human genome. As James Watson has observed, the Project has:

"An extraordinarily important objective: to work out the complete set of instructions which make us human, as distinct from say a monkey. It is a difficult question, however, to probe how much we are determined by our genes as opposed to our environment. Moreover, even given the sum of our genetic and environmental heritages, I don't think there is anyone ... who feels that in some sense or other he or she doesn't have free will. In any case, we go about our lives acting as if we are not constantly held back by our genes."

There is more than enough to discuss in respect of the social and legal implications of this major international project. Watson again:

"The question now faces us, as we work out the details of the human genetic message, as to how we are going to deal with these differences between individuals. In the past, at the time of the eugenics movement in the United States and in England, and during the reign of fascist thoughts in Nazi Germany, there was very little genetic knowledge. Most decisions then were made without solid genetic evidence. There were many prejudices, but almost no real human genetics. Now we have to face the fact that we soon will have the real facts and how are we going to respond to them? Who is going to take care of those people who are disabled by the genes they have inherited? How can we compensate them for the fact that many individuals are not as equal genetically as other people?"¹⁰

These are the kinds of questions which have been addressed and will be addressed by the meeting which I will be attending in Bilbao. I toyed with the idea of exploring with you a consideration of those issues which have occurred to date. Clearly, they are of great potential relevance to your branch of the medical profession perhaps more than any other. But it seemed to me that I would be in a wholly better position to examine this topic after my participation in the Bilbao meeting rather than before it. Judges have been known to decide cases before hearing the evidence and argument. For

8 -

myself, I generally find it is better to hear the evidence and argument first. Perhaps at some future time I will be allowed the privilege of discussing the Human Genome Project and its relevance for you and for our society. But now is not the time.

THE ISSUE OF INFORMED CONSENT

Instead of tackling circumcision, sex selection and the human genome I have retreated into the rather safer world of patient It is true that this is a perennial subject of consent. conferences. But it is one which is given significance by a number of recent decisions of the highest courts in Australia, Canada and England. It is therefore timely to return to the topic. It is certainly one of great significance for medical practitioners and hospitals, indeed for all healthcare workers. Every attendance by a health worker upon a patient carries the risk of an intrusion into the psychic privacy and physical person of the patient. It is therefore essential to get very clear, both in law and in daily practice, the rules which governs this sensitive and vital relationship. The point which the cases which I will mention demonstrate is that the ground rules have lately changed. The question then posed is whether the changes have gone too far and may have a counter-productive effect in the therapeutic relationship to which they attach.

For a very long time in this country (and still in England) the test to be applied for patient consent was that laid down in a passage of instruction to a jury in an important case of medical negligence. It became known as the *Bolam* test, after the plaintiff who had brought the case. Mr Bolam, a manic depressive, was given electro-convulsive therapy. A danger was that of seizures which would cause fractures of the patient's bones. Measures such as restraint and the provision of relaxant drugs reduced those dangers.

- 9 -

But Mr Bolam was given neither of these measures. Nor was he routinely warned about the danger of fracture or the availability of relaxants or restraints so that he could opt to have them applied to reduce the risk of injury to his person. Not unsurprisingly, being ignorant of these things, he did not ask about them. In the course of his therapy he suffered very severe fractures of his pelvis. He sued the hospital concerned. Following the direction to the jury by the trial judge, Justice McNair, Mr Bolam lost. The test stated in the trial judge's instruction to the jury was, however, upheld and applied by the English courts.¹¹ More recently it has been affirmed by a majority of the House of Lords, the highest judicial court of the United Kingdom.¹² This is the test of the law as Justice McNair stated it:

"[The doctor] is not guilty of negligence if he has acted in accordance with the practice accepted as proper by a reasonable body of medical men skilled in that particular art ... Putting it another way around, a man is not negligent if he is acting in accordance with such a practice merely because there is a body of opinion that would hold a contrary view."¹³

The test stated in the *Bolam* case was criticized roundly both in the United Kingdom itself and in other countries of the common law which have inherited the English legal system. In fact, it was suggested that the test was simply a hang-over of the Victorian age when "Nanny" was supposed to "know best" It was said that it grew out of the class system and hierarchical nature of English society and reflected the unwillingness of one profession (the law, represented by the judge) to countenance ordinary people challenging the rules laid down by another profession (medicine). It was also said that, effectively, it allowed the medical profession to set its own standards of care. A doctor could not be found negligent so long as he or she had-acted in accordance with the standard accepted as proper by a body of competent medical practitioners.

In the United States, a different principle was long accepted. Doubtless this arose from the different nature of United States society. Perhaps it was influenced by the different class structure and less hierarchical nature of the society of that country and the greater scepticism that has long existed concerning the claims of learned professions to set the community's standards. The American courts looked at the issue with a larger appreciation of the fundamental right of the patient to make an informed decision about medical procedures affecting his or her body. Justice Cardozo, for example, one of the great judges of this century in the United States laid down the basic principle which has permeated the law of that country on this topic in the following aphorism:

"Every human being of adult years and sound mind has a right to determine what should be done with his own body." $^{\rm 14}$

Upon the basis of this starting point, the United States courts repeatedly upheld the patient's right not to be given medical tests or treatment without fully informed consent on his or her part for such tests or treatment. Absent informed consent, the tests or treatment were unlawful. If harm resulted, the patient could sue and recover damages. Thus a patient had the right to be informed about the nature and implications of all proposed procedures. The patient had to be told of the material risks, complications and side-effects. Without such information the patient was considered to be incapable of giving the consent that was necessary to authorise the medical procedure in the first place. Defenders of this principle asserted that it was less paternalistic and more respectful of the individual bodily and spiritual integrity of the patient. Moreover, it was more likely to promote the solution of the constant complaints made concerning the lack of communication between the patient and the medical practitioner. Critics, on the other hand, suggested that it resulted in defensive medicine: posited a fundamental lack of trust between the patient and the doctor; confused patients unnecessarily with detail they did not want or need to hear; and bombarded them with information which they could not fully understand, possibly alarming them needlessly about risks which were remote - all of this taking up a great deal of time which could be better spent actually treating patients rather than talking to them.

In Canada, something of a compromise was struck between the United States and English positions in an important decision in 1980.¹⁵ The Chief Justice of Canada, Chief Justice Laskin observed:

"In my opinion, actions of battery in respect of surgical or other medical treatment should be confined to cases where surgery or treatment has been performed or given to which there has been no consent at all or where, emergency situations aside, surgery or treatment has been performed or given beyond that to which there was consent."¹⁶

However, the House of Lords in England, with a notable dissent from Lord Scarman, declined to follow the United States and Canadian decisions. This was the state of the law when the issue came up for decision in my own Court, the Court of Appeal of New South Wales, in the Full Court of the Supreme Court of South Australia and eventually in the High Court of Australia where it was finally settled for Australia.

In my own Court, as long ago as 1980, it was emphasised:

"It is not the law that if all or most of the medical practitioners in Sydney habitually fail to take an available precaution to avoid foreseeable risk of injury to the patients then none can be found guilty of negligence."¹⁷

- 12 -

This approach was followed in South Australia where, under the leadership of Chief Justice King, the Supreme Court refused to surrender to the medical profession the setting of standards which, if reached, would determine the entitlement of the patient who had suffered harm. In a very important decision, Chief Justice King explained why such an approach was not acceptable:¹⁸

"In many cases an approved professional practice as to disclosure will be decisive. But professions may adopt unreasonable practices. Practices may develop in professions, particularly as to disclosure, not because they serve the interests of the clients, but because they protect the interests and convenience of members of the profession. The Court has an obligation to scrutinize professional practices to ensure that they accord with the standard of reasonableness imposed by the law. A practice as to disclosure approved and adopted by a profession, or section of it, may in many cases be the determining consideration as to what is reasonable ... The ultimate question, however, is not whether the defendant's conduct accords with the practices of his profession or some part of it, but whether it conforms to the standard of reasonable care demanded by the law. That is a question for the Court and the duty of deciding it cannot be delegated to any profession or group in the community."

Notwithstanding this holding there were supporters in Australia of the Bolam principle. They were in the medical profession but also in the legal profession too.¹⁹ There was therefore a great deal of interest when the case of Rogers vWhittaker²⁰ came for consideration before the High Court of Australia and was determined in November 1992.

The facts were these. Mrs Whittaker developed an extremely rare condition in her left eye. She had been nearly blind in her right eye from an early age as a result of a penetrating injury. At the age of 47, after a routine eye check-up, she was referred to Dr Rogers for advice on possible surgery. He advised her that he could operate on her right eye to remove the scar tissue. He said that this would improve its appearance. It would also probably restore significant sight to that eye as well as assisting to prevent the development of glaucoma.

Unfortunately, following the operation, Mrs Whittaker developed an inflammation in the treated eye. This triggered sympathetic ophthalmia in the left (good) eye which led to a total loss of sight in the left eye, thereby leaving her almost totally blind.

The evidence at trial was that the risk of sympathetic ophthalmia developing after such surgery was estimated at 1 in 14,000 cases. Naturally, Mrs Whittaker did not ask Dr Rogers specifically whether the good eye could be affected by such a condition. However, it was found that she had incessantly questioned him as to complications and was keenly interested to know the outcome of the procedures and highly concerned that unintended injury could befall her good eye during the operation. This insistence was to such an extent that an entry was made in the hospital notes to the effect that Mrs Whittaker was apprehensive that the wrong eye would be operated upon.

The trial judge in the Supreme Court of New South Wales (Justice Campbell) found that Mrs Whittaker had not been properly warned about the risk of sympathetic ophthalmia and that, had she been so warned, she would not have undergone the surgery to the right eye. The lack of warning had therefore caused her to suffer the losses complained of. She was awarded just over \$800,000 damages. An appeal to the New South Wales Court of Appeal was dismissed.²¹ The High Court of Australia dismissed Dr Rogers's further appeal. The Court preferred the view propounded in the Australian cases to the English *Bolam* test. It preferred Lord Scarman's dissent to the majority position of the House of Lords in England. It accepted that medical practice was a "useful guide" as

- 14 -

to what should be told to a patient. It allowed an exception for the so-called "therapeutic privilege" in cases of possible harm to an unusually nervous, disturbed or volatile patient. One judge (Justice Gaudron) was inclined to confine this privilege to cases of emergency or an impaired ability to receive, understand or evaluate such information.

Yet the High Court of Australia was not attracted, as such, to the American jurisprudence of "informed consent". However, the judges said this:

"The law should recognise that a doctor has a duty to warn a patient of a material risk inherent in the proposed treatment; a risk is material if, in the circumstances of the particular case, a reasonable person in the patient's position, if warned of the risk, would be likely to attach significance to it or if the medical practitioner is or should reasonably be aware that a particular patient, if warned of the risk, would be likely to attach significance to it."

Of course, some would say that it was ridiculous to suggest that a patient should be warned of a risk as remote as 1 in 14,000. Others would say that the case was special, turning upon the very clear evidence of the insistence by Mrs Whittaker of her concern about her good eye and her anxiety that it should not be harmed. Still others might say that it was difficult to overcome an intense sympathy for a woman who had merely gone to have her glasses checked and had ended up almost totally blind.

Medical practitioners tend to see malpractice cases as involving a moral blight or stigma upon the practitioner concerned. From the point of view of the patient (and most lawyers) however, the issue is usually much more basic. It is whether a person who has suffered in some way as a result of medical or hospital procedures will be cast upon the genteel poverty of the social security system or be entitled to recover compensatory damages from the medical practitioner's insurance. To gain insurance the practitioner must pay premiums. These premiums become part of the costs of medical practice. In this way, all patients bear the cost of, and contribute to, the fund from which are paid damages when things go wrong.

In Queen Victoria's day an elderly Scottish judge observed of a case before him brought by a patient against a doctor:

"This action is certainly one of a particularly unusual character. It is an action of damages by a patient against a medical man. In my somewhat long experience I cannot remember having seen a similar case before."²²

Times have changed. The reasons for the changes are easy enough to see. They include the general advance of education of the population at large and thus of patients; the decline of the awe of professionals and indeed of all in authority; the termination of unquestioning acceptance of professional judgment; the widespread public discussion of matters concerning health, including in the electronic media; and the growing recognition in medical practice of the importance of receiving a full input from the patient so that the whole person is treated, not simply a body part.

We must see the moves towards the insistence of the law upon the provision of greater information to patients in the context of the wider social developments which affect society and the law. All professions, including the judges, are now more accountable. The bureaucracy is now obliged by law to provide answers to the Ombudsman and to account for things formerly held secret. Freedom of Information legislation has been enacted in every jurisdiction of Australia. The sun has set not only on the British Empire but upon the world in which "Nanny", Sir Humphrey and others put in authority over us, know best. In this context, if I ask have we gone too far by the decision in *Rogers v Whittaker*, the answer which I would suggest to you is that we have not.

OVERSEAS CASES

1.5

, 1

10

-(____

<u>а</u>.;

22

A number of overseas cases illustrate similar themes. Take the following recent case from Canada.²³ A patient made a request to her doctor for copies of the contents of her complete medical file. The doctor delivered copies of all notes, memoranda and reports which she had herself prepared. However, she refused to produce copies of the consultants' reports and records which she had received from the other physicians who had previously treated the patient. The doctor stated that these were the property of those physicians. It would be unethical for her to release them, at least without the consent of those physicians. She therefore suggested to her patient that the patient should contact the other physicians to gain their permission to release their records. The patient declined to do this. She brought an application to the trial court for an order that the entire medical file, being about herself, should be handed over to her by her doctor. The trial judge so ordered. The doctor appealed to the Provincial Court of Appeal. It affirmed the trial judge's order, by majority. A further appeal was taken to the Supreme Court of Canada. However, the appeal was dismissed.

The Supreme Court of Canada held that, in the absence of an Act of Parliament to the contrary, a patient was entitled, upon request, to examine and copy all of the information in her medical records which the physician attending her had considered in administering advice or treatment. This included records prepared by other doctors which the physician may have received. Access did not extend to information arising outside the doctor/patient relationship. The patient was not entitled to have the records themselves. The physical records belonged to the physician. But the Court held that the physician/patient relationship was fiduciary in nature. That is to say it involved an element of trust. From that trust relationship duties arose which required the medical practitioner concerned to evince trust and to earn confidence. He or she was obliged to act with the utmost good faith and loyalty to the patient, to hold information received from or about the patient in strict confidence and to make proper disclosure of information to the patient. The practitioner also had an obligation to grant access to the information used in administering treatment.

1

G

1.3

Ċ.,

Ę.

÷

ųđ

÷.

5

The Court held that this duty of trust was ultimately grounded in the nature of the patient's interests in the medical records. Information about oneself revealed to a doctor acting in a professional capacity remained "in a fundamental sense" one's own information. Whilst the doctor was the owner of the actual records, the information was held in a fashion somewhat akin to a trust and was to be used by the physician solely for the benefit of the patient. By confiding information to the physician for medical purposes, an expectation arose that the patient's interest in, and control over, the information concerning her would continue. Since the physician had a duty to act with utmost good faith and loyalty, it was also important that the patient should have access to the records being used by the physician to ensure the proper functioning of the doctor/patient relationship and to protect the well-being of the patient. The Court held that disclosure served to reinforce the patient's faith in her treatment and to enhance the trust inherent in the doctor/patient relationship. As well, the duty of confidentiality arising from the relationship was meant to encourage disclosure of information and communication, not to sustain secrets from the very person most intimately affected.

The Supreme Court of Canada emphasised that the general right of access to a patient's medical records was not, however, absolute.

- 18 -

If the physician reasonably believed that it was not in the patient's best interests to inspect the medical records, the physician might consider it necessary to deny access to the information. On the basis of the trust relationship, where a physician refused a request for access, the patient could apply to the court for protection against an improper exercise of the physician's discretion. The court would then superintend that decision. It might order access to the records in whole or in part if it considered that the decision to withhold them was unwarranted in the circumstances. The onus would lie upon the physician to justify a denial of such access. According to the Court, patients should have access to their medical records in all but a very small number of circumstances. Only if there was a significant likelihood of a substantially adverse effect on a patient's physical, mental or emotional health or harm to a third party would the physician be entitled to withhold the records.

I would emphasise that this is a Canadian decision. Whether it would be followed in Australia remains to be seen. The notion of extending the concepts of equity and the law of trusts into the relationship of doctor and patient is a novel one. It is not one which has so far been applied in Australia. But our legal system is sufficiently similar to carry the message that similar principles might be applied here. That could have consequences for the way in which medical reports are written and exchanged between practitioners. There might be some reduction of the candour of at least written expressions of opinions as between medical practitioners involved in the treatment of a particular patient. On the other hand, the decision shows, once again, the extent to which the law is now moving to the protection of the *rights* of the patient.

I turn to my third case, in England. The House of Lords was

obliged to consider an application to terminate all life sustaining treatment and medical support for a patient who had been seriously injured and suffered brain damage and who was being kept alive in a persistent vegetative state solely by artificial means. The application succeeded at first instance. The Court of Appeal of England upheld the order. So did the House of Lords.²⁴

Once again, their Lordships emphasised that the fundamental object of medical treatment and care was the benefit of the patient. However, in the case before them, since a large body of informed and responsible medical opinion was of the view that existence in the persistent vegetative state was not a benefit to the patient, the principle of the sanctity of life (which was not absolute) was not violated by ceasing to give medical treatment and care. The patient had never consented to that treatment, being incapable of doing so. According to the medical evidence it conferred no "benefit" upon him. He had been in the vegetative state for a period of more than three years. The point had therefore been reached where the patient had no further "interest in being kept alive". The necessity to do so created by the patient's inability to make a choice and the justification for the invasive care and treatment had disappeared. Accordingly, it was held that the omission to perform what had previously been a duty in an emergency, would no longer be necessary, or in the view of some of the judges, even lawful.

I suppose that there would be some absolutists who would question how it could ever be in the "best interests" of a patient in effect to terminate his or her life. But the House of Lords decision demonstrates the commonsense of the common law. The absolutists' preservation of life, in whatever form and at whatever cost and for however long, was rejected by the judges. We are not here dealing in absolutes. The courts in all of the cases which I have mentioned are

- 20 -

concerned to draw lines which are sensible and just. Sometimes the line-drawing is by no means easy. This much was admitted by Lord Browne-Wilkinson in his judgment in the last-mentioned case. He said candidly:

"[T]he conclusion I have reached will appear to some to be almost irrational. How can it be lawful to allow a patient to die slowly, though painlessly, over a period of weeks from lack of food but unlawful to produce his immediate death by a lethal injection, thereby saving his family from yet another ordeal to add to the tragedy that has already struck them? I find it difficult to find a moral answer to that question. But it is undoubtedly the law and nothing I have said casts doubt upon the proposition that the doing of a positive act with the intention of ending life is and remains murder."²⁵

CONCLUSIONS

There are many further cases which could be discussed. In one, for example, a judge in England granted a declaration that a Caesarean section and consequent treatment could lawfully be performed upon a pregnant woman despite her refusal of consent.²⁶ The case arose when the patient was admitted to the hospital with ruptured membranes and in spontaneous labour. The child was in a position of "transverse lie". In the opinion of the medical advisors, there was the gravest risk that the patient's uterus would rupture unless a Caesarean section were carried out. It was also believed that the baby could not be born alive unless the operation were performed. The patient refused consent because of her religious beliefs. It was found that her medical condition was such that she was otherwise perfectly competent to decide upon her medical treatment.

The judge took the responsibility of ordering the operation "in the vital interests of both [the patient] and of the unborn child. As a consequence of the court's declaration the Caesarean section was carried out, despite the fact that the unborn child, although alive

- 21 -

when the declaration was made, had died before the operation could be performed. The case has ignited a great deal of controversy in Britain.²⁷ The judge's decision was criticised as showing a "worrying policy preference for the rights of an unborn child over those of a pregnant woman".²⁸ If I were to venture properly upon this subject and to consider whether the same decision would be arrived at by the courts of Australia, I would detain you here much longer than I would wish and than you deserve.

I have sufficiently performed my task. I set out to show you how much the world has changed since Queen Victoria's day. The changes have permeated medical and healthcare. They affect the daily life of the hospital named for her. They have affected profoundly the law and the courts. Notions of authority and paternalistic decisions by experts have been increasingly replaced by notions of human rights and the obligation to account. The courts which once, in the words of a Scottish judge, were rarely troubled by review of medical decisions now face such questions all the time.

Have we gone too far? Is there too much talk of patients' rights? Each one of us as citizens, professionals and potential patients must answer those questions for ourselves. A return to the comfortable certitudes of "Nanny knows best" is inconceivable. In all probability the future holds more questioning and deeper challenges. Could there be a clearer signal of this than the global Human Genome Project which will engage me next week? By the miracle of flight I will be propelled in a day from Adelaide to Bilbao. I, a lawyer from Australia, will sit with some of the greatest geneticists of the world on the brink of unravelling the map of human genetics.

If we think we have seen and solved great problems before this, the lesson of our age is: You ain't seen nothing yet! The greatest challenges lie ahead. But through it all the dedication of our

- 22 -

professions to excellence and service and to the simple humility that comes from the privilege of helping others remains constant. Some things change. But let us make a promise to ourselves and to the community that the best will endure.

FOOTNOTES

- *
- President of the New South Wales Court of Appeal. Chairman of the Executive Committee of the International Commission of Jurists. Formerly Commissioner of the World Health Organisation Global Commission on AIDS.
- This was the description given by Princess Elizabeth in her radio speech in South Africa in April 1947 upon attaining her majority.
- 2. L Stratchey, Queen Victoria, Penguin, 1971.
- 3. Id, 101.
- 4. Id, 102.
- 5. Loc cit.
- 6. *Ibid*, 117.
- 7. The literature on neonatal circumcision is enormous. But see eg R L Poland, "The Question of Routine Neonatal Circumcision", 322 New England J Med, 1312 (1990); A J Fink, "Newborn Circumcision: A Long-Term Strategy for AIDS Prevention" (1990) 83 J Royal Soc Med 278; T E Wiswell, "Routine Neonatal Circumcision: A Reappraisal" (1990) AFP, 859; "New medical evidence suggests that circumcision may protect against cancer and AIDS" (March 1990), Mens Health, 10.
- 8. The Times (London) 23 January 1993.
- 9. J Watson, "Genetic Polymorphism and the Surrounding Environment" in Fundacion BBV, Human Genome Project: Ethics, 1992, 27.

- 23 -

- 10. Ibid.
- 11. Bolam v Friern Hospital Management Committee [1957] 1 WLR 582 (QBD).
- Sidaway v Governors of Bethlem Hospital [1985] AC 871 (HL),
 876.
- 13. Bolam, above n 11 at 586 (QBD).
- 14. Schloendorff v Society of New York Hospital 211 NY 125; 105 NE 92, 93 (1914) (NYCA). See also Canterbury v Spence 464 F 2d (1972) (USCA).
- 15. Reibl v Hughes (1980) 114 DLR (3d) 1 (SCC).
- 16. Ibid, 7.
- Albrighton v Royal Prince Alfred Hospital [1980] 2 NSWLR
 542 (CA), 562.
- 18. F v R (1983) 33 SASR 189 (SAFC) 194. See also Victorian Law Reform Commission, Report No 24, Informed Decisions About Medical Procedures, Melbourne, 1989, 7.
- See D I Cassidy, "Malpractice: Medical Negligence in Australia" (1992) 66 ALJ 67.
- 20. (1992) 67 ALJR 47 (HC).
- 21. (1991) 23 NSWLR 600 (CA).
- 22. Farquhar v Murray (1901) 3 F 859, 862 cited by Lord Kilbrandon in Foreword in D Giesen, International Medical Malpractice Law, Tubingen, 1988.
- 23. McInerney v MacDonald (1992) 137 NR (3d) 35 (SCC).
- 24. Airedale NHS Trust v Bland [1993] 2 WLR 316 (HL).
- 25. Ibid, 387.
- 26. In re 5 (Adult): Refusal of Treatment [1992] 2 WLR 806 (FD).
- 27. K Stern, "Court-Ordered Caesarean Sections: In Whose

Interest?" (1993) 56 Modern L Rev 238.

28. Ibid, 243.