THIRTY FOURTH ANNUAL CONFERENCE OF THE

NEW SOUTH WALES NURSES' ASSOCIATION

SYDNEY, 18 JULY 1979

LAW REFORM, PRIVACY AND NURSING

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

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THE AUSTRALIAN LAW REFORM COMMISSION

I am delighted to be here and to be given the opportunity of a few words with you at the opening of your Conference.

In days gone by, I had a lot to do with nursing and nurses. I shall say little of this today except to say that I am proud that my sister and other members of my family are part of your profession. I also remember battles long ago in the N.S.W. Industrial Commission when I appeared in a generally similar interest to the New South Wales Nurses' Association. I then learned what a doughty fighter for nurses Miss Henlen, the General Secretary of the Association, indubitably is.

It would be to insult this audience of professionals to speak in generalities. I realise that the major problem confronting nursing at the moment is the suggestion that certain hospitals in New South Wales will be closed with consequent staff cuts and relocation of professional nursing staff. Of course, this is a highly contentious question but it is one upon which I cannot speak. It is neither a matter before the Law Reform Commission nor is it one about which I have any special credential of expertise.

I have examined your agenda and am glad to see the wide range of subjects that will be addressed. In the midst of proper professional concerns of your own, you are not confining your attention to industrial issues. I am glad to see the close scrutiny you are giving to community health practice in its many forms. It is a selfless interest in higher issues that marks off a profession and its members. I hope that you will forgive me for not speaking about the most pressing and controversial subjects before your conference. Judges have a tendency to try to escape controversy in this way.

The Australian Law Reform Commission which I head is a permanent statutory authority of the Commonwealth. It was established in 1975 with the support of all parties. It is based in Sydney. There are 12 Commissioners. Sir Zelman Cowen was a part-time Commissioner until he assumed his present office.

The Commission receives references from the Federal Attorney-General. Its task is to review, modernise and simplify Commonwealth laws in our country. It prepares consultative documents setting out tentative ideas for reform of the law. It debates these ideas thoroughly before the expert and lay community. Ultimately it prepares a report which must be tabled in Parliament. Many of its proposals have been adopted both by State Governments and the Commonwealth. It is part of the machinery of providing orderly renewal of the legal system of Australia.

Through the many references given to the Law Reform Commission by successive governments have run two common themes. The first is the need to modernise the law to accord with change in social values, higher levels of education and the new means of providing knowledge and information.

The second theme is the impact of science and technology on the law. One of the tasks upon which we have already reported is the provision of new laws to govern

transplantation of organs and tissues from one person to another. In the preparation of our report on this subject, we had to face many vexed questions that will be familiar to many of you :

* Is the current legal definition of death i.e. in terms of blood circulation still apt in an age of ventilators which can sustain patients and artificially ensure blood circulation
* Should we introduce in Australia, as they have in France, the system of "opting out" so that every citizen is a potential donor for transplant material or should we continue, as at present, to insist that persons specifically donate their organs and tissues for use in transplantation
* Should children in any circumstances be permitted (and if so with what protections) to donate non-replaceable tissue to siblings who might otherwise die

All of these questions were addressed by the Commission with the aid of an interdisciplinary team drawn from the medical profession, theologians and others. The report we produced was praised in the British Medical Journal and the Medical Journal of Australia. The law we proposed has already come into force in the Federal Capital Territory. It is to be introduced shortly in Queensland. It is under consideration in most of the other States of Australia. In drawing our report, we were conscious of the special predicament in which medical and nursing staffs of hospitals are placed in the transplantation of organs and tissues from one patient to another.

All of the other tasks given to the Commission involve you as citizens. We are, for example, looking at the improvement of the laws for the punishment of federal offenders in Australia. We are re-examining, in the International Year of the Child, the law relating to child welfare. The improvement of debt recovery laws, in the consumer society, is under our study. Many of our projects throw us into specific contact with the nursing and medical

professions. None is more relevant than our reference on privacy.

NURSING AND PRIVACY

The Terms of Reference. During the 1975 Election Campaign, Mr. Fraser promised that if he were returned, the government would refer to the Law Reform Commission an inquiry into the laws protecting privacy in Australia. The reference was duly made. The Commission is well advanced in its research on the reference. One aspect of the task has been in part discharged. It relates to the publication of private facts in the media. That subject seemed appropriate to be dealt with in the context of the proposed uniform law of defamation. The balance of the reference remains. It has many problems and many facets. Some concern you specifically as nurses.

In Australian medical,nursing and hospital practice it is tradition rather than law that has protected privacy and confidentiality up to now. A number of pressures have lately diminished the security of medical and hospital information. The first is the growing perception of competing moral principles, not least at a time when medical care is passing from being almost exclusively a private responsibility to, substantially, a community responsibility. The development in this country and overseas of forms of national health insurance raise for consideration the rights of the insurance schemes to have information which, at the beginning of this century, would have been regarded as intimately private. For example, whether the schemes are government or privately funded, some form of auditing control may be necessary. This requires the divulging of details about the patient and his treatment.

Furthermore, since the War the focus of epidemiological research has been of chronic non-infectious diseases such as emphysema and cancer. But these require intensive medical surveillance of a substantial population over a long period of time. The moral issues are not limited to resolving the competition between an individual's right to the privacy of

of hospital information on him and outsiders' demands for information for society's greater good.

THE GENERAL RIGHT TO ACCESS TO ONE'S OWN FILE

This debate extends to demands by an individual for access to his own file. In the United States, the last decade has seen radical changes in this area. Until then, and still in this country, general medical and hospital practice was to deny the patient access to his own records. During the last ten years, the United States has seen a revolution in the provision of access to information. At a governmental level, the principle is found in the legislation known as the Freedom of Information Act. At a personal level, it is found in a wide range of legislation, the most famous of which is the Privacy Act 1974. It may seem curious to include rights of access to information in so-called privacy legislation. A moment's reflection will explain why it is thus. Nowadays, the threats to privacy arise not so much from the old fashioned physical intruder (the trespasser who enters the home or the listener at the door). The threat arises from the perception of a person through the growing mass of information accumulated on him. It is the desire to control such perceptions and to make sure they are accurate which has given rise to the United States legislation. Central to that legislation is the maintenance of security of personal information kept on people, the logging of access to ensure that security and the provision, with exceptions, of access by the individual to it so that he can check its accuracy and secure its correction, if wrong or unfair.

Certain federally aided hospitals have already come under the obligations of the access provisions in the U.S. Many objections were raised to them, some of cost and some of principle. However, in nine States of the United States legislation currently grants a patient a right to inspect and in some instances obtain copies of his medical record. Colorado applies its statute not only to hospital records but records held by private physicians, psychologists and

psychiatrists. Some States exlude psychiatric records. Some cover only hospital records. In some cases the hospital authorities determine how much of a medical record the patients may see. Certainly, the experience of federal hospitals under the current Privacy Act in the United States would appear to allay fears about the number of requests for patient access and the cost of administering it: At a federal level, with a total estimated patient population of 5 million, requests for records by patients from the Bureau of Medical Services has so far numbered about 3,000 in 3 years.

INCREASE IN THE BULK OF PERSONAL HEALTH RECORDS

One factor which causes calls for new laws is the enormous increase in the bulk of personal medical information held in society. Until the last War most confidential health information was secured by a local family physician in sole practice. In these circumstances the typical medical record was nothing more than a small card with entries showing the dates of visits, medications prescribed and charges. Security, confidentiality and privacy were protected by this system. The physician was usually able to elaborate the intimate private details of the patient's medical or emotional condition from the "safe crevices of his mind". A recent United States Commission puts the modern problems this way :

> "In contrast, a modern hospital medical record may easily run to 100 pages. The record of a family physician may still hold information on ailments and modes of treatment, but also now note the patient's personal habits, social relationships and the physician's evaluation of the patient's attitudes and preferences, often in extensive detail".

That abuse can occur is clearly demonstrated in the same United States report. It points out that :

> "Hospital records are routinely available to hospital employees on request. Most of these people are medical professionals who need such access in order to do their jobs, but not all of them are. Besides the physicians,

psychologists, nurses, social workers, therapists and other licensed or certified medical practitioners and para-professionals, there are nearly always medical students and other people in training programmes conducted either by the medical-care institution itself or affiliated with the institution. These people, too, have access to medical records for training or job-related purposes, as do non-professional employees and voluntary workers".

Attention is drawn to one case in 1976 where a firm was established in Denver precisely to provide a variety of investigative services by the surreptitious acquisition of medical record information from hospitals and physicians. It was then sold to investigators and lawyers for a variety of purposes. One of the sources of information was a hospital employee. A Grand Jury condemned the "laxity of hospital security measures". The question we have to ask is whether this kind of abuse could happen or has happened here in Australia. The Hospital and Allied Services Advisory Council was concerned that it could.

GROWING INTRUSIONS

There are other problems in addition to the burgeoning growth of medical hospital records now abetted increasingly by computerisation.The obligation to answer subpoenas, the increasing inquiries by insurers and researchers all procure information which would formerly have been thought private and confidential. The list of notifiable diseases expands. The reasons for securing this information increase is our interdependent society. Again, it is useful to look at the United States report :

"There are few statistics indicating the number of requests for medical-record information that are not directly related to the delivery of medical care, but testimony before the Commission suggests that the number is high. For example, the Director of the

> medical record department of a 600-bed university teaching hospital testified that he receives an estimated 2,700 requests for medical record information each month, some 34% of them from third party payers, 37% from other physicians, 8% in the form of subpoenas and 21% from other hospitals, attorneys and miscellaneous sources. The attorney for the [May Clinic] testified that the clinic receives an estimated 300,000 requests for medical record information a year, some 88% of them patient-initiated requests relating to claims for reimbursement by health insurers".

The existence of interdependence in society has led to the call for breaching the wall of confidentiality in the name of a higher value even than privacy, viz. "the public interest". On this basis the law has traditionally upheld the subpoena, the obligation to answer questions, statutory duties to provide information of communicable diseases, births and deaths, gunshot cases, drugs and so on. The latest addition, in the name of a higher public interest, is the obligation to report cases of suspected baby bashing. The point to be made here is that so many have become the exceptions, that the rule itself is rendered fragile. That is the conclusion of the recent American report. It is a conclusion which should concern hospital administrators, doctors and nurses anxious to uphold at least sufficient privacy so as not to damage the trusting relationship that is vital for the proper health care of the community. The U.S. report recommended many new laws to protect privacy in U.S. medical and hospital health care. These laws arising from the Commission's conclusion :

"The medical-care relationship in America today is becoming dangerously fragile as the basis for an expectation of confidentiality with respect to records generated in that relationship is undermined more and more. A legitimate, enforceable expectation of confidentiality that will hold up under the revolutionary changes now taking place in medical care and medical record-keeping needs to be created".

The Law Reform Commission is now consulting informed reaction of medical and hospital authorities throughout Australia to proposals for Australian laws. We do not start this exercise with a blank page. We have the benefit of the earlier Australian inquiries, the work of the New South Wales Privacy Committee and the conclusions of the United States Commission. We will secure the assistance of consultants including those who have already been appointed to acquaint us with the special problems in the health services area. The short review that I have given today indicates that there is a problem here which will not simply go away. To do nothing is to allow the gradual erosion of an important and efficacious privilege of privacy which has existed until now. The time has come for the law, stating today's standards, to face up to these issues.

WHAT IS BEING DONE

The Commission's Research Paper. In April 1979 the Commission issued a research paper seeking to analyse the approach that should be taken in Australia to the protection of the privacy of medical records. Any of you who are specially interested in this subject can secure copy of it for comment. This is not the time to detail at length the proposals contained in the research paper. A number, however, stand out as important.

1. So far as the collection of personal information is concerned, it is proposed that a person should not be required to disclose personal information which is not immediately relevant and necessary for proper health care.
2. Where standard forms are normal, they should be cleared to ensure that only minimum personal information is extracted by them
3. A patient should normally be entitled to direct access to any personal records maintained about him or her unless it falls within a limited number of exempted records.
4. The records exempted are those which contain information concerning the mental health of a patient, the health of a patient under 15 years of age or medical information that might be prejudicial to the physical or mental health of the patient.
5. In the event of direct access being refused, provision should be made for health care records to be accessed indirectly by a medical practitioner, next of kin or legal guardian nominated by the patient
6. Where disclosure follows legal process, as for example a subpoena directed to a hospital, the subject of the record should be notified as soon as possible so that he can, if he wishes, contest its scope or relevance
7. Record-keepers in health care centres should appoint an information manager with whom the subject can deal in relation to his personal record

8. Logs should generally be kept by information managers in respect of access to personal information.

As in all tasks before the Law Reform Commission, we seek out expert and lay opinion before delivering our final report to Parliament. The protection of privacy is important because the development of computing and other information sciences will put the individual in our society at risk. It is vital that whilst we take advantage of the new technology, we should preserve proper protections for the individual. It is important that he should never become a mere object, a file number or a record peered at and pried into by others, with no right to know how they are perceiving him and no assurance of the confidentiality of personal medical information.

This is a sober note upon which to end these observations. I am well aware of the devoted and conscientious attitude of the nursing profession and its sensitivity to confidentiality and the privacy protection of its patients. But perceptions of privacy are changing, as are the attitudes to privacy protection in the computing age. I hope that in the work of the Law Reform Commission, assisting Parliament to design new laws for the protection of privacy, we will have the support, wisdom and assistance of your profession.

Well, that is enough about privacy, the Law Reform Commission and lawyers. It is not a minor issue of transient relevance for hospitals and nursing. One distinguished overseas commentator put it well when he said "for privacy" read "individual liberty". I extend every good wish for the deliberations of the next two days and I have much pleasure in declaring your conference open.