BEARING PRIVACY IN PUBLIC AN ADDRESS TO THE AUCKLAND MEDICO-LEGAL SOCIETY FRIDAY 10 OCTOBER 2003 BRUCE SLANE DCNZM CBE LL.B

Hearing the introduction reminds me that when I was President of the Law Society someone told me that lawyers had one thing in common with chimpanzees: the higher they climb the more the more their unattractive features become evident.

In 1991 the Privacy of Information Bill was introduced in the "mother-of-all-budgets". It was soon bogged down in the select committee. It was decided to pass the Privacy Commissioner Act which would enable the appointment of a Privacy Commissioner and permit information matching between government departments under the supervision of the Commissioner. It was intended that the Commissioner would then work on the bill with the Department of Justice and produce recommendations to the select committee and Minister.

One or two people suggested that I ought to apply for this job so I put in a letter expressing my interest and giving what I thought was some plausible qualifications for the position. A couple of days before Easter in 1992 Doug Graham rang through to me and said "Gidday". He had a piece of paper in front of him and when he signed it, it would go to the Governor General and when she signed it I would be the first Privacy Commissioner. I said that I thought I had better talk to my wife about it and also discuss it with my partners as it would mean leaving the firm. He said not to take too long over it because the whole of the caucus knew about the appointment and there were other people who were aware of it too, and these things tend to leak out!

And so I became Privacy Commissioner. I worked on the bill by going and seeing all the groups who were making submissions opposing the passing of the bill. This I did over the next six-months or so including contact with the New Zealand Medical Association, which was at that time somewhat preoccupied with the proposed health reforms.

I started to get unsolicited mail. One computer company wrote to me as the "Privy Commissioner" and from the Direct Marketing Association a letter that read

"Dear Bruce,

Like most people in direct marketing you and I are probably guilty of thinking that data privacy legislation is a bit like a dreaded disease. It won't happen to us.

"We're wrong.

"Even as you read this, politicians in Wellington are preparing laws that will affect your ability to earn a living. Just two weeks ago a key privacy bill was reintroduced into Parliament. You need to know what's in that bill and what else they are planning and you need to know that you can

protect yourself and your business. You need to have lunch with the DMA."

The marketing letters continued to flow in. Some were personalised. One was addressed to Mr P Commissioner. Another reads:

"Dear Bruce, the privacy bill becomes legislation in a matter of months, how might this impact on you or your organisation, will you be able to use your database for commercial purposes?"

It was a small office at that time. (It has now about 25 staff). I started with just a secretary in April 1992 and gradually built up to having three other staff, two of whom are still with the office, one on a part time basis.

One of the reasons why the Privacy Act was going to go through by the end of June 1993 was a fear that the health reforms on 1 July could produce a competitive culture which could impact on people's privacy.

It was also important that there be something tailored and understandable for the health sector. I found considerable support in a number of sectors for the idea of codes of practice to be issued by the Commissioner and succeeded in persuading Parliament to insert a power that would enable these codes to include provisions that were stricter and less strict than the general law.

We started with a temporary Health Information Privacy Code which we drafted after consultations with something like 300 or 400 people, and this came into force in August 1993. In 1994 it was improved and made into a permanent code. I fear that the 1993 version is still around having been photocopied and probably is being used by practitioners today.

I soon learned about some of the abbreviations used in medical records, and other people proudly demonstrated them to me and so we had: FLK – funny looking kid; LOL – little old lady; DAFD – drunk and fell down; BUNDY – but unfortunately not dead yet; and HIVI – husband is village idiot.

There was a tendency in the medical profession to think that they were being particularly picked on, not realising the tremendous effort we made to actually fit in with current medical practice. They had no real code to guide practitioners. In most respects, the Health Information Privacy Code was a relaxation of the provisions in the information privacy principles. In fact we achieved a solution which has been a model for health information laws in provincial Canada.

A wider reaction was that people didn't care about privacy, it was being foisted upon an unwilling public. Well we did a survey and found that while privacy did not rate the highest level of concern that our health services did, it came very close to the same level of concern as the environment. More particularly in relation to 11 privacy issues causing concern, confidentiality of medical records came second, with 74% saying that they were concerned or very concerned about them. We found very high levels of concern about the way in which business dealt with people's information. For instance, 91% were concerned or very concerned about supplying information to a business for a specific purpose

when the business uses it for another purpose. Over 90% of respondents rated the way in which their personal details were dealt with by a business at the same level as their concerns about the quality of the product and the efficiency of the service. Similar levels of concern were expressed about collecting information that doesn't seem relevant to the transaction and when another business the person is not dealing with gets the personal details. Privacy is a real value and its protection is a mark of a civilised society.

These things need to be borne in mind by a parliamentary committee which against the weight of submissions, decided that health records should be made available to auditors without the consent of the patient. In this instance I believe it would be fair to say that there is considerable risk that some women's' lives will be put at risk if they pull out of the screening programme because of the fear of exposure of their medical records to unknown auditors.

People are also concerned about the accuracy of their records and the Privacy Act brings the right to access them and to ask for correction, or if the holder of the record is unwilling to make a correction, then the right to access and to ask for a statement of correction sought to be placed with that information. I think the system works pretty well. We did find some rather precious reactions initially, I remember one neurologist who refused to put a patient's statement of correction on his file because she had misused the word "psychotic" and he couldn't possibly have his medical records with incorrect use of language.

Of course the relationship between doctors and patients is always problematic. Particularly in those situations where considerable money is involved as is evidenced by an American cartoon that showed the doctor saying to the patient "if we go ahead with this procedure you will lose the use of about 40% of your income".

Of course the state financed budget systems bring their own problems too. In the UK a popular cartoon displayed a doctor saying to the patient that he had run out of budget and the best he could offer to do was to kiss it better.

In my experience there is considerable faith put in the medical profession and heightened disappointment when things don't go well. There's a tendency to believe that there must be a cure for everything and a failure of any procedure must be due to the fault of the practitioner concerned. Of course there are things that any professional person can do to improve their relationship with the individual they are serving. It was said that the sign of a good GP is that she doesn't start writing out the prescription until the patient has finished describing the symptoms.

There is, I fear, a tendency to want to tear down the professional edifices and I get many letters abusive of doctors and lawyers - or anybody seen to be in a privileged position. That I must say includes the Privacy Commissioner. One complainant wrote to me and, among other things, said:

"If you are unable to discern this then you are unfit for the job or a crook or a fool or just a scared little public servant trying to be faithful

to your own crowd ... you are not a commissioner's bootlace. You are a fraud and will be treated as such. I expect and demand justice where it is due and in real terms you are a stooge and a collaboratoring liar who wrongly sides with establishments and persons who least need it. You betray the law, you deny me justice, you demean your office, you lie to yourself, you take the easy way out, and then have the hide to act rudely and unsympathetically when a complainant is left in a quandary as your office swans around the decision for nearly two years. Bludger."

I had to decide what to do about that letter. After carefully considering it I decided to file it under "dissatisfied".

The Privacy Commissioner is not the advocate of the complainant and is merely a seeker of the truth of the matter. That is not always understood.

At one stage we playfully discussed whether there was some types of complainants that we could decline to deal with. We came up with the following suggestions:

The Commissioner may in his discretion decide to take no action if in the correspondence:

- any reference is made to the Magna Carta
- a threat is made to refer the matter to Paul Holmes, Fair Go or 60-Minutes
- the letter contains more than half a page of underlining, capital letters, more than 3 colours of biro or bold underlining of the word justice
- there is any over use of the following phrases: it's the principle; it's a whitewash; it would be repugnant to natural justice; a gross violation of
- the letter writer misspells my name or refers to the Privy Commissioner
- the letter is copied to the Prime Minister, the Queen, the Governor General or any of the media mentioned above
- the complainant requests that the Commissioner inflict serious fines or punishments
- any requests for monetary compensation over 6 figures.

Seriously, I have been asked sometimes if there was a credo that went with the privacy office and I suppose its more a credo that I've had as a lawyer, and it's a quote from Harry S Truman the 33rd President of the USA. He said this:

"In the cause of freedom, we have to battle for the rights of people with whom we do not agree; and whom, in many cases, we may not like. These people test the strength of the freedoms which protect all of us. If we do not defend their rights, we endanger our own."

(In the privacy context that includes respondents as well as complainants.)

One of the plagues of the office has been those people, (I hope there is nobody present who would dare do it) who blithely say they can't make information

available because of the Privacy Act. We call them BOTPA, Because of the Privacy Act. It implies that but for the Act the information would be made available. Most of the time we find that they never previously made the information available anyway and many who use it haven't read the Act. The Privacy Act was used as a brush off.

The best comment I've had on the Health Information Privacy Code was from a paediatrician at a Health Ministry seminar who said that he hadn't had time to read the Code, but he knew what was in it and it was nonsense.

One of the difficulties of the Act is dealing with the relationship of privacy to mental health. We have a strong lobby of mental health patients who are resentful of others routinely getting their health information. There are families who are concerned about the wellbeing of their family member with mental health problems who have to look after the patient from time to time and feel choked off from information – and what is worse - discouraged from providing what they feel is useful information to the health professionals. Fortunately we seem to have stopped blaming the Privacy Act for every suicide that occurs. More recently denial of information to families has been accepted by mental health workers as their problem and something to grapple with. A working party set up by the Mental Health Commission satisfied itself that it was not the Health Information Privacy Code that needed to be improved, but the training of those who were dealing with mental health and patient information.

Health agencies have attracted 12-15% of total complaints - a modest figure considering the number of transactions and the sensitivity of the information.

How then have lawyers behaved in relation to the Privacy Act? We didn't get many complaints about them. Some of them get really rather upset when they find that the Act doesn't permit them to hold on to people's information when the bill hasn't been paid. They can hold on to the documents but the information generally has to be made available. Despite rulings from the New Zealand Law Society, and publicity in their publications we still strike this difficulty from time to time.

Lawyers sometimes think they've got all the answers, and are very good at put downs. I read of a case where in Scotland a lawyer said to an accused woman, "when asked to show your income on the form, was it wise to write F All?" The accused replied "I didn't have time to write family allowance."

However, the best put down occurred on the David Letterman Show last month. Brittany Murphy appeared on the show and was asked how she felt about her ex-boyfriend Ashton Kutcher becoming Demi Moore's toyboy. She replied: "I suppose the crux of their relationship is that to him age doesn't matter, and to her size doesn't matter."

Life for lawyers has become more hectic. Gone are the days of the country solicitor who said he didn't like making appointments on a Wednesday as it was inclined to spoil both weekends.

I have got used to being regularly lectured about the rules of natural justice. Pomposity and even aggression occasionally flash themselves in legal correspondence. The aggression often comes from the lawyers who act for medical insurers. It must please their clients.

Those solicitors who referred many cases to us showed a good degree of understanding of the Act and how it could be used to their client's advantage. I certainly found in a number of cases, including some that went to the Tribunal, that if solicitors had been instructed to act then a great deal of public money would have been saved. There is a class of self-advised litigants who have a Perry Mason view of the law and think it quite normal to allege bias of the Tribunal and propose dismissal of people who give decisions they don't like. I have no doubt of the importance of legal representation in a number of these areas, although sometimes I have to say lawyers have prolonged the matter expecting a worse outcome than seemed to me to be likely from the beginning.

During the course of running an office we employed former students mainly lawyers who took out student loans. We send a regular statement to Inland Revenue Department showing the amounts that we deducted from salaries along with the PAYE. One day a statement of account arrived from the IRD for student loans. It acknowledged that the previous balance was nil and then showed an assessment on the 1st of October 1997 of \$2,862,854,920.90 and correctly acknowledged payment "thank you" of \$1,320.90. It imposed a late payment penalty of \$143,142,680 and interest of \$10,302,743.40. The Inland Revenue Commissioner reminded me that interest would be accruing daily at the rate of \$1,144,749.26.

Wouldn't it have been fun to have sent off a cheque for \$3,016,299,023 and see if the Inland Revenue tried to cash it?

I have always felt that the Privacy Commissioner gets probably the most interesting mail of any office in New Zealand. I was looking through some of the issues that we have dealt with, they range from telecommunications codes of practice, the question of domestic violence and access to vulnerable people's addresses from public registers, whistle blowing legislation, assisted reproductive technology, sports drug testing, video surveillance, mandatory reporting of child abuse, accident insurance and ethnicity, screening programmes, genealogists, information matching and so the list goes on.

In the early days of the office I kept up with all the mail that was coming in. On one occasion we had a man who wrote in to say that he had asked the police for a copy of his file. He'd had no response. This was not unusual with the police. We had a rather new investigating officer write to the police and ask why they hadn't answered the letter. He had to write a couple of times before he got a reply. The police eventually said that they were very happy to make the information available to the requester, but they just wanted to ask him a couple of questions first, then they would hand over the information. Unfortunately they had lost contact with him. As soon as they made contact again, they would ask him the questions and then hand over the information.

The rather new investigating officer passed this police response on to the requester. I saw the requester's reply come in in the mail. The requester said "I don't understand why the police say they have lost contact with me, I'm still serving life imprisonment in Paparua Prison".

What then are the issues that are going to arise in the future? I believe there will be more and more legislative inroads because of the political parties all espousing law and order programmes to appease public opinion about crime, and indeed, terrorism legislation has principally so far followed the agenda of the police rather than the agenda of a counter-terrorist strategy. Over the last 11 years I have often felt almost alone in defending the civil liberties of people who are not criminals. Usually only the Law Society is also taking a principled stand.

So surveillance will be on the menu. I think it will also crop up because of such technical changes as the mobile telephone camera. With the ability to record activities of neighbours I think more surveillance will be in the hands of amateurs, and our Privacy Act does not deal well with that situation. I think there will be more tracking of people. I have tried to encourage the legislature to ban use of tracking devices generally while permitting tracking for police purposes but this so far has not been successful.

I believe there will also be a number of issues arising from the use of biometrics for security purposes, the use of genetic information, on Guthrie Cards for instance. The activities of information brokers who would go far beyond credit reporting to providing profiling and lifestyle information will grow, all of course to increase economic efficiency.

Above all I think urgent action is needed to deal with public registers where the bulk use, such as that used by Pacific Retail Finance recently, to write to people on the Motor Vehicle Register, needs to be controlled, just as it will be necessary to pass legislation in New Zealand and many other countries to deal with spam. But use of public register information imposes threats to individual safety and that needs urgent attention.

There is a lot of work to be done, and someone said that "If you can find a job that you love doing, there would be no work involved". It hasn't quite been as good as that but pretty close to it and I have enjoyed it. I've been very lucky to occupy this position and to have a unique set of functions to perform.

It is easy to get immersed in this work, or in fact in any work.

The Times reported recently that:

Aaron Ross starts works at 6.15am, has a kip in the afternoon on the office floor and works through to 9.00 pm when he meets his partner for dinner. Over dinner he talks about work and is then back on his email until 1.00 am.

Last year he came back from holiday after three days, even though he had his laptop with him. Mr Ross is chairman of the Work-Life Balance Trust.

I leave you with a question tonight. Why are my staff so convinced that the full moon has something to do with an increase in crazy telephone calls?

A question also arises of course, whether it has anything to do with the star signs. I have never believed in astrology, we Leos are not so easily taken in.

It was Kelvin McKenzie, famous editor of the Sun, who dismissed his astrologer with a letter starting, "As you will already know...".

A former President of the American Bar Association heard that I would be retiring as Commissioner and gave me some advice. He said that when he retired his wife said to him that he needn't think that he was just going to get up every day and spend the morning looking out the window. He asked her why not, and she said because that's what you will be doing in the afternoon.