

In August 2002, **The Age** newspaper published two articles titled "Let us warn patients of gene mutation, say doctors" and "A test to know and the devil you don't". Following this, Federal Privacy Commissioner Malcolm Crompton, made comments regarding the Privacy act. The articles follow and you can find details of the media release by Commissioner Malcolm Crompton, by visiting the following website:
http://www.privacy.gov.au/news/media/02_16.html.

A test to know and the devil you don't

By Tom Noble

August 6 2002

For Michelle Ritchie, it began with a visit from her older brother Ross. There was a genetic family problem, he told her, and she might be affected. She could take a genetic test and find out - did she want to know? She did.

About a decade earlier, Ross, now 42, had developed bowel cancer. He recovered and life went on until he was told there might be a genetic cancer link. The family history and the early onset of his disease suggested a genetic disorder, and tests proved this right.

So, with her other brother James, Ms Ritchie gave blood a year ago to see whether she had HNPCC, a gene that triggers colon cancer in 80 per cent of carriers and can cause endometrial and ovarian cancer. A few weeks later came the results: James was clear but she had the gene.

Ms Ritchie, 28, now has yearly checks for cancer, and so far is clear. Her family has told relatives "and left it up to them if they wanted to get tested". Even relations in Scotland have been told and are having the test.

Ms Ritchie says knowing is a good thing. "It's got benefits. At the end of the day it's a mechanism to tell me to look after myself and monitor it. If you get something early, you might have a better prognosis."

This story was found at:

<http://www.theage.com.au/articles/2002/08/05/1028157906266.html>

Let us warn patients of gene mutation, say doctors

By Tom Noble
Health Editor
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Doctors have called for a review of medical privacy laws after revelations that a dying Melbourne man in his 20s could not be warned that he might be carrying a genetic mutation that causes bowel cancer.

A second man in his 20s, from another Melbourne family, faces a 50-50 prospect of survival after developing the same disease. His parents knew of the family's history of the disease but did not tell their son.

The men were not warned because under Australian laws only relatives have the right to pass on sensitive family information. In both cases, the cancers could have been cured if diagnosed early enough. Professor of colorectal medicine and genetics at Royal Melbourne Hospital, Finlay Macrae, said the law should allow doctors to tell people directly that they may be carrying a gene that causes a preventable life-threatening disease.

The present law allows doctors to warn people - and breach medical privacy laws - only if there is a "serious and imminent threat" to a person's life or health. Professor Macrae said legal advice indicated that unless death was likely within weeks, the threat was not "imminent".

Professor Macrae said the Cancer Council's familial cancer registry knew of the two men with advanced bowel cancer, although not by name.

"It knows they are out there but can't contact them because of privacy legislation," he said.

He said one man's case was now hopeless, the other potentially curable.

"In both cases, the disease was swept under the carpet by the older generation to the point where the younger generation had absolutely no clue as to what was going on," he said.

Southern Health head of colorectal surgery Paul McMurrick said the law should allow doctors to tell people they might be carrying serious genetic mutations.

"It's not clear what the law is to any of us," he said. "If a person has a 50 per cent chance of death from bowel cancer at a premature age, I feel strongly that person has a right to know. I feel they have a right to be informed of that risk." Only a handful of genetic mutations have been identified that have a high risk of causing fatal but preventable cancers in adults. These genes, which mostly cause bowel and breast cancer, are found in only a few hundred Victorian families. But Victorian Cancer Registry director Graham Giles said the problem was going to get worse "as more and more genes are discovered for more and more problems".

"We have to be extremely careful, given privacy laws and community expectations, so we don't overstep those lines," he said.

As more disease-carrying genes are found, debate about the right to privacy versus the right to know - and the need to be told - will become more intense. The dilemmas are acknowledged by Liberty Victoria, which believes guidelines may be needed to determine whether privacy can occasionally be breached.

"In Liberty's view the release of personal information about health matters without the consent of the person should not occur, except in exceptional circumstances," said president Chris Maxwell, QC.

"We accept, however, that where the non-release of the information could materially adversely affect the health of another person, then that may constitute exceptional circumstances."

The Australian Law Reform Commission is due to release a discussion paper this month on human genetic information - including the question of privacy and genetics - before making recommendations to the Federal Government next year.

Under a model proposed in an issues paper the commission released in March, genetic information would be shared in families and "people would not have the ultimate right to 'control' their information and the use of their tissue taken for genetic testing".

In Victoria, the privacy of health information falls under several acts and it appears to be unlawful, without consent, to advise someone that they may have a genetic condition. While some Victorians receive unexpected letters telling them a deadly gene has been found in their family and offering genetic testing, such letters can be sent only to people who consented - often years earlier because of a family history - to be on the Cancer Council's familial registry.

"This is one of the most difficult ethical areas that genetics faces," says Professor Bob Williamson, who oversees Genetic Health Services Victoria, the state's genetic counselling service. "When there is a conflict and the patient won't tell the family, the doctor is put in an extremely difficult position."

The key familial cancer genetic disorders treated in adults in Victoria are breast cancer - triggered by two genes; bowel cancer triggered by genes that cause a disease known as FAP; and bowel, endometrial and ovarian cancer triggered by the HNPCC gene.

Less than 5 per cent of breast cancer and about 2 per cent of bowel cancer is caused by these genes, although it tends to strike early in life and can develop rapidly.

With FAP, all of those who carry the gene will develop cancer, as will more than 80 per cent of those with HNPCC. The disease can be prevented or cured if found early enough.

"Most people will choose to take the test if they know the facts," says Professor Williamson.

In Victoria, people diagnosed with cancers that pose a high genetic risk are offered counselling during which they are encouraged to tell other family members about their condition and that a genetic test is available. In NSW, patients are asked to pass a letter to family members.

Director of familial cancer services at Sydney's Westmead Hospital Judy Kirk said it was unclear how effective this was. "We can't be sure the information gets through - or even what information gets through," she said. "And I am aware of situations where there is no link person in the family. In certain circumstances, if all other avenues have failed and someone is at high risk, there needs to be a mechanism to tell them." In South Australia, diagnosed people are asked to provide a list of relatives and to consent to letters being sent to them. While the patient may contact some relatives before the letter is sent, they may not contact all relatives. This means dozens of people receive unsolicited letters telling them they may be carrying a gene that causes a treatable condition. One NSW family received such a letter this year and was shocked, then thankful, Associate Professor Kirk said.

"They had a number to call, got good information and appropriate referral," she said. The NSW family has yet to receive its test results.

The head of Cancer Council SA's familial cancer registry, Graeme Suthers, said about 650 unsolicited letters would be sent this year, up from 200 last year.

Dr Suthers said most people replied, wanting more information. About a quarter made no contact, so were left alone. About 1 per cent asked not to be contacted again. He said the registry took people's addresses "with the explicit purpose of writing to those family members".

This story was found at:

<http://www.theage.com.au/articles/2002/08/05/1028157906558.html>