

TRANSCRIPT

Tuesday, 6 February 2024

Transcript: AMA President Professor Steve Robson radio interview on ABC Newcastle

Subject: Genetic discrimination in life insurance

QUESTION: Well, modern technology and science are wonderful things, aren't they? The fact that we can now test, for example, to see if we're predisposed to some health conditions. It can be a game-changer because there's maybe some proactive or intermediate step you can take to ensure longevity and better health. But it also impacts on our health insurance options, and the Australian Medical Association says that's not fair. AMA President Professor Steve Robson is here to discuss the issue with me. Now, it's a tenet of insurance in the Westminster system that we have a duty of disclosure. In fact, it's an ongoing duty. So how does that play out with genetic diseases and health insurance?

STEVE ROBSON: It's an incredibly good point. And I think it wasn't envisioned when a lot of our insurances were set up in the first place. There's been an explosion in genetic technology and it's now possible for people to learn an enormous amount about their risk of getting diseases. And the classic example is the cancer-causing mutations that many Australians will carry that make it, if they're not managed properly, very likely that women will, for example, get breast cancer or men might get pancreatic cancer. It's incredibly important information to help you plan your healthcare to screen and look after yourself.

But as things stand at the moment, there's no legislative impediment to life insurance companies saying: 'look, you carry these mutations, we're not going to insure you, or we only will with some sort of large caveat or financial penalty'. And we think it's just terrible that the legislative environment is such that Australians will have a financial discouragement from finding out about potentially lifesaving information about their genetics because they're worried they might not be able to get life or other types of insurance.

QUESTION: Steve, are patients already saying this to practitioners, that they don't want to run a certain test because they're just afraid of what they'll find out?

STEVE ROBSON: Yes, absolutely. And in fact, some work done by Monash University has shown this is a very, very strong factor in Australians' willingness to have genetic tests. They've dealt with large numbers. They ran a study of 10,000 Australians from around the country and found that a very significant proportion of people ultimately didn't want to undergo testing because they thought it might either compromise their own ability to get life insurance. And it's really important that if you are harmed (or become unwell) that your family has access to insurance so that they can be financially secure. And it's always important to understand that if you have a genetic test, the test may not only apply to you but may reflect other family members. So, there's enormous concern that potentially lifesaving tests are being forgone because Australians are concerned it will compromise the financial health of their family and their insurance capacity.

QUESTION: And it's further complicated by going to the other end of the spectrum and saying someone is now deceased. They had a life insurance policy and the insurer saying: 'well, part of our consideration insuring you was managing the risk. You knew at the time that you had a genetic predisposition and you didn't tell us.

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So we're not going to pay out on the policy'. Not only have they now got the capacity to not insure you in the first place, but in 20, 30, 40 years' time to turn around and say: 'well, hey, you should have told us' — that's going to make it hard, isn't it?

STEVE ROBSON: I think you're absolutely right, and there's a huge climate of fear around this. But what's important to understand is actually the more information you have about your risk, the better you are able to control it and deal with it. And a great example is the very common condition of breast cancer genes. And we know that the actress Angelina Jolie took action to have breast surgery and ovarian surgery, and now her risk is almost zero of getting these cancers. So it allows you to take action. But as things stand at the moment, there's no reason in the law that an insurance company can't discriminate against you if you carry these genes. So, people are making a choice not to have the testing — so putting themselves at risk when they could in fact get information, work with their medical team, and lower the risk, in some cases almost to zero.

QUESTION: I think most people would understand that if you have a pre-existing complaint then you should advise your insurer. But that's different, isn't it, for having some sort of predisposition to at some stage in the future contract an illness or injury?

STEVE ROBSON: You're 100 per cent correct. If somebody has an existing injury or illness, that's of course important to an insurer in adjusting how they deal with that, with your premium and so on. But if you have a genetic change, you don't actually have any disease, it actually says you may be more prone to, for example, get a breast or a bowel cancer in the future. But you can actually take steps once you have the information to protect yourself and to lower that risk. And in fact, if the information applies to your children, your other members of your family, you can actually protect multiple members of your family. There is a voluntary moratorium at the moment, but it's a very tenuous thing, and the government is reviewing the legislation at the moment. And we're absolutely firmly of the opinion that the more information you have about yourself, the more likely you are to protect yourself and to work to reduce that risk, and that you shouldn't have a disincentive. You shouldn't be afraid of having these tests because you're worried you can't get income protection insurance or life insurance or something like that.

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