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Important points

- In Australia, premiums for private health insurance are not based on risk assessment according to the individual's present or past health or their family history
- Premiums for life insurance products which include cover for life, disability, trauma, business and bank loans are calculated according to present and past health of the applicant and any genetic information including their family history or any genetic test result (underwritten)
- Insurance policies offered by Life Insurance companies in Australia are 'guaranteed renewable': an individual only has to apply for the cover once and is not subject to providing any other health or genetic information for the period of cover
- The Investment and Financial Services Association Ltd (IFSA) <http://www.ifsa.com.au> has a policy on genetic testing and life insurance that states that no applicant will be required to undergo a predictive genetic test
- Under law, an application for a life insurance product is required to disclose any health or genetic information **known** to the applicant
- Costs of insurance, and the ability to obtain insurance cover, may vary between different companies depending on health risk. Applicants may wish to make applications to a range of companies at the same time; an insurance broker or agent may be helpful in this process
- It is important to involve the family doctor, specialist or geneticist if necessary in negotiations with the insurance company and document your screening and prevention strategies, where applicable
- Where an individual has received their predictive genetic test result before securing insurance cover, they are required to make the results of any genetic test available
- Where a relative has had a predictive genetic test and the test result is known, disclosure of this information is required but not any other personally identifying information like a relative's name
- An insurance policy may be secured before having genetic testing
- Where a blood sample for a predictive genetic test has been taken and the sample has not yet been analysed by the laboratory, it is unclear how this would impact on the insurance application
- Where the laboratory has analysed the sample and a result is pending; the insurance company may delay the application until the result is available
- **Research Projects:** Disclosure of participation in a genetics research project is not required except in those projects where a personal result has been given
- **Dealing with insurance companies:**
 - Genetic counselling may be supportive and informative
 - Ensure any information provided by brokers or agents is in writing from the insurer
 - The complaint system provided by the insurance company or any other official process may be helpful to some

Genetic information, which includes your family medical history and the results of predictive genetic tests, may have implications for your life insurance options.

Life insurance products include cover for

- Life
- Disability
- Trauma
- Business and bank loans

Predictive genetic testing refers to testing in an individual who currently does not have symptoms or signs of a condition, but who may be at increased risk due to their family history.

If the genetic test result is positive, they will have inherited predisposition (susceptibility) ie. they are at increased risk for developing the condition over their lifetime but may never develop it unless other, often unknown triggering factors are also present. Examples of such conditions include some cancers, some cardiac

conditions and hereditary haemochromatosis (see Genetics Fact Sheets 47-51, 53-55 & 36).

Presymptomatic genetic testing refers to testing in an individual who currently does not have symptoms or signs of a condition, but who may be at increased risk due to their family history.

If the genetic test result is positive, they will develop the condition in their lifetime (if they live long enough) but it is not possible to determine with any accuracy at what age that might be or its severity. Examples of such conditions include Huntington disease and early onset Alzheimer disease (see Genetics Fact Sheets 44 & 45).

Predictive and presymptomatic genetic testing is currently available for a limited number of inherited conditions (see Genetics Fact Sheet 21).

Concerning insurance

The Investment and Financial Services Association Ltd (IFSA), an organisation representing most insurance companies in Australia, has a policy on genetic testing and life, disability and trauma insurance (see IFSA's fact sheet 'Life Insurance and Genetic Testing in Australia' at <http://www.ifsa.com.au>).

Under this policy, no applicant will be required to undergo a predictive genetic test in order to obtain insurance or to renew a policy that has not changed.

Life insurance policy applications usually require a disclosure of any known genetic information. This information, depending on the condition involved, may or may not lead to

- Higher (non-standard) insurance premiums
- A reduced period of coverage
- An exclusion for one or more medical conditions
- Offer of an alternate insurance product
- Deferral
- Denial of an offer for insurance

Costs of insurance, and the ability to obtain insurance cover, may vary between different companies depending on your risk. Applicants may wish to make applications to a range of companies **at the same time**. An insurance broker or agent may be helpful in this process.

Insurance for a limited amount may be available with a superannuation plan. This is called 'group insurance' and therefore not subject to health information, including family history and genetic testing results. If however, insurance is required for a higher amount than allowed under the superannuation scheme, the application will require disclosure of this information.

Insurance policies offered by Life Insurance companies in Australia are 'guaranteed renewable' so that an individual only has to apply for the cover once and is not subject to providing any other information for the period of cover.

- Under law, in the time between the application for this type of policy, and it being approved and accepted, the insurance company must be informed of anything that the applicant knows that may impact on their offer of insurance
 - Under the Insurance Contracts Act 1984, a person applying for insurance has a duty "to disclose to the insurer every matter that you know, or could reasonably be expected to know, that is relevant to the insurer's decision...". Some companies will ask for more details than others. You are obliged to provide answers to the questions asked honestly and to the best of your knowledge"
- Once a guaranteed renewable policy has been issued there is no longer any obligation to inform the company of any changes in circumstances, such as the result of a predictive test
- If a predictive genetic test result indicates that an individual was at **lower risk** than previously estimated based on their family history alone, they should inform the insurance company so that the policy can be reassessed with this new information
- Insurance policies that are offered by General Insurance

companies covering 'sickness and accidents' are renewable during the time of cover of the policy. At every renewal period, disclosure of any information that the individual **now has**, including any change in genetic information (family medical history or predictive genetic test results) must be disclosed.

With these policies, each renewal period is like making a new application

It is important to involve the family doctor, specialist or geneticist if necessary in negotiations with the insurance company and document your screening and prevention strategies, where applicable.

Situations that are relevant for people regarding predictive or presymptomatic genetic testing and life insurance include:

1. Where a blood sample has not yet been taken for the predictive genetic test:

An individual may wish to investigate their insurance options before considering predictive genetic testing. Securing a policy may take several weeks or more.

Some companies may ask whether advice and/or counselling has been sought about health or future health. In answer to this question, if **genetic counselling** had been attended to discuss risks based on a family medical history (but where a sample was not taken for a predictive genetic test), informing of attendance is required.

What is known about the health of parents, brothers and sisters ie. first-degree relatives should be provided to a potential insurer.

Sometimes genetic counselling can clarify that an individual's family history does not indicate that they are at potentially high risk for a certain condition, and this can be helpful when applying for insurance.

2. Where a blood sample for a predictive genetic test has been taken (a) A test sample has not yet been analysed by the laboratory:

As with all types of medical treatment, anyone may withdraw their consent for a procedure at any time. It is possible to withdraw consent to a sample being analysed at any time prior to the laboratory starting the process.

In this situation, disclosure is still required to a potential insurer, about the fact that a sample was provided for a predictive genetic test but that the individual had withdrawn from the testing process without a result.

It is unclear how this will impact on an insurance application. Insurance companies are bound, under IFSA's genetic testing policy, to respect an applicant's right 'not to know' their predictive genetic test result (see No 6. *Dealing with insurance companies*).

Sometimes an individual will give a sample for analysis to be done in the future. This is called 'DNA banking'. If a person provides a sample for DNA banking they have not yet undergone a genetic test.

(b) A laboratory has analysed a sample and a result is pending:

Providing a sample for testing and laboratory analysis assumes that a predictive genetic test has been undertaken.

Disclosure of undertaking such a test is required by a potential insurer.

In this situation an insurance company may await a result before proceeding with the application.

(c) The laboratory has analysed the sample but an individual has chosen not to have their result:

There may be a number of reasons why someone may choose not to have their predictive genetic test result. For example, an individual may have a test only for the benefit of other family members but does not wish to know their own result.

- Obligations to disclose to the insurance company that a test had been undertaken is not clear
- The insurance companies are bound, under IFSA's genetic testing policy, to respect an individual's right 'not to know' their predictive genetic test result (see #6 Dealing with insurance companies)

3. Where a predictive genetic test result has been received before securing insurance cover:

The insurance company will require that the results of any genetic test be made available.

4. Where a relative has had a predictive genetic test and the test result is known by the insurance applicant:

When applying for insurance, it is required to disclose any *health* information that is **known**, about oneself, their parents, brothers and sisters. This is relevant to an assessment of their risk.

- This would include past and present health problems and predictive genetic test results but would not include providing personally identifying information like a relative's name.
- The insurer may also request written consent from the applicant to access their medical records from their doctor
- If there is information about a relative's genetic test result in an individual's medical record, their doctor may be obliged to disclose the test result information
- In the written consent it is possible to request that a doctor does not disclose any personally identifying information about relatives

5. Research Projects

Disclosure of participation in a genetics research project is required only in the following circumstances:

(a) The research protocol states that during, or at the completion of the research project, a personal test result would be received:

Disclosure of the result is also required.

(b) The research protocol states that a personal test result is not given, but that a family test result might be important to one's future health, and so the opportunity to investigate options further through a clinical service becomes important:

- Once informed of this, an individual is made aware of a matter that the insurer may consider relevant, and is expected to disclose this information in an application for a policy or a renewal
- If an individual chooses to undergo a further predictive genetic test in a clinical setting, similar obligations to disclose apply

6. Dealing with insurance companies

An insurance company may be a member of IFSA and may therefore be bound by the IFSA policy.

- If the company is not a member of IFSA, enquire about their policy regarding genetic testing
- If advised by an agent/broker that an insurance offer may be declined, deferred, offered at non-standard rates or impacted on the basis of a particular genetic test result:
 - The applicant should check that this advice is received from the company's underwriter in writing and a copy requested
 - A genetics specialist may be able to explain the reasons for a decision, and if necessary may discuss the decision with the company's Chief Underwriter or Chief Medical Officer
 - If there are difficulties with an insurance company over an application or renewal, it is possible to follow the Internal Disputes Resolution process that each company has documented in their product disclosure brochure; this is the brochure that contains the application form

Other Genetics Fact Sheets referred to in this Fact Sheet: 21, 36, 44, 45, 47, 48, 49, 50, 51, 53, 54, 55

Information in this Fact Sheet is sourced from:

The Investment and Financial Services Association Ltd (IFSA) [online]. Available from: <http://www.ifs.com.au>. [Accessed June 2007]
 Otlowski M, Barlow-Stewart K, Taylor S, Stranger M and Treloar S. (2007). Investigating genetic discrimination in the Australian life insurance sector: use of genetic test results in underwriting 1999-2003. *Aust J Law and Medicine* 14: 367-396

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