

In Australia genetic information, which includes your personal medical history and results of genetic tests and information about the health of your parents, children, brothers and sisters can have implications for life insurance policies.



IN SUMMARY

- **Private health insurance** is not based on a risk assessment of your health.
 - You will not be asked about genetic test results or your family history of health conditions.
- **Most life insurance products such as cover for death, permanent disability, trauma and income protection are based on a risk assessment (underwritten contracts). This may impact on the cost or terms of the policy.**
 - You are not required to have a genetic test as part of the risk assessment when applying for life insurance
 - If you have already had a genetic test, your life insurance company must not use your genetic test results (up to the financial limits set above) unless you choose to declare them.

You may be asked

- Your age, gender, current health and medical history, including any signs, symptoms and any diagnosed conditions you have had or continue to have, even if diagnosed through a genetic test
- Your results of medical tests you have had
- Any health conditions that have been diagnosed in your first degree relatives (parents, children, brothers, sisters) **only** and the age they were diagnosed.

- **You are not required** to provide any other information about your first degree relatives including their genetic/genomic test result(s) if known to you, their name or date of birth.
- The life insurance products are guaranteed renewable
 - As long as the premiums are paid, you do not have to notify the insurer of any change in your health or of the results of any medical or genetic/genomic test taken after your policy has started.
- A genetic/genomic test undertaken after a policy has been secured that shows you have not inherited a gene variant (DNA change) causing a health condition in the family, and you choose to declare the results, means that the impact of a family history may be removed from your risk assessment that informed the cost and terms of the contract. Contact your insurer to discuss.
- The Moratorium does not apply to any existing life insurance policies.
- Involve your family doctor, medical or genetics specialist if necessary, in negotiations with the insurance company.

More information is available at the [Financial Services Council \(FCS\)](#)

The Moratorium on Genetic Tests in Life Insurance came into effect from 1 July 2019 and will be in place until at least 30 June 2024 at which time there will be a decision about continuation.

The Moratorium on Genetic Tests in Life Insurance means that up to 2024, life insurance companies will not be able to use genetic test results as part of an insurance application up to the value of \$500,000 (for death and total permanent disability), \$200,000 for trauma and \$4,000 a month for income protection.

INSURANCE IN AUSTRALIA

When you take out insurance that is related to your current or future health, you are entering a contract with the company. Companies that provide life insurance or sickness and accident insurance, base an offer and cost of the policy on the level of the risk that is being taken on. These are risk-rated insurance policies. **Underwriting** is the word that insurers use to call their risk assessment. Most types of insurance in Australia are risk-rated to some extent. Further examples are motor vehicle insurance and home and contents insurance.

In Australia, the many different types of insurance come under three general headings: **Life Insurance, General Insurance and Health Insurance (medicare and private health insurance)**.

Private Health Insurance premiums are not risk rated (underwritten), so that everyone pays the same premiums for the same policy, regardless of their age or health status. You do not have to provide any genetic/genomic test information to the company when applying. Private health insurers can impose waiting periods for pre-existing conditions.

A person who has a genetic/genomic test result indicating susceptibility to a genetic condition, but does not show signs or symptoms, does not have a pre-existing condition and so waiting periods should not be imposed.

RISK-RATED INSURANCE POLICIES

A. Life insurance from a life insurance company

Life insurance products include cover for life and living benefit policies such as permanent disability, trauma, income protection insurance and those taken out for business and bank loans.

A life insurance policy is a contract between you (the policyholder) and the insurer that requires an assessment of the risk that you will make a claim. Living benefit policies are linked with different chances of making a claim than policies for death, and so higher premiums may be charged.

Based on the level of risk and the type of policy applied for, the insurer will decide the level of premium to charge, and may impose limits on the cover or even deny you insurance cover.

The *Insurance Contracts Act 1984* (Cth) sets out requirements for the insurer and the applicants. Further, the Financial Services Council (FSC) provides Standards of Practice for life insurance companies operating in Australia.

All companies offering new life insurance policies in Australia are currently members of the FSC and subject to the Life Insurance Code of Practice and the FSC Standards. The Act and the Standards define responsibilities on both the insurer and the applicant.

Applying for life insurance

a. *Where a genetic/genomic test result has been received before securing insurance cover:*

In regard to the use of genetic information in the risk assessment, there are two FSC Standards:

- Standard No. 11 Moratorium on Genetic Tests in Life Insurance
- Standard No. 16 Family Medical History Policy.

What the insurer should do:

- Assess your risk using statistical, actuarial data or other factors where that is available or other appropriate information
- Take into account any screening, treatment or preventive health strategies to reduce health risks

- Do not require a genetic test be undertaken as part of the application process.

What you may be asked:

The application form may ask about:

- Your age
- Your gender
- Your current health
- Your past medical history, including any signs, symptoms and any diagnosed conditions you have had or continue to have, even if diagnosed through a genetic test
- Results of your medical test(s) undertaken
- Information about health condition(s) affecting your first degree relatives only (mother, father, brother, sister, children)
 - The number of these relatives who have been diagnosed with the condition(s); i.e. have signs and symptoms of the condition
 - The age at diagnosis of the condition(s) of each relative(s)
 - *Note: Standard 16 does not require you to provide any other information about your first degree relatives including their genetic test result(s) if known to you, their name or date of birth*
- Other risk factors such as your personal environment, occupation, smoking or excessive consumption of alcohol and lifestyle.

Note any screening, treatment or preventive health strategies you have or are taking.

In meeting your duty to disclose, you also have to disclose any risk factors or changes in circumstances that happen after completing an application until the policy starts.

b. Where you have a family history of a condition but you do not have any signs or symptoms of the condition and you have not had a genetic/genomic test before securing insurance cover:

You must disclose all information known to you about the health of your first degree relatives but not about any other relatives.

Depending on the condition, however, your family history may impact on how your risk is assessed and affect the cost of premiums or the terms of the policy or even being able to access insurance.

Securing a policy could take several weeks or more.

c. Where a blood sample for a genetic/genomic test has been taken before securing insurance cover that is higher than the financial limits set out in the Moratorium:

- *A test sample has not yet been analysed by the laboratory:*

As with all types of medical treatment, you can withdraw your consent for a sample being analysed at any time prior to the laboratory starting the process. If you withdraw, you will not know the result so you do not need to disclose that you have had the test. Sometimes a person will give a sample for testing to be done in the future for the benefit of family members.

This is sometimes called **DNA banking**. If you provide a sample for DNA banking you have not undergone a genetic/genomic test.

- *A laboratory has analysed your sample and a result is pending:*

The insurer will ask you to tell them this.

- *The laboratory has analysed your sample but you have chosen not to know your result:*

There may be a number of reasons why you might choose not to have your genetic/genomic test result. In these circumstances you do not know your result and so do not have to disclose that a genetic test has been undertaken. The insurer should then underwrite the risk only on the basis of your family history and the other respective disclosures made in your application.

After a policy has been obtained

Most insurance policies offered by life insurance companies in Australia are **guaranteed renewable**.

This means that as long as the premiums are paid, you do not have to notify the insurer of any change in your health or of the results of any medical or genetic/genomic test or a change in any other relevant circumstance.

If, however, you wish to alter the policy, the insurer will need to reassess the risk at this time if the risk to the insurer has increased, so all the information above will need to be provided.

Importantly, a genetic/genomic test done after a policy has been secured that shows you have not inherited the genetic variation in the family, and you choose to declare the results, means that the impact of a family history may be offset by this. Of course, other factors that affect your risk may also now be present but if the family history is the only factor that you believe impacted on the decision to offer a policy on non-standard terms, you should contact your insurer to discuss. You may wish to involve your health professional, geneticist or genetic counsellor in this process.

B. Travel insurance

Travel insurance is insurance cover for accidents and emergencies which may arise when travelling within Australia or overseas. Application forms will commonly ask about medical history. Some travel insurance providers will also ask about whether genetic/genomic testing has been undertaken. Travel insurance is a type of General Insurance, and therefore does not come under the guidance of the Financial Services Council and the Financial Services Council Moratorium (because it is not a life insurance product).

C. Sickness and Personal Accident Policies

These insurance policies are usually renewable, often annually, unlike life insurance policies. At every renewal period, you must tell the insurer of any information that you now have, including any change in genetic information (family medical history or genetic/genomic test results). Sickness and Personal Accident insurance are classed as types of General Insurance.

INSURANCE POLICIES THAT DO NOT ASSESS YOUR RISK

A. Private health insurance

See above

B. Group insurance (often obtained through superannuation plans)

Life insurance cover for a limited amount (up to a predetermined limited level) might be available, for example, as part of a superannuation plan. This is called 'group insurance'.

As group insurance provides a limited cover, no individual or family health information or genetic/genomic testing results is requested. A number of life insurance products can be obtained via this insurance option for most employees in Australia.

Your employer might be able to assist you with this. Eligibility to obtain such insurance requires you to be working and carrying out your usual duties at the time of the application. If you are a sole proprietor of a business, you should consult your insurance broker or agent for advice.

If you leave your employer and your group insurance cover is still in place, you should talk to your current and prospective employer about your options with regard to carrying your insurance cover into your superannuation plan with your new position.

If you need or want life insurance for a higher amount, the requirements for application outlined above for policies from life insurance companies apply.

GENETIC/GENOMIC TESTING IN RESEARCH PROJECTS

The Moratorium applies equally to research and other genetic tests, unless you are not going to get the test result.

Below are several scenarios of how a genetic research project could be conducted and whether or not you need to disclose that you have had the genetic test.

1. You will not receive any personal or family information from the research.

You do not need to disclose that you have had the genetic/genomic test.

2. You will not be given a personal genetic test result but you might be contacted by the researchers at a later date and told that the research has indicated that a family test result could be important to your future health.

If you have not been contacted at the time of application, you do not need to disclose that you have had the genetic test as you do not know of any personal result.

If, however, at the time of application you have been advised that there is an opportunity to look into options further through a specialist service, you are now aware of a matter that an insurer might consider relevant, and are therefore expected to disclose the information in an application for a policy.

If you choose to undergo a further genetic test in a clinical setting, obligations to disclose any new information that you now have will apply above the financial limits set.

3. You will receive a personal result from the research

This is treated as no different to having the test done in a clinical setting. Your life insurance company must not use your genetic test results (up to the financial limits set above) unless you choose to declare them.

DEALING WITH INSURANCE COMPANIES

If the insurance company is a member of FSC, it will be bound by the FSC standards described above. If you receive an offer at a non-standard rate, the insurer is required under the Life Insurance Code of Practice to provide the reason/s for the decision.

If, however, this has not been provided and you think that the risk assessment has been inappropriate or has not taken into account any preventive strategies or treatment you are

doing, you may contact the insurance company's underwriter and request a reason for the decision in writing. A genetics specialist may be able to explain the reasons for a decision, and if necessary might discuss the decision with the company's Chief Underwriter or Chief Medical Officer.

If advised by an agent/broker that an insurance offer might be declined, deferred, offered at non-standard rates or impacted on the basis of a particular genetic test result, you may check that this advice was received from the company's underwriter in writing and request a copy.

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). Alternatively, assistance can be sought from the [Australian Financial Complaints Authority](#), the [Australian Human Rights Commission](#), and the Courts.

Involve your family doctor, medical or genetics specialist if necessary, in negotiations with the insurance company. Document your screening, treatment and preventive health strategies, where applicable.

The Centre would like to thank Associate Professor Kristine Barlow-Stewart for providing expert guidance on the content of this fact sheet following consultation with the Financial Services Council (FSC) July 2019.

You can find more about the underlined topics by following the links in the online version of this document. Go to www.genetics.edu.au/FS20 for an online and downloadable copy.

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Consumer Information Sheet

Genetic variant of unknown significance

This leaflet is for people who had a genetic test, and the genetic test found a variant of unknown significance, also called a variant of uncertain significance or VUS.

Genetic testing is done to answer certain questions. Two common questions are

- > Does my condition have a genetic cause?
- > Can my relatives inherit my condition?

Unfortunately, genetic testing cannot always answer these questions.

DNA and genes

The human body is made up of millions of cells. Each cell contains DNA. DNA spells out the genetic instructions (genes) the cells need. Some genes tell cells how to grow, divide and work properly. Some genes help keep DNA healthy. DNA is spelt out by the 4 'letters' of the genetic code (A, T, C and G).

DNA variation

Every person's DNA has many genetic differences or variations.

- > Most genetic variations are harmless. They do not cause a genetic condition or health problem. They are called normal variants.
- > Some genetic variations change how a gene works and cause a genetic condition or health problem. There are many names for this type of variant. The names include disease-causing variant, pathogenic variant, mutation, genetic error and genetic fault.
- > Some variants are not understood yet. They are called variants of unknown significance or VUS. We all have thousands of VUS, but we do not know about them unless we have a genetic test.

What does a VUS mean?

A VUS is neither good nor bad. Its meaning is just not known yet.

What does a VUS mean for a person's medical care?

A VUS result cannot be used to make medical decisions. Medical care is based on other factors. These include a person's medical and family history, and the results of other (non-genetic) tests.

Sometimes more testing can help to understand the meaning of a VUS. This is why people with a VUS should see a genetic health specialist.

Science is changing fast. With time the meaning of a VUS may become known. People should regularly ask their doctor if more has been learned about their VUS (usually every 3-5 years).

Where can I get more information or support?

- > Adult Genetics Unit, Royal Adelaide Hospital Tel: 08 7074 2697
- > Centre for Genetic Education <http://www.genetics.edu.au>
- > Genetics Home Reference <https://ghr.nlm.nih.gov/primer>

The information contained within this publication does not constitute medical advice and is for general information only. Readers should always seek independent, professional advice where appropriate.

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Consumer Information Sheet

Talking to family and friends about your test result

This leaflet has been written for people who have had genetic testing for inherited variants in cancer genes. The leaflet does not replace a face-to-face discussion with a healthcare professional.

After getting your genetic test result you may decide to tell family members or friends about your result. People often struggle with the where, when, and how to share important information with family members, especially their children. This can be even harder when talking about potentially upsetting issues like genetic test results.

People may experience a range of emotions. They may want to 'spare' their relatives or children from the pain of difficult information or they may fear how relatives will react to and cope with information about increased cancer risk.

Not telling does not change the reality of the situation. In fact, it makes family members powerless to make informed choices about their own current and future plans.

Friends and family members may have an unwelcome reaction to your news. This is often because of lack of knowledge and understanding about inherited risk. They may express different opinions about decisions you make, which can be difficult.

It is important to take care of your own needs and remember that decisions about genetic risk are very personal and may be approached differently by each person.

Talking to young children

Parents may fear telling their children about an inherited risk that may have a detrimental effect on their lives. However, being aware of the situation allows children to cope more effectively. Having knowledge will also help them with future decision making.

Children can be very perceptive. They may already be aware of the family history and be frightened for their parents or themselves. Children are often aware of tension and anxiety within the home. These tensions and anxieties may increase when a relative or parent is unwell or when that person is making difficult decisions around genetic testing.

Sometimes children use their imagination to try and make sense of a change in the adults around them. If their questions are answered in a supportive, loving, open and honest way a lot of their fears and anxieties will be addressed. If they feel listened to and understood they will also feel comfortable to ask more questions as they arise.

Relationships between parents and children can suffer if a parent is trying to hide information. Research has shown many people who are not told about genetic risk before reaching adulthood feel angry and resentful that information was kept from them.

Talking to teenagers

Teenagers are at a difficult developmental age. During this life stage, teenagers start building more relationships outside of the family and press their parents for greater independence. Their emotional and cognitive maturity is also developing. This means that a teenager's response to difficult information may vary from being child-like to being adult-like. This is normal for a teenager but can make communication more complicated.

You will have already talked to your child about difficult issues as they were growing up (e.g. "the birds and the bees"). Draw on what has worked before and recognise that you already have skills that will help you to talk to your teenager about inherited risk.

Consumer Information Sheet

Your family situation is unique. Your teenager may already be aware of the family cancer history and be thinking about what this may mean for them in the future or for other relatives. Talking to your teenager may give you a chance to find out what thoughts and feelings your teenager has and to correct any misinformed beliefs.

As a parent you know your child or teenager best. You will know how they deal with new and potentially distressing information. You need to feel comfortable about speaking to them. You also need to be prepared for questions when you least expect them. If you do not know the answers to their questions, be honest and say so, but be prepared to look for answers with your child.

Some practical suggestions from other parents

A recent research paper¹ asked parents what advice they would give other parents who need to talk to their children about an inherited gene variant in the family. They emphasised the importance of preparation and careful consideration before deciding when and how to speak to their child.

The parents in the research study suggested:

- > Parents consider many things including
 - their child’s maturity, level of anxiety, and awareness of genetics
 - the family history of illness and any current stressful issues in the family
 - their child’s level of concern for their parent who has the gene variant
- > Parents be conscious of their own reasons for telling their child, think about their own wishes and hopes about the process and outcome of telling.
- > If parents decide to tell, discuss the setting and timing of telling.
- > For couples, consider if it is okay for one parent to do the telling on their own if an appropriate time unexpectedly arises.
- > Discuss the actual words to use to convey the information (the parents in the research study felt that this was where the most help was needed).
- > Think about if it would be useful to have help from friends, relatives or professionals.
- > Recognise that you don’t need to tell each child everything at the first discussion; it is important to wait for reactions and answer questions.
- > Remember the most important outcome is to keep communication open so fears and misconceptions can be addressed.
- > Know that most parents find telling a relief.
- > If parents decide not to tell they suggested planning for when and how to convey the information in the future.

Extra support

The staff of the Adult Genetics Unit can help you and your family work through how to speak to children and other relatives.

- > Adult Genetics Unit, Royal Adelaide Hospital
Telephone: 08 7074 2697, Email: adultgenetics@sa.gov.au

1. Reference: Talking to Children About Maternal BRCA1/2 Genetic Test Results: A Qualitative Study of Parental Perceptions and Advice. Patenaude et al, J Genet Counsel 2013;22:303-314

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Coping strategies for people with a cancer gene variant

This leaflet has been written for people who have had a cancer gene variant found on genetic testing. It does not replace the need for a face-to-face discussion with an experienced genetic professional.

Being identified as having a cancer gene may be unexpected and many people will require a period of psychological adjustment. Repeated readjustment may be needed at different times in life as a person's circumstances change.

Coping is the attitudes and behaviours people use to meet goals and challenges in their life, and to promote emotional well-being. Different people use different coping strategies and people may use different strategies at different times in their life. Below are some attitude and behaviour strategies you can consider:

Attitudes

Challenge negative and unhelpful thoughts

- > Try to disengage the gene from the cancer diagnosis, remember one does not always equate to the other
- > Recall the reasons you undertook genetic testing
- > Acknowledge the feelings behind negative thoughts and give yourself permission to have an "off" day

Find positives

- > The results might present a new opportunity for cancer treatment
- > You may have more cancer screening or prevention opportunities
- > Remember genetic information may be valuable information for your family members that could reduce or prevent cancer

Maintain self-esteem

- > Create time to pursue activities or hobbies you enjoy and time to relax
- > Reduce the expectations you place on yourself

Reduce stress in your life

- > Try to keep positive
- > Accept there are things you cannot control
- > Be assertive (not aggressive)
- > Exercise, eat well, rest and sleep

Take it one day at a time

- > Focus on what you can achieve today rather than challenges that may lie ahead
- > Don't let your enjoyment of the present be ruined by worrying about the future

Behaviours

Establish a plan

- > Set dates for follow up with your specialist
- > Discuss the treatment or surgical options with your specialists

Find different ways to manage anxiety

- > Hyper-vigilance or heightened anxiety will usually reduce over time
- > Remember today's feelings won't be forever

Consumer Information Sheet

Develop a positive therapeutic relationship with your doctors

- > Ensure decision-making is shared
- > Build a relationship based on trust and confidence
- > Be prepared to seek a second opinion

Adopt a participatory stance

- > Asking questions and discussing options may help you feel more in control
- > Be aware that avoidance is a tricky long-term strategy

Timing is everything

- > Tell people about your test result when you are ready
- > Draw boundaries you are comfortable with

Support

Express your emotions

- > Find an outlet for your feelings
- > Use a professional or “outside” person if you want to protect people close to you or avoid over-burdening them

Reach out for support

- > Use friends or family to accompany you to difficult appointments
- > Find others in similar circumstances (support groups, peer support or web sites)

Relaxation Exercises

2 minute relaxation. Switch your thoughts to yourself and your breathing. Take a few deep breaths, exhaling slowly. Mentally scan your body. Notice areas that feel tense or cramped. Loosen up these areas, letting go of as much tension as you can. Rotate your head in a smooth, circular motion once or twice. (If any movement causes pain, stop immediately). Roll your shoulders forward and backward several times. Let all your muscles completely relax. Recall a pleasant thought for a few seconds. Take another deep breath and exhale slowly. You should feel relaxed.

Mind relaxation. Close your eyes. Breathe normally through your nose. As you exhale, silently say to yourself the word “one”, a short word such as “peaceful”, or a short phrase such as “I feel quiet”. Continue for 10 minutes. If your mind wanders, gently remind yourself to think about your breathing and your chosen word or phrase. Let your breathing become slow and steady.

Deep Breathing Relaxation. Imagine a spot just below your navel. Breathe into that spot and fill your stomach with air. Let the air fill you from the navel up. Let it out, like deflating a balloon. With every long, slow breathe out, you should feel more relaxed.

The staff of the Adult Genetics Unit are available to answer your questions or to help you and your family adjust to learning about a cancer gene variant.

- > Adult Genetics Unit, Royal Adelaide Hospital Tel: 08 7074 2697
- > Pink Hope <https://www.pinkhope.org.au/>
- > Lynch Syndrome Australia <https://lynchsyndrome.org.au/>

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Consumer Information Sheet

Emotional responses following genetic testing

This leaflet has been written as an aid for people who have had genetic testing in the cancer setting. The leaflet does not replace a face-to-face discussion with an experienced health professional.

Genetic testing for a familial predisposition to cancer can raise complex emotions. These feelings can occur when the test is done, while waiting for the results, or when you receive the result. Sometimes these feelings can occur later (days, weeks, or months) after you received your test results.

Of course, not everyone has such thoughts and feelings. Everyone is different and everyone's experience is different.

This leaflet briefly outlines the range of emotions some people experience so you can be prepared. Expressing these feelings and talking them through with a family member or friend can help. You can also seek professional support.

Waiting for the test result

Many people find waiting for the test result is stressful.

- > During the wait it is sensible to be kind to yourself and recognise that you are in an unusual situation. Genetic testing is not commonplace and may be an experience many of your friends, acquaintances or colleagues cannot easily relate to.
- > If you find that you are "obsessing" about the result and the "what ifs", try writing down the concerns and questions you have, so you can bring them up with your doctor.
- > During the wait for your result try to do activities that you find enjoyable and may take your mind off the waiting.

If you have a cancer gene variant

People who are found to have a cancer gene variant may experience fear, anxiety, sadness, and powerlessness. There may also be a sense of anger.

Some people also experience distress in the form of intrusive thoughts about their health. They may dwell on the result, have recurrent thoughts, or think about it when they don't mean to.

On the other hand, some people are relieved that the uncertainty has been resolved and they may be able to access more or different treatments options. There can also be a heightened sense of being in control.

These thoughts and feelings may fluctuate from time to time, with marked "highs" and "lows" that do not seem to make sense. They may also be emphasised at special times such as anniversaries or if another family member becomes unwell.

Consumer Information Sheet

If you do not have a cancer gene variant

People who do not have a cancer gene variant found may have a sense of relief upon receiving their test result. This result may be good news for their family and help reduce worry.

However, some people feel disappointed they do not have a cancer gene variant, as this may reduce or change the treatment options available.

Some people experience both types of emotions. These emotions can be puzzling and distressing but are normal.

Responses in the families

Other members of your family may not feel the same way before and after the test result as you did. Everyone is different and there is no “right” way to respond to having a genetic test.

You may find other family members have significant emotional responses to your test result. For example, a parent may feel anxious or guilty if their child has a gene variant. These are common responses. It is important to be open, supportive, and respectful of other family members responses.

Preparing for your result

People who prepare for how they might feel when they get their test result and who talk openly about this seem to cope better with learning that they have a gene variant.

In addition, having a plan of what steps to take if a gene variant is found helps many people to feel more in control and less anxious.

Extra Support

Remember there are genetic counsellors who can provide you with advice and support throughout the process of genetic testing and adjusting to your result.

If you have questions or concerns, or you would like extra support you can discuss your worries with your specialist, family doctor (GP), or contact the Adult Genetics Unit.

Knowing there are other people experiencing similar things can also be helpful and online groups may also provide extra support.

- > Adult Genetics Unit, Royal Adelaide Hospital Tel: 08 7074 2697
- > Pink Hope <https://www.pinkhope.org.au/>
- > Lynch Syndrome Australia <https://lynchsyndrome.org.au/>

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