



# Understanding genetic tests for Lynch syndrome

Information and decision aid

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## Who is this booklet for?

This booklet is for anyone thinking about having genetic testing for a rare group of cancers called Lynch syndrome. This syndrome is caused by a fault in genetic information resulting in a high risk of bowel cancer and some other cancers.

Lynch syndrome was previously known as hereditary non-polyposis colorectal cancer (HNPCC).

The information is not a replacement for discussing genetic testing with your doctor or family cancer service. Only some sections might be useful to you. This booklet combined with information from health professionals will assist you in making a decision that is right for you.

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## Genetic testing might be suitable if your family includes one or more of the following:

- A genetics specialist has suggested genetic testing might be helpful in your situation
- Tumour test results suggest that there might be a fault in a Lynch syndrome gene
- You have had two or more separate cancers as below:
  - bowel cancer
  - endometrial cancer (cancer of the uterus)
  - ovarian cancer
- A blood relative has had a genetic test revealing a faulty Lynch syndrome gene
- You do not have a Lynch syndrome cancer but have three relatives on the same side of the family in at least two generations who do
- You do not have a Lynch syndrome cancer but have two relatives on the same side of the family in at least two generations who do – one of which has had Lynch syndrome cancer before the age of 50 OR has had multiple Lynch syndrome cancers.

Cancers included in Lynch syndrome are listed P7.

These checkboxes are only a guide. It is recommended that you discuss your family's suitability for genetic testing with a genetics specialist.

# About Lynch syndrome

Cancer is common in Australia. Many families include one or more people who have had bowel or other cancers.

When cancer occurs among siblings or in a number of generations, this is called a family history of cancer.

## Why do I have a family history of cancer?

There are three reasons why you might have a family history of cancer:

### 1. Just by chance

Cancer is a common disease. This means that many people have several people in their family who have developed cancer.

### 2. Environmental factors

Many families live in similar environments and share similar diets and lifestyles. These non-inherited factors could influence the chance of developing cancer.

### 3. Inherited factors

We inherit genetic information from our parents and pass it on to our children.

Inherited genetic information can play a role in the small number of families with a history of cancer, as occurs with Lynch syndrome.



## Lynch syndrome cancers

People affected by Lynch syndrome have a higher risk of bowel cancer and some other cancers listed in the table below.<sup>1</sup> The cancers shown in bold are the most common.

Men with Lynch syndrome are at <b>high</b> risk of developing:	<b>large bowel cancer</b>
Women with Lynch syndrome are at <b>high</b> risk of developing:	<b>large bowel cancer</b> <b>*endometrial cancer</b> ovarian cancer
Men and women have an increased risk of developing:	cancers of the stomach, small bowel, kidney, brain, pancreas, ureter (tube from kidney to bladder)

\*Cancer of the endometrium (lining of the uterus) can occur almost as often as bowel cancer in families with a history of Lynch syndrome cancers.

### How are Lynch syndrome cancers managed?

Early signs of bowel cancer can be detected by a colonoscopy that looks for polyps in the bowel. Polyps are small, usually non-cancerous growths in the bowel that can become cancerous over time. Removal of polyps can prevent most bowel cancers linked with Lynch syndrome.

Screening and strategies to reduce the chance of developing other Lynch syndrome cancers are explained in more detail P34.

## Cancer and our genes

Our genetic information provides instructions for growth and development and is in the form of many thousands of different genes including cancer protection genes.

Some cancers occur when cells grow out of control in a particular part of the body and a lump might be the first sign of cancer.

Cancer protection genes stop cells from growing out of control.

Variations in genes are common and can:

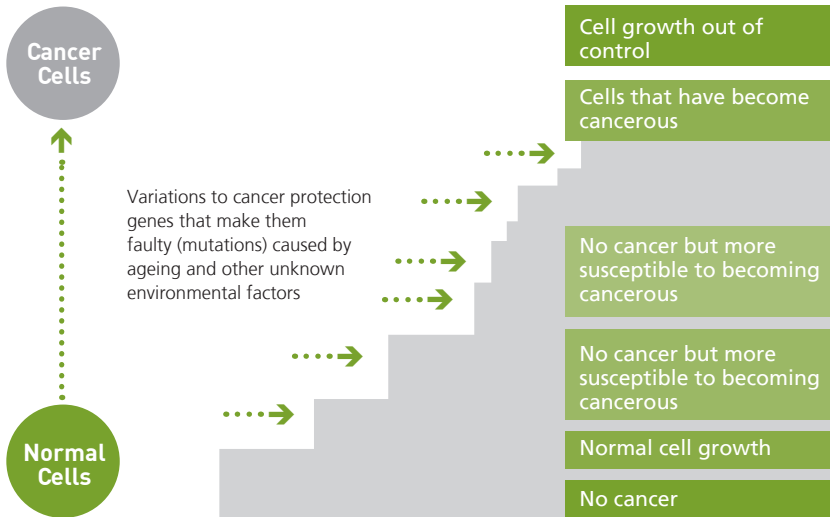
- occur when genes are copied for the growing of new cells and tissues
- be caused by environmental factors
- happen as we age
- be inherited from our parents.

Most variations do not cause problems for growth and development.

However, occasionally, variations in cancer protection genes cause faults that could lead to cancer. Faults in genes are called mutations.

As we age, faults in cancer protection genes increase. This is why we are more susceptible to cancer later in life.

As shown in the diagram below, each short arrow indicates a new fault in different cancer protection genes over time. A cell becomes cancerous when too many cancer protection genes become faulty.



It takes a long time for enough faults to build up in different cancer protection genes and cause cancer.

In fact, enough faults might never build up and cancer might never develop.

## Lynch syndrome and faulty genes

Four faulty cancer protection genes called MLH1, MSH2, MSH6 and PMS2 are known to cause Lynch syndrome cancers.

### Inheriting a faulty cancer protection gene




Most people are born with **two working copies** of each gene in every cell - one copy from their mother and one from their father.



Rarely, people might be born with **a faulty copy** of a cancer protection gene inherited from either their mother or father. The working copy provides protection against cancer even though the faulty gene copy does not work properly.

**Key**  working copy of a cancer protection gene for Lynch syndrome

 faulty copy of a cancer protection gene for Lynch syndrome

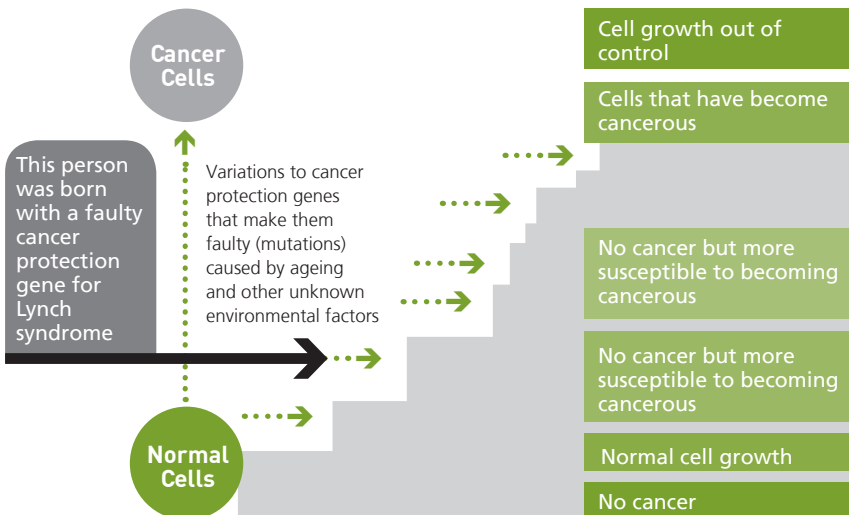
Both men and women can inherit a faulty Lynch syndrome gene. They then have a 50% chance (1 in 2) of passing it on to each of their children.

## If you have inherited a faulty gene for Lynch syndrome

As shown in the diagram below, if you have inherited a faulty Lynch syndrome gene, you are at the level of the black arrow.

You are already on the path that could lead to a cell becoming cancerous. This means you have an increased chance of developing a Lynch syndrome cancer.

Nevertheless, because faults in other cancer protection genes take time to build up, you might still never develop a Lynch syndrome cancer.



## **Bowel cancer and endometrial cancers that are caused by faulty Lynch syndrome genes**

The exact chance of developing bowel or endometrial cancer for people who have a faulty Lynch syndrome gene is not certain. The graphs on the following pages show estimates from a recent scientific study.<sup>2</sup>

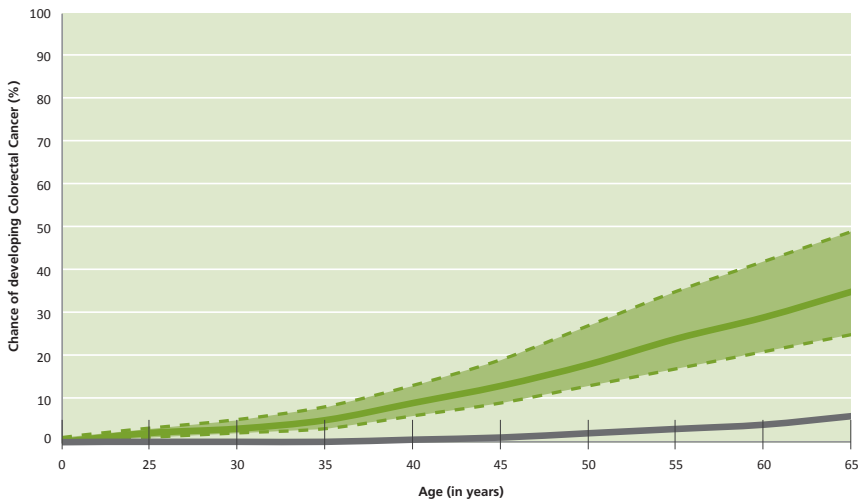
Depending on the particular gene that is faulty, your chance of developing cancer might be higher or lower than these estimates. Faulty MLH1 and MSH2 genes are associated with the highest chance of developing cancer.

With regular colonoscopy and removal of polyps the chance of developing bowel cancer can be as low as that of most people in the general population.

Men have a slightly higher chance of developing bowel cancer than women with Lynch Syndrome.

If you have had bowel or other Lynch Syndrome cancers previously you have a higher chance of developing another cancer.

## The lifetime chance of developing bowel (colorectal) cancer for people with Lynch syndrome



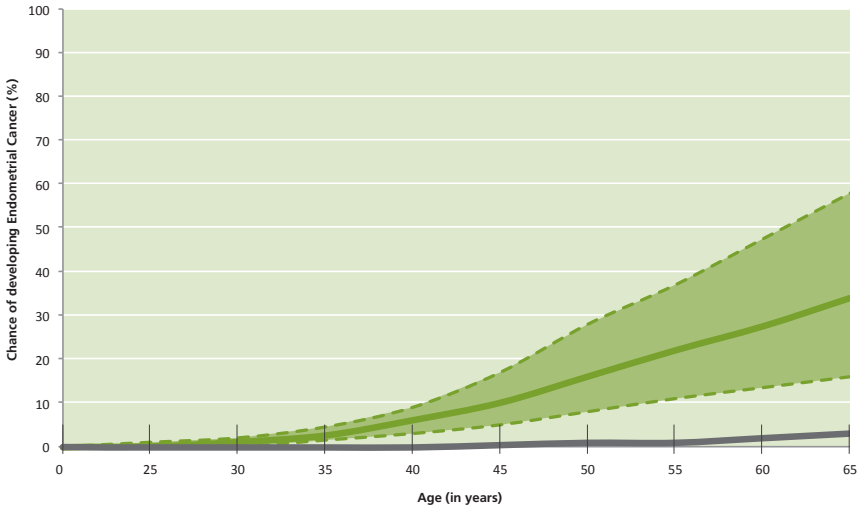
● Men & Women with a faulty Lynch Syndrome gene

● Most people in the general population

### The average age when bowel cancer develops is:

- about 45 years<sup>3</sup> for people with a faulty Lynch syndrome gene
- about 69<sup>4</sup> years for the general population

# The lifetime chance of developing endometrial (uterine) cancer for women with Lynch syndrome



● Women born with a faulty Lynch syndrome gene

● Most women in the general population

## The average age when endometrial cancer develops is:

- about 42-49 years<sup>4,6</sup> for women with a faulty Lynch syndrome gene
- about 64 years<sup>4</sup> for most women in the general population



## Genetic tests for Lynch syndrome

Two types of tests are currently available.

### Mutation search

A mutation search is a blood test that searches for a faulty cancer protection gene that is running in a family. It is the first type of test for a family with suspected Lynch syndrome cancers. A result for a mutation search may take up to 12 months. See P16 for information about the mutation search.

### Predictive test

A predictive test searches for a previously detected family-specific faulty gene in blood relatives, whether or not they have had a suspected Lynch syndrome cancer. A result for a predictive test can be obtained in a shorter time frame. See P25 for information about the predictive test.

# Mutation search. A genetic test for a faulty cancer protection gene

A mutation search attempts to find the faulty gene causing cancers in your family.

In most families, a person who has had a suspected Lynch syndrome cancer is the best person for a mutation test.

## Mutation search

Your doctor or family cancer team will be able to tell you if a mutation search is suitable for you.

Some families will be offered tumour testing as a starting point. Tumour testing looks for signs indicating Lynch syndrome cancers and could also assist the mutation search.

You could be offered a mutation search if:

- you have had a suspected Lynch syndrome cancer and have a family history of Lynch syndrome cancers
- tumour testing indicates a possible Lynch syndrome cancer
- rarely, you have not had cancer but might have had a parent or sibling and a child with a suspected Lynch syndrome cancer.

## Why might I consider this type of test?

Finding out that you have a faulty Lynch syndrome gene:

- will give you more accurate information about your chance of developing another cancer
- could influence your decisions about cancer screening, prevention and management
- could also help clarify who in your family could have a higher chance of developing a Lynch syndrome cancer
- makes it possible to offer a predictive test to blood relatives (Predictive testing P25).

## Mutation search: possible test results

There are three possible test results from a mutation search:

### 1) Inconclusive (a gene fault was not found)

Many families receive this result. However, this result is inconclusive as there might still be a faulty gene causing cancer in your family. If you receive this result:

- It was not possible to find a fault in your Lynch syndrome genes.
- You might still have an increased chance of developing another cancer because of your family history of cancer. You need to continue cancer screening and management as if you haven't had the test. See P34.

Why might you receive an 'inconclusive' result?

- Your family might carry a fault as yet unknown.
- Current technology cannot find all of the faults in genes.
- Your family history of cancer might be due to a combination of many factors (both genetic and environmental), but not Lynch syndrome.

If you receive an inconclusive result, other members of your family cannot be offered a predictive test.

## 2) A faulty gene was found

A faulty gene is found in about 20-50% of the families who have a mutation search for Lynch syndrome.

If you receive this result:

- You have inherited a faulty gene that is likely to be causing the cancer in your family.
- You have an increased chance of developing more than one of the Lynch syndrome cancers. Screening and other health management strategies are explained in more detail P34.
- Your results will tell you which of your Lynch syndrome genes is faulty. Different faulty genes have different effects.
- If you are a woman you have an increased chance of developing endometrial cancer.
- Each of your children has a 50% chance of inheriting your faulty Lynch syndrome gene copy (1 in 2 chance). They also have a 50% chance that they will inherit your working gene copy (1 in 2 chance).
- Blood relatives can choose to have a predictive genetic test and find out if they have inherited the family-specific faulty gene (Predictive testing P25).

### 3) Unclassified variant

If you receive this result:

- The mutation search has found a variation in a Lynch syndrome gene but it is not currently clear whether the variation is harmless or if it makes the gene faulty.
- You could still have an increased chance of developing another cancer because of your family history. You need to continue cancer screening and management as if you haven't had the test. See P34.
- Predictive testing is not possible for other members of your family.

# The mutation search process

## Start

You have already had a Lynch syndrome cancer and have a strong family history of the cancer.

Or tumour tests indicate a possible Lynch syndrome cancer.

Or rarely, you might not have had a Lynch syndrome cancer but have a parent and a child who has.

Talk to a genetic counsellor or the phone

Attend genetic counselling at a family cancer service

**Take time to make your decision**

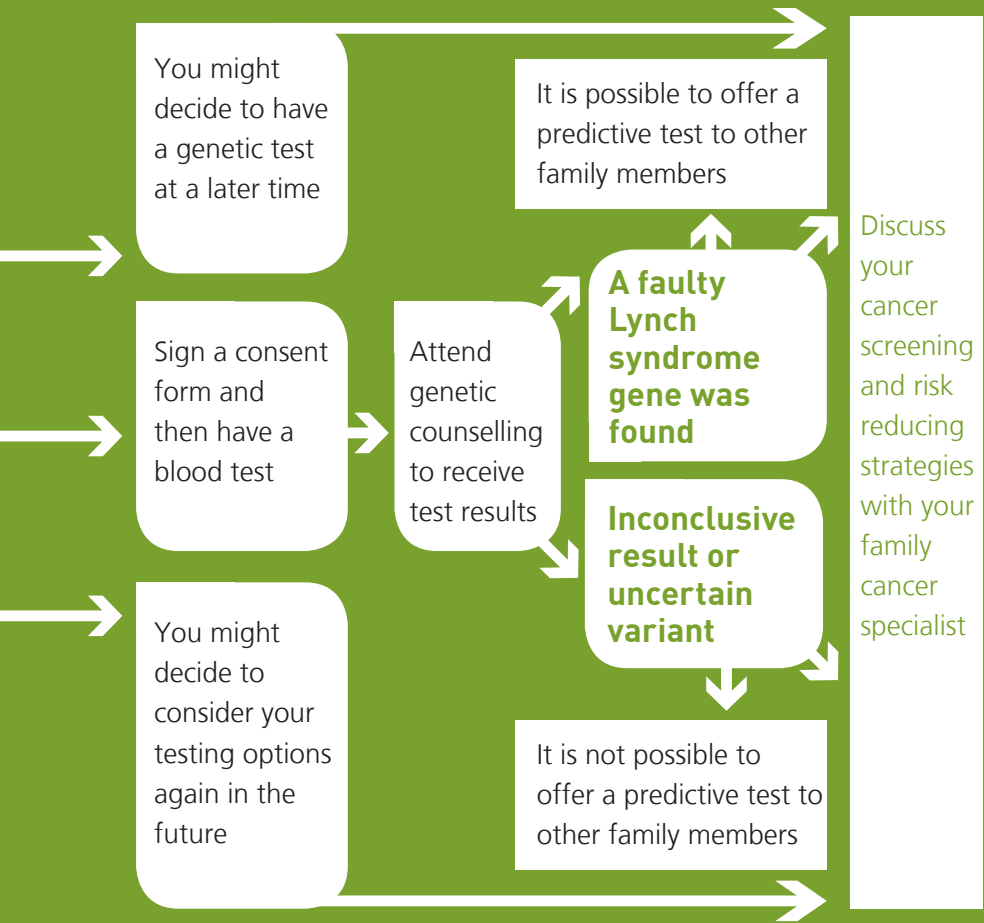
Your decision might be...

'No' to the test

'Yes' to the test

Defer the decision





## **The impact of a mutation search on you**

### **Waiting time**

You might feel frustrated or disappointed by the length of time it takes to receive a mutation search result. There is a lot of information in the Lynch syndrome genes. The laboratory work can sometimes take a long time.

### **An inconclusive or uncertain variant result**

It can be frustrating to receive this result, generally because you do not know what has caused your family history of cancer.

You might feel some relief after this result, even though you might still have an increased chance of developing further cancer.

This result also means other family members cannot have a predictive genetic test.

### **A faulty gene was found result**

This result could cause an increase in worry or anxiety about developing another cancer. Research has found that for women who have had genetic testing, anxiety usually lessens over about 12 months to the level that is normal for them.<sup>7</sup> However people often continue to feel anxiety leading up to regular screening appointments.

You might feel less anxious after this result because you understand the cause of cancer in your family and can plan future health management. You might be glad other family members now have the option of a predictive test.

# Predictive test. A genetic test for the family-specific faulty gene

A predictive genetic test is for blood relatives and searches for the previously found family-specific faulty gene.

Blood relatives may or may not have had a Lynch syndrome cancer themselves. Your doctor or family cancer service will be able to tell you if a predictive test is suitable for you.

## Why might I consider a predictive test?

If you learn that you have inherited a faulty Lynch syndrome gene:

- you can make more informed decisions about managing your future chance of developing Lynch syndrome cancer, including screening and cancer prevention strategies
- your adult offspring might wish to investigate testing.

If you learn that you have not inherited the family-specific faulty Lynch syndrome gene:

- you do not have an increased chance of developing cancer. Your chance of developing cancer is the same as other people in the general community
- you and your children could avoid the extra anxiety and cancer screening necessary for members with a family history.

## The predictive test: possible test results

There are two possible test results from a predictive test.

### The family-specific faulty gene copy was not found

If you receive this result:

- you have not inherited the faulty copy of the gene known to be in your family

- you do not have an increased chance of developing a Lynch syndrome cancer. Your chance of developing cancer is the same as that of other people in the general community
- you cannot pass a faulty copy of the gene found in your family on to your children. This means your children do not have an increased chance of developing a Lynch syndrome cancer.

### The faulty gene was found

If you receive this result:

- you have inherited the faulty copy of the gene that was found in your family
- you have an increased chance of developing bowel cancer and other Lynch syndrome cancers. Screening and other health management strategies are explained in more detail P34
- if you are a woman you have an increased chance of developing endometrial cancer
- each of your children has a 50% chance of inheriting your faulty Lynch syndrome gene (1 in 2 chance). They also have a 50% chance of inheriting your working copy (1 in 2 chance).

# The predictive test process

**Start**  
Your family has a history of Lynch syndrome cancers.  
Testing of a close blood relative has identified the family-specific faulty gene that is likely to be causing the cancers in your family.

Talk to a genetic counsellor on the phone

Attend genetic counselling at a family cancer service

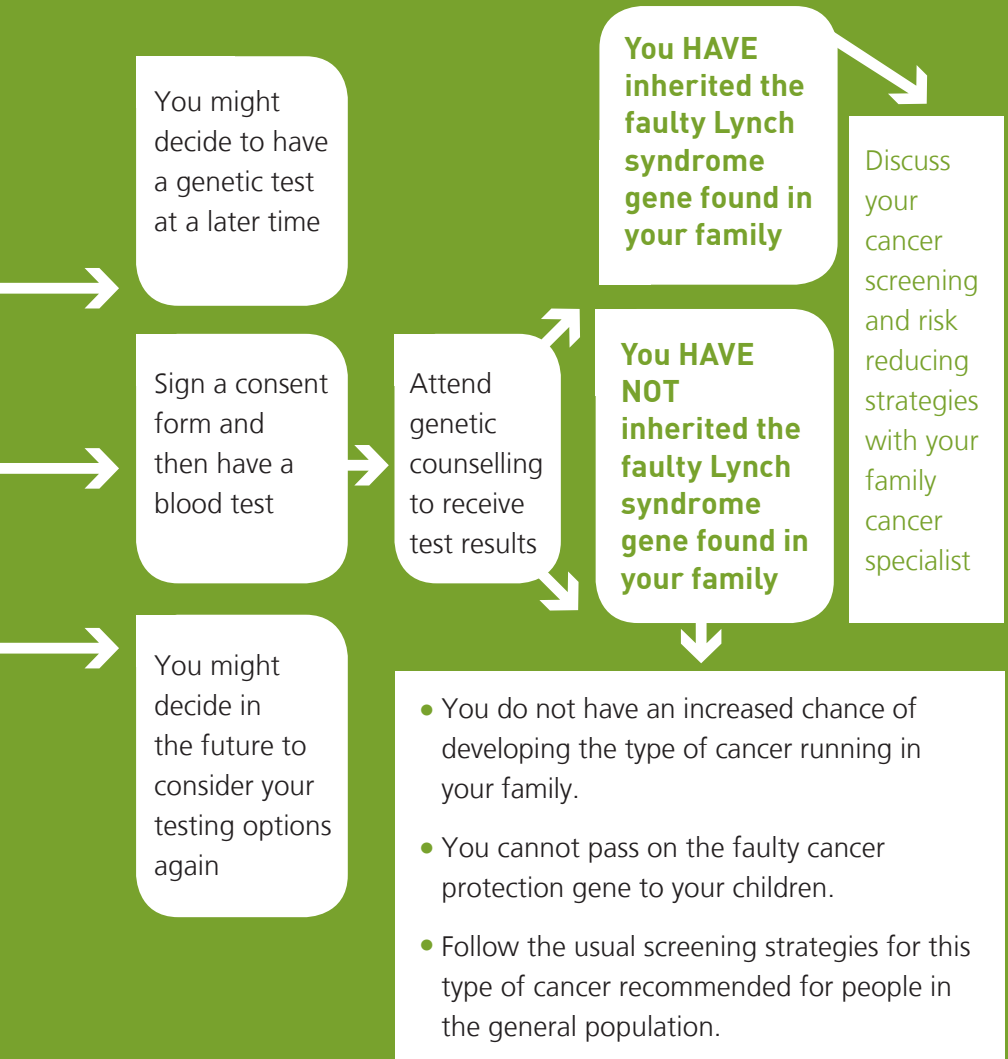
**Take time to make your decision**

Your decision might be...

'No' to the test

'Yes' to the test

Defer the decision



You might decide to have a genetic test at a later time

Sign a consent form and then have a blood test

You might decide in the future to consider your testing options again

Attend genetic counselling to receive test results

**You HAVE inherited the faulty Lynch syndrome gene found in your family**

**You HAVE NOT inherited the faulty Lynch syndrome gene found in your family**

Discuss your cancer screening and risk reducing strategies with your family cancer specialist

- You do not have an increased chance of developing the type of cancer running in your family.
- You cannot pass on the faulty cancer protection gene to your children.
- Follow the usual screening strategies for this type of cancer recommended for people in the general population.

## **The impact of a predictive test on you**

### **Waiting time**

It takes about four to six weeks for the predictive test result to be available.

The laboratory staff will only test for the specific gene fault previously identified in the family.

### **Your family's faulty gene was not found in you**

If you receive this result you might feel relieved that you and your children do not have an increased chance of developing a Lynch syndrome cancer.

If you do not receive the same result as other family members, you might find it difficult because you cannot share their experiences.

### **Your family's faulty gene was found in you**

This result could cause an increase in worry about developing cancer in the future. Research has found that for women who have had genetic testing, anxiety usually lessens over about 12 months to the level that is normal for them.<sup>7</sup> However people often continue to feel anxiety leading up to regular screening appointments.

You might feel less anxious after you receive this result because you have a better idea of your chance of developing cancer and can plan future health management.



# Other information about genetic testing

- How might my result affect my family?
- What about my children and future children?
- How could my genetic test result affect my health management?
- How could my result affect my finances?

## How might my result affect my family?

Sometimes the process of having a genetic test can bring families closer together. Sometimes it can lead to disagreements.

Your genetics specialist can help you decide on how best to talk to your family about this information. It is important to remember that your genetic testing experience could give information to others in your family who could have a higher chance of developing cancer.

### Different choices

Each person in a family has the right to make the decision that is best for them about genetic testing. However, it can be difficult for other family members to accept these decisions.

### Different feelings

There is no single set of feelings that everyone considering genetic test experiences.

Partners of people considering genetic testing might find the process difficult too. They could feel left out because they are not blood relatives, and yet the results are important for their children.

### Different results

Sometimes family members who receive the same result will feel closer to each other. Family members who receive different results may feel uncomfortable with each other and find it harder to talk to each other. This is less likely to happen if you talk about it ahead of time.

## **What can I do to avoid family disagreements?**

It might help to think about any potential disagreements in your family ahead of time. Then you can plan the best ways to handle this before deciding about a genetic test.

You might like to consider who, when, and how to tell other people about your genetic testing decision. You might want to choose a support person to share your thoughts and feelings with.

## **What about my children and future children?**

### **If your children are already adults**

You might like to think about what information you want to share with them about your family history of cancer and genetic testing.

You might suggest they visit a genetic counsellor for information regarding the condition. They can then decide whether or not they want to have a genetic test.

Even if they do not want to consider genetic testing, it is important that they are advised to start a screening program at the age of 25.

### **If your children are not adults**

Children are not usually offered predictive genetic testing. This is because even if they have inherited the faulty gene, they do not have an increased chance of developing cancer until adulthood.

## How could my genetic test result affect my health management?

The results of your genetic test could influence the way you manage your chance of developing cancer.

### Your family's faulty gene was not found

You have the same chance of developing cancer as any other person in the general population. Now you only need the cancer screening suggested for any person your age in the general population.

### An inconclusive or unclassified variant result

You need to continue your cancer screening and management plan as if you haven't had the test. You are likely to still have an increased chance of developing another Lynch syndrome cancer due to your family history.

### Your family's faulty gene was found

You have an increased chance of developing cancer compared to the general population. You might want to talk to your doctor about:

- a colonoscopy every 12-24 months that will identify polyps that can be removed from the bowel
- preventative bowel surgery, although there is some disagreement about whether this is necessary
- screening of other organs depending on your family history

- If you are a woman you might also want to consider risk reducing surgery after completing your family. This might include a hysterectomy (surgery to remove the womb) and salpingo-oophorectomy (surgery to remove both ovaries and the fallopian tubes).

For women who do not choose preventative surgery, if an ultrasound shows thickening of the lining of the womb, endometrial sampling (testing of tissue taken from the lining of the womb) is sometimes considered.

- New research trials.

More information about possible options to manage your chance of developing cancer is available from your family cancer clinic or the Centre for Genetics Education (contact details P48).

## How could my result affect my finances?

### Cost of genetic testing

Patients are not usually charged for genetic testing at public hospital family cancer services. Private pathology laboratories usually charge for genetic testing.

## Health insurance

Your genetic testing decision will not affect your health insurance.

## Life insurance including trauma/disability and income protection policies

If you find you have inherited a faulty Lynch syndrome gene you will only have to tell the insurance company your results if you take out a new policy or change your existing policy.

Your results will not affect any life insurance you have secured previous to testing.

The Investment and Financial Services Association (IFSA) have also agreed that its insurance companies will:

- consider the potential beneficial effects of cancer screening or other preventive strategies
- not make someone have a genetic test if they do not want to
- not use one family member's results to assess other family members' policies when applying to the same company
- ensure confidentiality of your results.

FSC: **(02) 9299 3022**

Information is also available from the Centre for Genetics Education. Visit **www.genetics.edu.au** or **(02) 9462 9599**.

# My worksheet. An aid for decision making

There might be lots of reasons why genetic testing is suitable or not for you. Part of making an appropriate decision is to consider all the pros and cons (positives and negatives) of genetic testing.

The worksheets on the following pages are designed to assist you to put all the facts together and consider what is important to you.

You will find two examples of worksheets filled out by others P40 and P42.

## What's important to me?

### Step 1: Clarify the decision

#### What is the decision I face?

"I am deciding whether or not to have a mutation search (or a predictive genetic test) for Lynch syndrome."

What is your reason for making this decision?

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### Step 2: Weighing the options

#### What I know

In the table on P44, please list the pros and cons for you that are associated with genetic testing.

#### What is important to me?

Show how important each pro and con is to you by placing one star (\*) or up to five stars (\*\*\*\*\*) in the columns labelled 'Personal Importance'. More stars show more importance to you. If a pro or a con is not important to you at all, then give it zero stars.

#### How sure do I feel?

See which column has the most stars in it. The side with the most stars is probably the right option for you. Using the scale, tick the box that most closely reflects how you're feeling about a genetic test at the moment.



### Step 3: Plan the next steps

You might like to list here what you need to do before making your decision. You will find a list of helpful contacts at the end of this booklet.

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### Step 4: Questions to ask your doctor

You might like to write down here any questions and take them to your consultation.

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The design of this worksheet is based on the Ottawa Personal Decision Guide, developed by O'Connor, Jacobsen and Stacey. 2002.

## Other people's experiences...

Les has a family history of bowel cancer and has had bowel cancer himself. He completed this worksheet to help him decide whether or not to have a **mutation search**. He listed all the pros and cons he could think of.

Personal importance	Possible pros for having a mutation search*
***	'I can manage my risk of developing cancer.'
***	'I will be able to help my children to make choices regarding their risk.'
*	'I prefer to know things no matter how bad; I don't like mystery or suspense.'
**	'So I can know if I have passed it on to my children.'
*	'I have to be prepared...and not live with "what ifs."'
<b>TOTAL 10</b>	

You might think of other pros and cons that might be more important to you than the ones listed here.

\* Actual quotes from people considering genetic testing for cancer risk during an Australian research project in 2006/07.

This list does not include all the possible pros and cons of a **mutation search** for you.

Possible cons against having a mutation search*	Personal importance
'I am afraid I will get another cancer if I have the faulty gene.'	*****
'It may be worrying for some family members.'	***
'I may worry about the effect of my genetic testing decision on my children in the future.'	***
'May cause arguments with my immediate family, who have different opinions.'	**
'I might not want to know.'	**
	<b>TOTAL 14</b>

At this point in time are you leaning towards wanting to have a mutation search or not? (Tick the box that is closest to how you feel)

I am leaning towards having a mutation search

I am not sure yet

I am leaning towards not having a mutation search

## Other people's experiences...

Myra has a family history of bowel cancer but has not had cancer herself. A faulty gene causing the cancer has been identified in one of her relatives. She completed this worksheet to help her decide whether or not to have a **predictive test**.

Personal importance	Possible pros for having a predictive test*
*****	'I can manage my risk of developing cancer.'
****	'I will be able to help my children to make choices regarding their risk.'
***	'I prefer to know things no matter how bad, I don't like mystery or suspense.'
**	'So I can know if I have passed it on to my children.'
**	'I have to be prepared...and not live with "what ifs."'
**	'If negative, it will assist me in negotiating mortgages and insurance.'
<b>TOTAL 19</b>	


You might think of other pros and cons that might be more important to you than the ones listed here.

\*Actual quotes from people considering genetic testing for cancer risk during an Australian research project in 2006/07.

She listed all the pros and cons she could think of. This list may not include all the possible pros and cons of a **predictive test** for you.

Possible cons against having a predictive test*	Personal importance
'I am afraid I will get cancer if I have the gene fault.'	***
'It may be worrying for some family members.'	**
'I may worry about the effect of my genetic test decision on my children in the future.'	**
'My (future) life insurance premiums might increase.'	**
'May cause arguments with my immediate family, who have different opinions.'	*
'If I am positive, it will force me to look at strategies such as surgery to lower my risk.'	**
'I might not want to know.'	*
	<b>TOTAL 13</b>

At this point in time are you leaning towards wanting to have a predictive search for Lynch syndrome or not? (Tick the box that is closest to how you feel)



I am leaning towards having a predictive search

I am not sure yet

I am leaning towards not having a predictive search

# My worksheet

You might want to use this worksheet to help you to work through your decision about whether to have a mutation search or a predictive test for Lynch syndrome.

Personal importance	My list of PROS for having a genetic test
<b>TOTAL</b>	

List all the pros and cons for you that you can think of and then work out how important they are to you.

My list of <b>CONS</b> against having a genetic test	Personal importance
At this point in time are you leaning towards wanting to have a genetic test or not? (Please tick the box that is closest to how you feel.)	<b>TOTAL</b>

I am leaning towards having a genetic test

I am not sure yet

I am leaning towards not having a genetic test

## Some words used in this booklet

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**Blood relatives** Relatives related to you by birth. They do not include family members related to you by marriage or adoption. First-degree relatives include your parents, brothers and sisters and your children. Second-degree relatives include your grandparents, aunts, uncles, nephews and nieces.

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**Cancer protection genes** are genes that act to prevent cancer developing. Several cancer protection genes have been linked to Lynch syndrome. The main ones are the MLH1, MSH2, MSH6 and PMS2 genes. When they are functioning correctly they help to prevent bowel and other Lynch syndrome cancers.

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**Colonoscopy bowel cancer screening** The inside of the bowel is viewed.

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**Endometrium** Inner lining of the uterus/womb.

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**Family history** Having a family history of cancer means having one or more blood relatives on the same side of the family (either your mother's or your father's side) who have cancer.

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**Genetics team** Your genetics team might include a clinical geneticist or oncologist who has completed specialist training in genetics or cancer medicine after their general medical training. Your team might also include a genetic counsellor who is a university trained health professional with specialist training in counselling and in genetics.

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**Genes** are in every cell in our body. They have the instructions that tell the cell how to build proteins and other products.

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**Faulty genes** do not function correctly and do not give the right instructions to cells for growth and development.

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**Genetic testing** searches for genes for specific faults.

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**Mutation search genetic tests** are usually conducted on a person who has already had cancer. This test searches for the specific gene fault that might be running in a family.

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**Predictive genetic tests** are usually only offered to people who have already had a specific gene fault identified in a blood relative. A predictive test for blood relatives only looks for the family-specific faulty gene.

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**Hereditary cancer** is caused by a faulty gene which can be passed on through generations of a family.

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**Mutations** are variations in a gene that stop it from working properly.

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**Polyps** are small, usually non-cancerous growths that might become cancerous over time.

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**Tumour tests** If Lynch syndrome is suspected in your family, screening tests can be done on tumour tissue from an affected family member.

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## Where to from here?

### Family cancer services

You may have already visited a family cancer service. If not, you may wish to contact one of the family cancer services in your area.

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#### AUSTRALIAN CAPITAL TERRITORY

ACT Genetics Service  
The Canberra Hospital  
GARREN ACT 2605  
Phone: (02) 6174 7630

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#### NEW SOUTH WALES

##### **Camperdown**

Dept of Cancer Genetics  
Royal Prince Alfred Hospital  
CAMPERDOWN NSW 2050  
Phone: (02) 9515 8780

##### **Kogarah**

Hereditary Cancer Clinic  
St George Hospital  
KOGARAH NSW 2217  
Phone: (02) 9113 3815

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##### **St Leonards**

Family Cancer Service  
Royal North Shore Hospital  
ST LEONARDS NSW 2065  
Phone: (02) 9463 1554

##### **Wollongong**

Wollongong Hereditary Cancer Clinic  
Illawarra Cancer Care Centre  
Wollongong Hospital  
Private Mail Bag 8808  
South Coast Mail Centre NSW 2521  
Phone: (02) 4222 5576

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**Newcastle and rural  
outreach services**

Hunter Family Cancer Service  
Hunter Genetics  
PO Box 84  
WARATAH NSW 2298  
Phone: (02) 4985 3132

**Randwick**

Hereditary Cancer Clinic  
Level 2 Prince of Wales Hospital  
High St RANDWICK NSW 2031  
Phone: (02) 9382 2551

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**Darlinghurst**

Family Cancer Clinic  
St Vincents Hospital  
DARLINGHURST NSW 2011  
Phone: (02) 9355 5647

**Westmead**

Familial Cancer Service  
Westmead Hospital  
WESTMEAD NSW 2145  
Phone: (02) 9845 6947

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**Liverpool**

Department of Cancer Genetics  
Liverpool Hospital  
Locked Mail Bag 7103  
Liverpool BC NSW 1871  
Phone: (02) 9616 4475

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**NORTHERN TERRITORY**

Northern Territory Clinical Genetic  
Service  
Royal Darwin Hospital  
TIWI NT 0810  
Phone: (08) 8944 8731

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## QUEENSLAND

### **Brisbane**

Genetic Health Queensland  
Royal Brisbane and Women's Hospital  
HERSTON QLD 4029  
Phone: (07) 3636 1686

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## SOUTH AUSTRALIA

Familial Cancer Unit  
SA Clinical Genetics Service  
Women's and Children's Hospital  
NORTH ADELAIDE SA 5006.  
Phone: (08) 8161 6995

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## TASMANIA

Clinics held regularly at Burnie,  
Launceston and Hobart.  
Tasmanian Clinical Genetics Service  
Royal Hobart Hospital  
PO Box 1061  
HOBART TAS 7001  
Phone: (03) 6222 8296

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## VICTORIA

### **Clayton**

Southern Health Familial  
Cancer Centre  
Special Medicine Building  
246 Clayton Rd  
CLAYTON VIC 3168  
Phone: (03) 9594 2009

### **Parkville**

Familial Cancer Centre  
Royal Melbourne Hospital  
Gratten St  
PARKVILLE VIC 3050  
Phone: (03) 9342 7151

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### **East Melbourne**

Peter MacCallum Cancer Centre  
The Jack Brockhoff Foundation Familial  
Cancer Centre  
10 St Andrew's Place  
EAST MELBOURNE VIC 3002  
Phone: (03) 9656 1199

### **Heidelberg West**

Austin Health Genetic Service  
1<sup>st</sup> Floor Building 6  
Repatriation Campus  
300 Waterdale Road  
HEIDELBERG WEST VIC 3084  
Phone: (03) 9496 3027

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## **WESTERN AUSTRALIA**

### **Subiaco**

Familial Cancer Program  
Genetic Services of Western Australia  
King Edward Memorial Hospital  
Level 3, Agnes Walsh House  
374 Bagot Rd  
SUBIACO WA 6008  
Phone: (08) 9340 1603

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### **Other locations in NSW**

For contact details of genetic  
counselling services in other areas of  
NSW that might also provide cancer  
genetics services, phone the Centre  
for Genetics Education NSW on  
(02) 9462 9599

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## Other helpful organisations

These organisations can provide you with useful support and might be able to send you helpful books and articles. They also have very informative websites.

### Hereditary Cancer Registry

Cancer Institute NSW

PO Box 825

Alexandria NSW 1435

The Hereditary Cancer Registry (HCR) provides information and support to people affected by hereditary cancer syndromes such as Lynch syndrome.

The Cancer Registry has also produced 'A Guide for people with HNPCC (Lynch syndrome) and their family and friends.' It can be found at: [www.cancerinstitute.org.au/media/121946/hnpcc-guide.pdf](http://www.cancerinstitute.org.au/media/121946/hnpcc-guide.pdf)

**Ph 1800 505 644**  
**Fax (02) 8374 5744**  
**[www.cancerinstitute.org.au/cancer\\_inst/programs/hcr.html](http://www.cancerinstitute.org.au/cancer_inst/programs/hcr.html)**

### The Cancer Council NSW

153 Dowling Street

Woolloomooloo NSW 2011

**Ph: (02) 9334 1900**  
**Fax (02) 9358 1452**  
**[www.cancercouncil.com.au](http://www.cancercouncil.com.au)**

### Cancer Helpline

This is a free and confidential telephone service provided by each state and territory Cancer Council.

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## Centre for Genetics Education

Royal North Shore Hospital  
St Leonards NSW 2065

Ph (02) 9462 9599  
Fax (02) 9906 7529  
[www.genetics.edu.au](http://www.genetics.edu.au)

## Websites

The Cancer Council Australia

The Cancer Council has more information about hereditary cancer at the following website:  
[www.cancer.org.au/AboutCancer/FamilyCancers](http://www.cancer.org.au/AboutCancer/FamilyCancers)

You can also access other state Cancer Council websites from this page.

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The design of this booklet is based on the Ottawa Personal Decision Guide (OPDG), developed by O'Connor, Jacobsen and Stacey, 2002. The OPDG and more information about decision guides are available on the web at [www.ohri.ca/decisionaid](http://www.ohri.ca/decisionaid).

The information in this booklet is correct at the time of publication. However, as research is ongoing, the booklet will be updated every two years.

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Further copies are available from:

**Centre for Genetics Education, NSW Health**

RNS Community Health Centre

Level 5, 2c Herbert Street

St Leonards NSW 2065

Phone: (02) 9462 9599 Fax: (02) 9906 7529

Email: [contact@genetics.edu.au](mailto:contact@genetics.edu.au)

[www.genetics.edu.au](http://www.genetics.edu.au)

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**Important**

This information was correct at date of production.

Please check with your doctor or genetic counselling service for any new information.