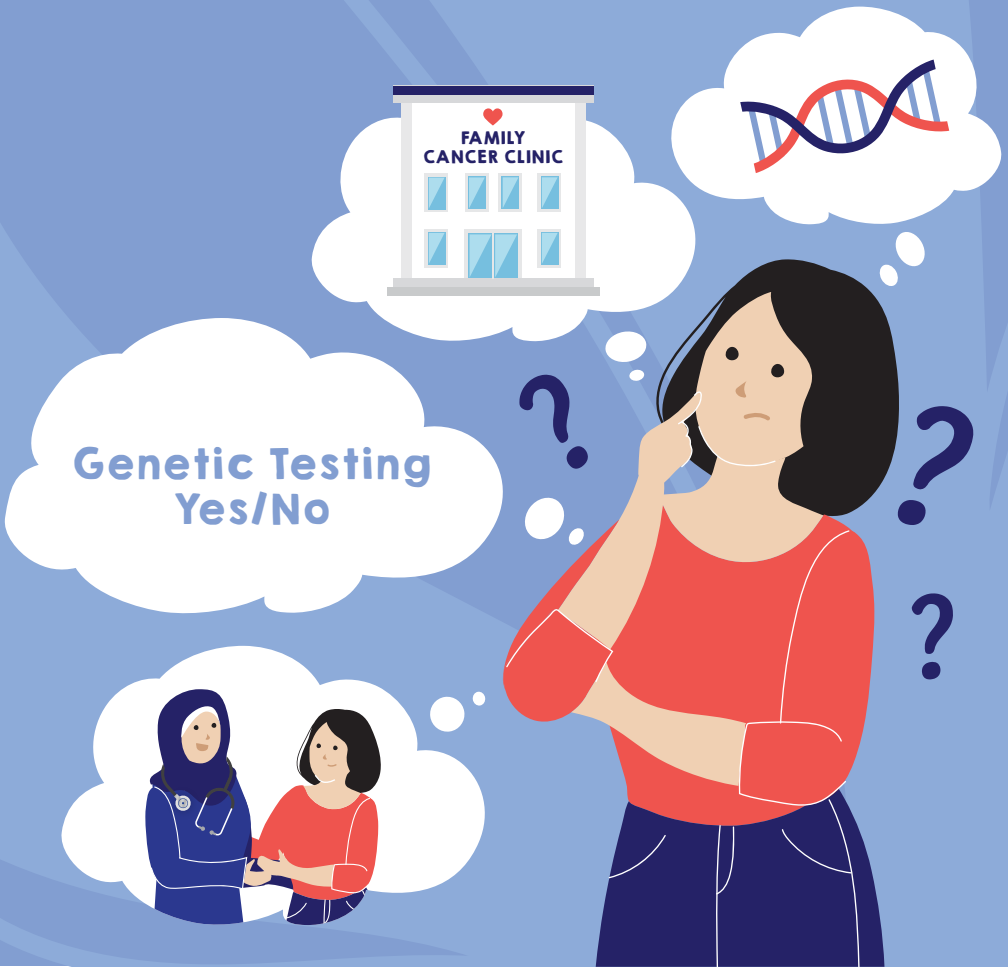
cancer research malaysia

Making Decisions about Genetic Tests for Inherited Breast and Ovarian Cancer



About this booklet

- This booklet is for women who have **breast and ovarian cancer that runs in their family.**
- It tells you about **genetic testing.**
- **Genetic testing l**ooks to see if you have an **increased chance** of getting breast and ovarian cancer.
- Knowing about genetic testing can help you to make an **informed decision that is right for you.**
- Reading the booklet is not meant to replace talking to your doctor. We suggest that you **read the booklet and also speak to your doctor.**

At the back of this booklet, there are some questions you might want to ask your genetics specialist (page 40) and a worksheet to help you decide about genetic testing (page 32).

The medical words are explained on page 44 to 47.

Is genetic testing right for me?

It may be if you and your family has one or more of the following:

- [ ] Your doctor or a genetics specialist has suggested genetic testing might be helpful.

- [ ] **One of your blood relatives*** has had a genetic test. The results told them they have an increased chance of breast and ovarian cancer.

  **Note: Blood relatives are people related to you by birth, such as your parents, siblings, children, grandparents, aunts, uncles and cousins. Blood relatives do not include people related to you by marriage or adoption.*

- [ ] **You** have at least one of the following:

  - Breast cancer diagnosed at 45 years old or younger
  - Two primary breast cancers, both diagnosed at 60 years old or younger
  - Triple-negative breast cancer, diagnosed at 60 years old or younger
  - Ovarian cancer (epithelial non-mucinous ovarian cancer)
  - Male breast cancer
  - Breast cancer plus parent, sibling or child with any of the above criteria

Remember that these checkboxes are only a guide.

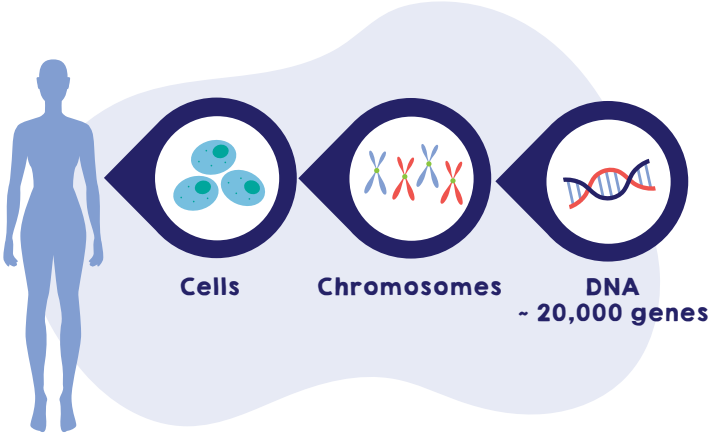
We suggest talking to your doctor or genetics specialist.

What is in this booklet?

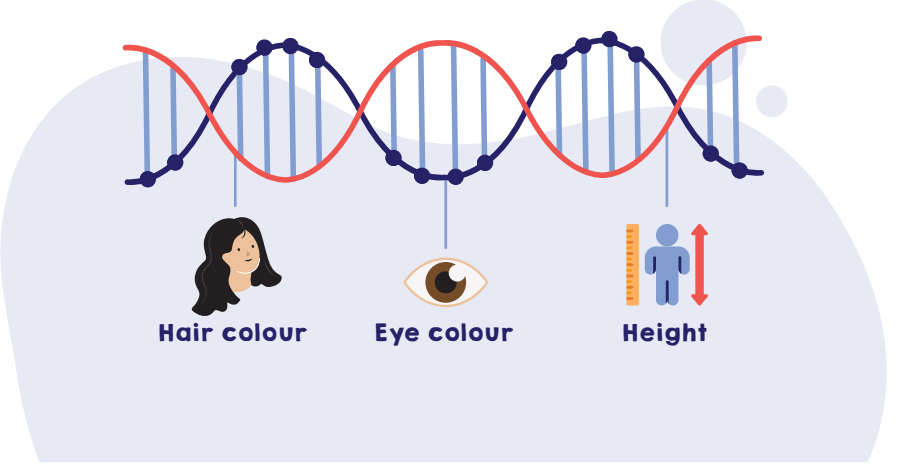
What are genes?

What are genes?

- Your body is made up of tiny building blocks called cells. Inside every cell is a set of genes (see picture)
- Genes are made up of DNA.



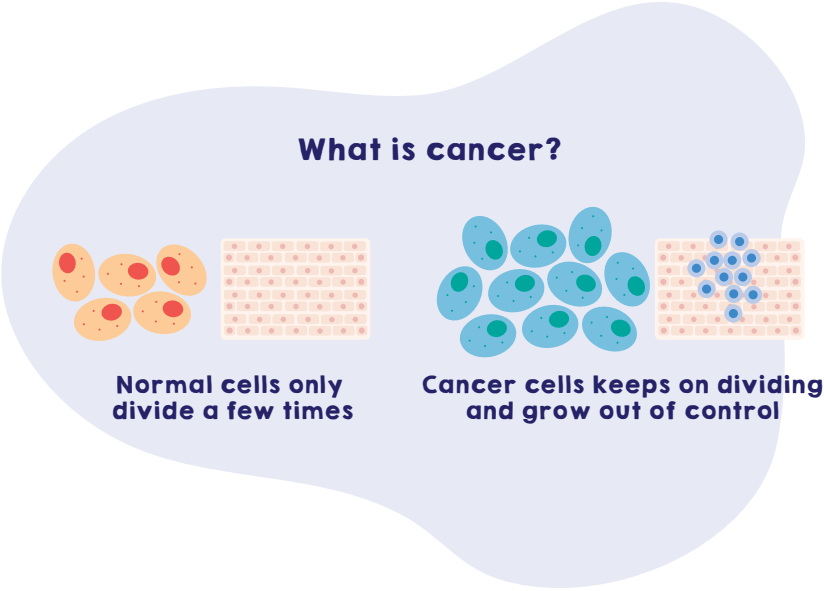
- The DNA in our genes makes messages that tell our body to grow, and work as it should.
- The DNA messages say what we look like (**for example, our eye colour, hair colour, height**), and how we work on the inside. This information is passed down from generation to generation (inherited).



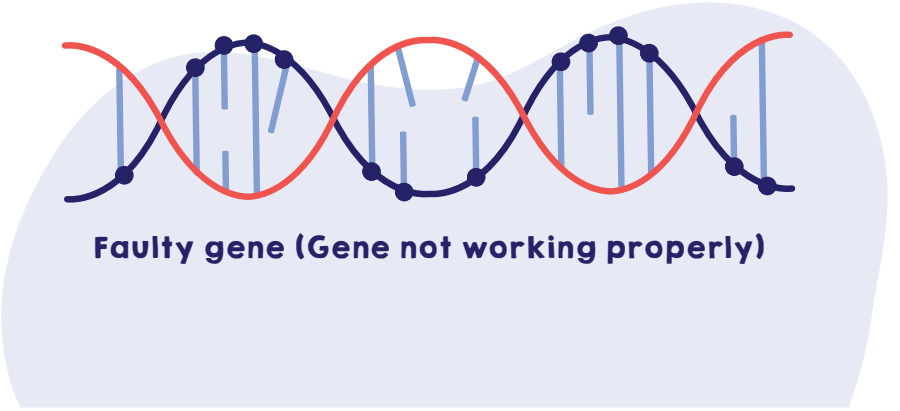
Faulty genes and cancer

Faulty genes and cancer

- Cancer occurs when cells grow out of control in parts of our bodies. (See picture)
- Cancer is caused by faults (mistakes) in genes which stop them working properly. You might hear this being called faulty gene or gene mutations.



- Cancer is more common as you get older. This is because over time, faults can build up in our genes.

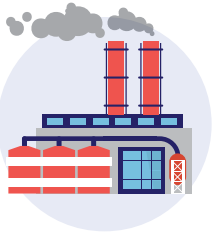


There are many factors that have a role in whether or not you develop cancer. They are the genes you inherit, your family history, lifestyle and the environment.

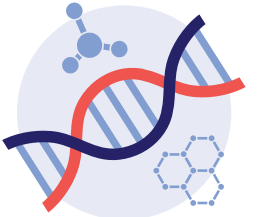
Cancers caused by inherited faulty genes are **much less common** than those caused by other things such as aging, smoking, being overweight, lack of exercise, and not eating healthily.

Cancer risk factors

Lifestyle

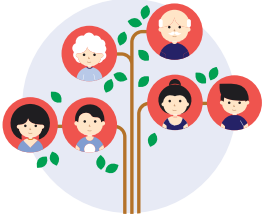


Environment



Genes or DNA

Chance



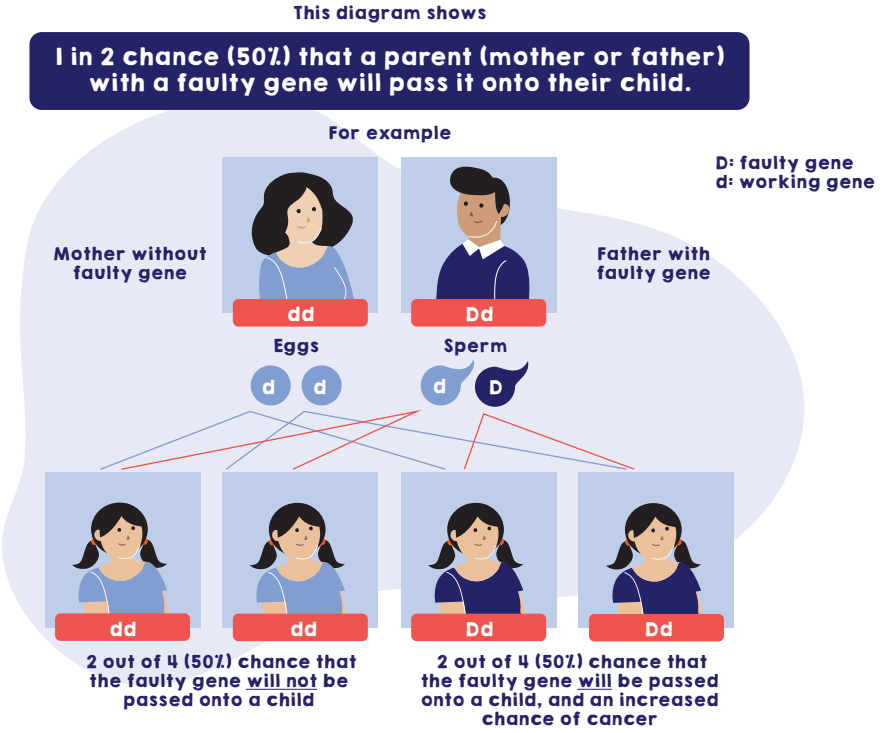
Family history

Breast and ovarian cancer that runs in the family

- Lifetime chance of getting breast cancer
- Lifetime chance of getting ovarian cancer
- What does it mean for women born with a faulty BRCA1 or BRCA2 gene?
- What does it mean for men born with a faulty BRCA1 or BRCA2 gene?

Breast and ovarian cancer that runs in the family

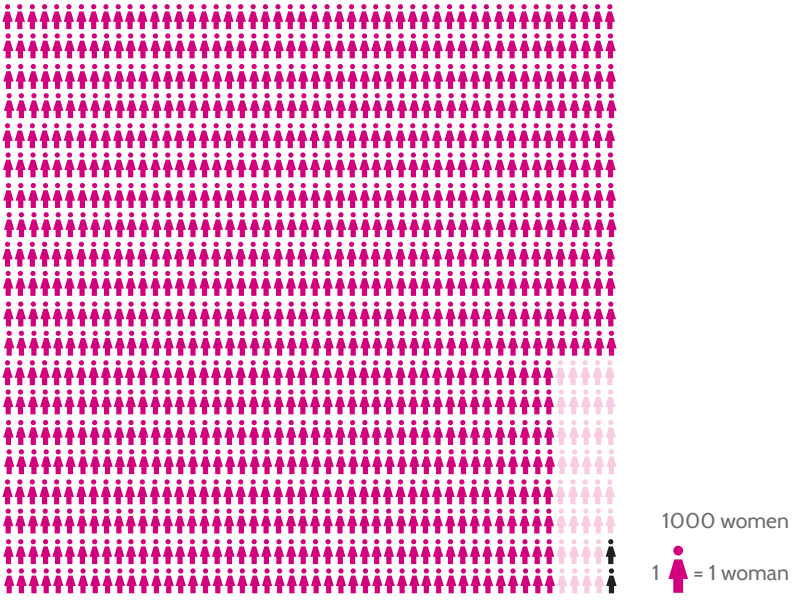
- Your chance of getting breast or ovarian cancer is increased if you have a close blood relative (parent, brother, sister) who have or had these types of cancer.
- Having a family history of cancer does not mean you will definitely get cancer, but you may have an increased chance compared to other people.
- The **two most common genes** that protect against breast and ovarian cancer are called **BRCA1 (BReast CAncer 1)** and **BRCA2 (BReast CAncer 2)** – see page 42 for more information.
- We are all born with two copies of a BRCA1 gene and two copies of a BRCA2 gene – we get one copy each from our mother and one from our father. See diagram below.
- A small number of people will be born with a faulty BRCA1 or BRCA2 gene passed on from one of their parents.



Lifetime chance of getting breast cancer

About **40 out of 1000 (4%)** women in Malaysia will get breast cancer some time in their life.

- About **2 of the 40 (5%)** women will have breast cancer mostly because they have a faulty gene (BRCA1 or BRCA2) passed on from one of their parents.



About **960 out of 1000** women will not get breast cancer at any time.

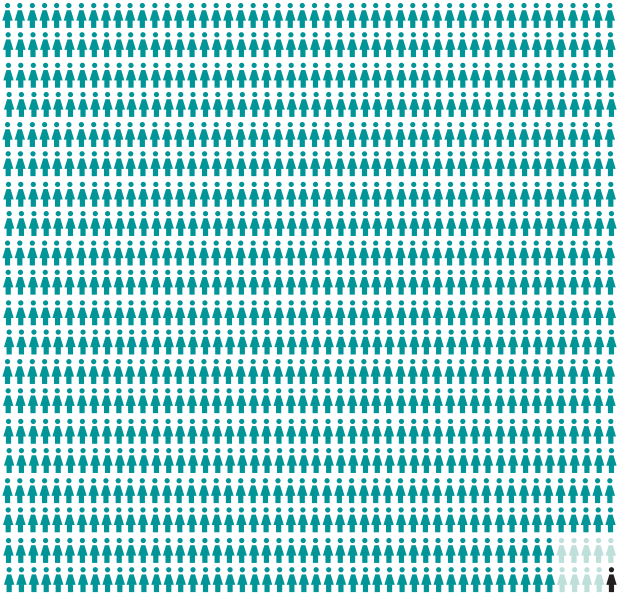
About **40 out of 1000 (4%)** women will get breast cancer sometime in their lifetime.

About **2 of the 40 (5%)** women will have breast cancer mostly because of a faulty gene.

Lifetime chance of getting ovarian cancer

Ovarian cancer is less common among Malaysian women than breast cancer. About **10 out of 1000 women (1%)** in Malaysia will get ovarian cancer some time in their life.

- About **1 of these 10 women** (10%) will have ovarian cancer mostly because they have a faulty gene (BRCA1 or BRCA2).
- The average age that most women get ovarian cancer is around the age of 53 years .



About **990 out of 1000** women will not get ovarian cancer at any time.

About **10 out of 1000 women (1%)** will get ovarian cancer sometime in their lifetime.

About **1 of these 10 women (10%)** will have ovarian cancer mostly because of a faulty gene.

What does it mean for women born with a faulty BRCA1 or BRCA2 gene?

- They have an increased chance of getting breast and/or ovarian cancer, as well as some other cancers including pancreatic cancer.
- Having a faulty gene does not mean you will definitely get cancer, because faults in genes take time to build up. Other things such as age, lifestyle and environment also affect the chance of getting cancer.
- If women do get breast and/or ovarian cancer, it is likely to be at an earlier age than women without a faulty gene.
- Their children have a 1 in 2 chance (50%) of having the faulty gene.

What does it mean for men born with a faulty BRCA1 or BRCA2 gene?

- They have a slightly increased chance of prostate, breast, and other types of cancer, including pancreatic cancer.
- Their chance of getting these cancers is only slightly higher than other men in Malaysia.
- Their children have a 1 in 2 chance (50%) of having the faulty gene.

Genetic Testing

- Searching for the faulty gene
- Family testing

Genetic testing

This section of information tells you about two genetic tests which look for faults in cancer genes.

1. Searching for the faulty gene – pages 12 to 17.

Read this section if...

☐ *You have breast and/or ovarian cancer AND a strong family history of cancers*

2. Family testing- Page 18 to 23

Read this section if...

☐ *A faulty gene has been found in one of your close blood relatives (Parent, siblings, children)*

1. Searching for the faulty gene

Who is the test for?

- Women who have or had breast and/or ovarian cancer **and** have a strong family history of the cancer.

- Someone who has not had breast or ovarian cancer, but who has a parent and a child who has. This does not happen very often.

What does this test involve?

- A blood or saliva test to find out if there are faults in your BRCA1 or BRCA2 genes that increase the chance of breast and/or ovarian cancer.

Why might you consider doing the test?

- It may tell you about your chance of getting a new cancer so you can make decisions about cancer screening, prevention and management.

- It helps to work out who in your family has an increased chance of these cancers.

- If a faulty gene is found, your blood relatives, who do not have cancer, can have family testing (page 18) to see if they have the family's faulty gene.

What do the test results mean?

Faulty gene found

- This means you have inherited a faulty cancer gene.
- This does not mean you will definitely get cancer, but you have an increased chance of getting more than one cancer. If you already had breast cancer, there might be an increased chance of getting a new breast cancer (in the other breast) or ovarian cancer.
- Other blood relatives will be able to have family testing.

Faulty gene not found (inconclusive)

- A faulty gene was not found.
- The tests does not test all genes, so it may have been missed.
- Because of your family history of cancer, you may still have an increased chance of cancer.
- Carry on with your cancer screening plan as if you haven't had the genetic test.

Uncertain

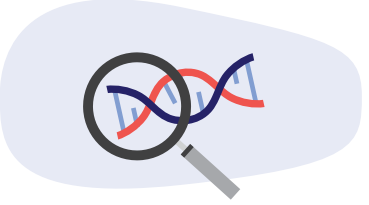
- A change has been found, but it is not clear if the change is harmless, or if it is making the gene faulty.
- Because of your family history of cancer, you may still have an increased chance of cancer.
- Carry on with your cancer screening plan as if you haven't had the genetic test.

If a faulty gene is found, see page 25 to 26 on ways to manage your increased chance of a new cancer.

How could a test result affect me?

Waiting time

- It can take a while to receive your result. This might make you feel upset.



A faulty gene was found

- Finding a faulty gene can cause worry. For some, feelings of worry may continue, particularly before cancer screening.
- On the other hand, finding a faulty gene may be a relief because you know more about your family history and what has caused your cancer.

An inconclusive or uncertain result

- An inconclusive or uncertain result can be confusing, because you do not know what has caused your family history of cancer.
- You might feel some relief, even though you might still have an increased chance of getting another cancer.

Testing to search for the faulty gene

Women who had breast and/or ovarian cancer AND a strong family history of cancers. On rare occasions, the test is available for women who do not have cancer, but their parent or child has.

***Discussion with genetic specialist**

- Talk to genetic specialist on the phone.
- Attend genetic counselling at the genetics service.

Decision- making

- Take time to make a decision - there is a worksheet at the back of the booklet to help you make your decision.
- **Postpone the decision -** consider testing options again in the future.
- **Yes -** have a blood or saliva test.
- **No -** you might decide to do the test at a later time.

Test results and what they mean for you and your family

- **Receive results and attend appointment.**
- **Faulty gene found**
  Family testing can be offered to other family members.
- **Faulty gene not found (inconclusive)**
  It is not possible to offer family testing to family members.
- **Uncertain result**
  It is not possible to offer family testing to family members.
- Discuss cancer screening and other ways to reduce your chances of getting cancer with your genetics specialist.

**Genetic specialist: Genetics doctor and genetic counsellor. Could also include specialist doctor like breast and gynaecological surgeon or oncologist*

How do other women feel about searching for the gene fault?

Ms Lee (35 years old) has a family history of breast cancer and has had breast cancer herself.

She is deciding whether or not to have a test to search for the faulty cancer gene

At the back of this booklet (page 32 to 35), there is a worksheet to help you decide about genetic testing.

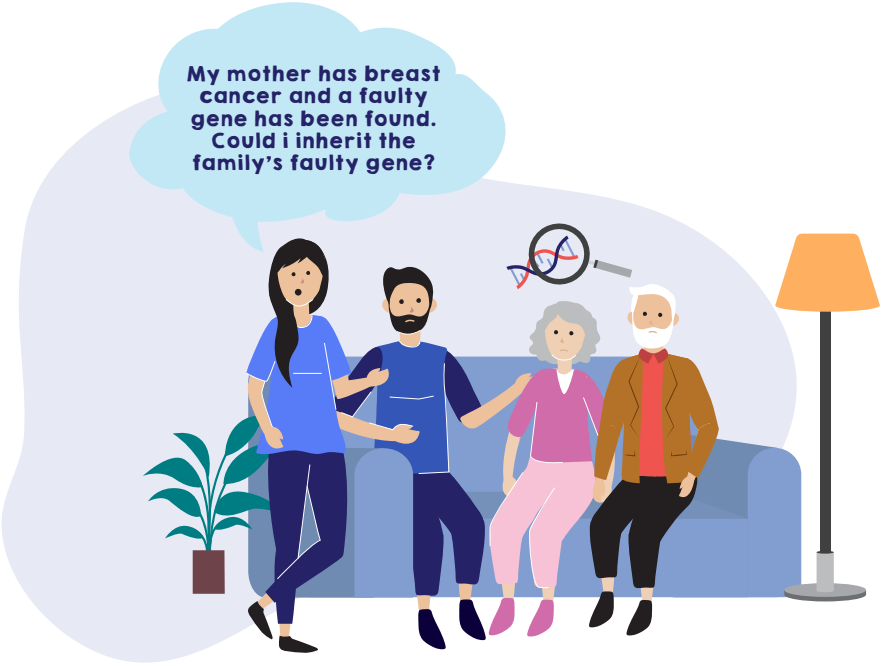
Lakshmi (45 years old) has had ovarian cancer, and ovarian cancer runs in her family.

She is deciding whether or not to have the test to search for the faulty cancer gene.

Family testing

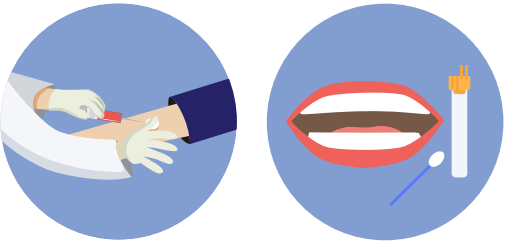
Who is the test for?

For women who have a close blood relative who had a faulty BRCA1 or BRCA2 gene found.



What is the test?

Family testing is a blood or saliva test to look for the fault in the BRCA1 or BRCA2 gene running in your family that increases the chance of breast and/or ovarian cancer.



What the test results mean?

Family faulty gene found

- If a family faulty gene is found, you have an increased chance of getting breast and/or ovarian cancer. Remember, you might not develop cancer.
- Because of your increased chance of cancer, there is a 1 in 2 chance (50%) that you will pass the faulty gene to each of your children.

Family faulty gene not found

- If a family faulty gene is not found, this means that you have not inherited the faulty cancer gene.
- You do not have an increased chance of breast and/or ovarian cancer, but you may still develop cancer.
- Your chance of getting cancer is the same as other people in the general population. Therefore, you only need cancer screening that is advised for women of your age.
- You cannot pass on the faulty gene to your children.

If a family faulty gene is found, see page 25 to 26 on ways to manage your increased chance of a new cancer.

What might happen if you have family testing?

Who is the test for?
• A faulty cancer gene has been found in one of your close blood relatives*

****Discussion with genetic specialist**

- Talk to a genetic specialist on the phone
- Attend genetic counselling at the genetics service.

Decision- making

- Take time to make a decision - there is a worksheet at the back of the booklet to help you make your decision.
- **Postpone the decision -** consider testing options again in the future.
- **Yes -** have a blood or saliva test.
- **No -** you might decide to do the test at a later time.

Test results and what they mean for you and your family

- Family faulty gene found

- Family faulty gene not found

- Discuss cancer screening and other ways to reduce your chances of getting cancer with your genetics specialist

***(Parents, siblings, children)**

***Genetic specialist: Genetics doctor and genetic counsellor. Could also include specialist doctor like breast and gynaecological surgeon or oncologist*

How could the test results affect me?

Your family's faulty gene was not found in you

- If you find out that the BRCA1 or BRCA2 gene fault running in your family was not found in you, you might feel relieved that you and your children do not have an increased chance of breast and/or ovarian cancer.

- If you do not receive the same result as other family members, you might find it hard because you cannot share what they are going through.

Your family's faulty gene was found in you

- If you find out that the faulty gene was found, you might feel worried about getting cancer. Some women feel less worried. Others may continue to feel worried, particularly before cancer screening appointments.

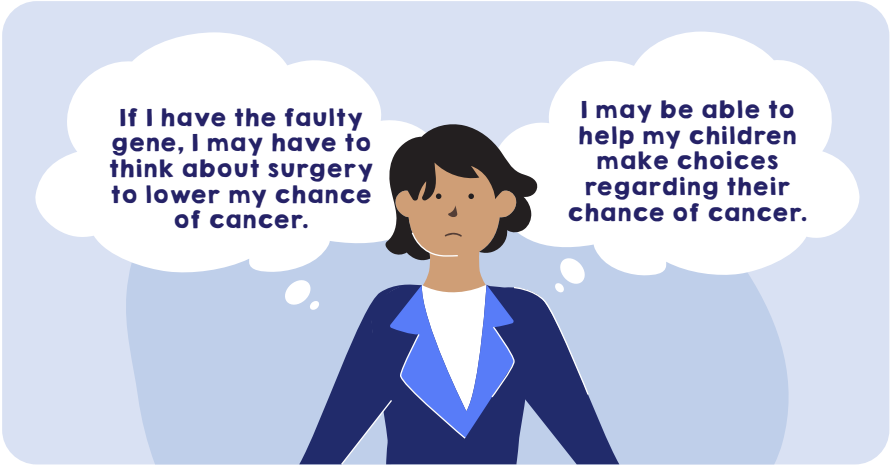
- You may feel less worried after you get this result because you have a better idea of your chance of getting cancer, and you can manage your health.

How do other women feel about family testing?

Siti (50 years old) has a family history of breast cancer, but has not had cancer herself.

A faulty gene has been found in one of her relatives. She is deciding whether to have family testing.

At the back of this booklet (page 32 to 35), there is a worksheet to help you decide about genetic testing.



Susan (40 years old) has a family history of ovarian cancer, but has not had cancer herself.

A faulty gene has been found in one of her relatives. She is deciding whether to have family testing.

At the back of this booklet (page 32 to 35), there is a worksheet to help you decide about genetic testing.

Impact of testing

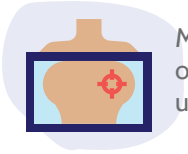
- How can I manage my health in the future?
- How could my result affect my family?
- How will it affect my children?
- How could it affect my finances/insurance?

How can I manage my health in the future?

Cancer screening options may include:

Increased breast awareness and telling your doctor of any changes.

Regular breast examination by your doctor or breast specialist.



Mammogram with or without a breast ultrasound.

Magnetic Resonance Imaging (MRI) of the breast.

Some women might **consider**

surgery

medication

lifestyle changes

to reduce their chance of getting (or getting another) breast cancer and/or ovarian cancer.

Surgical options may include:

- Removal of breast tissue (mastectomy to reduce your chance of getting breast cancer).
- Removal of the ovaries and fallopian tubes.

More information about managing your chance of cancer is available from your doctor or genetic specialist.

How could my result affect my family?

Different people, different decisions

- Each family member has the right to make their own decision about genetic testing.
- There is no right or wrong decision.
- Sometimes, it can be hard for other family members to understand decisions. For example, deciding not to have a test to **search for the gene fault (page 12 to 17)** may mean that other relatives cannot have **family testing (page 18 to 23).**
- For family testing, sometimes, family members who receive the same result will feel closer to each other. Family members who receive different results may find it harder to talk to each other.
- Partners of people who are deciding about genetic testing may feel left out of the decision making, because they are not blood relatives. Yet, the results might be important for their children and family planning.
- Some people may also ask religious advisors for advice.

What could the results mean for me and my family?

- A result might tell **you, who** in your family could have an increased chance of getting cancer.
- Sometimes, genetic testing can bring families closer. Sometimes, it can lead to difficult conversations.

What can I do to avoid family disagreements?

- Everyone reacts differently to genetic information. Before deciding about genetic testing, think about how family members may react and how you might deal with any problems.
- You might like to think about who, when and how to tell other people about your decision. It might help you to have a support person to share your thoughts and feelings with.
- Your genetic specialist can help you talk to your family. For example, they may give you a letter to explain the results and what they mean.
- Sharing information from this booklet may also help.

How will it affect my children?

If your children are adults (21 years and older)

- You might want to think about what to tell your children about your family history of cancer and genetic testing.
- You might suggest they speak to a genetics specialist. They can then decide whether or not they want to have family testing.

If your children are not adults

- Children are not usually offered family testing. This is because even if they have inherited a faulty cancer gene, they do not have an increased chance of getting cancer until they are adults.

Future children:

- It might be helpful to think about how your decision about genetic testing and the possible results might affect your future plans to have children.

- If you are pregnant or thinking of getting pregnant, you might want to consider testing options of the unborn baby in pregnancy to tell you more about their health. These tests however are not widely available.

If you have a faulty BRCA1 or BRCA2 gene there is a 50% chance (1 in 2) that you will pass on the faulty gene to each of your children.

How could it affect my finances/insurance?

Cost of genetic testing

- We suggest you discuss the cost of genetic testing with your genetics service as it may vary because of your situation or chances of carrying a faulty gene.

Health insurance / life insurance

- There is no law in Malaysia to protect against being treated unfairly because of your family history or genetic test result (genetic discrimination).

- Your results will not affect any life insurance you have already signed up. However, if you apply for a new life insurance policy or change your existing policy, you will have to tell the insurance company if you have a faulty gene if they ask.

- If you find out you have a faulty gene, it may affect your health and medical insurance.

A worksheet to help you decide about genetic testing

A worksheet to help you decide about genetic testing

This worksheet helps you to think about what is important to you when making your decision about genetic testing (either testing to search for the faulty gene or family testing).

How to fill in the worksheet

- Listed below are some points that others have said about genetic testing.
- Think about how each point makes you feel about having genetic testing (tick the box that matches your response).
- You can also add your own points.
- Once you have filled it in, see if your responses fall more into which column "I want to have genetic testing", "I am unsure" or "I dont want to have genetic testing".
- It is your decision, there are no right or wrong answers.

When I read this point I feel that	I want to have genetic testing	I am unsure	I don't want to have genetic testing
I can manage my chance of getting another cancer.			
If a faulty gene is found, I may be advised to have cancer screening.			
I prefer to know things even if they are bad.			
If a faulty gene is found, the information may be helpful for other family members.			
I may need to talk to my family, which may lead to disagreements.			
The genetic information may help other family members to understand their chances of getting cancer.			
I may be able to help my children make choices regarding their chances of getting cancer.			

When I read this point I feel that	I want to have genetic testing	I am unsure	I don't want to have genetic testing
I may be able to find out if I have passed it onto my children.			
I can be prepared and not live with what if's.			
The decision I make about genetic testing may effect decisions for my children in the future.			
It may affect my, or my family's, financial situation.			
I am concerned about insurance.			
It may impact my family's future health.			
If a faulty gene is found, I may have to think about having surgery, medication, and/or lifestyle changes to reduce my chances of cancer			
I just don't want to know.			
Other things important to my decision. List down -	How does it make me feel about genetic testing?		

Making my decision

After doing the worksheet, how do you feel about having the genetic test (please tick the box)?

☐ **I want to have a genetic test**
- How to make an appointment, see page 36
- Preparing for your appointment, page 37
- Genetics service contact details, page 38

☐ **I do not want to have the genetic test, or I would prefer to make the decision in the future**
- You might decide to think about testing again in the future.

☐ **I am not sure about whether to have the test**
- Think about giving yourself more time to decide
- Arrange an appointment with your doctor or genetics specialist at the genetics service

How to make an appointment at the Genetics Service

Contact the below genetic services

Institution	Contact Information
Cancer Research Malaysia	Genetic Counselling Cancer Research Malaysia, 2nd Floor, Outpatient Centre, Subang Jaya Medical Centre, 47500 Subang Jaya, Selangor, Malaysia Tel (O): 603 2712 3224 Tel (M): 6012 374 7426 / 6012 368 4742 Email: familialteam@cancerresearch.my Website: www.cancerresearch.my
University Malaya Medical Centre (UMMC)	Medical Genetics Unit, University Malaya Medical Centre, Jalan Universiti, Lembah Pantai, 59100 Kuala Lumpur. Tel (O): 603 7949 6304 Email: ppumgeneticmo1@gmail.com
General Hospital of Kuala Lumpur (GHKL)	Department of Genetics, Hospital Kuala Lumpur, Jalan Pahang, 50586 Kuala Lumpur Tel (O): 6032615 5555 ext 7062 Email: klinikalgenetik.hkl@moh.gov.my
University Kebangsaan Malaysia Medical Centre (UKMMC)	Genetics Clinic (Paediatrics Department), Ground Floor, UKM Medical Centre, Jalan Yaacob Latiff, Bandar Tun Razak 56000 Cheras, Kuala Lumpur Tel (O): 603 9145 7049 Website: www.ppukm.ukm.my

Or talk to your doctor to find a genetic counselling service near you

Preparing for your appointment

☐ Write down your main concerns

☐ To better understand your family history of cancer, use the table below to list who has had cancer in your family, what type of cancer and the age they got cancer.

Relationship to you	Mother's or Father's side of the family	Type of cancer	Age they got the cancer
Example: Aunt	*Father's side*	*Breast Cancer*	*40*

☐ Bring your cancer medical report. You may ask your doctor if you do not have copy a of the report.

☐ Bring the results of any family members who already had cancer genetic testing (with written permission from family members).

☐ You may wish to bring a support person with you to the appointment.

My support people include (family, friends etc):

Other helpful organisations

Genetic Counselling Society of Malaysia (GCSM)
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Email: admin@gcsocietymalaysia.org.my

Breast Cancer Welfare Association Malaysia (BCWA)
5th Floor, Bangunan Sultan Salahuddin Abdul Aziz Shah, 16, Jalan Utara, 46200 Petaling Jaya. Malaysia.
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Email: info@breastcancer.org.my

National Cancer Society of Malaysia (NCSM)
66, Jalan Raja Muda Abdul Aziz, Kampung Baru, 50300 Kuala Lumpur, Wilayah Persekutuan Kuala Lumpur
Tel: +603-2698 7300
Email: contact@cancer.org.my

Questions to ask your doctor or genetics specialist

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Here are some questions that you might like to ask your doctor or genetics specialist about genetic testing.

1. If I do the genetic test now, do I have to do it again in the future?
2. How is this different from the genetic test I did on my tumour sample (somatic testing)?
3. What are the options to manage my chance of getting breast and ovarian cancer if I have the faulty gene?
4. How will the genetic test result affect my cancer treatment?
5. Will the result tell me about chances of the cancer coming back?
6. Why do I need to have a test to search for the faulty gene when I already have cancer?
7. How will this test affect my siblings / children's insurance?
8. Since it's breast and ovarian cancer, do I only need to worry about female relatives?

Notes

Write down any other questions you may wish to ask

Further information

Further information about BRCA1 and BRCA2

- BRCA1 and BRCA2 are two genes that everyone has. BRCA stands for BReast CAncer susceptibility gene.
- The BRCA1 and BRCA2 genes normally protect us from getting breast and ovarian cancer by helping to repair mistakes or faults in our cells.
- When a fault in one of these genes occurs, that protection is lost. Over time, breast and ovarian cancer may develop.
- The main difference between **BRCA1** and **BRCA2** is that...
    - **BRCA1** is linked with getting breast cancer at around 41 years of age, and an increased chance of ovarian cancer.
    - **BRCA2** is linked with getting breast cancer at around 46 years of age, and an increased chance of ovarian cancer and pancreatic cancer (the pancreas is an organ in the upper part of the abdomen).

Medical words

Medical words

Blood relatives
People related to you through birth rather than marriage or adoption. A close blood relative in your immediate family such as mother, father, child or sibling.

Blood test
A blood test usually involves taking a blood sample from a blood vessel in your arm.

Breast cancer
Cancer that develops in the breast cells.

Breast ultrasound
Ultrasound uses sound waves to take images of inside the breast. It is used to help diagnose breast lumps or other abnormalities your doctor may have found during a physical exam, mammogram or breast MRI. Ultrasound is safe, non-invasive and does not use radiation.

BRCA1 and BRCA2 genes
BRCA stands for BReast CAncer susceptibility gene. Your body is made up of tiny building blocks called cells. Inside every cell is a set of genes. These genes are the instructions the cell needs to work properly. BRCA1 and BRCA2 are two genes that everyone has.

Cancer
An abnormal growth of cells that causes a risk to your health. The BRCA1 and BRCA2 genes normally protect us from breast and ovarian cancer. A fault in one of these genes means that protection is lost. Over time, this may mean cancers are more likely to develop.

Cancer protection genes
Genes that, when they are working correctly, help to prevent cancer from developing.

Cancer screening
Tests that look for early signs of cancer. Cancer may be prevented or found early by screening, thus improving the outcomes of treatment. Common cancer screening tests include mammograms for breast cancer or blood tests for prostate cancer.

Cells
The basic building blocks of the human body. All tissues in the body are made of cells and each cell type has a specific function (e.g. blood cells or skin cells).

Chromosomes
Carry genetic information. Chromosomes are made up of DNA and each chromosome contains many genes. Chromosomes come in pairs: one set from the mother; the other set from the father.

DNA
DNA is short for deoxyribonucleic acid. Cells get their instructions on what do to from DNA. It acts like a recipe to give our bodies instruction how to develop and function.

Embryo
The early stage of human development in the uterus (womb) in which organs are formed. A baby is called an embryo until the 11th week of pregnancy.

Family history (of cancer)
Having one or more blood relatives on the same side of the family who have had cancer. These relatives could be on either your mother's or your father's side of the family.

Family testing (also known as 'predictive testing') – a test usually offered to people who have a relative who has been found to have a faulty cancer gene. A predictive genetic test looks for the specific faulty gene that has been found to cause cancer in your family.

Faulty genes
Genes that are not working properly due to a fault (mistake) and so do not give the cell the correct instructions for growth and development

Genes
Packages of information in your cells. Genes control growth and development, keeping our bodies healthy and making us who we are. Genes are also passed from parents to children, which is why families share traits.

Genetic
Refers to things that relate to your genes (see genes).

Genetic testing
A blood test to look at your genes. These tests can tell you information about your health, such as your risk of cancer or other conditions.

Genetic counselling
The process of understanding your genetic risk at the genetic services. Genetic counselling may include collecting the family health history, education, genetic testing, counselling support and health advice. Genetic counselling is usually provided by a genetic counsellor.

Genetic counsellor
A health professional specially trained in genetics, education and counselling. They work directly with patients and families offering genetic/genomic information and support health decisions making.

Genetic service
A centre that provides genetic information and testing services.

Genetic specialist
A doctor who specialises in diagnosing and managing genetic conditions. This could include a genetic counselor or specialist doctor (clinical geneticist, oncologist, breast and gynaecological surgeon) who has completed specialist training in genetics or cancer medicine after their general medicine training.

Generations (family)
People born and living at about the same time, regarded altogether. The average 'generation' is usually about thirty years, during which children are born and grow up, become adults, and begin to have children of their own. For example, three generation families are families represent by a grandparent, a parent, then a grandchild.

Hereditary
The passing down of traits from parents to children (through genes). Many things are hereditary, such as eye colour, height and health.

Increased chance (or risk) of cancer
Some people have a risk of cancer higher than the average person. This can be due to genes, or environmental factors such as smoking. An increased risk of cancer does not mean that cancer is definite; it just means it's more likely. Extra cancer screening and other prevention options can help to manage the risk.

Laboratory
A place for doing scientific tests.

Inherit
The process by which genetic information is passed on from parent to child.

Magnetic Resonance Imaging (MRI)
A type of scan that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body.

Mammogram breast screening
An X-ray test that can spot cancers when they're too small to see or feel. A screening mammogram is used to look for signs of breast cancer in women who don't have any breast symptoms or problems to find cancer early. X-ray pictures of each breast are taken, typically from 2 different angles.

Mastectomy
An operation to remove a breast. It's used to treat breast cancer in women or breast cancer in men. It can also be used to reduce the risk of cancer developing in the breast.

Mutations
Changes in genes that make the gene faulty or damaged.

Mutation search
Genetic testing is usually done on the first person who has already had breast and/or ovarian cancer. The test tries to find the specific gene change that is causing the cancer to run in your family.

Pancreatic cancer
The pancreas is an organ in the upper part of the abdomen (tummy).

Ovarian cancer
A type of cancer that affects the ovaries.

Ovaries
A pair of small organs located low in the tummy that are connected to the womb and store a woman's supply of eggs.

Salpingo-oophorectomy
Surgery to remove the ovaries and fallopian tubes. It is used to treat ovarian cancer.

Variant of Uncertain or Unknown Significance
A fault in one of your genes has been found, but it is unclear whether it increases your risk of cancer or is just a normal difference between people.

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