MACMILLAN
CANCER SUPPORT

# CANCER AND GENETICS

## HOW CANCER SOMETIMES RUNS IN FAMILIES

# About this booklet

## This booklet is about cancer and genetics. It is for anyone who is worried cancer might run in their family, or has been told there is a higher risk of cancer in their family. It is also for anyone who has been told there is a gene mutation in their family that may increase their risk of cancer.

The booklet explains how genes affect the risk of developing cancer. It also gives information about:

- testing for gene mutations
- understanding test results
- ways to manage a higher risk of cancer.

We hope it helps you deal with some of the questions or feelings you may have.

We cannot give advice about the best treatment for you.
You should talk to your doctor, who knows your medical history.

## How to use this booklet

The booklet is split into sections to help you find what you need. You don't have to read it from start to finish. You can use the contents list on page 3 to help you. It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

In this booklet, we have included quotes from people who have a genetic risk of cancer or have been worried that cancer might run in their family. These quotes are from people who have chosen to share their story with us. To share your story, visit **macmillan.org.uk/shareyourstory**

## For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use. If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

# Contents

# UNDERSTANDING CANCER AND GENES

# Cancer and genes

Your body is made up of tiny building blocks called cells. Inside every cell is a set of genes. They are the instructions the cell needs to work properly. Genes control:

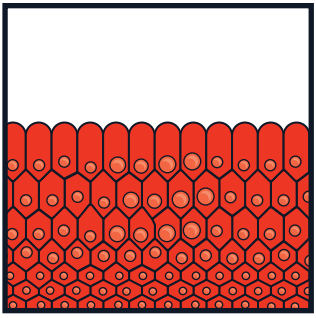
- how a cell does its job in the body
- when it divides to make new cells
- the cell's death when it is not needed any more.

Sometimes the structure inside a gene is permanently changed, so the gene no longer gives the correct instructions. This change is called a gene mutation.

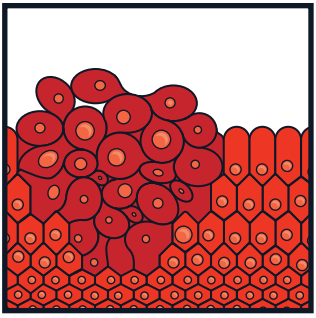
Some cells in your body develop gene mutations during your lifetime. These are called acquired mutations (see opposite page). It is also possible to have a gene mutation because it passed from one of your parents to you. This is called an inherited mutation (see pages 8 to 9).

Eventually, gene mutations in a cell may mean the cell stops working normally. Cancer develops when cells like this can multiply in an abnormal way and grow out of control.

Normal cells



Cells forming a tumour



## Acquired mutations

Most cancers are caused by acquired mutations. These are gene changes that happen in a person's cells during their lifetime.

A cancer may develop because of acquired mutations in cells in a certain part of the body. For example, if genes in cells in the lungs are damaged, lung cancer may eventually develop.

Acquired mutations may happen:

- by chance, as a cell divides or does its job in the body
- because of your lifestyle (for example, your diet or physical activity levels)
- because of things in your environment (such as sunlight or tobacco smoke).

Your cells can repair a lot of this damage. But over time, enough damage may build up in a cell to allow cancer to develop. This can take many years, which is why cancer is more common in older people.

Remember, this type of mutation only affects genes in some cells. It rarely affects genes in sperm or egg cells. This means acquired mutations cannot be passed on to children.

## Inherited mutations

Genes are passed from parent to child (inherited) when a sperm and egg join to start a pregnancy (conception). We have two copies of each gene – one from our mother and the other from our father. The sperm contains one copy of the father's genes. The egg contains one copy of the mother's genes. If one of the sets of genes contains a mutation, the child will have this mutation in their cells (see the illustration opposite).

Some inherited mutations make a person more likely to develop certain types of cancer. If you inherit a gene mutation like this, it does not mean you have cancer. More damage (acquired mutations) still needs to happen before a cancer can develop. The inherited gene mutation may allow this damage to build up faster.

Usually, the risk of cancer is only higher once you are an adult. Only a few inherited mutations increase the risk of cancer in children (see page 29).

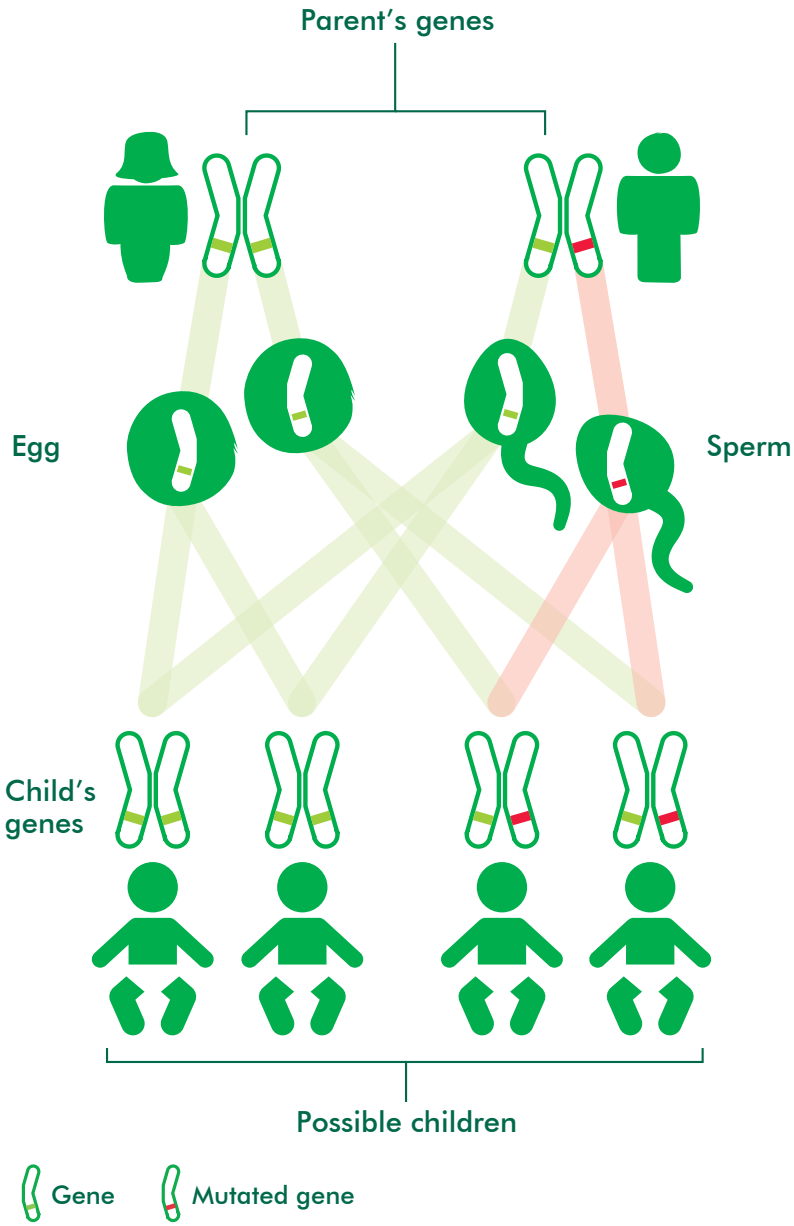
You might hear different names for the inherited mutations that make cancer more likely. These include:

- inherited cancer genes
- cancer predisposition genes
- cancer susceptibility genes.

### What are the chances of inheriting a gene mutation?

You only get one copy of each of your parent's genes. If one parent has a gene mutation, you either will get the copy containing the mutation, or you will not. There is a 1 in 2 (50%) chance the mutation is passed on. If you have the gene mutation, there is a 1 in 2 (50%) chance any children you have will inherit it.

## How genes are passed on



# Inherited cancer genes

Scientists have found many of the inherited mutations that are linked to common cancers, such as breast, bowel, ovarian and womb cancer. There are likely to be other inherited mutations that have not been found yet for these and other types of cancer.

If a family is affected by a gene mutation, there may be a pattern of cancers diagnosed in that family. There may be several people who:

- have the same types of cancer
- were younger than usual when they were diagnosed.

## When cancers happen together

A mutation in one gene may be linked to several types of cancer. This means a family with one inherited mutation may be affected by a group of cancers.

The most common patterns where cancers happen together are:

- breast and ovarian cancer
- bowel and womb cancer (sometimes with cancers of the ovary, stomach or kidney).

Less often, other patterns of cancers are seen in a family. We have more information about other inherited cancers (see pages 64 to 65).

## Lower-risk genes

Some inherited cancer genes cause a high risk of cancer. Scientists have also found other gene mutations that slightly increase the risk of cancer. These are sometimes called low-penetrance genes. The effect of each mutation on its own is small. But if a person has several of these mutations, they may still have a high risk of certain cancers. These genes are not yet routinely tested for.

There are probably many lower-risk genes we do not know about yet. Researchers are trying to find out more about these genes and how they interact with other risk factors to cause cancer to develop.

## Can cancer genes 'skip' a generation?

Cancer genes cannot 'skip' or miss a generation. If one of your parents has a gene mutation, there is a 1 in 2 (50%) chance it has been passed on to you. So either you inherit it or you do not. If you do not inherit the mutation, you cannot pass it on to your children.

Sometimes it can seem like the cancer skipped a generation. This is usually because a person in the family has the mutation and passes it to their child. But they do not develop cancer themselves.

Gene mutations linked to breast and ovarian cancers can pass through the father's side of the family. A man who inherits this type of mutation is unlikely to develop breast cancer and cannot develop ovarian cancer. But he still has a 50% chance of passing it on to his children. If his daughter inherits the mutation from him and develops breast cancer, it can look like the cancer gene has skipped a generation.

## How often is cancer caused by inherited cancer genes?

Most cases of cancer are not caused by an inherited mutation. Only a small number of people get cancer that is clearly linked to an inherited cancer gene. Experts think that less than 5 in 100 (5%) of all cancer cases are caused by an inherited cancer gene.

# UNDERSTANDING YOUR RISK OF CANCER

# If you are worried about cancer in your family

It is important to remember that cancer is very common. Most of us have relatives who have had cancer. This does not always mean there is a cancer gene in your family, or that you have a much higher risk of developing cancer.

If you are worried about the pattern of cancer in your family, talk to your GP. They will ask you about any close blood relatives who have had cancer. Close blood relatives are your parents, brothers, sisters, children, aunts, uncles and grandparents. People you are related to by marriage are not blood relatives.

Your GP will use the information about your family to assess your risk of cancer. If your GP thinks there is a chance that cancer may run in your family, they can refer you to a genetics specialist. This could be in a family cancer clinic or a cancer genetics clinic.

## When cancer may run in a family

Signs that your family may have an inherited cancer gene include the following:

- Two or more close blood relatives on the same side of the family had the same type of cancer.
- Certain groups of cancers have affected one side of the family (see page 10).
- A close relative has had more than one primary cancer. This means they have had cancer twice, not that one cancer has spread to another part of the body.
- Members of your family have had cancer at an unusually young age.
- You have a family history of certain cancers and you are from an Eastern European or Ashkenazi Jewish (Eastern European Jewish) background. Some inherited cancer genes are more common in these ethnic groups.

## If you are referred to a specialist

You may wait for a few weeks or months before the clinic contacts you. They may send you a family history form to fill out before you have an appointment. This will usually ask you:

- the names and ages of your family members
- their relationship to you
- whether they are on your mother's side or father's side of the family
- what cancer types your relatives have had
- the age they were diagnosed.

It is not always possible to fill out the form completely. It may be difficult to contact or speak to some of your family members. Sometimes talking about a family member or their illness is painful or upsetting. Some relatives may not want to know more about possible cancer risk in your family.

Do not worry if you cannot get all the facts, but try to complete the form as much as you can. The team at the genetics clinic will understand.

A genetics specialist uses the information you give to work out if there might be an increased risk of cancer in your family. They may also use information from public records or a cancer registry to find out more about the cancers in your family.

Sometimes the genetics specialist can find useful information about a relative's cancer diagnosis in their health records. If the relative is alive, they can only do this with their permission.

'The first thing I did was fill in a family history form. It would show whether there was a pattern that could indicate a gene mutation. It took a bit of time to get names and dates right!'

**Daloni**

## If an inherited cancer gene is unlikely

The pattern of cancer in your family may not show that an inherited gene mutation is likely. In this case, the clinic may decide you are unlikely to have a high risk of cancer and do not need an appointment to see them. They will usually tell you this in a letter. If you have not heard from the clinic after a few months, check with your GP.

If you have questions about their decision, you can call the genetics clinic. The letter they send usually includes a contact number for a genetics specialist.

If another diagnosis of cancer is made in your family in the future, talk to your GP again. This may give them more information to check your level of risk.

# Genetic counselling

If you are given an appointment, you will meet a genetics specialist. This is called genetic counselling.

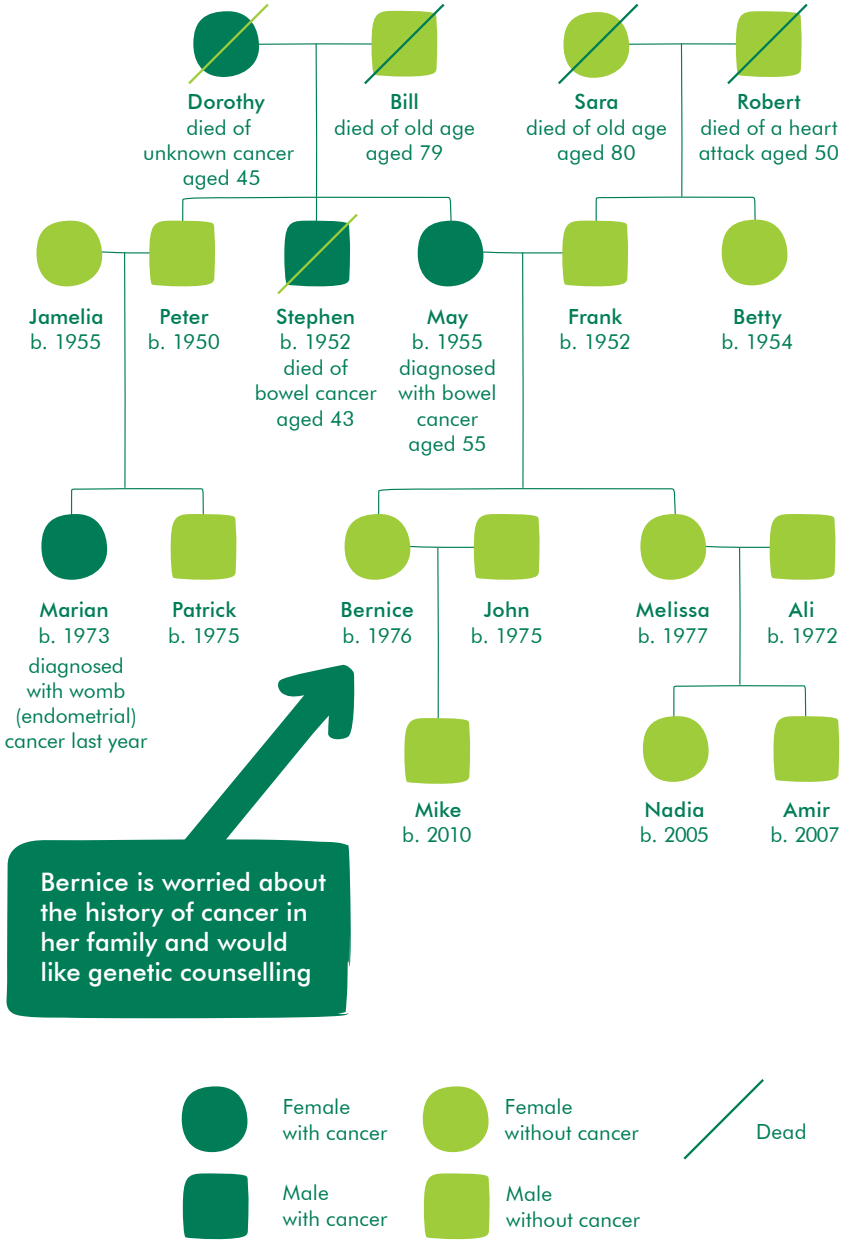
The meeting will last between 30 to 60 minutes. The genetics specialist will draw a diagram called a family tree. It will show all your close blood relatives and their illnesses. The genetics specialist uses this to assess your risk of developing cancer.

During the meeting, you will be able to discuss:

- whether you are likely to have a higher than average risk of certain types of cancer
- whether a genetic test is possible and useful in your situation (see pages 26 to 29)
- the benefits and limits of genetic testing
- ways of managing your cancer risk, including information about symptoms of cancer, cancer screening and risk-reducing treatments.

We have a video on our website which has more information about meeting a genetics specialist – visit **macmillan.org.uk**

# Example of a family tree



## Getting the most out of your meeting

It is a good idea to write any questions down before you meet the genetics specialist. You can use the space opposite to do this.

Here are some questions you may want to ask:

- What is my risk of getting a particular cancer?
- How sure are you about my risk?
- Is there anything I can do to reduce my risk?
- Who else might be at risk in my family?
- Do I need to tell anyone in my family?
- When and how should I tell my children?
- If I do not have a high risk of getting cancer, should I have any follow-up appointments?
- What shall I do if I want a test or screening, but it is not offered to me?
- Do I have to tell insurance companies about my family history or genetic tests?

It may be helpful to bring someone with you to the meeting, such as a partner, family member or friend. You can share your thoughts afterwards.

If there is something you do not understand, tell your genetics specialist so they can explain. You can also contact them again if you have more questions. You will usually get a letter after the meeting that lists all the important points.

# Assessing your risk

This means estimating your risk of getting certain cancers that may run in your family.

This happens at the genetics clinic when you meet the genetics specialist. Your GP may also do this when they decide whether to refer you to a genetics clinic.

To assess your risk, they look at:

- how many of your relatives have had cancer
- what age they were when they got cancer
- how many of your relatives have not had cancer
- whether there have been any rare cancers in your family
- whether there have been groups of cancers in your family, for example breast and ovarian cancer or bowel and womb cancer
- your age.

Based on this information, they may explain that your risk of getting cancer is one of the following.

## Average or low risk (population risk)

Your risk is the same as, or close to, anyone without a family history of cancer.

## Moderate (raised) risk

Your risk of some cancer types is a bit higher than average. It is not likely there is an inherited cancer gene they can test you for.

## High risk

You have a higher risk of developing some cancer types in your lifetime. This does not mean you will definitely get cancer. There may be an inherited cancer gene they can test for in your family.

Knowing your cancer risk can help you decide what to do to reduce it. This might include lifestyle changes, treatments to prevent cancer or screening to find it early (see pages 78 to 85).

# Genetic testing

Genetic testing can be used to look for inherited gene mutations that raise the risk of cancer in a family. Tests may be possible and useful if:

- you are diagnosed with a cancer that is likely to be linked to an inherited mutation
- a close blood relative has already had a test that found an inherited cancer gene.

## Genetic testing – a 2-step process

There are usually 2 steps to genetic testing.

### Step 1 – Mutation search

This is also called diagnostic testing. First, the laboratory looks for the gene mutation that may run in your family. They do this on a blood sample from someone in your family who has had cancer. It usually takes up to about 8 weeks to get the results.

The test may:

- find a cancer gene mutation
- not find a cancer gene mutation
- find a variant of uncertain significance (see page 39).

## Step 2 – Predictive testing

If the mutation search finds a cancer gene mutation, other family members can then be tested for the same mutation.

A predictive test is faster than a mutation search. This is because the laboratory knows which gene change to look for and where to find it.

Having a blood test

## If there is no living relative with cancer

Usually, a person in the family who has had cancer is tested first. If a cancer gene mutation is found, other members of the family can have predictive testing.

But sometimes there is no living relative with cancer who can be tested first. You may still be offered a genetic test if:

- the pattern of cancer in your family strongly suggests there could be a gene mutation
- you have a family history of cancer and you are from an Eastern European or Ashkenazi Jewish (Eastern European Jewish) background – some inherited cancer genes are more common in these ethnic groups.

## Genetic testing in children

Most inherited cancer genes do not cause cancers in children. Because of this, children are not usually tested. Once they become adults, they can make their own decisions about testing.

A child may be tested if there is a chance they have a gene mutation that causes health problems before adulthood. For example, a condition called familial adenomatous polyposis (FAP) causes growths in the bowel (polyps). These usually start to appear when a person is in their teens. Unless the polyps are treated, they will eventually develop into bowel cancer.

It is useful to know if a child carries the gene mutation that causes FAP, so they can have regular tests to monitor the bowel from their early teens. We have more information about FAP on page 45.

Other rarer conditions where children are tested for inherited gene mutations include:

- the multiple endocrine neoplasia (MEN) syndromes MEN1 and MEN2
- Von Hippel-Lindau syndrome (VHL)
- Li-Fraumeni syndrome.

Children affected by these conditions have a higher risk of cancer and other health problems before they are adults.

# Before having genetic testing

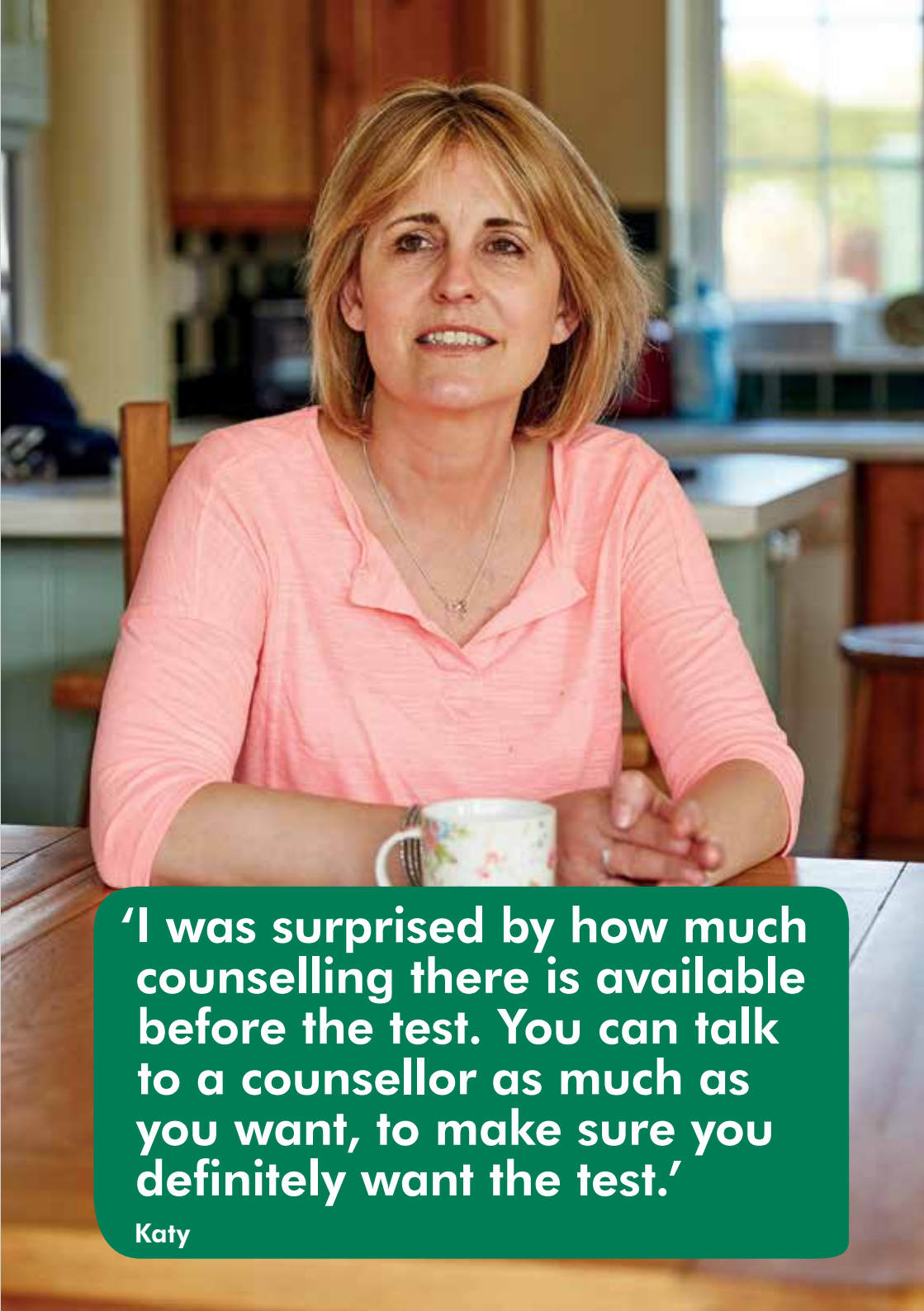
Your genetics specialist will explain what to expect. There may be several things to think about before you decide to have a genetic test.

## Possible advantages

- The test may show you do not have the gene mutation and that your cancer risk is low. You will not need to consider extra screening or risk-reducing treatments. You will know you cannot pass on the cancer gene to any children you have.
- If you find out you have a gene mutation, this may help you decide how to reduce your cancer risk (see pages 78 to 85). Your options may include having screening to find a cancer early, making lifestyle changes and having treatments to reduce your risk of getting cancer.

## Possible disadvantages

- If you find out you have a gene mutation, you may feel more worried about getting cancer.
- Tests do not always give clear answers. Some people find out they have a change in a gene, but it is not known how this affects their cancer risk. Doctors call this a variant of uncertain significance (see page 39).
- You may be told you have a raised cancer risk, even if testing does not find a gene mutation. This is because your family history may still show that an unknown gene mutation is likely.
- If you find out you have a gene mutation, you will need to decide whether or how to tell relatives. Many people find this difficult.



‘I was surprised by how much counselling there is available before the test. You can talk to a counsellor as much as you want, to make sure you definitely want the test.’

**Katy**

## Insurance

Some people worry insurance companies will refuse to insure them or will charge more if they have a genetic test. There is no law to prevent this. But for now, the Association of British Insurers (ABI) and the government have agreed how an insurer can use the results of genetic testing. This is called the Concordat and Moratorium on Genetics and Insurance.

The agreement lasts until 2019. It may change after that. It only covers genetic testing. It is not about your personal or family history of cancer. Insurance companies may still ask questions about your and your family's health, and any cancer diagnoses.

The agreement says that an insurer will not ask you to take a genetic test. Sometimes they will ask for the results of genetic testing you have already had. If you do not have cancer, they will not ask for results of genetic tests for inherited cancer genes.

You can find more information from:

- the ABI's website – **abi.org.uk**
- the Genetic Alliance – **geneticalliance.org.uk**
- your genetics specialist.

## Confidentiality

Your doctor and genetic specialist cannot tell anyone you have had a genetic test, or the result, unless you agree to this.

When they take your blood for the genetic test, they may ask if they can also take a sample for research. This may help scientists to find other cancer genes in the future. The research scientists will not know your personal details.

If you are worried about your personal details and confidentiality, talk to your doctor or nurse. They will explain how your information is used and protected.

'I gave consent for my sample to be kept and tested if future tests become available. This also means they can do research to find out what works for people.'

**Mariam**

# Your test results

## If a cancer gene is found

This means you have inherited a gene mutation that increases your risk of getting some cancer types.

### Other members of your family

If you have an inherited cancer gene, this may affect other people in your family. You may have to decide if and how to tell them.

Your genetics specialist may give you a letter you can give to family members. It will help explain your results and what it may mean for them. They can then decide whether they also want to have genetic counselling and predictive testing. Their GP can refer them to their nearest genetics clinic or family cancer centre.

Some people in your family may find they have the same gene mutation and an increased risk of getting cancer. Others may find they have not inherited it. They still have the same risk of getting cancer as people in general, but they will not need extra screening or risk-reducing treatments. They should still consider taking part in NHS screening when they are sent an invitation. They should also follow a healthy lifestyle.

‘Since my diagnosis as a carrier of the HNPCC gene mutation, my uncle has tested negative. So his side of the family have no greater chance of developing bowel cancer than the general public.’

**Helen**

## Your feelings

Talking about an inherited cancer gene with your family can be difficult. People may have questions that you cannot answer or have feelings you did not expect.

It is important to remember that no one is to blame for the genes they inherit or pass on. People with a gene mutation sometimes have feelings of guilt, blame or responsibility. But we cannot control the genes we pass on.

If there are children in your family, we have more information about talking to children about an inherited cancer gene that you may find helpful (see pages 72 to 77).

Your genetics specialist can help you talk through your feelings. Some organisations can offer support (see pages 93 to 96). You can also talk to our cancer support specialists on **0808 808 00 00** (Monday to Friday, 9am to 8pm).

## If the mutation search does not find a cancer gene

The mutation search may not find a cancer gene. This can happen even if you have a strong family history of cancer. It may be that:

- there is a gene mutation in the family, but it is not one we currently know about or test for routinely
- there are several 'lower-risk' genes in the family – these, together with environmental factors, can still increase the risk of cancer
- the cancers in the family are not due to an inherited cancer gene – the cancers may have happened by chance or for other reasons we do not understand.

## Your feelings

You may have mixed feelings if you are told the test has not found a gene mutation.

You may feel relieved that an inherited cancer gene has not been found. But this result also means you cannot know for certain if cancer is an inherited problem in your family.

Your genetics specialist may explain that you still have a higher risk of cancer based on your family history. This means the pattern of cancer in your family is unusual and may be caused by an unknown gene mutation. You may be offered extra screening or risk-reducing treatments. Because you have less clear information about your risk, it may be more difficult to decide what you want to do.

You may decide to reduce your cancer risk and improve your health in other ways. This may include giving up smoking, eating a healthy diet and being more physically active (see pages 84 to 85).

## Variants of uncertain significance (VUS)

Sometimes the mutation search finds a gene mutation that has not been clearly linked to cancer. Doctors call this a variant of uncertain significance. This means it is not clear whether the gene mutation is the cause of the cancer.

Because of this, the genetics specialist cannot offer predictive testing to other people in the family. They may ask for blood samples from them to try to get more information. These extra tests may help them decide if the gene mutation is the reason for the pattern of cancer in the family.

The family may also be asked to keep in contact with the genetics clinic. This is in case they find out more about the gene in future.

# CANCERS THAT CAN RUN IN FAMILIES

# Bowel cancer

Bowel cancer is the third most common cancer in the UK for men and for women. But only a small number of bowel cancers are clearly linked to inherited cancer genes. 19 out of every 20 people (95%) with bowel cancer do not have a gene mutation running in their family.

## Understanding bowel cancer in your family

An inherited bowel cancer gene may be more likely if there is a pattern of cancer in your family. These are examples of patterns:

- One of your first-degree relatives was diagnosed with bowel cancer before the age of 50. First-degree relatives are your parents, brothers, sisters and children.
- One of your first-degree relatives and one of their first-degree relatives were diagnosed with bowel cancer at any age (for example, your father and his sister).
- You have relatives on the same side of the family with certain types of cancer. These types of cancer include:
    - bowel cancer
    - womb cancer
    - ovarian cancer
    - stomach cancer
    - pancreatic cancer
    - small bowel cancer
    - ureter and renal pelvis cancer.

If you are worried about the pattern of cancer in your family, start by talking to your GP. If needed, they will refer you to a genetics specialist (see pages 16 to 19).

## Inherited bowel cancer genes

There are two main conditions caused by inherited gene mutations that are linked to bowel cancer:

- Lynch syndrome
- familial adenomatous polyposis.

### Lynch syndrome

Lynch syndrome (also called hereditary non-polyposis colorectal cancer, or HNPCC) can be caused by several different inherited gene mutations. People affected by Lynch syndrome have a higher risk of bowel cancer and some other types of cancer, including womb cancer.

Bowel cancer usually affects people over the age of 50. If you are diagnosed with bowel cancer before 50, there is a higher chance it may be caused by Lynch syndrome. Your doctors can test a sample of the bowel tumour for signs it was caused by Lynch syndrome. If the test shows a gene mutation is likely, you may have a genetic test to look for it.

We have more information about Lynch syndrome on our website (**macmillan.org.uk**).

## Familial adenomatous polyposis (FAP)

FAP is caused by an inherited mutation in a gene called the APC gene. This condition causes hundreds or thousands of growths in the bowel. These growths are called polyps. They usually start to appear when a person is in their teens. If the polyps are not removed, one or more of them will almost certainly develop into cancer. Less often, FAP may also cause other types of cancer.

We have more information about FAP on our website (**macmillan.org.uk**).

## Other inherited bowel cancer genes

There are other rare inherited conditions that can increase the risk of bowel cancer. These include:

- MUTYH-associated polyposis (MAP)
- juvenile polyposis syndrome
- Peutz-Jeghers syndrome
- serrated polyposis syndrome.

Genetic Alliance UK offers information and support about rare inherited conditions (see page 94 for contact details).

## Managing a higher risk of bowel cancer

If your family history or genetic test shows you have a higher risk of bowel cancer, there are ways to reduce that risk. This may include:

- bowel screening tests
- being aware of the symptoms of bowel cancer
- risk-reducing treatments
- lifestyle changes.

### Bowel screening tests

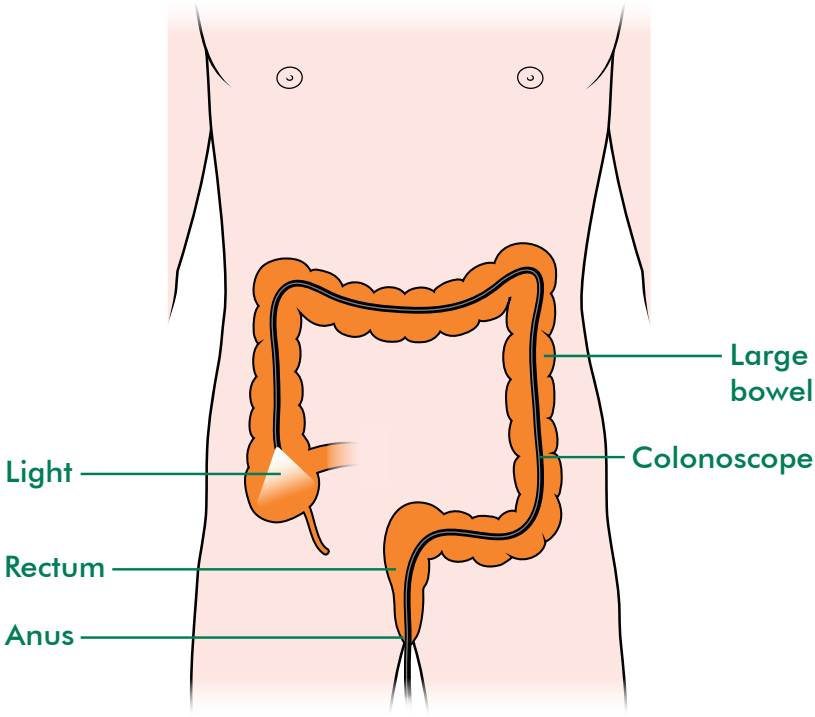
You may be offered a test called a colonoscopy. This checks for bowel cancer or polyps that may develop into bowel cancer. Your genetics specialist will explain whether you need this test, when you should start having it and how often.

A colonoscopy is done with a thin, flexible tube with a light and camera on the end (a colonoscope). Once you are lying on your side, the doctor or nurse gently passes the tube into your back passage and into the bowel (see the illustration opposite).

You may have a sedative before the test to help you relax. If you find the test uncomfortable or painful, you may be given Entonox®. This is a gas that can relieve pain. It is sometimes called gas and air. You breathe it in through a mouthpiece.

During the test, the doctor or nurse checks the lining of the bowel for polyps or abnormal areas. If there are small polyps, the doctor or nurse may remove these during the colonoscopy. They may also take small samples of any abnormal areas to test for cancer cells.

## A colonoscopy



Surgery is often the most effective way to treat or prevent bowel cancer. Your doctor may talk to you about having surgery to remove an area of bowel if a colonoscopy finds:

- changes that are very likely to develop into cancer
- cancer cells.

## Be bowel aware

When it is found early, bowel cancer can be treated very successfully. Try to be aware of changes that could be a sign of bowel cancer. See your GP if you have any of these symptoms:

- Bleeding from the back passage (rectum) or blood in your poo.
- Looser poo or diarrhoea that lasts for 3 weeks or more.
- A feeling that your bowel is not properly empty after going to the toilet.
- A pain or lump in the tummy or back passage.
- Loss of weight or appetite.
- Feeling more tired (fatigued) than usual for some time, with no obvious reason.

Bowel problems are very common, so these symptoms may not be caused by cancer. But if you have a higher risk of bowel cancer, it is important to get them checked.

## Risk-reducing treatments and Lynch syndrome

If you have Lynch syndrome, you may be offered the following treatments:

- **Aspirin** – Taking aspirin tablets regularly may help prevent cancer in people affected by Lynch syndrome. More research is needed to know what the most helpful dose is. Aspirin can also have harmful side effects.
- **Surgery to remove areas of healthy bowel** – If you have surgery to remove a bowel cancer, you may also decide to have areas of healthy bowel removed. This reduces your risk of more bowel cancers developing in the future.
- **Surgery to remove the womb and ovaries** – Women with Lynch syndrome may choose to have this surgery. It reduces the risk of womb and ovarian cancer. After the surgery, you will start the menopause if you have not already. This means you will no longer be able to get pregnant.

It is important to talk to your doctor about the side effects, risks and benefits of any treatment you are offered. If you have questions about fertility, you can ask to see a fertility specialist for further advice. If a treatment causes an early menopause, there are treatments that can help manage any symptoms.

## Risk-reducing treatments and FAP

For people affected by FAP, the only effective way to prevent bowel cancer is surgery to remove the large bowel. Most people choose to have bowel screening in the early stages for a while, before they have surgery. When the number of polyps increases, this may be a sign that surgery is needed.

Most people are advised to have surgery between the ages of 16 and 25. The thought of this may be stressful or difficult to cope with. Although surgery is very effective at preventing bowel cancer, there are risks and side effects. It is important to talk to your doctor about the side effects, risks and benefits of surgery before you make a decision.

## Healthy lifestyle

There may also be factors in your lifestyle that affect your bowel cancer risk.

We have more information about healthy living and cancer risk on pages 84 to 85.

# Breast and ovarian cancer

Breast cancer is one of the most common cancers in the UK. It affects 1 in 8 women (around 13%) and 1 in 870 men (around 1%) during their lifetime. Ovarian cancer is less common. 1 in 52 women (around 2%) will be diagnosed with ovarian cancer during their lifetime. Many people have someone in their family who is affected by one of these cancers. Only a small number of cases are clearly linked to inherited cancer genes.

## Understanding breast and ovarian cancer in your family

An inherited gene mutation that increases the risk of breast and ovarian cancer is more likely if there is a pattern of cancer in your family. These are examples of patterns:

- One of your first-degree relatives was diagnosed with breast cancer before the age of 40. First-degree relatives are your parents, brothers, sisters and children.
- Several family members have been diagnosed with breast cancer or ovarian cancer.
- A male relative was diagnosed with breast cancer.
- A relative had breast cancer in both breasts (bilateral breast cancer).
- You have a family history of cancer and you are from an Eastern European or Ashkenazi Jewish (Eastern European Jewish) background.

If you are worried about the pattern of cancer in your family, talk to your GP. If needed, they will refer you to a genetics specialist (see pages 16 to 19).

## Inherited breast and ovarian cancer genes

Inherited mutations in several different genes can cause an increased risk of breast and ovarian cancer.

### BRCA1 and BRCA2

The genes most often linked to breast and ovarian cancer are called BRCA1 and BRCA2. BRCA is short for BReast CAncer.

Women with an inherited BRCA1 or BRCA2 gene mutation have a higher risk of developing breast or ovarian cancer during their lifetime.

Men can also inherit a BRCA1 or BRCA2 mutation, but they are less likely to develop cancer because of it. They may have a higher than average risk of prostate cancer or breast cancer.

For both men and women, a mutation may also cause a slightly higher than average risk of some other types of cancer.

We have more information about BRCA1 and BRCA2 mutations on our website (**macmillan.org.uk**).

## PALB2, ATM and CHEK2

Women with an inherited mutation in the PALB2, ATM or CHEK2 genes have a moderate risk of developing breast cancer during their lifetime. Women who also have many relatives or younger relatives with breast cancer have a higher risk of developing it. They may also have a slightly higher than average risk of some other types of cancer.

One type of ATM mutation, called c.7271T>G, seems to cause a high risk of breast cancer in women.

Men can also inherit mutations in these genes, but they are less likely to develop cancer because of them.

## BRIP1, RAD51C and RAD51D

Women with an inherited mutation in the BRIP1, RAD51C or RAD51D genes have a moderate risk of developing ovarian cancer during their lifetime.

It is not known if it causes a higher risk of other cancer types in women or in men.

## Other inherited breast cancer genes

Other rare inherited conditions that can increase breast cancer risk in women include:

- Cowden syndrome
- hereditary diffuse gastric cancer
- Li-Fraumeni syndrome
- Peutz-Jeghers syndrome
- neurofibromatosis type 1.

These conditions are caused by inherited mutations in genes, including the TP53, CDH1, PTEN and SKT11 genes. There are also likely to be other gene mutations that we currently do not know about. This means some families have a clear pattern of breast or ovarian cancer, but genetic tests do not find a mutation.

Genetic Alliance UK offers information and support about rare inherited conditions (see page 94 for contact details).

## Managing a higher risk of breast and ovarian cancer

If your family history or genetic test shows you have a higher risk of breast and ovarian cancer, there are ways to reduce that risk. This may include:

- breast screening tests
- being aware of the symptoms of breast and ovarian cancer
- risk-reducing treatments
- lifestyle changes.

### Breast screening

Regular breast screening cannot prevent breast cancer. But it can often help find it at an early stage, when many breast cancers can be cured. Screening is done using breast x-rays (mammograms) or MRI scans.

Your genetics specialist will explain if you need these tests, when you should start having them and how often.

Our booklet **Understanding breast screening** has more information (see page 88).

‘Once I had understood my personal risk, I decided against surgery and now have regular mammograms to manage the breast cancer risk.’

**Daloni**

## Ovarian screening

So far in the UK, screening is not offered for ovarian cancer. This is because current screening tests cannot find ovarian cancer early enough to make it more treatable.

Researchers are still trying to find the most effective way to screen for ovarian cancer. Some women are offered screening as part of a clinical trial. Your doctor can explain if this is available and the possible risks and benefits of taking part in a clinical trial.

## Risk-reducing treatments

Women with a high risk of breast and ovarian cancer may be offered the following treatments:

- **Surgery to remove both breasts** – This reduces the risk of breast cancer by about 95%. We have more information about risk-reducing breast surgery (see pages 78 to 79).
- **Surgery to remove the ovaries and fallopian tubes** – This reduces the risk of cancer in and near the ovary by over 95%. Women who decide to have this surgery will start the menopause if they have not already. They will no longer be able to get pregnant.
- **Drug treatment** – Taking an anti-oestrogen tablet (such as tamoxifen, anastrozole or raloxifene) every day for 5 years can reduce the risk of breast cancer. The drugs used are not suitable for everyone and can cause side effects.

It is important to talk to your doctor about the side effects, risks and benefits of any treatment you are offered. If you have questions about fertility, you can ask to see a fertility specialist for more advice. If a treatment causes an early menopause, there are treatments that can help manage any symptoms.

‘Knowing about the BRCA2 gene mutation was hugely important in making decision about treatment. Having the double mastectomy was the right choice for me in the end.’

**Katy**

## Know your body

Cancer can often be successfully treated, especially when it is found at an early stage. Knowing what is normal for your body means you are more likely to recognise any changes that could be a sign of cancer. This means if you do develop a cancer, it can be treated as early as possible.

### Be breast aware

When it is found early, breast cancer can often be treated successfully. It is important to be aware of how your breasts and chest normally look and feel, so you can recognise any changes.

You could try checking in the bath or shower using a soapy hand, or when you are getting dressed. If you are not sure how to check your breasts and chest, ask your practice nurse or GP for advice.

Your breasts and chest will change as you get older and at different stages of your life. For women, this happens:

- before the menopause – breasts can feel different at various times of the month
- before you start a period – they may feel tender and lumpy, especially near the armpits
- after the menopause – breasts normally feel soft, less firm and not lumpy.

In most cases, changes to your breasts or chest do not mean you have cancer. But you should see your GP if you notice a change that is not normal for you, such as:

- a new lump or an area that feels thicker in your breast or armpit
- a change to your nipple, such as a rash, discharge or the nipple changing direction or turning in
- a change to the skin on your breast or chest, such as dimpling or redness
- a change in the size or shape of your breast
- constant discomfort or pain in one breast.

'I noticed that I had a lump in my breast. But I had always had very lumpy breasts during my periods, and I just ignored it. Then one morning in the shower, I noticed that my nipple had turned in.'

**Jodie**

## Know the signs of ovarian cancer

Your GP should offer cancer tests if you have any of these symptoms for no reason, or you get these symptoms regularly (especially if it is more than 12 times a month):

- A long-lasting bloated or swollen tummy.
- Feeling full quickly when you eat, or loss of appetite.
- Pain in the lower tummy or back.
- Peeing (passing urine) more often than usual or more urgently (feeling like you cannot hold on).

Other symptoms may include the following:

- A change in your normal bowel habit (diarrhoea or constipation).
- Weight gain or weight loss.
- Unexplained or extreme tiredness (fatigue).
- Vaginal bleeding after the menopause.

If you are aged 50 or older and develop symptoms of irritable bowel syndrome (IBS) for the first time, you should also have tests. IBS can cause bloating and changes in bowel habit, but it does not usually start after 50.

Most women with these symptoms do not have ovarian cancer, but it is important to get them checked.

## Healthy lifestyle

There may also be factors in your lifestyle that affect your breast and ovarian cancer risk.

We have more information about healthy living and cancer risk (see pages 84 to 85).

# Other inherited conditions

There are some rare inherited conditions that increase the risk of less common types of cancer. If you or a family member is affected by a rare inherited condition, you may want to contact Genetic Alliance UK for information and support (see page 94 for contact details).

## Hereditary diffuse gastric cancer

This causes a higher risk of stomach cancer and some other types of cancer.

## Familial melanoma

This is linked to skin cancer and sometimes pancreatic cancer.

## Von Hippel-Lindau syndrome (VHL)

This causes an increased risk of cysts or tumours in the:

- brain and spinal cord
- eyes and ears
- kidneys
- adrenal glands
- pancreas.

## Multiple endocrine neoplasia (MEN) syndromes

These are linked to benign growths and cancer in different endocrine glands. We have more information about MEN1 and MEN2 syndromes on our website (**macmillan.org.uk**).

## Li-Fraumeni syndrome

This causes an increased risk of several cancers from childhood onwards, including breast cancer, sarcoma, brain tumours and leukaemia.

# Other cancer types

There may be other genes we currently do not know about that probably increase the risk of cancer in some families. Researchers are trying to identify these genes. For example, it is likely that cancers of the testicle, pancreas, prostate, stomach or kidney sometimes run in families.

Having one relative with testicular, pancreatic, prostate, stomach or kidney cancer usually does not greatly increase your cancer risk. But if you are worried about several cases of one or more types of cancer in your family, talk to your GP.

If there is a chance there could be an unknown cancer gene in your family, you may be able to take part in a research study. You may be offered screening tests to help detect cancer early. You will also be told what symptoms to look for. This can help you find cancer earlier if it does happen.

# COPING WITH YOUR CANCER RISK

# Coping with a high risk of cancer

You may be told you have a high risk of developing a certain type of cancer because:

- you had a genetic test that found an inherited cancer gene
- the pattern of cancer in your family is likely to be caused by an unknown inherited cancer gene.

Even if you think you are prepared for this news, hearing it can come as a shock. Some people feel like they are being told they already have cancer. Others find that knowing the result helps them make choices to reduce their risk.

## Living with uncertainty

It is natural to want to know what is likely to happen, so you can plan for your future. Family history and genetic testing only lets us estimate levels of risk. It does not tell us who will definitely get cancer or when they will develop it. You may still have questions that have no clear answers. You may have to find ways to cope with the unknowns (see opposite page).

## Your family

Having an inherited cancer risk can affect relationships in a family. Genetic tests may show that some family members have a higher risk and others do not. This can make people feel angry or guilty.

Some families find their relationships become stronger. You may feel closer to some relatives or find you can rely on each other more than before.

Many people say that knowing about a higher cancer risk helps them make healthier lifestyle decisions for their whole family. We have more information about cancer risk and living a healthy lifestyle (see pages 84 to 85).

## Getting support

If you are struggling to cope with a high risk of cancer, talking about your feelings and worries may help. You can get support from your genetics specialist or your family and friends. You can also talk to our cancer support specialists on **0808 808 00 00**, or share your thoughts with members of our Online Community (**community.macmillan.org.uk**).

'My sister and her daughters are making the steps to protect themselves. Before, I told myself "knowledge is power", and it felt true in my head but not in my heart. Now it feels true in my heart too.'

**Daloni**

# Talking to children

Children in families with a gene mutation that can cause cancer in childhood or teenage years are offered genetic testing at an early age. This is so they can have screening or treatments to prevent cancer if needed.

But most inherited cancer genes do not increase the risk of cancer until adulthood. Usually, children in families with these types of cancer gene wait until they are older to think about genetic testing. This can make it harder for parents to decide when to tell them there is an inherited cancer gene in the family.

There are no rules about this. Every family is different. You know your child best and understand what is right for them. In general, parents say they think about their child's age, maturity and emotional state.

Some parents tell their child soon after finding out their family is affected. Other parents wait because they feel their child is too young, or it is not the right time because there are other things happening.

Here are some reasons parents give for telling a child:

- They want to be honest and open.
- They worry the child will find out by chance, for example by overhearing conversations.
- They want to help the child understand why a parent is having risk-reducing treatment or screening tests.
- They want to help the child understand and talk about cancer in the family. This can involve answering their questions and anything they do not understand.
- They want to help the child understand how this may affect them in the future.

## Preparing to talk to children

Before you talk to your child, you may want to:

- give yourself time to adjust to the news first
- decide whether you want to talk to your child alone or with someone else.

## What to tell children

Think about what you want your child to understand and what you think they can cope with. The following tips may help:

- Younger children only need a small amount of information. They often understand things slowly over time.
- Teenagers usually want to know more and ask more questions.
- Use language and words your child can understand. But try to use the correct words when you need to. For example, saying 'boob job' for mastectomy may seem less worrying. But it can also mean a child does not understand the seriousness of the operation.
- Talking to your child during an everyday activity, such as a walk, may help them feel more relaxed.
- Ask your child to tell you what they understand. If they have not understood something, you can explain again.
- Ask them how they feel and talk about how you feel.
- Ask them if they have questions.

‘I dreaded telling my daughters. Meeting a clinical psychologist helped. I decided to tell them, even though they cannot be tested yet. It’s an ongoing conversation, not a one-off.’

**Daloni**

Try to include positive messages when you talk with your child. You may find the following information useful:

- Having a gene mutation does not mean you have cancer or that you will definitely get cancer.
- Knowing you have the gene mutation gives you choices, like having screening tests or treatments. This can help reduce your risk.
- Your child may not have the gene mutation, but they can find out when they are ready.
- When your child is older, there may be even better treatments available.

## Answering questions

It is important that your child feels you are okay to answer questions. You can help by encouraging them to ask. Reassure them that you are happy to talk about it again. Let them know they can ask questions any time.

It is easy to give too much information. Always check what your child wants to know. Ask them 'What makes you ask that question?' before trying to answer.

Many children and young people do not ask questions because they are worried about upsetting their parents. Some may find it easier to write their questions instead of asking you face to face. There may also be another person you both trust who they can talk to.

Your genetics specialist can give you more information about talking to children and teenagers about your genetic test results.

# Managing your cancer risk

## Screening to find cancer early

Screening looks for early signs of cancer or for changes that happen before a cancer develops. There are different screening tests for different types of cancer.

Most types of screening aim to find cancers at an early stage when they are easier to treat. Some types of screening look for abnormal changes in cells that can develop into cancer. For example, bowel screening checks for pre-cancerous growths called polyps. This means you can have treatment to remove the growth before cancer develops.

## Treatments that reduce your risk

### Surgery

Some people with a high cancer risk decide to have risk-reducing surgery. This means removing the tissues that are at risk of getting cancer, for example the breasts or ovaries. This type of surgery is usually only offered to people with a very high risk, such as people who have inherited certain cancer gene mutations.

Surgery greatly reduces the risk of cancer, but it does not get rid of it completely.

No one can tell you if risk-reducing surgery is the right or wrong thing for you to do. It is your choice. It may depend on:

- your age
- whether you know for sure that you have an inherited cancer gene
- how you feel about the cancer risk and the treatment
- how you feel about other family members' experiences of cancer and treatment
- if you still want to have children (if surgery involves removing the ovaries or womb).

If you are thinking about having risk-reducing surgery, take your time to decide. You can get help and advice from doctors and counsellors.

Surgery has risks and possible side effects. It is helpful to discuss the benefits and disadvantages with your doctor. You may also want to talk it over with your family and other people you trust before making your decision.

If you decide to have risk-reducing surgery, you may also need to decide at what age to have it. Your genetics specialist can explain more, based on the type of gene mutation you have and the ages when your family members developed cancer. In general, the younger you are when you have risk-reducing surgery, the more likely it is to prevent cancer.

## Chemoprevention

Chemoprevention means taking a drug to reduce the risk of certain types of cancer. Some women who have a high risk of breast cancer may take anti-oestrogen tablets to reduce their risk. People with Lynch syndrome may take aspirin to reduce their risk of bowel cancer developing (see page 49).

Risk-reducing drugs may cause side effects and occasionally may cause serious complications. It is important to discuss the benefits and disadvantages with your doctor.

## Clinical trials

If you know you have an increased risk of getting cancer, you may be able to join a clinical trial. These look into genetic causes of cancer or ways of preventing it.

Taking part in a clinical trial is completely up to you. Ask your genetics specialist for more information.

Our booklet **Understanding cancer research trials (clinical trials)** has more information (see page 88).

## Fertility

Some risk-reducing treatments can affect your ability to get pregnant (fertility).

Surgery to remove the womb and ovaries will mean you cannot get pregnant. Chemoprevention for breast cancer may harm a developing baby, so your doctor will advise you not to become pregnant when taking this treatment. People usually take it for 5 years, which means you have less time to become pregnant.

If you are considering risk-reducing treatments that could affect your fertility, you can talk with your genetics specialist about this. You may think about starting your family earlier than you had planned. You can ask your doctor about ways of preserving your fertility. You can also ask to see a fertility specialist for more advice.

## Planning a family

If you have an inherited cancer gene, there is a 1 in 2 (50%) chance that any child you have could inherit it from you. Your genetics specialist can talk to you about this if you have questions.

Many people choose to have children and accept that the child may have a higher cancer risk. They may feel the child will have the same or perhaps better ways to manage that risk when they grow up.

If you have an inherited cancer gene and want to be sure you do not pass it on to any children, sometimes other options are available.

### Pre-implantation genetic diagnosis (PGD)

This test is done during in vitro fertilisation (IVF). Doctors collect egg and sperm cells from you and a partner. They use these to create embryos in the laboratory. They test these embryos for the cancer gene (PGD). The fertility specialist then transfers an embryo that does not have the cancer gene into the woman's womb.

PGD is not available to everyone. There are age limits, and funding may not always be available. PGD is only done in a few centres in the UK. You may need to travel some distance to have it. You can find more about PGD on the Human Fertilisation and Embryology Authority's website (**hfea.gov.uk**).

## Egg or sperm donation

Some couples decide to use:

- donor eggs (if the woman has the gene mutation)
- donor sperm (if the man has the gene mutation).

## Prenatal testing

Some couples choose to have a test early on during the pregnancy to check for the cancer gene. The couple can decide whether to continue with the pregnancy when they know the results.

# Health and lifestyle

There may be factors in your lifestyle that affect your cancer risk. For someone with no family history of cancer, the lifestyle factors that can help reduce their risk of cancer include:

- not smoking
- keeping to a healthy weight
- being physically active
- limiting alcohol intake (not regularly drinking more than 14 units of alcohol in a week)
- eating a healthy diet.

Many people who find out they have a high cancer risk decide to improve their lifestyle in these ways. Some people find a healthy lifestyle makes them feel they are doing everything they can to control their cancer risk.

There is not always clear evidence about how much these factors affect cancer risk in people with a family history of cancer. But there is strong evidence they improve your general health and well-being. Ask your genetics specialist for advice about your risks. Your genetics specialist, GP or practice nurse can give you more information about healthy living.

We have more information about healthy living in a range of formats (see page 88).

# FURTHER INFORMATION

# About our information

## We provide expert, up-to-date information about cancer. And all our information is free for everyone.

### Order what you need

You may want to order more leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets on different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer and information for carers, family and friends.

### Online information

All of our information is also available at **macmillan.org.uk/information-and-support** There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

### Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats** If you'd like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

## Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk** You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.

# Other ways we can help you

## At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you.

### Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

**Macmillan Support Line**
Our free, confidential phone line is open 7 days a week from 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

**Information centres**
Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

## Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That's why we help to bring people together in their communities and online.

### Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand.

Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

### Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

## The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

**Mal**

## Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

### Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

### Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

### Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area.

Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

## Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

### Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 9am to 5pm).

# Other useful organisations

## There are lots of other organisations that can give you information or support.

### AMEND
**www.amend.org.uk**
A patient support group helping people with multiple endocrine neoplasia (MEN) disorders and their related tumours. Has trained telephone and email buddies who are patients and carers affected by MEN.

### Bowel Cancer UK
**Tel** 020 7940 1760
**Email** nurse@bowelcanceruk.org.uk
**www.bowelcanceruk.org.uk**
Raises awareness of bowel cancer. Provides information and has an online forum for people to talk about their experiences.

### Breast Cancer Care
**Helpline** 0808 800 6000 (Mon to Fri, 9am to 4pm, Sat, 9am to 1pm)
**Email** info@breastcancercare.org.uk
**www.breastcancercare.org.uk**
Provides information and support across the UK. Offers accessible, high-quality services for everyone affected by breast cancer.

### Breast Cancer Now
**Tel** 0333 20 70 300 (Mon to Thu, 9am to 5pm, Fri, 9am to 4pm)
**Email** supporterengagement@breastcancernow.org
**www.breastcancernow.org**
Aims to fight breast cancer through research and awareness. Has information for women with a family history of breast cancer.

### FAP Gene Support Group
**Email** enquiries@fapgene.com
**www.fapgene.com**
FAP Gene Support Group gives information about FAP (familial adenomatous polyposis).

### Genetic Alliance UK
**Tel** 020 7831 0883
**Email** contactus@geneticalliance.org.uk
**www.geneticalliance.org.uk**
A national charity working to improve the lives of patients and families affected by all types of genetic conditions. They are an alliance of over 200 patient organisations.

### Ovacome
**Helpline** 0800 008 7054
(Mon to Fri, 10am to 5pm)
**Email** support@ovacome.org.uk
**www.ovacome.org.uk**
A national support group for everyone affected by ovarian cancer, including patients, families, friends, carers and health professionals.

### PolyPeople
**Email** contact@polypeople.online
**www.polypeople.online**
PolyPeople is a support group for people with polyposis syndromes.

### The Polyposis Registry
**Tel** 0208 235 4270
**Email** LNWH-tr.polyposisregistry@nhs.net
**www.polyposisregistry.org.uk**
The Polyposis Registry is the UK's only specialist centre for patients with a polyposis syndrome. The nurse practitioners run an advice line for anyone with a polyposis syndrome – you do not have to be one of their patients. It is based at St Mark's Hospital, Harrow.

### Prostate Cancer UK
**Tel** 0800 074 8383
(Mon to Tue, 9am to 6pm, Wed, 10am to 8pm, Thu to Fri, 9am to 6pm)
**www.prostatecanceruk.org**
Provides information on prostate cancer. A confidential helpline is available to anyone worried about prostate cancer.

## General cancer support organisations

### Cancer Black Care
**Tel** 020 8961 4151
**Email**
info@cancerblackcare.org.uk
**www.cancerblackcare.org.uk**
Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

### Cancer Focus Northern Ireland
**Helpline** 0800 783 3339
(Mon to Fri, 9am to 1pm)
**Email**
nurseline@cancerfocusni.org
**www.cancerfocusni.org**
Offers a variety of services to people affected by cancer in Northern Ireland.

### Cancer Research UK
**Helpline** 0808 800 4040
(Mon to Fri, 9am to 5pm)
**www.cancerresearchuk.org**
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

### Cancer Support Scotland
**Tel** 0800 652 4531
(Mon to Fri, 9am to 5pm)
**Email**
info@cancersupportscotland.org
**www.cancersupportscotland.org**
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

### Maggie's Centres
**Tel** 0300 123 1801
**Email**
enquiries@maggiescentres.org
**www.maggiescentres.org**
Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

### Tenovus
**Helpline** 0808 808 1010
(Daily, 8am to 8pm)
**Email**
info@tenovuscancercare.org.uk
**www.tenovuscancercare.org.uk**
Has mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

## General health information

### Health and Social Care in Northern Ireland
**www.hscni.net**
Provides information about health and social care services in Northern Ireland.

### NHS.UK
**www.nhs.uk**
The UK's biggest health information website.
Has service information for England.

### NHS Direct Wales
**www.nhsdirect.wales.nhs.uk**
NHS health information site for Wales.

### NHS Inform
**Helpline** 0800 22 44 88
(Daily, 8am to 10pm)
**www.nhsinform.scot**
NHS health information site for Scotland.

## Emotional and mental health support

### Mind
**Helpline** 0300 123 3393
**Text** 86463
**Email** info@mind.org.uk
**www.mind.org.uk**
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

### Samaritans
**Helpline** 116 123
**Email** jo@samaritans.org
**www.samaritans.org**
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

## Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

## Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Marc Tischkowitz, Reader and Honorary Consultant Physician in Medical Genetics.

With thanks to: Nicola Bradshaw, Macmillan Principal Genetic Counsellor; Jennifer Gorrie, Cancer Genetic Counsellor; Professor Shirley Hodgson, Consultant Clinical Cancer Geneticist; and Alexandra Murray, Consultant Clinical Geneticist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

## Sources

We've listed a sample of the sources used in the publication below. If you would like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Balmana J, et al. Familial risk-colorectal cancer: ESMO clinical practice guidelines. Annals of Oncology. 2013. 24 (s6): vi73-vi80.
Cairns SR, et al. Guidelines for colorectal cancer screening and surveillance in moderate and high risk groups (update from 2002). Gut. 2010. 59: 666-690.
NICE Guidance. Familial breast cancer: classification, care and managing breast cancer and related risks in people with a family history of breast cancer. Clinical Guideline [CG164]. 2013. www.nice.org.uk/guidance/cg164 [accessed October 2017].

# Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.


**Share your cancer experience**
Support people living with cancer by telling your story, online, in the media or face to face.

**Campaign for change**
We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

**Help someone in your community**
A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

**Raise money**
Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

**Give money**
Big or small, every penny helps. To make a one-off donation see over.

## Call us to find out more

# 0300 1000 200

**macmillan.org.uk/getinvolved**

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Security number

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Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

**This booklet is about cancer and genetics. It is for anyone who is worried cancer might run in their family or has been told there is a higher risk of cancer in their family.**

**It explains how genes affect the risk of developing cancer. It also gives information about genetic testing, understanding test results and ways to manage a higher risk of cancer.**

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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