WE ARE MACMILLAN. CANCER SUPPORT

A practical guide to living with and after cancer

CANCER GENETICS

HOW CANCER SOMETIMES RUNS IN FAMILIES

About this booklet

This booklet is for people who are worried cancer might run in their family because a number of relatives have had it. It is also for people who have been told there is a cancer gene in their family and want to know how this may affect them. We hope it answers any questions you may have.

If you don't have at least two relatives with the same type of cancer on the same side of your family, this booklet probably isn't relevant to you. Only a small proportion of cancers, up to 5 out of 100 cases (5%), are clearly linked to an inherited 'cancer gene'.

Throughout this booklet, we've included quotes from people who have a genetic risk of cancer. We've changed some names. These quotes are from people who've chosen to share their story with us. To share your story, visit **macmillan.org.uk/cancervoices**

If you want to talk about anything in the booklet, call the Macmillan Support Line on **0808 808 00 00**. It's open Monday–Friday from 9am–8pm. This is a free service. If you're hard of hearing you can use textphone **0808 808 0121**, or Text Relay. For non-English speakers, interpreters are available. Or you can visit **macmillan.org.uk**

How to use this booklet

We have divided this booklet into sections. You can go straight to any section or chapter in the booklet and start reading from there.

It's fine to skip sections that aren't relevant to you. For example, if the main cancers in your family are breast and ovarian cancer, there is no need to read the sections on bowel cancer or other inherited cancers.

Looking into cancer in the family can be very emotional. There is some information on coping with a high risk of cancer on pages 61–62. You will also find useful addresses, helpful books and websites at the end of the booklet (see pages 80–83). We've included a notes pages for you to write down any questions you may have (see pages 84–85).

If you find this booklet helpful, you could pass it on to your family or friends. They may also want information so they can support you.

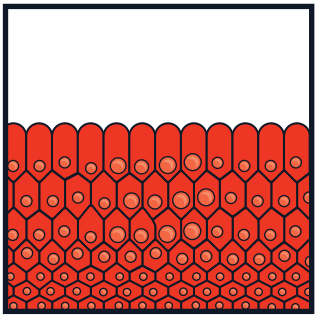
Contents

GENES AND INHERITED CANCERS

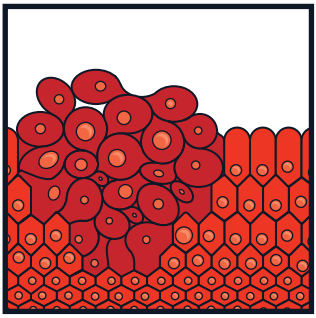
Cancer and genes

Our body is made up of tiny building blocks, called **cells**. Cancer develops when some cells are damaged and our body can't repair them. The damaged cells keep growing out of the body's control. These are cancer cells.

Normal cells



Cells forming a tumour



There are **genes** in every cell. All cancers are caused by changes (mutations) in genes. Genes contain the information a cell needs to work properly. This information is in a code called **DNA** (deoxyribonucleic acid).

Our body needs to make new cells to replace old or damaged ones. Genes control this process. They also tell cells how to repair damage. If a cell can't be repaired, or is not needed, genes inside the cell tell it to die.

The genes that control cell growth, repair and death are called **oncogenes** and **tumour suppressor genes**. Mutations in these types of gene can increase the chance of cancer developing.

Oncogenes

These genes encourage cells to grow and multiply. A mutation in an oncogene can lead to a cell growing and multiplying out of control.

Tumour suppressor genes

These genes help protect against cancer. They control cell growth. They also repair damage to DNA.

If a cell has a mutation in a tumour suppressor gene, it may lose the 'brakes' on its growth. The cell can then multiply out of control.

Some tumour suppressor genes repair damage to DNA. Doctors call them **DNA repair genes** or **caretaker genes**.

When there is a mutation in a DNA repair gene, the cell can't repair damage to itself. So cancer is more likely to develop.

Acquired mutations

Most cancers develop because of gene mutations that happen during a person's lifetime. Doctors call these mutations **acquired mutations**.

Acquired gene mutations happen in the part of the body where the cancer later develops. For example, gene mutations happen in the lungs before lung cancer develops.

Many things can cause gene mutations. These include:

- getting older
- things in our environment such as tobacco and sunlight
- our hormones
- our diet.

Doctors call substances that increase the chance of gene mutations **carcinogens**. Radiation and the chemicals in cigarette smoke are examples of carcinogens.

Usually, several gene mutations must happen in a cell before cancer develops. This can take many years. This is why cancer is more common in older people. Cancers caused by gene mutations that happen during someone's lifetime are called **sporadic cancers**.

Genes and inheritance

We inherit our genes from our parents. Everyone has two copies of each gene; one from their mother and one from their father.

Some people are born with a gene mutation that puts them at higher risk of getting cancer. Inherited mutations that make cancer more likely are called **inherited cancer genes**. Doctors may also call them **cancer predisposition genes** or **cancer susceptibility genes**.

If you inherit a gene mutation, it is in all your cells. This includes the sperm cells in men and the egg cells in women. So there is a 50% (1 in 2) chance of passing the gene mutation on to any children.

Inheriting a cancer gene doesn't mean you have cancer. But, it does mean you have an increased risk of developing certain types of cancer. Further gene changes (acquired mutations) need to happen for a cancer to develop.

How genes are passed on

Doctors call cancers that develop in a family because of an inherited cancer gene **inherited cancers** or **hereditary cancers**.

Inherited cancers often develop at a younger age than sporadic cancers. Most inherited cancer genes don't increase cancer risk until people are adults. But a few inherited cancer genes increase the risk of cancer in children (see pages 30–31).

Can cancer genes 'skip' a generation?

Cancer genes cannot 'skip' a generation. There is a 1 in 2 (50%) chance of inheriting the gene from one of your parents. So you either inherit it or you don't. If you don't inherit the gene, you can't pass it on to your children. But not everyone with the mutation develops cancer. So it can seem that the cancer skipped one generation.

The gene mutations for female cancers such as breast or ovarian cancer can pass through the father's side of the family. Men who have the cancer gene for breast and ovarian cancer often don't develop cancer. But they still have a 50% chance of passing the cancer gene on to their children.

If a daughter inherits a cancer gene from her father and develops breast cancer, it can seem as if the cancer gene has skipped a generation. But this isn't the case. The mutation can't skip a generation.

Inherited cancer genes

If a particular type of cancer occurs in a family more than in the general population, some people in the family may have an **inherited cancer gene**.

Scientists have found inherited cancer genes for some common cancers. These include cancers of the **breast**, **bowel**, **ovary** and **womb**.

There are other cancers that happen in some families more than usual. These include prostate, pancreatic and testicular cancers. But doctors haven't found specific inherited cancer genes for these cancers yet.

Sometimes, there are many different types of cancer in a family. Usually, these are sporadic cancers (see page 8) and are due to risk factors such as age, lifestyle and the environment. But some inherited cancer genes can increase the risk of more than one type of cancer.

When cancers happen together

There are two main patterns where cancers happen together:

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

Other rare patterns of cancers can happen.

Low-risk genes

Not all families with more cancers than usual have an inherited cancer gene. But some families may share several genes, which increase their risk of certain cancers. These genes have a weaker effect on the risk of cancer than inherited cancer genes. They are sometimes called **low-risk** or **low-penetrance** genes.

Scientists have found several of these genes. But the effect of each gene on its own is small. And there aren't tests available to check for them. Researchers are trying to find out how these genes interact with other risk factors to affect cancer risk.

ASSESSING YOUR RISK OF CANCER

If you're worried about cancer in your family

Most cancers aren't caused by inherited cancer genes. If only one or two older relatives have had cancer, your family is not likely to have a cancer gene. If you think cancer might run in your family, talk to your GP. They will ask you about any close blood relatives who have had cancer. People you are related to by marriage are not blood relatives. Close relatives are parents, brothers, sisters, sons, daughters, aunts, uncles and grandparents.

When cancer may run in a family

It's possible your family may have an inherited cancer gene if:

- two or more close blood relatives on the same side of the family had the same type of cancer
- members of your family have had cancer at a young age (under 50)
- certain cancers have occurred on the same side of the family (see pages 8–10)
- a close relative has had more than one primary cancer, which means that they have had cancer twice, but the second cancer was a new cancer and not the first cancer spreading to another part of the body
- you have a family history of cancer and have Polish, or Ashkenazi Jewish (Eastern European Jewish) ancestry – certain inherited cancer genes are more common than in the general population.

Your GP may ask you questions to assess your risk of cancer (see pages 24–25). This is based on your family history of cancer. If your GP thinks cancer may run in your family, they will refer you to a genetics specialist. This could be in a family cancer clinic or a cancer genetics clinic.

After referral to a genetics clinic

You may wait for a few weeks or months before you see a genetics specialist.

Genetics specialists use your family history to work out if there might be an increased risk of cancer in your family. They will use your GP's referral but may need more information.

They may send you a family history form to fill out and send back to them before your meeting. This will usually ask you:

- the names and ages of your family members (this usually begins with grandparents)
- their relationship to you
- whether they are on your mother's side or father's side of the family
- what cancers your relatives have had
- at what age were they diagnosed.

Some of this may be difficult. For example, if you have to speak to family members you haven't been in touch with for a long time. Or talking about these issues may bring back painful memories. Some family members may have different feelings about looking into cancer in the family.

Don't worry if you aren't able to find out all the facts. Your genetics specialist will understand.

There are cancer registries across the UK. Genetics specialists can check them to find which cancers people have had in the last 20 years. They can use this to find out some of the information if necessary. They will need permission from your living relatives who have had cancer before they can check their health records.

Your family history of cancer may not show a clear pattern of inherited cancers in your family. In this case, the genetics clinic may decide you are unlikely to have a high risk of cancer and don't need an appointment to see them. The clinic should tell you of their decision in a letter. But sometimes this doesn't happen. So, if you don't hear about your referral after a few months, check with your GP.

Sometimes, the genetics clinic may decide you are unlikely to have inherited a cancer gene. But they may suggest you have extra screening based on your family history.

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

Your cancer risk assessment is based on your family history. If there is a new diagnosis of cancer in your family in the future, this may change your risk. You can always go back to your GP for a further assessment if your family history changes.

'The counsellor drew up a family tree back to my grandparents' siblings. I had to go through every person and points would be allocated for every case of breast or ovarian cancer. You have to have a certain number of points before they agree to a test.'

Hazel

Genetic counselling

When you go to the genetics clinic you will meet a genetics specialist.

The meeting will last between 30–60 minutes. The genetics specialist will draw up a simple family tree. It will show all your close blood relatives and their illnesses.

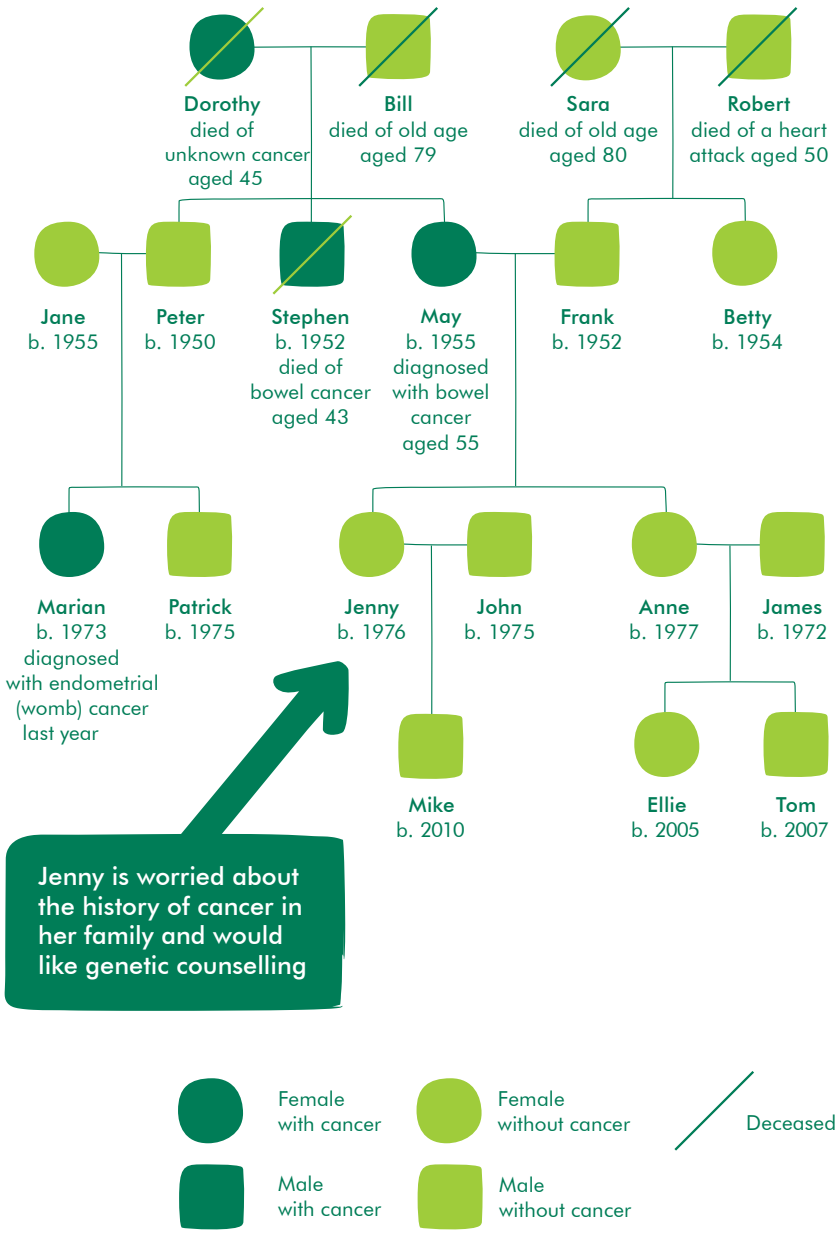
The genetics specialist will use this to assess your risk of developing cancer (see page 24–25).

You'll be able to discuss whether a genetic test might be appropriate for you (see page 26–28). They will also explain the benefits and limitations of genetic testing.

You will have the chance to talk about ways of managing your risk. This will include information about screening (see page 67) and risk-reducing treatments (see pages 67–69).

There is a video on our website of a genetic counsellor. They explain what genetic counselling is and the issues around genetics and cancer. Visit **macmillan.org.uk/geneticcounselling**

Example of a family tree for a family with a suspected 'cancer gene'



Getting the most out of your consultation

It's a good idea to write down your questions before the consultation. This will help you remember what you want to ask. You could use pages 84–85 to do this. Here are some suggestions of 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'm not at high risk of getting cancer, will I get any follow-up?
- What 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 consultation such as your partner, if you have one, or a relative or friend. You can share your thoughts afterwards.

If there is something you don't understand, tell your genetics specialist so they can explain. You can also see them again if you have more questions later on. You will usually get a letter after the meeting covering 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 deciding whether to refer you to a genetics clinic.

You will be asked:

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

Based on this information they may assess your risk of getting a certain cancer as one of the following:

- **Average risk (population risk)** – Your risk is the same as, or close to, that of people without a family history of the cancer. You're more likely not to get the cancer than to get it.
- **Moderate risk (raised risk)** – Your risk is higher than average. But it's not likely there is an inherited cancer gene in the family. You are more likely not to get the cancer than to get it.
- **High risk** – You have a high risk of developing the cancer in your lifetime. But it doesn't mean you'll definitely get it. There may be an inherited cancer gene in your family.

Knowing your cancer risk can help you decide what to do to reduce it. This might include treatments to prevent cancer and screening to find it early.

Before having a genetic test

Your genetic specialist may talk to you about having a genetic test. They will usually do this if your family history shows you have a high risk of developing the cancer. Or if a close blood relative has had a test that found an inherited cancer gene.

There are several things to think about before having a genetic test. We have listed some of the possible advantages and disadvantages of having a genetic test on the following page.

It's natural to want genetic testing to find out you have not inherited a cancer gene. But you also need to prepare yourself for the news that you have a cancer gene.

You may also want to think about how you feel about screening and other options for reducing your cancer risk (see pages 67–69).

'Before you undergo having a genetic test, it's important to know that you can handle the answer, because it's not a piece of knowledge that you can unknow.'

Becky

Possible advantages

- If you find out you have a cancer gene mutation, this may help you to decide how to reduce your risk. Your options may include having screening to find cancer early, making lifestyle changes or having treatments to reduce your risk of getting cancer.
- If the test shows you don't have the cancer gene mutation in your family you won't need to consider extra screening or risk-reducing treatments. You will know you can't pass on the cancer gene to any children you have.

Possible disadvantages

- If the test finds you have a cancer gene mutation, you may feel more worried about getting cancer (see pages 60–61).
- Tests don't always give a clear answer. Some tests find a change in a gene but it isn't known how this affects your cancer risk. There is more information about variants of uncertain significance on page 37.
- If a test doesn't find a gene mutation in the family, doctors may still assess your risk as high based on your family history.
- If you have a test that finds a cancer gene mutation, you will need to decide whether or how to tell relatives. Many people find this difficult.
- Insurers can't ask you about the results of a genetic test for a cancer gene mutation. But this could change in the future (see page 28).

Through the testing process, you may find out things about your family that you didn't know before. If you find out you are not related by blood to one or both of your parents, you won't have the same genes as other family members. If this happens, there are people such as professional counsellors who can help if needed.

Insurance

Some people worry insurance companies may discriminate against them if they have a genetic test. There isn't a law to prevent this. But the Association of British Insurers (ABI) and the government have agreed to a temporary ban on asking people for the results of genetic tests for cancer. This is called the **Concordat and Moratorium on Genetics and Insurance**.

The Moratorium is in place until 2019 and will be reviewed in 2016. This means that the situation may change after the Moratorium expires in 2019.

The details of the agreement can be found online on the ABI's website (**abi.org.uk**). You can get a leaflet called **Genetic tests and insurance: what you need to know** from the ABI website or by contacting them.

If you've had cancer already, or if several close relatives had cancer when they were younger, companies may increase your premium just because of your family history.

The same applies for private health insurance for cancer care and treatment. If you (or a high number of your relatives) have had cancer already, it will be harder (and more expensive) to get insurance cover.

If you have a predictive genetic test that shows you have not inherited the cancer gene in your family, you can tell insurers this. It may help to reduce your insurance premiums.

Confidentiality

Your doctor cannot tell anyone you have had a genetic test, or the result, without your consent.

When they take your blood for the genetic test, they may ask if they can also take a sample for cancer genetics research. This may help scientists to find other cancer genes in the future. The sample is handled by other scientists who won't know your personal details.

If you're concerned about the confidentiality of your blood test information, ask your doctor or nurse about it. They will explain how your sample will be handled and who has access to it.

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

Helen

Genetic testing

Usually a person in the family who has had cancer has the test first. If a cancer gene is found, other members of the family can choose to have a test.

Sometimes, no living relative with cancer can be tested. In this case you may be offered a genetic test. But only if your family history strongly suggests there could be a cancer gene in your family.

If you have a family history of cancer, and have Ashkenazi Jewish or Polish ancestry, you may also be able to have a genetic test without a relative who has had cancer being tested first.

You can watch our video of Wendy talking about her experience of having genetic testing on our website **macmillan.org.uk/genetictesting**

Genetic testing in children

Most cancer genes don't cause cancers in children. Because of this children aren't usually tested. Once they become adults they can make their own decisions about testing.

There are some exceptions to this. The main one is **familial adenomatous polyposis (FAP)**. The FAP gene can cause growths in the bowel (polyps) from the age of 13. Because of this, young people with FAP usually have bowel screening from the age of 12 (see pages 43–44).

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

- **Multiple endocrine neoplasia type 2 (MEN2)** which can cause medullary thyroid cancer in young children.
- **Von Hippel-Lindau (VHL)** which can cause non-cancerous growths in the body in childhood as well as cancer in the kidney in young adults.
- **Li Fraumeni syndrome** which increases the risk of cancer in childhood.

We have information about MEN2 that we can send you. Contact our support line on **0808 808 00 00**.

Genetic testing – a two-step process

Genetic testing is usually done in two stages. These are the **mutation search** and **predictive testing**.

Step 1 – mutation search

First, the laboratory looks for the cancer gene that may run in your family. They do this on a blood sample from a member of your family who has had cancer. Doctors call this the mutation search. It usually takes up to about eight weeks for the results to be available.

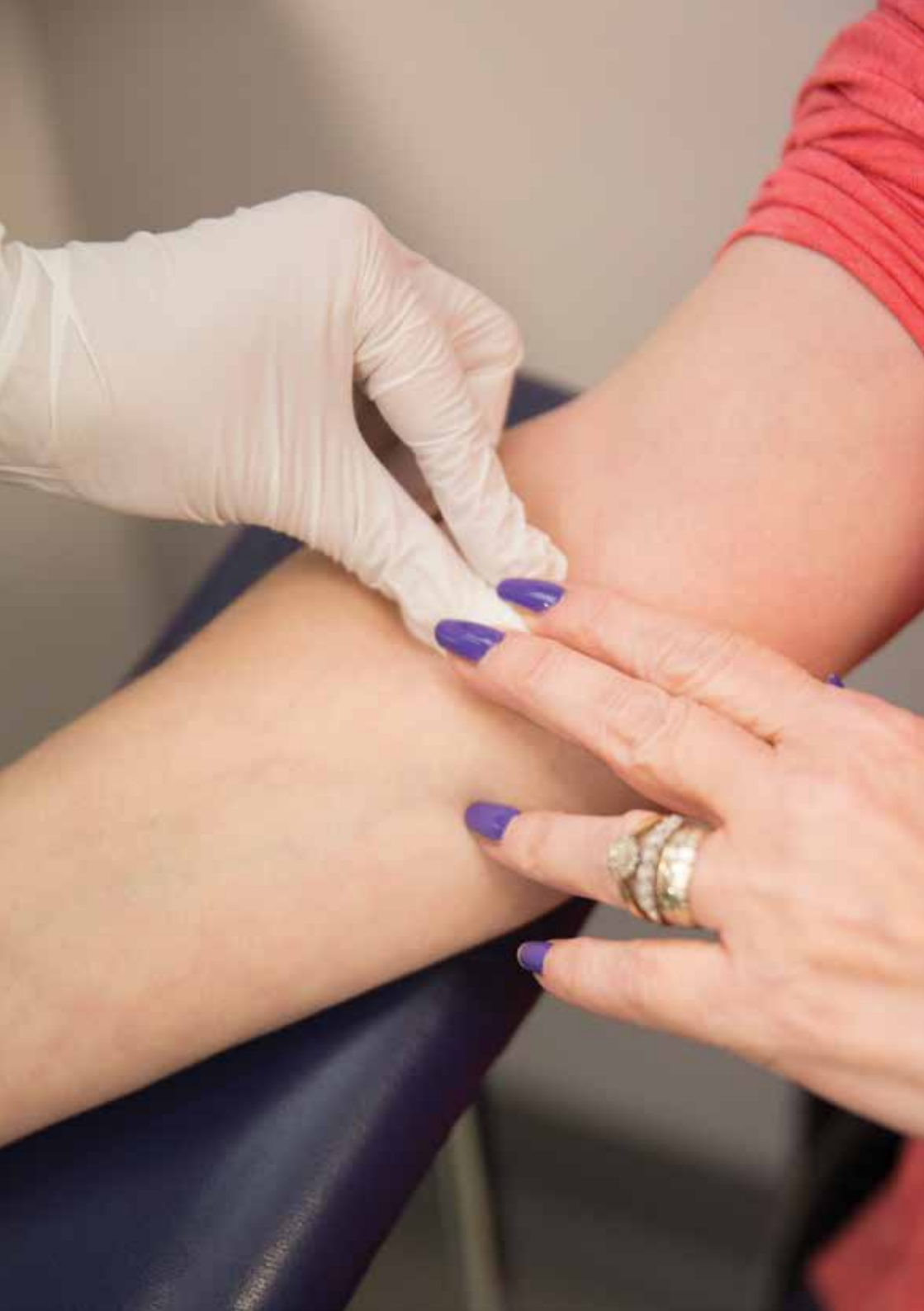
Results of a mutation search may:

- find a cancer gene mutation
- not find a cancer gene mutation
- find a gene mutation that isn't known to cause cancer.

Step 2 – predictive testing

If the mutation search finds a cancer gene mutation, you and other family members can have a genetic test. Doctors call this predictive testing.

Predictive testing is faster than mutation searching. This is because the laboratory knows which gene change to look for and where to find it.



If a cancer gene mutation is found

This means you have inherited a cancer gene. This gene increases your risk of getting a specific cancer. Doctors sometimes call this a positive test result.

Other members of the family

If you have an inherited cancer gene, you may wish to tell family members so they can decide whether to have genetic counselling and predictive testing. This can identify who in your family has an increased risk of getting cancer and who doesn't.

Medical test results are always confidential. Because of this, no one but you can tell your relatives about your test results.

Your genetics specialist may give you a letter you can give to family members. It will help explain the results and what it may mean for them. Their GP can refer them to their nearest genetics clinic or family cancer centre.

'I have been to see a genetics consultant and he recommended that my daughters be screened from their late 20s, which I'm happy with.'

Olivia

Family members who find they have not inherited the gene mutation in the family have a much lower risk of getting cancer. But it doesn't mean they definitely won't get cancer. They still have the same risk of getting cancer as people in general.

They won't need extra screening or risk-reducing treatments. But they should still consider taking part in national screening programmes for the general population when invited to do so.

Your feelings

Talking about a cancer gene in the family can be difficult. People often worry about when and what to tell their children if they find out they have an inherited cancer gene. You can read more about this on pages 62–66.

It's important to remember that having a cancer gene mutation isn't your fault. No one is to blame for the genes they inherit or pass on.

Families sometimes have feelings of guilt, blame or responsibility. But, the genes we inherit and pass on is down to chance. We are no more responsible for inheriting a cancer gene than we are for our eye colour.

Your genetics specialist can help you talk through your feelings. The organisations listed on pages 80–83 can also offer support. You can call our cancer support specialists on **0808 808 00 00**.

If a cancer gene mutation is not found

If the mutation search does not find a cancer gene mutation, doctors call this **no mutation detected** or **NMD**.

Genetic testing does not always find a cancer gene in the family even if there is a strong family history.

There are several possible reasons for a test not showing a gene mutation:

- There is a gene mutation in the family but it is in a gene that doctors have not yet identified.
- There are several 'low-risk' genes in the family. These, in combination with environmental factors, can still increase the risk of cancer (see page 13).
- The cancers in the family are not due to an inherited cancer gene. The cancers have happened by chance or for other reasons we don't understand.

Your feelings

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

You may feel relieved that a gene mutation, which greatly increases the risk of cancer, hasn't been found. But this result also means that you can't know for certain if cancer is an inherited problem in your family. And it's not possible for you to find out your individual risk of cancer.

Your doctor and genetics specialist may still consider you at increased risk of cancer based on your family history. This means that you may be offered screening (see page 67). Some people are also offered risk-reducing treatments (see pages 67–69). But deciding about having risk-reducing treatment can be more difficult when you don't have definite information about your risk.

You may decide to make certain changes to your lifestyle to improve your general health. This may include giving up smoking, eating a healthy diet and being more physically active (see page 72).

Genetic mutations of uncertain significance

Sometimes a genetic test finds a mutation in a gene. But the mutation has not been clearly linked with increased cancer risk. Doctors call this a **variant of uncertain significance (VUS)**. This means it is unclear whether the gene mutation is the cause of the cancers in your family.

Because of this, the genetics specialist cannot offer predictive testing to other people in your family. But they may ask for samples from them to try to get more information. These extra tests may help them to decide if the gene mutation (VUS) is the reason for a family history of cancer.

You may also be asked to keep in contact with the genetics clinic. This is in case they discover more about the particular mutation found in your gene in future.

INHERITED CANCERS

Bowel cancer

Bowel cancer is the third most common cancer in the UK for men and for women.

Every year, more than 40,000 people develop it. If you have one older relative who had bowel cancer, it's unlikely you will have a significantly increased risk.

General risk factors for bowel cancer include getting older, eating foods such as red meat and processed meats and being overweight.

Our leaflet **Are you worried about bowel cancer?** has more information on the risk factors for bowel cancer. You can order a free copy from our website **be.macmillan.org.uk**

Up to 5% of bowel cancers are linked to inherited cancer-susceptibility genes. This means about 19 out of every 20 people (95%) with bowel cancer don't have an inherited type of bowel cancer.

In families with an inherited bowel cancer gene, there will usually be two or more blood relatives with bowel cancer. The cancers may have developed at a younger age than usual.

If you're worried about your family history of bowel cancer

You may want to talk to your GP if you have:

- a close relative who developed bowel cancer under the age of 50
- two or more close blood relatives on the same side of the family with bowel cancer, womb cancer or cancer of the kidney, ovary, stomach or ureter, at any age.

Close relatives are your parents, children, brothers, sisters, aunts, uncles and grandparents.

The GP will assess your family history and may refer you to a genetics clinic or for genetic counselling (see page 20–22).

Genetic testing

If a cancer genetics specialist thinks your family is likely to have an inherited bowel cancer gene, you may be offered genetic testing. A person in the family who has had bowel cancer will usually need to have the test first before anyone else can be tested.

There is more information on genetic testing on pages 30–32.

If genetic testing can't be done or you decide not to have it, you will be offered screening according to your estimated risk of bowel cancer. See page 45 for more information.

Bowel cancer under 50

People who get bowel cancer before the age of 50 may have another type of genetic test when they are diagnosed. Doctors may test cancer cells from the bowel tumour for:

- a genetic trait called **microsatellite instability** (MSI)
- changes in **mismatch repair** (MMR) genes.

If either of these are found, the cancer may be due to an inherited gene mutation.

The doctor will then offer genetic testing to look for an inherited bowel cancer gene. This test is done on a blood sample.

Inherited bowel cancer

There are two main types of inherited bowel cancer:

- **Lynch syndrome,** also called hereditary non-polyposis colorectal cancer (HNPCC) – linked to up to 4 in 100 bowel cancers (4%).
- **Familial adenomatous polyposis** (FAP) – linked to fewer than 1 of 100 bowel cancers (1%).

Lynch syndrome

Lynch syndrome is the most common cause of inherited bowel cancer. It causes non-cancerous growths (polyps) in the bowel. If these are not removed, they can develop into bowel cancer.

Lynch syndrome can also increase the risk of cancers of the womb, ovary, stomach, prostate, kidney and ureter (the tube that connects the kidney to the bladder).

If someone has Lynch syndrome, there is a 1 in 2 chance (50%) that they will pass on the cancer gene to any children. There is an illustration on page 9 that shows how cancer genes can be passed from parents to children.

People with Lynch syndrome have a high risk of getting bowel cancer. They will be offered 1–2 yearly bowel cancer screenings (see page 45). This usually begins by the age of 25. They may also be offered screening for other types of cancer and risk-reducing treatments.

We can send you more information about Lynch syndrome. Call us on **0808 808 00 00**.

Familial adenomatous polyposis (FAP)

With FAP, hundreds or thousands of polyps develop in the bowel. They start during teenage years. Without treatment there is a high chance that some polyps will develop into cancer.

There is a 1 in 2 chance (50%) that someone with FAP will pass on the faulty gene to their child. If a child inherits the faulty gene, they will develop FAP.

In about 1 in 4 people (25%) with FAP, there is no history of FAP in the family. The person has probably developed it due to a new change (mutation) in the gene causing FAP. Their children will still have a 1 in 2 chance (50%) of inheriting the cancer gene mutation.

People who have the gene for FAP will have yearly bowel screening from about the age of 12. They will also be offered risk-reducing surgery.

We can send you more information about FAP. Call us on **0808 808 00 00**

Other rare gene mutations

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

- **MYH-associated polyposis (MAP)**
- **juvenile polyposis**
- **Peutz Jeghers syndrome**.

MYH-associated polyposis (MAP) is inherited in a different way from other cancer gene mutations covered in this booklet. A person needs two copies of the faulty MYH gene, one from each parent, to develop MAP. This makes it far less likely for children to inherit MAP. Both their parents would need to carry the MYH gene mutation, and the child would need to inherit the faulty copy from both parents.

People with MAP, juvenile polyposis and Peutz Jeghers syndrome are offered regular bowel cancer screening. This is done every 1–3 years depending on the condition. Most people will have begun bowel screening by the age of 25.

Screening if you have an increased risk of bowel cancer

Your specialist will offer you bowel screening if your family history suggests you have an increased risk of bowel cancer.

Screening can help find polyps or bowel changes that can lead to cancer. It can also detect cancer at an early stage when treatment is more successful.

For the screening, you'll have a colonoscopy. A thin, flexible tube with a camera at the end is inserted into your back passage (rectum) and up into your bowel (colon). This allows the doctor or nurse to see whether there are polyps or tumours developing inside your bowel.

The doctor or nurse can remove small polyps during the colonoscopy. If there are pre-cancerous changes or a tumour, doctors usually recommend surgery to remove that section of bowel.

How early you start bowel cancer screening and how often it's done depends on your estimated risk.

Bowel cancer awareness

Bowel cancer can often be successfully treated, especially when it is discovered at an early stage. It's important to be aware of symptoms that might mean you have cancer so that, if you do develop it, it's found as early as possible.

You should always see your family doctor if you have:

- blood or mucus in your bowel motions
- a change in bowel habits that lasts for more than three weeks
- tiredness that doesn't get better after three weeks
- weight loss you can't explain.

These symptoms can be due to other causes but it's important to get them checked.

It's also important to tell your doctor about your family history of bowel cancer.

Reducing your risk of bowel cancer

There are also things you can do that may reduce your risk of bowel cancer. You can find some advice on pages 67–69.

Breast and ovarian cancer

Breast cancer is a common cancer. It affects about 1 in 8 women (12.5%) in the UK. If you have just one, or even two, older relatives with breast cancer, it is unlikely your risk is greatly increased.

Most breast cancers (19 in 20 or 95%) and ovarian cancers (17 in 20 or 85%) are not due to an inherited cancer gene.

The genes most commonly involved in inherited breast and ovarian cancer are the **BRCA1** and **BRCA2 genes**. BRCA is short for **BR**east **CA**ncer.

Doctors estimate that women with BRCA1 or BRCA2 mutations have a 45–85% risk of developing breast cancer in their lifetime.

BRCA1 and BRCA2 also affect the risk of ovarian cancer. Doctors estimate that women with BRCA1 have a 25–50% chance of getting ovarian cancer in their lifetime. For women with BRCA2, the risk is estimated to be 15–30%.

BRCA2 mutations can also increase the risk of other cancers but by a smaller amount. These include prostate cancer in men, melanoma, and pancreatic cancer.

Mutations in other genes, including the **TP53 gene**, **PTEN gene** and **SKT11 gene,** can also affect the risk of breast cancer but these are much rarer. Not all the genes involved in causing a high risk of breast cancer have been identified.

If you're worried about your family history of breast and ovarian cancer

If any of the following are present on the same side of your family, you may be at increased risk:

- three close relatives have developed breast cancer at any age
- two close relatives have developed breast cancer under 60
- a close relative has developed breast cancer aged 40 or younger
- a close male relative with breast cancer
- a close relative with breast cancer in both breasts or who has had breast cancer twice (not breast cancer that has come back)
- a close relative has had a type of breast cancer called triple negative cancer before the age of 50
- a close relative who has had a type of ovarian cancer called high-grade serous papillary ovarian cancer before the age of 60
- a close relative who has had ovarian cancer and a close relative diagnosed with breast cancer when they were under 50 (this can also be in the same person)
- two or more close relatives diagnosed with ovarian cancer.

Close relatives are parents, brothers, sisters, sons, daughters, uncles, aunts and grandparents. They must be related to you by blood not marriage.

Our online tool OPERA can give you personalised information about your risk. It asks about 10 questions before giving you an individual assessment. Visit **macmillan.org.uk/opera**

If you are worried about breast and/or ovarian cancer in your family, you usually start by seeing your GP. They will assess your family history and may refer you to a genetics clinic (see page 17).

Genetic testing

If a genetics specialist thinks breast or ovarian cancer could run in your family, they may offer you genetic testing. You can read more about genetic testing on pages 30–32.

If genetic testing can't be done or you decide not to have it, you will be offered screening according to your estimated risk of breast cancer (see below).

Breast screening

Regular breast screening can't prevent breast cancer. But it can often help to find it at an early stage when many breast cancers can be cured.

Screening is usually done using breast x-rays (mammograms) and MRI (magnetic resonance imaging) scans. The type of screening you are offered depends on your estimated level of risk and your age.

You may find our information **Breast screening in women under 50 with a family history of breast cancer** and our booklet **Are you worried about breast cancer?** helpful. To order your free information, visit **be.macmillan.org.uk**

Ovarian screening

Regular screening of the ovaries can't prevent ovarian cancer. And there isn't clear evidence that screening for ovarian cancer is effective at detecting cancer early when it is more treatable.

But research is trying to find reliable screening methods for detecting ovarian cancer at an early stage when it is more likely to be cured. You may be offered screening as part of a clinical trial.

Your specialist can discuss the possible benefits and disadvantages of screening for ovarian cancer with you.

Risk-reducing treatments

Women at high risk of breast or ovarian cancer may be offered risk-reducing treatments such as surgery or drug treatment. The section on managing your risk (see pages 67–69) has helpful advice on making decisions about risk-reducing treatments.

Risk-reducing surgery

There are two types of risk reducing surgery:

- An operation to remove both breasts, called **risk-reducing breast surgery** or **prophylactic mastectomy**. This reduces the risk of breast cancer by 95%. Most women have breast reconstruction at the same time.
- Surgery to remove the ovaries and fallopian tubes. This is called **risk-reducing bilateral salpingo-oophorectomy (BSO)**. It greatly reduces the risk of ovarian cancer. It may also reduce the risk of breast cancer.

Removing the ovaries will make you infertile so it can't be done until after you have completed your family. Women having surgery to remove their ovaries usually have it after the age of 35 and before the menopause.

We have a booklet about risk-reducing breast surgery. Call us on **0808 808 00 00** or visit **be.macmillan.org.uk** to order a copy.

Risk-reducing drug treatment (chemoprevention)

This involves taking an anti-oestrogen tablet every day for five years. It's estimated that this reduces breast cancer risk by 30%–40%. But, the tablets can cause side-effects, including hot flushes, vaginal discharge, urinary problems and weight gain.

Women can't take risk-reducing drugs if they are trying to get pregnant.

Women with a BRCA1 gene change don't generally get oestrogen-dependent breast cancer. So if you have a BRCA1 gene change, chemoprevention may not be as effective. The clinical trials using chemoprevention for women at high risk of breast cancer had very small numbers of women with BRCA1 in them. So, the evidence is still uncertain.

Before deciding on risk-reducing treatment, you will have time to talk through all the possible benefits and disadvantages with a genetics or breast cancer specialist.

Be aware

Cancer can often be successfully treated, especially when it is discovered at an early stage. It's important to be aware of symptoms that might mean you have cancer so that if you do develop it it's found as early as possible.

Breast cancer

You should see your doctor if you notice any changes in your breast such as:

- a lump
- a change in size or shape
- dimpling of the skin or thickening in the breast tissue
- a nipple that's turned in (inverted)
- a rash (like eczema) on the nipple
- discharge from the nipple
- swelling or a lump in the armpit.

Ovarian cancer

You should see your doctor if you have tiredness or weight loss you can't explain. You should also see your doctor if you have any of the following symptoms, especially if they happen 12 days or more in a month:

- feeling bloated (swollen tummy)
- feeling full quickly or loss of appetite
- pain or discomfort in the lower tummy area or back
- needing to pass urine more often or more urgently.

Men and BRCA1 or BRCA2 gene changes

Men who have a BRCA1 or BRCA2 mutation have a higher risk for breast cancer than men in general. But, as breast cancer in men is rare, the risk is still low. Experts estimate that men with a BRCA1 gene mutation have a 2% risk of getting breast cancer in their lifetime and men with BRCA2 have about an 8% risk.

Men with BRCA2 gene also have a higher risk of getting prostate cancer. Experts think the lifetime risk of prostate cancer for men with BRCA2 is about 20–25%.

Other inherited cancers

There are some rare inherited cancer genes that increase the risk of less common types of cancer. These include:

- familial gastric cancer
- familial melanoma, which may be linked with abnormal skin moles and sometimes with an increased risk of pancreatic cancer
- von Hippel-Lindau syndrome (VHL), which causes an increased risk of cysts or tumours in the brain and spinal cord, eyes and ears, kidneys, adrenal glands and pancreas
- multiple endocrine neoplasia type 2 (MEN2), which is linked to medullary thyroid cancer (MTC) and to tumours of the adrenal glands – MTC may develop in infants and young children
- Li-Fraumeni syndrome, which causes an increased risk of several cancers, including breast cancers, sarcomas, brain tumours and leukaemias – in families with Li-Fraumeni several members of the family may have developed cancer at a young age (children, adolescents or young adults).

If you, or a member of your family, are affected by a rare genetic condition, you may want to get in touch with Genetic Alliance UK (see page 81) for information and support. Some support groups for people with cancer are also mentioned on pages 82–83.

We have more information on MEN2, which we can send you. We also have information on rare cancers. If you'd like to find out more, contact our cancer support specialists on **0808 808 00 00.**

Doctors believe that, in a small number of people, gene mutations may increase the risk of some other types of cancer. These include cancers of the testicle, pancreas, prostate, stomach and kidney.

When these cancers happen together with bowel cancer, they may be connected to Lynch syndrome (see pages 42–43). Some families with BRCA2 gene mutations also have a higher prostate cancer or pancreatic cancer risk (see page 48).

But it's likely that there are other genes that may cause an increase in the number of these cancers in some families. Researchers are trying to identify these genes.

It's unlikely that having one relative with testicular, pancreatic, prostate, stomach or kidney cancer greatly increases other family members' risk of developing the same cancer. But there may be an inherited gene if at least two relatives on the same side of the family develop the same type of cancer.

If you're worried about several cases of these, or other cancers in your family, talk to your GP. If there's a possibility there could be a cancer gene in your family, you may be able to take part in a research study. You will be told if there is a type of screening that may help to detect that cancer early. You will also be told what symptoms to look out for. This can help you to 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. This may be because you had a genetic test that found an inherited cancer gene. Or it may be because of your family history.

Knowing that you and some of your family have a higher cancer risk can be difficult to accept. Even if you think you have prepared for this news, having it confirmed can come as a shock. To some people this may feel like being told they already have cancer. To others, knowing may feel more empowering and help them make choices to lessen their risk.

Living with uncertainty

Genetic testing doesn't tell us who will definitely get cancer. This can cause anxiety. It's natural to want to know what is likely to happen so that you can plan for your future. But definite answers are often not possible, so you may have to find ways of living with uncertainty.

Your family and other sources of support

Living with the threat of cancer in your family can be difficult. Talking about your feelings and worries may help. You can also get support from outside your family and friends. You can talk to a genetic counsellor and to our cancer support specialists on **0808 808 00 00**. Or you can share your thoughts with members of our online community **community.macmillan.org.uk**

Relationships in your family can feel strained when you're coping with inherited cancer risk. Genetic tests may show that some family members are at an increased risk and others aren't. This can make people feel guilty or embarrassed for different reasons.

Inherited cancer can be a difficult issue to come to terms with. Some people find their relationships and family ties become stronger. You may feel that you can rely on your family for support more than you could before.

Many people say that knowing about the cancer risk in their family has allowed them to make decisions to increase their own and their children's chances of good health. You can read more about lifestyle factors on page 72.

Talking to children

Many parents have concerns about when to tell their children about an inherited cancer gene mutation in the family.

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

But, most inherited cancer genes don't increase the risk of cancer until adulthood. This can make it difficult to decide when to tell children or teenagers. There aren't any set rules about this. Every family is unique. You know your children best and what feels right for them.

In general, parents say they consider their children's age, maturity and emotional state when deciding when to share their test results.

Many parents tell their children about their genetic test results within a year of having a positive genetic test. Other parents may feel their child is too young or it may not be the right time because of other things going on in the family.

Reasons parents give for telling their children include:

- wanting to be honest and open with their child/children
- avoiding their child/children finding out by chance, for example by overhearing conversations
- helping their child/children understand if a parent is planning to have risk-reducing treatment or screening tests
- finding out what their child/children are thinking about cancer in their family, answering their questions and correcting any misunderstandings
- helping the child/children understand how this may affect some of their decisions in the future, such as planning when to start a family – this is something girls may need to consider if there is a BRCA1 or BRCA2 gene in family.

Preparing to talk to children

Before you talk to your children you may want to:

- give yourself time to adjust to the news first
- decide whether you want to talk to your children alone or with your partner (if you have one).

What to tell children

Before talking to your children, you may want to consider the following:

- Younger children only need a small amount of information. They come to understand things gradually over time.
- Teenagers usually want to know more and ask more questions.
- Using language appropriate to your child's age will help them understand the situation.
- Talking to children during an everyday activity such as a walk may help them feel more relaxed.
- Using the correct words is important. Some parents think using expressions such as 'boob job' for mastectomy is less worrying for children. But this can mean children don't understand the seriousness of the operation.
- Include positive messages such as:
    - your test result doesn't mean you have cancer or will definitely get cancer
    - knowing you have the gene gives you choices, like having screening tests or treatments that can help reduce your risk
    - your children are as likely not to have the gene as to have it.
    - when your children are older there may be even better treatments available.
- Ask children to tell you what they understand so that if they've misunderstood something you can put them right.
- Discuss their feelings.
- Ask your children if they have questions.

Answering questions

It's important that your children feel that you are willing to answer their questions. You can help by giving them permission to ask questions. And you can reassure them that you are willing to talk. Many children and young people do not ask questions because they fear they might upset their parents.

It's 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.

Let your children know they can always speak to you again if they have questions or are worried about anything.

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

You can also visit our online community at **macmillan.org.uk/community** to get support from people who have been through similar experiences to you.

Managing your cancer risk

Early detection of cancer – screening

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

Most types of cancer screening aim to detect cancers at an early stage when they are easier to treat. But some types of screening can detect pre-cancerous cell changes. For example, bowel screening (see page 45) can find pre-cancerous growths. This means you can have treatment to remove the growth before cancer develops.

Reducing your risk of cancer

Surgery

Some people with a high cancer risk decide to have risk-reducing surgery. This means removing the tissues which are at risk of getting cancer, for example the breasts or ovaries. This type of surgery is only offered to people with a very high risk, such as those who have inherited certain cancer gene mutations. Although surgery greatly reduces the risk of cancer, it does not get rid of it entirely.

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

- your age
- whether you know for sure that you have a cancer gene mutation
- how you feel
- if you still want to have children (if surgery involves removing the ovaries or womb).

If you're considering 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's helpful to discuss the advantages 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'll need to think about when to have it. This will depend on what age the cancer may develop. Your genetic counsellor can tell you about how your risk of getting cancer changes with age. This depends on the cancer gene mutation you have. It also takes into account the ages at which 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 consists of taking a drug to reduce the risk of certain types of cancer. Some women at high risk of inherited breast cancer may take anti-oestrogen tablets to reduce their risk (see page 53). People with Lynch syndrome may take aspirin to reduce their risk of bowel cancer developing.

Risk-reducing drugs may cause side effects and occasionally may cause serious complications. So it's important you discuss the advantages and disadvantages with your doctor.

Research trials

If you know that you have an increased risk of getting cancer, you may be able to join a research trial. These look into genetic causes of cancer or ways of preventing it. Taking part in a research trial is completely up to you.

We have a booklet about research trials that you may find helpful. Call us or visit **be.macmillan.org.uk** to order a free copy.

Fertility

Some risk-reducing treatments for breast or ovarian cancer can have an effect on fertility.

Surgery to remove the ovaries before the menopause will make you infertile. If you take drug treatments to reduce the risk of breast cancer, you'll usually take these for five years. You can't become pregnant during this time. This can reduce the number of years you have to become pregnant.

If you are considering risk reducing treatments that could affect your fertility you can discuss these issues with your genetics specialist. You may think about starting and completing your family earlier than you would otherwise have done. You can ask your doctor about ways of preserving fertility. You can also ask to see a fertility specialist for further advice.

Our booklet **Cancer and fertility in women** has more information. Call our support line on **0808 808 00 00** to order a free copy.

Planning a family

For most inherited gene mutations, there is a 1 in 2 chance (50%) that each of your children could inherit the gene mutation. If you have questions about the risk for any children you may have, your genetics specialist can discuss this with you.

Most people choose to have their family without any intervention. Screening, risk-reducing treatments and cancer treatments are likely to continue to improve.

If you want to avoid passing on a cancer gene mutation, other options are available:

Pre-implantation genetic diagnosis (PGD)

This procedure involves in vitro fertilisation (IVF). Doctors take egg and sperm cells from the couple. They then create embryos outside the woman's body. These embryos are tested for the cancer gene mutation in the family. The fertility specialist then implants an embryo that doesn't have the cancer gene mutation 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 carried out in a few centres in the UK. You may need to travel some distance to have it. You can find information about PGD at **www.pgd.org.uk/home.aspx**

Egg or sperm donation

Some couples use donor eggs (if the woman has the cancer gene mutation) or donor sperm (if the man has the cancer gene mutation).

Prenatal testing

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

Health and lifestyle

Many people who find out they are at an increased risk of cancer look for ways to improve their health and lifestyle.

There may be specific lifestyle factors that can affect your cancer risk. Ask your specialist for advice to fit your situation.

There are lifestyle factors that can reduce the risk of cancers developing in the general population, such as:

- not smoking
- doing regular physical exercise
- maintaining a healthy body weight
- limiting alcohol intake (up to 1 unit a day for women and no more than 2 units a day for men)
- eating a healthy balanced diet (high in fibre, fruit and vegetables and low in salt, fat and red and processed meat).

There isn't clear evidence about how much these factors affect cancer risk in people with a family history of cancer. But some people say living a healthy lifestyle makes them feel they are doing what they can to control their risk of cancer.

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.

All of our information is also available online at **macmillan.org.uk/cancerinformation** 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. No one should face cancer alone.

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 Monday–Friday, 9am–8pm. Our cancer support specialists can:

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial advice
- 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

Other useful organisations

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

AMEND
The Warehouse,
Draper Street,
Tunbridge Wells TN4 0PG
Tel 0189 251 6076
Email jo.grey@amend.org.uk
www.amend.org.uk
A patient support group supporting 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.

Beating Bowel Cancer
Harlequin House,
7 High Street,
Teddington TW11 8EE
Helpline 0845 071 9301
(Mon–Thu, 9am–5.30pm,
Fri, 9am–4pm)
Email nurse@beatingbowel cancer.org
www.beatingbowel cancer.org
Raises awareness of symptoms, promotes early diagnosis and encourages open access to treatment choice for people affected by bowel cancer.

Bowel Cancer UK
7 Rickett Street,
London SW6 1RU
Email
admin@bowelcanceruk.org.uk
www.bowelcanceruk.org.uk
Raises awareness of bowel cancer and campaigns for best treatment and care. Provides information and support.

Breakthrough Breast Cancer
Weston House,
246 High Holborn,
London WC1V 7EX
Helpline 0808 010 0200
Email info@breakthrough.org.uk
www.breakthrough.org.uk
Aims to fight breast cancer through research and awareness. Has information on its website for women with a family history of breast cancer.

Breast Cancer Care
5–13 Great Suffolk Street,
London SE1 0NS
Helpline 0808 800 6000
(Mon–Fri, 9am–5pm,
Sat, 10am–2pm)
www.breastcancercare.org.uk
Provides breast cancer information and support across the UK. Offers accessible, high-quality services for everyone affected by breast cancer.

The Daisy Network
PO Box 183,
Rossendale BB4 6WZ
www.daisynetwork.org.uk
A support group for women with a premature menopause run by volunteers who have this condition. Also has information on its website.

Genetic Alliance UK
Leroy House,
Unit 4D,
436 Essex Road,
London N1 3QP
Tel 0207 704 3141
Email contactus@geneticalliance.org.uk
www.gig.org.uk
A national alliance of over 150 charities that support children, families and people affected by genetic disorders.

National Hereditary Breast Cancer

Helpline 0162 981 3000
(open 24 hours a day)
www.breastcancergenetics.co.uk
A 24-hour helpline giving information to people concerned about their family history of breast cancer. Also has a useful database of individuals prepared to share their own experiences with others.

Ovacome

City Cloisters,
Suite B5,
196 Old Street,
London EC1V 9FR
Helpline 0845 371 0554
Tel 0207 299 6654
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.

Cancer support organisations

Cancer Black Care

79 Acton Lane,
London NW10 8UT
Tel 0208 961 4151
Email
info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers information and support for people with cancer from ethnic communities, their friends, carers and families.

Cancer Focus Northern Ireland

40–44 Eglantine Avenue,
Belfast BT9 6DX
Tel 0800 783 3339
(Mon–Fri, 9am–1pm)
Email
hello@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

Cancer Research UK
Angel Building,
407 St John Street,
London EC1V 4AD
Tel 0300 123 1022
www.cancerhelp.org.uk
Has patient information on all types of cancer and has a clinical trials database.

Cancer Support Scotland
The Calman Centre,
75 Shelley Road,
Glasgow G12 0ZE
Tel 0800 652 4531
Email info@cancersupportscotland.org
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland.

Maggie's Centres
20 St James Street,
London W6 9RW
Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.org
Provides information about cancer, benefits advice, and emotional or psychological support.

Tenovus
Head Office,
Gleider House,
Ty Glas Road, Cardiff CF14 5BD
Tel 0808 808 1010
(Mon–Sun, 8am–8pm)
www.tenovus.org.uk
Aims to help everyone get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, and benefits advice.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)
BACP House,
15 St John's Business Park,
Lutterworth,
Leicestershire LE17 4HB
Tel 0145 588 3300
Email bacp@bacp.co.uk
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

YOUR NOTES AND QUESTIONS

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.

Thanks

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Sources

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

Hilgart, et al. *Cancer genetic risk assessment for individuals at risk of familial breast cancer.* 2012.
National Institute for Health and Care Excellence. *Classification and care of people at risk of familial breast cancer and management of breast cancer and related risks in people with a family history of breast cancer.* 2013.
National Institute for Health and Care Excellence. *Ovarian cancer: the recognition and initial management of ovarian cancer.* 2011.
World Cancer Research Fund. *Reduce your cancer risk: 10 ways to a healthier you.* 2012.

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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I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
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Don't let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

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Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

FRSB give with confidence

If you'd rather donate online go to macmillan.org.uk/donate

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

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay. Non-English speaker? Interpreters available. Braille and large print versions on request.

Health & care information you can trust

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WE ARE MACMILLAN. CANCER SUPPORT