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 change 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 changes
- 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.

This booklet does not have information about how the genes in cancer cells can be used to develop or plan cancer treatment. We have more about this in our online information about:

- personalised medicine
- cancer genomics.

To find out more, visit **macmillan.org.uk**

How to use this booklet

This booklet is split into sections to help you find what you need. You do not 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.

On pages 86 to 93, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (pages 94 to 96).

Quotes

In this booklet, we have included quotes from people who have had genetic testing, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, 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

Gene changes and cancer

Our bodies are made up of tiny building blocks called cells. Inside every cell is a set of genes. Genes are the instructions the cell needs to work properly.

If a gene is changed, it may not give the correct instructions anymore. A change in a gene is called a gene variant or mutation.

Over time, gene variants in a cell may stop the cell working normally. Cancer may develop if cells like this multiply in an abnormal way and grow out of control.

Gene variants that increase cancer risk

Some gene variants are linked to a higher risk of certain types of cancer. For example, people who have a change in the BRCA1 or BRCA2 gene may have a higher risk of breast, ovarian and some other types of cancer.

Gene variants that increase a person's cancer risk are also called:

- pathogenic variants
- disease-causing variants
- cancer gene variants
- clinically actionable variants.

Acquired variant

A gene change that happens during a person's lifetime is called an acquired gene variant or a somatic gene variant.

Acquired variants may happen:

- by chance, when a cell divides or does its job in the body
- because of lifestyle – for example, diet or physical activity levels
- because of things in a person's environment – for example, sunlight or tobacco smoke.

This type of gene change only affects certain cells in the person's body. It cannot be passed from a parent to child (inherited). A cancer may develop where there are cells with acquired variants. For example, if genes in lung cells are damaged because of smoking, this may eventually allow lung cancer to develop.

Inherited variant

A gene change that is passed from parent to child is called an inherited variant or mutation. This type of gene change is there from birth. It is in almost every cell in the person's body for their whole life.

Some inherited gene variants cause a higher risk of certain types of cancer. The gene variant by itself does not cause cancer. But it may allow other damage to build up faster in cells. This increases the chance that cancer will develop.

Inherited cancer genes

Genes are passed from parent to child (inherited) when a sperm and egg join to start a pregnancy. This is called conception.

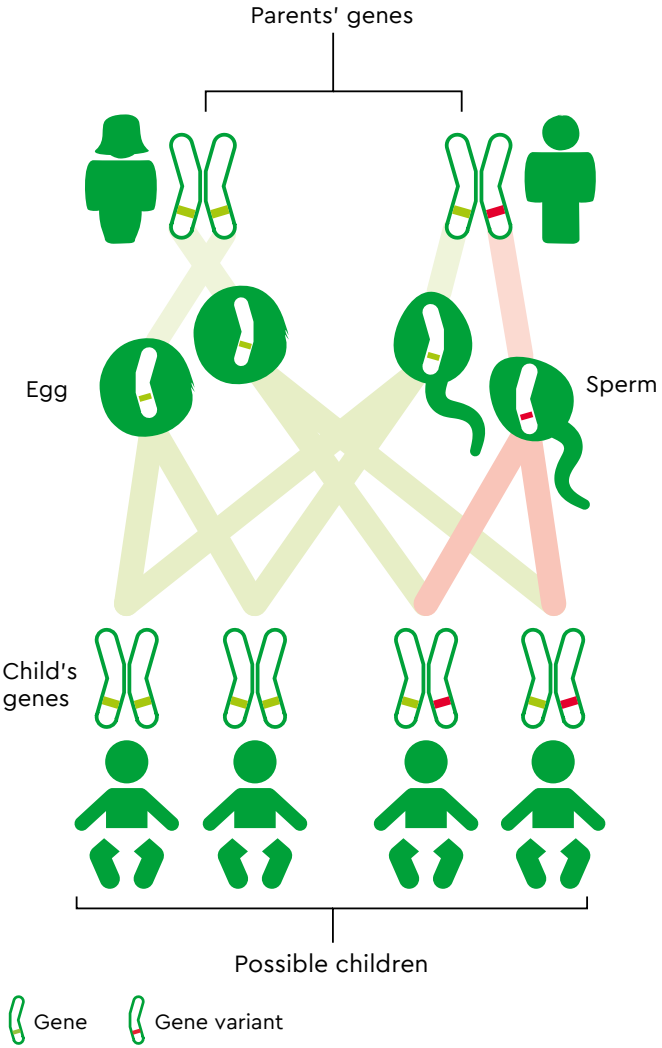
Each person has 2 copies of each gene – 1 is from our mother and the other from our father:

- The sperm contains 1 copy of the father's genes.
- The egg contains 1 copy of the mother's genes.

You only get 1 copy of each of your parent's genes. If 1 parent has a gene variant, you either get the copy with the variant or the copy without the variant.

If you have the gene variant, there is a 1 in 2 (50%) chance any children you have will inherit it.

How genes are inherited



Is cancer hereditary?

Cancer cannot be passed from a parent to their child (inherited). But genes are passed from parent to child when a sperm and egg join and start a pregnancy (conception).

This means it is possible for a cancer gene variant to be inherited by several people in the same family. Because of this, the family may have more cases of certain types of cancer than you would usually find in the general population. This is called a familial or hereditary cancer syndrome.

Experts think inherited gene variants cause fewer than 5 to 10 in 100 cancer cases (5 to 10%). In fact, the numbers are much lower than this for many cancer types. Lifestyle factors such as smoking or being overweight are more likely to cause cancer.

If you inherit a cancer gene variant from 1 of your parents, it does not mean you have cancer or will definitely develop cancer. More damage to cells in your body needs to happen before cancer can develop. The inherited gene variant may allow this damage to build up faster. This means that your risk of certain cancers is likely to be higher than someone without that gene variant.

Can cancer genes skip a generation?

Cancer gene variants cannot skip or miss a generation. If 1 of your parents has a gene variant, there is a 1 in 2 (50%) chance it has passed to you. You either inherit it or you do not. If you do not inherit the variant, you cannot pass it to your children.

Sometimes it can seem like the cancer skipped a generation. This is usually because a person in the family has the variant which is then passed on to their child. But the person does not develop cancer themselves.

This might happen because of the following reasons:

- Having a cancer gene variant raises a person's risk of developing cancer. But it does not mean they will definitely develop cancer. Sometimes the person does not develop cancer, but their child inherits the variant and does. This can seem like the cancer gene has skipped a generation.
- A person may inherit and pass on a cancer gene variant for a cancer type they cannot develop themselves. For example, gene variants linked to breast and ovarian cancers can pass through the father's side of the family. A father who inherits this type of variant is unlikely to develop breast cancer and cannot develop ovarian cancer. But they still have a 1 in 2 (50%) chance of passing the variant to their children. If their daughter inherits the variant and develops breast or ovarian cancer, it can seem like the cancer gene has skipped a generation.

Understanding your risk of cancer

Family history and cancer risk

If a family is affected by a cancer gene variant, there may be a pattern of cancers in that family. For example, there may be:

- several people who have the same type of cancer
- people who were younger than usual when they were diagnosed
- someone who has had more than 1 primary cancer – this means they have had cancer twice, not that cancer has spread to another part of the body.

Some gene variants are linked to several types of cancer. A family with this type of variant may be affected by a group of different cancers. The most common patterns where cancers happen together are:

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

Some cancer gene variants are more common in certain ethnic groups. For example, families from a Central or Eastern European or Ashkenazi Jewish (Central or Eastern European Jewish) background are more likely to be affected by certain gene variants.

If you are worried about cancer in your family

Most of us have relatives who have had cancer. This does not always mean there is a cancer gene variant in your family or that you have a much higher risk of cancer. Most cases of cancer are not caused by an inherited gene variant.

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 they think there is a chance cancer may run in your family, they can refer you to a genetics specialist. This is a doctor or other professional who helps to diagnose, manage, predict and screen for genetic disease.

The genetics specialist will check whether you are likely to have a higher-than-average risk of certain types of cancer. They may offer you genetic counselling to help you understand the cancer risks in your family (pages 16 to 21). They can also tell you whether genetic testing is possible and useful in your situation (pages 24 to 30).

Genetic counselling

Genetic counselling means talking with a genetics specialist to help you understand a genetic condition that runs in your family.

There are different names for the services that offer genetic counselling. For example, you may be referred to a family cancer clinic or a cancer genetics clinic.

After your GP has referred you, the clinic should contact you within a few weeks. They may send you a family history form to complete before you have an appointment. This will usually ask you the names and ages of your family members and:

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

It is not always possible to fill out the form completely. For example, if you are adopted, you may not have access to your family history. 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 family members 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 whether 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 cancer in your family. We have more information about cancer registries at **macmillan.org.uk/cancerregistry**

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

If an inherited cancer gene variant is unlikely

The pattern of cancer in your family may show that an inherited gene variant is unlikely (page 7).

In this case, the clinic may decide you 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 your family has another diagnosis of cancer in the future, talk to your GP again. This may give them more information to check your level of risk.

Having genetic counselling

If you are given an appointment, you will meet a genetics specialist. This is called genetic counselling. The meeting will last 30 to 60 minutes. It may be face to face, by phone or by video call.

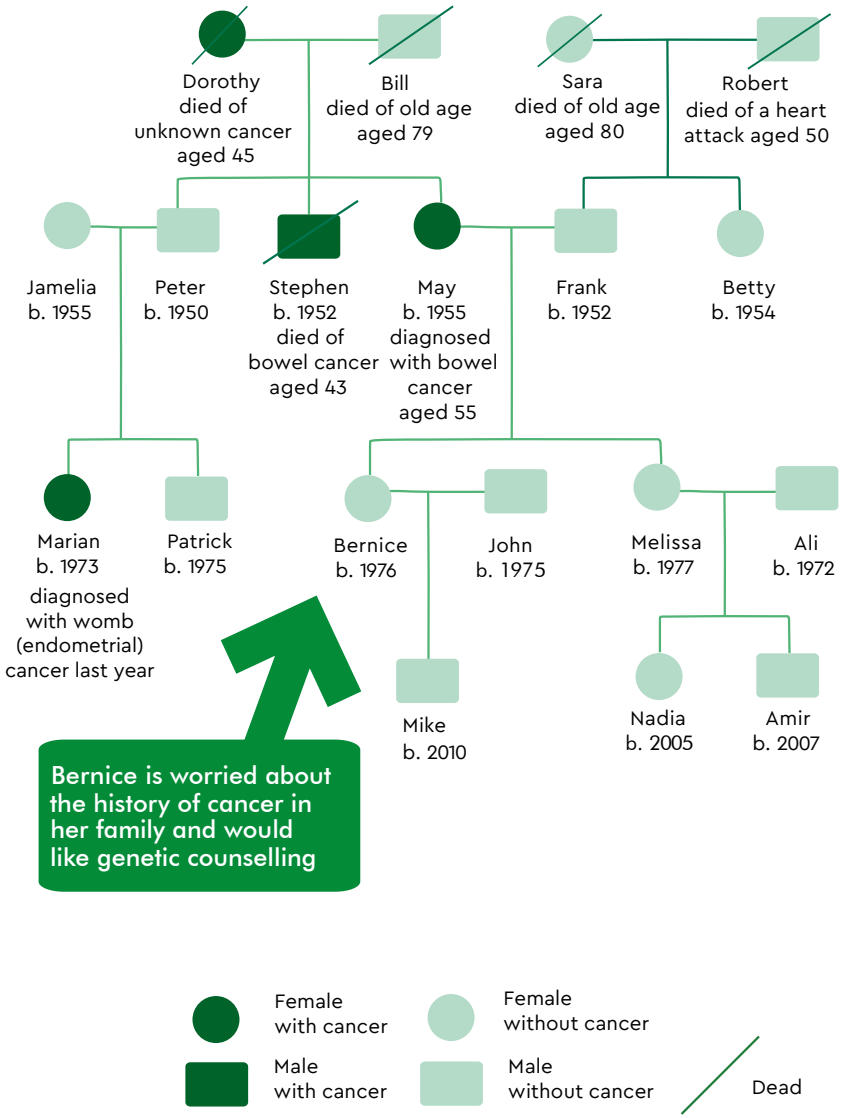
The genetics specialist will draw a diagram called a family tree, like the one opposite. This shows all your close blood relatives, how they are related and their illnesses. The genetics specialist uses it to assess your risk of cancer.

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 genetic testing is possible and useful in your situation (pages 24 to 30)
- the benefits and limits of genetic testing
- ways of managing your cancer risk.

You will get information about symptoms of cancer, cancer screening and risk-reducing treatments.

Genetics family tree



"I was still reeling from my breast cancer diagnosis when I had genetic counselling. But my genetics counsellor drew diagrams and dumbed down the scientific information just the right amount. "

Laura

Getting the most out of your meeting

You may have questions you want to ask the genetics specialist. It is a good idea to write them down before your appointment. Here are some examples 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 do not have a high risk of getting cancer, should I have any follow-up appointments?
- What should 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. After the meeting, you will usually get a letter that lists all the important points.

Assessing your cancer risk

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

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

To assess your risk, your GP or genetics specialist looks 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 in the general population.
- Moderate (raised) risk – your risk of some cancer types is a bit higher than average. It is not likely there is an inherited gene variant they can test you for.
- High risk – you have a higher risk of some cancer types in your lifetime. This does not mean you will definitely get cancer. You may be offered genetic testing to check for an inherited gene variant that may explain your family history of cancer.

Genetic testing

Genetic testing can be used to look for gene variants that increase the risk of cancer in a family. A genetics specialist can tell you whether a test may be possible and useful in your situation (page 15).

How is testing done?

Usually, a person in the family who has had cancer is tested first. This is called diagnostic testing. If a cancer gene variant is found, other members of the family can be tested for the same variant. This is called predictive testing.

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 a gene variant. This is called an indirect genetic test.

First, the laboratory looks for the gene variant 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 variant
- not find a cancer gene variant
- find a variant of uncertain significance (page 34).

If diagnostic testing finds a cancer gene variant, other family members can be tested for the same variant. This is called predictive testing or pre-symptomatic testing.

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

Having a blood test

"I was keen to do the test to find out of if there was any gene. It was a scary time waiting for those results to come back, because there wasn't just the impact they would have on me. "

Kimberley

Genetic testing in children

Most inherited cancer genes do not cause cancers in childhood. This means children are not usually tested. When they become adults, they can make their own decisions about testing.

A child may be tested if they might have inherited a gene variant that causes health problems before adulthood. For example, a variant in the APC gene can cause a condition called familial adenomatous polyposis (FAP) – pages 67 to 71. FAP causes a high risk of bowel cancer. People affected by FAP may need to start treatment to prevent bowel cancer when they are in their teens.

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

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

We have more information about these conditions on page 75.

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 benefits

- Predictive genetic testing may show you do not have a gene variant carried by someone else in your family. This means that your cancer risk is the same as anyone in the general population. You will not need to consider extra screening or risk-reducing treatments. You will know you cannot pass the gene variant to any children you have.
- If you find out you have a gene variant, this may help you decide how to reduce your cancer risk. Your options may include screening to find a cancer early, risk-reducing treatments and lifestyle changes.

Possible disadvantages

- If you find out you have a gene variant, you may feel more worried about getting cancer.
- Diagnostic genetic testing does 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 (page 34).
- Even if diagnostic genetic testing does not find a gene variant, you may be told you have a raised cancer risk. This is because your family history may show that there could be an unknown gene variant. Or there could be a combination of lower-risk inherited gene variants that increase your cancer risk.
- If you find out you have a gene variant, you will need to decide whether or how to tell other family members who may be affected.

Confidentiality and genetic testing

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

When they take your blood for the genetic test, they may ask whether they can also take a sample for research. This may help researchers find other cancer gene variants in the future. Researchers are not given your personal details.

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

"My sisters and I saw the genetic counsellor together and separately before we all had the blood tests. We all agreed we wanted to know and wanted to find out together."

Nicole

Insurance and genetic testing

Some people worry insurance companies will refuse to insure them or will charge more if they have genetic testing for cancer. There is no law to prevent insurance companies from doing this. But some insurance companies have signed up to the Code on Genetic Testing and Insurance. This means they will not:

- ask you to have a predictive or diagnostic genetic test
- ask for, or use the result of, a predictive genetic test if you are applying for insurance.

Insurance companies may still ask about your health, your family's health, and whether anybody in your family has had cancer. They may ask for the results of diagnostic testing if you have already had this.

You can find more information from:

- the Code on Genetic Testing and Insurance – visit **gov.uk/government/publications/code-on-genetic-testing-and-insurance**
- the Association of British Insurers (ABI) – visit **abi.org.uk**
- your genetics specialist
- Genetic Alliance UK (page 86).

Your test results

Your genetics specialist will tell you when you are likely to get your test results. You may feel anxious about getting your results. It can help to have someone with you for support and to help you to remember what was said.

If a cancer gene variant is found

This means you have a gene variant that increases your risk of getting some cancer types. Your genetics specialist will give you more information about:

- your level of risk
- the types of cancer you are at risk of getting
- ways of managing the risk.

This can be a lot to understand and think about. Your genetics specialist may give you information to read. They will support you and answer any questions you have.

If you have a cancer gene variant, this may affect other people in your family. You may have to decide whether and how to tell them.

Talking about this with your family can be difficult. People may have questions that you cannot answer. They may have feelings you did not expect.

It is important to remember that nobody is to blame for the genes they inherit or pass on. People with a gene variant sometimes have feelings of guilt, blame or responsibility. But nobody can control the genes they inherit or pass on.

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 (pages 16 to 21). Their GP can refer them to their nearest genetics clinic or family cancer centre.

If there are children in your family, your genetics specialist can explain what your test results may mean for them at different ages. The genetics specialist can support you with more information about talking to children and teenagers about your test results.

If diagnostic testing found no cancer gene variant

This can happen even if you have a strong family history of cancer. It may be 1 of the following:

- The cancers in the family are not due to an inherited gene variant. They may have happened by chance or for other reasons doctors do not understand.
- There is a gene variant in the family, but it is not one doctors know about or usually test for.
- There are several lower-risk gene variants in the family. These are not usually tested for, but they can increase the risk of cancer when combined with environmental factors.

You may feel relieved an inherited cancer gene has not been found. But you may not know for certain whether 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 variant.

It can be hard coping with uncertainly about the future. It may help to talk about your feelings with your family, friends, GP or genetics specialist. You can also call the Macmillan Support Line on **0808 800 00 00**.

You may be offered extra screening or risk-reducing treatments (pages 39 to 40). Because you have less-clear information about your risk, it may be more difficult to decide what 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 (page 41).

"Since my diagnosis, my uncle has tested negative. So his side of the family have no greater chance of developing bowel cancer than the general public."

Helen

Variants of uncertain significance

Sometimes diagnostic testing finds a gene variant 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 variant 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 whether the pattern of cancer in the family is due to the gene variant.

The family may also be asked to keep in contact with the genetics clinic. This is in case more information becomes available about the gene variant. The variant may be found to be the cause of the cancer in the family. Or it may be found to be harmless.

If predictive testing found no cancer gene variant

Predictive testing only looks for a cancer gene variant that is known to run in your family. If the test does not find that cancer gene variant, your cancer risk is the same as anyone in the general population. You will not need extra screening or risk-reducing treatments. You cannot pass that gene variant to any children you have.

You may feel relieved that you are not affected by the cancer gene variant that affects your family. But other family members may be affected, and you may feel guilty or worried for them.


EAB

Coping with your cancer risk

Coping with a high risk of cancer

Even if you think you are ready for the news, it can be a shock to find out you have a higher risk of developing cancer.

You may want to know what is likely to happen so you can plan for your future. By using family history and genetic testing, a genetics specialist can only estimate levels of risk. They will not be able to say who will definitely get cancer or when they will develop it. You may still have questions that have no clear answers. You may need to think about what can help you cope with the uncertainty.

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, and you might find it helps to talk to family and friends. You can also talk to our cancer support specialists on **0808 808 00 00**, or talk to others on our Online Community. Visit **macmillan.org.uk/community**

Managing hereditary cancer risk

Your genetics specialist will give you information about reducing your risk of cancer. Depending on the type of cancer and your level of risk, they may give you information about the following things.

Cancer screening tests

You may be offered screening tests. 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.

> **"I have been given an 80% lifetime risk of developing breast cancer and 50% for ovarian cancer. Thankfully, I now have a choice as to how to mitigate the risk I carry."**
>
> Josephine

Risk-reducing surgery

This type of surgery is usually only offered to people with a very high risk of cancer. It involves removing the tissues that are at risk of getting cancer. For example, risk-reducing breast surgery means removing healthy breast tissue to reduce the risk of breast cancer.

Surgery greatly reduces the risk of cancer, but it does not get rid of it completely. Surgery also has risks and possible side effects. It is important to understand these before deciding whether to have this treatment.

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 variant you have and the ages 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.

We have more information about this in our booklet **Understanding risk-reducing breast surgery**.

Risk-reducing drugs

This is also called chemoprevention. It means using drugs to reduce the risk of certain types of cancer. For example:

- anti-oestrogen tablets can help reduce a very high risk of breast cancer (page 55)
- aspirin may reduce the risk of bowel cancer for people with Lynch syndrome (pages 63 to 65).

Risk-reducing drugs may cause side effects. Occasionally, they 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 cancer, you may be able to join a clinical trial. Some trials look at genetic causes of cancer or ways of preventing it. Taking part in a clinical trial is your decision. Ask your genetics specialist for more information.

We also have more information about clinical trials on our website. Visit **macmillan.org.uk/clinical-trials**

Having a healthy lifestyle

Having a healthy lifestyle can reduce your risk of cancer. It can also improve your general health and well-being. Your genetics specialist, GP or practice nurse can give you more information about diet and weight, physical activity and other factors such as smoking and sun safety. The World Cancer Research Fund has more information about healthy lifestyle choices to reduce your risk of cancer (page 91).

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Planning a family

If you have an inherited cancer gene variant, 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. Sometimes tests and fertility treatments can be used to ensure a parent's gene variant is not passed to a child. The Human Fertilisation & Embryology Authority (HFEA) and Genetic Alliance UK have information about this (page 86).

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. Visit **macmillan.org.uk/community**

Inherited breast and ovarian cancer

About inherited breast and ovarian cancer

Many people have someone in their family who is affected by breast or ovarian cancer. Most of these cases are not likely to be caused by an inherited gene variant.

A gene variant that increases the risk of breast and ovarian cancer can cause a pattern of cancer in a family. This is called hereditary breast and ovarian cancer syndrome. For example, in the family there may be:

- several people affected by breast cancer or ovarian cancer
- people diagnosed with breast cancer before the age of 50
- people diagnosed with triple negative breast cancer or high-grade serous ovarian cancer
- a man, or person assigned male at birth, diagnosed with breast cancer
- someone who has had breast cancer in both breasts (bilateral breast cancer) or who has had breast and ovarian cancer.

Families from some ethnic groups are also more likely to carry a gene variant that increases the risk of breast and ovarian cancer. This includes families from a Central or Eastern European or Ashkenazi Jewish (Central or Eastern European Jewish) background.

If you are worried about the pattern of cancer in your family, or a test has shown that someone in your family has a cancer gene variant, talk to your GP. If needed, they will refer you to a genetics specialist (page 15).

Inherited breast and ovarian cancer genes

Some gene variants can increase the risk of breast and ovarian cancer.

Your genetics specialist will explain more about your risk. Some of these variants also increase the risk of other cancer types.

Variants in the following genes can increase the risk of breast and ovarian cancer:

- BRCA1
- BRCA2
- PALB2
- RAD51C
- RAD51D
- STK11 (Peutz-Jeghers syndrome).

Variants in these genes can increase the risk of breast cancer:

- ATM
- CHEK2
- TP53 (Li-Fraumeni syndrome)
- CDH1 (hereditary diffuse gastric cancer)
- NF1 (neurofibromatosis type 1)
- PTEN (Cowden syndrome).

Variants in this gene can increase the risk of ovarian cancer:

- BRIP1.

If genetic testing shows you have 1 of these variants, this does not mean you will definitely get cancer. But you may have a higher risk of breast, ovarian and some other types of cancer.

There are likely to be other gene variants that experts currently do not know about. This means some families may have a clear pattern of breast or ovarian cancer, but genetic tests do not find a variant.

We have more information about inherited breast and ovarian cancer genes on our website. Visit **macmillan.org.uk/inherited-breast-and-ovarian-cancer**.

Managing a higher risk of breast or ovarian cancer

If your family history or a genetic test shows you have a higher risk of breast or ovarian cancer, there may be ways to reduce or manage that risk.

Your genetics specialist will give you information about this. The information they give you will depend on:

- your sex assigned at birth (male or female)
- your age
- the type of gene variant
- your family history
- your medical history
- other factors in your lifestyle.

Your specialist will explain whether cancer screening tests or risk-reducing treatments might help in your situation. They can explain whether factors in your lifestyle affect your cancer risk.

They can also give you information about possible symptoms of cancer. If you know what is normal for your body, you are more likely to recognise any changes that could be a sign of cancer. We have more information about the signs and symptoms of cancer on our website. Visit **macmillan.org.uk/signs-and-symptoms-of-cancer**

Breast cancer screening

Breast cancer screening is a way of finding signs of early breast cancers that are too small to see or feel. It does not prevent breast cancer, but it can help find it at an early stage, when many breast cancers can be cured.

The NHS offers screening from the age of 50, every 3 years. During screening, doctors or nurses use low-dose x-rays called mammograms to take pictures of each breast.

We have more information about breast cancer screening on our website. Visit **macmillan.org.uk/breast-cancer-family-history**

"I encourage all women to attend their screening mammogram appointment. The short time of possible discomfort is a small price to pay for a better chance to live a long healthy life."

Lurline

Ovarian cancer screening

In the UK, screening is not usually offered for ovarian cancer. 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. Ovarian cancer screening is sometimes available as part of a clinical trial.

Risk-reducing options

Women, and people assigned female at birth, with a high risk of breast and ovarian cancer may be offered:

- surgery to remove the breasts (called risk-reducing breast surgery)
- surgery to remove the ovaries and fallopian tubes (called risk-reducing bilateral salpingo-oophorectomy)
- a risk-reducing drug for a number of years (called chemoprevention).

Breast surgery

Some gene variants and patterns of cancer in a family may cause a very high risk of breast cancer. In this case, you may be offered risk-reducing breast surgery. This means surgery to remove both breasts. Breast reconstruction to make new breast shapes can be done at the same time.

Surgery does not remove the risk of breast cancer completely. But it may reduce your risk of developing breast cancer by about 95%. This means that if 100 people with a very high risk of breast cancer have surgery, 95 will not develop breast cancer in their lifetime. 5 of the 100 people (5%) will develop breast cancer despite having surgery.

Making a decision about having this type of surgery can be complicated. We have more information about what risk-reducing breast surgery involves and things to think about before you make a decision. You can find this in our booklet **Understanding risk-reducing breast surgery** (page 80).

Ovarian and fallopian tube surgery

Surgery to remove the ovaries and the fallopian tubes is called a bilateral salpingo-oophorectomy.

At the moment, there is no way to screen for signs of early ovarian cancer. Surgery may reduce your risk of cancer in or near the ovary by over 95%. This means more than 95 out of 100 people who have this surgery will not develop ovarian cancer in their lifetime. Less than 5 of the 100 people (5%) will develop cancer despite having the surgery.

You may be offered this surgery if you have a high risk of developing ovarian cancer due to:

- a gene variant that increases your risk
- the pattern of cancer in your family.

Your genetics specialist will explain more about your situation. They will talk to you about your overall lifetime risk of developing ovarian cancer and your risk at different ages. If surgery is an option, they will give you information about the possible risks and benefits of having surgery. They will discuss the age at which you should consider having the operation.

Removing the ovaries will cause an early menopause if you have not already had it. It will also mean you will no longer be able to get pregnant. Some people choose to delay the operation until they are sure they no longer want to get pregnant.

After surgery, you usually take hormone replacement therapy (HRT) until the age you would be expected to have the menopause. This is usually around the age of 50. HRT protects your bones and heart health and helps prevent menopausal symptoms. In this situation, HRT does not increase the risk of breast cancer.

Chemoprevention

Chemoprevention means using drugs to reduce the risk of certain types of cancer. If you have a higher risk of breast cancer, you may be offered anti-oestrogen drugs to reduce this risk. Treatment involves taking a tablet every day for 5 years.

How much this treatment reduces your risk of developing breast cancer depends on:

- the type of gene variant you have
- your family history.

Some people will develop breast cancer despite taking this treatment.

Your genetics specialist will explain more about your situation. They will give you information about the possible risks and benefits of having treatment and the possible side effects of the drug.

The drugs most commonly used are tamoxifen, anastrozole or raloxifene. If you have not been through the menopause, you will usually be offered tamoxifen. You need to use contraception while taking it. It is not suitable if you are trying to get pregnant.

If you have been through the menopause, you may be offered anastrozole, tamoxifen or raloxifene.

Inherited bowel cancer

About inherited bowel cancer

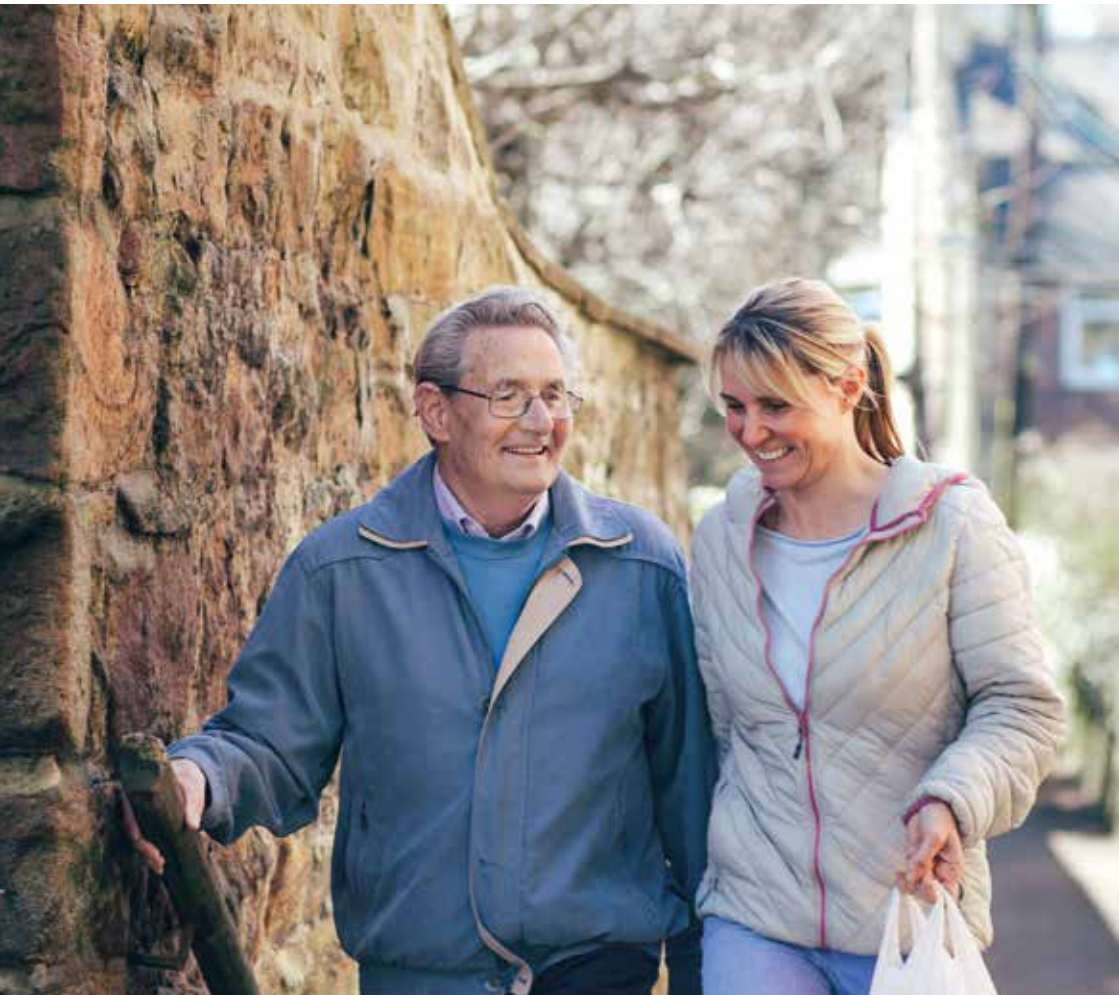
Bowel cancer is the 4th most common cancer in the UK. Many people have someone in their family who has had bowel cancer. Most cases of bowel cancer are not likely to be caused by an inherited gene variant.

A gene variant that increases the risk of bowel cancer can cause a pattern of cancer in a family. Here are some examples of patterns of cancer:

- You have a first-degree relative who was diagnosed with bowel cancer before the age of 50. First-degree relatives are your parents, brothers, sisters and children.
- Your first-degree relative and one of their first-degree relatives are both diagnosed with bowel cancer. For example, this could be your father and his sister (your aunt). They may be diagnosed at any age.
- Relatives on 1 side of your family are affected by 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.

Or 1 or more relatives may have lots of growths in the bowel. These growths are called polyps.

Talk to your GP if you are worried about the pattern of cancer in your family. You should also tell them if a test shows that someone in your family has a cancer gene variant. If needed, your GP will refer you to a genetics specialist (page 15).



Inherited bowel cancer genes

Some conditions are caused by gene variants that are linked to a higher risk of bowel cancer. We have more information about these on our website (page 80). Your genetics specialist will explain more about your risk. Some of these conditions also increase the risk of other cancer types:

- Lynch syndrome (LS) – pages 63 to 65
- familial adenomatous polyposis (FAP) – pages 67 to 71
- MUTYH-associated polyposis (MAP)
- juvenile polyposis syndrome
- Peutz-Jeghers syndrome (STK11 gene variant)
- PTEN hamartoma tumour syndrome (Cowden syndrome).

There are likely to be other gene variants that experts currently do not know about. This means genetic tests do not always find a variant in some families. A family may still have a higher risk of bowel cancer if there:

- is a clear pattern of cancer in the family
- are people who have more bowel polyps than usual
- are people affected by certain types of bowel polyps.

Managing a higher risk of bowel cancer

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

Your genetics specialist will give you information about this. The information they give you will depend on:

- your sex assigned at birth (male or female)
- your age
- the type of gene variant
- your family history
- your medical history
- other factors in your lifestyle.

Your genetics specialist will explain whether cancer screening tests or risk-reducing treatments might be helpful in your situation. They can explain whether there are factors in your lifestyle that affect your cancer risk.

They can also give you information about possible symptoms of cancer. Knowing what is normal for your body means you are more likely to recognise any changes that could be a sign of cancer.

We have more information about the signs and symptoms of cancer on our website. Visit **macmillan.org.uk/signs-and-symptoms-of-cancer**

Bowel cancer screening

You may be offered bowel cancer screening with a test called a colonoscopy. This test checks the lining of the bowel from the inside. You may have it to check for and remove polyps and to look for signs of bowel cancer.

Your genetics specialist will explain whether this test is useful for you. They will also say when you should start having it and how often.

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

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.

Risk-reducing options and Lynch syndrome

Lynch syndrome (LS) is a rare condition that can run in families. It used to be called hereditary non-polyposis colorectal cancer (HNPCC).

People affected by LS have a higher risk of developing:

- colon cancer
- rectal cancer
- womb (endometrial) cancer
- ovarian cancer.

And they have a slightly higher risk of developing:

- stomach cancer
- pancreatic cancer
- small bowel cancer
- ureter and renal pelvis cancer.

We talk about risk-reducing options for LS over the next few pages.

We also have more information about LS on our website.
Visit **macmillan.org.uk/lynch-syndrome-ls**

Bowel screening

Guidance in the UK advises that people affected by LS are offered a colonoscopy every 2 years (page 62):

- from age 25 if they have a variant in the MLH1 or MSH2 gene
- from age 35 if they have a variant in the MSH6 or PMS2 gene.

Screening for other cancers

There is currently no effective screening for womb cancer. Your doctor or genetics specialist can give you information about symptoms of womb cancer and about risk-reducing surgery.

Your risk of other types of cancer linked to LS is much lower than the risk of bowel or womb cancer. There are currently no effective screening tests for these other types of cancer.

Sometimes screening for other types of cancer is offered as part of a clinical trial. Your doctor can explain whether this is available and the possible risks and benefits of taking part in a clinical trial. Visit **macmillan.org.uk/clinical-trials**

Aspirin

Taking aspirin regularly helps prevent bowel cancer in people affected by LS. More research is needed to know what the most helpful dose is. Aspirin can also have harmful side effects.

If you want to know more about taking aspirin, ask your doctor for advice.

H. pylori testing and treatment

H. pylori is a bacteria found in the stomach. For people with LS, it can increase the risk of stomach cancer. Your doctor can arrange a stool sample or breath test to check whether you have H. pylori. You may need antibiotics to get rid of the bacteria.

Surgery

Risk-reducing surgery means removing the tissues that are at risk of developing into getting cancer. If you have LS, you may have surgery to reduce the risk of bowel, womb and ovarian cancer.

If you develop bowel cancer, you will usually have surgery to remove the area of bowel affected by the tumour. If you have LS, you may be offered surgery to remove healthy bowel as well. This reduces the risk of bowel cancer developing again.

Women, and people assigned female at birth, with LS may choose to have surgery to remove the womb or ovaries, or both. This reduces the risk of womb and ovarian cancer. But it will also mean you cannot get pregnant. You may think about starting your family earlier than you had planned or have questions about preserving your fertility. You can ask to see a fertility specialist for further advice.

If you have surgery to remove the ovaries, you will start the menopause if you have not already. Your genetics specialist or doctor can explain more about this. You may be offered hormone replacement therapy (HRT) to help with the effects of the menopause.

All types of surgery have risks and possible side effects. It is helpful to discuss the benefits and disadvantages with your doctor. Before deciding to have surgery, you may want to talk it over with your family and other people you trust.

"I was diagnosed with Lynch syndrome. At that point, I felt I needed to be the healthiest I could, so I took up running. It has helped with my mental well-being. My wife signed me up to represent Macmillan at the London Marathon. "

Jake

Risk-reducing options and familial adenomatous polyposis (FAP)

Familial adenomatous polyposis (FAP) is a rare condition that can run in families.

FAP causes hundreds or thousands of small growths in the large bowel. These are called polyps or adenomas. They usually start to appear when a person is in their teens. If the polyps are not treated, 1 or more of them will almost certainly develop into cancer. This usually happens by the age of 40. To prevent this, many people affected by FAP decide to have surgery to remove the large bowel.

FAP can also affect other parts of the body. The effects depend on the type of gene variant. They may include:

- polyps in the stomach and duodenum (the first part of the small bowel) – these may sometimes develop into cancer
- more rarely, cancer in other parts of the body.

Risk-reducing options for FAP include bowel screening and bowel surgery.

We have more detailed information about FAP on our website. Visit **macmillan.org.uk/familial-adenomatous-polyposis-fap**

Cancer screening

If you have FAP, you will be offered regular bowel screening with a colonoscopy (page 62). If the number of polyps in your bowel is increasing, you may need surgery.

You may also be offered a test called an upper endoscopy. This looks for early signs of cancer in the stomach or small bowel. Your specialist can tell you how often you will have this test.

Your risk of other types of cancer linked to FAP is much lower than your risk of bowel cancer. There are currently no effective screening tests for these other types of cancer. But you may be offered screening for other types of cancer as part of a clinical trial. Your doctor can explain whether this is available. They can also tell you the possible risks and benefits of taking part in a clinical trial.

Your doctor will explain which tests you need, when and how often.

We have more information about clinical trials on our website.
Visit **macmillan.org.uk/clinical-trials**

Bowel surgery for FAP

Without surgery to remove the large bowel, most people affected by FAP will develop bowel cancer. Your doctor will talk to you about your risk and the best age for you to have surgery. This may depend on:

- the type of APC gene variant you have
- your age
- your feelings about surgery and the risk of cancer
- the results of your bowel screening tests.

The thought of surgery may be stressful or difficult to cope with. Although surgery is very effective at preventing bowel cancer, there are risks and side effects. For some people, there may be a risk that surgery will affect their fertility. Your surgeon will explain what to expect and the risks and benefits of your surgery.

Sometimes surgery can be delayed, as long as you do not have too many polyps. If surgery is delayed, it is important to have a colonoscopy at a specialist centre every 6 to 12 months.

If you have any questions or worries, talk to your surgeon, nurse or FAP specialist.

Sometimes it helps to talk to other people in the same situation. You can talk to others on our Online Community. Visit **macmillan.org.uk/community**

Removing the colon

It may be possible to remove the colon and join the small bowel to the top of the rectum or the sigmoid (the section of bowel that attaches the colon to the rectum). This operation is called an ileo-rectal or ileo-sigmoid anastomosis. After the operation, you will be able to go to the toilet normally, but will need to go more often. There is still a risk that polyps may develop in the rectum. You will need a test to check this every 6 to 12 months, depending on how many polyps are growing in the rectum.

Removing the colon and rectum

Sometimes the lining of the rectum is also removed to avoid the risk of polyps forming there. If the rectum is removed, it may be possible to replace it with a pouch. This is made using a piece of the small bowel.

This is a complex operation. It involves making a stoma. To make a stoma, the surgeon brings the end of the small bowel out on to the skin of the tummy (abdomen). You wear a bag over the small bowel opening. This collects stools (poo).

Having a stoma allows the joins that hold the pouch in place to heal. After about 3 months, you may have another operation to reverse the stoma.

You will then be able to go to the toilet normally. But you will need to go more often than before. The stools you pass will be looser, and you might need to take anti-diarrhoea medicine. If the rectum has been removed, you will still need to have the pouch checked every year. This is because polyps can continue to grow there.

Sometimes the rectum is removed but it is not possible to replace it with an internal pouch. In this situation, you will have a permanent stoma.

It can take a while to get used to having a stoma. There are specialist nurses who can help and support you through this. They are called stoma nurses.

We have more information about stomas on our website.
Visit **macmillan.org.uk/what-is-a-stoma**

Other inherited cancers

Other inherited conditions that can increase cancer risk

There are some rare inherited conditions that can increase the risk of some types of cancer. These conditions are caused by a change in a gene that can be passed from parent to child (inherited). A change in a gene is called a gene variant or mutation. Different gene variants cause different conditions.

If you or a family member has a rare inherited condition, you may find it helpful to contact Genetic Alliance UK for information and support (page 86).

Hereditary diffuse gastric cancer

People with this have a high risk of developing diffuse stomach cancer and lobular breast cancer.

Familial atypical multiple mole melanoma (FAMMM)

This increases the risk of a type of skin cancer called melanoma. It may also increase the risk of pancreatic cancer.

Von Hippel-Lindau syndrome (VHL)

This increases the risk of cysts or tumours in the:

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

Multiple endocrine neoplasia (MEN) syndromes

These are linked to non-cancerous (benign) growths and cancer in different endocrine glands.

MEN1 and MEN2 are very different conditions. We have more information about them on our website. Visit **macmillan.org.uk/multiple-endocrine-neoplasia-1-men1** and **macmillan.org.uk/multiple-endocrine-neoplasia-2-men2**

Li-Fraumeni syndrome

People with this have an increased risk of several cancers from childhood. These include soft-tissue sarcoma, bone cancer, breast cancer, brain tumours and leukaemia. They are likely to develop more than 1 type of cancer.

Other cancer types

There may be other gene variants that increase the risk of cancer in some families. Researchers are finding some of these and hope to find more in the future.

Some cancers seem to run in families. These include cancers of the pancreas, prostate, stomach or kidney. If you have a relative with one of these types of cancer, it does not usually mean you have an increased risk of that type of cancer. But if you are worried about several cases of 1 or more types of cancer in your family, talk to your GP. They may consider referring you to a genetics specialist (page 15).

If there is a chance of an unknown cancer gene variant 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 develops.

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 booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring 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 would 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**.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are 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, 8am to 8pm. We 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.

Our trained cancer information advisers can listen and signpost you to further support. Call us on **0808 808 00 00**. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to **macmillan.org.uk/talktous**

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

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

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial guidance

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

Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. 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 energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

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 find out more about Macmillan Grants.

Help with work and cancer

Whether you are 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.

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 is why we help bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, 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**

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support advisor or an information and support advisor any questions you have.

Macmillan healthcare professionals

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.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

General genetics support organisations

Association for Multiple Endocrine Neoplasia Disorders (AMEND)

www.amend.org.uk
Support and information for people with multiple endocrine neoplasia (MEN) disorders and their related tumours.

Genetic Alliance UK

Tel **0300 124 0441**
www.geneticalliance.org.uk
Alliance of organisations supporting people with genetic, rare and undiagnosed conditions in the UK. Offers information on their website about living with a genetic condition.

Human Fertilisation & Embryology Authority (HFEA)

www.hfea.gov.uk
UK independent regulator of fertility treatment and research using human embryos. Provides free information about fertility treatment, including information about pre-implantation genetic testing of embryos.

Cancer-specific genetics information

Bowel Cancer UK

Email 'Ask the Nurse' **nurse@bowelcanceruk.org.uk**
www.bowelcanceruk.org.uk
Information and support for everyone affected by bowel cancer. Has an online forum for people to talk about their experiences and an 'Ask the Nurse' service.

Breast Cancer Now

Tel **0808 800 6000**
www.breastcancernow.org
Information and support for people affected by breast cancer. Including information about breast cancer, genes and family history.

Lynch Syndrome UK

www.lynch-syndrome-uk.org
Information and support for people affected by Lynch syndrome.

Ovacome

Helpline **0800 008 7054**
www.ovacome.org.uk
A national support group for everyone affected by ovarian cancer, including patients, families, friends, carers and health professionals.

Polyposis Patient

www.polyposispatient.support
A support group for people affected by polyposis syndromes. Offers information on their website about different polyposis syndromes.

St Mark's Centre for Familial Intestinal Cancer

Tel **0208 453 2656**
www.polyposisandlynch.com
Supports and cares for people with a genetic condition associated with bowel cancer or from a family at high risk of bowel and other cancers. Its website offers information about polyposis and Lynch syndromes.

The George Pantziarka TP53 Trust

www.tp53.co.uk
Information and support for people affected by Li-Fraumeni Syndrome and related conditions.

PTEN UK & Ireland

www.ptenuki.org
Information and support for people affected by PTEN hamartoma tumour syndrome or Cowden syndrome.

General cancer support organisations

Cancer Black Care

Tel **0208 961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and minority ethnic communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**
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**
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 300 0118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline **0808 808 1010**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

World Cancer Research Fund

www.wcrf-uk.org
Provides information on how diet, weight and physical activity affect your risk of cancer

General health information

Health and Social Care in Northern Ireland

www.northerntrust.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 111 Wales

111.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88**
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK

www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

Emotional and mental health support

Mind

Helpline **0300 123 3393**
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.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Live Through This

www.livethroughthis.co.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. LTT runs a peer support group with Maggie's Barts.

Your notes and questions

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. 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: Jennifer Gorrie, Genetic Counsellor; Helen Hanson, Consultant in Cancer Genetics; Tricia Heaton, Genetic Counsellor; Shirley Hodgson, Professor of Cancer Genetics; Fiona Lalloo, Consultant in Clinical Genetics; Jacquie Peck, Clinical Nurse Specialist; and Sara Rose, Genetic Counsellor.

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

Below is a sample of the sources used in our genetics information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Monahan KJ, Bradshaw N, Dolwani S, et al. Guidelines for the management of hereditary colorectal cancer from the British Society of Gastroenterology (BSG)/Association of Coloproctology of Great Britain and Ireland (ACPGBI)/United Kingdom Cancer Genetics Group (UKCGG). Gut. 2020; 69: 411–444.

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Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are 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 are here 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.

5 ways you can help someone with cancer

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

2. **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.

3. **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?

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

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

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

If you would rather donate online go to **macmillan.org.uk/donate**

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MACMILLAN CANCER SUPPORT

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.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** 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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