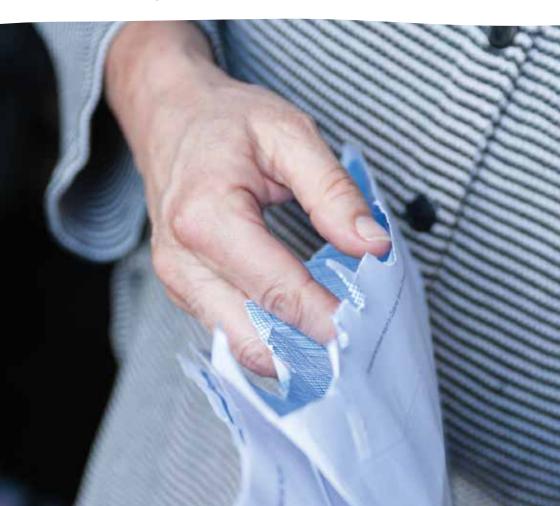


# UNDERSTANDING BOWEL CANCER SCREENING



# About this booklet

This booklet is about bowel cancer screening. It is for anyone who is thinking of taking part in a bowel cancer screening test. You might also find it helpful if you have had a bowel screening test and have been invited to have further tests.

Screening is a way of testing people to see if a disease can be found early, when it has the best chance of being cured. This booklet explains how bowel cancer screening is done, its risks and benefits, and what happens if you have an abnormal test result.

The booklet explains the different tests and what the results might mean. It also explains where there are differences between the countries in the UK.

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

# 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.

If you are deaf or hard of hearing, use textphone 0808 808 0121 or Text Relay.

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**.

# How to use this booklet

The booklet is split into sections to help you find what you need. You don't have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

We have included guotes from people who have had bowel cancer screening tests, which you may find helpful.

Some guotes are from our Online Community (macmillan. org.uk/community). Others are from people who have chosen to share their story with us. To share your experience, visit macmillan.org.uk/shareyourstory

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# ABOUT BOWEL CANCER SCREENING

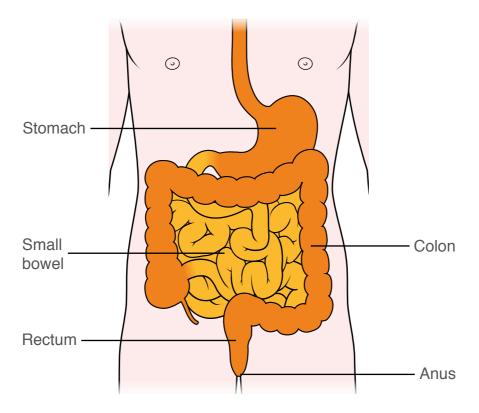
**Bowel cancer screening** 

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# **Bowel cancer screening**

Bowel cancer screening aims to find bowel cancer early, before symptoms develop. About 9 out of 10 bowel cancers (around 90%) can be cured if they are found early.

# The small and large bowel



# **Bowel cancer**

Bowel cancer is the fourth most common cancer in men and in women in the UK. Around 1 in 20 people in the UK (about 5%) will develop it in their lifetime.

Bowel cancer is most common in people in their 60s and 70s. More than 95 out of 100 bowel cancers (over 95%) happen in people over 50.

Most bowel cancers develop in the large bowel, which is made up of the colon and the rectum. The colon is made up of four parts:

- ascending colon
- transverse colon
- descending colon
- sigmoid colon.

Bowel cancer often starts from small, non-cancerous growths called polyps. If doctors find polyps in the bowel during screening, they can remove them. This reduces the risk of bowel cancer developing.

# Who is offered bowel cancer screening?

If you are registered with a GP, you will be offered your first bowel screening test between the ages of 50 and 60. This depends on which country in the UK you live in. There are different bowel screening programmes in each country (see pages 16 to 18).

Bowel cancer screening is for people who do not have symptoms. If you have any bowel symptoms that continue for three weeks or more, see your GP. Do not wait for a bowel screening invitation.

Bowel screening might not be suitable for certain people. This includes people who:

- are being treated for bowel cancer
- have had their large bowel removed
- are part of a hospital programme that checks for bowel adenomas (polyps)
- are on a surveillance programme for inflammatory bowel disease such as Crohn's or ulcerative colitis
- are waiting for bowel tests that have been arranged by their GP.

If you are invited for screening but are not sure you should have it, contact your country's screening helpline number (see pages 16 to 18) or your GP for advice.

'I'm a great believer in any screening they do, because I think prevention is better than cure. I think people should take advantage of all the things that are available.

David

# Screening for people with a higher risk

Some people have a higher risk of developing bowel cancer. People with a higher risk of developing bowel cancer are offered extra bowel screening, usually at their local hospital. This usually starts at a younger age than bowel screening for the general population.

People with a higher risk of developing bowel cancer include people with:

- a genetic condition that increases their risk of bowel cancer, such as familial adenomatous polyposis (FAP) or Lynch syndrome
- ulcerative colitis or Crohn's disease these can cause inflammation in the bowel
- a strong family history of bowel cancer this would mean two or more close family members on the same side of the family with bowel or womb cancer, or one person who was diagnosed at a young age (under 50)
- polyps in the bowel
- a previous bowel cancer.

We have more information about FAP, Lynch syndrome and inherited cancers available to order (see page 50).

People with a higher risk of developing bowel cancer are usually offered screening with a colonoscopy (see pages 32 to 38).

Speak to your doctor if you think you might have a higher risk of developing bowel cancer. They will be able to advise you.

# Your choice

You do not have to take part in the bowel cancer screening programme. It is your choice.

You will get a reminder letter if you do not take part. You will also continue to receive an invitation to take part every 2 years, until you are 74.

If you do not want to be screened, you can contact the free number on the letter.

You can call a bowel cancer screening helpline to find out more about taking part. There are different bowel cancer screening programs in the UK. See pages 16 to 18 to find out more, and for the helpline phone number for the country you live in.





# BOWEL CANCER SCREENING TESTS

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# **Bowel cancer** screening overview

The main tests used in bowel cancer screening are:

- the FOB (faecal occult blood) test
- the FIT (faecal immunochemical test)
- the bowel scope test.

### **FOB** and **FIT** tests

These tests are very similar. They both check for hidden blood in poo, which can be a sign of polyps or bowel cancer. The tests come as a home screening kit. You collect a small sample of your poo and send it to a laboratory. It is checked for tiny amounts of blood.

The main difference between the two tests is that you only need to send one sample of poo for the FIT test. The FOB test needs three samples to get a complete result.

See pages 21 to 26 for more information about these tests.

# **Bowel scope test**

This test is used in some parts of England and it is being tested in Scotland. It is not part of the bowel screening programme in Wales or Northern Ireland.

Bowel scope screening uses a tube with a light and a camera to look inside the lower part of the bowel.

The scope can find cancers in the lower part of the bowel. This is where most cancers develop. It also helps prevent bowel cancer by removing polyps before they could turn into cancer.

You have the test in the hospital as an outpatient. It takes about 15 minutes to have the test

See pages 27 to 31 for more information about this test.

### Other tests

Most people have normal results from the FOB test, FIT test and bowel scope screening. But some people have an abnormal result. These people are offered an extra test to look at all of their large bowel. This test is usually a colonoscopy. See pages 32 to 40 for more information about this test.

# **UK screening programmes**

There are different bowel screening programmes in the four countries of the UK. The screening programmes are based on research done in each country and reflect the different needs of the populations.

Your screening test will be sent to the address your GP has for you. So it is important to make sure your GP has the right contact details for you.

# **England**

Currently, if you are aged 60 to 74 you are sent a FOB home screening kit every 2 years. This will change, as the National Screening Committee has recommended that the FOB test is replaced with the FIT test. If you are not sure which test kit you have been sent, call the national screening helpline number below.

People in England will also be offered a bowel scope screening test at around the age of 55.

If you are older than 75, you will not automatically be sent a FOB or FIT test. But you can still take part in screening if you choose to. You can call the bowel screening helpline and ask to be sent a test kit.

For more information about bowel screening in England, call the helpline on **0800 707 6060**, Monday to Friday, 9am to 5pm.

# Scotland

If you are aged 50 to 74, you will be sent a FIT home screening kit every 2 years.

If you are older than 75, you will not automatically be sent a FOB or FIT test. But you can still take part in screening if you choose to. You can call the bowel screening helpline and ask to be sent a test kit.

In some parts of Scotland, bowel scope screening is being tested on people around the age of 60. If it works well, bowel scope screening will be offered to everyone of that age in Scotland.

For more information about bowel screening in Scotland, call the helpline on 0800 0121 833, Monday to Friday, 8am to 5pm.

# **Wales**

If you are aged 60 to 74, you will be sent a FOB home screening kit every 2 years. You cannot request a kit if you are 75 or older.

If you have an unclear result, you may also be sent a FIT test. See page 26 for more information about unclear results.

For more information about bowel screening in Wales, call the helpline on **0800 294 3370**, Monday to Friday, 8am to 5pm.

# Northern Ireland

If you are aged 60 to 74, you will be sent a FOB home screening kit every 2 years. You cannot request a kit if you are 75 or older.

If you have an unclear result, you may also be sent a FIT test. See page 26 for more information about unclear results.

For more information about bowel screening in Northern Ireland, call the helpline on **0800 015 2514**, Monday to Friday, 9am to 5pm.



# Benefits and disadvantages of screening

We have listed the main benefits and disadvantages of bowel cancer screening tests. You can use this to help you decide if you want to take part in the FOB test, FIT test and bowel scope screening programmes.

## **Benefits**

- Bowel cancer screening can detect bowel cancer at its earliest stage, when there is a 9 in 10 (90%) chance of curing it.
- Bowel screening can prevent some bowel cancers from developing.
- With regular screening, the number of people who die from bowel cancer is reduced by 16%.

# **Disadvantages**

- Screening cannot detect all bowel cancers. You should always go to see your doctor if you have any bowel symptoms, even if you had a negative screening result.
- Not all cancers found during bowel cancer screening can be cured.
- Rarely, a bowel scope test or a colonoscopy can cause bleeding or a tear in the bowel. If this happens, an operation is needed to repair the bowel.

# The FOB and FIT tests

The FOB and FIT tests can detect tiny amounts of blood in your poo.

Blood in your poo does not mean you have cancer, but bowel cancers and polyps sometimes bleed. There can be other causes for blood in poo. If your test finds blood, you will be offered another test to find the cause of the bleeding. This will usually be a test called a colonoscopy (see pages 32 to 38).

# Using the test kits

You will get a home screening kit when you reach the age that bowel cancer screening starts in your country. See pages 16 to 18 to read about the different screening programs.

'I read it through and made sure I had everything prepared. It told you exactly what to do and how to set it up. I thought it was very straightforward."

**Evelyn** 

The main difference between FOB and FIT tests are the number of samples you need to take:

- For the FOB test, you need to take three different poo samples, each on different days.
- For the FIT test, you only need to take one sample.

You return the samples to the test centre in a pre-paid envelope. The test kit comes with a set of instructions. Before you take a sample, it is helpful to:

- read through all the instructions
- get everything you need ready
- write any details on the test kit, for example the date.

If you have any questions about the sample collection, or have a disability that makes using the kit difficult, call your country's screening helpline. If you need a new test kit, they can send you one. These are the helpline numbers:

- In England, call 0800 707 6060, Monday to Friday, 9am to 5pm.
- In Scotland, call 0800 0121 833, Monday to Friday, 8am to 5pm.
- In Wales, call 0800 294 3370, Monday to Friday, 8am to 5pm.
- In Northern Ireland, call 0800 015 2514, Monday to Friday, 9am to 5pm.

If you live in England, you have 14 days to return the test card after taking the first sample.

In the rest of the UK, you have 10 days to return the test card after taking the first sample. You will get a reminder after about 4 weeks if you do not return the test kit.

If you decide not to take part in the screening programme, you can choose not to respond. Or you can contact your country's helpline to say you will not be sending your kit back.



### Test results

Waiting for your results can be an anxious time. It may help to talk things over with a relative or close friend. Or you can talk to one of our cancer support specialists on 0808 808 00 00.

You should get a letter with the results of your home screening test within 2 weeks. Your GP will also get a letter.

With the FOB test, there are three possible test results:

- normal
- abnormal
- unclear.

The FIT test gives only a normal or abnormal test result.

#### Normal result

Around 98 out of 100 people (about 98%) have a normal result. This means no blood was found.

2 years after your test, you will be sent another test kit if you are still within the age range.

If you have any symptoms before your next screening test, it is important to go to see your GP. Do not wait for your next test kit.

### Symptoms of bowel cancer include:

- an unexplained change in bowel habit, such as diarrhoea, constipation or both, that does not go away
- bleeding from the back passage (rectum) or blood in your poor
- looser poo or diarrhoea that lasts for 3 weeks or more
- a feeling of not having emptied your bowel properly after going to the toilet
- a pain or lump in your tummy or back passage
- loss of weight or appetite
- feeling more tired than usual for 2 to 3 weeks, with no obvious reason.

#### Abnormal result

About 2 in 100 people (around 2%) have an abnormal result.

If you have this result, it means blood was found in your test. Blood in your test result does not mean you have bowel cancer. Only about 1 in 10 people with an abnormal result (about 10%) have cancer.

Blood in poo can be caused by other conditions. Some people may have bleeding from small, non-cancerous growths in the bowel called polyps. Or it may be something less worrying, such as piles (haemorrhoids).

If you have an abnormal result, you will be offered an assessment and probably a bowel test called a colonoscopy (see pages 32 to 38).

### Unclear result

A small number of people may have an unclear result. This means there was some blood detected, but not enough to give an abnormal result.

Having an unclear result does not mean you have bowel cancer. It just means you need to do a second test to check for blood in your poo. You will be sent another home screening kit. Most people who do the second test get a normal result. If the result of your second test is normal, you may be sent another kit to confirm the result.

If the result of the second test is unclear or abnormal, you will usually be offered a colonoscopy.

Sometimes you may be asked to repeat the test. This may be because of the following reasons:

- A technical failure. This means there was a problem when your samples were tested in the laboratory. If this happens, you will be sent a letter and another test kit to collect more samples.
- A spoilt kit. This means the test kit cannot be tested in the laboratory, because it has not been used properly or has been damaged. If this happens, you will be sent a letter and another test kit to try again.

# **Bowel scope screening**

Bowel scope screening is starting to be used in England and is being tested in Scotland. It is not used in Wales or Northern Ireland

A one-off bowel scope test can help detect bowel polyps and prevent some bowel cancers. It can also help detect bowel cancers at a very early stage, which can reduce the risk of dying from them.

The test looks at the inside of the back passage (rectum) and the part of the large bowel that is closest to the rectum (the sigmoid colon) – see page 28. This is where most polyps and cancers develop. You have bowel scope screening as an outpatient at the hospital.

Bowel scope screening only looks at the lower part of the bowel. It does not replace the FOB or FIT home screening test (see pages 21 to 26).

# Before bowel scope screening

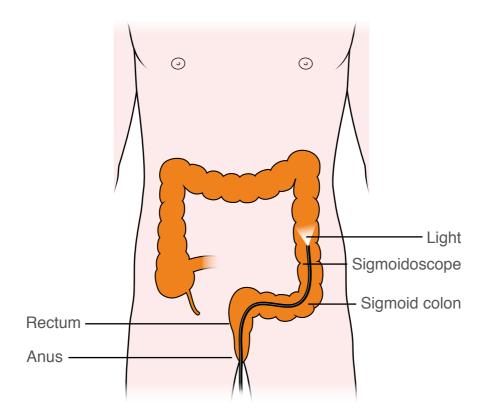
You will get a letter inviting you to have bowel scope screening. The letter will include some information about the test. Your appointment time is usually sent 2 weeks after the first letter.

If you accept the bowel scope screening, you will also get a letter with an enema and instructions for how to use it. An enema is a liquid used to soften the poo. It does not give you diarrhoea, but you will need to go to the toilet straight away. This clears poo out of the lower part of the bowel and makes it easier for the nurse or doctor to see inside the bowel. You use the enema on the day of the test. Most people find it easy to use.

# What does bowel scope screening involve?

Bowel scope screening is done using a bendy tube with a light and camera on the end. This is called a sigmoidoscope. You lie on your left side and a doctor or nurse passes the tube into the back passage (rectum). A small amount of air is pumped into the bowel to make it easier to see inside. This can make you feel bloated for a few hours afterwards.

# Bowel scope



Most people find the bowel scope screening painless or have only mild discomfort. If you find it very painful, tell the doctor or nurse straight away. If you have pain, they will give you a gas that can relieve pain (Entonox®). It is sometimes called gas and air. You breathe it in through a mouthpiece.

The doctor or nurse will remove any polyps they find during the test. They can also take samples of tissue (biopsies) from any areas of the bowel that look abnormal. The doctor or nurse will tell you at the time if they remove any polyps or take biopsies.

If you have polyps removed or biopsies taken, you will get the results by letter within 3 weeks.

You can go home after the test is over.

Some people find bowel scope screening embarrassing. But it may help to remember that the doctors and nurses are used to dealing with this every day. They will try to make you feel as comfortable as possible.

# Risks of bowel scope screening

Bowel scope screening is a safe test and most people do not have any problems after it. But rarely, there can be problems.

About 1 in 250 people have heavy bleeding after having a polyp removed. They may need to go into hospital to have this treated

Sometimes the bowel can be torn or damaged, but this is very rare. If it happens, you will need an operation to repair the tear. Symptoms of a tear include:

- severe tummy pain
- a high temperature
- bleeding from the back passage
- being sick.

If you have any of these symptoms, contact your GP or go to your nearest emergency department (A&E) straight away.

# **Bowel scope results**

#### Normal result

About 95 out of 100 people (95%) have a normal result from the test. This means the test found no polyps or anything abnormal in the bowel. You will be told straight away if your test is normal.

It is important to be aware of bowel cancer symptoms in future, even if you have a normal result. See page 44 for more information about bowel cancer symptoms.

# **Polyps**

Around 5 out of 100 people screened (about 5%) have polyps. The nurse or doctor usually remove any polyps they find. They will tell you if they have done this.

They send the polyp to the laboratory to be checked by a pathologist. This is a doctor who specialises in studying tissue samples and cells. Most polyps are not cancerous (benign).

If you had polyps removed during your bowel scope test, you will be contacted within 3 weeks. This is to tell you whether you need further tests or a follow-up appointment. Your GP will also get a letter with your results.

You may be offered another test to check all of your large bowel. This is usually a colonoscopy (see pages 32 to 38).

Waiting for your results can be an anxious time. It may help to talk things over with a relative or close friend. Or you can talk to one of our cancer support specialists on 0808 808 00 00.

#### Cancer

Rarely, the screening will find bowel cancer. About 1 in 300 people who have bowel scope screening are found to have cancer. If cancer is found, it is likely to be at an early stage. Around 9 out of 10 of bowel cancers (about 90%) can be cured if found at an early stage. Your nurse or doctor will arrange for you to see a specialist as soon as possible.

You may find our booklets Are you worried about bowel cancer?, Understanding colon cancer and **Understanding rectal cancer** helpful (see page 50).

We also have online information about small bowel cancer (see page 50).

# Colonoscopy

A colonoscopy looks at the inside of the whole length of the large bowel. You can usually have this test as an outpatient. It takes about 30 minutes.

This test may be done for people who have:

- an abnormal FOB or FIT test result (see pages 21 to 26)
- a second or third unclear FOB test result
- polyps found during bowel scope screening (see pages 27 to 31).

# Assessment

You will usually be assessed at your local hospital or screening centre. In some parts of Scotland and Wales, you may be assessed over the phone.

The nurse will explain what your test result means and answer your questions. They will also assess whether you are fit enough to have a colonoscopy. They will explain how a colonoscopy is done, as well as the benefits and risks of having it. The nurse may be called a specialist screening practitioner (SSP).

Some people may not be able to have a colonoscopy. This may be because of other health conditions or medications they are taking. If a colonoscopy is not suitable in your situation, you may be offered a different test. This is usually a virtual colonoscopy (sometimes called a CTC scan or colonogram) see page 40.

# Before a colonoscopy

Your bowel has to be completely empty before you have a colonoscopy. Your doctor or nurse will tell you what you can eat and drink the day before the test. You will also take a medicine to empty your bowel. This is called a laxative. Just before the test, you may have a sedative as an injection into a vein (intravenously). This will help you feel more relaxed and sleepy while you have the colonoscopy.

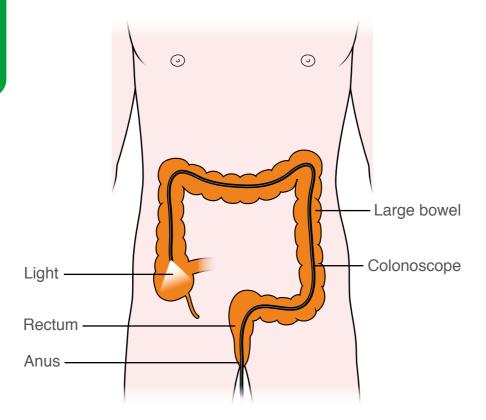
The colonoscopy is usually done in the hospital endoscopy unit. It takes about 30 minutes. The test can also see if there are any polyps in the bowel.

# Having a colonoscopy

Once you are lying comfortably on your side, the doctor or nurse will gently pass a flexible tube into the back passage (rectum). This tube is called a colonoscope. There is a tiny light and camera on the end of it. During the test, the doctor or nurse will use this to photograph any areas of the bowel that look abnormal. They may also take samples (biopsies) from these areas. They will send the biopsies to the laboratory to see if there are any cancer cells.

Having a colonoscopy can be uncomfortable. If you do have pain, it is usually mild. If you find it very painful, tell the doctor or nurse straight away. They may give you Entonox®, which is a gas that can relieve pain. It is sometimes called gas and air. You breathe it in through a mouthpiece.

# A colonoscopy



# After a colonoscopy

Most people are ready to go home a couple of hours after their test.

If you had a sedative, you will need someone to collect you from the hospital. After having a sedative, you should have someone with you for 12 hours. You should not drive for 24 hours.

If you only had Entonox® (gas and air), you should be able to drive home when the nurses say you have recovered. You will not need someone to stay with you overnight.

It is rare to have any serious problems after the test. Contact your GP or go to your nearest emergency department (A&E) straight away if you:

- have severe tummy pain
- have a high temperature
- are being sick
- are bleeding from the back passage.

Sometimes it is not possible to see the whole bowel during a colonoscopy. This can happen if the bowel is not completely empty. It may also happen if the colonoscope cannot pass around a bend in the bowel to reach the end. If this happens, you may be asked to have another colonoscopy, or a virtual colonoscopy. See pages 32 to 40 for more information about these tests.

# Risks of a colonoscopy

Most people who have a colonoscopy have no problems. But rarely, there can be problems.

A small number of people have heavy bleeding after having a polyp removed or a biopsy. This can usually be treated quickly during the test. But some people may need to be admitted to hospital to have this treated.

Rarely, the bowel can be torn or damaged. If this happens, you will usually need an operation to repair the tear.

Very rarely, a person may die as a result of having a colonoscopy. This happens in about 1 in every 10,000 colonoscopies. You will be assessed before you have a colonoscopy to check it is suitable for you. If the assessment shows you may be at a higher risk of problems, you will be offered a different test.

'They offer sedation for the procedure which is a good idea. I felt no pain, and was able to watch what they were doing on the screen. I did not feel the biopsies. I bled a bit afterwards, but I was fine. It is usually a day procedure. Not my favourite thing, but quite doable!'

**Aoife** 

# Colonoscopy results

You should get a letter with the results of your colonoscopy within 3 weeks. Some hospitals may phone you with the results. If you have polyps removed or biopsies taken during your test, the letter will say if you need further tests or a follow-up appointment. Your GP will also get a letter with your results.

Waiting can be an anxious time. You may find it helps to talk to a relative or close friend. Or you can talk to one of our cancer support specialists on 0808 808 00 00.

# Normal result

This means no polyps or cancer have been found in your bowel. Or some people may have small polyps that do not need to be removed. Even if you have a normal result, it is important to be aware of bowel cancer symptoms in future (see page 44).

After 2 years, you will be invited to take part in bowel cancer screening with a home testing kit again. You will only be invited if you are still within the screening age range for your country (see pages 16 to 18).

# **Polyps**

Some people may have polyps that need to be removed. This might be because there are:

- quite a lot of polyps
- one or two large polyps.

Polyps can usually be removed during the colonoscopy. This can help prevent bowel cancer developing.

The removed polyps will be sent to a laboratory to be checked by a doctor who specialises in looking at cell and tissue samples (pathologist). Depending on the results, you may be invited to keep having bowel cancer screening every 2 years. Or you may have another colonoscopy in the next few years.

Polyps may come back after being removed.

### Other non-cancerous bowel conditions

Some people may have other changes in their bowel. The most common findings are piles (haemorrhoids) or a bowel condition such as diverticular disease. These conditions may not need treatment if they are not causing symptoms.

If this test shows you have a bowel condition, you can ask your GP for information and advice.

#### Cancer

Around 1 in 10 people who have a colonoscopy after an abnormal FOB or FIT test result (about 10%) are diagnosed with bowel cancer. If a cancer is found, you will be referred to a cancer specialist for treatment.

There is a good chance of curing cancer if it is found at its earliest stage. Around 9 out of 10 bowel cancers (about 90%) can be cured if found at an early stage.

If you are diagnosed with cancer in the colon or rectum, you may find it helpful to read our information about colon cancer or rectal cancer. See page 50 for ways to order this information.



# Virtual colonoscopy (CT colonography)

This test uses a CT scanner to create a picture of the bowel.

In a virtual colonoscopy, a CT scanner takes a series of x-rays, which builds up a three-dimensional picture of your bowel. It is done in the hospital CT department. You can usually have it as an outpatient.

This test may be done instead of a colonoscopy, or it may be done if the colonoscopy did not give a clear enough picture.

You will need to follow a special diet for a few days. You will also be given a liquid to drink, called gastrografin. The liquid works like a laxative to help clear out your bowel. It also helps show poo still in the bowel on the scan picture. Your hospital will give you instructions of how and when to take the gastrografin.

Your doctor may give you an injection to help the muscles in the bowel relax. You may also have an injection of a dye (contrast) at the same time. Your doctor will tell you if you are going to have this.

Just before the scan, your doctor passes a tube into the back passage (rectum) and pumps in some air and gas (carbon dioxide).

This expands the bowel and helps give a clearer picture. You will have two CT scans - one lying on your back and one lying on your front.

# Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or one of the organisations listed on pages 55 to 56, can also provide support. You can also talk things over with one of our cancer support specialists on 0808 808 00 00.



# REDUCING YOUR RISK OF BOWEL CANCER

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# Be bowel aware

When it is found early, bowel cancer can usually be treated very successfully. More than 9 out of 10 people (90%) survive bowel cancer when it is diagnosed at an early stage.

It is important to be aware of any changes that could be a sign of bowel cancer, even if you decide not to take part in bowel screening. Go and see your GP if you have any of the following symptoms:

- an unexplained or persistent change in bowel habit, such as diarrhoea, constipation or both, that does not go away
- bleeding from the back passage (rectum) or blood in your poo
- looser poo or diarrhoea that lasts for 3 weeks or more
- a feeling of not having emptied your bowel properly after going to the toilet
- a pain or lump in your tummy or back passage
- loss of weight or appetite
- feeling more tired than usual for 1 to 2 weeks, with no obvious reason.

Bowel problems are very common and these symptoms may not be caused by cancer. It is still important to get them checked. Do not be embarrassed to speak to your doctor about your symptoms. Conversations like this are part of their everyday work.

# Reducing your risk

Changes to lifestyle could prevent over half of bowel cancers in the UK. Here are some things you can do to reduce your risk of bowel cancer.

# Eat a healthy diet

Following a healthy diet can reduce your risk of bowel cancer. Eat plenty of fibre, such as beans, oatmeal, fruit and vegetables. Aim to eat 5 portions of fruit and vegetables every day. Avoid processed meat and reduce the amount of red meat, fat and salt you eat. Our website has more advice (see page 50).



# **Keep physically active**

Regular physical activity can reduce your risk of bowel cancer. Being physically active does not mean you have to go to the gym - regular walking, cycling or swimming can be enough.

Try to do at least  $2\frac{1}{2}$  hours of moderate-intensity physical activity a week. This could be made up of 30 minutes of activity each day, for 5 days. You could break it up further into 10 minutes of activity, 3 times a day.

Moderate-intensity physical activity is when you are still able to talk, but your breathing is quicker and deeper. Your body is warming up and your face may have a healthy glow. Your heart is beating faster than normal, but not racing.

If you are not sure how to get started, your GP can give you advice. We also have information on our website (see page 50).

# Keep to a healthy weight

Keeping to a healthy weight can help reduce your risk of bowel cancer. If you are overweight, working towards a healthy weight will help.

Having an active lifestyle, following a healthy diet and controlling the size of your portions can help you maintain a healthy weight. Your GP can give you more advice on your ideal weight and on losing weight if you need to.

We also have more information that may help you on our website (see page 50).

# Give up smoking

Smoking tobacco increases your risk of developing bowel cancer and many other types of cancer. Giving up smoking is the most important thing you can do for your health.

Help is available if you want to stop smoking. Ask your GP for advice, or contact your national stop-smoking service. Visit **nhs.uk/livewell/smoking** to find your local service.

# Limit how much alcohol you drink

NHS guidelines suggest that both men and women should:

- not regularly drink more than 14 units of alcohol in a week
- spread the alcohol units they drink in a week over 3 or more days
- try to have several alcohol-free days every week.

A unit of alcohol is half a pint of ordinary-strength beer, lager or cider, one small glass (125ml) of wine, or a single measure (25ml) of spirits.

There is more information about alcohol and drinking guidelines at drinkaware.co.uk



# FURTHER INFORMATION

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# **About our information**

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

# Order what you need

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

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

### Online information

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

# Other formats

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

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

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

# Help us improve our information

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

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

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



# Other ways we can help you

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

#### Talk to us

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

### **Macmillan Support Line**

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

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

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

#### Information centres

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

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

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

#### Talk to others

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

### Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting macmillan.org.uk/ selfhelpandsupport

# **Online Community**

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

# The Macmillan healthcare team

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

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

Mal

# Help with money worries

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

## Financial guidance

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

# Help accessing benefits

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

#### Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit macmillan.org.uk/ financial support to find out more about how we can help you with your finances.

# Help with work and cancer

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

### My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

# Other useful organisations

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

# NHS bowel cancer screening programmes

**Bowel Screening England** Helpline 0800 707 60 60 (Mon to Fri, 9am to 5pm) www.nhs.uk/livewell/ screening/pages/screening. aspx

**Bowel Screening Scotland** Helpline 0800 0121 833 (Mon to Fri, 8am to 5pm) www.nhsinform.co.uk/ screening/bowel

**Bowel Screening Wales** Helpline 0800 294 3370 (Mon to Fri, 8am to 5pm) www.bowelscreening.wales. nhs.uk

**Bowel Screening** Northern Ireland Helpline 0800 015 2514 (Mon to Fri, 9am to 5pm) www.cancerscreening. hscni.net

# General bowel cancer organisations

**Bowel Cancer UK** Tel 0207 940 1760 **Email** 

nurse@bowelcanceruk.org.uk www.bowelcanceruk.org.uk Offers support to everyone affected by bowel cancer. They provide information and they have an online forum for people to talk about their experiences.

# Scotland Tel 0131 281 7351 **Email** scotadmin@ bowelcanceruk.org.uk

Wales **Email** lowri.griffiths@ bowelcanceruk.org.uk

Northern Ireland Tel 0779 852 3668 Email niamh.mcdaid@ bowelcanceruk.org.uk

# General health information

# **Health and Social Care** in Northern Ireland www.hscni.net

Provides information about health and social care services in Northern Ireland.

### Healthtalk **Email**

info@healthtalk.org www.healthtalk.org

Has information about cancer. and videos and audio clips of people's experiences. Also provides advice on topics such as making decisions about health and treatment.

# NHS.UK www.nhs.uk

for Wales.

The UK's biggest health information website. Has service information for England.

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

# NHS Inform Helpline 0800 22 44 88 (Mon to Fri, 8am to 10pm) 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 evidencebased information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

# **LGBT-specific support**

### **IGBT** Foundation

Tel 0345 330 3030

(Mon to Fri, 10am to 6pm) **Email** helpline@lgbt.foundation

# 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.

# 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 Chief Medical Editor, Prof Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Ms Christine Bronder, Consultant Colorectal Surgeon; Mr James Crosbie, Consultant Colorectal Surgeon; TJ Day, Informed Choice Co-ordinator, NHS Screening Programmes; and Christine Ireland, Bowel Screening Unit Manager.

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

#### **Sources**

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

NHS bowel cancer screening programme. Public Health England. August 2017. Northern Irish bowel cancer screening programme. Information for health professionals.

Scottish bowel screening programme. Health Improvement Scotland. November 2017. UK NSC bowel cancer recommendation. January 2016.

# 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

# 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

# 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.

I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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.

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

Security number

Issue no

Signature

Date

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

REGULATOR

This booklet is about bowel cancer screening. Bowel cancer screening helps find bowel cancer early, when it has the best chance of being cured.

This booklet is for anyone thinking of taking part in a bowel screening test. It also includes information about what the results of a bowel screening test might mean.

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

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

Need information in different languages or formats?
We produce information in audio, eBooks, easy read,
Braille, large print and translations. To order these,
visit macmillan.org.uk/otherformats or call our support line.

# MACMILLAN CANCER SUPPORT

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