

Bowel health and screening: carers guide

A booklet for carers of people who use easy read materials



Contents

Page 3: About this booklet

Page 4: What is the bowel?

Page 5: Helping someone to have good bowel health

Page 6: What is bowel cancer screening?

Page 7: Who gets bowel cancer?

Page 8: Caring for someone with a learning disability

Page 8: Giving consent

Page 10: Using the home test kit

Page 11: Getting the test results

Page 12: Next steps

Page 13: Bowel scope screening for people aged 55 years

Page 14: Going to the doctor

Page 14: Questions the doctor might ask

About this booklet

Carers can play an important role in helping people make the best choices about their health. We have written this booklet to help you talk with the person or people you support, about keeping their bowel healthy and getting their bowel checked.

We have produced three easy read booklets. These are

- Keeping your bowel healthy
- Bowel health and the home test kit – the NHS Bowel Cancer Screening Programme for people 60 years old and over
- Checking your bowel is healthy – the NHS bowel scope test for people who are 55.

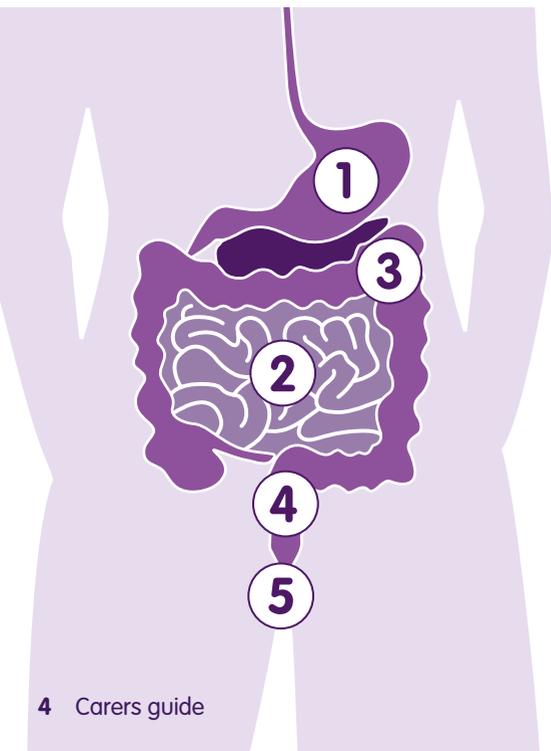
What is the bowel?

The bowel is part of our digestive system. It is made up of the small and large bowel and runs from the stomach to the anus.

The bowel plays an important part in breaking down the food we eat, giving us energy, vitamins, minerals and water. Eating a healthy, well balanced diet helps our digestive system to work better so we feel good and our bodies work efficiently.

The bowel processes waste from the food we eat. If we eat healthily then the bowel usually works well. But, if we eat unhealthy foods, have little or no exercise, smoke or drink too much alcohol, then our bowel health can suffer.

When we talk about cancer in the bowel, we mean the large bowel, as in the diagram below.



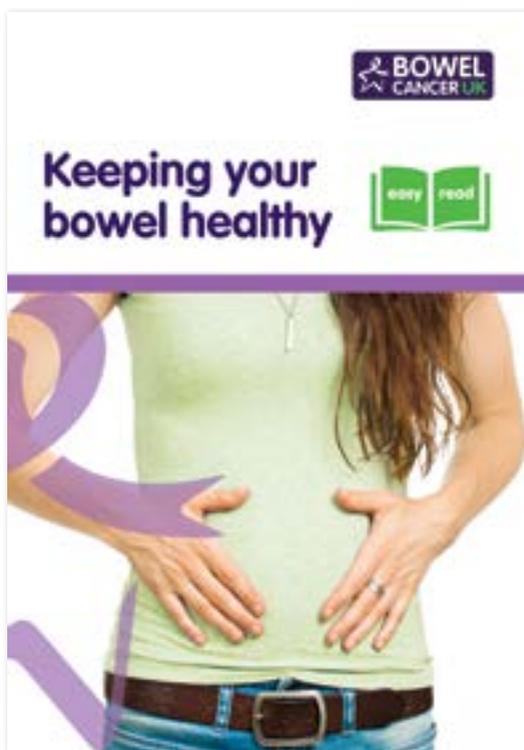
1. Stomach
2. Small bowel
3. Colon
4. Rectum
- (3+4 = large bowel)
5. Anus

Helping someone to have good bowel health

Giving clear health messages to everyone, including people with learning disabilities, can really help keep the bowel healthy so that people have a lower risk of developing bowel cancer.

Poor bowel health can cause problems such as constipation, loose and watery poo or diarrhoea, tiredness, bloating, swelling, and can even lead to bowel cancer.

The easy read booklet **Keeping your bowel healthy** has some great information on how to have a healthier lifestyle. Take a look with the person you care for so they can find out more about how to stay healthy and have a balanced, active lifestyle.



What is bowel cancer screening?

Bowel cancer screening can help to detect bowel cancer at an early stage, when a person may not be showing any symptoms.

People aged 60 and over can take part in the bowel cancer screening home test. There is information about this on page 10 or you can read **Bowel health and the home test kit**.

In some areas, people aged 55 can take a bowel scope test. There is more information about this on page 13 and in **Checking your bowel is healthy**.

These screening tests look for signs the person may have a higher risk of getting bowel cancer. Signs can include blood in poo that cannot always be seen. This hidden or unseen blood can be a sign of bowel cancer.

Bowel cancer screening can also diagnose other bowel problems, like polyps. Polyps are small growths inside the bowel that can't be felt or seen, but may sometimes bleed, and could lead to bowel cancer in the future. Removing these polyps can stop cancer from developing.

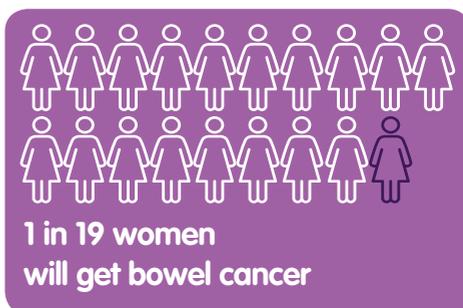
Bowel cancer is preventable, treatable and curable, especially if it's diagnosed early. Getting your bowel screened is the best way to catch any hidden signs of bowel cancer early. If you or someone you care for has symptoms or any other concerns about the health of your bowel, you should make an appointment to see the GP immediately.

To find out more about the NHS Bowel Cancer Screening Programme, please call **0800 707 6060** or visit our website at **bowelcanceruk.org.uk/screening**

Who gets bowel cancer?

After lung, breast and prostate cancers, bowel cancer is the fourth most common cancer in the UK. More than 41,000 people are diagnosed with bowel cancer each year. Bowel cancer is more common in people over the age of 50.

Around 1 in 16 people over the age of 50 will get bowel cancer at some point in their lives. It is more common in men than it is in women.



In the past, people with learning disabilities were not expected to live very long and so had a lower risk of developing cancer. But life expectancy in people with learning disabilities is increasing so the risk of getting bowel cancer is also higher.

Here are some symptoms to look out for that could be a sign of bowel cancer

- Bleeding from your bottom or blood in your poo
- A change in your bowel habit that lasts for three weeks or more
- Losing weight for no reason
- Extreme tiredness for no reason
- Any pains or lumps in your tummy.

Most people with these symptoms don't have bowel cancer. Other health problems can cause these symptoms.

Caring for someone with a learning disability

You can support people with learning disabilities understand what screening is and help them decide whether to take part by reading the letter and leaflet sent to them.

You may like to use the easy read booklets in this pack or you can get other easy read materials by calling the NHS bowel screening helpline on **0800 707 6060**.

Knowing the early signs and symptoms can be crucial in catching bowel cancer early. Seeing the GP as quickly as possible is very important.

Giving consent

The person you care for needs to be able to give their consent to do the bowel cancer screening home test. They need to know what the test means and how to carry it out. If they are not able to do this, then you should speak to their GP, learning disability nurse and/or their family, to find out what the best approach might be.

You can find out more about making decisions for someone who can't give their consent, by going to this website:

[gov.uk/make-decisions-for-someone](https://www.gov.uk/make-decisions-for-someone)

Using the home test kit

The person you care for may need support to use the home test kit. This support can come from you, a family member, their GP, nurse or community health team.

Before you start the test, the person taking the test should give their consent. Read through the letters and booklets that come with the screening kit.

Here are some important points to remember

- You must take two samples from three different poods within 14 days
- Make sure you have everything you need from the kit ready before you start – keep tissues and a bin close to hand
- Write the date each poo sample is done in the right space on the test kit
- Use a clean disposable container to catch the poo before it goes into the toilet – a take away box or an ice cream tub is ideal
- Don't let any urine or water go into the container – this will change the sample and it won't give a clear result
- After the sticks have been used, wrap the sticks in toilet paper and put them in the bin
- Whoever has collected the samples must wash their hands when they've finished.

If the person you look after uses an incontinence pad instead of going to the toilet, you can take the poo samples from their pad, if they say it is ok to do this.

Take the poo sample as soon as possible after the person has done a poo. Don't take samples from an old poo. Don't forget – you need to take two samples from three different poods. There is a calendar at the back of the booklet **Bowel health and the home test kit** you can use to keep track of dates.

Getting the test results

The kit will be tested at the screening hub, and results will be sent out within two weeks.

If the person you support has any questions, they can talk to their community team, GP or nurse. They can also call the screening helpline on **0800 707 6060**.

A negative, or clear result

Most people will have a 'negative' result. This means no blood was found in any of the samples and they do not need any further screening at this point. Test kits will be sent out every two years until a person is 74 years old. After this age, they can request a kit by phoning the helpline number above.

An unclear result

An 'unclear' result means that traces of blood were found in some of the samples. The person will need to do another test to see if there is still blood in the samples.

A positive, or abnormal result

If the result is 'positive' then it means most of the samples have blood in them. The person will be invited to an appointment with a screening nurse. A positive result does not mean the person has cancer but it does mean that they need further tests. The nurse will explain the next steps.

Next steps

If blood is found in the test, the person will be invited to speak to a specialist screening practitioner about what happens next. Further tests may be required, such as a colonoscopy.

A colonoscopy is the best way to find out what is causing the bleeding inside the bowel. A flexible tube with a camera on the end is inserted into the back passage and moved around the bowel to see if there is inflammation or signs of polyps or cancer. It is different to a bowel scope test.

You can order an easy read guide, which explains what a colonoscopy is and why you might need one. Please call the NHS bowel screening helpline on **0800 707 6060**.

You can also download a copy online from **[gov.uk/government/publications/bowel-cancer-screening-colonoscopy-easy-guide](https://www.gov.uk/government/publications/bowel-cancer-screening-colonoscopy-easy-guide)**

Bowel scope screening for people aged 55 years

Men and women aged 55 will be invited to have a bowel scope test. The test uses a tiny camera on the end of a tube called a scope, to look inside the bowel. The test can help to prevent bowel cancer.

The scope test camera looks for tiny growths called polyps. If polyps are seen then they can be removed during the test. Removing these polyps can help to stop a person getting bowel cancer.

The person you care for must consent to having this test and have full understanding of what it is for and what will happen. If you are unsure whether they should have this test, speak to their GP, nurse or family. You can talk the test through with them, using one of our easy read guides.

You can also call the screening helpline on **0800 707 6060**.

Going to the doctor

If the person you care for seems to be showing signs or symptoms of a bowel problem, you must take them to see their GP. Don't worry about wasting the GP's time. If either of you are worried that something is wrong, the GP will want to see the person as soon as possible.

Even if the person has taken part in bowel cancer screening, they should still report any symptoms to their GP as soon as possible.

Remember that most symptoms will not be a sign of bowel cancer.

Before they go to see the GP, you could both make notes of any changes in their bowel habits or other symptoms. This will help you both to remember what you want to say to the GP. You could also write a list of questions you want to ask the GP at the appointment. You can ask for a longer GP appointment if you think you need it.

Questions the doctor might ask

- Have you noticed any changes in your bowel habits?
- Are you going to the toilet more often or less often than usual?
- How long has this been happening?
- Have you noticed any blood when you go to the toilet?
- Do you have any pain in your bottom when you have a poo?
- Do you have any pains in your tummy?
- Have you been feeling more tired than usual?
- Have you lost any weight recently without trying?
- Do you sometimes feel your bowel is not 'empty' even after you have a poo?
- Are any symptoms in your bowel waking you at night?

Bowel Cancer UK is the UK's leading bowel cancer research charity. We are determined to save lives and improve the quality of life for all those affected by bowel cancer.

We support and enable research, educate patients, public and professionals about bowel cancer and campaign for early diagnosis and best treatment and care for all those affected.

Find out more at bowelcanceruk.org.uk

 /charitybcuk

 @Bowel_Cancer_UK

To find out more about this booklet or tell us what you think email feedback@bowelcanceruk.org.uk

