

Bowel health and screening: carers guide

A booklet for carers of people who use easy read materials



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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 taking the bowel screening test.

We have produced two easy read booklets. These are:

- Keeping your bowel healthy
- Bowel health and the bowel screening test in Scotland

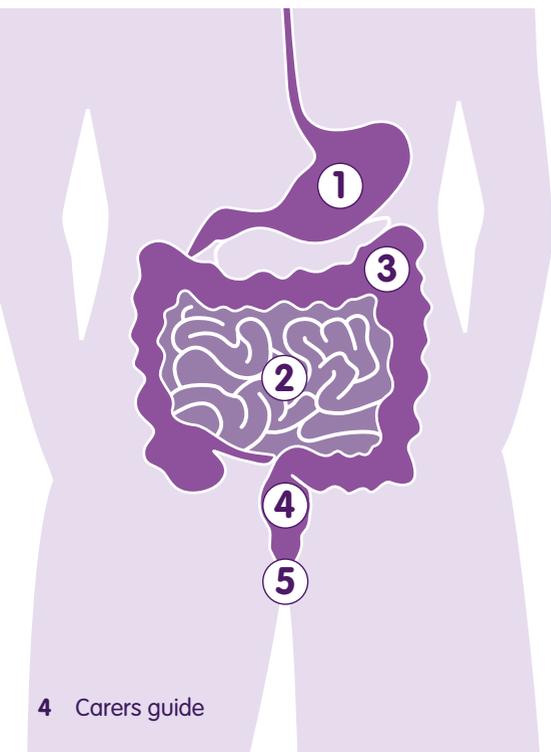
What is the bowel?

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. 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

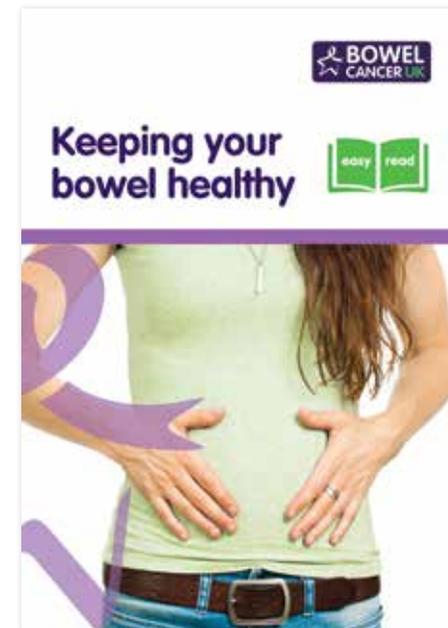
Helping someone to have good bowel health

Good bowel health is important. If you can, try to talk to the person or people you support about keeping their bowel healthy.

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.



Who gets bowel cancer?

After lung and breast cancers, bowel cancer is the third most common cancer in Scotland. Almost 3,700 people are diagnosed with bowel cancer each year. Bowel cancer is more common in people over the age of 50.

Around 1 in 16 men and 1 in 20 women will get bowel cancer at some point in their lives. It is more common in men than it is in women.



Bowel cancer is the second biggest cancer killer in Scotland. However it shouldn't be because it is treatable and curable especially if diagnosed early.

The importance of early diagnosis

More than nine out of ten people diagnosed with stage 1 bowel cancer survive five years or more after diagnosis. However this drops significantly as the disease develops.

To help detect bowel cancer at an early stage, when treatment has the best chance of working, it is important for everyone to be aware of:

- The symptoms to look out for
- How bowel screening works

Helping someone to know the symptoms

If you can, try and help the person that you support to be aware of the symptoms to look out for and to tell someone if they experience them.

The symptoms of bowel cancer can include:

- Bleeding from your bottom and/ 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. But if you or someone you support has one or more of these, or if things just don't feel right, you should make an appointment to see the GP immediately.

See page 14 for more information on going to the doctor.

What is bowel cancer screening?

Screening can detect bowel cancer early before any symptoms appear, when it is easier to treat.

All men and women aged between 50 and 74 are invited to take part in bowel screening.

If the person you support is aged 50–74 and registered with a GP, they should receive a letter and a free NHS bowel screening test in the post every two years.

People aged 75 and over can still get a bowel screening test every two years by calling the NHS Scotland bowel screening helpline on **0800 0121 833** (textphone 18001 0800 0121 833) or emailing **bowelscreening.tayside@nhs.net**

The test involves sending just **one small sample** of poo and the results will be posted within two weeks. It looks for hidden blood in the poo, which could be an early sign of bowel cancer.

The test should be completed at home and returned using the pre-paid envelope.

Bowel cancer screening can save lives. Taking part in bowel cancer screening is one of the best ways to get diagnosed early.

While the screening test is one of the best ways to find bowel cancer, some cancers may be missed. This is why as well as doing the test, it is important to look out for any of the symptoms listed on page 7.



Helping someone to understand what screening is

You can help the person you support to understand what screening is and help them decide whether or not to take part.

The booklet **Bowel health and the bowel screening test** will help you explain the test and what to do if they have any questions or concerns.

You may like to contact the NHS Scotland bowel screening helpline on **0800 0121 833** (textphone 18001 0800 0121 833) or **bowelscreening.tayside@nhs.net**. The helpline staff will be happy to help you and answer any questions about the test.

Giving consent

Before the person you support takes the test, they should give their consent. They need to know what the test means and how to carry it out. Think about how you can help them to make an informed choice.

- Read through the letters and booklets that come with the screening test.
- Talk to them about what happens after they take the test. For example, if the result is abnormal, they may need to go for further tests, such as a colonoscopy, to find out what is causing the bleeding (see page 12).
- Let them know that while the screening test is one of the best ways to find bowel cancer, some cancers may be missed. This is why as well as doing the test, it is important to look out for any symptoms (see page 7).

If the person you support is not able to give their consent, then you should speak to their GP, learning disability nurse and/or their family, to find out what the best approach might be.

Helping someone to use the test

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

You can reassure the person that you are there to support them.

Try to make sure they have the test ready and everything they need to do the test.

Getting the test ready:

- Peel off the label from the accompanying NHS letter and stick it on the side of the test marked with a +.
- Write the date of the poo sample on the other side.



Doing the test:

- Help the person you support to decide how they are going to collect a sample of poo. They could use a clean disposable container to catch the poo before it goes into the toilet. Keep toilet roll and a bin close to hand.
- If the person you support needs some help to collect their sample you can assist if they say this is OK.
- If they use an incontinence pad instead of going to the toilet, you can take the poo sample from their pad, if they say this is ok.

Getting the screening results

The test will be sent to the Scottish Bowel Screening Centre, 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 0121 833** (textphone 18001 0800 0121 833) or email **bowelscreening.tayside@nhs.net**.

Most people will be told that they do not need any further investigation. This means that the test looked normal so no further tests or follow up are needed. The screening test will be sent out every two years until a person is 74 years old. After this age, they can request a test by phoning the helpline number above.

Follow up required

If the test shows that the amount of blood found in the poo sample is above the normal screening limit, this means that further tests are needed. The person will be invited to an appointment with a screening nurse.

An abnormal result does not mean the person has cancer but it does mean that further investigation is required to check their risk of bowel cancer. The nurse will explain the next steps.

Next steps

If follow up is required, the person will be invited to speak to a specialist 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. This is done in hospital. Most people are offered an outpatient appointment.

A thin 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.

Polyps are pre-cancerous growths that can be removed during a colonoscopy to lower the risk of bowel cancer developing.

If the person you support is invited for a colonoscopy, they'll receive information about the benefits and risks of the procedure before their appointment.

You can find out more on our website. Visit: **bowelcanceruk.org.uk**

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.

While the screening test helps to find bowel cancer at an early stage, it doesn't find all bowel cancers. Even if the person you support has taken part in bowel cancer screening, they should still report any symptoms to their GP as soon as possible.

Remember that most people with these symptoms will not have bowel cancer. Other health problems can cause similar symptoms.

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 and 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 habit?
- 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?

Further information

The Scottish Bowel Screening Centre

If you would like further information on the screening test for yourself or the person you support, you can contact the Scottish Bowel Screening Centre.

Call this helpline number: **0800 0121 833** (textphone 18001 0800 0121 833)

Or email: **bowelscreening.tayside@nhs.net**

Or visit this website: **nhsinform.scot/bowelscreening**

The helpline staff will be happy to help you and answer any questions about the test.

Bowel Cancer UK

Visit our website: We have a range of information and publications that are free to order and download at: **bowelcanceruk.org.uk**

Book our training: Do you have staff or volunteers who are tasked with spreading awareness messages? Our team offers training in all aspects of bowel health and screening. Email: **training@bowelcanceruk.org.uk**

Book a bowel cancer awareness talk: Our award winning team of trained volunteers provide free talks, covering symptoms, risk factors and screening. Talks can be tailored to the setting and time available. You can book a talk via our website: **bowelcanceruk.org.uk/bookatalk**

Feedback: Please tell us what you think – is this information booklet useful? Do you have suggestions for future resources? How have you used this information? Email **feedback@bowelcanceruk.org.uk**

Find out more: Call us on **0131 281 7351**
or email **scotadmin@bowelcanceruk.org.uk**

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

