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# Bowel Screening in Lothian

## What is the aim of the programme?

Bowel cancer is the fourth most common cancer in Scotland. Bowel screening aims to find cancer at an early stage when there are no signs or symptoms. Early detection is key.

At least 9 out of 10 people will survive bowel cancer if it's found and treated early.

## Who is invited to take part in screening?

Bowel screening is currently offered every 2 years to people who are aged between 50 and 74 and live in Scotland. The test is for people aged 50 years and older because their risk of having bowel cancer is higher.



## How are people invited for screening?

The Scottish Bowel Screening Centre sends the screening test to eligible people at the address linked to their CHI number. It is important that the person's correct address is registered with their GP practice.

The information included with the test covers instructions for completing the bowel screening test, who to contact about results and where to request a replacement test.

The test can be completed at home and returned to the Screening Centre in the pre-paid envelope provided. Results are usually sent within 2 weeks.

About 3% (1 in 33 people) will have a positive test (NHS Lothian, 2025). A specialist from the bowel screening team will contact the patient or carer to discuss the possible next steps. This may involve a colonoscopy (a scope test to look inside the bowel), or a CT scan to look at the bowel, or the patient may not require any further tests.

## **Family history**

Some bowel cancers can run in families. If you or the person you care for is concerned about family history, please speak to a GP.

## **Benefits and risks of screening**

Taking part in screening is an individual's choice. It is important that they understand the benefits and risks of screening to help decide if taking part is right for them.

### **Benefits of bowel screening**

- Bowel screening can help find bowel cancer early, even if a person is well and does not have any symptoms.
- At least 9 out of 10 people survive bowel cancer if it is found early.
- People can complete the bowel test at their place of residence.

- The bowel screening test is quick and easy to do, with just one small sample of poo needed.

### Risks of bowel screening

- Bowel screening is not 100% accurate.
- Some cancers may not be found and some cancers may not be cured.

### Promoting informed choice for friends and family

You may think that taking part in screening is straightforward. For some people, this is the case. However, for others, taking part in screening can be a complicated process with many factors to consider.

You may not always agree with an individual's decision. In fact, you may think they have made an unwise decision. On a professional or personal level, this can prove to be very challenging.

It is important to remember that your role is to provide the person with the correct information (in an appropriate format) so that they can make an informed decision to take part in screening or not. It is essential to remember that if they are able to make a decision, **their decision must be accepted as being final.**

## How can I help someone make an informed choice?

To make an informed choice, a person must have:

- Access to clear, concise, and accurate information, in an appropriate format
- Further support, if necessary, to help them understand screening information
- Time to consider and take in the information
- The capacity to make their own decisions.

At this stage the person should be able to make an informed decision and confirm their decision by giving informed consent (permission) to take part, or not to take part, in screening. Those who do not have capacity can still participate if an Adults with Incapacity (AWI) assessment has been undertaken.

### Definition of capacity

The law in Scotland generally presumes that adults (i.e. those over the age of 16) are capable of making personal decisions for themselves and of managing their own affairs. The starting point is a presumption of capacity and this can only be overturned where there is medical evidence stating otherwise.

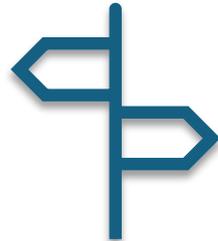


## Adults with Incapacity (AWI)

The Adults with Incapacity (Scotland) Act 2000 introduced a system for safeguarding the welfare and managing the finances and property of adults who lack capacity to make some or all decisions for themselves.

For the purposes of this Act, “incapable” means incapable of; acting; or making decisions; or communicating decisions; or understanding decisions; or retaining the memory of decisions.in relation to any particular matter due to mental disorder or inability to communicate because of physical disability.

This is not an ‘all or nothing’ definition as the Act recognises that an individual may lack capacity to make certain decisions relating to their affairs but might have capacity to make other decisions.



For example, someone may have capacity to deal with pocket money however they might need some help in making decisions about paying their bills and dealing with their bank accounts.

You may have to support family members who have varying levels of capacity (or none at all). It is very important that you know what you can and cannot do in relation to the Act.

A leading medical practitioner (usually a GP, a liaison psychiatrist or an Advanced Nurse Practitioner (ANP), with additional AWI training) will be expected to provide evidence of assessing people’s capacity and any decisions they have made in a person’s ‘best interests’ under the Act.

This evidence should be accurately recorded and copies of any **AWI legislation (Power of Attorney/Welfare Guardian or AWI**

Section 47 certificate and treatment plan) should be held in the resident's records (original within GP notes). These documents can expire, or capacity can change and so require to be reviewed and updated on a regular basis.

Anyone acting under the Act must apply key principles when deciding which measure will be the most suitable for meeting the needs of the individual.

The principles must also be used whenever decisions need to be made on behalf of the adult.

## **The Key Principles are:**

### **1. Benefit**

Any action or decisions must benefit the adult and only be taken when that benefit cannot reasonably be achieved without it.

### **2. Least restrictive option**

Any action or decision taken should be the minimum necessary to achieve the purpose. It should be the option that restricts the person's freedom as little as possible.

### **3. Take account of the wishes of the adult**

In deciding if an action or decision is to be made, and what that should be, account shall be taken of the present and past wishes and feelings of the adult as far as they can be ascertained. The adult should be offered appropriate assistance to communicate their views.

### **4. Consultation with relevant others**

In deciding if an action or decision is to be made, and what that should be, account shall be taken of the views of the nearest relative and the primary carer of the adult, the adult's named

person, any guardian or attorney with powers relating to the proposed intervention, and any person whom the Sheriff has directed should be consulted, in so far as it is reasonable and practicable to do so.

### 5. Encouraging the adult

Any guardian, attorney, or manager of an establishment exercising functions under this Act shall in so far as it is reasonable and practicable to do so, encourage the adult to exercise whatever skills he or she has concerning property, financial affairs or personal welfare as the case may be and to develop new such skills.



## Completing the Bowel Screening Test

If you have been asked to help someone do the test, you may find this section useful as it tells you how to use the bowel test kit.

If the person you are helping has capacity to make their own decisions, please make sure that you have their consent from the outset.

If the person lacks capacity, you must make sure that the appropriate power of attorney of health and welfare is in place or that a decision in the person's best interests has been reached and recorded.

If you are supporting a person to complete the bowel screening test, you can access additional information including easy read resources or watch the videos available on the website:

[www.nhsinform.scot/healthy-living/screening/bowel-screening](http://www.nhsinform.scot/healthy-living/screening/bowel-screening)



Before doing the test with the person you are supporting, please read through the leaflet that came with the kit. This tells you what is involved and how to do the test and may make it easier when explaining the test to your family member.

## About the bowel test

The bowel screening test does not tell you if you have bowel cancer. The test looks for hidden blood in your poo which can be a sign of bowel cancer or other changes.

You may need to discuss how you will help the person. Jointly, you may want to decide the following:

- When is the best time to do the bowel screening test?
- Who will write the date on the bowel screening test?
- Who will collect the poo sample?

If you want advice on carrying out the test, or would like another kit, contact the Scottish Bowel Screening Centre on the freephone number:

0800 0121 833 (textphone 18001 0800 0121 833) to speak to a member of the team.

Or by email – [TAY.scottishbowelscreening@nhs.scot](mailto:TAY.scottishbowelscreening@nhs.scot)

Some important things to remember:

- ✓ Wash your hands before and after doing the test
- ✓ Wear gloves
- ✓ Check the information on the test kit is correct and attach the label from the front of the letter to the tube
- ✓ Have a pen ready to write the date on the bowel screening test tube
- ✓ If you make a mistake, we can send out another test kit in the post.



## After doing the bowel screening test kit

The test kit should be posted back to the Scottish Bowel Screening Centre as soon as possible after completion.

A result letter is produced and posted within 14 days.

The result will indicate one of the following:

- no blood was found. If still eligible, the person will be invited to complete another test in two years' time.
- blood was found and further medical investigations are needed.
- the sample was not suitable for testing and another kit will be issued.

## Signs and Symptoms

Bowel cancer can develop between screening tests, so it is important for people to be aware of any changes in their bowel habits. Screening may miss some cancers, so a normal result does not mean that a person does not have, or will never develop, bowel cancer in the future.

The person you care for should see their GP if they have any of the following symptoms:

- B**leeding from their bottom or blood in their poo
- O**bvious change in bowel habits
- W**eight loss without trying
- E**xtrême tiredness for no obvious reason
- L**ump or pain in their tummy

These symptoms may be caused by a range of conditions and should be discussed with a medical professional without delay.

If you are caring for someone and you notice bowel changes, you should discuss their symptoms with them. If they do not have the ability to understand, you should talk to their relatives or a responsible health professional and suggest they make an appointment with their medical professional. If the person you care for is in a care home, it is advised that you discuss your concerns with the home manager and visiting medical professional.

## Frequently asked questions (FAQs)

### **1. The person that I care for is physically unable to complete their bowel screening test kit following a stroke. Can I do the test for them?**

You can do the test on their behalf if they have asked you to. It is very important that the person understands the information in the booklet and that completing the test may result in further tests at the hospital if blood is found in the sample. Within a care service, this discussion should be clearly recorded in the individual's Care Plan

### **2. The person that I care for has dementia. Can I do the test for them?**

It is very important that the person understands the information in the booklet and that completing the test may result in further tests at the hospital if blood is found in the sample. Providing the person understands this, you can help them complete the test kit if they have asked you to do so.

If the person cannot make this decision, we recommend you discuss the situation with the person's medical professional and whoever has power of attorney (legal authority to act) or Guardianship. Following this, a 'best interests' decision will need to be made on the person's behalf. Their medical professional will decide if they would benefit from screening and whether they are fit and well enough for further investigations to be undertaken if this was required.

### **3. The person that I care for refuses to do their bowel screening test but I have seen blood in their poo. What should I do?**

The bowel screening programme is for people who do not have symptoms.

You should make the person aware that you have noticed blood. If they understand your concerns, you should encourage them to see their medical professional. If they do not understand, you should speak to their relatives, guardian or person with power of attorney and suggest they make an appointment with the person's medical professional or contact the GP yourself and explain your concerns.

### **4. The person that I care for does not want to take part in screening, but I could do the test when I help them with going to the toilet. Can I do this?**

No. You can only do the test on someone else's behalf if they have asked you to do so and they have fully understood the risks and benefits of completing this. If you do the test without their permission, you will be acting against their will.

### **5. The person that I care for suffers from diarrhoea or constipation. Can I do the test for them?**

If the person that you care for is suffering from either diarrhoea or constipation, we would advise you that you wait until normal bowel habits resume before doing the test.

If the person is experiencing persistent bowel changes, it is important that they get medical advice from their medical professional.

## **6. I take care of the hygiene needs of a person who suffers from incontinence. Can I do the test for them?**

You can only do the test if the person has asked you to. It is very important that they consent to you doing this and fully understand the information in the booklet and that carrying out the test may result in further tests at the hospital if blood is found in the sample.

You should take a sample from the middle of a formed (solid) poo. This will avoid the poo being contaminated with urine which may affect the result.

## **7. The person I care for has recently moved into a care home. Will they still receive a bowel screening test kit?**

It is very important that they or a member of their family give their GP practice their new address or that they are registered with the Lead GP Practice for the care Home they have moved into. The bowel screening kits are sent to the address linked to a person's CHI number so it is very important that records are updated to ensure people receive their bowel screening invitation.

## **8. Can the test kit be completed if a person is menstruating (having a period)?**

No, wait until the bleeding has stopped before completing the test kit.

## **9. The person I care for has had a positive result, what does this mean?**

When the kit was tested in the laboratory they found traces of blood in the sample. This does not always mean that the person has bowel cancer but means the person will need further medical investigations to find out the reason for the blood in the

sample. The person needs to have a pre- assessment appointment with one of NHS Lothian’s Bowel Screening Nurses to find out if they are suitable to have further investigations.

## **10. What does the Bowel Screening Nurse do?**

The Bowel Screening Nurses work for NHS Lothian and are based in local hospitals. Their role is to support people who have had a positive test result and who may need further bowel investigations.

The nurse will carry out a telephone assessment with the person who received the positive result or whoever is supporting them. This assessment will ensure that the person is suitable for further investigations. This telephone call may last for up to an hour. If the person with the positive result (or whoever is supporting them) feels that a telephone assessment is not appropriate, the nurse can carry out a face-to-face assessment.

The nurse will explain everything clearly to the person and their family or carers and discuss with them any concerns or questions that they may have. They will continue to support the person through the next stages.

You may receive a letter from the pre assessment service which informs you that a bowel investigation has been undertaken within the last 12 months so another bowel screen is not required at this time. A letter may also advise that, as an outcome of a clinical review, it is not appropriate to continue with bowel screening or further investigation at this time.

## Contact information

If you want advice or support or would like to speak to someone about the Bowel Screening process, please contact the Scottish Bowel Screening Centre Freephone number on

0800 0121 833

Textphone 18001 0800 0121 833

Or by email – [TAY.scottishbowelscreening@nhs.scot](mailto:TAY.scottishbowelscreening@nhs.scot)

## Useful links

Visit the websites or scan the QR codes using the camera on your phone.

<p><b>Age Scotland</b> <a href="http://www.agescotland.org.uk">www.agescotland.org.uk</a></p>	
<p><b>Alzheimer Scotland</b> <a href="http://www.alzscot.org/Bowel">www.alzscot.org/Bowel</a></p>	
<p><b>Bowel Cancer UK</b> <a href="http://www.bowelcanceruk.org.uk">www.bowelcanceruk.org.uk</a></p>	
<p><b>Carers Scotland</b> <a href="http://www.carersuk.org/scotland">www.carersuk.org/scotland</a></p>	
<p><b>Stroke Association</b> <a href="http://www.stroke.org.uk/home">www.stroke.org.uk/home</a></p>	

