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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 is found and treated early.

## Who is invited to take part in the 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

As a healthcare worker or a healthcare provider 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.

As someone who supports service users or clients, 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 service users 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). As these documents can expire or capacity can change the Multidisciplinary Team (MDT) including the Care Home staff, should be mindful of review or expiry dates.

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 his or her 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 are a healthcare worker or a healthcare provider and have been asked to help someone do the test, you may find this section useful as it tells you how to use the bowel screening test.

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 you care for lacks capacity, you must follow AWI Act principles and consult the Power of Attorney/Welfare guardian if one is in place. If there isn't one, consult the leading medical practitioner (GP usually) to check AWI section 47 status and if included in treatment plan. In addition, consider a MDT discussion and if the decision is in resident's best interests. Document all discussions and outcomes. Capacity can change therefore ensure this is reassessed when appropriate.

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 service user or client.

## About the bowel test kit

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.

## Scenarios

The next section provides you with several examples which may help you when you are considering issues to do with consent and capacity. These scenarios are based on real-life situations.

**A:** Geoff is 72 and suffers from dementia.

He has recently been admitted to a care home. He has had a recent assessment of capacity under the Adults with Incapacity Act in relation to his wellbeing and finances, which showed that he did not have the capacity to make decisions about his wellbeing or finances. Geoff has a daughter who has Power of Attorney.

Geoff has been sent a routine bowel screening invitation pack and bowel test kit.

### Points to consider

Geoff may have indicated previously his thoughts about the bowel screening process and whether he wanted to undertake further investigation. This is why having these conversations with residents and their close family members is so important and why a Future Care planning conversation should always be considered.

Completing the bowel screening kit should be a discussion that takes place between the GP and his Power of Attorney or Guardian as to whether a screening investigation would be in Geoff's best interest in the absence of symptoms and Geoff's ability to comply with any further invasive investigations, should the screening test result require further investigation.

Any discussion and/or decision should be recorded in Geoff's Care Plan, Key information Summary (KIS), and considered important for his Future Care Plan.

**B:** Malcolm is 62 years old with a mild learning disability.

He lives in a supported living environment and is supported closely by his healthcare support worker. Malcolm and his support worker have been reading the information sent to them about bowel screening. They have also been working through the easy read materials online, which explains what will happen in more detail. After discussing the test with his support worker, Malcolm feels that he is now ready to do the test.

A member of his family thinks that Malcolm has enough health problems and tells Malcolm that he should not bother completing the kit.

### Points to consider

No one should be stopped from making a decision just because others may think this unwise. As Malcolm has the capacity to make his own decision, it is entirely his decision whether or not to take part in screening.

**C:** Wilf, aged 71, is recovering from a stroke and lives in a care home.

Staff at the home are aware that, due to Wilf's condition, his capacity to make decisions fluctuates. Wilf recently received a routine bowel screening test kit. At the time Wilf received the test kit he had capacity and completed the test. The results showed that Wilf needed to go for further investigations. Staff in the home explained to Wilf that he needed to go for further investigations.

However, during discussions Wilf appeared to be vacant and lacking insight. The staff contacted the most appropriate medical professional, who agreed to carry out a mental-capacity assessment. After completing this, it was considered that Wilf lacked capacity and a 'best interests' meeting was arranged.

### Points to consider

The home has correctly recognised that Wilf's capacity has changed and has passed this on to the appropriate medical professional for a 'best interests' meeting. At this meeting a decision will be made in Wilf's best interests.

**D:** Josie is 68-year-old and has had mental health problems and has recently come to live in a care home.

Josie has capacity to make her own decisions. She has strong views that she doesn't want to take part in bowel screening and feels that she would know if something was wrong with her. Josie has not opted out of the bowel screening programme and has recently received her routine bowel screening test kit. She has told staff in the home that she does not want to take part in the programme and her family are supporting her in her decision.

A healthcare assistant, who helps Josie, has a family history of bowel cancer and feels Josie's decision is unwise. Without Josie's permission she completes the test kit and returns it for testing. When Josie receives her results, she cannot understand how this has happened. Her results show that she needs to repeat the test. Josie speaks to a different health professional and is angry that her wishes have not been followed.

## Points to consider

Josie has capacity to make her own decision and has clearly said she does not want to take part in the bowel screening programme. The healthcare assistant has broken her organisation's policies and procedures and, if it applies, their professional code of conduct.

As Josie was clear that she did not want to take part in the bowel screening programme and did not give her consent, it could be argued that this goes against her human rights, and the healthcare assistant could face a disciplinary procedure.

It may have been better if an appropriate person had taken the opportunity to discuss the various available options with Josie when the kit arrived, to ensure she was fully informed about the risks and benefits of taking the test and to raise her awareness of the signs and symptoms of bowel cancer

As the home now knows that Josie needs to do a repeat test, they have a 'duty of care' to discuss with Josie the possible options, while respecting her decision whether or not to go ahead with the repeat test. All discussions about this matter should be recorded in Josie's care plan.

**E:** Elizabeth is 73-year-old and lives in a care home.

She has recently received her routine bowel screening test kit. Elizabeth has capacity to make decisions for herself. She has consistently refused to take part in bowel screening. Staff in the home have discussed at length with Elizabeth whether she wants to complete the bowel screening test, but she decides that she does not want to take part.

The healthcare worker who helps Elizabeth with her personal care has noticed that Elizabeth has blood in her stools.

## Points to consider

Bowel Screening is for people who are well and do not have symptoms. As Elizabeth is able to make her own decisions, staff at the home must respect this and not do the test on her behalf.

The healthcare worker who helps Elizabeth should report this to the registered manager or another appropriate person. She should also make sure that she records it on Elizabeth's care plan.

An appropriate staff member should discuss with Elizabeth that her healthcare worker has noticed blood in her stools and encourage Elizabeth to allow the home to make an appointment with her medical professional or agree that the visiting GP (if this applies) can speak with her about her health as she may require further investigations, if Elizabeth consents to this.

It is important to reassure people that blood in their stools does not mean that they have cancer. It may be caused by bleeding from polyps (small growths) or other conditions such as haemorrhoids (piles).

## Frequently asked questions (FAQs)

### **1. The person that I care for is physically unable to complete their bowel screening test 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 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 important that records are updated to ensure people receive their bowel screening invitation.

## **8. A resident in our care home has recently died. Do I need to tell the Scottish Bowel Screening Centre to remove them from their records?**

There is no need to tell the Scottish Bowel Screening Centre if a care home resident dies, as they automatically update their records from CHI and GP information.

You are unlikely to receive a test kit for someone who has died, but if you do, please contact the Scottish Bowel Screening Centre.

## **9. 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.

## **10. 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.

## **11. 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.

If further investigation is required the bowel screening nurse will carry out a pre assessment phone call. 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

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. 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

**Age Scotland:** <https://www.agescotland.org.uk/>

**Alzheimer Scotland:** <https://www.alzscot.org/Bowel>

**Bowel Cancer UK:** [www.bowelcanceruk.org.uk](http://www.bowelcanceruk.org.uk)

**Carers Scotland:** <https://www.carersuk.org/scotland/>

**Stroke Association:** [www.stroke.org.uk/home](http://www.stroke.org.uk/home)

**Adults with Incapacity (Scotland Act) 2000**

<https://www.legislation.gov.uk/asp/2000/4/contents>

<https://www.gov.scot/collections/adults-with-incapacity-forms-and-guidance/>

## Notes

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