Bowel Screening Wales

Information for Carers

Sgrinio Coluddion Cymru
Bowel Screening Wales

GIG CYMRU NHS WALES
Iechyd Cyhoeddus Cymru
Public Health Wales

0800 294 3370

www.phw.nhs.wales/bowel-screening

We welcome phone calls in Welsh

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Who are Bowel Screening Wales (BSW)?

We are managed by Screening Division which is part of Public Health Wales, NHS Trust. The bowel screening programme was launched in October 2008.

What is the aim of the programme?
Bowel cancer is the third most common cancer in Wales. Bowel screening aims to find cancer at an early stage when treatment is likely to be more effective. 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?
Bowel screening is currently offered to people who are aged between 50 and 74 and live in Wales. We get address information directly from GPs. It is important that the person's correct home address is registered with the GP. We do not hold any medical information.

How are people invited for screening?
A bowel screening test kit and information pack will be sent through the post. People will be able to carry out the test at their place of residence.

How often are people invited for screening?
People will be automatically invited to take part in the bowel screening programme every two years.

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.

Section 2

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 screening

- Finding bowel cancer early gives a person the best chance of survival.
- At least 9 out of 10 people survive bowel cancer if it is found early.
- Bowel screening can help find bowel cancer early, even if a person is well and does not have any symptoms.
- People can complete the bowel test kit at their place of residence.
- The bowel screening test kit is quick and easy to do, with just one small sample of poo needed.

Risks of screening

- Bowel screening is not 100% accurate.
- Some cancers may not be found and some cancers may not be cured.
- There may be risks with having further tests. If a person needs further tests a screening nurse or doctor will talk to them about these.

Promoting informed choice

It is important that people can make an informed choice about whether to take part in screening or not.

To do this, they must have all the facts, good and bad, so that they can make a truly informed decision.

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
- capacity and understanding to make their own decisions

At this stage the person should be able to make an informed decision and be able to confirm their decision, by giving informed consent (permission) to take part, or not to take part, in screening.

Making decisions

As a carer you may have your own personal views about taking part in screening. Your view may differ from that of the person you care for and you may feel that the person you care for is not making the 'right' decision.
You must remember that your role is to provide the person with the correct information (in an appropriate format) and support, so that they can make an informed decision to take part in screening or not.

Section 4

Mental capacity

You may have to support someone who:

- can make their own decisions
- can make decisions sometimes
- cannot make decisions for themselves.

It is important that you know what you can and cannot do legally to help the person in these situations.

If a person can make their own decision it is up to them to choose what they would like to do.

If the person can make decisions sometimes or cannot make decisions at all, there is a legal framework in place to check if they have the ability to make their own decisions. This legal framework is known as the Mental Capacity Act (2005).

It is very important that you know what you can and cannot do in relation to the Mental Capacity Act. If you are supporting someone through bowel screening and are not sure what to do, you should contact our helpline on 0800 294 3370 or talk to their GP.

Things to remember before doing the bowel screening 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 for health and welfare is in place or that a decision in the person's best interests has been reached and recorded.

About the bowel test kit

The bowel screening test kit 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.

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

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 kit?
- Who will write the date on the bowel screening test kit?
- Who will collect the poo sample?

If you want further information, you can contact us on our Freephone helpline, 0800 294 3370. You can also download our easy read material or watch the available videos on our website: www.phw.wales/bowel-screening.

Some important things to remember -

- √ Check the information on the test kit is correct
- √ Have a pen ready to write the date on the bowel screening test kit
- √ If necessary, wear gloves
- √ Wash hands before and after doing the test
- √ 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 laboratory as soon as possible after completion.

Once received by the laboratory it is tested and a result letter is produced and posted within 7 days.

The test kit result will indicate one of the following:

- the kit was not suitable for testing and another kit will be issued
- further medical investigations are needed
- the person will be automatically invited to complete another FIT test in two years' time, if they are still within the eligible age range.

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:

Bleeding from their bottom or blood in their poo

Obvious change in bowel habits

Weight loss without trying

Extreme tiredness for no obvious reason

Lump 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.

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 do it. 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.

For more advice on doing the test on behalf of someone who has a physical disability, call our freephone helpline on 0800 294 3370.

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 GP and whoever has lasting power of attorney (legal authority to act) for their health and welfare. Following this, a 'best interests' decision will need to be made on the person's behalf. Their GP 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.
For more advice, please contact the freephone helpline on 0800 294 3370.

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

The bowel screening programme is aimed at people who are well and does not routinely screen people with symptoms.

You should make the person aware that you have noticed blood. If they understand your concerns, you should encourage them to see their GP. If they do not understand, you should speak to their relatives and suggest they make an appointment with the person's GP 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 GP.

6. I take care of the hygiene needs of a person who suffers from incontinence. Can I do the test for them by taking the sample from the incontinence pad?

You can do the test if the person has asked you to. It is very important that they 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.

For more advice on doing the test on behalf of someone who has a disability or suffers from incontinence, please contact the freephone helpline on 0800 294 3370.

7. 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.

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

When the kit was tested in our 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 an assessment appointment with one of our Specialist Screening Practitioners (SSP) to find out if they are suitable to have further investigations.

9. What does the Specialist Screening Practitioner (SSP) do?

SSPs work for Bowel Screening Wales but are based in local hospitals. Their role is to support people who have had a positive test result and who may need further investigations.

The SSP 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 SSP can carry out a face-to-face assessment.

The SSP 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.

Section 8

Contact information

Call the Bowel Screening Wales Freephone Helpline (Monday-Friday 08:00-17:00, excl. Bank Holidays) on **0800 294 3370**

Or visit the Bowel Screening Wales website at:

www.phw.nhs.wales/bowel-screening

Or Email us on:
bowel-screening@wales.nhs.uk

Useful Links

Age Cymru
www.ageuk.org.uk/cymru/

Alzheimer's Society
www.alzheimers.org.uk/

Bowel Cancer UK
www.bowelcanceruk.org.uk

Carers Wales
www.carersuk.org/wales

Disability Wales
www.disabilitywales.org/

Learning Disability Wales
www.learningdisabilitywales.org.uk/

Understanding the Mental Capacity Act
www.gov.uk/government/publicationsmental-capacity-act-code-of-practice

Stroke Association
www.stroke.org.uk/home