

carers guide



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# BOWEL HEALTH AND SCREENING

Resource for carers of people with learning disabilities



# Introduction

As a carer you can provide a key role in helping the person you support to make choices about their health on a daily basis. The contents of this pack are for you the care provider as well as the person you support.

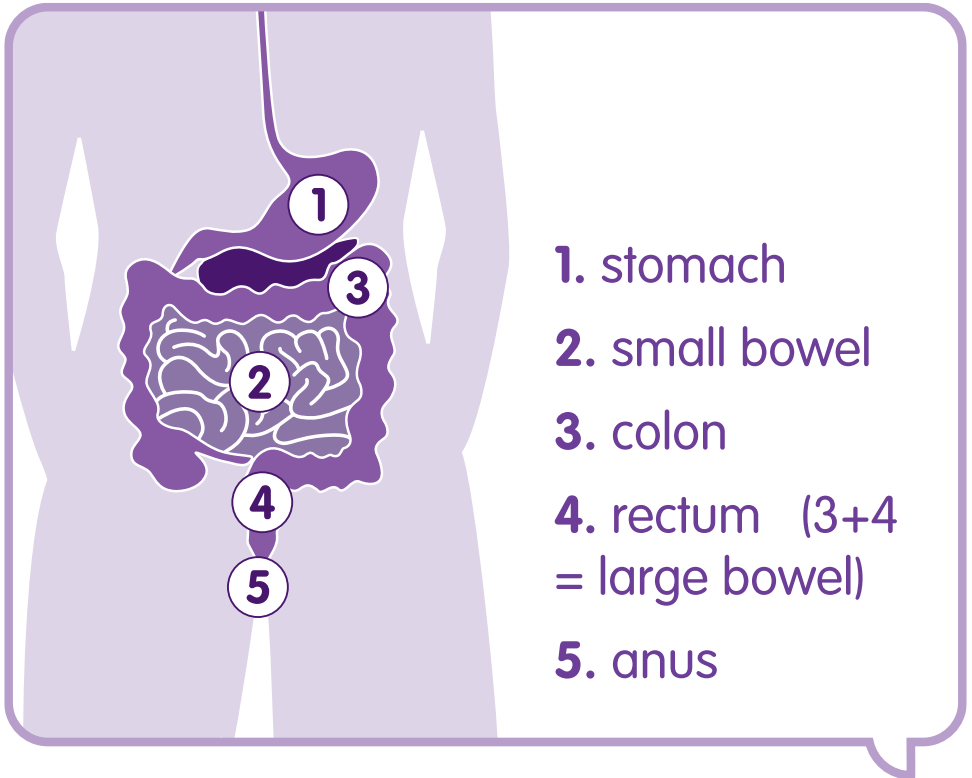
This booklet will cover:

- 04 Why is bowel health important?
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- 08 Bowel cancer – who is at risk?
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This will give you the confidence to discuss good bowel health.

# Why is bowel health important?

The bowel is part of our digestive system. Our digestive system is set up to give us water, energy, vitamins and minerals from the food we eat and the liquids we drink. The more we take care of our diet and help our digestive system, the better we feel. When there is a problem our body suffers and we do not work at our best.



The bowel is our body's waste disposal system. When we look after our bowel by eating the right food, drinking lots of water and being active, our bowel works well. However, if we don't look after it by eating the wrong balance of food, or drinking too much alcohol, it can lead to poor health. Poor bowel health can cause a number of illnesses including constipation, irritability, fatigue and cancer.

# Helping someone to have good bowel health

There are changes that people can make to their lifestyle that encourage good bowel health and reduce their risk of bowel cancer. Key messages are especially important for people with a learning disability who often may not have as much opportunity to be able to make healthy lifestyle choices.

The following resources can be used with a person with a learning disability to discuss healthy eating and physical activity.

[www.cwt.org.uk/publications.html#ewld](http://www.cwt.org.uk/publications.html#ewld)

[www.easyhealth.org.uk/listing/healthy-eating-\(leaflets\)](http://www.easyhealth.org.uk/listing/healthy-eating-(leaflets))



For more information on good bowel health please see Bowel Cancer UK's Good Bowel Health booklet included in this pack.

# Helping someone to complete the screening kit

It is important that people with a learning disability are supported by a family member or carer when they receive their bowel screening kit.

They may need help to decide whether or not they want to complete it. It is a good idea to sit with them and go through the booklets, using the easy read versions which are available from FAIR ([www.fairadvice.org.uk](http://www.fairadvice.org.uk)). The DVD can also be used and this will show how to complete the kit and what happens next. There is also a film produced by NHS Lanarkshire specifically for people with a learning disability and this can be accessed here:

[www.healthlanarkshire.co.uk/medicine-and-health-matters/bowel-screening/bowel-screening/video](http://www.healthlanarkshire.co.uk/medicine-and-health-matters/bowel-screening/bowel-screening/video)

When completing the screening kit, there are some key points to remember:

- A container, a 'clean' margarine tub for example, and some toilet paper will be needed
- Write the date of each sample onto the correct flap on the kit
- No urine or water can get into the container or touch the poo
- Wrap up the collecting sticks and throw them in the bin after use
- Ensure that you and the person you support wash your hands after each sample is collected
- Three samples need to be collected within 10 days. Each sample must be taken on a different day. It may help to mark the dates on the calendar as a reminder.

The results are posted back to the screening participant and they may need further support to understand them. They can talk to their GP or practice

nurse with any questions, or contact the Scottish Bowel Screening Centre on **0800 0121 833** (text phone **01800 0800 0121 833**). Or visit [www.bowelscreening.scot.nhs.uk](http://www.bowelscreening.scot.nhs.uk)

## Bowel cancer screening results

Once the kit has been returned, the Bowel Screening Centre will send the results within two weeks. Most people will have a 'negative' result, which means that no blood was found in the samples given. If this negative result is given it means that no further investigations are needed, but participants will be invited to attend screening in two years time.

Some people are asked to repeat the test if the results are unclear. They will be sent another kit in this case. It is important to remember the screening test is looking for blood and helps to find 2 out of every 3 bowel cancers. However some cancers or polyps do not bleed all of the time, which means not all cancers will be detected. Therefore it is important that you repeat the screening test every 2 years and never ignore changes in your bowel health (see symptoms on page 8) and go to your GP if you are concerned. If the result comes back showing that blood has been found in the samples, a health professional will be in contact. Having blood in your sample does not mean cancer, but does mean it should be checked further. The next stage of tests will then be explained. A colonoscopy is the most effective test for finding bowel problems. This requires an appointment where the bowel is examined using a flexible tube with a camera.

NHS Lanarkshire have designed a great web tool to help explain a colonoscopy to people with learning disabilities. This resource can be found here:

[www.bowelscreening.scot.nhs.uk](http://www.bowelscreening.scot.nhs.uk)

# Symptoms of bowel cancer

Some symptoms of bowel cancer can be:

- Bleeding from your bottom and/or blood in your poo
- A change in bowel habit lasting for 3 weeks or more especially to looser or runny poo
- Unexplained weight loss
- Extreme tiredness for no obvious reason
- A pain or lump in your tummy

You might experience one, some, all of the above or no symptoms at all.

**Remember most symptoms will not be bowel cancer.**

## Bowel Cancer - who is at risk?

Bowel cancer is the third most commonly diagnosed cancer for both men and women in Scotland with over 4,000 new cases every year. Bowel cancer is more common in people over 50 years of age, especially in men.

One in 20 people over 50 years of age will get bowel cancer at some point in their lives. In the past people with a learning disability had lower life expectancy and cancer incidence was lower because they did not live long enough to develop it.

The risk of developing bowel cancer is increasing in people with learning disabilities as their life expectancy increases, and people develop less healthy lifestyles.



# Bowel screening - why is it important?

Bowel screening aims to find bowel cancer at an early stage in people with no symptoms. The screening test looks for hidden blood in the poo, as this may suggest a higher chance of bowel cancer. Other changes in the bowel can also be found through screening. One example of this is non-cancerous growths called polyps. Polyps can be easily removed and often prevent future cancers developing.

Every year in Scotland almost 4,000 people are diagnosed with bowel cancer. If bowel cancer is detected early enough through screening, there is a 90% chance of treating the disease successfully. For approximately every 650 people invited for regular screening one bowel cancer death will be prevented. This will mean the screening programme in Scotland will prevent at least 150 deaths from bowel cancer each year.

For more information on the Scottish Bowel Screening Programme please call **0800 0121 833** (textphone **018001 0800 0121 833**) or see the Know the Facts leaflet found here:

[www.nhsinform.co.uk/screening/bowel](http://www.nhsinform.co.uk/screening/bowel)

## Your role as a carer

Having good bowel health is really important for everyone. It reduces the risk of many bowel conditions, including cancer. You can support people with learning disabilities to have good bowel health, and to be aware of the signs and symptoms that they should contact their GP about.

# Going to your doctor

The most important thing is not to be embarrassed to talk to a doctor. Remember, they deal with many patients with similar problems every day. It is also important to remember that most symptoms do not turn out to be bowel cancer. Before the visit it would be useful to make notes of any changes in normal bowel habit and it is often better to keep a diary of any symptoms than rely on memory alone. Also, write a list of questions for the GP. A longer GP appointment can be requested.

During the visit it might be helpful to:

- Make notes
- Ask as many questions as you need



Questions the GP might ask are:

- Have you noticed a change in your bowel habit?
- How long have any changes been going on?
- Are they continuous or do they come and go?
- Have you noticed blood in your poo?
- Do you have any pain when going to the toilet?
- Are any symptoms waking you at night?
- Do you feel sick or get indigestion?
- Have you lost any weight recently?
- Are you feeling particularly tired for no obvious reason?



# Bowel Cancer UK aims to save lives and improve the quality of life for all those affected by bowel cancer

If you would like to find out more about helping to improve your bowel health then visit our website or call our Bowel Cancer Information and Support Service on Freephone:

**0800 8 40 35 40** or visit  
**[www.bowelcanceruk.org.uk](http://www.bowelcanceruk.org.uk)**

For more information on bowel screening please contact the Scottish Bowel Screening programme on:

**0800 0121 833** (text phone 018001 0800 0121 833) or visit  
**[www.nhsinform.co.uk/screening/bowel](http://www.nhsinform.co.uk/screening/bowel)**

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 @Bowel\_Cancer\_UK

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