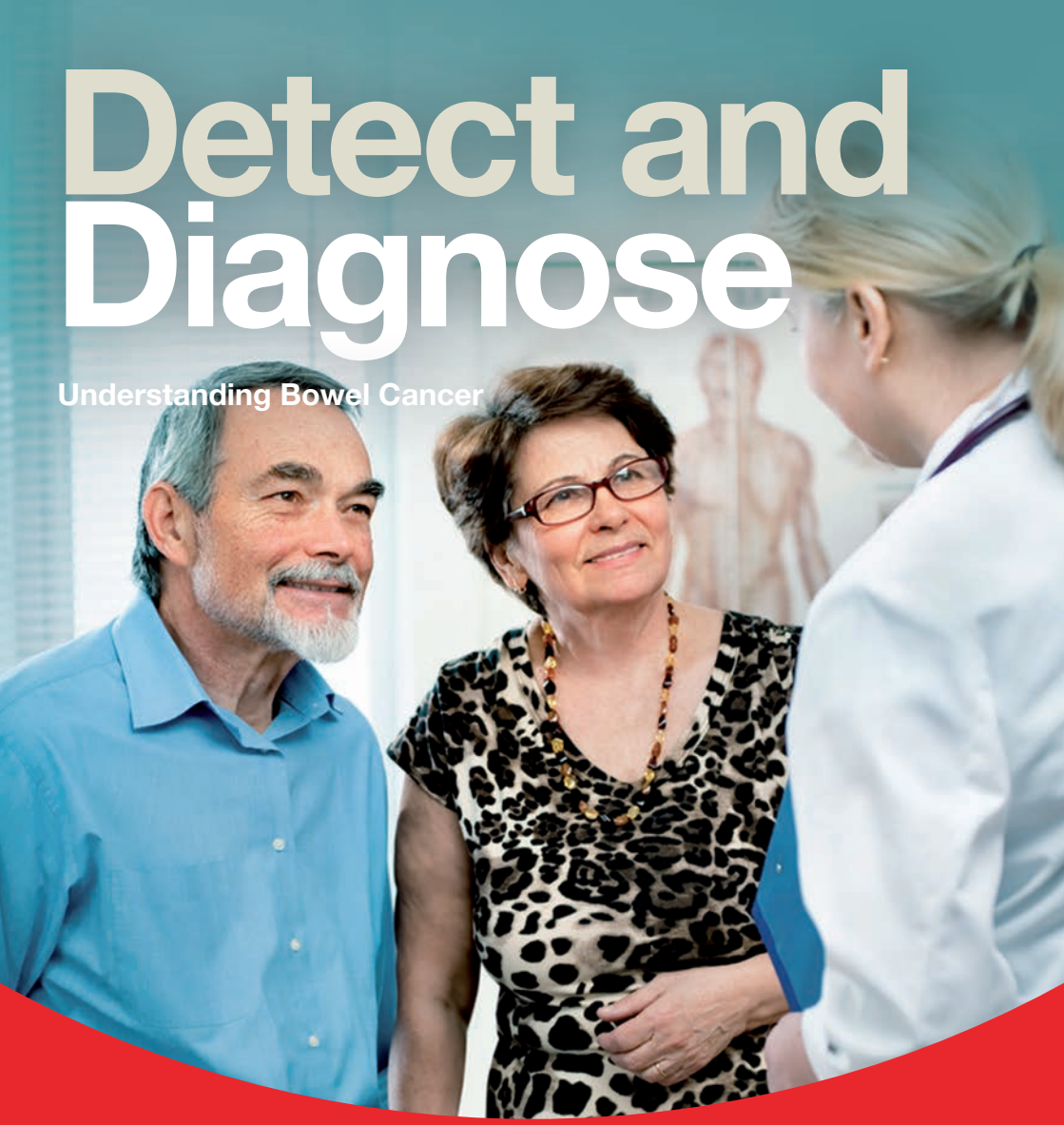
Detect and Diagnose

Understanding Bowel Cancer



Here for you

beatingbowelcancer.org

beating bowel cancer

Introduction

Bowel cancer is the fourth most common cancer in the UK today, affecting around 1 in 19 women and 1 in 14 men. According to Cancer Research UK, there are now more than 41,900 new cases of bowel cancer being diagnosed every year.

If diagnosed at an early stage, bowel cancer can be treated very successfully in over 90% of cases. In spite of this, bowel cancer remains the UK's second biggest cancer killer.

43% of bowel cancer cases are diagnosed in people aged 75 years and over and 95% are diagnosed in those aged 50 and over. However, bowel cancer can affect anyone at any age – around 5% of new bowel cancer cases are in people aged under 50.

This booklet aims to explain some key facts about bowel cancer. It outlines some of the most common symptoms you should be aware of and some of the diseases with similar symptoms.

We explain the importance of talking to your GP if you are concerned and how long you should wait before being referred for further tests. We also describe in detail the national bowel screening programmes and when you will be invited to participate. Finally, we offer some guidance about different types of investigations for bowel-related problems, and what to expect with each one.

Contents

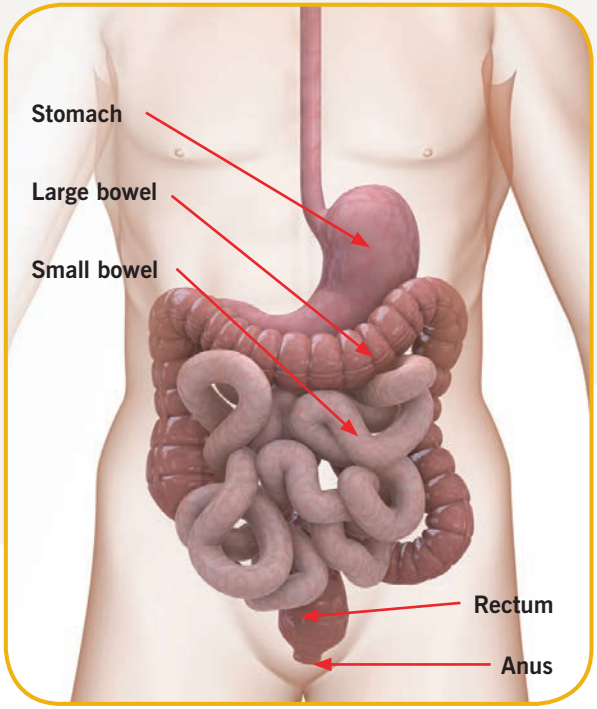
About your bowel

The large bowel is made up of the colon and the rectum. This long tube of muscular tissue, about 120cm (4 feet) long, sits in the lower part of your abdomen. It runs in a loop from the appendix on the lower right hand side of your pelvis (near your hip bone) up and across the abdomen at the waist line and then down into the pelvis again on the left hand side, before it curves backward towards the back passage (rectum) and anus.

Liquid waste from the upper part of your digestive system (stomach and small bowel) passes through your large bowel, where the water is gradually reabsorbed, turning this waste material into formed poo (faeces) as it moves towards the rectum.

At some time in our lives most of us will experience problems with our bowels and the process of getting rid of these waste materials. Tummy upsets and bleeding from the bottom are both very common symptoms associated with many minor problems that are easily treated, or which settle down again on their own (see page 6). However, it is very important to see your GP about symptoms that don't seem to settle on their own, or that don't respond to the recommended treatments. He / she can help you to access the investigations that will ensure you get the right treatment as quickly as possible, whatever the cause of the problem.

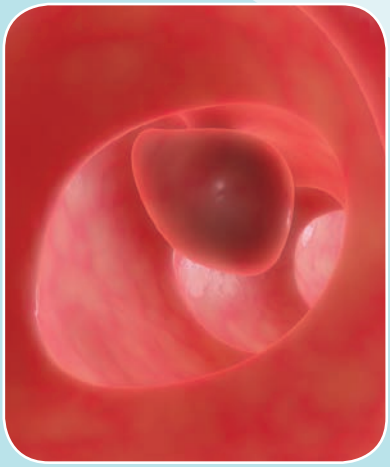
The digestive system



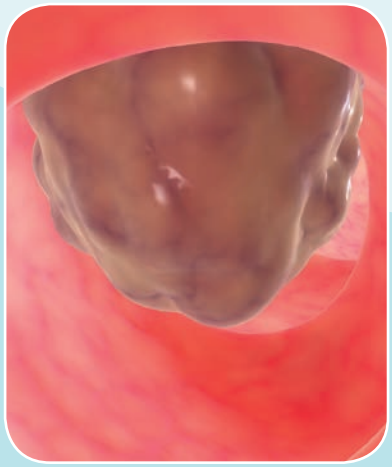
What is bowel cancer?

Bowel cancer (also known as colorectal cancer) can affect any part of the colon, rectum or anus – the three main parts of the large bowel. Most bowel cancers start as benign, innocent growths, called polyps, on the inner lining of the bowel. Polyps can look like flat warts or like cherries on stalks. Polyps are more common as we get older and most do not cause any problems.

However, one type of polyp called an adenoma can become cancerous (malignant). If left undetected, the cancer cells will multiply to form a tumour in the bowel, causing pain, bleeding and other symptoms. If untreated, the tumour can grow into the wall of the bowel or back passage. Within this group of adenoma-related bowel cancers, there are one or two rare types of disease which do not seem to behave in quite the same way as these slow growing polyps. These uncommon types of bowel cancers develop and spread much more quickly, and seem to affect much younger people.



A polyp in the large bowel



A tumour in the large bowel

What are the symptoms?

Being aware of the symptoms of bowel cancer is the most important part of protecting yourself from the disease. If you notice any one or more of the higher risk symptoms listed here, it is usually quite safe to watch and wait for up to three weeks. But if the symptoms have not settled down after this time, you should get advice from your GP. He/she will often be able to offer a simple explanation and reassurance once they have taken a history of your symptoms and examined you. The GP will also be able to make a referral to the appropriate person if they feel you should be investigated further.

Most people with these symptoms DO NOT have bowel cancer, but your GP will certainly want to examine you and may refer you or do further tests to rule it out.

Higher risk symptoms:

- Bleeding from the bottom (rectal bleeding) or blood in your poo without any obvious reason, such as local soreness, piles (haemorrhoids), a tear (anal fissure).
- Any change in bowel habit that lasts for three weeks or more, especially if you are going to the toilet more often or experiencing unexplained looser stools or ribbon-like stools. Symptoms may also include unexpected constipation, and a feeling of fullness or incomplete emptying from your back passage (rectum) after you have used the toilet.
- Any constant, unexplained pain anywhere in the abdomen, especially if it is severe. It may also be linked to going to the toilet, or it might come and go like cramps or colic.
- An unexpected lump in your abdomen, especially if it is on your right hand side.
- Unexpected weight loss perhaps due to loss of appetite, or feeling bloated or sick.
- Unexplained tiredness, dizziness or breathlessness (symptoms of anaemia).

What else could it be?

Your symptoms could be caused by any one of a number of other common conditions that can be treated and managed by your GP:

- **Piles (haemorrhoids)** – soft swellings just inside (or outside) the anus – are very common. They are actually just small veins that have become congested. Piles can cause bright red bleeding from the bottom, itching and pain around the anus. You might be able to feel them with a finger, or see them in a mirror, especially after going to the toilet.
- **Anal fissure** – a tear in the skin around the opening of the anus, often caused by constipation, for example.
- **Irritable Bowel Syndrome (IBS)** – a collection of symptoms, such as stomach cramps or pain, diarrhoea and/or constipation, or a fluctuating bowel habit. The causes of IBS are unknown, although food intolerance, infection or bacteria, lifestyle and emotional stress are thought to be linked in some way and may trigger many cases. People with IBS do not have a higher risk of developing bowel cancer, or any other serious bowel condition.
- **Diverticular disease** – this is a common condition in middle-aged and older people. Small bulges develop in the wall of the large bowel to form pockets called diverticulae. In many people, this process causes no problems at all, however one in four people will develop symptoms from this condition.
- **Crohn's disease, ulcerative colitis** – are examples of long-term inflammatory bowel diseases (IBD). The symptoms may include abdominal pain that comes and goes, tiredness, weight loss, bloating, bleeding and mucus. IBD can put you more at risk of developing bowel cancer, if you have had them for a long time. You should talk to your GP about this risk, the support that is available to help you manage the symptoms, and being monitored regularly.

Please see page 26 for organisations that may offer support with these diseases

What is my risk of bowel cancer?

Both men and women get bowel cancer. Just over 8 out of 10 cases of bowel cancer are diagnosed in people aged 60 years and over. We also know that people with certain diseases and illnesses seem to be more prone to developing bowel cancer:

- people with Type II diabetes
- people with inflammatory bowel diseases (IBD) – Crohn's, ulcerative colitis
- people who have Ashkenazi Jewish blood
- people who have had bowel cancer before, or some other closely linked cancers such as testicular or ovarian cancer, or cancer affecting other parts of the digestive system.

There is no clear reason why some people develop bowel cancer while others do not. However, the World Cancer Research Fund states that about half of bowel cancers could be prevented through healthy lifestyle choices.

Here are some ways to lower your personal risk:

Stop smoking
Long-term smokers are more likely than non-smokers to develop bowel cancer.

Watch your weight
Being overweight and carrying extra inches around your waist increases your risk of bowel cancer.

Be more active
Being physically active uses up extra calories and helps you avoid gaining weight. It also helps food to move through your digestive system more quickly.

Cut down on alcohol
Bowel cancer has been linked to a heavy intake of alcohol. The more you cut down, the more you reduce your risk.

Eat well
There is strong evidence of a link with bowel cancer from eating too much red meat, and processed meats in particular (e.g. bacon, ham, salami), so we recommend avoiding these as much as possible. Make sure you eat plenty of dietary fibre from whole grains, fruit and vegetables, and drink plenty of water. Fibre helps to move waste quickly through your digestive system.

Patient story

Amanda, aged 42

"I first visited my GP after experiencing abdominal pain and weight loss which worsened over a period of months. I had no bleeding and no noticeable change in my bowel habits. I very rarely get ill, so I was immediately sent for tests. Despite being referred straight away, my lack of bowel symptoms and the belief that due to being so young, it was 'unlikely to be anything serious' led to delays in my cancer diagnosis. It took five months for bowel cancer to be confirmed following a process of elimination. Each referral for tests involved a lengthy wait for appointments, followed by another wait for the results and for my consultant to rule out other conditions. I was investigated for gallstones (by ultrasound scan), then a stomach ulcer (by endoscopy) and finally my cancer was detected following a colonoscopy.

I've had surgery to remove two thirds of my large colon, followed by three months of chemotherapy. Despite the late diagnosis, I have remained positive throughout and with the support of family, friends and work colleagues I have recovered well and returned to full-time employment.

Three years on and every day is still a challenge, but what has changed is my outlook and the realisation that life is for living. I embrace every opportunity with both hands. I have accomplished more following diagnosis than I ever have done before.

My experience has taught me that early diagnosis is key. It's important to know your own body, trust your instincts and take action when you know that something isn't quite right."

Patient story

David, aged 58

"I was working in my study early in the morning on Halloween, 2013, when I had a sudden rush of what I thought was severe diarrhoea, but on going to the bathroom I saw I had lost a concerning amount of blood. I believe I might have lost small amounts of blood before this, but not in any quantity to make me concerned. Obviously this blood loss wasn't normal and I contacted my doctor as soon as the surgery opened. I gained an appointment for a few days later.

At the appointment, I explained my symptoms. At this stage I realised it may be serious, but cancer was only one possibility in my mind.

The GP did a brief examination of me and he had no hesitation in referring me to a specialist as an urgent case. He did mention cancer as a potential cause of the loss of blood, but it took a couple of visits to the colorectal clinic before I was given the absolute diagnosis of a tumour in my rectum.

I had surgery in April 2014 after four sessions of radiotherapy. Biopsies confirmed that my cancer was at an early stage with no lymph nodes affected, so I did not need follow up chemotherapy.

I have no doubt my instant reaction to the first significant symptom, combined with my doctor's rapid action, at least saved me the prospect of the cancer spreading and may have saved my life."

"I had surgery in April 2014 after four sessions of radiotherapy. Biopsies confirmed that my cancer was at an early stage with no lymph nodes affected, so I did not need follow up chemotherapy."

Talking to your GP

If you have been experiencing any of the higher-risk symptoms of bowel cancer for 3 weeks or more, your GP will want to see you. Some people struggle with working up the courage or finding the time to make an appointment, and this delay only increases the worry and fear.

Your GP will listen carefully to your concerns. They will encourage you to talk about the symptoms you have been having, including those problems affecting your bottom and your bowel habits. Whatever you have to say, they will encourage and support you to share your concerns with them, so that they can help you.

The more information you can give to your doctor about your bowel habits and what has changed recently, the easier it will be for them to make an accurate diagnosis – so don't be shy, and don't put it off.

Before you go to the GP

Before you go to the doctor, it might be useful to keep a diary recording the symptoms you have been experiencing, and for how long. It may also be worth considering your answers to the questions below and take the information with you to your appointment.

If you go to the GP with a bowel related problem, here is a list of routine questions which your doctor should ask as part of your consultation:

- How recently did you start to notice the symptoms?
- Have you noticed any bleeding from your bottom? If you have, what did it look like – bright red, dark red – and how much blood was there?
- Have you noticed looser, more diarrhoea-like poo, and going to the toilet more often?
- Are you straining to go and feel that you are constipated, or unable to completely empty your bowel?
- Has your stool become thinner and more ribbon like?
- Is there any family history of bowel cancer, or any other cancer?
- Have you experienced any unusual abdominal (tummy) pain or lumps?
- Have you unexpectedly lost weight or become more tired recently?

Your doctor should also ask you additional questions on:

- your lifestyle and diet (to identify any other possible risk factors)
- your own past medical history
- any medicines you might be taking (including pain killers, anti-inflammatory medicines, indigestion remedies or laxatives).

Your GP will need to know how your symptoms are affecting your quality of life. You may be having to take time off because of embarrassing problems with changing bowel habit, or if your ability to work is being affected by pain; you may be feeling tired or dizzy or getting short of breath; not being able to eat properly or needing to go to the toilet more frequently.

In addition to asking questions about your symptoms, your GP will feel your abdomen for any lumps or tenderness, and should also perform a **rectal examination** (a gentle examination with a gloved finger to look for and feel for any unusual lumps in your anus or rectum).If your GP does not examine you, you should ask why they have chosen not to. Your GP may also ask you to have a **blood test** to see if you have anaemia or anything else that may help with a diagnosis.

What next?

If your GP cannot find any clear cause for your symptoms, you may be asked to watch and wait for a week or so, to see if they settle on their own, or with the treatment your doctor prescribes to make you more comfortable. The younger you are, the more likely it is that your GP will want to exclude other reasons for your symptoms as they are usually, but not always, related to diet and lifestyle choices.

It is very important to be clear about when you should go back to your doctor again if the problems you are having do not get better. You should then be referred to your local hospital for further investigations by a specialist.

However old you are, you should never be told by your GP that you are too young to have bowel cancer. Whilst bowel cancer is more common in the 60+ age group, bowel cancer is becoming increasingly common in younger people too.

Referral guidelines

If your symptoms include any unexplained higher risk signs – bleeding from the bottom, changed bowel habit, anaemia or a lump in your abdomen, regardless of your age, you should be referred immediately. However, most people with high risk symptoms do not have cancer, but need further investigations to rule it out.

An urgent referral means you should be seen within two weeks, in line with the national target for cancer referrals (NICE guidelines [NG12] June 2015) if you are:

- a patient aged 40 and over with unexplained weight loss and abdominal pain or
- a patient aged 50 and over with unexplained rectal bleeding or
- a patient aged 60 and over with iron-deficiency anaemia or changes in their bowel habit, or
- a patient where a test has shown that there is faecal occult blood (hidden blood in their stool).

In addition, GPs should consider referring the following people for an appointment within two weeks:

Patients with a mass (lump) in their rectum or abdomen
Patients under 50 with rectal bleeding and any of the following unexplained symptoms:

- abdominal pain
- change in bowel habit
- weight loss
- iron-deficiency anaemia.

Testing for occult blood in faeces (hidden blood in your stool) should be offered to patients who do not have rectal bleeding but who:

- are 50 and over with unexplained abdominal pain or weight loss, or
- are under 60 with changes in their bowel habit or iron-deficiency anaemia, or
- are 60 and over and have anaemia even in the absence of iron deficiency.

Non-urgent referral

If your GP refers you for a condition that isn't urgent, you have the right to start treatment led by a consultant within 18 weeks from when you are referred.

Family history of bowel cancer

Do you know if anyone in your family has had bowel or any other kind of cancer?

If you think you have a strong family history of bowel cancer, you should make an appointment with your GP to talk about your concerns. If you only have one elderly relative who has had bowel cancer, this does not greatly increase your own personal risk. Indeed, up to 30% of people will have a close relative with bowel cancer.

There are two inherited conditions which can increase the risk of bowel cancer, known as FAP and HNPCC. FAP stands for familial adenomatous polyposis. HNPCC stands for hereditary non polyposis colorectal cancer (also called Lynch syndrome). These gene changes can increase the risk for people who have them, but they are very rare. FAP and HNPCC together are only responsible for about 1 in 20 cases of bowel cancer (5%).

For most people with a family history of bowel cancer, the national bowel cancer screening programme (see page 16) provides an adequate level of screening. For some people with a stronger family history, there is now a national guideline which recommends regular screening by colonoscopy, rather than with the stool tests. Your doctor can help you to understand your own personal level of risk.

The type and frequency of screening you will be offered will depend on what that level of risk might be. If you have a very close relative (a parent, sibling or child) with bowel cancer, under the age of 50, or more than one such very close relative at any age, then you should be referred by your doctor and you may be offered additional screening, according to the national guidelines.

People who have strong links to bowel cancer in one or more generations of their family should be referred to a family history of bowel cancer clinic. The team can help you to understand what your own risk might be, and help you to work out what kind of screening and support will suit you best.

For more information about family history and the national guidelines for screening people at higher risk of bowel cancer: http://familyhistorybowelcancer.wordpress.com

Lynch syndrome (HNPCC)

Lynch syndrome (also known as HNPCC or hereditary non-polyposis colorectal cancer) is a rare condition that may cause a family history of bowel cancer. Conditions that run in families are known as familial or hereditary and are caused by mutated (faulty) genes.

The term 'non-polyposis' is an important one which helps to distinguish Lynch syndrome from another condition called familial adenomatous polyposis (FAP), where hundreds of polyps (small growths) develop in the lining of the bowel. Lynch syndrome is the most common cause of hereditary bowel cancer and it is linked to 1-4% of all bowel cancers. This syndrome means there is also a risk of developing cancer in other areas of the body including the stomach, pancreas and kidney. Women with Lynch syndrome have a higher risk of developing cancer in their womb and ovaries and may be offered screening for this too.

People with Lynch syndrome in their family can have a genetic test to determine whether or not they have inherited the same faulty genes which cause the condition. They can also have screening with a colonoscopy every 1-2 years, which is an effective way of reducing the risk of developing bowel cancer in people with Lynch syndrome.

For more information about Lynch syndrome, contact **www.lynch-syndrome-uk.org**

Patient story

"I was diagnosed with bowel cancer 12 years ago and had surgery to remove most of my colon followed by chemotherapy. My mother, brother and grandfather died from bowel cancer, so I requested a genetic test. It was discovered I carry the HNPCC gene and because of this I have a colonoscopy every 18 months. My children also asked for genetic testing; my son is clear, but my daughter carries the gene and after being tested aged 25 had several polyps removed; she also has regular checks. I believe regular checks and colonoscopies save lives."

Stuart, 57

Family history of bowel cancer

Familial adenomatous polyposis (FAP)

FAP is a rare, inherited condition which causes hundreds or thousands of polyps (pre-cancerous growths) to grow in the colon (large bowel).

FAP most commonly runs in families, but it can also affect people who don't have a family history of it. FAP is usually inherited from a parent who has the condition, and is caused by a mutation on the APC gene. However, you can have FAP even if there are no other cases in your family. In about 1 in 4 cases, the gene mutation comes about by accident and not because you've inherited it. FAP is responsible for about 1 out of every 100 bowel cancers.

The polyps (sometimes called adenomas) can start to appear when a person is in their teens, and if left untreated, one or more of them will almost certainly develop into cancer, usually by the age of 40. In some people there are no symptoms until a polyp has changed into a cancer. Specialists therefore recommend that people with FAP have surgery to have their colon removed by the age of 25 to prevent them getting bowel cancer. This can be hard for a young person to cope with, and they will need the specialist help and support of an experienced colorectal team to help make the right decisions about their treatment.

Screening

In families where there is a clear history of FAP, screening usually commences by the age of 13, because it has been known to affect adolescents and teenagers. Screening involves an annual sigmoidoscopy for the first few years, and then an annual colonoscopy using a special dye spray.

Where FAP is suspected, your GP will refer you to your regional genetics centre or family history of bowel cancer clinic for support and on-going management of the condition.

Support for individuals affected by FAP can be found at:
FAP Gene Support
www.fapgene.org.uk

Bowel screening programmes

Bowel screening tests are mailed out automatically to all UK residents registered with a GP, once they reach age 60 in England, Wales and Northern Ireland (age 50 in Scotland).

The test is sent to you every two years up until age 74. In England and Scotland you can still request a kit every two years if you are over 75. (This option is not currently available in Wales and Northern Ireland).

The method used by the NHS bowel screening programme is a simple FOB (faecal occult blood) test which detects blood hidden in small samples of faeces (poo). You complete the test over the course of a few days, in the privacy of your own home. Once complete, you post it in the envelope provided to a central laboratory for testing.

A FOB test does not diagnose bowel cancer, but will identify blood in the faeces (poo). A positive test will trigger an invitation to have a colonoscopy (see page 23) to find out what is causing the bleeding.

There are plans to replace the current screening kit with a new FIT test (faecal immunochemical test) which is more user-friendly and has the potential to be more accurate.

Why take part?

Regular screening has been shown to be very effective in detecting early changes in the bowel, such as polyps, before they become a life threatening illness. Results from the national screening programme show that it has reduced the risk of dying from bowel cancer by 16%.

The message is simple – the later a diagnosis is made, the more difficult bowel cancer is to treat. If you have been invited to take part in bowel cancer screening, make sure you do it, as it could save your life.

If you are eligible to begin screening but have not received a test kit, contact your national helpline for more information.

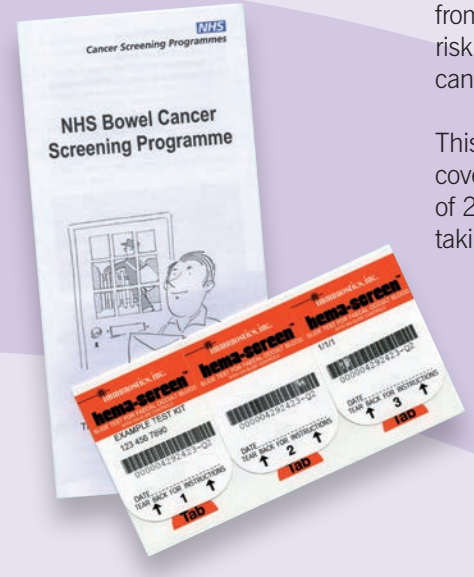
UK National Bowel Screening Helplines

England
T: 0800 707 60 60
W: www.gov.uk/topic/population-screening-programmes/bowel

Scotland
T: 0800 0121 833
W: www.bowelscreening.scot.nhs.uk

Wales
T: 0800 294 3370
W: www.wales.nhs.uk/bsw

Northern Ireland
T: 0800 015 2514
W: www.cancerscreening.hscni.net



Bowel scope screening

Public Health England has introduced a new, one-off, flexible sigmoidoscopy or bowel scope screening programme for men and women in England aged 55 years. This is an additional investigation within the current national bowel screening programmes.

We explain flexible sigmoidoscopy on page 22. The scope only examines the lower part of the large bowel and rectum, where the majority of polyps and cancers are found, so this test is done alongside the current FOB test, which detects bleeding from any part of the large bowel.

Bowel scope was introduced following the results of a long term study, funded by CRUK. The research found that a single flexi-sig test, in those aged 55 to 64 years, reduced the risk of individuals dying from bowel cancer by 43% and the risk of individuals developing bowel cancer by 33%.

This programme should achieve full coverage across England by the end of 2016. Pilot schemes are also taking place in Scotland.

Patient story

"I had a major operation followed by thirteen sessions of chemotherapy. It's been a very difficult time for me and my family, but my most recent scan showed no evidence of the disease. If it hadn't have been for the screening test – I wouldn't be here."

Joy, aged 61

"I was busy working full time as a secondary school teacher. I went to the gym and swimming four times a week. I was healthy – or so I thought – although always quite tired at the end of the day.

When I turned 60 the NHS screening kit came through the post (see page 16). I thought it was pointless to complete it as there was nothing wrong with me and surely I'd know about it if something was wrong? So I left it for two weeks. However, while I was off work I decided to take the test. The first one I sent off came back as an abnormal reading, so I was asked to do it again. The second one was normal, but as I'd previously had an abnormal result they asked me to do one more to make sure. This one came back abnormal again.

I was sent a letter asking me to go for a colonoscopy, a camera test to look inside my bowel. During this the procedure, on reflection I noticed that they moved the screen away from my view. In the recovery room whilst drinking tea, the nurse asked if I could get my husband to come in as well. The consultant said they'd found a large tumour in my bowel and they'd need to operate soon.

I had a major operation followed by thirteen sessions of chemotherapy. It's been a very difficult time for me and my family, but my most recent scan showed no evidence of the disease. If it hadn't have been for the screening test – I wouldn't be here. So I'd urge anyone who receives it to take part, even if you feel well. It really could be a life-saver."

Patient story

Steve, aged 60

"This year I turned 60. I am a happy, healthy, semi-retired rugby fanatic, slightly overweight, living a near perfect life. I was aware of the symptoms of bowel cancer but as far as I was concerned I did not think I had a problem. I had experienced slight traces of blood after going to the toilet but I did suffer from haemorrhoids, which I had discussed with my GP and was happy with his diagnosis. Soon after my birthday, the NHS bowel screening test dropped through my letter box. I read the information regarding the programme and set the card aside, not with the intention of ignoring it but waiting for that right moment when I could provide three samples and send it off. A couple of weeks later and with a bit of a nudge from my wife I completed the samples and popped the card in the post. Within days of sending off my samples I received a letter informing me that my test was abnormal and that I needed a colonoscopy. It was during this investigation that the cancer was detected and I experienced that awful feeling of dread. I was, however, determined that whatever the cancer would throw at me I would remain positive and respond to the advice given to me.

My bowel cancer was in the early stages but I do not consider that I was lucky: the screening programme gave me the best chance of recovery. Bowel cancer can be beaten if detected early, and it disappoints me to know that only just over 50% of people return their screening kit. In my mind that means nearly half are playing 'Russian roulette' with cancer."

Blood tests
for bowel cancer

Unlike some other cancers, there are no standard blood tests currently available in the UK that can be used to test routinely for bowel cancer. A few clinical trials are under way currently in the US and in the UK, to test the accuracy of some newer tests under development. These look at specific chemicals produced by abnormal changes and tumours in the bowel. However, the most common tests for bowel cancer are based on tests to look for blood or haemoglobin in your poo (faeces), alongside investigations which look directly at the bowel (endoscopy).

If you are experiencing problems with your bowel, your doctor may want to do some routine blood tests which will help them to decide whether or not you have other problems that can be linked to symptoms of bowel disease, or other undiagnosed health problems. These blood tests will depend on your symptoms, and may include:

- **Hb (Haemoglobin) or an FBC (full blood count)** – to check for anaemia or other problems
- **TFT – Thyroid function tests** – to check how well your thyroid gland is working
- **LFT – Liver function tests** – to check how well your liver is working
- **U&E – Urea and electrolytes** – to check how well your kidneys are working

CEA – Carcinoembryonic antigen – is a protein produced by some tumours. A CEA test is used on confirmed bowel cancer patients as a marker to monitor active disease. It cannot be used on its own to diagnose bowel cancer, because not all bowel cancers produce the protein.

Investigations for bowel symptoms

Investigations for bowel-related symptoms usually involve looking directly at the lining of the rectum (back passage) and colon (large bowel) using a technique called endoscopy. The most common types of endoscopy are sigmoidoscopy and colonoscopy.

A long, thin, flexible telescope fitted with a special probe, camera and lights – known as an endoscope – is passed inside the bowel, using the natural opening through the anus and rectum. This technique is safe, quick and effective in picking up problems inside the bowel, and it can also be used to remove small polyps.

Endoscopy is only carried out by nurses and doctors who have both specialist training and experience. It is usually done in an endoscopy suite - rooms in an outpatients department or screening clinic.

Other investigations may involve using specialist scanning equipment to take a sequence of photographs of the bowel, building up a picture of what the lining of the bowel looks like from outside. These 'virtual' CT colonography tests can help your doctors to understand what the problem might be without having to use more invasive endoscopy techniques. However, further endoscopy investigation will still be needed if anything unusual or abnormal is found in these scans.

From a patient's point of view, a vital part of all these tests is that you'll need to prepare your bowel in advance. Bowel preparation is important because it makes sure that your bowel is completely clean and empty before the test begins. It is very important to follow the instructions you have been given by the endoscopy team to make sure you are ready to have the test on the day of your appointment. If the preparation is not done properly, it can be difficult to see the lining of the bowel clearly and problems can be missed, or the investigation will have to be repeated because the findings are unclear.

We explain each of these different tests on the next three pages.

Sigmoidoscopy

A sigmoidoscopy can be done safely and comfortably in an outpatient clinic and does not require any anaesthetic or sedation. It usually takes less than 30 minutes to complete and you can go home as soon as you feel ready afterwards.

The bowel preparation in advance of the test usually involves having a small enema which you may be able to manage yourself at home in the morning before your test. A rigid sigmoidoscopy is a quick, straightforward investigation to look inside your rectum though an endoscope (like a thin, short telescope) passed into the back passage.

A flexible sigmoidoscopy allows the doctor to see inside the rectum and up into the lower part of the bowel on your left hand side. This is where the majority of polyps and bowel cancers are found. During this fairly short procedure, if the doctor or nurse sees anything that needs further investigation, samples (biopsies) can be taken for examination in the laboratory.

As well as using sigmoidoscopy as an aid for diagnosis, the test is now being offered to people aged 55 as part of the national bowel screening programme – see page 16.

Colonoscopy

A colonoscopy is a longer, more detailed examination to look at the lining of your whole large bowel. You may be given medicine (sedation) through a small tube into a vein in your hand, to relax you before the investigation starts. But this is not always the case and you should ask if you are not sure, or if you have any particular concerns about having the test.

During the test, a long flexible tube (endoscope) with a bright light and a camera on the end is introduced through your anus (back passage), and it is slowly moved up and around the bowel. It enables the doctor or nurse to get a clear view of the bowel wall all the way around from the rectum on the left to the appendix on the right. During the test, if the endoscopist sees anything that needs further investigation, photographs and samples (biopsies) can be taken. Simple polyps can be quickly removed during a colonoscopy.

You will be provided with information about the procedure and about the bowel preparation you will need to have before the procedure. This will involve taking special laxative medicines at set times and restricting your diet for 24 hours before the test.

For example, for a morning colonoscopy appointment you would not eat anything after breakfast on the day before the procedure. Breakfast should be low fibre (eg white meat, fish, cheese, white bread or rice, clear soup). You should avoid high fibre foods (eg fruit, salad, vegetables, nuts, beans, potato skins, wholemeal or brown bread, rice and pasta) and also avoid red meat and blackcurrant drinks.

Throughout the day you can have clear soups and drinks without milk. At 5 pm on the day before the procedure you will start to drink the bowel preparation supplied, which will cause you to empty your bowels several times. You will need to stay near a toilet until your bowel is completely clear and the urgency has stopped.

You will be given slightly different timing instructions for an afternoon or evening appointment.

You will be provided with information about the procedure and about the bowel preparation you will need to have beforehand.

Virtual colonoscopy
(CT colonography)

Virtual colonoscopy involves using a CT scanner to produce two and three dimensional images of the large bowel and rectum. Modern CT scanners are so fast that they can scan through large sections of the body in just a few seconds.

During the procedure, air is used to inflate the bowel via a thin flexible tube placed in your back passage. CT scans are then performed with you lying on your back, and then on your front, to enable the doctors to get a clear set of scans of your bowel. This generates a detailed 3-D model of your abdomen and pelvis, which the radiologist uses to view your bowel in a way that simulates travelling down through it.

Before the procedure, you will be given information about the bowel preparation that you must do to make sure that the bowel is empty. The bowel-cleansing instructions for CT colonography are similar to that for a colonoscopy, and this allows the doctor to perform the procedure effectively.

If anything abnormal is detected you may still need to have a colonoscopy to allow the doctor to take samples (biopsies) or to have a closer look at the inside of the bowel. Virtual colonoscopies are not currently available in every hospital.

Getting your results

Waiting for the results of any tests is a nerve-racking time. Find out from the specialist nurse when you can expect to find out the results and how you will be told. Sometimes you are asked if you are happy to receive the results over the telephone.

Think carefully about this – if you do have cancer you might prefer to be with the doctor and nurse when they tell you. You may also want to take a family member or friend with you. When you are told the results, if you do have bowel cancer, your doctor and specialist nurse will talk to you about what happens next.

There are likely to be very many questions in your head before you see your specialist, and while you are waiting for your test results. It might help to write them down so that you don't forget them during the consultation. Some hospitals allow you to record your consultations, to help you remember what was said.

Questions you may want to ask

- **What did you find during the investigation?**

If it is cancer –

- **Which part of my bowel is affected – can you draw me a picture?**
- **What other investigations will I need to have now?**
- **How long would I expect to wait for these appointments?**
- **Who will be my main contact within the team if I have any more questions?** A contact telephone number or email address can be very useful if you have a question that can't wait.
- **Have I been referred to a colorectal cancer specialist or a general surgeon?** Colorectal specialists have additional training and extensive knowledge about bowel cancer and its treatment.
- **Does my hospital have a specialist colorectal multi-disciplinary team and on what day of the week does it meet?** If the team only meets on a Monday, for example, decisions may be delayed in weeks where there are bank holidays.
- **How long will I have to wait to begin treatment?** Treatment for bowel cancer should begin within 31 days of the specialist team receiving the referral.
- **Who is my specialist colorectal nurse and how will I contact him/her?** This is likely to be the person who becomes your 'key worker' throughout your treatment for bowel cancer.

Who else can help?

Beating Bowel Cancer has a range of resources and a dedicated patient services team. We can answer your questions and offer information and signposting if you have any concerns relating to symptoms or the treatment and management of bowel cancer.

You can contact our **Specialist Nurse Advisors** and get further information in several ways:
T: 08450 719 301
or 020 8973 0011
E: nurse@beatingbowelcancer.org

Online forum at
www.beatingbowelcancer.org/forum

Download or order booklets at
www.beatingbowelcancer.org

Other useful contacts

The Bladder and Bowel Foundation
T: 0845 345 0165
W: www.bladderandbowelfoundation.org

Crohn's and Colitis UK
T: 01727 73 44 70
W: www.crohnsandcolitis.org.uk

The IBS Network
T: 0114 272 3253
W: www.theibsnetwork.org

NHS Choices
W: www.nhs.uk/conditions

World Cancer Research Fund
W: www.wcrf-uk.org
For more information on decreasing your risk of bowel cancer

Gary Logue Colorectal Nurse Awards
These awards were set up in memory of our nurse advisor, Gary Logue, who passed away in 2014. Bowel cancer patients are warmly invited to show recognition of the fantastic work that nurses do by nominating their colorectal cancer nurse specialist for an award. Each year, two nurses will receive £500 each towards their personal development.

Please visit **beatingbowelcancer.org/nurse-awards** and tell us why your nurse deserves this special recognition.

Support our work

We provide practical and emotional support

- We provide specialist support and information to anyone affected by bowel cancer.
- We run the UK's only nurse-led specialist helpline for bowel cancer. Patients call it a 'lifeline' and often build up long term relationships with our nurses over many years.

We bring people with bowel cancer together

- Bowel cancer affects people physically and emotionally and a problem shared can make a world of difference.
- We connect people through the power of our website, social media and major events such as our Patient Days.

We promote early diagnosis

- 9 in 10 people with bowel cancer will survive if they're treated early. That's why we work tirelessly through innovative campaigns to promote greater awareness of symptoms, and the key message that bowel cancer can be beaten.

We campaign for the highest quality treatment and care

- Everyone affected by bowel cancer, no matter who they are or where they live, should get the best possible support, care and information. We campaign nationally and locally to make sure Governments and health services do better by providing the highest quality care and treatments, and by making beating bowel cancer a priority.

We raise money to fund our vital work

- We need you to help us continue our work that provides such vital support for people with bowel cancer.
- We are a charity that relies entirely on voluntary donations and gifts in Wills and by giving a donation you will help fund a range of vital services that give people with bowel cancer help, hope and reassurance.

Please join us and together we can beat bowel cancer.

To make a donation please visit **beatingbowelcancer.org/donate** or call **020 8973 0000.**

Beating Bowel Cancer is the support and campaigning charity for everyone affected by bowel cancer.

We provide vital practical and emotional help – on the phone, digitally and face to face. We're proud to run the UK's only nurse-led specialist helpline for bowel cancer which patients call a 'lifeline'.

We bring patients together to share invaluable experience and support, through our website, social media and major events.

Our high impact campaigns have led to the introduction of the bowel cancer screening programme, which is helping save lives, as well as new funding and greater patient access to life-changing cancer treatments.

If you have any questions or comments about this publication, or would like information on the evidence used to produce it, please write to us, or email **info@beatingbowelcancer.org**

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