



BOWEL CANCER AND IBD

INTRODUCTION

If you have Ulcerative Colitis (UC) or Crohn's Disease (the two main forms of Inflammatory Bowel Disease – IBD) you might wonder whether you have a greater chance of developing bowel cancer than the general population. There is an increased risk for some people with IBD, especially those with longstanding and extensive UC or with Crohn's Disease affecting all or much of the large bowel. However, the overall number of people with IBD who develop bowel cancer (also known as colorectal cancer) is small. Your IBD team should carry out regular checks to see if there are any signs of cancer, since cancer can be treated more successfully when detected early.

This information sheet looks at what may increase your risk of bowel cancer if you have IBD, and how you can reduce this risk. It also describes changes in the lining of the bowel that may develop into cancer, and how these are detected.

WHO IS AT RISK?

There are a number of known risk factors linked to any cancer, including family history of cancer and smoking. For people with IBD, there can be extra risks of bowel cancer according to the type of IBD and its location.

Ulcerative Colitis

UC affects the lining of the large bowel, which includes the colon and rectum. The risk of developing bowel cancer is linked to three main factors:

- How long you have had UC
- How much of your large bowel is affected
- How severe your inflammation is

Research shows that the risk of developing cancer usually begins to increase about 8-10 years after the start of IBD symptoms. This is not from the date of your diagnosis, which could be much later than when your symptoms started.

Your risk of cancer is highest if the whole of your colon is affected by disease (often referred to as extensive, total or pancolitis).

If only the left side of your colon is affected by UC (distal colitis), there is less risk of developing cancer than for those with total colitis.

If your UC is limited to the rectum (proctitis), your risk is little or no greater than for the general population.

IBD has been recognised as a high risk condition for bowel cancer since the 1920s. It is difficult to say what the actual risk of developing bowel cancer is if you have UC, because reports have varied greatly in their conclusions. Largely, this is because studies have differed as to whether patients were recruited from specialist centres (with severe disease) or general practices (with milder disease).

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However, one large study found that for people with extensive disease, about 3 in every 100 might be expected to develop cancer after 20 years. The risk increases gradually to about 8 people out of every 100 after 30 years and to 11 people after 40 years. In comparison, in the general population as a whole, around 5 people in every 100 will develop cancer of the large bowel at some time in their lives. Although these figures may seem alarming, it is worth bearing in mind that, even among people with IBD, only a small minority will develop bowel cancer. Encouragingly, studies show the number of IBD patients with bowel cancer has declined in recent years. This decrease has been attributed to more widespread use of IBD medicines leading to less inflammation, greater take-up of screening for bowel cancer and factors we don't yet fully understand.

Crohn's Disease

Crohn's may affect any part of the digestive system from the mouth to the anus. The risk of cancer in people with Crohn's Disease has been less explored. If you have Crohn's affecting all or much of the large colon (Crohn's Colitis), your risk of developing colorectal cancer is about the same as for someone who has had extensive UC for the same length of time.

ARE THERE OTHER RISK FACTORS?

There are several other factors which may increase your risk of bowel cancer:

- **Severity of inflammation** - A number of studies have shown that you may have an increased risk of cancer if you have severe ongoing inflammation. While the exact mechanisms are unknown, inflammation damages the cells lining the bowel, which can lead to changes in the DNA of these cells that might start cancer.
- **Family history of bowel cancer** - If anyone in your family has had bowel cancer, even if they do not have IBD, research suggests that you have an increased risk of developing cancer. The risk is greatest if you have a parent or sibling who has suffered from bowel cancer under the age of 50.
- **Age at start of symptoms** - There is some evidence that you have a slightly increased risk if you developed IBD during your childhood, adolescence or as a young adult.
- **Primary Sclerosing Cholangitis (PSC)** - Having PSC (an inflammatory condition affecting bile ducts transporting digestive juices from the liver) increases the risk of bowel cancer. PSC is known to affect around 8% of people with UC and up to 3% of people with Crohn's. Your IBD team will tell you if you have this condition. Explanations for the link to bowel cancer include shared genes for PSC and bowel cancer, and alterations in digestive juices.
- **Gender** - Men with IBD have been found to have a slightly higher chance of developing bowel cancer than women.

CAN I REDUCE THE RISK?

- **Taking regular medication**
A number of studies suggest that taking a 5-aminosalicylic (5-ASA) drug regularly may reduce the risk of cancer. In addition to helping to reduce and prevent long term inflammation, 5-ASA drugs, widely used in IBD for maintenance of remission, may have other actions including blocking cancer cell growth and promoting cancer cell death.

A large study on azathioprine and 6-mercaptopurine (the thiopurine drugs) suggests that they also protect people with IBD from bowel cancer (particularly those with long standing disease), although smaller studies found no such effect.

If you have PSC as well as IBD, research suggests that you may be able to reduce your cancer risk by taking ursodeoxycholic acid, which is thought to work by diluting the toxic components of bile. Your doctor will advise you if you should take this.

- **Visiting your doctor regularly** - Seeing your doctor for regular check-ups at least once a year, even when your IBD is in remission, can ensure you remain on the most appropriate treatment, and that you have regular checks for any sign of cancer. Of course, if you have any changes in symptoms at any time, it is best to speak to your doctor promptly.
- **Having regular colonoscopies** - Regular colonoscopies (see below) mean that specialists can look for early changes in the colon before cancer develops. This is known as surveillance colonoscopy. If you have had IBD for 8-10 years and have not recently had a colonoscopy, it may be a good idea to contact your doctor to discuss whether this would be appropriate for you.

CAN ANYTHING ELSE REDUCE THE RISK?

There has been a lot of research into ways of reducing the risk of bowel cancer in the general population.

It has been found that physical activity and a high fibre diet may help to prevent bowel cancer. For more information about taking exercise see our leaflet: **Staying Well with IBD**.

If you have IBD and have problems with a high fibre diet, you may find it helpful to speak to your IBD team, or ask to be referred to a dietitian. Studies also suggest that a diet high in saturated fats and red meat may increase the risk of colon cancer, so it may be a good idea to eat less of these and more fish and skinless chicken.

Recently, the International Agency for Research on Cancer (IARC) concluded (after reviewing around 800 studies) that eating more than 50g of processed meat a day increased the risk of colon cancer. Examples of processed meats include bacon, hot dogs, sausages and corned beef. Put in perspective, they estimated that if everyone ate the equivalent of two pieces of bacon a day, an additional one person in 100 would develop bowel cancer. There is more information about diet in our booklet: **Food and IBD**.

Alcohol has also been linked to an increased chance of developing bowel cancer - even one glass a day appears to increase the risk.

Smoking is another factor which has been shown to play a part in increasing bowel cancer risk in the general population, and one study suggested that the younger a person starts smoking, the greater the risk. You can get more information about smoking from our leaflet: **Smoking and IBD**.

Research has also looked at the potential of calcium and vitamin D to protect against the development of cancer. So far the results have been inconclusive, although one recent study in patients with IBD showed that low blood levels of vitamin D were associated with colon cancer.

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Since being diagnosed with a cancerous polyp, which was successfully treated, I am extra vigilant. I do everything I can with my diet and exercise to ensure I remain healthy.

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Pat, age 72

diagnosed with Crohn's Disease in 1972

However, taking supplements of calcium and vitamin D may have other health benefits such as strengthening the bones, which may be weakened if you have IBD. (See our information sheet: **Bones and IBD**.) Talk to your IBD team if you have questions about taking supplements.

Some studies have shown taking aspirin reduces the risk of bowel cancer. One key study showed over a period of 20 years regular aspirin reduced the risk of bowel cancer by nearly one quarter and death from bowel cancer by over one third. The benefits need to be balanced against aspirin's potential to cause serious adverse effects, such as bleeding from the stomach. You should not take aspirin for long periods without checking with your doctor first. It is unclear whether aspirin has any additional benefits for bowel cancer prevention if you are already taking 5-ASA, which is similar to aspirin but works in a different way.

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Before the colonoscopy, to improve the taste of the laxative bowel clearing preparation, I always add orange juice to it and store it in the fridge overnight.

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John, age 41
diagnosed with Crohn's Disease in 1992

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Having a flexi-sigmoidoscopy can feel uncomfortable, but the sedation they give you really does its job well! Make sure you communicate with the doctors and nurses around you so that they can provide as much help as possible.

”

Ellie, age 21
diagnosed with Ulcerative Colitis in 2013

WHAT IS A COLONOSCOPY?

A colonoscopy is a type of examination that allows a specialist doctor or nurse to look directly at the lining of the colon and rectum using a colonoscope. This is a long flexible tube, about the thickness of your little finger, with a bright light and camera at the end. It is inserted through the anus (back passage), and is long enough to examine the whole colon and the end of the small intestine. The specialist can check the extent and severity of any inflammation, and whether you have any narrowed areas, polyps or dysplasia (see below).

Your colon needs to be completely clean for the colonoscopy so that the specialist can get a clear view of the lining of your bowel. You will be asked to take a laxative either the evening before or the day of the test.

Chromoendoscopy, which involves spraying special dyes onto the lining of the colon during the examination, is the colonoscopy technique now recommended by organisations such as the British Society of Gastroenterology (BSG) and the National Institute for Health and Care Excellence (NICE). Studies show chromoendoscopy is more effective at detecting abnormal cells lining the colon than the older technique that involved taking multiple tissue samples ('random biopsies') along the length of the colon. For more information on this see our information sheet: **Tests and Investigations for IBD**.

You may be given sedation to make you feel relaxed. The examination usually takes 30-40 minutes. As well as looking at the lining of the bowel, the specialist will take biopsies (small pieces of bowel lining) to examine later under a microscope in the laboratory. The specialist may also remove any polyps (small fleshy growths that form on the normally smooth lining of the colon) to examine them in more detail.

WHAT IS A COLONOSCOPY LOOKING FOR IN RELATION TO CANCER?

During a colonoscopy, the specialist will look for any abnormalities of the lining of the colon and rectum including the degree of inflammation, precancerous changes called dysplasia (see below) and polyps.

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After surgery for Crohn’s Disease, I had no symptoms for 36 years, but I was then diagnosed with a cancerous polyp. My experience shows how you need to be on your guard even after a long period of remission.

”

Pat, age 72
diagnosed with Crohn’s Disease in 1972

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Being told you have cancer is devastating and the treatment is unpleasant. But the point is, the colonoscopy helped them find it while it was still treatable, and I have now been cancer-free for five years.

”

Annie, age 62
diagnosed with Ulcerative Colitis in 2010 and Cancer in 1980

There are several different forms of polyps. Two common types are:

- **Inflammatory polyps (including post-inflammatory polyps and pseudopolyps)**
These polyps generally need no treatment, but may sometimes be removed during a colonoscopy so they can be examined under a microscope to confirm the diagnosis.
- **Adenomatous polyps**
These polyps have the potential to develop into cancer. They are a type of dysplasia and will need to be removed (see below).

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WHAT IS DYSPLASIA?

Dysplasia means a change in the size, shape and pattern of normal cells, which is not in itself cancer – but can be a sign that cancer may develop in these cells. Polyps are one form of dysplasia – which is often categorised according to the way it appears and whether it is raised or flat. Flat dysplasia is often much more difficult to see but will still need treatment.

Adenomatous polyps may be removed endoscopically (during a colonoscopy) if there is no sign of any dysplasia in the surrounding bowel wall. However, if it is not possible to remove dysplasia fully endoscopically, then surgery to remove all or part of the colon may be required.

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HOW OFTEN SHOULD I HAVE A COLONOSCOPY?

The BSG and NICE recommend that if you have UC or Crohn’s Colitis, you should have a colonoscopy about 10 years after the start of your symptoms to see whether there have been any changes in your colon. The exception is people with PSC and UC who should be enrolled in a surveillance programme from the time of diagnosis. It is best to have a colonoscopy done when your IBD is not active.

The BSG also recommends that you then have follow-on colonoscopies every 3 or 5 years or, less commonly, yearly. This will depend on what was seen during your previous colonoscopy and any other risk factors you may have. For example, you may need a colonoscopy every year if you have both PSC and UC, or have had dysplasia detected.

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HOW EFFECTIVE IS A COLONOSCOPY IN FINDING CANCER OR PREVENTING IT OCCURRING?

Colonoscopy is very effective at detecting established colorectal cancer. However, the precancer changes of dysplasia can be much harder to detect, and can be missed because it is not possible to take samples of the whole lining of the bowel. Bowel cancer also can develop in people who do not have a prior history of dysplasia.

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Research comparing historic populations who have undergone screening by colonoscopy with those who have not, reported mixed results. One study showed no benefits, while a subsequent study found that bowel cancer was diagnosed at an earlier tumour stage in screened patients, and that their survival was increased.

Having a colonoscopy is currently accepted as the best way available to detect cancer early. The earlier the cancer is found, the better the survival rate. The main advantage of regular examinations is that if early warning signs are detected, curative treatment by endoscopy or surgery is more likely to be an option. Sometimes abnormal cells can be removed at the time of colonoscopy, avoiding the need for a surgical procedure.

There are disadvantages to having colonoscopies. The examination can be time consuming, and some people find the bowel preparation unpleasant. Sometimes a colonoscopy can be very uncomfortable, or it may cause bleeding or a tear of the lining of the bowel (perforation), although complications from having a colonoscopy are rare.

It is best to discuss the potential benefits and disadvantages of having regular colonoscopies with your IBD team.

WHAT OTHER TESTS ARE AVAILABLE?

The NHS has a bowel cancer screening programme for people aged 60 to 74, using a Faecal Occult Blood (FOB) test. This test, which is sent through the post every two years, does not diagnose cancer, but looks for hidden blood in your bowel motions (stools), which could be due to cancer. For many people with IBD however, the results can be misleading as there may already be traces of blood in their stools from their IBD, but you should have a colonoscopy if offered as part of the screening programme. If you are uncertain whether or not to have this test, discuss it with your IBD specialist.

In England, the NHS has recently launched an additional screening programme inviting all 55 years olds for a 'one-off' bowel scope test that looks at the lower bowel and rectum. The aim is for this test to be available in all English screening centres by December 2016, but if you are already undergoing IBD surveillance you will not need this investigation.

Other methods for detecting bowel cancer are being researched. For the time being however, taking your medication regularly, maybe adjusting your diet and, if appropriate, having regular colonoscopies, are likely to be the most effective ways of reducing your risk of bowel cancer.

HELP AND SUPPORT FROM CROHN'S AND COLITIS UK

All our information sheets and booklets are available to download from our website: **www.crohnsandcolitis.org.uk** If you would like a printed copy, please contact our information line – details below.

Crohn's and Colitis UK Information Line: 0300 222 5700. Open Monday to Friday, 9 am to 5 pm, except Thursday open 9 am to 1 pm, and excluding English bank holidays. An answer phone and call back service operates outside these hours. You can also contact the service by email **info@crohnsandcolitis.org.uk** or letter (addressed to our St Albans office). Trained Information Officers provide callers with clear and balanced information on a wide range of issues relating to IBD.

Crohn's and Colitis Support: 0121 7379 931: Open Monday to Friday, 1 pm to 3.30 pm and 6.30 pm to 9 pm, excluding English bank holidays. This is a confidential, supportive listening service, which is provided by trained volunteers and available to anyone affected by IBD. These volunteers are skilled in providing emotional support to anyone who needs a safe place to talk about living with IBD.

OTHER ORGANISATIONS

Beating Bowel Cancer

08450 719 300
Helpline: 08450 719 301
Website: www.beatingbowelcancer.org
Email: nurse@beatingbowelcancer.org

Bowel Cancer UK

020 7940 1760
Advisory Service: 0800 8 40 35 40
Email: admin@bowelcanceruk.org.uk
Website: www.bowelcanceruk.org.uk
Scotland: 0131 225 5333
Email: scotadmin@bowelcanceruk.org.uk

Cancer Research UK

Helpline: 0808 800 4040
Websites: www.cancerresearchuk.org and www.cancerhelp.org.uk

Macmillan Cancer Support

020 7840 7840
Helpline: 0808 808 00 00
Website: www.macmillan.org.uk

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ABOUT CROHN'S & COLITIS UK

We are a **national** charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Diseases. We have over 28,000 members and 50 Local groups throughout the UK. Membership costs start from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

This publication is available free of charge, but we would not be able to do this without our supporters and members. Please consider making a donation or becoming a member of Crohn's and Colitis UK. To find out how call **01727 734465** or visit www.crohnsandcolitis.org.uk

