Bowel Cancer and IBD

Introduction

If you have Inflammatory Bowel Disease (IBD), which includes Ulcerative Colitis and Crohn's Disease, you may wonder whether you have an additional risk of developing cancer, particularly in the bowel, because of your IBD. Even where there is an increased risk of bowel cancer, it is important to remember that it can be cured if it is caught early enough. You are more likely **not** to get cancer.

This information sheet looks at who with IBD may have an increased risk of bowel cancer and how you can reduce the risk. It also describes changes in the bowel that may develop into cancer.

Who is at risk?

There are a number of known risk factors linked to cancer, including family history and smoking. For many people with IBD there is little or no greater risk of developing bowel cancer than in the general population.

Ulcerative Colitis (UC) affects the lining of the large bowel (also called the colon). If you have UC there are two main risk factors:

- How long you have had the disease
- How much of your colon is affected by disease

Research shows that the risk only begins to increase 8-10 years after the start of symptoms. This is not from the date of your diagnosis, which could be much later.

After this period your risk of cancer is highest if the whole of your colon (called extensive, total or pancolitis) is affected, even if you have few symptoms.

If only the left side of your colon (called distal colitis) is affected, there is less risk of developing cancer than for those with total colitis. If only the lowest part of your colon (called proctitis) is affected, your risk is little or no greater than for the general population.

It is difficult to know the actual risk of developing bowel cancer if you have UC, as studies vary in their conclusions. However, a recent study found that for people with extensive disease about 7 in every 100 might be expected to develop cancer after 20 years. The risk increases gradually to about 16 people in every 100 after 30 years, but after 40 years the risk does not seem to increase. It is important to remember that even among people without IBD, about 5 people in every 100 will develop cancer of the large bowel at some time in their lives.

Crohn's Disease

Crohn's Disease may affect any part of the digestive system from the mouth to the anus. If you have Crohn's affecting all or most of the large colon, sometimes called Crohn's Colitis, your risk of colon cancer is similar to that of extensive UC that has lasted for 8-10 years or more.

If you have Crohn's only in the small intestine your risk of cancer is low. Studies of the cancer risk in Crohn's of the small intestine are very limited. Research suggests there is an increased risk, but as small bowel cancer accounts for only about 1 in 100 of all gastrointestinal cancers, the actual risk is extremely small.

Are there other risk factors?

If you have had extensive Ulcerative Colitis for at least 8-10 years, there are some additional factors that may slightly increase your risk of developing cancer. These include:

- **Age at start of symptoms**

There is some evidence that you have a slightly increased risk if you developed UC in childhood.

- **Severity of inflammation**

A number of studies have shown that you have an increased risk of cancer if you have severe ongoing inflammation.

- **Family history of cancer**

If you have any family member with colorectal cancer research suggests that you have an increased risk of developing cancer.

- **Primary Sclerosing Cholangitis (PSC)**

Having PSC and UC is linked to an increased risk of cancer. However, very few people with UC develop PSC.

There is little research about these additional risks for people with Crohn's Colitis. However, PSC can affect those with Crohn's Disease and if you develop PSC you would have a similar risk as those with UC.

Can I reduce the risk?

There are three main ways that may help you to reduce the risk of bowel cancer:

- **Taking regular medication**

A number of studies suggest that taking a 5-ASA drug regularly, particularly mesalazine (Asacol, Pentasa, Salofalk, Mesren and Ipocol), reduces the risk of cancer. How these drugs work to prevent cancer is not fully understood, but it is thought that long-term prevention or reduction of inflammation is a key factor.

If you have PSC as well as UC you can reduce your cancer risk by taking ursodeoxycholic acid. Some research shows that this medication is effective, but it is not clear how it works.

- **Visiting your doctor regularly**

By seeing your doctor for regular check-ups at least once a year, even when your IBD is in remission, you can ensure you remain on the most appropriate treatment.

Of course, if you have any changes in symptoms at any time, it is best to speak to your doctor promptly.

- **Having regular colonoscopies**

Having regular colonoscopies (see below) means 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?

Physical activity and a high fibre diet may help to prevent cancer. On the other hand, 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. Having IBD you may find it difficult to increase the fibre in your diet and you could speak to your nurse or doctor for help, or to be referred to a dietitian. You can get more information about diet in our booklet: Food and IBD.

There have been numerous studies on the potential of calcium and vitamin D to protect against the development of cancer. The results have been varying, but some research suggest that high levels of these supplements may be protective. Taking supplements of calcium and vitamin D can also strengthen the bones, which may be weakened if you have IBD. (See our information sheet: *The Bones and IBD.)*

There is considerable evidence to suggest that taking folic acid supplements may protect against the development of cancer. However, more recent studies suggest that once there are changes in the colon indicating cancer, then high levels of folic acid seem to increase the development of cancer (see below *'What is dysplasia?*'). This suggests that having regular colonoscopies to check for pre-cancerous changes is particularly important.

What is a colonoscopy?

A colonoscopy is a procedure using a colonoscope which allows the specialist to look directly at the lining of the colon. A colonoscope is a long flexible tube about the thickness of your little finger, with a bright light and camera at the end. It is long enough to examine the whole colon and the end of the small intestine. The specialist can check the extent of your colitis, how inflamed your colon is, and whether you have any polyps (see below) or narrowed areas.

You will have to prepare for a colonoscopy by emptying your bowel beforehand, so that the specialist can get a clear view of the lining of your bowel. Your hospital will usually advise you about your diet and taking fluids and a laxative before the examination.

You may be given an injection to sedate you for the procedure. During the examination, which takes about 40 minutes, the specialist will painlessly remove small pieces of bowel lining to examine under a microscope in the laboratory. These are called biopsies. Biopsies usually reveal only normal cells, but occasionally there are early warning signs that cancer may develop (dysplasia – see below). The specialist can also remove any polyps to examine in more detail.

What are polyps?

Polyps are small fleshy growths, like warts, that form on the usually smooth surface of the colon lining. They can be either just harmless little bulges of swollen, inflamed tissue, called inflammatory polyps, or adenomatous polyps.

- **Inflammatory polyps**

These polyps need no treatment but are removed during a colonoscopy to be examined under the microscope to confirm the diagnosis.

- **Adenomatous polyps**

These polyps have the potential of developing into cancer, but they are not specifically related to IBD – they may develop in anyone. They are removed during a colonoscopy for further investigation in the laboratory. This is to find out whether the polyps have the potential to develop into cancer. If the polyps show signs of pre-cancerous change only, no further treatment is required. However, if there are signs of cancer then surgery is needed.

What is dysplasia?

Dysplasia is not cancer, but is a sign of the possibility of cancer developing in the future. Dysplasia means a change in the size, shape and pattern of normal cells seen in a biopsy. This may develop as a result of having had IBD. Depending on the appearance under the microscope it may be described as low grade or high grade.

- **Low grade dysplasia**

Low grade or slight dysplasia (LGD) can be difficult to identify. Further biopsies may be needed to confirm dysplasia and once it is confirmed there may be a number of treatment options. This may include more frequent colonoscopies, but may also include the possibility of surgery as recent research suggests that even LGD may increase your risk of cancer.

- **High grade dysplasia**

If you have high grade dysplasia there is a real possibility of undetected cancerous cells and you are at a greater risk of developing cancer. In this situation the BSG recommends surgery to remove the bowel; the operation is usually a proctocolectomy or an ileal pouch-anal anastomosis. See our information on Surgery for Crohn's Disease and Surgery for Ulcerative Colitis for more information.

How often should I have a colonoscopy?

The British Society of Gastroenterology guidelines (BSG) recommend that if you have Ulcerative Colitis or Crohn's Colitis you have a colonoscopy at approximately 10 years after the start of symptoms to see whether there have been any changes in

your colon. This is best done when your IBD is not active.

It is then recommended that you have a colonoscopy to screen for cancer every 5 or 3 years or yearly, depending on what was seen during your previous colonoscopy and also depending on any other risk factors you may have. You may, for example, have a colonoscopy every year if you have both PSC and UC.

How effective is colonoscopy in finding cancer?

There is no ideal way of detecting early warning signs of cancer and unfortunately those at risk may still develop cancer of the large bowel even though they may have had no symptoms of their IBD for many years.

However, having a colonoscopy is still the best way currently available to detect early, curable cancer. The main advantage of regular examinations is that if early warning signs are detected, surgical treatment is an option. At this stage an early cancer can usually be removed and cured by surgery. On the other hand, since only a small number of those people who are at risk actually develop cancer, regular checks avoid unnecessary surgery.

There are though, some disadvantages to having a colonoscopy. It is only possible to sample a small proportion of the total surface area of the large bowel, even if a large number of biopsies are obtained. Sometimes the warning signs are patchy, so that there may be occasions when the samples obtained may be normal although dysplasia is present elsewhere in the bowel.

The examination can be time consuming and unpleasant, as it needs thorough bowel preparation. Sometimes it can also be uncomfortable and in some cases it can cause heavy bleeding. Some people require repeated colonoscopies every 1-2 years, so will have to go through frequent examinations. Nearly all of these examinations will be normal because the early warning signs and the development of cancer of the large bowel are uncommon.

Although complications from having a colonoscopy are rare, there is a small risk of damaging the bowel during the procedure.

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

Are there any other kinds of tests available?

A new technique called chromoendoscopy has been developed and is becoming more widely available. This uses dye sprayed on the inner lining of the colon during a colonoscopy, which helps to show up dysplasia more clearly.

The NHS has a bowel cancer screening programme for people aged 60 to 69, using a Faecal Occult Blood (FOB) test. This test does not diagnose cancer, but looks for hidden blood in your bowel motions, which could be due to cancer. For most people with IBD the test is not usually recommended and if you have had a recent colonoscopy you do not need to take part in the bowel screening programme.

And finally…

Further research will look at less invasive ways of identifying cancer and the role of medication in reducing the risk of developing cancer. It is encouraging though that recent studies suggest that the risk of cancer for people with IBD has been decreasing over time. The reason for this change is not known, but it is thought that the more widespread use of regular medication and surveillance colonoscopy may be part of the explanation. So, taking your medication regularly and having regular colonoscopies, when appropriate, are for the time being, possibly the best ways of reducing your risk of cancer.

Further Help

Crohn's and Colitis UK information Line: 0845 130 2233, open Monday to Friday 10am -1pm. Information staff will help with any IBD related queries. There is an answerphone service outside these hours or you may email info@crohnsandcolitis.org.uk

Crohn's and Colitis Support Line: 0845 130 3344, open Monday to Friday 1pm - 3.30pm and 6.30pm-9pm. This is a supportive listening service staffed by trained volunteers with personal experience of IBD.

Other organisations

Beating Bowel Cancer
Harlequin House
7 High Street, Teddington, TW11 8EE
☎ 08450 719 300
Helpline 08450 719 301
Mon-Thurs 9am-5.30pm, Fri 9am-4pm
Web: www.beatingbowelcancer.org

Bowel Cancer UK
7 Rickett Street, London SW6 1RU
☎ 020 7381 9711
Advisory Service: 0800 8 40 35 40
Email: admin@bowelcanceruk.org.uk
Website: www.bowelcanceruk.org.uk

Scotland:
20 Queen Street, Edinburgh EH2 1JX
☎ 0131 225 5333
Email: scotadmin@bowelcanceruk.org.uk

Cancer Research UK
PO Box 123, Lincoln's Inn Fields
London WC2A 3PX
☎ Helpline: 0808 800 4040
9am-5pm Monday to Friday
Web: www.cancerresearchuk.org and www.cancerhelp.org.uk

Macmillan Cancer Support
89 Albert Embankment, London SE1 7UQ
☎ 020 7840 7840
Helpline: 0808 808 00 00
9am-8pm Monday to Friday
Web: www.macmillan.org.uk

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We hope that you have found the information helpful and relevant. We welcome any comments from readers, or suggestions for improvements. References or details of the research on which this publication is based, and details of any conflicts of interest, can be obtained from Crohn's and Colitis UK at the address below. Please send your comments to Helen Terry at Crohn's and Colitis UK, 4 Beaumont House, Sutton Road, St Albans, Herts, AL1 5HH, or email h.terry@crohnsandcolitis.org.uk

Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease (NACC). NACC is a voluntary Association, established in 1979, which has 30,000 members and 70 Groups throughout the United Kingdom.

Membership of the Association costs £12 a year. New members who are on lower incomes due to their health or employment circumstances may join at a lower rate. Additional donations to help our work are always welcomed.