CROHN'S & COLITIS UK

FIGHTING INFLAMMATORY BOWEL DISEASE **TOGETHER**

INFORMATION SHEET

BOWEL CANCER RISK

WHAT YOU NEED TO KNOW IF YOU HAVE CROHN'S OR COLITIS

INTRODUCTION

Crohn's and Colitis can increase the risk of bowel cancer in some people, particularly for those whose condition affects all or most of their large bowel.

The good news is that only a small number of people with Crohn's or Colitis will develop bowel cancer (also known as colorectal cancer), and the numbers have been declining in recent years. Cancer can be treated more successfully if diagnosed early – which is why regular checks are recommended for people with Crohn's or Colitis thought to be at greater risk. See **Who is at risk?**

This information sheet looks at the relationship between bowel cancer and Crohn's and Colitis, and how you can reduce your risk. It also describes changes in the lining of the bowel that may develop into cancer, and how these changes are detected.

CONTENTS

WHAT IS BOWEL CANCER?

Cancer starts when cells in our body go wrong and keep dividing and growing in an uncontrolled way. These abnormal cells can grow into surrounding tissues and organs and may spread to other parts of the body. Bowel cancer, also known as colorectal cancer, includes two types of cancer:

- **colon cancer** – cancer that starts in the colon (large bowel)
- **rectal cancer** – cancer that starts in the rectum (back passage)

Bowel cancer does not include anal cancer. Anal cancer is a different type of cancer with different risk factors – around 9 in 10 cases of anal cancer are linked to human papilloma virus (HPV) infection. You can find out more about anal cancer on the Cancer Research UK website: **cruk.org/about-cancer/anal-cancer**

WHAT ARE THE SYMPTOMS?

The symptoms of bowel cancer can be similar to those of Crohn's and Colitis, and include:

- bleeding from your bottom and/or blood in your poo
- long-lasting and unexplained changes in your bowel habit
- unexplained weight loss
- extreme tiredness or fatigue
- a pain or lump in your tummy

Most people with these symptoms don't have bowel cancer. You know your body, so if something doesn't feel right or you are concerned speak to your doctor.

WHO IS AT RISK?

There are a number of known risk factors linked to any cancer, including family history of cancer and smoking. If you have Crohn's or Colitis, there can be extra risks of bowel cancer.

Ulcerative Colitis
Ulcerative Colitis 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 Colitis
- how much of your large bowel is affected
- how severe your inflammation is.

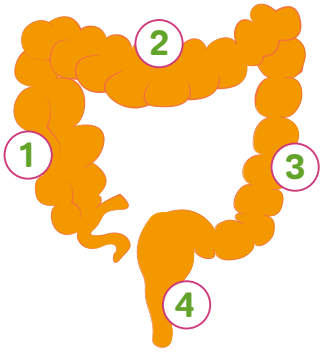
The risk of developing cancer usually begins to increase about 8-10 years after the start of your Ulcerative Colitis symptoms. This is not from the date of your diagnosis, which could be much later than when your symptoms started.

Your risk of cancer is highest if all, or most, of your colon is affected by Colitis (often referred to as extensive, total or pancolitis).

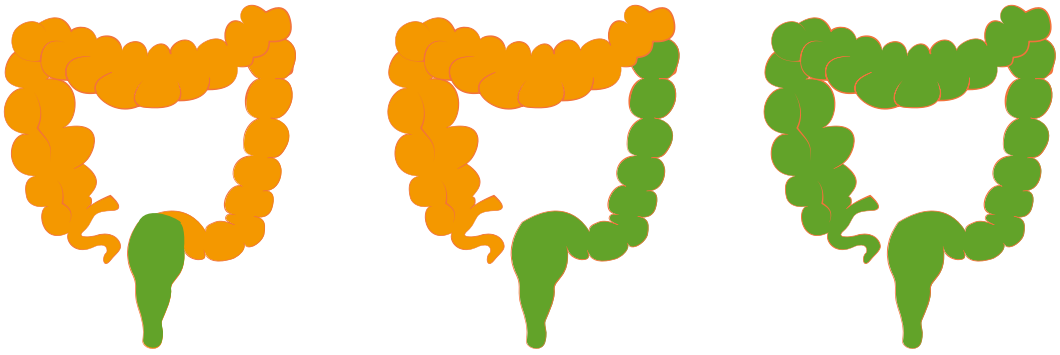
If only the left side of your colon is affected by Ulcerative Colitis (distal colitis), there is less risk of developing cancer than for those with total colitis.

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

1 ASCENDING COLON
2 TRANSVERSE COLON
3 DESCENDING COLON
4 RECTUM



MAIN TYPES OF ULCERATIVE COLITIS



PROCTITIS

LEFT–SIDED (DISTAL) COLITIS

TOTAL COLITIS

Microscopic Colitis
Microscopic Colitis is a condition that affects the bowel (the colon and rectum). Unlike Crohn's Disease and Ulcerative Colitis, inflammation of the bowel lining is only visible when tissue samples are viewed through a microscope. There is no additional risk of bowel cancer in people with Microscopic Colitis.

Crohn's Disease
Crohn's can affect any part of the digestive system from the mouth to the anus. The risk of cancer in people with Crohn's is less known.

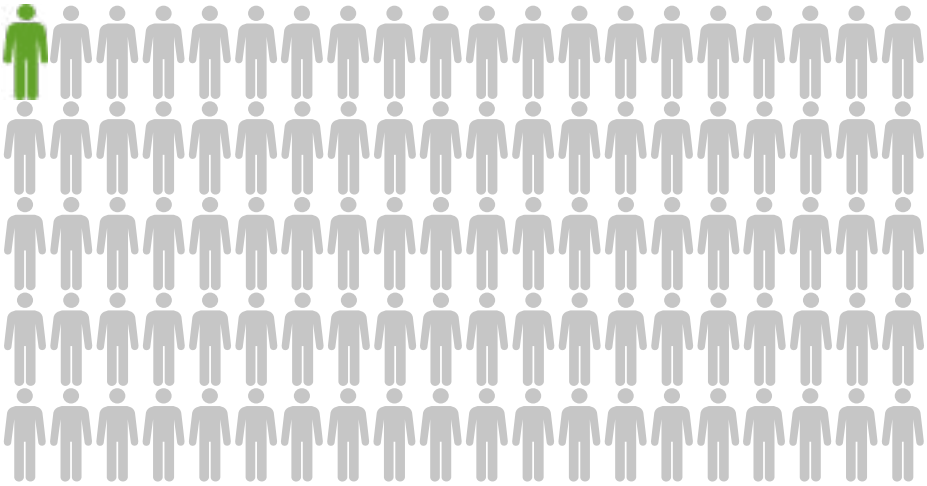
If you have Crohn's affecting all or much of the large colon (Crohn's Colitis), your risk of developing bowel cancer is about the same as for someone who has had Ulcerative Colitis affecting much of their large bowel for the same length of time.

WHAT IS THE RISK?

It is difficult to say what the actual risk of developing bowel cancer is if you have Crohn's or Colitis, because reports have had different findings.

However, in a recent study, it has been found that for people with disease affecting all or much of the large bowel, about one person in every 100 might be expected to develop cancer after 10 years. This risk increases to two people after 20 years and five people after more than 20 years.

RISK OF CANCER AFTER 10 YEARS OF SYMPTOMS:



1 IN 100 PEOPLE WITH ALL OR MOST OF THEIR BOWEL AFFECTED BY CROHN'S OR ULCERATIVE COLITIS

The number of people with Crohn's or Colitis and bowel cancer has declined in recent years. This drop in numbers could be due to more widespread use of medicines for Crohn's and Colitis which has perhaps led to fewer people having inflammation. See **Are there other risk factors?** below. There is better screening of Crohn's and Colitis by colonoscopy, which might also have led to this drop. See **What is a colonoscopy?** But there may also be other reasons for this decline which we don't yet fully understand.

ARE THERE OTHER RISK FACTORS?

Several other factors may increase your risk of bowel cancer:

- **Severity of inflammation**
  You may have an increased risk of cancer if you have severe ongoing inflammation. 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 don't have Crohn's or Colitis, 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.
- **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 one in 25 people with Ulcerative Colitis and up to one in 50 people with Crohn's. Your IBD team will tell you if you have this condition. Due to the increased risk of developing bowel cancer for people with Crohn's or Colitis and PSC, it is recommended that people with both conditions have a yearly surveillance colonoscopy from the time of diagnosis. See **Can I reduce this risk?**

- **Gender**
  Men with Crohn's or Colitis have been found to have a slightly higher chance of developing bowel cancer than women.

- **Age**
  The risk of bowel cancer is higher in people over the age of 50. As there is a greater risk of bowel cancer in some people with Crohn's or Colitis, even those under 50 should be aware of the symptoms.

CAN I REDUCE THE RISK?

You may be able to reduce your risk of developing bowel cancer by:

- **Taking regular medication**
  Long-term inflammation is linked to developing bowel cancer, so making sure that you're taking your medication regularly gives your bowel a chance to heal. This may mean the risk of developing bowel cancer is reduced.

  Taking azathioprine or 6-mercaptopurine might protect you from bowel cancer, particularly in those who have had disease for some time and been in remission with this drug. But some studies haven't found this effect, so more research needs to be done in this area.

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

- **Visiting your doctor regularly**
  Seeing your doctor at least once a year, even when your Crohn's or Colitis 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 as soon as you can.

- **Having regular colonoscopies**
  Regular colonoscopies (see **What is a colonoscopy?**) mean that specialists can look for early changes in the colon before cancer develops. This is known as a surveillance colonoscopy. If you've had Crohn's affecting the colon, or Colitis, for 8-10 years and have not recently had a colonoscopy, it's a good idea to contact your doctor or IBD team to discuss whether this would be appropriate for you. If you have Ulcerative Colitis and PSC, you will need to have annual surveillance colonoscopies from the date of diagnosis of PSC. See **How often should I have a colonoscopy?**

  If you have proctitis (inflammation of the rectum – the lower part of the large bowel) your risk is little or no greater than for the general population. You won't need surveillance colonoscopies unless your diagnosis changes.

> "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 eight years."
>
> Annie, age 62
> diagnosed with Ulcerative Colitis in 1980 and Cancer in 2010

CAN ANYTHING ELSE REDUCE THE RISK?

There are several things you can do to reduce your risk of bowel cancer:

- **Physical activity and a high fibre diet**
  Physical activity and a high-fibre diet can help to prevent bowel cancer. For information on being active see our booklet, **Living with Crohn's or Colitis**.

If you have Crohn's or Colitis and have problems with a high-fibre diet, speak to your IBD team, or ask to be referred to a dietitian.

- **Reducing how much processed and red meat you eat**
  A diet high in saturated fats and red meat may increase the risk of bowel cancer. If you eat more than 90g of red or processed meat a day, it's recommended that you reduce your intake to 70g a day.

  Red meat includes:
  - Beef
  - Lamb and mutton
  - Pork
  - Veal
  - Venison
  - Goat

  Processed meat includes:
  - Sausages
  - Bacon
  - Ham
  - Deli meats such as salami
  - Pates
  - Canned meat such as corned beef
  - Sliced luncheon meats, including those made from chicken or turkey.

  You can find more information on sizes and cutting down on red and processed meat on the NHS website:
  www.nhs.uk/live-well/eat-well/red-meat-and-the-risk-of-bowel-cancer

  There is more information about diet in our booklet: **Food.**

- **Limiting how much alcohol you drink, or avoiding it**
  Alcohol has been linked to an increased chance of developing seven types of cancer, including bowel cancer. To reduce your cancer risk, it's best not to drink alcohol at all. If you do drink alcohol, it's recommended that you drink no more than 14 units a week and you try to spread it out over at least three days. For more guidance on drinking alcohol, see the NHS website:
  www.nhs.uk/live-well/alcohol-support/calculating-alcohol-units

- **Stopping smoking**
  Smoking is another factor which is increasing bowel cancer risk in the general population. For help and advice on how to stop smoking, see NHS SmokeFree:
  www.nhs.uk/smokefree

  There is more information about smoking in our leaflet: **Smoking and IBD**.

- **Vitamin D supplements**
  Low blood levels of vitamin D have been linked to an increased risk of colon cancer. This has been seen in people with Crohn's and Colitis, and in the general population. More research needs to be done to really understand the link between vitamin D and colon cancer. If you have low levels of vitamin D taking a supplement may have other health benefits, such as strengthening the bones which may be weakened if you have Crohn's or Colitis. See our information sheet: **Bones**. Talk to your IBD team if you have questions about taking supplements.

"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."

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

WHAT IS A COLONOSCOPY?

> My first colonoscopy was without sedation and I found it very unpleasant. It put me off having another one. If I could go back and have my first colonoscopy again, I would definitely ask for sedation. It made such a difference for me.

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

You're probably familiar with colonoscopies, as they're regularly used to diagnose and assess the activity of Crohn's or Colitis. They're also the best way to detect bowel cancer.

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's inserted through the anus and back passage, and it's 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 **What is dysplasia?**).

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'll be asked to take a laxative either the evening before or the day of the test.

Some hospitals offer chromoendoscopy, which involves spraying special dyes onto the lining of the colon during the examination. 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 offered sedation to make you feel relaxed, which many people find makes the process easier. 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?

> 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

During a colonoscopy, the specialist will look for any abnormalities of the lining of the colon and rectum, including:

- how inflamed it is
- precancerous changes called dysplasia (see **What is dysplasia?**)
- polyps.

There are several different forms of polyps. The 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 **What is dysplasia?**).

- **Serrated polyps**
  These growths stick out of the surface of the colon or rectum and they are recognised by their saw-toothed appearance under a microscope. They can be difficult to find and can become cancerous. They may need to be removed.

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. Dysplasia is often recognised by the way it appears and whether it is raised or flat. Flat dysplasia is 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 in an endoscopy, then surgery to remove all or part of the colon may be required.

HOW OFTEN SHOULD I HAVE A COLONOSCOPY?

If you have Ulcerative Colitis or Crohn's Colitis, it is recommended that you have a colonoscopy 8 to 10 years after the start of your symptoms to see whether there have been changes in your colon. The exception is people with PSC and Ulcerative Colitis who should be enrolled in a surveillance programme from the time of diagnosis. It is best to have a surveillance colonoscopy done when your Crohn's or Colitis is not active.

It is recommended 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 Ulcerative Colitis, or have had dysplasia detected.

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's not possible to take samples of the whole lining of the bowel. Bowel cancer can also develop in people who do not have a prior history of dysplasia.

Having a colonoscopy is currently the best way 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, 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.

Having a colonoscopy isn't easy. 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?

For people aged 55
In England, the NHS has recently launched a screening programme inviting all 55 year olds for a 'one-off' bowel scope test that looks at the lower bowel and rectum. If you're registered with a GP and live in an area where the test is available, you'll automatically be sent an invitation. If you are being treated for your Crohn's or Colitis, you may not be able to have this test. Contact the NHS free bowel cancer screening helpline for further information. See **Other organisations** for details.

For people aged 60 to 74
The NHS has a bowel cancer screening programme for those between 60-74, 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.

If blood shows up in your stool in the FOB test, this may be due to your Crohn's or Colitis, rather than another condition. Blood in your stool can mean that there is inflammation in your bowel, even if you don't have any symptoms of diarrhoea or bleeding. If the inflammation is confirmed in a colonoscopy, treatment can be prescribed to heal the bowel.

If you receive an invite for the FOB test, it is worth telling them that you have Crohn's or Colitis and when your last colonoscopy was. They will be able to discuss whether the screening is necessary for you. You could also let your IBD team know that you have received an invite for bowel screening and they will be able to advise you further.

Other methods for detecting bowel cancer are being researched. For the time being 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.

"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

WHAT IF I AM DIAGNOSED WITH BOWEL CANCER?

Bowel cancer is treatable and curable particularly if diagnosed at an early stage. Because you'll be regularly assessed due to your Crohn's or Colitis, it's likely that if you develop cancer, it will be found early. Nearly everyone survives bowel cancer if diagnosed at the earliest stage, and there is only a small chance of the disease coming back after five years.

If you are diagnosed with bowel cancer, your healthcare team will discuss the benefits and risks of the different treatment options available. One of those options may be surgery, and possibly a stoma. See our **Living with a Stoma** leaflet for more information about this procedure.

If you would like more information on bowel cancer, diagnosis and treatment, see the websites for Bowel Cancer UK and/or Cancer Research UK. They offer additional services such as an email enquiry service to nurses, and a helpline, which might be helpful if you have questions. See **Other organisations** for further details.

RISK OF SMALL BOWEL CANCER

Small bowel (small intestine) cancer is a rare type of cancer and is different to the more common bowel (colorectal) cancer. People with Crohn's have an increased risk of developing small bowel cancer if they have disease affecting most of their small bowel and have had symptoms for more than 10 years. Even with an increased risk, the risk is still very small. It's not possible to screen for small bowel cancer using endoscopy (unlike with bowel cancer). Speak to your IBD team if you're worried that you may be at an increased risk of developing small bowel cancer. Your IBD team will keep a check on whether you develop any new symptoms, particularly if you suddenly become unwell after a long period of good health, or if you stop responding to treatment. Let your IBD team know if you develop any symptoms that could mean you have a blockage (obstruction) in your gut, such as feeling sick (nausea), vomiting and tummy pain. While this can be worrying, remember that these are also common symptoms of Crohn's - and it's much more likely that your Crohn's is making you unwell.

HELP AND SUPPORT FROM CROHN'S & COLITIS UK

We're here for you whenever you need us. Our award-winning publications on Crohn's Disease, Ulcerative Colitis, and other forms of Inflammatory Bowel Disease have the information you need to help you manage your condition.

All publications are available to download from:
crohnsandcolitis.org.uk/publications

Health professionals can order booklets in bulk by using our online ordering system accessed through the link above.

If you would like a printed copy of a booklet or information sheet, please contact our Helpline - a confidential service providing information and support to anyone affected by Crohn's and Colitis.

Our team can:

- help you understand more about Crohn's or Colitis, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- help you to find support from others living with the condition

Call us on **0300 222 5700** or email **helpline@crohnsandcolitis.org.uk**

See our website for LiveChat: **crohnsandcolitis.org.uk/livechat**

Crohn's & Colitis UK Forum
This closed-group community on Facebook is for everyone affected by Crohn's and Colitis. You can share your experiences and receive support from others at:
facebook.com/groups/CCUKforum

Help with toilet access when out and about
If you become a member of Crohn's & Colitis UK, you will get benefits including a Can't Wait Card and a Radar key to unlock accessible toilets. This card shows that you have a medical condition, and combined with the Radar key will help when you need urgent access to the toilet when you are out and about. See our website for further information: **crohnsandcolitis.org.uk/membership** or call the membership team on: **01727 734465**.

OTHER ORGANISATIONS

Bowel Cancer UK
020 7940 1760
Email: nurse@bowelcanceruk.org.uk
bowelcanceruk.org.uk
Scotland: 0131 281 7351
Email: scotadmin@bowelcanceruk.org.uk

Cancer Research UK
Helpline: 0808 800 4040
cancerresearchuk.org

Macmillan Cancer Support
020 7840 7840
Helpline: 0808 808 00 00
macmillan.org.uk

NHS Bowel Cancer Screening Programme
England: 0800 707 60 60
Scotland: 0800 0121 833
Wales: 0800 294 3370
Northern Ireland: 0800 015 2514
nhs.uk/bowel

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ABOUT CROHN'S & COLITIS UK

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. To improve diagnosis and treatment, and to fund research into a cure, to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.

This publication is available for free thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis: call **01727 734465** or visit **crohnsandcolitis.org.uk**.

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