

**UNDERSTANDING  
CROHN'S AND COLITIS**



## INTRODUCTION

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# ABOUT THIS BOOKLET

Being told you have Crohn's or Colitis can be a shock. You might be feeling anxious about what comes next and how your life will change.

Because it will change. But it can also improve. Now that you've put a name to your symptoms, you can start to manage them. And we're here to help, every step of the way.

This booklet is a brief introduction to Crohn's Disease and Ulcerative Colitis for anyone affected by these conditions, including families and friends. More detailed information is available from our website.

All our publications are research-based and produced in consultation with patients, medical advisers and other health or associated professionals. They are prepared as general information on a subject and are not intended to replace specific advice from your doctor or any other professional. Crohn's & Colitis UK does not endorse or recommend any products mentioned.

If you would like more information about the sources of evidence on which this booklet is based, or details of any conflicts of interest, or if you have any feedback on our publications, please contact **publications@crohnsandcolitis.org.uk**.

### **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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## WHAT ARE CROHN'S AND COLITIS?

**Crohn's Disease and Ulcerative Colitis are types of Inflammatory Bowel Disease, often collectively referred to as IBD.**

In both conditions, parts of the digestive system become swollen, inflamed and ulcerated. There are some differences in the two conditions, mainly in the areas affected and the depth of inflammation.

If it's unclear which of the two conditions you have, you may be given a diagnosis of IBDU (IBD Unclassified) or Indeterminate Colitis.

The illustration below shows the areas that may be affected.

### CROHN'S DISEASE



**Crohn's Disease** may affect any part of the digestive system from mouth to anus. All layers of the lining of the bowel may be inflamed.

**Ulcerative Colitis** affects the large intestine, which is made up of the rectum and colon. Only the inner lining of the bowel is inflamed.

### ULCERATIVE COLITIS



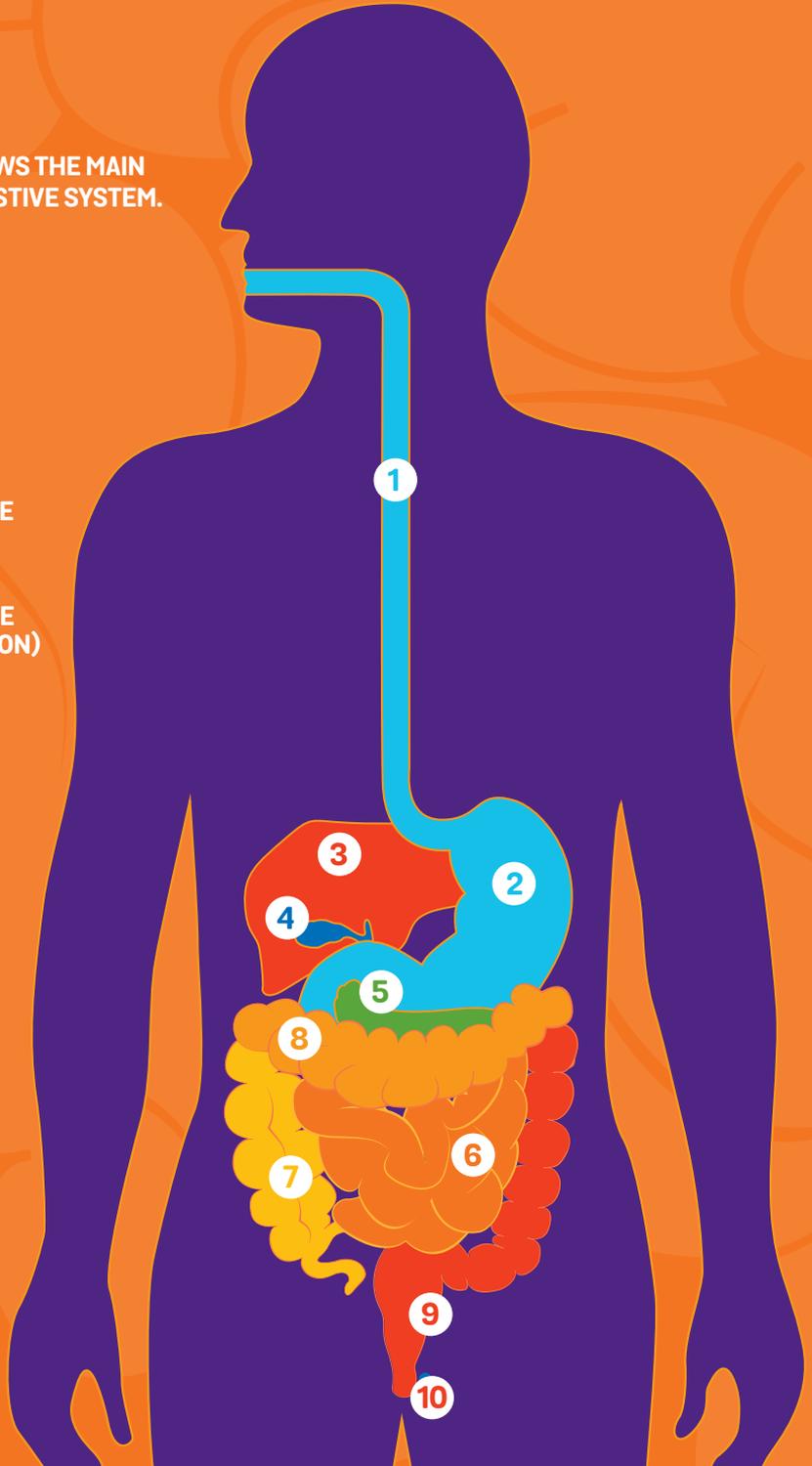
If Crohn's affects only the colon it may be called Crohn's Colitis.

When Colitis affects only the rectum it is often called proctitis.

## THE DIGESTIVE SYSTEM

THIS DIAGRAM SHOWS THE MAIN PARTS OF THE DIGESTIVE SYSTEM.

- 1 OESOPHAGUS
- 2 STOMACH
- 3 LIVER
- 4 GALL BLADDER
- 5 PANCREAS
- 6 SMALL INTESTINE
- 7 END OF ILEUM
- 8 LARGE INTESTINE (INCLUDING COLON)
- 9 RECTUM
- 10 ANUS



## WHAT ARE THE MAIN SYMPTOMS?

With both conditions, common symptoms can include:

- cramping pains in the abdomen
- diarrhoea, which sometimes includes blood and mucus
- loss of appetite and weight loss
- tiredness and fatigue

Crohn's and Colitis can often lead to anaemia, a reduced number of red blood cells, which can also make you feel very tired.

Some people experience swollen joints, mouth ulcers, and eye, skin and liver problems. You are also more likely to develop osteoporosis (thinner bones) if you have IBD.

Crohn's can cause anal problems such as fissures, which are cracks or splits in the skin, and ulcers. Sometimes inflammation spreads through the bowel wall and forms a collection of pus known as an abscess. As the abscess develops it may 'hollow out' a chamber or hole, which can become a fistula - a channel or passageway linking the bowel to another loop of bowel, another organ, or the outside skin. See our information sheet **Living With a Fistula** for more details.

Not everyone will experience all these symptoms, and how you are affected can also change over time.

**Crohn's and Colitis are as chronic conditions, meaning they are ongoing and life-long. You will probably have periods of good health known as remission when you feel a lot better, as well as relapses or flare-ups when your symptoms are more active.**

At present there is no cure for Crohn's or Colitis, but drugs and sometimes surgery can give long periods of relief from symptoms. Research, including work funded by Crohn's & Colitis UK, is continuing into new treatments to improve patients' quality of life and eventually find a cure. Visit [crohnsandcolitis.org.uk/research](http://crohnsandcolitis.org.uk/research) to find out more.

“

I have had many ups and downs since my diagnosis of Crohn's Disease, but I've now been in remission for 3 years and I'm living life to the full. I have found that there is hope even in the dark times! ”

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**Glenda**, age 36,  
diagnosed with Crohn's  
Disease in 2012

## WHAT CAUSES CROHN'S AND COLITIS?

Although there has been a lot of research, we do not know exactly what causes IBD. However, over the past few years major advances have been made, particularly in genetics.

**Researchers now believe that both Crohn's and Colitis are caused by a combination of factors:**



Viruses, bacteria, diet, smoking and stress have all been suggested as environmental triggers, but there is no definite evidence that any one of these is the cause of IBD.

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## WHO IS AFFECTED BY THESE ILLNESSES?

**At least 300,000 people in the UK have Ulcerative Colitis or Crohn's Disease – about 1 person in 210.**

These illnesses can occur at any age, but most frequently start in people aged between 10 and 40. Recent surveys suggest that Crohn's is becoming increasingly common, especially among young people. Both conditions are found worldwide, but are more common in developed countries.

## IS IBD THE SAME AS IBS?

No. IBS stands for Irritable Bowel Syndrome. This is a different condition, although some of the symptoms are similar. Like IBD, IBS can cause abdominal pain, bloating and bouts of diarrhoea or constipation. However, it does not cause the type of inflammation typical of Crohn's or Colitis, and there is no blood loss with IBS.

Some people with Crohn's or Colitis develop IBS-like symptoms. They may, for example, get diarrhoea even when their IBD is inactive. These symptoms may need slightly different treatment from their usual IBD symptoms.

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## HOW ARE THE CONDITIONS DIAGNOSED?

It can often take time to confirm a diagnosis of Crohn's or Colitis, as it may be necessary to exclude other diseases. Blood tests are the usual first step – these can check for general signs of inflammation, anaemia, and vitamin and mineral deficiencies. Stool tests can be used to rule out infections that may be causing symptoms such as diarrhoea, and to look for raised levels of proteins that can be a sign of active inflammation.

Blood and stool tests cannot confirm a diagnosis of IBD, so most people will also need an examination of the bowel. One way to do this is an endoscopy – an examination using a long, thin tube with a camera in its tip known as an endoscope.

There are several types of endoscopy. In a colonoscopy, the endoscope is inserted through the anus so the doctor or specialist endoscopist can look at the lining of the colon. If Crohn's Disease is suspected, you may have a gastroscopy in which a tube is passed through the mouth. Tiny samples of tissue known as biopsies can be taken during the endoscopy. These can then be examined under a microscope to help confirm the diagnosis.

Ultrasound, CT and MRI scans are also increasingly used to look at the location and extent of any inflammation. More details of all these tests can be found in our information sheet **Tests and Investigations for IBD**.

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“

I found the prep for the colonoscopy tough. The procedure itself wasn't all that bad. I was more relieved that I might finally be getting some answers.”

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**Katryna**, age 36,  
diagnosed with Ulcerative  
Colitis in 2005

## HOW IS ULCERATIVE COLITIS TREATED?

Treatment for Colitis depends on how severe the symptoms are and how much of the colon is affected by inflammation.

Initially, especially if your Colitis is quite mild, you will probably be treated with aminosalicylates, also known as 5-ASA drugs, such as mesalazine or sulphasalazine. You may also be given steroids. These drugs help reduce inflammation in the gut. Once the active inflammation has settled down, 5-ASAs are usually prescribed as long-term maintenance therapy to reduce the chance of a flare-up.

Immunosuppressant drugs, such as azathioprine or mercaptopurine, may be prescribed for people who continue to have frequent flare-ups or ongoing symptoms. They are often used in patients who relapse when they come off steroids.

For more severe Colitis, treatment with steroids given intravenously (directly into a vein through a drip) may be necessary. If this does not work, you may be given another immunosuppressant called ciclosporin. Biologic drugs such as infliximab, adalimumab, golimumab and vedolizumab are also used in people who have not responded to previous therapies. You can find more information about all these treatments in our specific **drug treatment information sheets**.

If the disease is very severe and is not responding to drug therapy, your doctor may suggest surgery to remove part or all of the large bowel. This can mean having an ileostomy and a stoma bag. It may be possible to create an internal pouch after a period of time, so that the stoma is removed. For more information on these operations, see our leaflet **Surgery for Ulcerative Colitis**. You may also wish to read our **Living With a Stoma** leaflet.

Although the idea of bowel surgery can be daunting, many people find they can cope better with a stoma or a pouch than with the UC symptoms they were experiencing. There will usually be time for you to discuss your options with the surgeon and your IBD team. You may find it helpful to talk to a colorectal or stoma care nurse.



“

Azathioprine has made my immune system weaker so I can feel run down, but overall this drug has been great for me. It has got me into remission. ”

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**Louise**, age 34,  
diagnosed with Ulcerative  
Colitis in December 2013

## HOW IS CROHN'S DISEASE TREATED?

Treatment for Crohn's depends on which part and how much of the gut is affected. Active inflammation is usually treated with steroid drugs that reduce the swelling and the pain of inflammation. Less often, mild inflammation may be treated with 5-ASAs such as mesalazine or sulphasalazine. Immunosuppressants such as azathioprine, mercaptopurine or methotrexate may be used for more persistent Crohn's.

Biologic drugs such as infliximab, adalimumab, vedolizumab and ustekinumab are available for more severe Crohn's Disease that has not responded to previous treatments. For more details, see our specific **drug treatment information leaflets**.

In children, another way to treat a Crohn's flare-up is with enteral nutrition – a specially formulated liquid diet that can be taken instead of food, usually for up to eight weeks. In adults, this type of liquid food is more likely to be prescribed as a supplement.

Crohn's can sometimes cause blockages due to inflammation or scarring in the intestines. If medical treatment is not effective in resolving blockages, surgery may be suggested. In an operation called a resection, severely inflamed or scarred sections of intestine are removed, and the healthy ends joined together.

Some people may have a stricture or narrowing of the intestine. This can often be treated with a strictureplasty operation in which the intestine is surgically widened or stretched.

Occasionally, for severe Crohn's in the colon that is not responding to drug treatment, surgery to remove the whole colon may be recommended. You would then have an ileostomy or stoma, as described earlier. More information can be found in our leaflet **Surgery for Crohn's Disease**. You may also wish to read our **Living With a Stoma** leaflet.



### RESEARCH FACT

Crohn's is more likely to occur in people who smoke, and stopping smoking can reduce the severity of Crohn's.

“

Since my surgery I barely get pain, and I don't have to worry about things like eating, going out, or being far from a toilet.”

Kate, age 29, diagnosed with Crohn's Disease in 2004

## HOW IS MICROSCOPIC COLITIS TREATED?

There is less guidance on how to manage Microscopic Colitis. More than 1 in 3 people with Microscopic Colitis find that their symptoms stop without the need for treatment. It could help to eliminate factors that could be contributing to diarrhoea, such as certain medications like aspirin, as well as lifestyle factors such as consuming alcohol, caffeine and dairy products, and smoking.

Antidiarrhoeal drugs such as loperamide (including the Imodium brand) may be effective, as can steroid treatment for people with more severe disease. For more details, see our information sheet on **Microscopic Colitis**.



“

One thing I've learned is that you can't go through it alone. Having a strong support network is key; friends, family and organisations like Crohn's and Colitis UK are invaluable. You can get through anything if you let people help you.”

**Mathew**, age 32, diagnosed with Crohn's Disease in 2000

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## HOW WILL CROHN'S AND COLITIS AFFECT MY LIFE?

**There is no single answer to this question because people's experiences with IBD vary so widely.**

Some people will have mild Crohn's or Colitis that does not affect their lives very much. Others may have severe symptoms and may need to adjust their lifestyles considerably.

While many people's symptoms can be controlled with medication, about 2 in 10 people with Colitis may need surgery at some stage. 1 in 5 people with Crohn's will have surgery within 5 years of disease, and 1 in 4 within 10 years.

Our booklet **Living With Crohn's or Colitis** looks at some of the challenges of everyday life with IBD. We also have more detailed booklets on both **Crohn's Disease** and **Ulcerative Colitis**, and information sheets on a wide range of other IBD-related topics.

You are likely to see your GP and specialist doctor on a fairly regular basis if you have IBD. Our booklet **My Crohn's and Colitis Care** has some suggestions on what you should expect, and how to get the most from your time with health professionals.

## HOW IMPORTANT IS MY DIET?

A healthy balanced diet is important for everyone. Our booklet **Food** gives details of the Eatwell Plate approach to healthy eating and how this can be adapted by people with IBD.

There is no evidence to suggest that special food supplements are needed by most people with Crohn's or Colitis. However, some people can develop specific dietary deficiencies due to difficulty in absorbing particular nutrients, and supplements can be useful to correct these. Also, blood loss during an IBD flare-up can lead to anaemia, which may need to be treated with extra iron.

Some people with Crohn's or Colitis may find they are sensitive to certain foods. Keeping a food diary may help to identify the foods that affect you most. Fibre can be a particular problem. You may need to adjust your fibre intake, either reducing it or increasing it, according to your individual condition. Spicy foods can also be a trigger for some people. If you have a stricture, you may need to avoid eating foods that are hard to digest, because they might cause a blockage.

**It is important to keep your diet well-balanced, so talk to your doctor or a qualified dietitian before making any major changes.**

More information on these points is also given in our booklet on **Food**.

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“

Keeping an eye on my emotional state is almost as important as monitoring my physical symptoms. I didn't get help for many years, but when I finally did I realised just how important it is to look after mental health when dealing with such a complex condition. ”

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**Kate**, age 29,  
diagnosed with Crohn's  
Disease in 2004

## WHO CAN I TALK TO?

It can be helpful to build a good relationship with both your GP and your hospital IBD team. IBD specialist nurses can be especially supportive. Being open and frank about your symptoms and how they affect you, emotionally as well as physically, will make it easier for your doctors and nurses to make sure you get the right treatment. It can also make you feel more confident about managing your IBD.

**Some people with Crohn's or Colitis feel embarrassed talking about their symptoms, even with their doctor. Remember that medical professionals are very used to discussing all bodily functions.**

Having a long-term illness such as IBD can sometimes have a serious impact on emotional wellbeing, and some people find it helpful to talk to a professional counsellor. There may be one available through your GP's practice, or you can ask your IBD team or a social worker at your hospital. Our information sheet **Counselling and IBD** has more details on how counselling may help and how to find a therapist.

Crohn's and Colitis Support is a listening service for anyone who needs to talk about living with Crohn's or Colitis. It's provided by volunteers who have personal experience of these conditions. Call 0300 222 5700 to find out more and make an appointment.

Many people with IBD find that our Local Networks are a valuable way to meet other people with the same condition. You can join Crohn's & Colitis UK using the application form in this booklet or online at [crohnsandcolitis.org.uk/membership](http://crohnsandcolitis.org.uk/membership).

## HOW WE CAN HELP YOU

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.

We have information on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships, school and employment. We'll help you find answers, access support and take control.

All publications are available to download from [www.crohnsandcolitis.org.uk/publications](http://www.crohnsandcolitis.org.uk/publications). If you would like a printed copy, please contact our helpline.

Our helpline is a confidential service providing information and support to anyone affected by Inflammatory Bowel Disease.

Our team can:

- help you understand more about IBD, 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
- put you in touch with a trained support volunteer who has a personal experience of IBD

Call us on **0300 222 5700** or email [helpline@crohnsandcolitis.org.uk](mailto:helpline@crohnsandcolitis.org.uk)

See our website for Live Chat:  
[www.crohnsandcolitis.org.uk/livechat](http://www.crohnsandcolitis.org.uk/livechat)

## OTHER USEFUL ORGANISATIONS

**Bladder and Bowel Community**  
[www.bladderandbowel.org](http://www.bladderandbowel.org)

**Colostomy Association**  
[www.colostomyassociation.org.uk](http://www.colostomyassociation.org.uk)

**Crohn's in Childhood Research Association**  
[www.cicra.org](http://www.cicra.org)

**IA – The Ileostomy and Internal Pouch Support Group**  
[www.iasupport.org](http://www.iasupport.org)

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