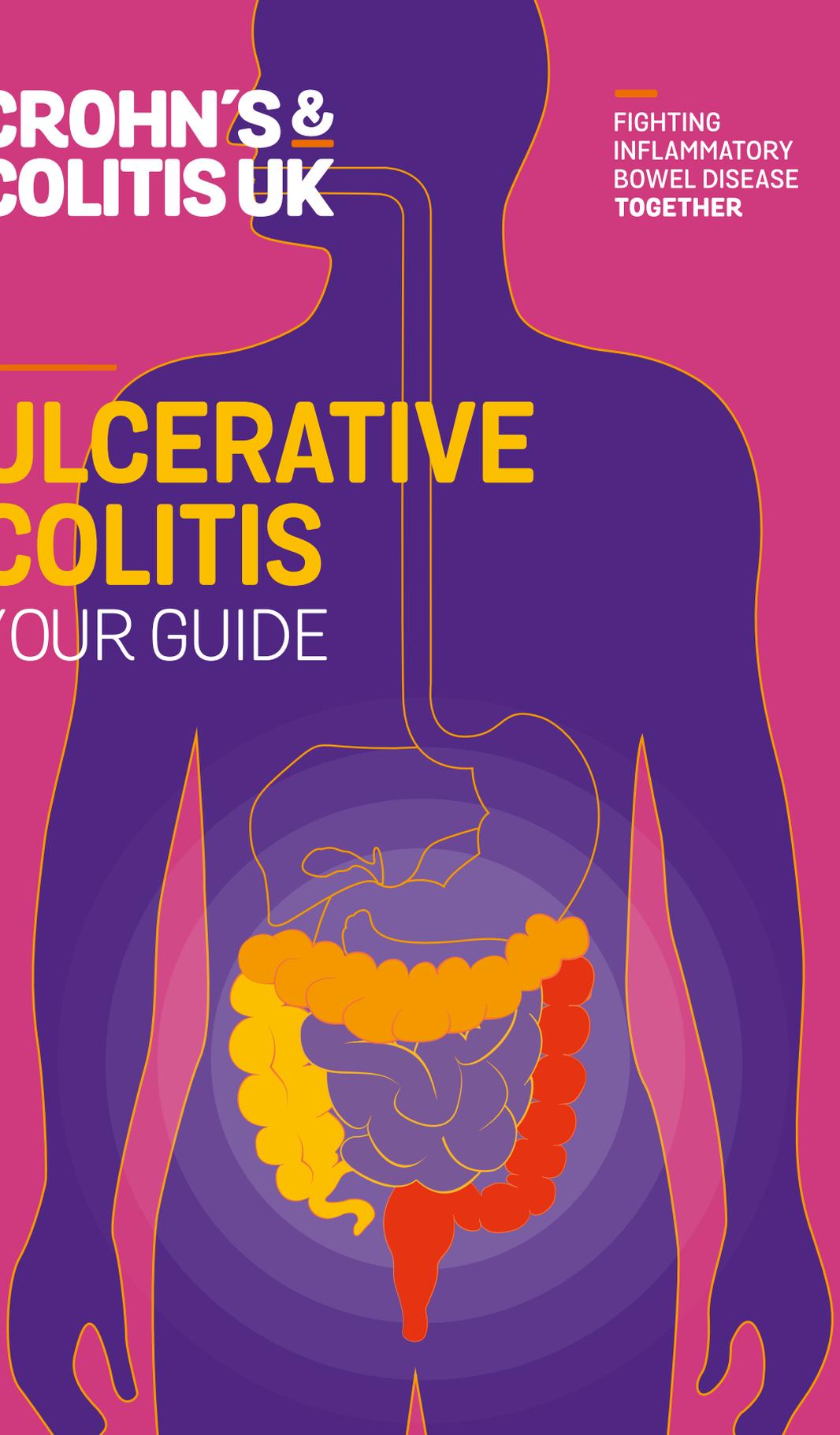


**CROHN'S &  
COLITIS UK**

**FIGHTING  
INFLAMMATORY  
BOWEL DISEASE  
TOGETHER**

**ULCERATIVE  
COLITIS**  
YOUR GUIDE



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## ABOUT THIS BOOKLET

If you have recently been diagnosed with Ulcerative Colitis (UC) or even if you have had UC for some time, you may have many questions about the condition. Knowing more about your UC can help you to feel better informed and able to take a more active part in decisions about your treatment. We hope this booklet will give you and your family and friends a better understanding of Ulcerative Colitis and how it is treated.

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

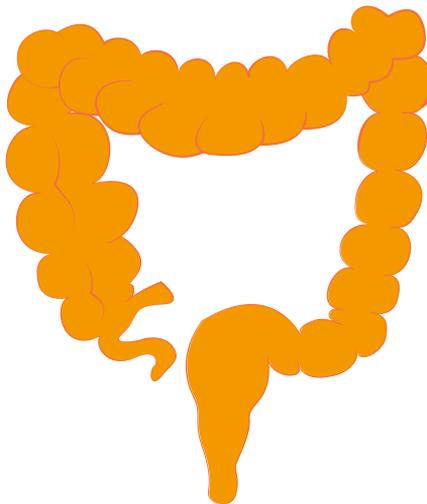
### **About Crohn's and Colitis UK**

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](http://www.crohnsandcolitis.org.uk)**

## CONTENTS

<hr/>	
<b>1. Ulcerative Colitis</b>	
What is Ulcerative Colitis?	04
What causes Ulcerative Colitis?	05-06
How does Ulcerative Colitis affect the gut?	07
What are the main symptoms?	08
How common is Ulcerative Colitis?	09
What are the main types of Ulcerative Colitis?	11-12
Can Ulcerative Colitis affect other parts of the body?	13-16
Can Ulcerative Colitis lead to bowel cancer?	17
<hr/>	
<b>2. Diagnosis, Tests and Treatment</b>	
How is Ulcerative Colitis diagnosed?	18-19
Will I need repeated tests?	20
Could my symptoms be Irritable Bowel Syndrome?	20
What treatments are there for Ulcerative Colitis?	20
What drugs are used to treat Ulcerative Colitis?	21-22
What about surgical treatment for Ulcerative Colitis?	23-26
<hr/>	
<b>3. Living with Ulcerative Colitis</b>	
Do I need to change my diet?	27-28
What about complementary and alternative approaches?	29
What about pregnancy and Ulcerative Colitis?	30-31
Does Ulcerative Colitis run in families?	31
How does Ulcerative Colitis affect children and young people?	32
How will Ulcerative Colitis affect my life?	33
Help and support from Crohn's and Colitis UK	34
Other useful organisations	34





“

Life is difficult with UC with so many flare-ups and medicines but I am keeping up with it. ”

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Ahad, age 13,  
diagnosed in 2015

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**WHAT IS ULCERATIVE COLITIS?**

Ulcerative Colitis (UC) is a condition that causes inflammation and ulceration of the inner lining of the rectum and colon (the large bowel). Inflammation is the body's reaction to injury or irritation, and can cause redness, swelling and pain. In UC, tiny ulcers develop on the surface of the lining and these may bleed and produce pus.

The inflammation usually begins in the rectum and lower colon, but it may affect the entire colon. If UC only affects the rectum, it is called proctitis.

**ULCERATIVE COLITIS IS ONE OF THE TWO MAIN FORMS OF INFLAMMATORY BOWEL DISEASE, SO MAY ALSO BE CALLED 'IBD'. THE OTHER MAIN FORM OF IBD IS A CONDITION KNOWN AS CROHN'S DISEASE.**



**FACT**

**ULCERATIVE COLITIS IS NOT INFECTIOUS**

UC is sometimes described as a chronic condition. This means that it is ongoing and life-long, although you may have long periods of good health (remission), as well as times when your symptoms are more active (relapses or flare-ups).

## WHAT CAUSES ULCERATIVE COLITIS?

Although there has been a lot of research, we still don't really know what causes Ulcerative Colitis. However, over the past few years, major advances have been made, particularly in genetics.

.....

## RESEARCHERS NOW BELIEVE THAT ULCERATIVE COLITIS IS CAUSED BY A COMBINATION OF FACTORS:

**THE GENES A PERSON HAS INHERITED**

**+**

**AN ABNORMAL REACTION OF THE IMMUNE SYSTEM (THE BODY'S PROTECTION SYSTEM AGAINST HARMFUL SUBSTANCES) TO CERTAIN BACTERIA IN THE INTESTINES**

**+**

**PROBABLY TRIGGERED BY SOMETHING IN THE ENVIRONMENT**

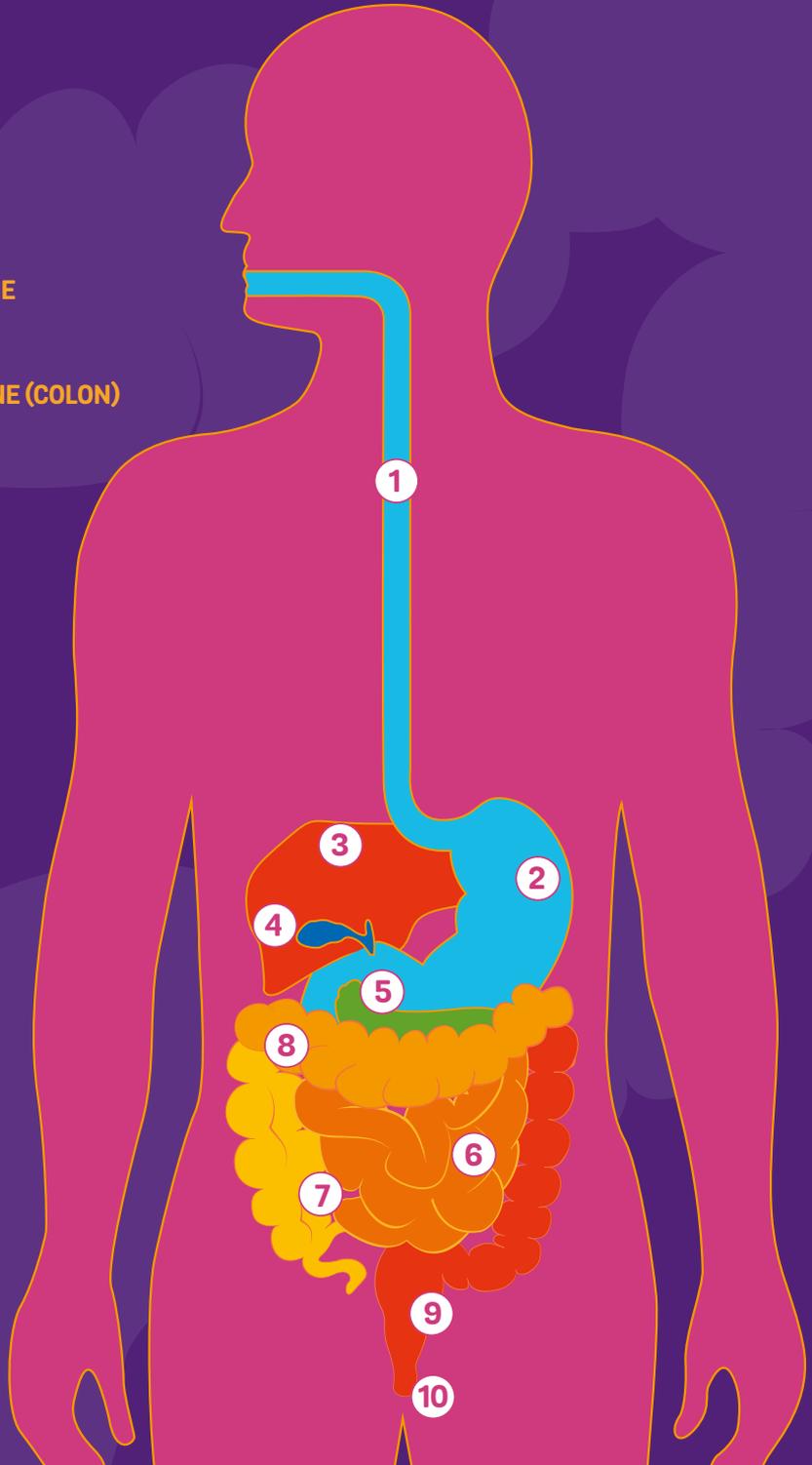
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Viruses, bacteria, diet and stress have all been suggested as environmental triggers, but there is no definite evidence that any one of these factors is the cause of UC.

## ULCERATIVE COLITIS

### THE DIGESTIVE SYSTEM

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



## HOW DOES ULCERATIVE COLITIS AFFECT THE GUT?

As you can see from the diagram, the gut (digestive system) is like a long tube that starts at the mouth and ends at the anus.

When we eat, the food goes down the oesophagus into the stomach, where gastric (digestive) juices break it down to a porridge-like consistency. The partly-digested food then moves into the small intestine (also known as the small bowel). Here it is broken down even further so that nutrients (useful parts of food) can be absorbed into the bloodstream through the wall of the intestine. The waste products from this process – liquid and undigested parts of food – are then pushed into the colon (also known as the large intestine or large bowel). The colon absorbs the liquid, and the left over waste forms solid faeces (stools). These collect in the last part of the colon and the rectum until they are passed out of the body through the anus in a bowel movement.

## **IN UC, PARTS OF THE COLON AND/OR RECTUM BECOME INFLAMED AND SORE. TINY ULCERS CAN DEVELOP ON THE COLON LINING AND THESE CAN BLEED OR PRODUCE PUS.**

The inflamed colon is less able to absorb liquid and this can lead to a larger volume of watery stools. Also, because the colon cannot hold as much as usual, you may have very frequent bowel movements (six or more a day).



## WHAT ARE THE MAIN SYMPTOMS?

### ULCERATIVE COLITIS SYMPTOMS MAY RANGE FROM MILD TO SEVERE AND WILL VARY FROM PERSON TO PERSON.

They may also change over time, with periods of good health when you have few or no symptoms (remission), alternating with times when your symptoms are more active (relapses or 'flare-ups').

Ulcerative Colitis (UC) is a very individual condition – some people can remain well for a long time, even for many years, while others have frequent flare-ups.

**Your symptoms may vary according to the extent and severity of the inflammation, but the most common symptoms during a flare-up are:**

- **Diarrhoea.** This is often with blood, mucus and pus.
- **Cramping pains in the abdomen.** These can be very severe and often occur before passing a stool.
- **Tiredness and fatigue.** This can be due to the illness itself, from anaemia (see below), or from a lack of sleep if you have to keep getting up at night with pain or diarrhoea.
- **Feeling generally unwell.** Some people may feel feverish.
- **Loss of appetite and loss of weight.**
- **Anaemia (a reduced number of red blood cells).** You are more likely to develop anaemia if you are losing a lot of blood and are not eating well. Anaemia can also make you feel very tired.

## ULCERATIVE COLITIS

### HOW COMMON IS ULCERATIVE COLITIS?

**IT IS ESTIMATED THAT ULCERATIVE COLITIS AFFECTS ABOUT ONE IN EVERY 420 PEOPLE IN THE UK.**

It's more common in urban rather than rural areas and in northern developed countries, although the numbers are beginning to increase in developing nations. Ulcerative Colitis (UC) is also more common in white people of European descent, especially those descended from Ashkenazi Jews (those who lived in Eastern Europe and Russia).

UC affects women and men equally. It tends to develop more frequently in non-smokers and ex-smokers than smokers. However, health professionals consider the risks of smoking heavily outweigh any benefits seen in UC, and strongly discourage smoking in everyone, whether or not they have Inflammatory Bowel Disease. For more details see our information sheet **Smoking and IBD**.



### RESEARCH FACT

**ULCERATIVE COLITIS CAN START AT ANY AGE, BUT IT IS RARE IN CHILDREN UNDER FIVE, AND OFTEN APPEARS FOR THE FIRST TIME BETWEEN THE AGES OF 15 AND 25.**





“

I try not to let my UC affect my social life but it can be hard because I'm always thinking 'am I going to be well enough' or 'where is the nearest toilet.' ”

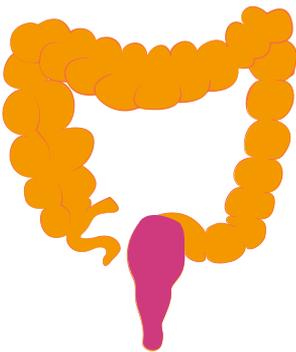
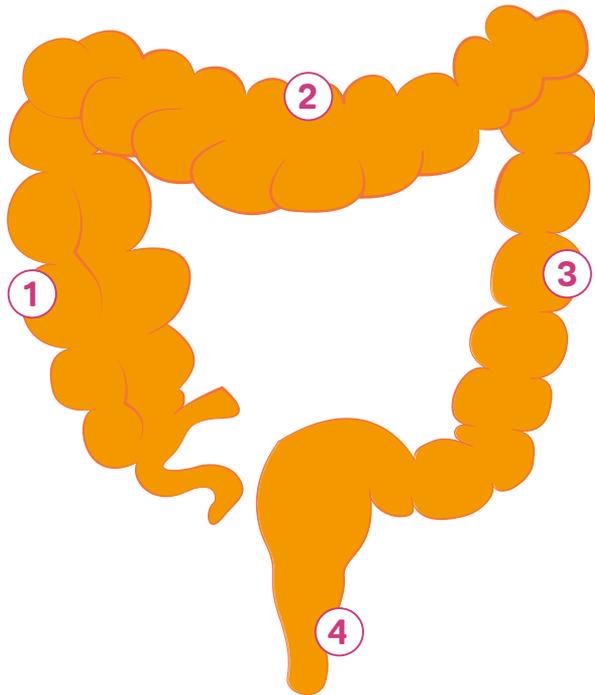
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Louise, age 34,  
diagnosed with UC in 2013

## WHAT ARE THE MAIN TYPES OF ULCERATIVE COLITIS?

Ulcerative Colitis (UC) is generally categorised according to how much of the colon is affected. The diagram below shows the three main types: proctitis, left-sided or distal colitis, and extensive or total colitis.

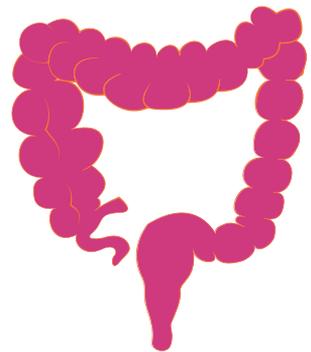
- 1 ASCENDING COLON
- 2 TRANSVERSE COLON
- 3 DESCENDING OR DISTAL COLON
- 4 ANUS



PROCTITIS



LEFT-SIDED  
(DISTAL) COLITIS



TOTAL COLITIS

## ULCERATIVE COLITIS

### PROCTITIS

In proctitis, only the rectum is inflamed. This means that the rest of the colon is unaffected and can still function normally. For many people with proctitis the main symptom is passing fresh blood, or blood stained mucus. You may get diarrhoea, or you may have normal stools or even constipation. You may also feel an urgent need to rush to the toilet. Some people with proctitis often feel that they have an urge to pass a stool, but cannot pass anything because the bowel is actually empty. This is called tenesmus. In some people, the sigmoid colon (the short curving piece of colon nearest the rectum) may also be inflamed – a form of UC sometimes known as proctosigmoiditis. The symptoms are similar to those of proctitis, although you are less likely to have constipation with proctosigmoiditis.

### LEFT-SIDED (OR DISTAL) COLITIS

In this type of UC the inflammation starts at the rectum and continues up the left side of the colon (also known as the distal or descending colon). Symptoms include diarrhoea with blood and mucus, pain on the left hand side of the abdomen, urgency, and tenesmus.

### EXTENSIVE AND TOTAL COLITIS

Extensive colitis extends along most of the colon. Extensive colitis that affects the whole colon may be called total colitis or pancolitis. Extensive or total colitis can cause very frequent diarrhoea with blood, mucus, and sometimes pus. You may also have severe abdominal cramps and pain, tenesmus, and weight loss. In milder flare-ups the main symptom may be diarrhoea or looser stools without blood.

Very rarely, when the inflammation is severe, digestive gases may get trapped in the colon, making it swell up. This is known as toxic megacolon and it can cause a high fever as well as pain and tenderness in the abdomen. It is essential to get treatment quickly for this condition, as it may need surgery.



## CAN ULCERATIVE COLITIS AFFECT OTHER PARTS OF THE BODY?

**ULCERATIVE COLITIS (UC) CAN CAUSE COMPLICATIONS (EXTRA PROBLEMS) OUTSIDE THE DIGESTIVE SYSTEM. OVER A THIRD OF PEOPLE WITH ULCERATIVE COLITIS DEVELOP OTHER CONDITIONS, MAINLY AFFECTING THE JOINTS, EYES AND SKIN.**

.....

These often occur during active disease, but they can develop before any signs of bowel disease or during times of remission. Ulcerative Colitis (UC) may also lead to a loss of bone density, mouth ulcers, liver problems, an increased risk of blood clots, and anaemia.

### JOINTS

Inflammation of the joints, known as arthritis, affects about one out of 10 people with UC. The inflammation usually affects the large joints in the arms and legs, including elbows, wrists, knees and ankles. Fluid collects in the joint space causing painful swelling, although there can sometimes be pain without obvious swelling. Symptoms usually improve with treatment for intestinal symptoms and there is generally no lasting damage to the joints. A few people develop swelling and pain in the smaller joints of the hands or feet. This may be longer lasting and may persist even when the IBD is in remission.

More rarely, the joints in the spine and pelvis become inflamed – a condition called ankylosing spondylitis. This can flare up independently of the UC. The most common problem is pain over the sacroiliac joints, which are on either side of the lower part of the spine. Stiffness and pain of the spine itself may eventually lead to loss of movement. Drugs and physiotherapy can be helpful in treating these symptoms.

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## ULCERATIVE COLITIS

### SKIN

UC can also cause skin problems, including mouth ulcers. A condition known as erythema nodosum may also affect about one in 10 people with UC. Its main symptom is painful red swellings, usually on the legs, which fade leaving a bruise-like mark. This condition tends to occur during flare-ups and generally improves with treatment for the UC.

More rarely, people with UC may develop a condition known as pyoderma gangrenosum. This starts as small tender blisters, which become painful, deep ulcers. These can occur anywhere on the skin, but most commonly appear on the shins or near stomas. This condition is sometimes, but not always linked to an IBD flare-up. It is usually treated with immunosuppressants or steroids, but may need biological therapy.

### EYES

Some people with UC develop inflammation of the eyes. The most common condition is episcleritis, which affects the layer above the white of the eye, making it red, sore and inflamed. Two other eye conditions linked with UC are uveitis, (inflammation of the iris) and scleritis (which affect the white outer coating of the eye). These are more serious eye disorders which may eventually lead to loss of vision if left untreated. These conditions can usually be treated with steroid drops given into the eye, although uveitis and scleritis may need treatment with immunosuppressants or biologic drugs. If you get any kind of eye irritation or inflammation, always mention it to your doctor, who may refer you to an eye specialist.

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### BONES

People with UC are more at risk of developing thinner and weaker bones. Bone loss can be due to the inflammatory process itself, poor absorption of the calcium needed for bone formation, low calcium levels from avoiding dairy foods, or the use of steroid medication or smoking. Calcium supplementation and, for some people, drug treatment can be helpful. For more information see our information sheet **Bones and IBD**.

### MOUTH

About one in 25 people with UC gets painful sores in the mouth, usually when the condition is more active. These sores can be minor and disappear within a few weeks, but occasionally they can last for many weeks and may require steroid treatment.

### LIVER

Some people with UC develop liver inflammation. A condition called Primary Sclerosing Cholangitis (PSC) affects up to one in 13 people with UC. PSC is a rare disease that causes inflammation of the bile ducts and can eventually affect the liver. Symptoms include fatigue, pain, itching, jaundice, and weight loss. Treatment is usually with a drug called ursodeoxycholic acid.

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### BLOOD CIRCULATION

People with IBD are about twice as likely to develop blood clots in the veins, including DVT (deep vein thrombosis) in the legs. You may be particularly at risk during a flare-up or if you are confined to bed, for example in hospital. If you get pain, swelling and tenderness in your leg, or chest pains and shortness of breath, contact your doctor straight away. You can reduce your risk by keeping as mobile as possible and drinking plenty of fluids. Precautions like these, and others such as wearing support stockings, can be especially helpful when travelling by air, which increases the risk of blood clots for anyone. See our information sheet **Travel and IBD**.

### ANAEMIA

Anaemia is a common complication of IBD. If you are anaemic, it means you have fewer red blood cells than normal and/or lower levels of haemoglobin in your blood. (Haemoglobin is a protein found in red blood cells that helps carry oxygen around the body). There are several different types of anaemia. People with UC are most likely to develop iron deficiency anaemia. This is caused by a lack of iron in the diet or poor absorption of iron from food, but can be made worse by ongoing blood loss. Some of the drugs used for UC, such as sulphasalazine, azathioprine and mercaptopurine, may also cause anaemia.

If the anaemia is very mild there may be few or no symptoms. With more severe anaemia, the main symptoms are chronic (ongoing) tiredness and fatigue. You might also develop shortness of breath, headaches and general weakness. How the anaemia is treated will depend on its cause. For iron deficiency anaemia you may be prescribed iron supplements, either as tablets or as IV (intravenous) iron, which is given by injection or in an infusion, through a drip. IV iron is often better tolerated and so can be more effective than iron tablets.

## CAN ULCERATIVE COLITIS LEAD TO BOWEL CANCER?

**ULCERATIVE COLITIS IS NOT A FORM OF CANCER. HOWEVER IF YOU HAVE HAD EXTENSIVE OR TOTAL COLITIS (PANCOLITIS) FOR MANY YEARS, YOU HAVE A GREATER RISK THAN NORMAL OF DEVELOPING CANCER IN THE COLON OR RECTUM.**

This increased risk is not as great for people with left sided colitis, and people with proctitis have no increased risk. Research shows that this risk of developing cancer usually begins to increase about 8-10 years after the start of the Inflammatory Bowel Disease (IBD) symptoms. (This is not from the date of your diagnosis, which could be much later than when your symptoms started). Having Primary Sclerosing Cholangitis (PSC) may also increase your risk of bowel cancer.

It is possible to develop dysplasia before the growth of an actual tumour. 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. A doctor can look for these changes during a colonoscopy (see **How is Ulcerative Colitis diagnosed?**).

This means that if you have had extensive Ulcerative Colitis for eight years or longer it may be a good idea to talk to your doctor about whether you need a surveillance colonoscopy to check for signs of dysplasia or cancer.

**HOWEVER, THE OVERALL NUMBER OF PEOPLE WITH IBD WHO DEVELOP BOWEL CANCER IS VERY SMALL, AND CANCERS CAN OFTEN BE MORE SUCCESSFULLY TREATED IF DETECTED EARLY.**

For more information, see our information sheet **Bowel Cancer and IBD**.



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## HOW IS ULCERATIVE COLITIS DIAGNOSED?

If you develop diarrhoea with bleeding and abdominal pain, your doctor may suspect you have Ulcerative Colitis (UC), particularly if you are a young adult or have a family history of Inflammatory Bowel Disease (IBD). You will need tests and physical examinations to confirm a diagnosis. These may include:

### BLOOD AND STOOL TESTS

Simple blood tests can show whether you have inflammation somewhere in your body and whether you are anaemic. Your stools can also be tested for signs of bleeding or inflammation, and to check whether your diarrhoea is caused by an infection. If inflammation is confirmed, you may then have an examination to look inside your body, such as an endoscopy, x-ray or scan.

### ENDOSCOPIES

In an endoscopy a doctor or specialist endoscopist uses an endoscope – a long thin, usually flexible, tube with a camera in its tip – to examine your digestive system. There are several types of endoscopy which can have different names according to the part of the gut being examined. The type of endoscope used will also vary (some are longer and thinner and more flexible than others) and may have a different name.

You may have, for example:

- An upper GI (Gastrointestinal Tract) endoscopy – If you have symptoms in the upper part of your digestive system as well as in your colon, you may be given what is known as an upper GI endoscopy, or gastroscopy, to rule out Crohn's Disease. In this, the doctor or specialist endoscopist inserts the endoscope through your mouth so they can examine your oesophagus, stomach and duodenum (the first part of the small intestine or bowel).

## ULCERATIVE COLITIS – DIAGNOSIS, TESTS AND TREATMENT

- A colonoscopy or sigmoidoscopy – These types of endoscopy are often used to help diagnose or monitor UC. In these tests a sigmoidoscope (a short endoscope) or a colonoscope (a longer and more flexible endoscope) is inserted through the anus (back passage) to examine the rectum and colon.

Endoscopies like these should not be painful but may be uncomfortable, so you may be given a sedative (medication that has a calming effect) to help you relax. Biopsies (small samples of tissue) are often taken during an endoscopy. These can then be examined under a microscope to confirm the diagnosis.

### MRI AND CT SCANS

Other tests that are increasingly used to look at the location and extent of inflammation include MRI (Magnetic Resonance Imaging) and CT (Computerised Tomography) scans. MRI scans use magnets and radio waves, and CT scans use a special kind of x-ray to build up a '3D' image of the body. Some centres also use ultrasound.

You can find more detailed information about all the tests mentioned above in our leaflet, **Tests and Investigations for IBD.**

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**SOMETIMES IT CAN BE DIFFICULT TO TELL ULCERATIVE COLITIS APART FROM OTHER INFLAMMATORY BOWEL CONDITIONS, ESPECIALLY CROHN'S COLITIS (CROHN'S DISEASE IN THE COLON). IF IT REMAINS UNCLEAR YOU MAY BE GIVEN A DIAGNOSIS OF IBD UNCLASSIFIED (IBDU) OR INDETERMINATE COLITIS. THIS SHOULD NOT AFFECT THE START OF ANY TREATMENT.**

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## **WILL I NEED REPEATED TESTS?**

You may need to have certain tests repeated from time to time to check on your condition and/or to monitor how your treatment is working. Some drug treatments may also require a series of blood tests and, occasionally, x-rays or scans to check for any potential side-effects. However, your specialist will avoid giving you any unnecessary tests or investigations. You may need more regular colonoscopies when you have had Ulcerative Colitis (UC) for a long time to check for any signs of cancer.

## **COULD MY SYMPTOMS BE IRRITABLE BOWEL SYNDROME?**

Sometimes people with Ulcerative Colitis (UC) get bowel symptoms when their disease is not active. This might be due to Irritable Bowel Syndrome (IBS), which may be more common in people with Inflammatory Bowel Disease (IBD) than in the general population. There is no blood loss in IBS, but common symptoms include abdominal pain, bloating and a varying bowel habit with diarrhoea and/or constipation. If you are having symptoms like these, and tests do not show active inflammation or an infection, then it may be IBS. Your doctor will advise you about appropriate treatment.

## **WHAT TREATMENTS ARE THERE FOR ULCERATIVE COLITIS?**

**ULCERATIVE COLITIS CAN OFTEN BE MANAGED BY MEDICATION (DRUG TREATMENT), BUT SURGERY MAY BECOME NECESSARY IF THE INFLAMMATION IS VERY SEVERE, AND IN SOME OTHER SITUATIONS. YOUR TREATMENT WILL DEPEND ON THE TYPE AND SEVERITY OF YOUR UC AND THE CHOICES YOU MAKE IN DISCUSSION WITH YOUR DOCTOR.**

## WHAT DRUGS ARE USED TO TREAT ULCERATIVE COLITIS?

Drug treatment for Ulcerative Colitis (UC) usually aims to reduce symptoms and control flare-ups, and then to prevent a relapse once the disease is under control. This can mean that you need to take your medication on an ongoing basis, sometimes for many years. Or, you may need only a short course of drugs. If your condition is mild and limited to a small part of your colon, you may be able to stop treatment on advice from your doctor if you have been free of symptoms for more than two years.

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### RESEARCH FACT

**RESEARCH SUGGESTS THAT TAKING SOME 5-ASA DRUGS MAY HELP TO REDUCE THE SMALL CHANCE OF BOWEL CANCER DEVELOPING.**

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## ULCERATIVE COLITIS – DIAGNOSIS, TESTS AND TREATMENT

The main types of drugs commonly used in UC are anti-inflammatory drugs and symptomatic drugs.

### ANTI-INFLAMMATORY DRUGS

These help to reduce inflammation and include:

- 5-ASAs or aminosalicylates such as mesalazine (brand names include Asacol, Ipocol, Octasa, Pentasa, and Salofalk), sulphasalazine (Salazopyrin), olsalazine (Dipentum), balsalazide (Colazide)
- Corticosteroids, often just called steroids, such as prednisolone, hydrocortisone, budesonide (Entocort), Beclometasone dipropionate (Clipper)
- Immunosuppressants such as azathioprine (Imuran), mercaptopurine or 6MP (Purinethol), methotrexate, mycophenolate mofetil, tacrolimus and ciclosporin
- Biological drugs such as infliximab (Remicade, Inflectra and Remsima), adalimumab (Humira) and vedolizumab (Entyvio).

### SYMPTOMATIC DRUGS

These help to control and reduce common symptoms such as pain, diarrhoea and constipation. They include:

- Anti-diarrhoeals such as codeine phosphate, diphenoxylate (Lomotil) and Loperamide (Imodium, Arret)
- Laxatives such as Movicol and Lactulose
- Bulking agents such as Fybogel
- Analgesics (pain killers) such as paracetamol and aspirin.

You can find more information about drugs used for UC in our drug treatment information sheets: **Adalimumab, Azathioprine and Mercaptopurine, Methotrexate and Infliximab.**

## **TAKING OVER THE COUNTER MEDICINES FOR UC SYMPTOMS**

**IT IS BEST TO CHECK WITH YOUR DOCTOR OR IBD TEAM BEFORE YOU TAKE ANY OVER-THE-COUNTER MEDICINES AS THEY MAY NOT BE SUITABLE FOR YOU, OR COULD INTERACT WITH YOUR IBD DRUGS.**

For example, some anti-diarrhoeals may make your Ulcerative Colitis symptoms worse if you take them during a flare-up. Certain painkillers are a type of drug known as non-steroidal anti-inflammatory drugs (or NSAIDS), and these may possibly trigger a flare-up.

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## **WHAT ABOUT SURGICAL TREATMENT FOR UC?**

If your quality of life has been affected by repeated flare-ups and you have not responded well to medication, you may be advised to consider surgery.

**RECENT ESTIMATES SUGGEST THAT ABOUT TWO IN 10 PEOPLE WITH ULCERATIVE COLITIS MAY EVENTUALLY NEED SURGERY, DEPENDING ON HOW SEVERE THE DISEASE IS AND WHICH PART(S) OF THE COLON ARE AFFECTED.**

Surgery may also be recommended if dysplasia (pre-cancerous changes) or cancer is found in your colon during a colonoscopy.

Most people who decide to have surgery for their UC have time to discuss their options in advance. This allows them to prepare for having an operation. More rarely, people with very severe UC which does not respond to intensive medical treatment will need urgent surgery (within a few days) or emergency surgery (within a few hours).

## WHAT ARE THE MOST LIKELY OPERATIONS FOR UC?

When the surgery is planned in advance you are most likely to be offered a proctocolectomy with a permanent ileostomy, or a proctocolectomy with an ileoanal pouch.

### PROCTOCOLECTOMY WITH PERMANENT ILEOSTOMY

In this operation the surgeon removes the whole colon, rectum and anal canal, and brings out the end of the lower small intestine onto the wall of the abdomen through a permanent opening, called a stoma (ileostomy). An external bag is fitted on to the opening on the outside of the abdomen. This collects the waste from the small intestine that would previously have gone into the colon. The bag is emptied or changed when necessary. If you have this operation you will no longer have a colon to become inflamed or develop bowel cancer. However, this form of surgery is irreversible.

Having a major part of the bowel removed may be a frightening thought, and you may also be concerned at the prospect of using a stoma bag. However, in recent years there have been great advances and improvements in the design of stoma products, and they are now much more discreet and comfortable. Specialist nurses are usually available to help support you if you have an ileostomy or colostomy. There are also several organisations that can give practical advice and support. Contact details for these are given at the end of the booklet.



### RESTORATIVE PROCTOCOLECTOMY WITH ILEOANAL POUCH

This procedure is often called pouch surgery, or IPAA (Ileal Pouch-Anal Anastomosis) and is often the preferred form of surgery for Ulcerative Colitis. It generally requires two operations, but may occasionally be done in a single stage or in 3 stages. In the first operation the surgeon removes the whole colon and the rectum, but leaves the anus. Then a pouch is made using the lower end of the ileum (small intestine) and this is joined to the anus. Finally, a looped section of the small intestine is brought out onto the wall of the abdomen through a temporary opening. This is an ileostomy or stoma. This opening allows the waste from digestion to be collected in a stoma bag until the newly-formed pouch has had a chance to heal. This will probably take several months. You will then need a second operation to close the temporary ileostomy so the pouch can be used. In very rare cases, the whole procedure is done in one stage, without the ileostomy.

“

Dealing with a colostomy bag is very easy...modern bags are small and inconspicuous. I can still wear tight fitting clothes, and there are aids that allow me to go swimming. ”

---

Peter, age 65,  
diagnosed with Ulcerative Colitis in 2009

## ULCERATIVE COLITIS – DIAGNOSIS, TESTS AND TREATMENT

The following operation is much less common, as it is only suitable for a small number of people with UC:

### COLECTOMY WITH ILEORECTAL ANASTOMOSIS

In this operation the surgeon removes the colon and joins the end of the ileum (the lower part of the small intestine) to the rectum. It avoids the need for a stoma, so it may be useful for people who could not cope with a stoma or who are unsuitable for pouch surgery. However, this operation is only suitable if there is little or no inflammation in the rectum or if there is no long-term risk of developing cancer in the rectum.

If you need emergency surgery, you are likely to have the following operation:

### COLECTOMY WITH ILEOSTOMY (SUBTOTAL)

In this procedure the surgeon removes the colon, but leaves the rectum. This allows for the possibility of pouch surgery in the future. As in the proctocolectomy, the lower end of the small intestine is brought out onto the abdomen wall to form an ileostomy or stoma to collect the waste from digestion. The upper end of the rectum is either closed or brought out to the surface to form another opening or stoma. This additional stoma (sometimes called a mucous fistula) may be needed because the rectum may still produce mucus for a while. After recovering from this surgery, you can then decide whether to opt for pouch surgery or a permanent ileostomy, which may depend on your individual medical condition.

Our information sheet **Surgery for Ulcerative Colitis** gives more details about these operations.



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## DO I NEED TO CHANGE MY DIET?

There has been extensive research into diet as a possible cause or trigger of Ulcerative Colitis (UC), but so far there are no clear answers and there is little evidence that diet plays a role in UC.

**GENERALLY, THE MOST IMPORTANT THING IS TO EAT A NUTRITIOUS AND BALANCED DIET TO MAINTAIN YOUR WEIGHT AND STRENGTH, AND TO DRINK SUFFICIENT FLUIDS TO STOP YOU GETTING DEHYDRATED.**

You may find, however, that certain foods affect your symptoms. For example, when you have a flare-up, you may discover that bland, soft foods cause less discomfort than raw vegetables, spicy or high-fibre foods.

You may also discover that eating foods high in fibre can increase the urge to go to the toilet – and perhaps increase worries about having an ‘accident’. The urge to open the bowels is usually caused by inflammation in the lower colon, but, as fibre adds bulk to faeces, it can act as a trigger and make the urgency worse. So it may be helpful during flare-ups to reduce the amount of fibre you eat and perhaps to go on a low fibre diet. However, do talk to your IBD team before trying this. Once the flare-up is over, it is important to increase your intake of fibre again. Fibre is useful because it keeps the colon healthier as well as providing fuel for beneficial bacteria.

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I have be careful now that I have an ileostomy, as certain foods don't digest well, and can cause blockages, which are not only painful, but can be very dangerous. ”

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

## ULCERATIVE COLITIS – LIVING WITH ULCERATIVE COLITIS

Some people with UC may be concerned that dairy products could trigger their symptoms – although, in general, people with UC are no more likely to be lactose intolerant than the general population. Your IBD team or your dietitian can help you discover if you are lactose intolerant. Because milk and dairy products are an important food group it is better not to give them up until you have spoken to your IBD team.

You may sometimes need nutritional supplements to replace the loss of vitamins and minerals. This can happen when you have a poor appetite, do not eat enough or when you have ongoing diarrhoea. Before taking any supplements or making any changes to your diet, always check with your doctor or a qualified dietitian.

For more information on healthy eating with UC see our booklet **Food and IBD**.



## WHAT ABOUT COMPLEMENTARY AND ALTERNATIVE APPROACHES?

Some people with Ulcerative Colitis (UC) find complementary and alternative medicines (CAM) helpful in treating their symptoms.

Examples of complementary and alternative therapies that have been used by people with UC include Boswellia Serrata, acupuncture, wheat grass juice, aloe vera gel, and omega 3 fish oils. However, many of these supplements and treatments are still being researched, and although they may help some people, there is no conclusive evidence about when or how they will work. It is difficult to know, with confidence, whether there is a direct physical effect, or a general psychological benefit (placebo). Also, everyone is different, and what may help one person may not have any effect on another.

There is stronger evidence that some probiotics (a mixture of live ‘friendly’ (beneficial) bacteria taken by mouth) may have a role in treating UC. For example, a probiotic known as VSL#3 has been shown to be helpful in preventing pouchitis (inflammation of an ileo-anal pouch). Research also suggests that some probiotics may have a use in maintaining remission in people with UC. Studies into curcumin (a natural anti-inflammatory agent found in the spice turmeric) have shown some positive effect on UC symptoms, but more research needs to be done in this area.

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**IF YOU DO WANT TO TAKE A COMPLEMENTARY OR ALTERNATIVE PRODUCT, TALK TO YOUR DOCTOR FIRST, ESPECIALLY IF YOU ARE THINKING OF TAKING ANY HERBAL MEDICINES AS THESE MAY INTERACT WITH SOME PRESCRIPTION DRUGS. IT IS ALSO IMPORTANT THAT YOU DO NOT STOP TAKING ANY PRESCRIBED TREATMENT WITHOUT DISCUSSION, EVEN IF YOUR SYMPTOMS IMPROVE.**

## WHAT ABOUT PREGNANCY AND ULCERATIVE COLITIS?

The majority of women with Ulcerative Colitis (UC) can expect a normal pregnancy and a healthy baby. Also, for most women, having a baby does not make their Inflammatory Bowel Disease (IBD) worse. That said, it is important to discuss your pregnancy with your IBD team. You may need to take special care with some aspects of your pregnancy or perhaps change your treatment slightly.

If you have UC your chances of conceiving are not usually affected by the disease. However, if you have pouch surgery your fertility could be affected. This appears to be much less likely with a colectomy and the formation of an ileostomy – the usual alternative to pouch surgery. The 5-ASA drug sulphasalazine can lead to a temporary loss of fertility in men but alternative medication is available.

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**DOCTORS USUALLY RECOMMEND TRYING TO GET YOUR IBD UNDER CONTROL BEFORE YOU GET PREGNANT. IF YOU ARE WELL WHEN YOUR PREGNANCY BEGINS YOU ARE MORE LIKELY TO HAVE AN UNCOMPLICATED PREGNANCY. ALSO, IF YOU CAN REMAIN IN REMISSION THROUGHOUT YOUR PREGNANCY THEN YOUR CHANCES OF A NORMAL PREGNANCY AND A HEALTHY BABY ARE ABOUT THE SAME AS THOSE OF A WOMAN WITHOUT IBD.**

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If you do get pregnant during a flare-up, you may be more likely to give birth early or have a baby with a low birth weight. Very severe UC can put your baby at greater risk. However, your doctor should be able to help you to control your symptoms as much as possible – and, with a few exceptions, most IBD treatment can be continued while you are pregnant.

For example, it is generally considered safe to continue taking steroids, most 5-ASAs, and azathioprine, although you should not take methotrexate or mycophenolate mofetil when pregnant or trying to conceive, because they can cause an increased risk of birth defects.

The evidence about the safety of infliximab and adalimumab is still fairly limited. However, some doctors now consider that if they are keeping your IBD in check, it may be better to continue with these drugs for at least the first six months of a pregnancy. Guidelines also suggest that doctors should discuss the risks and benefits with each woman on an individual basis, and you may find it helpful to talk through your options with your own IBD team.

For more details see our information sheets **Fertility and IBD** and **Pregnancy in IBD** (which also covers breastfeeding).

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## **DOES ULCERATIVE COLITIS RUN IN FAMILIES?**

**ULCERATIVE COLITIS DOES TEND TO RUN IN FAMILIES, AND PARENTS WITH IBD ARE SLIGHTLY MORE LIKELY TO HAVE A CHILD WITH IBD. STUDIES SHOW HOWEVER, THAT FOR MOST PEOPLE THE ACTUAL RISK IS STILL RELATIVELY SMALL, ALTHOUGH IT CAN BE HIGHER IN SOME POPULATION GROUPS.**

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If one parent has Ulcerative Colitis (UC), the risk of their child developing IBD is generally thought to be about 2%. That is, for every 100 people with UC, about two of their children might be expected to develop Inflammatory Bowel Disease (IBD) at some time in their lives. However, genes are only part of the picture and research suggests that environmental triggers also play an important role.

## HOW DOES ULCERATIVE COLITIS AFFECT CHILDREN AND YOUNG PEOPLE?

Around a quarter of people diagnosed with Inflammatory Bowel Disease (IBD) are children or adolescents at the time they are diagnosed. In young people with Ulcerative Colitis (UC), symptoms often first appear around the age of 12. The symptoms are the same as in adults, although they tend to be more severe. This may be because UC tends to be more extensive in children – the whole colon is affected in about eight out of 10 children with UC.

Inflammation of the bowel can sometimes affect a child's growth, and may delay puberty, but this tends to be more of a problem with Crohn's Disease than UC. Talk to your child's doctor if you are concerned and you may be referred to a specialist. Steroid treatment can also affect growth in children, but this usually improves once the steroids are stopped. Some children may also need additional vitamin and mineral supplements to help their growth.

Although most children and young people with UC are able to attend school, there may be times when they have to miss lessons due to ill health. They may also have a sense of being 'different' from other children. We have an information sheet for schools, and a booklet entitled **IBD in Children: a parent's guide**, which you may find helpful.

Your child's IBD nurse or specialist should also be able to help you if you have any concerns about your child's development and treatment.



## HOW WILL ULCERATIVE COLITIS AFFECT MY LIFE?

**THERE IS NO SINGLE ANSWER TO THIS QUESTION BECAUSE EVERYONE IS DIFFERENT, ULCERATIVE COLITIS IS SUCH AN 'INDIVIDUAL' CONDITION AND PEOPLE'S EXPERIENCES VARY SO WIDELY. ALSO, SO MUCH CAN DEPEND ON THE SEVERITY OF YOUR CONDITION AND ON WHETHER YOUR DISEASE IS IN A QUIET OR AN ACTIVE PHASE.**

Some people with Ulcerative Colitis (UC) may never have more than mild and infrequent symptoms of diarrhoea and pain, so the illness may not affect their lives very much. Other people do have continuous and severe symptoms in spite of medical and surgical treatment, and have to adapt their lifestyle considerably.

Our booklet **Living with IBD** looks at some of the challenges of day-to-day life with UC. We also have information sheets on **Managing Bloating and Wind**, and **Diarrhoea and Constipation**.

You are likely to see your GP and specialist doctor or nurse on a fairly regular basis if you have UC. So, it can be very helpful if you can build up a good relationship with them. **Staying Well with IBD** has some suggestions on how to get the most from your time with health professionals.

Living with a chronic condition can have both an emotional and practical impact. It can help to have the understanding and support of those around you – your family, friends, work colleagues and employers. We have a number of information sheets that may be useful, such as **IBD and Employment: a guide for employers**, and **IBD and Employment: a guide for employees**. There are also similar publications for students and universities.

## HOW WE CAN HELP YOU

We produce over 40 information sheets, booklets and guides about all aspects of IBD which are available to download for free on our website: [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

We run confidential support services for anyone affected by Inflammatory Bowel Disease.

Our **Information Service** is staffed by a team of trained Information Officers and provides callers with clear and balanced information on a wide range of issues relating to IBD.

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

We also run the **Crohn's and Colitis Support Line**, a supportive listening service provided by trained volunteers who are skilled in providing emotional support to anyone who needs a safe place to talk about living with IBD. **Call 0121 7379 931.**



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## OTHER USEFUL ORGANISATIONS

### **Bladder and Bowel Foundation**

[www.bladderandbowelfoundation.org](http://www.bladderandbowelfoundation.org)

### **Colostomy Association**

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

### **Core – Fighting Gut and Liver Disease**

[www.corecharity.org.uk](http://www.corecharity.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)

### **NASS – National Ankylosing Spondylitis Society**

[www.nass.co.uk](http://www.nass.co.uk)

### **National Osteoporosis Society**

[www.nos.org.uk](http://www.nos.org.uk)



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# CROHN'S & COLITIS UK

## SUPPORTING YOU TO MANAGE YOUR CONDITION

# CROHN'S & COLITIS UK

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FIGHTING  
INFLAMMATORY  
BOWEL DISEASE  
TOGETHER

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Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease. Charity registered in England and Wales Number 1117148, Scotland Number SC038632. A company limited by guarantee in England: Company number 5973370. General enquiries 01727 830 038.

# BECOME A MEMBER TO

## RECEIVE SUPPORT & INFORMATION

Free of charge publications & guides accredited by health professionals, access to support & information helplines & our member magazine full of research news & features. Membership will help you to better manage your care, for example with our Can't Wait Card & through support groups, online advice & member only offers.

## BELONG TO A COMMUNITY

Share experiences & support each other online, at events & through local group networks which are supported by health professionals & policy makers. Help us raise awareness and campaign for better health services & support life-changing research to increase the knowledge of causes & best treatments.

## JOINING IS EASY

You can become a member if you are 16 years or over, are a parent or carer, a health professional or if you just want to support the charity.

If you have internet access, join faster online at [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

### ABOUT YOU

Please return this form along with payment to Crohn's & Colitis UK, 45 Grosvenor Road, St Albans, Herts, AL1 3AW  
Contact the membership team on 01727 734465 if you have any queries.

Are you?

A patient

Crohn's Disease

Ulcerative Colitis

Other

Date of diagnosis

A parent of a child under 16 years

A relative of a patient

Health professional

General supporter

Name and date of birth of who you want to appear on the Can't Wait Card if not yourself (child/relative/friend)

### PERSONAL DETAILS

Please complete all fields and use **BLOCK CAPITALS**:

Surname

Title

First name

Gender Male/Female

Address

Postcode

Email

Telephone number

Mobile number

Date of birth

Ethnic group

Occupation

## PAYMENT DETAILS

Individual membership

- £15 per year Direct Debit  
 £19 per year Cheque/Credit or Debit Card

If you are a student, are experiencing financial issues or on a low income due to health or employment issues then please contact the membership team on 01727 734465 to discuss joining at a reduced rate.

1. Please make cheques payable to Crohn's and Colitis UK.
2. If you would like to pay by credit card please call the membership team on 01727 734465 or join online at [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk).
3. Direct debit is the most efficient way to pay. If you would like to pay by direct debit please Fill out the form below

Subscription £ ..... Additional donation £ ..... **TOTAL £** .....

### By Direct Debit



Instructions to your Bank or Building to pay by Direct Debit

Amount to be taken £  Every month  Every year

Name(s) of account holder(s)

Name of Bank/Building Society

Branch name

Bank Building society account number

Sort code

Date

Organisation ID

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#### Instructions to your Bank or Building

Please pay Crohns and Colitis UK Direct Debits from the account detailed in this Instruction subject to the safeguards assured by The Direct Debit Guarantee. I understand that this Instruction may remain with the Crohns and Colitis UK and, if so, details will be passed electronically to my Bank/Building Society.

Signed \_\_\_\_\_

Date \_\_\_\_\_

**Gift aid your donation at no extra cost:** I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand that the charity will reclaim 28p of tax on every £1 that I gave up to 5 April 2008 and will reclaim 25p of tax on every £1 that I give on or after 6 April 2008.

Yes I am a UK tax payer and would like to gift aid  please tick No, I am not a UK tax payer  please tick

#### Data protection

Crohn's and Colitis UK will hold the information you have given on this form and will use it in connection with your membership and to keep you informed about the activities of the Charity. A copy of our Data Protection policy is available on request. At all times we comply with the Data Protection Act 1988.

From time to time we may want to contact you regarding the general work of the charity, tick here if you would not like to receive this information.