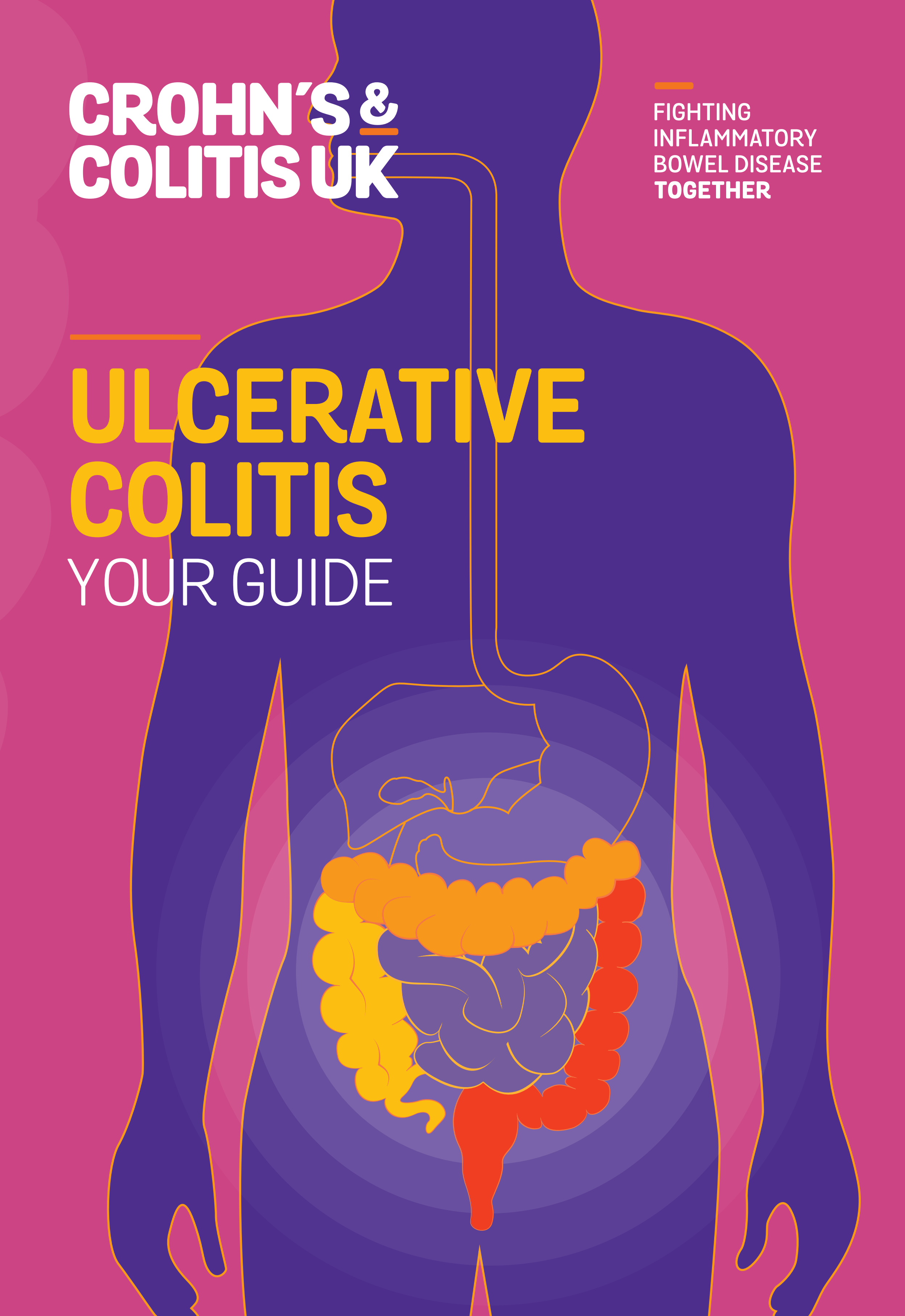
CROHN'S & COLITIS UK

FIGHTING
INFLAMMATORY
BOWEL DISEASE
TOGETHER

ULCERATIVE COLITIS

YOUR GUIDE



ABOUT
THIS BOOKLET

Being diagnosed with Ulcerative Colitis (UC) can be a shock, and you probably have many questions. Now that you've put a name to your symptoms, you can start to manage them. The more you know about your UC, the more you'll be able to take an active part in decisions about your care. This booklet will give you and your family and friends a better understanding of Colitis, how it is treated, and how it will affect your life.

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 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.

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 email **publications@crohnsandcolitis.org.uk**.

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 Disease. We have over 35,000 members and 50 Local Networks 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**

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WE ARE AMBITIOUS

WE ARE COMPASSIONATE

WE ARE STRONGER TOGETHER

ABOUT ULCERATIVE COLITIS

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

Ahad, age 13,
diagnosed with Ulcerative
Colitis in 2015

1

WHAT IS ULCERATIVE COLITIS?

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

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.

UC is sometimes described as a chronic condition. This means that it is ongoing and lifelong, although you may have long periods of good health known as remission, as well relapses or flare-ups when your symptoms are more active. Everyone is different – in many people the disease is mild with few flare-ups, while other people may have more severe disease.

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

FACT

Ulcerative Colitis is not infectious

THE DIGESTIVE SYSTEM

1 OESOPHAGUS

2 STOMACH

3 LIVER

4 GALL BLADDER

5 PANCREAS

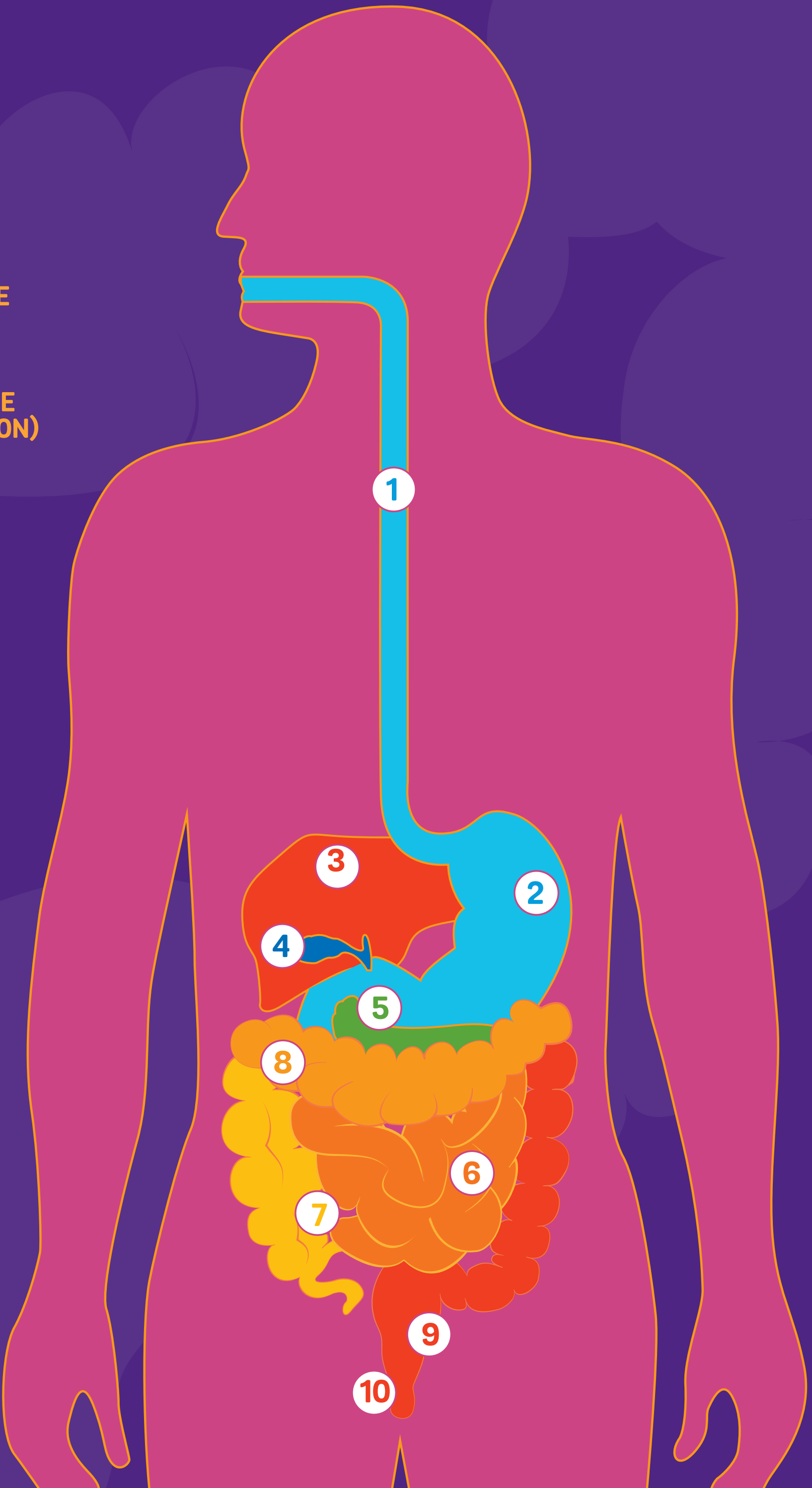
6 SMALL INTESTINE

7 END OF ILEUM

8 LARGE INTESTINE (INCLUDING COLON)

9 RECTUM

10 ANUS



HOW DOES ULCERATIVE COLITIS AFFECT THE GUT?

As you can see from the diagram, the gut, or digestive system, is 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 the useful nutrients from 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 - then pass into the colon, which is also known as the large intestine or large bowel. The colon absorbs the liquid, and the leftover waste forms solid faeces (stools). These collect in the last part of the colon and the rectum until they are pushed out of the body through the anus in a bowel movement.

In UC, parts of the colon and/or rectum become inflamed and sore. Ulcers can develop on the colon lining and these can bleed or produce mucus.

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

WHAT ARE THE MAIN SYMPTOMS?

Ulcerative Colitis symptoms may range from mild to severe and vary from person to person.

They may also change over time, with periods of remission where you have good health and no symptoms, alternating with relapses or flare-ups, when your symptoms are troublesome.

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 how much of the colon is inflamed and how severe the inflammation is, but the most common symptoms during a flare-up are:

- **Diarrhoea**. This is often with blood and mucus, and an urgent need to rush to the toilet
- **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 have a raised temperature and feel feverish, with a fast heartbeat
- **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 or not eating well. Anaemia can make you feel very tired

HOW WILL ULCERATIVE COLITIS AFFECT MY LIFE?

There is no single answer to this question because everyone is different, and people's experiences with UC vary so widely. Also, 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 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 have continuous and severe symptoms in spite of medical 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**, amongst other symptoms.

You are likely to see your GP and specialist doctor on a fairly regular basis if you have UC. Many hospitals also have a specialist IBD nurse, who is often the first point of contact for information and support when you are unwell. It can be very helpful to build a good relationship with your healthcare team, so that you can ask about your options and discuss any concerns and worries. 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.

> “I have a good relationship with my local hospital and am fortunate to have an excellent IBD nurse. Knowing that I can contact her when I start to experience a flare-up, and knowing that she will help as much as she can, helps to reduce the stress of the situation and speed up treatment.”

Andrew, age 38,
diagnosed with Ulcerative Colitis in 2007

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**, as well as similar publications for students and universities. We also run a confidential helpline and over 50 Local Networks throughout the UK, where you can connect with others who have IBD. See the **How we can help you** section at the end of this booklet for more information.

You may still find that UC takes a considerable toll on your emotional wellbeing. In this case, you may find it helpful to talk to a counsellor. Our information sheet **Counselling and IBD** has information on how counselling may be able to help.

HOW COMMON IS ULCERATIVE COLITIS?

It is estimated that Ulcerative Colitis affects about one in every 420 people in the UK.

UC is more common in urban than rural areas, and in northern developed countries - although the numbers are beginning to increase in developing nations. UC is also more common in white Europeans, especially those of Ashkenazi Jewish descent (those who lived in Eastern Europe and Russia).

UC affects women and men equally. It tends to develop more frequently in people who don’t smoke or used to smoke than current smokers. However, health professionals consider the risks of smoking greatly outweigh any benefits seen in UC, and strongly discourage smoking in anyone, whether or not they have IBD. For more details, see our information sheet **Smoking and IBD**.

RESEARCH FACT

UC 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.

WHAT CAUSES ULCERATIVE COLITIS?

Although there has been much research, we still do not know exactly what causes Ulcerative Colitis. However major advances have been made over the past few years, 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

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.

WHAT ARE THE MAIN TYPES OF ULCERATIVE COLITIS?

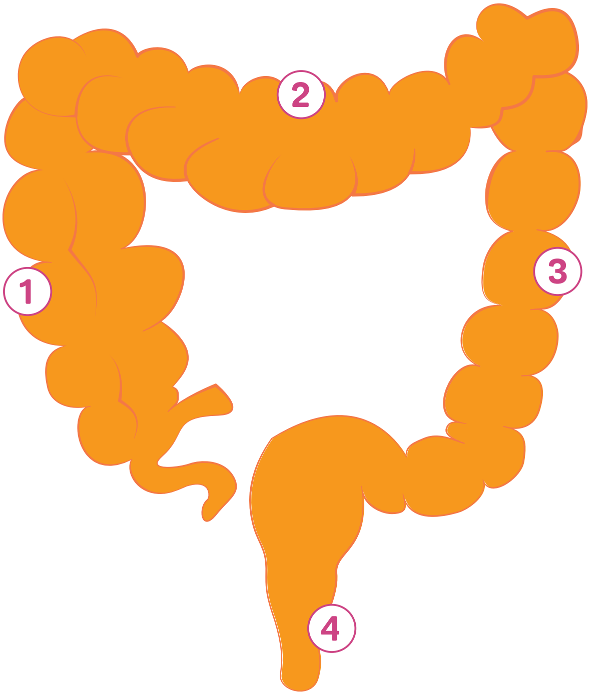
Ulcerative Colitis is generally categorised according to how much of the large intestine is affected. The diagram shows the three main types: proctitis, left-sided or distal colitis, and total or pancolitis.

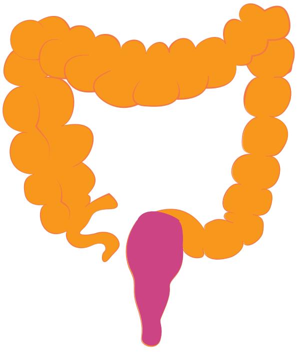
1 ASCENDING COLON

2 TRANSVERSE COLON

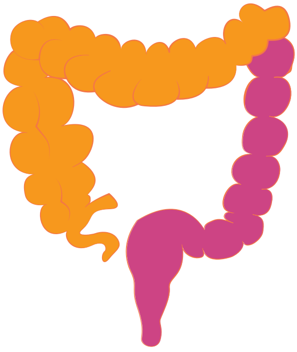
3 DESCENDING COLON

4 RECTUM

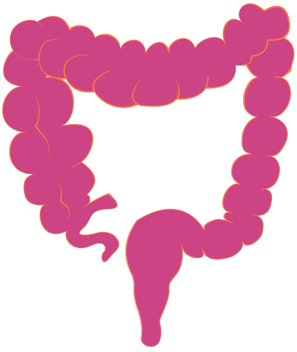




PROCTITIS



LEFT-SIDED (DISTAL) COLITIS



TOTAL COLITIS

PROCTITIS

In proctitis, only the rectum (the lowest part of the large bowel) 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 bloodstained 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. Because the inflamed rectum is more sensitive, some people with proctitis often feel that they have an urge to pass a stool, but cannot pass anything as 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 constipation is less likely.

LEFT-SIDED (OR DISTAL) COLITIS

In this type of UC, the inflammation involves the distal colon, which includes the rectum and the left side of the colon (also known as the descending colon). Symptoms include diarrhoea with blood and mucus, pain on the left side of the abdomen, urgency and tenesmus.

TOTAL COLITIS/PANCOLITIS

UC that affects the whole colon is known as total colitis or pancolitis. If the inflammation affects most of the colon, but not all of it, it is known as extensive colitis. Extensive and total colitis can cause very frequent diarrhoea with blood, mucus, and sometimes pus (a thicker, more yellow fluid than mucus). You may also have severe abdominal cramps and pain, tenesmus, fever and weight loss. In milder flare-ups, the main symptom may be diarrhoea or looser stools without blood.

CAN ULCERATIVE COLITIS HAVE COMPLICATIONS WITHIN THE BOWEL?

In very rare cases, Ulcerative Colitis can cause additional problems in the gut. These complications include:

STRICTURES

A stricture is a narrowing of the bowel caused by ongoing inflammation that can make it difficult for faeces (stool) to pass through the colon. Strictures do not usually occur in UC, but can sometimes be a sign of bowel cancer (see **Can Ulcerative Colitis lead to bowel cancer?**).

PERFORATIONS

Very active inflammation in the bowel wall or a severe blockage caused by a stricture may occasionally lead to a perforation (rupture) of the bowel. This makes a hole which the contents of the bowel can leak through. This is a rare medical emergency, symptoms of which include severe abdominal pain, fever, nausea and vomiting.

TOXIC MEGACOLON

When the inflammation is extensive and severe, digestive gases may get trapped in the colon, making it swell up. This is known as toxic megacolon, which can occur in up to one in 40 people with UC. Symptoms include a high fever as well as pain and tenderness in the abdomen. It is essential to get treatment quickly for this condition, as surgery may be necessary.

FISTULAS

People with UC, in particular those who have had pouch surgery (see **What about surgical treatment**), can in rare circumstances develop fistulas. A fistula is an abnormal channel or passageway connecting one internal organ to another, or to the outside surface of the body. Most fistulas (also called fistulae if more than one) start in the wall of the intestine and connect parts of the bowel to each other, the vagina, bladder, or skin (particularly around the anus). Fistulas very rarely occur in people with UC and are more common in people with Crohn's Disease. For more details, see our information sheet **Living With a Fistula**.

CAN ULCERATIVE COLITIS AFFECT OTHER PARTS OF THE BODY?

Ulcerative Colitis can cause problems outside the digestive system. Over a third of people with UC develop other conditions, mainly affecting the joints, eyes and skin. These are often referred to as extraintestinal manifestations (EIMs) and are most likely to occur during active disease. However they can also develop during times of remission, or even before any signs of bowel disease appear.

JOINTS

Inflammation of the joints, known as arthritis, affects about one in 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, causing painful swelling, although pain may occur without obvious swelling. Symptoms usually improve with treatment for UC 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, which may be longer lasting and persist even when the IBD is in remission. Occasionally, some biologic drugs can also cause joint pain as a side effect.

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 join the spine to the pelvis. Stiffness and pain of the spine itself may eventually lead to loss of movement. Drugs and physiotherapy can be helpful in treating these symptoms.

SKIN

UC can also cause skin problems. A condition known as erythema nodosum affects about one in 10 people with UC. Its main symptom is painful red swellings, usually on the legs, that fade to 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 often treated by a dermatologist with topical therapy, but may need drug therapy with steroids, immunosuppressants or biologics.

EYES

Some people with UC develop inflammation of the eyes. The most common condition is episcleritis, which affects the layer overlying the white of the eye, making it red, sore and inflamed. Episcleritis tends to flare up at the same time as IBD, and may need anti-inflammatory treatment; sometimes steroid drops are prescribed.

Two other eye conditions linked with UC are uveitis, (inflammation of the iris) and scleritis (which affects the white outer coating of the eye). These are more serious eye disorders which may eventually lead to loss of vision if left untreated. If you get any kind of eye irritation, grittiness or inflammation, always mention it to your doctor or optician, who may refer you to an eye specialist. These conditions can usually be treated with steroid drops, although sometimes immunosuppressants or biologic drugs are needed.

BONES

People with UC are more at risk of developing thinner and weaker bones. This 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. Smoking also increases this risk. Weight-bearing physical activity, calcium and vitamin D supplements - as well as drug treatment for some people - can be helpful. For more information see our information sheet **Bones and IBD**.

MOUTH

About one in 25 people with UC get sores or ulcers in the mouth, usually when the condition is more active. These sores can be minor and disappear within a few weeks, but can occasionally 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 25 people with UC. PSC causes inflammation of the bile ducts and can eventually affect the liver cells. Symptoms include fatigue, pain, itching, jaundice and weight loss. Treatment is usually with a drug called ursodeoxycholic acid.

Some of the drugs used to treat UC, for example azathioprine and methotrexate, may affect the liver. Changes in treatment may help to reduce this type of complication.

HEART AND 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 of blood clots by not smoking, keeping as mobile as possible, drinking plenty of fluids, and wearing support stockings. Precautions like these can be especially helpful when travelling by air, which increases the risk of blood clots for everyone. For more details see our information sheet **Travel and IBD**.

Research also suggests that people with active IBD may have a slightly increased risk of cardiovascular disease, including heart attacks and strokes. This risk tends to be lower for people in remission. If you experience chest pain, shortness of breath, and a feeling of numbness or weakness in your arms and legs, contact your doctor immediately.

ANAEMIA

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

If the anaemia is mild there may be few or no symptoms. With more severe anaemia, the main symptoms are persistent tiredness and fatigue. You might also develop shortness of breath, headaches and general weakness. Treatment will depend on the cause of the anaemia. For iron deficiency anaemia you may be prescribed oral iron supplements. Some people with IBD find that they cannot tolerate iron by mouth, so are given IV (intravenous) iron, which is delivered by injection or an infusion through a drip.

COULD MY SYMPTOMS BE IBS?

Irritable Bowel Syndrome (IBS) is a different condition from IBD, 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 UC, and there is no blood loss with IBS.

Some people with UC may develop IBS-like symptoms, for example experiencing diarrhoea even when their IBD is inactive. These symptoms may need slightly different treatment from their usual IBD symptoms. IBS is more common in people with IBD than in the general population.

CAN ULCERATIVE COLITIS LEAD TO BOWEL CANCER?

Ulcerative Colitis is not a form of cancer. However if you have had UC for many years, you have a greater risk than normal of developing cancer in the colon or rectum.

This risk increases with the extent of the colon affected by UC, and so is greater if you have extensive colitis than left-sided colitis. People with proctitis have no increased risk. Research shows that the risk of developing cancer usually begins to increase about 8-10 years after the start of the 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) also increases 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 the cells lining the bowel wall. This 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 UC diagnosed?**).

This means that if you have had total, extensive or left-sided 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 be more successfully treated if detected early.

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

DIAGNOSIS, TESTS AND TREATMENT

HOW IS ULCERATIVE COLITIS DIAGNOSED?

If you develop diarrhoea with bleeding and abdominal pain, your doctor may suspect you have UC, particularly if you are a young adult or have a family history of 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, flexible tube with a camera in its tip – to examine your digestive system. There are several types of endoscopy, each with a different name according to the part of the gut being examined. The type of endoscope used will also vary - some are longer, thinner and more flexible than others - and may have a different name. For example:

- **An upper GI endoscopy** - If you have symptoms in the upper part of your digestive system as well as in your colon, you may have what is known as an upper GI (gastrointestinal tract) endoscopy or gastroscopy to rule out Crohn's Disease. In this, an endoscope is inserted through your mouth or nose to examine your oesophagus, stomach and duodenum (the first part of the small intestine or bowel).
- **A colonoscopy or sigmoidoscopy** - These types of endoscopy are often used to help diagnose and monitor Ulcerative Colitis. In these tests, a short endoscope called a sigmoidoscope, or a longer and more flexible colonoscope, is inserted through the anus to examine the rectum and colon. Some people may have an ileocolonoscopy, which allows the endoscopist to examine the ileum (the last part of the small intestine) as well as the colon.

> “I’ve had negative effects with colonoscopies but this has been taken into consideration, and I am now given alternative sedation as a result. Comfort and wellbeing play an important part of your treatment.”
>
> **Bev**, age 48,
> diagnosed with Ulcerative Colitis in 1980

Endoscopies should not be painful but may be uncomfortable, so you may be given a sedative medication to help you relax. For young people under 18, and in rare circumstances for adults, endoscopies may be performed under general anaesthesia. You may be offered pain relief using Entonox (‘gas and air’) as an alternative to intravenous sedation. Biopsies (small samples of tissue) are often taken during the endoscopy. These can then be examined under a microscope to confirm the diagnosis.

MRI AND CT SCANS

Other tests that can sometimes be used to help diagnose UC 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 to locate areas of inflammation.

Sometimes it can be difficult to tell Ulcerative Colitis apart from other inflammatory bowel conditions, especially 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.

It is likely that you will need a combination of investigations. You can find more detailed information about all the tests mentioned above in our information sheet **Tests and Investigations for IBD**.

WILL I NEED REPEATED TESTS?

You may need to have tests repeated from time to time to check on your condition and 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. Your specialist will avoid giving you any unnecessary tests or investigations. You may need more regular colonoscopies when you have had Ulcerative Colitis for a long time to check for any signs of cancer.

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 UC aims to reduce symptoms and control flare-ups, and then maintain remission) once the disease is under control. This can mean that you need to take your medication on an ongoing basis, sometimes for many years. It is less likely that you will need only a short course of drugs. However 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 a few years, and an endoscopy shows disease healing in the gut.

THE MAIN TYPES OF DRUGS

The aim of drug treatment for Ulcerative Colitis is to reduce inflammation. The main types of drugs are:

- **Aminosalicylates (5-ASAs**) reduce inflammation in the lining of the intestine. Examples include mesalazine (brand names include Asacol, Ipocol, Octasa, Pentasa, and Salofalk), olsalazine (Dipentum), sulphasalazine (Salazopyrin) and balsalazide (Colazide).
- **Corticosteroids (steroids)** work by blocking the substances that trigger allergic and inflammatory responses in your body. They include prednisolone, prednisone, methylprednisolone, budesonide (Cortiment), hydrocortisone and beclometasone dipropionate (Clipper).
- **Immunosuppressants** suppress the immune system, and reduce levels of inflammation. The main immunosuppressants used in IBD are azathioprine (Imuran), mercaptopurine or 6MP (Purinethol), methotrexate, ciclosporin and tacrolimus. They are often used in patients who relapse when they come off steroids.
- **Biological drugs** are the newest group of drugs used to treat IBD. Anti-TNF drugs, such as infliximab (Remicade, Remsima, Inflectra), adalimumab (Humira) and golimumab (Simponi) target a protein in the body called TNF, or tumor necrosis factor, preventing inflammation. Another type of biological drug is vedolizumab (Entyvio), which works by stopping white blood cells from entering the lining of the gut and causing inflammation.

You can find more information about some of the drugs used for UC in our drug treatment information sheets: **Adalimumab, Aminosalicylates (5-ASAs), Azathioprine and Mercaptopurine, Biologic Drugs, Golimumab, Methotrexate, Infliximab, Steroids** and **Vedolizumab**.

RESEARCH FACT

Research suggests that taking some 5–ASA drugs may help to reduce the small chance of bowel cancer developing.

OTHER MEDICATIONS AND OVER–THE–COUNTER DRUGS

Other medications may be used to help ease the symptoms of Ulcerative Colitis, rather than reduce the inflammation. However, you should check with your IBD team before using them and they should be used with caution. Examples include:

- **Painkillers** such as paracetamol. It is best to avoid NSAIDs (non-steroidal anti-inflammatory drugs) such as ibuprofen and aspirin because they may make IBD worse, or trigger a flare-up.
- **Antidiarrhoeal drugs** such as loperamide (Imodium, Arret) and diphenoxylate (Lomotil). These work by slowing down the contractions (muscle movements) in the gut, so food moves more slowly. It is very important to not use these in a flare-up as this could lead to serious complications.
- **Laxatives** such as Movicol. These help relieve constipation by increasing the amount of water in the large bowel and making stools softer and easier to pass.
- **Bulking agents** such as Fybogel are made from plant fibre and make stools easier to pass.
- **Antispasmodics** such as hyoscine butylbromide (Buscopan) and mebeverine can reduce painful cramps and spasms by relaxing muscles. They are most commonly recommended for people with IBS, but are occasionally helpful for people with IBD.

You can find out more about these medications in our information sheet **Other Treatments for IBD**.

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. Some may even make your UC symptoms worse if you take them during a flare–up.

WHAT ABOUT SURGICAL TREATMENT?

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.

Up to one in four people with Ulcerative Colitis may eventually need surgery, depending on how severe the disease is and which part(s) of the colon are affected. People with extensive or total colitis are more likely to require surgery than those with proctitis.

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

Most people who decide to have surgery will usually have time to discuss options in advance. More rarely, people with very severe UC that does not respond to intensive medical treatment will need urgent surgery (within a few days) or emergency surgery (within a few hours).

See our information sheet **Surgery for Ulcerative Colitis** for more details about operations. The following are the most likely:

WHAT ARE THE MOST LIKELY OPERATIONS FOR ULCERATIVE COLITIS?

COLECTOMY WITH ILEOSTOMY (SUBTOTAL)

Subtotal colectomies are the most common type of surgery for UC. The surgeon removes the colon, but leaves the rectum, and brings the lower end of the small intestine out through an opening in the wall of the abdomen. This is called an ileostomy or stoma. An external bag is fitted onto the opening to collect waste from digestion. After recovering from this surgery, you can then decide whether to opt for pouch surgery (see below) or a permanent ileostomy, depending on your individual condition.

> “I’ve had my ileostomy since January 2008 and I simply cannot fault the life I have led ever since.”
>
> **Aisha**, age 45, diagnosed with Ulcerative Colitis in 1990

RESTORATIVE PROCTOCOLECTOMY WITH ILEO–ANAL POUCH

This procedure is often called pouch surgery, or IPAA (Ileal Pouch-Anal Anastomosis), and generally requires two or three operations. The surgeon removes the whole colon and the rectum, leaving the anus. A pouch is made using the lower end of the ileum (small intestine) and joined to the anus. A looped section of the small intestine is then brought out through an opening in the abdomen to create a temporary ileostomy. This allows waste to be collected in a stoma bag until the pouch has healed. A final operation closes the ileostomy so the pouch can be used.

PROCTOCOLECTOMY WITH PERMANENT ILEOSTOMY

The surgeon removes the colon, rectum and anal canal, and brings out the end of the lower small intestine onto the wall of the abdomen to form a permanent ileostomy. A bag is fitted onto the opening to collect waste.

COLECTOMY WITH ILEORECTAL ANASTOMOSIS

During this operation the surgeon removes the colon and joins the end of the ileum to the rectum, avoiding the need for a stoma. This operation is only suitable if there is little or no inflammation in the rectum and low long-term risk of developing cancer there.

COMING TO TERMS WITH SURGERY

Having a major part of the bowel removed may be a frightening thought, and you may also be concerned about using a stoma bag. However there have been great improvements in the design of ostomy products, and they are now much more discreet and comfortable. Stoma nurses are usually available to support you. Contact details for organisations that can give practical advice are given at the end of this booklet.

For more information see our information sheet **Living With a Stoma**.

LIVING WITH ULCERATIVE COLITIS

DO I NEED TO CHANGE MY DIET?

There has been extensive research into the role of diet in Ulcerative Colitis, but so far there is little evidence that any particular food or additive can cause or improve UC.

Generally, the most important thing is to eat a nutritious and balanced diet to maintain your weight and strength, and to drink enough fluids to prevent you from becoming dehydrated.

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

You may also find that eating too much fibre can increase the urge to go to the toilet (and associated fears of 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 go on a low-fibre diet. In order to make sure your diet remains healthy and well-balanced, it is important to get advice from your doctor or dietitian before you make any major changes.

> “I have to 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.”
>
> **Katryna**, age 36, diagnosed with Ulcerative Colitis in 2005

Once the flare-up is over, you should try to increase your intake of fibre again. Fibre is useful because it keeps the colon healthier as well as providing fuel for beneficial bacteria.

Some people with UC have noticed that dairy products trigger their symptoms – although research suggests that, in general, people with UC are no more likely to be lactose intolerant than the general population. 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 low levels of vitamins and minerals. This can happen when you have a poor appetite, do not eat enough, or when you have ongoing diarrhoea. Many people with IBD are also deficient in vitamin D. Vitamin D is formed by the action of sunlight on the skin, and is also found in foods such as eggs and oily fish. It is important for the immune system, and is also needed for healthy bones. Some studies have also suggested that vitamin D supplements may help people with Ulcerative Colitis to stay in remission, though more research is needed in this area.

Before taking any supplements or making any changes to your diet, always check with your doctor or a qualified dietician.

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

WHAT ABOUT COMPLEMENTARY AND ALTERNATIVE APPROACHES?

Some people with Ulcerative Colitis find complementary and alternative medicines help their symptoms. Examples include acupuncture, wheatgrass juice, aloe vera gel, omega 3 fish oils and faecal microbiota transplantation. 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. Everyone is different, and what may help one person may not work, or even have a harmful effect, on another.

It is possible that people who benefit from such treatments might have gone into remission coincidentally, given the unpredictable course of Ulcerative Colitis. They could also be experiencing a placebo effect, where their symptoms improve simply because they believe the treatment will work.

It is thought that certain probiotics may help treat some cases of UC by altering the balance of bacteria in the gut. Probiotics are live microorganisms (‘friendly’ bacteria) that can be added to drinks or yoghurts, or taken in capsule form. Research has shown that a specific formulation of high-potency probiotics, previously found in VSL#3 but now sold as Vivomixx, can be effective in preventing pouchitis, an inflammation of an ileo-anal pouch that can occur after surgery for Ulcerative Colitis. Some research also suggests that these probiotics may have a use in maintaining remission in people with UC, although evidence for this is inconclusive. Studies into curcumin (a natural anti-inflammatory agent found in the spice turmeric) have shown some positive effect on UC symptoms, but more research is needed.

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.

HOW DOES ULCERATIVE COLITIS AFFECT CHILDREN AND YOUNG PEOPLE?

About a quarter of people diagnosed with IBD are children or adolescents at the time they are diagnosed. In young people with UC, symptoms often first appear around the age of 12. The symptoms are the same as in adults, although they are often 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 how well a child grows 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 referral to a growth specialist may be recommended. Steroid treatment can also affect growth, but this improves once the steroids are stopped. Some children may also need additional vitamin and mineral supplements to help their growth.

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.

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.

We also have a **Transition: Moving to adult care** booklet for young people who are transitioning from the children's to the adult IBD team.

Visit **crohnsandcolitis.org.uk/young-person** to hear from young people about how they cope with the challenges of living with Crohn's and Colitis.

DOES ULCERATIVE COLITIS RUN IN FAMILIES?

Ulcerative Colitis tends to run in families, and parents with IBD are slightly more likely to have a child with IBD. However, studies show for most people the actual risk is relatively small.

If one parent has UC, the risk of their child developing IBD is about 2% - that is, for every 100 people with UC having a child, about two of the children may be expected to develop IBD at some time in their lives. This risk is higher if both parents have IBD.

However, we still cannot predict exactly how UC is passed on. Even with genetic predisposition, additional factors are needed to trigger IBD.

WHAT ABOUT FERTILITY AND PREGNANCY?

Women with inactive Ulcerative Colitis usually have no more difficulty becoming pregnant than women without IBD, and can expect to have a normal pregnancy and a healthy baby. Also for most women, having a baby does not make their IBD worse.

Your chances of conceiving are not usually reduced by UC, though your fertility could be affected if you have pouch surgery. Reduced fertility 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.

Even if your condition is inactive, 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.

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. 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.

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.

It is generally considered safe to continue taking steroids, most 5-ASAs and azathioprine, although you should not take methotrexate when pregnant or trying to conceive, because it increases the risk of birth defects.

The evidence about the safety of biologic drugs such as infliximab and adalimumab is still fairly limited. However, doctors generally now believe that if they are keeping your IBD in check, it may be better to continue with these drugs at least for the first six months of a pregnancy. Your doctor should discuss the risks and benefits with you.

If you are trying to start a family, or if you are already pregnant, discuss this with your doctor or IBD team. For more details see our information sheets **Fertility and IBD** and **Pregnancy in IBD**, which also covers breastfeeding.

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HOW WE CAN HELP YOU

We produce more than 45 publications about all aspects of IBD, from individual medicines to coping with symptoms and concerns about relationships, school and employment. These are available to download for free on our website: **crohnsandcolitis.org.uk**. Contact our helpline for a printed copy.

Our helpline is a confidential service providing information and support to anyone affected by Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease (IBD).

Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you 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

Contact us by telephone on **0300 222 5700** or email **info@crohnsandcolitis.org.uk**

See our website for Live Chat:
crohnsandcolitis.org.uk/livechat

OTHER USEFUL ORGANISATIONS

Colostomy Association
www.colostomyassociation.org.uk

Core – Fighting Gut and Liver Disease
www.corecharity.org.uk

Crohn's in Childhood Research Association
www.cicra.org

IA – The Ileostomy and Internal Pouch Support Group
www.iasupport.org

NASS – National Ankylosing Spondylitis Society
www.nass.co.uk

Health & care information you can trust
The Information Standard
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JAMES TUDOR
FOUNDATION

This booklet was made possible due to the support of the **James Tudor Foundation**, which had no input into the design or content of the guide.

PAYMENT DETAILS

Individual membership

○ £15 per year Direct Debit

○ £19 Cheque/Credit or Debit Card per year

We could not do what we do without the support of our members so are always very grateful for any additional donations that you may be able to give

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.**
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

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Please pay Crohn's 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 Crohn's and Colitis UK and, if so, details will be passed electronically to my Bank/Building Society.

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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 like to receive this information.

Please return this form along with payment to Crohn's & Colitis UK, 45 Grosvenor Road, St Albans, Herts AL1 3AW