

**CROHN'S &
COLITIS UK**

**FIGHTING
INFLAMMATORY
BOWEL DISEASE
TOGETHER**

**CROHN'S
DISEASE**

YOUR GUIDE



ABOUT THIS BOOKLET

If you have recently been diagnosed with Crohn's Disease or even if you have had Crohn's Disease for some time, you may have many questions about the condition. Knowing more about your Crohn's Disease 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 Crohn's Disease 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.

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 visit our website.

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 more than 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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**ABOUT
CROHN'S
DISEASE**



1

WHAT IS CROHN'S DISEASE?

Crohn's Disease is a condition that causes inflammation of the digestive system (also known as the gastrointestinal tract or gut). Inflammation is the body's reaction to injury or irritation, and can cause redness, swelling and pain.



FACT

Crohn's Disease gets its name from a New York doctor, Burrill Crohn, who reported a number of cases in 1932.

Crohn's Disease is one of the two main forms of Inflammatory Bowel Disease (IBD). The other main form of IBD is a condition known as Ulcerative Colitis (UC).

Crohn's is sometimes described as a chronic condition. This means that it is ongoing and life-long, although you may have periods of good health (remission) as well as times when symptoms are more active (relapses or flare-ups). In many people the disease runs a benign course with few flare-ups, while other people may have more severe disease. Crohn's Disease is not infectious.

At present there is no cure for Crohn's, but drugs, and sometimes surgery, can give long periods of relief from symptoms.

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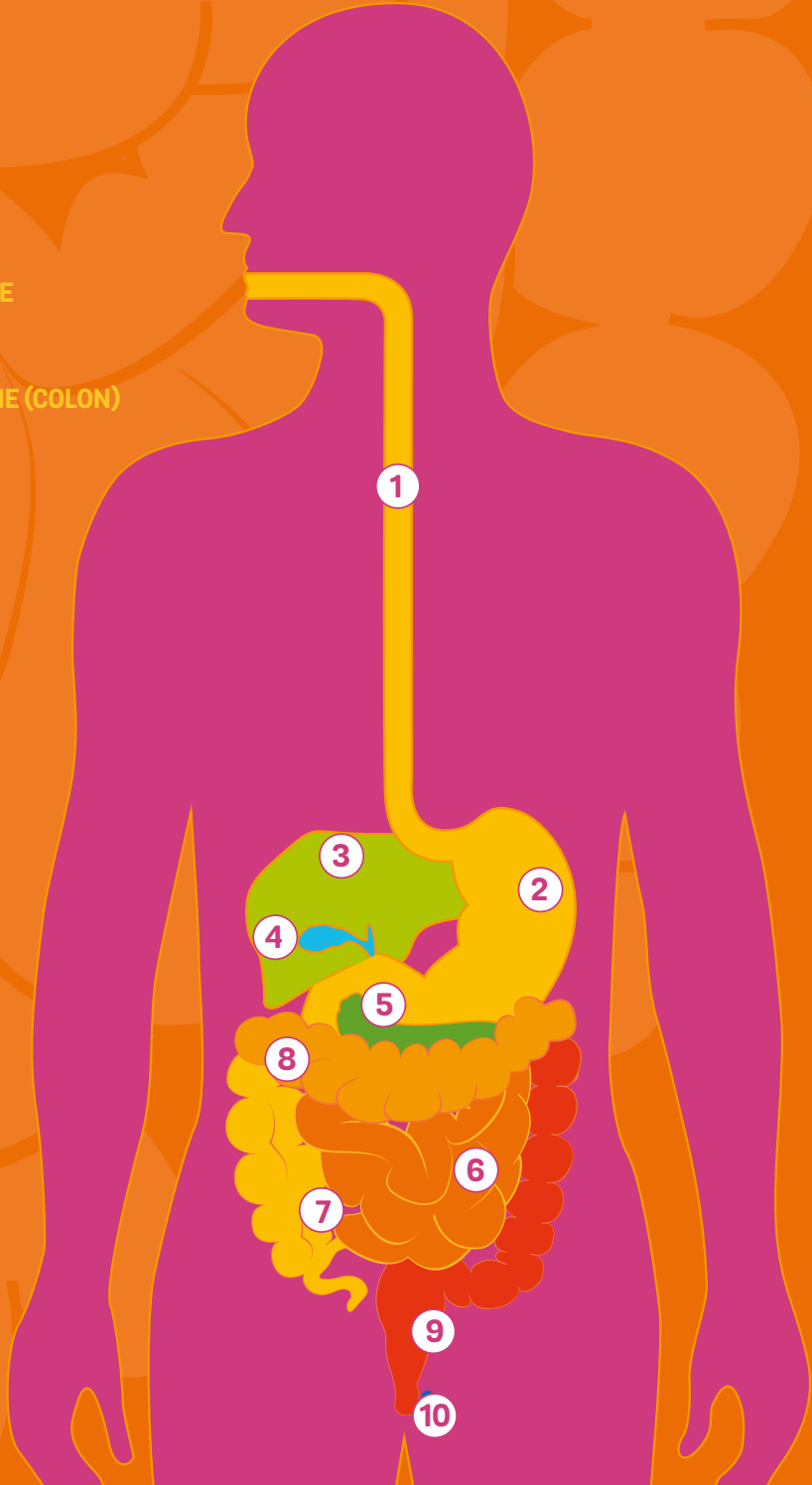
Being diagnosed with Crohn's disease hit me pretty hard and took a long while to mentally and physically adjust to. Since then I've had good days and bad days, but I've tried not to let it stop me living my life. If anything it has given me that extra motivation to say yes more and to go after my dreams. ”

Tom, age 29,
diagnosed with Crohn's in 2011

CROHN'S DISEASE

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 CROHN'S 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 through the small intestine (also known as the small bowel). Here it is broken down even further so that the nutrients (useful parts of the food) can be absorbed into the bloodstream. The waste products from this process – liquid and non-digestible parts of food – then pass into the colon (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 passed out of the body in a bowel movement.

Crohn's causes ulceration and inflammation, which affects the body's ability to digest food, absorb nutrients and eliminate waste, in a healthy way.

Crohn's can affect any part of the gut, but is most likely to develop in the ileum (the last part of the small intestine) or the colon. The areas of inflammation are often patchy, with sections of normal gut in between.

A patch of inflammation may be small, only a few centimetres across, or extend quite a distance along part of the gut. As well as affecting the lining of the bowel, Crohn's may also penetrate deeper into the bowel wall causing abscesses and fistulas (abnormal tracts or passages between organs such as between two sections of bowel, or the bowel and skin).



WHAT ARE THE MAIN SYMPTOMS?

Crohn's 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').

Crohn's is a very individual condition and some people may remain well for a long time, even for many years, while others may have more frequent flare-ups.

Your symptoms may also vary depending on where in your gut you have Crohn's. However, the most common symptoms during a flare-up are:

- **Abdominal pain and diarrhoea.** Sometimes mucus, pus or blood is mixed with the diarrhoea.
- **Tiredness and fatigue.** This can be due to the illness itself, from the weight loss associated with flare-ups or surgery, from anaemia (see below) or to a lack of sleep if you have to keep getting up in the night with pain or diarrhoea.
- **Feeling generally unwell.** Some people may have a raised temperature and feel feverish.
- **Mouth ulcers**
- **Loss of appetite and weight loss.** Weight loss can also be due to the body not absorbing nutrients from the food you eat because of the inflammation in the gut.
- **Anaemia (a reduced level of red blood cells).** You are more likely to develop anaemia if you are losing blood, are not eating much, or your body is not fully absorbing the nutrients from the food you do eat. Anaemia can make you feel very tired.



HOW WILL CROHN'S AFFECT MY LIFE?

There is no single answer to this question because everyone is different and people's experiences vary greatly. Also, much depends on the severity of your condition and whether your disease is in a quiet or active phase.

With medication, many people with Crohn's have mild and infrequent symptoms of diarrhoea and pain, and their illness may not affect their lives very much. Most people follow a course of intermittent relapses (flare-ups) with periods of well-being (remission) in between, when they are able to lead a full and complete working and social life. Less commonly, some people have more frequent or continuous 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 Crohn's. We also have information sheets on **Managing Bloating and Wind, Diarrhoea and Constipation, Managing Bowel Incontinence in IBD** and **Fatigue and IBD**.

You are likely to see your GP, and perhaps also your hospital IBD team, on a fairly regular basis if you have Crohn's Disease. So, it can be very helpful if you 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.

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For me, it's really important to listen to my body and know when to take it easy and rest, because when I'm stressed and tired, that's when my symptoms flare. It is a bit like being on a rollercoaster, sometimes being well, sometimes being poorly, but you can live your life to the full. ”

Claire, age 43
diagnosed with Crohn's
in 2005

HOW COMMON IS CROHN'S DISEASE?

IT IS ESTIMATED THAT CROHN'S DISEASE AFFECTS ABOUT ONE IN EVERY 650 PEOPLE IN THE UK.

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

Crohn's can start at any age, but usually appears for the first time between the ages of 10 and 40, although there is a small peak in the number of people diagnosed over the age of 60.



RESEARCH FACT

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

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Recent surveys suggest that new cases of Crohn's are being diagnosed more often, particularly among teenagers and children. The reason for this is not clear. Crohn's appears to be slightly more common in women than in men. It is also more common in smokers.

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CROHN'S DISEASE

WHAT CAUSES CROHN'S DISEASE?

Although there has been much research, we still do not know exactly what causes Crohn's Disease. However major advances have been made over the past few years, particularly in genetics.

RESEARCHERS NOW BELIEVE THAT CROHN'S 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, smoking, certain medications, and stress have all been suggested as environmental triggers, but there is no definite evidence that any one of these is the cause of Crohn's.

WHAT ARE THE DIFFERENT TYPES OF CROHN'S DISEASE?

Crohn's is often categorised according to which part or parts of the gut are most affected. Sometimes it can affect more than one part of the gut. The main types are as follows:

- **Terminal ileal and ileocaecal**

Crohn's in the ileum (the last part of the small intestine) may be called ileal or sometimes 'terminal ileal' Crohn's – because it is affecting the terminus or end of the ileum. If it also affects the beginning of the large bowel it is known as ileocaecal Crohn's. This is one of the most common forms of Crohn's Disease.

Typical symptoms are pain in the lower right side of the abdomen, especially after eating, diarrhoea and weight loss. Any bleeding is unlikely to be visible in stools, but stools may appear black and blood tests may show that you are anaemic.

- **Small bowel**

This type of Crohn's is also referred to as ileitis or jejunoileitis, depending on the part of the small bowel affected. Abdominal pain and diarrhoea are also typical symptoms of Crohn's in the small bowel, along with nutrient deficiencies. Again, the diarrhoea is unlikely to be blood-stained, but you may still have anaemia, and also weight loss. The small bowel is commonly affected in children and young people.

- **Colonic**

Crohn's Disease in the colon (large intestine or large bowel) is often called Crohn's Colitis. This is also a common form of Crohn's Disease, but is not the same as Ulcerative Colitis. The main symptom tends to be diarrhoea, with blood and mucus. Because of the inflammation, the colon cannot hold as much waste as normal and you may have very frequent bowel movements, especially if your rectum is inflamed. You may also have urgency to pass stools, and tenesmus (feeling the need to pass a stool although the rectum is empty).

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- **Gastroduodenal**

Crohn's in the upper gut – the oesophagus, stomach or duodenum – is much less common, but may occur on its own or alongside Crohn's in other parts of the digestive system. Key symptoms include indigestion-like pain, nausea with or without vomiting, loss of appetite, and weight loss and anaemia.

- **Perianal**

Crohn's in the area around the anus (back passage) can occur on its own or at the same time as inflammation in other parts of the body. It is quite common, and some people notice perianal symptoms before they develop intestinal symptoms. It causes a number of symptoms, such as:

- **Fissures** – these are tears or splits in the lining of the anal canal (back passage), which can cause pain and bleeding, especially during bowel movements.
- **Skin tags** – small fleshy growths around the anus.
- **Haemorrhoids (piles)** – swollen blood vessels in or around the anus and rectum.
- **Abscesses** – collections of pus that can become swollen and painful. They are often found in the area around the anus and can cause a fever or lead to a fistula.
- **Fistulas** – these are narrow tunnels or passageways between the gut and the skin or another organ. In perianal Crohn's, fistulas often run from the anal canal to the skin around the anus. They appear as tiny openings in the skin that leak pus or sometimes faecal matter. They can irritate the skin and are often sore and painful, but can usually be treated with medication and/or surgery. For more information see our information sheet **Living with a Fistula**.

- **Oral Crohn's**

Crohn's can occasionally affect the mouth. True oral Crohn's is often referred to as 'orofacial granulomatosis' and is more likely to affect children, although it is rare. It typically causes swollen lips and mouth fissures. Some people with Crohn's may develop mouth ulcers during flare-ups. This can sometimes be due to nutritional deficiencies such as vitamin B12, folate and iron.

CAN CROHN'S HAVE COMPLICATIONS WITHIN THE BOWEL?

Crohn's can sometimes cause additional problems in the gut. These complications include strictures, perforations and fistulas.

- **Strictures**

Ongoing inflammation and then healing in the bowel may cause scar tissue to form, which can create a narrow section of the bowel. This is known as a stricture. A stricture can make it difficult for food to pass through and, if severe, may cause a blockage (obstruction). Symptoms include severe cramping abdominal pain, nausea, vomiting and constipation. The abdomen may become bloated and distended, and the gut may make loud noises. Strictures are usually treated surgically, often with an operation known as a stricturoplasty. However, in some cases it may be possible to treat them endoscopically with balloon dilatation (see **What are the most likely operations for Crohn's Disease**). Some people have 'inflammatory strictures', where inflammation, not scar tissue, narrows the intestines. Often, medication can reduce this inflammation.

- **Perforations**

Although rare, inflammation deep in the bowel wall or a severe blockage caused by a stricture may lead to a perforation or rupture of the bowel, making a hole. The contents of the bowel can leak through the hole. This complication is a medical emergency. Symptoms include severe abdominal pain, fever, nausea and vomiting. In some cases, the leak will form an abscess.

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- **Fistulas**

Some people with Crohn's may develop a fistula. 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) start in the wall of the intestine and might connect parts of the bowel to each other, or the bowel to the vagina, bladder, or skin (particularly around the anus). A fistula forms when the inflammation in Crohn's spreads through the whole thickness of the bowel wall and then continues to tunnel through the layers of other tissues. Fistulas may be treated medically or with surgery. For more details see our information sheet **Living with a Fistula**.

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HOW DOES CROHN'S AFFECT OTHER PARTS OF THE BODY?

Crohn's Disease can also cause problems outside the gut. Some people with Crohn's develop conditions affecting the joints, eyes or skin. These can be known as extraintestinal manifestations (EIMs) and often occur during active disease, but they can develop before any signs of bowel disease or during times of remission. Many of these are not very common.

- **Joints**

Inflammation of the joints, often known as arthritis, is a common complication of Crohn's Disease. It is most common in those with Crohn's Colitis (Crohn's Disease in the colon). The inflammation usually affects the large joints of the arms and legs, including the elbows, wrists, knees and ankles. Fluid collects in the joint space, causing painful swelling, although pain may occur without obvious swelling. Symptoms usually improve with treatment of 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 persist even when the IBD is in remission.

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Sometimes, the joints in the spine and pelvis become inflamed – a condition called ankylosing spondylitis (or sacro-iliitis, in its less severe form). This can flare up independently of Crohn's. It often causes pain over the sacroiliac joints, on either side of the lower part of the spine. Stiffness and pain in the spine itself may eventually lead to loss of flexibility. Drugs and physiotherapy can be helpful in treating these symptoms, and the condition is usually managed jointly by rheumatology and gastroenterology specialists.

- **Skin**

Crohn's can also cause skin problems. The most common skin problem is erythema nodosum, which affects about one in seven people with Crohn's, and is more common in women than men. It consists of raised tender red or violet swellings 1.5cm in diameter, usually on the legs. This condition tends to occur during flare-ups and generally improves with treatment for Crohn's.

More rarely, a condition called pyoderma gangrenosum affects people with Crohn's Disease. This starts as small tender blisters or pustules, 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 biological therapy.

Another skin condition associated with Crohn's Disease is Sweet's Syndrome, where tender red nodules appear on the upper limbs, face and neck, sometimes with a fever. It is generally associated with active Crohn's Disease, and can be treated by steroids or immunosuppressants.

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- **Eyes**

Eye problems affect some people with Crohn's. The most common condition is episcleritis, which affects the layer of tissue covering the sclera, the white outer coating 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.

The two other eye conditions linked with Crohn's are scleritis (inflammation of the sclera itself) and uveitis (inflammation of the iris). These conditions are a lot more serious and can lead to loss of vision if not treated. If you get any kind of eye irritation, redness or inflammation, always mention it to your doctor, who may refer you to an eye specialist. Scleritis and uveitis can usually be treated with steroid drops, although sometimes immunosuppressants or biological drugs are needed.

- **Bones**

People with Crohn's are more at risk of developing thinner and weaker bones. This can be diagnosed by a dual-energy x-ray absorptiometry (DEXA) scan. Bone thinning can be due to the inflammatory process itself, poor absorption of calcium needed for bone formation, low calcium levels because the diet does not contain enough dairy foods, smoking, low physical activity or the use of steroid medication. Calcium and vitamin D supplements, stopping smoking, weight bearing physical activity, avoiding steroids, and, for some people, drug treatment can be helpful. For more details, see our information sheet **Bones and IBD**.

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- **Kidneys**

People with Crohn's Disease have an increased risk of developing kidney stones. This can be due to inflammation in the small bowel causing fat malabsorption, so the fat binds to calcium, leaving a molecule called oxalate free to be absorbed and deposited in the kidneys where it can form stones. Another cause of kidney stones is dehydration, which can be caused by fluid loss from diarrhoea. More concentrated urine results from dehydration, which can lead to kidney stones. Symptoms of kidney stones include pain, nausea, vomiting and blood in the urine.

Inflammation in the small bowel can affect the ureters (tubes which carry urine from the kidneys to the bladder) by pressing on the tubes and blocking them, preventing the urine from draining. This makes the kidney swell up, and surgery may be needed to remove the inflamed section of tissue so the urine can flow again.

- **Liver**

Some complications are related to the liver and its function. About one in three people with Crohn's develop gallstones. These are small stones made of cholesterol which may get trapped in the gallbladder, just beneath the liver, and can be very painful. Several factors linked with Crohn's can make gallstones more likely – for example, removal of the end of the small intestine or severe inflammation in this area, which can lead to poor absorption of bile salts (which help to digest fat in the gut).

- Some of the drugs used to treat Crohn's (for example, azathioprine and methotrexate) may affect the liver. Changes in treatment may help to reduce this type of complication.

Primary Sclerosing Cholangitis (PSC) is a rare disease that affects up to one in 50 people with Crohn's. It causes inflammation of the bile ducts and can eventually damage the liver. Symptoms include fatigue, itching, jaundice, and weight loss.

- **Blood circulation**

People with Crohn's are more than twice as likely to develop blood clots, including DVT (deep vein thrombosis) in the legs, and pulmonary embolisms in the lungs. 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 not smoking, by 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**.

- **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 lower levels of haemoglobin in your blood (haemoglobin is a protein found in red blood cells and carries oxygen around the body). There are several different types of anaemia. People with IBD 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. Blood loss from the bowel commonly causes anaemia in people with Crohn's, even if the blood loss is not visible. It is important to try and ensure a good intake of foods containing iron to help prevent anaemia.

Another type of anaemia is vitamin deficiency anaemia, caused by a low intake or poor absorption of certain vitamins, such as vitamin B12 or folic acid. This may particularly affect people with Crohn's who have had sections of the small intestine removed. Some of the drugs used for IBD (for example, sulphasalazine and azathioprine) can also cause anaemia.



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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 anaemia is treated will depend on its cause. For iron deficiency anaemia you may be prescribed iron supplements as tablets or as IV (intravenous) iron, which is given by injection or in an infusion through a drip. Some people with IBD find that they cannot tolerate iron by mouth, so are given IV iron which can be more effective. For vitamin deficiency anaemia you may be given extra B12 or folic acid, as tablets or by injection.

COULD MY SYMPTOMS BE IBS?

IBS stands for Irritable Bowel Syndrome. This 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 Crohn's or UC, and there is no blood loss with IBS.

However, some people with Crohn's may develop IBS-like symptoms. They may, for example, get diarrhoea even when their IBD is inactive. IBS is more common in people with IBD than in the general population.

CAN CROHN'S LEAD TO CANCER?

You may have a slightly increased risk of bowel cancer if you have had Crohn's Disease affecting all or most of the colon for more than 8 to 10 years. Bowel cancer risk is increased further if you have primary sclerosing cholangitis, which also increases the risk of developing cancer in the liver. For more details, see our information sheet **Bowel Cancer and IBD**.

**DIAGNOSIS,
TESTS AND
TREATMENT**



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HOW IS CROHN'S DIAGNOSED?

If you develop diarrhoea, abdominal pain, and weight loss lasting for several weeks or longer, or have blood in your stools, your doctor may suspect that you have Crohn's, particularly if you are a young adult or have a family history of IBD. You will then need tests and physical examinations to confirm a diagnosis. These may include:

Blood Tests 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 suspected, you may then have an examination to look inside your body, such as an endoscopy or scan.

Endoscopy

There are several types of endoscopy which have different names according to the part of the bowel being examined. For example:

- Upper GI endoscopy (or gastroscopy) – If you have symptoms coming from the upper part of your gut, you may have what is known as an upper GI (Gastrointestinal Tract) endoscopy. In this, the specialist inserts an endoscope (a thin flexible tube with a camera in its tip) through your mouth to examine your oesophagus, stomach and duodenum.
- Sigmoidoscopy or colonoscopy – If you have symptoms in your ileum or colon, you will have a sigmoidoscopy or a colonoscopy. This means a sigmoidoscope (a short endoscope) or a colonoscope (a longer endoscope) will be inserted through the anus (back passage) to examine the rectum and colon. A sigmoidoscopy examines the left side of the colon, while a colonoscopy allows the whole of the colon and the terminal ileum to be examined.

DIAGNOSIS, TESTS AND TREATMENT

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

Capsule Endoscopy

For a capsule endoscopy, you will be asked to swallow a capsule about the size of a small grape, containing a tiny camera, transmitter and light source. As it passes through your intestine, it takes photos of the inside of the gut and transmits these to a data recorder worn around the waist. The capsule is disposable and passes out of the body naturally in a bowel movement. Not all centres offer capsule endoscopy and it may not be suitable for everyone, for example if you have a stricture. It is particularly useful in examining the small bowel.

MRI and CT Scans

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

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

When inflammation only affects the colon, it can sometimes be difficult to know if the diagnosis is Crohn's Disease or Ulcerative Colitis (UC). UC also affects the lining of the colon, causing inflammation and tiny ulcers. If it remains unclear which condition you have, you may be given a diagnosis of IBD Unclassified (IBDU) or Indeterminate Colitis. This should not affect the start of any treatment.

WILL I NEED REPEATED TESTS?

You may need to have the 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 potential side effects. However, your specialist will avoid giving you any unnecessary tests or investigations.

WHAT TREATMENTS ARE THERE FOR CROHN'S?

Treatment for Crohn's may be medical, surgical or a combination of both. If your condition is mild, not having any treatment might also be an option. Dietary therapy may be another option for some people, particularly children.

Your treatment will depend on the type of Crohn's you have and the choices you make in discussion with your doctor.

WHAT DRUGS ARE USED TO TREAT CROHN'S?

Drug treatment for Crohn's usually aims to reduce symptoms, control flare-ups and achieve remission, and then to prevent a relapse (maintain remission) once the disease is under control. This can mean that you need to take your medication on an on-going basis, sometimes for many years.

Or, you may need only a short course of drugs.

DIAGNOSIS, TESTS AND TREATMENT

The main aim of drug treatment for Crohn's Disease is to reduce inflammation. The main types of drugs are:

- **Aminosalicylates (5-ASAs)** reduce inflammation in the lining of the intestine. Examples include mesalazine, olsalazine, sulphalazine and balsalazide.
- **Corticosteroids (steroids)** work by blocking the substances that trigger allergic and inflammatory responses in your body. They include prednisolone, prednisone, methylprednisolone, budesonide, hydrocortisone, and beclometasone dipropionate.
- **Immunosuppressants** suppress the immune system, and reduce levels of inflammation. The main immunosuppressants used in IBD are azathioprine, mercaptopurine, methotrexate, mycophenolate mofetil, ciclosporin, and tacrolimus. They are often used in patients who relapse when they come off steroids.
- **Antibiotics** such as metronidazole and ciprofloxacin are sometimes used in Crohn's Disease (for example to treat abscesses or fistulas, and after some types of surgery).
- **Biological drugs** are the newest group of drugs used to treat Crohn's. Anti-TNF drugs, such as infliximab, adalimumab, and golimumab target a protein in the body called TNF, preventing inflammation. Another type of biological drug is vedolizumab, which works by stopping white blood cells entering the lining of the gut and causing inflammation. Ustekinumab, the newest biological drug to be recommended for Crohn's, works by targeting two specific, naturally occurring proteins which play a key role in inflammatory and immune responses.

OTHER MEDICATIONS AND OVER THE COUNTER DRUGS:

Other medications may be used to help ease the symptoms of Crohn's, 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:

- **antidiarrhoeal drugs** such as loperamide and diphenoxylate. These work by slowing down the contractions (muscle movements) in the gut, so food moves more slowly. They should not be used in a flare-up, particularly if the colon is affected or if you have a stricture. You should check with your IBD team before taking anti-diarrhoeals.
- **bile salt binders** such as colestyramine. These bind to bile salts, which may enter the colon in excess and cause diarrhoea if the ileum is affected or removed by surgery.
- **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. However, they should be avoided if you have a stricture (narrowing of the bowel).
- **painkillers** such as paracetamol. NSAID (non-steroidal anti-inflammatory drugs) such as ibuprofen are best avoided because they may make IBD worse, or trigger a flare-up.
- **antispasmodics** such as hyoscine butylbromide 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, although caution must be used especially if there is a risk of developing an obstruction.

It is best to talk to 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 over the counter drugs may make your symptoms worse and can cause blockages.

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WHAT IS DIETARY TREATMENT?

Some people with IBD may be prescribed exclusive enteral nutrition (a special liquid-only diet), usually for 2-8 weeks. People on this diet do not eat ordinary food or drink because the liquid diet provides them with all the nutrients they need.

Not everyone likes the taste of these specialised feeds, but they do come in a range of flavours. Some people have found that taking the liquid ice-cold or through a straw makes it easier to drink. An alternative may be to take the feed overnight through a naso-gastric tube (a fine tube passed through the nose down into the stomach).

It is commonly used in children because it can improve growth by providing easily digested nutrients. It may also make it less likely that steroids are needed, by helping to 'rest' the bowel and allow it to heal. Adults are less likely to need exclusive enteral nutrition, but this can be an option for treating flares. Diets such as this are usually supervised by a dietitian.

Some people may find it helpful to have supplemental drinks alongside normal food, in order to obtain more nutrients. This may also be useful for children.

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WHAT ABOUT SURGICAL TREATMENT FOR CROHN'S?

Over the last decade, advances such as the development of biological drugs have produced increasingly effective medical therapies for Crohn's Disease. There have also been changes in the way surgery for Crohn's is now managed. For example, extensive resections (wide-spread removal of sections of the intestine) are now less common. However, surgery remains an important treatment option, often in combination with medical therapies. Up to 8 out of 10 people with Crohn's will still need surgery at some point in their lives.

Some people may choose to have surgery when other treatments are not sufficiently controlling their symptoms. This may have the advantage of giving time to prepare for an operation. For example, if you are very underweight, your doctor may advise you to improve your nutrient intake before having surgery, perhaps by taking a special liquid feed to supplement your diet (see **What is dietary treatment?** on page 26). Also, if you smoke, you will be strongly advised to stop smoking before you have surgery. Research has shown that continuing to smoke increases the risk of needing further operations for Crohn's Disease.

Very occasionally, some people will need an urgent operation – for example, if they have a severe blockage in the intestines or a hole or tear in the bowel.

WHAT ARE THE MOST LIKELY OPERATIONS FOR CROHN'S?

The two operations most commonly carried out are stricturoplasty and resection.

Stricturoplasty (also known as strictureplasty)

A stricture is a narrowing of the intestine, which can make it difficult for food and waste products to move through the narrowed section. In a stricturoplasty operation the surgeon widens the narrowed part by

DIAGNOSIS, TESTS AND TREATMENT

opening it up, reshaping it, and then sewing it together again. The advantage of this operation is that you can get relief from symptoms of a blockage without losing any of the bowel.

For very short strictures that are accessible by colonoscopy, it may be possible to have an endoscopic balloon dilatation. In this procedure, an endoscope with a balloon attached is used to widen the narrowed part of the intestine.

Resection

This involves removing the severely inflamed parts of the intestine, which may have a blockage or a fistula, and then joining the healthy ends together again.

For more details on these operations see our information sheet: **Surgery for Crohn's Disease**.



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I've found life much easier since I had surgery to form my ileostomy – I was very lucky because it completely changed my life for the better. I still have issues with my joints and eyes sometimes, but my weight has been stable for years now, I'm no longer housebound, and I'm very grateful that I rarely have pain anymore.”



Kate, age 28,
diagnosed with Crohn's in 2004

ARE THERE OTHER OPERATIONS FOR CROHN'S?

Very occasionally for people with Crohn's in the colon (large bowel), it may be necessary to remove the whole colon and perhaps the rectum. In this case your surgeon may suggest one of the following operations:

Proctocolectomy and ileostomy

In this operation the surgeon removes the whole colon and rectum, and brings the end of the small intestine out through an opening in the wall of the abdomen. This is a permanent ileostomy or stoma. A bag is fitted on to the opening to collect the waste that would previously have gone into the colon. The bag can be emptied or changed when necessary.

Ileo-rectal anastomosis

Sometimes when the whole of the colon has to be removed, it may be possible to join the ileum (lower end of the small intestine) to the upper end of the rectum. This is only possible if the rectum has not been affected.

Partial colectomy and colostomy

If only part of the colon is affected it may be possible to remove just the damaged section and rejoin the healthy colon or bring out the end of the colon as a stoma, usually on the lower left side of the abdomen. This is known as a colostomy.

Temporary stoma: ileostomy or colostomy

Sometimes your doctor may recommend a temporary ileostomy or colostomy to divert the waste produced from digestion away from the inflamed intestine to give it a chance to heal. Once the intestine has sufficiently recovered, the stoma will be closed. This might be after three to six months, or longer, depending on how the inflammation behaves.

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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 many advances and improvements in the design of stoma products, which are now much more discreet and comfortable. Specialist nurses are usually available to help if you have an ileostomy or colostomy. There are also several organisations that give practical advice and support - contact details are given at the end of this booklet.

Our information sheets **Surgery for Crohn's Disease** and **Living With a Stoma** give more details about these operations and coping with an ostomy.

SURGERY FOR FISTULAS AND ABSCESSES

If you have an abscess it might require draining. An abscess is a localised collection of pus caused by infection.

Visible abscesses, such as those around the anus, look like boils and treatment often involves lancing (opening the abscess with a blade and letting the infection drain out). Symptoms of an abscess include swelling, tenderness, pain, and fever. Once the abscess is drained, the symptoms resolve. Antibiotics are usually given to clear up any remaining infection.

An abscess may form in the intestinal wall sometimes causing it to bulge out. This is an intra-abdominal abscess, which may need draining, either during an operation or by a radiologist.

If you have a fistula, you might require surgery to close the tract or to place a seton (a thin string that ensures pus can drain away, preventing abscess formation). For more information on this see our information sheet **Living with a Fistula**.

Sometimes an examination may be carried out under anaesthetic in order for the doctor to examine a fistula or abscess in detail.

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DO I NEED TO CHANGE MY DIET?

There is no clear evidence that any food or food additive directly causes or improves Crohn's.

Generally, the most important thing is to try to eat a nutritious and balanced diet so that you maintain your weight and strength, and to drink sufficient fluids to stop you getting dehydrated.

On the other hand, some people with Crohn's have found certain foods seem to trigger their symptoms or make them worse, and, for example, it can help if they adjust the amount of fibre they eat or cut out wheat, spicy or dairy products. It may be worth looking at your own diet to see if you can find similar triggers. However, 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. It may help to keep a food diary to track what you have eaten and if your symptoms change.

If you have a stricture, you may need to avoid eating 'hard to digest' or 'lumpy' foods that might cause a blockage. Your dietitian should be able to advise you on this. Typically, such foods include high-fibre foods, nuts and seeds, fruit and vegetable skins, and tough meat or gristle. It may also help to have small, frequent meals or snacks, and to chew food thoroughly.

There is some evidence that avoiding cinnamon and benzoates (for example, found in carbonated drinks) may help children with Crohn's affecting the mouth.

People with Crohn's are at risk of vitamin deficiencies, particularly if they have trouble absorbing nutrients due to inflammation in the small intestine. It may be necessary to take a vitamin supplement – your doctor or IBD nurse will tell you if this is the case.

LIVING WITH CROHN'S DISEASE

- Many people with Crohn's are **iron deficient**, which can lead to anaemia (where there is less haemoglobin or fewer red blood cells to carry oxygen around the body). You may be given iron supplements as tablets by mouth or via an infusion (an injection using a drip into a vein). See **How does Crohn's affect other parts of the body**.
- People who have had their terminal ileum (the last part of the small intestine) removed, or who have inflammation in that area, may have **vitamin B12 deficiency**. This can lead to a form of anaemia, which is treated by vitamin B12 injections.
- Some of the drugs used for Crohn's can also lead to deficiencies, for example sulphasalazine can affect the body's ability to absorb folates, and steroids can cause **calcium** loss which can lead to osteoporosis. Calcium supplements (with vitamin D) may help prevent osteoporosis (for more information, see our information sheet **Bones and IBD**).
- **Vitamin D** is another common deficiency amongst people with IBD. Vitamin D is formed by the action of sunlight on the skin, and can also be 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 suggest that low vitamin D levels may lead to an increased risk of surgery and hospitalisations, particularly in people with Crohn's. Another study found that giving vitamin D supplements to people with Crohn's reduced the risk of having a flare-up.

For more information on diets and on healthy eating and Crohn's Disease see our booklet **Food and IBD**.

WHAT ABOUT COMPLEMENTARY AND ALTERNATIVE APPROACHES?

Some people with Crohn's Disease have found complementary and alternative medicines (CAM) helpful for controlling symptoms such as abdominal pain and bloating.

However, there are few reliable scientific studies to show the effectiveness of such therapies and it is possible that those people might have gone into remission coincidentally, given the unpredictable course of conditions such as Crohn's. Or there may have been a 'placebo' effect – there is evidence that if people take a placebo (a harmless inactive substance) but believe that it will help, then their symptoms may improve regardless of the actual effectiveness of that treatment.

Small studies have shown that acupuncture and a herbal medicine containing wormwood may help with Crohn's Disease, but more work is needed in this area.

There has also been research into the use of probiotics in Crohn's Disease, but as yet there is no clear evidence that probiotics help to induce or maintain remission in people with Crohn's Disease.

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 have improved.

You should be cautious about taking treatments that can boost an already overactive immune system, as this could make your condition worse.

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WHAT ABOUT FERTILITY AND PREGNANCY?

Women with inactive Crohn's usually have no more difficulty becoming pregnant than women without IBD, and can expect to have a normal pregnancy and a healthy baby.

However, if you have active Crohn's, it may be more difficult to get pregnant, particularly if you are underweight or eating poorly. Severe inflammation in the intestines can also affect the normal function of the ovaries and may cause adhesions (bands of scar tissue) that affect the fallopian tubes. In general, male fertility is not affected by IBD, although men taking sulphasalazine may have reduced fertility whilst on the drug. A few studies have suggested that sperm quality may be affected by Crohn's Disease, but it is not clear whether this is more likely to be the effect of poor nourishment. Treatment of the disease should restore fertility to its usual level.

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.

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. Severe active Crohn's can put the 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 treatments can be continued while you are pregnant.

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However, you should not take methotrexate, mycophenolate mofetil or thalidomide when pregnant or trying to conceive, because they increase the risk of birth defects.

The evidence about the safety of biological drugs such as infliximab and adalimumab is still fairly limited. However, most doctors now consider that if they are keeping your IBD in check, it may be better to continue with these drugs 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, do discuss this and your drug treatment 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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DOES CROHN'S RUN IN FAMILIES?

Crohn's does tend 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 still relatively low.

If one parent has Crohn's, the risk of their child developing IBD is generally thought to be between 5% and 10% – that is, for every 100 people with Crohn's having a child, 5 to 10 of the children may develop IBD. However, we still cannot predict exactly how Crohn's is passed on. Even with genetic predisposition – that is, an increased risk because of a person's genes – additional factors are needed to trigger IBD.

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HOW DOES CROHN'S AFFECT CHILDREN AND YOUNG PEOPLE?

As many as a quarter of people with IBD are diagnosed when under the age of sixteen. Over the last few decades a number of studies have shown Crohn's is occurring more often in children and young people. There is also evidence to suggest that when Crohn's begins in childhood the inflammation can be more severe and affect more of the bowel.

Inflammation of the bowel can affect growth patterns and may lead to delayed puberty. Poor nutrition and prolonged use of steroids can also contribute to the slower growth found in many children with Crohn's. Reducing steroid use and moving to treatment with enteral nutrition and immunosuppressants or even surgery may help encourage catch-up growth. Although children with IBD may grow more slowly than other children, four out of five should reach their full adult height.

Although most children and young people with Crohn's 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.

HOW WE CAN HELP YOU

We offer more than 45 publications on many aspects of Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease. These are available to download for free on our website: www.crohnsandcolitis.org.uk

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

Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has a personal experience of IBD

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

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

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OTHER USEFUL ORGANISATIONS

Bladder and Bowel Community

www.bladderandbowel.org

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

National Osteoporosis Society

www.nos.org.uk



PAYMENT DETAILS

Individual membership

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

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

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 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.

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 like to receive this information.

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

BECOME A MEMBER TO

RECEIVE SUPPORT & INFORMATION

Free publications and guides accredited by health professionals. Access to support and information helplines. A members magazine filled with inspiring feature stories, news and research progress. Membership will help you to better manage your care, with online advice, Local Networks, our Can't Wait Card for toilet access, and members-only offers.

BELONG TO A COMMUNITY

Share experiences and connect with each other online, at events and through Local Networks supported by health professionals and policymakers. Help us raise awareness and campaign for better health services. Support life-changing research to increase the knowledge of causes and best treatments.

JOINING IS EASY

You can become a member if you are 16 years or older. In addition to patients, we welcome parents, family members and friends, health professionals and anyone who wants to support the charity.

If you have internet access, join faster at 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 patient

A relative of a patient

Health professional

General supporter

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

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