

Crohn's Disease



**Improving life for people affected
by inflammatory bowel diseases**

www.crohnsandcolitis.org.uk

About this booklet

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

All our booklets and information sheets are research based and produced in consultation with patients, medical advisers and other health or associated professionals.

However, they are prepared as general information on a subject. They are not intended to replace specific advice from your own doctor or any other professional. Crohn's and Colitis UK does not endorse or recommend any products mentioned.

About Crohn's and Colitis UK

We are a UK-wide charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Diseases such as Ulcerative Colitis and Crohn's Disease. We have over 30,000 members and 70 Local Groups throughout the UK.

Membership costs £15 a year. Students, over 65s and people on lower incomes may join at a lower rate.

We do not charge for copies of this booklet, but we do need funds to be able to produce it. Please consider making a donation or becoming a member of Crohn's and Colitis UK. To find out how call **0845 130 2233** or visit www.crohnsandcolitis.org.uk

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Crohn's Disease

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.

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, so may also be called 'IBD'. The other main form of IBD is a condition known as Ulcerative Colitis.

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).

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

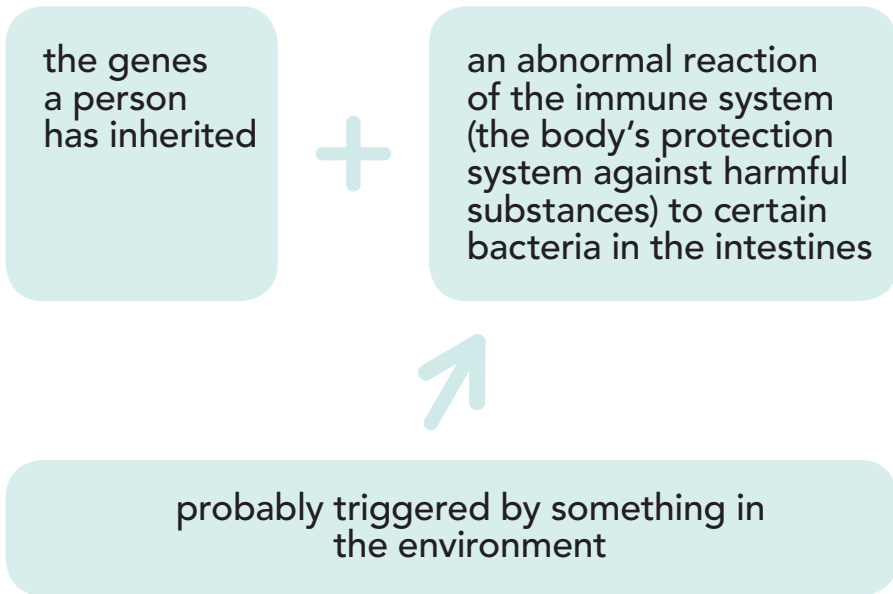


Fact: Crohn's is not infectious

What causes Crohn's Disease?

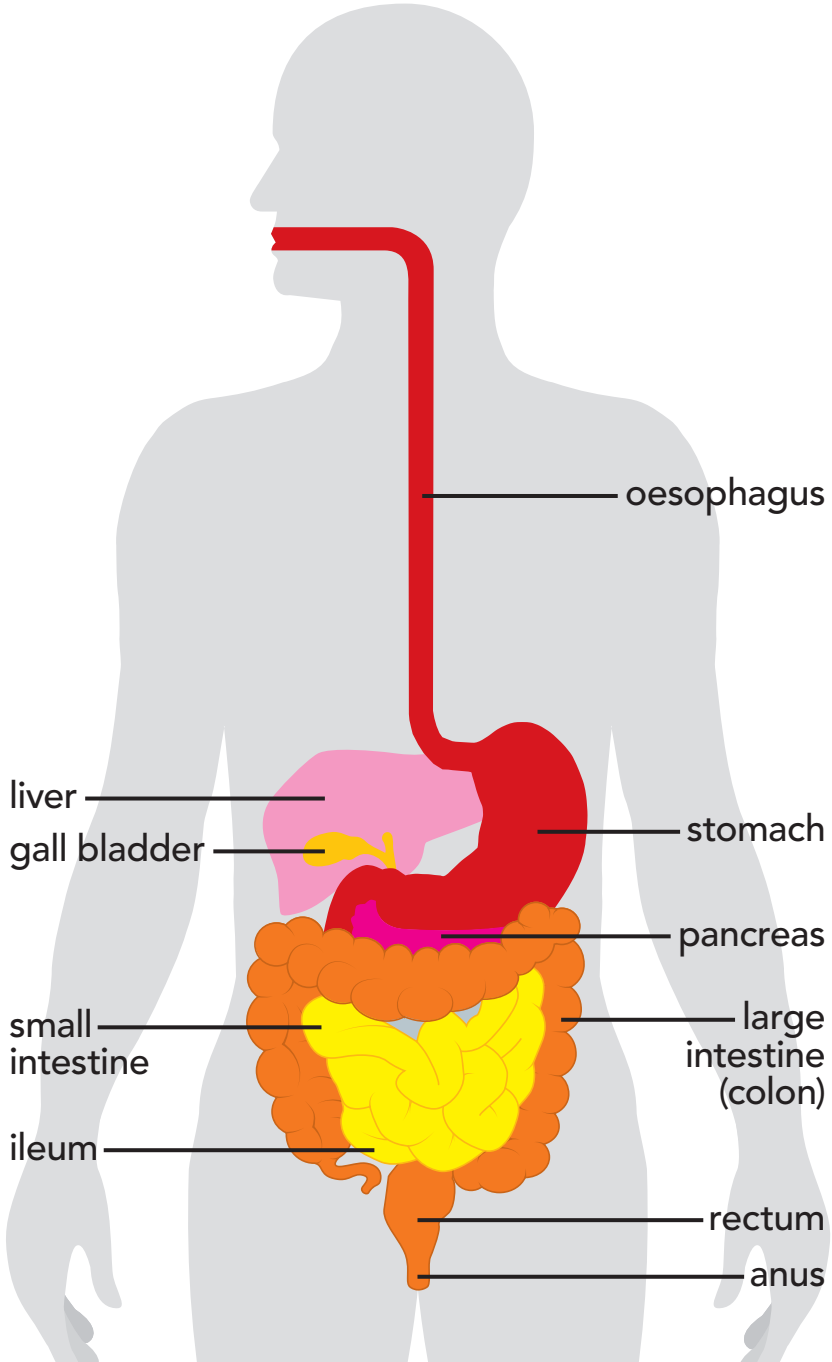
Although there has been a lot of research, we still don't really know what causes Crohn's Disease. However, over the past few years major advances have been made, particularly in genetics.

Researchers now believe that Crohn's is caused by a combination of factors:



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

The digestive system



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 undigested parts of food – are then pushed into the colon (also known as the large intestine or large bowel). The colon absorbs the liquid, and the left over waste forms solid faeces (stools). These collect in the last part of the colon and the rectum until they are passed out of the body in a bowel movement.

Crohn's causes ulceration and inflammation that 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, or extend quite a distance along part of the gut. As well as affecting the lining of the bowel, Crohn's may also go deeper into the bowel wall.

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').

It is a very individual condition and some people may remain well for a long time, even for many years, while others have 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 a straightforward 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 also make you feel very tired.

How common is Crohn's Disease?

It's estimated that Crohn's Disease affects about **one in every 650 people** in the UK.

It's more common in urban rather than rural areas and in northern developed countries, although the numbers are beginning to increase in developing nations. 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. 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.



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, particularly after surgery.

What are the main types of Crohn's Disease?

Crohn's is often categorised according to which part or parts of the gut are most affected. 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. With this type of Crohn's you may feel pain in the lower right side of your abdomen, especially after eating. There is often weight loss, and you may have diarrhoea. Because Crohn's in the ileum can make it difficult for your body to absorb bile salts, and bile salts can irritate the bowel lining, the diarrhoea may be watery. It is unlikely to be bloody, as any blood lost will be digested by the time it reaches the rectum. About four out of 10 people with Crohn's have ileal or ileocaecal disease.

Small bowel

Abdominal pain and diarrhoea are also common symptoms of Crohn's further up the small bowel. Again, the diarrhoea is unlikely to be blood stained, but you may still have weight loss and anaemia. Nearly a third of people with Crohn's have it in the small bowel.

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. The main symptom tends to be blood stained diarrhoea. Because of the inflammation, the colon cannot hold as much waste as normal and you may have very frequent bowel movements (six or more a day), especially if your rectum is inflamed.

Gastroduodenal

Crohn's in the upper gut – the oesophagus, stomach or duodenum – is much less common. Key symptoms include indigestion-like pain, nausea, loss of appetite, and weight loss.

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 can cause a number of symptoms such as:

- **Fissures** – these are tears 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** – swollen areas in the anal canal.
- **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, which typically causes swollen lips and mouth fissures, is rare. However, about one in five people with Crohn's has a tendency to develop mouth ulcers.

Can Crohn's have complications?

Crohn's can sometimes cause complications (extra problems). These may be in the gut itself or can involve other parts of the body. Complications in the gut may include strictures, perforations and fistulas.

Strictures

Ongoing inflammation and then healing in the bowel may cause scar tissue to form. This can create a narrow section of the bowel, known as a stricture. A stricture can make it difficult for food to pass through and may then cause a blockage. 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 (see [What are the most likely operations for Crohn's Disease](#)).

Perforations

Very occasionally, 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 and form an abscess. This causes pain and a fever. An abscess may also develop into a fistula.

Fistulas (Fistulae)

A fistula can form 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. These tunnels or passageways can connect the bowel to other loops of bowel, to the surrounding organs, such as the bladder and vagina, or to the outside skin, including the skin around the anus, as mentioned above (see [Perianal Crohn's](#)). Fistulas may be treated medically or with surgery. For more details see our information sheet [Living with a Fistula](#).

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 often occur during active disease, but they can develop before any signs of bowel disease or during times of remission. Crohn's may also lead to bone thinning, liver problems, blood clots and anaemia.

Joints

Inflammation of the joints, often known as arthritis, affects up to one in three people with IBD. In people with Crohn's 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 there can be pain without obvious swelling. Symptoms usually improve with treatment for intestinal symptoms and there is generally no lasting damage to the joints. A few people develop swelling and pain in the smaller joints of the hands or feet. This may be longer lasting and persist while the IBD is in remission.

More rarely, the joints in the spine and pelvis become inflamed – a condition called ankylosing spondylitis. This can flare up independently of the Crohn's. This often causes pain over the sacroiliac joints, on either side of the lower part of the spine. Stiffness and pain of the spine itself may eventually lead to loss of movement. Drugs and physiotherapy can be helpful in treating these symptoms.

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. Painful red swellings appear, usually on the legs, and then fade leaving a bruise-like mark. This condition tends to occur during flare-ups and generally improves with treatment for the Crohn's.

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

Eyes

Eye problems affect about one in 20 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. Two other eye conditions linked with Crohn's are scleritis (inflammation of the sclera itself) and uveitis (inflammation of the iris). These conditions can usually be treated with steroid drops given into the eye, although uveitis and scleritis may need treatment with immunosuppressants or biologic drugs. If you get any kind of eye irritation or inflammation, always mention it to your doctor, who may refer you to an eye specialist.

Bones

People with Crohn's are more at risk of developing thinner and weaker bones. 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, or the use of steroid medication. Calcium supplementation and, for some people, drug treatment can be helpful. For more details, see our information sheet [Bones and IBD](#).

Liver

Some complications are related to the liver and its function. About one in four people with Crohn's develops 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. (Bile salts help to digest fats during digestion). Some of the drugs used to treat Crohn's, for example azathioprine and methotrexate, may affect the liver. Changes in treatment may help reduce this type of complication.

A condition called Primary Sclerosing Cholangitis (PSC) affects up to one in 25 people with Crohn's, usually those with the disease in the colon. PSC is a rare disease that causes inflammation of the bile ducts and can eventually damage the liver. Symptoms include fatigue, pain, itching, jaundice, and weight loss. Treatment is usually with ursodeoxycholic acid.

Blood circulation

People with Crohn's are about twice as likely to develop blood clots in the veins, including DVT (deep vein thrombosis) in the legs. You may be particularly at risk during a flare-up or if you are confined to bed, for example in hospital. If you get pain, swelling and tenderness in your leg, or chest pains and shortness of breath, contact your doctor straight away. You can reduce your risk by not smoking, and 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 anyone. For more details see our information sheet [Travel and IBD](#).

Anaemia

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

If the anaemia is very mild there may be few or no symptoms. With more severe anaemia, the main symptoms are chronic (ongoing) tiredness and fatigue. You might also develop shortness of breath, headaches and general weakness. How the anaemia is treated will depend on its cause. For iron deficiency anaemia you may be prescribed iron supplements, either as tablets or as IV (intravenous) iron, which is given by injection or in an infusion, through a drip. IV iron is often better tolerated, so is more effective than oral iron (tablets). For vitamin deficiency anaemia you may be given extra B12 or folic acid, as tablets or by injection.

Can Crohn's lead to cancer?

You may have a slightly increased risk of bowel cancer if you have had severe Crohn's Disease affecting all or most of the colon for at least eight to 10 years. For more details, see our information sheet **[Bowel Cancer and IBD](#)**.

Diagnosis, Tests and Treatment

How is Crohn's diagnosed?

If you develop diarrhoea, abdominal pain, and weight loss lasting for several weeks or longer, 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 confirmed, you may then have an examination to look inside your body, such as an endoscopy, x-ray or scan.

Endoscopy

There are several types of endoscopy which can have different names according to the type of scope used and the part of the gut being examined. For example:

- An upper GI endoscopy – 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 or gastroscopy. In this, the doctor or specialist endoscopist inserts an endoscope (a thin flexible tube with a camera in its tip) through your mouth so they can examine your oesophagus, stomach and duodenum.

- A 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 and more flexible endoscope) will be inserted through the anus (back passage) to examine the rectum and colon.

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

Barium X-ray Tests

Barium sulphate is a harmless white chalky substance which can be used to coat the lining of the gut and so give a clearer outline in an x-ray. It can be given as a drink to help show up problems in the stomach or small intestine, or in an enema to show up inflammation in the colon.

MRI and CT Scans

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

You can find more detailed information about all the tests mentioned above in our information sheet [Tests and Investigations for IBD](#).

Sometimes it can be difficult to tell Crohn's in the colon apart from other inflammatory bowel conditions, especially Ulcerative Colitis (UC). UC 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.

“This diagnosis [of Crohn's] made sense of a lot of my problems over the years, and I have been able to cope with them in a positive way.”

Beryl

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.

Could my symptoms be IBS?

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

What treatments are there for 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 be an option. Dietary therapy may be another option for some people. 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 and control flare-ups, and then to prevent a relapse once the disease is under control. This can mean that you need to take your medication on an on-going basis, sometimes for many years. Or, you may need only a short course of drugs.

The main types of drugs most commonly used in Crohn's are anti-inflammatory drugs, symptomatic drugs, and antibiotics.

Anti-inflammatory drugs

These help to reduce inflammation and include:

- 5 ASAs or aminosalicylates such as mesalazine (brand names include Asacol, Pentasa, Salafalk, and Octasa), sulphasalazine (Salazopyrin), and balsalazide (Colazide)
- Corticosteroids, often just called steroids, such as prednisolone, hydrocortisone and budesonide (Entocort)
- Immunosuppressants such as azathioprine (Imuran), mercaptopurine or 6MP (Purinethol), methotrexate and tacrolimus
- Biological or 'anti-TNF' drugs such as infliximab (Remicade) and adalimumab (Humira).

Symptomatic drugs

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

- Anti-diarrhoeals such as loperamide (Imodium, Arret), cholestyramine (Questran)
- Bulking agents such as Fybogel
- Painkillers such as paracetamol and aspirin.

“I’ve had several major flare-ups of Crohn’s, but since they’ve changed my medication I’ve been in remission – fingers crossed it’ll keep working.” Anita

Antibiotics

These are used to treat bacterial infections and include metronidazole (Flagyl) and Ciprofloxacin.

You may also be treated with other drugs or medication if you develop complications such as anaemia.

You can find more information on all these drugs, how they work and details of their main side effects in our booklet **Drugs used in IBD**, and our drug treatment information sheets **Adalimumab, Azathioprine and Mercaptopurine, Methotrexate** and **Infliximab**.

Taking over the counter medicines for Crohn's symptoms

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.

For example, some anti-diarrhoeals may make your Crohn's symptoms worse if you take them during a flare-up, and bulking agents can cause blockages if you have a narrowing or stricture. Certain pain-killers are a type of drug known as non-steroidal anti-inflammatory drugs (or NSAIDS) and these may possibly trigger a flare-up.

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 (removal of diseased sections of the intestine) are now less common. However, surgery remains an important treatment option, often in combination with medical therapies. It is estimated that about seven 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 cannot sufficiently control their symptoms. This can have the advantage of giving you more time to prepare for having the operation. 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 as a supplement to your diet (see [What is dietary treatment?](#) on page 28). 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 the surgery again.

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 stricturoplasty)

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 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, it may be possible to have an endoscopic 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.**](#)

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 lower small intestine out through an opening in the wall of the abdomen. This is an 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 the lower part of the colon is affected and the upper part can remain, it may be possible to remove just the damaged section and bring out the end of the healthy part 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 from digestion away from the inflamed colon to give it a chance to heal. Once the colon has sufficiently recovered, the stoma will be closed. This may be after three to six months or longer, depending on your particular medical condition.

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

Our information sheet **Surgery for Crohn's Disease** gives more details about all these operations.

“Three months on from surgery and I can't believe how far I've come. I have applied to University, joined the Gym and Pilates and I'm getting my social life back on track – all things I couldn't have imagined doing a few months ago!” Molly

What is dietary treatment?

Dietary treatment – sometimes called nutritional therapy or enteral nutrition – involves drinking a special liquid 'food' instead of normal food, usually for a number of weeks.

These feeds contain all the essential nutrients in a simple form that your body can absorb with little or no digestion. Not everyone likes the taste of these dietary feeds, but they do come in a range of flavours and some people have found that taking the liquid iced or through a straw can make 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).

Enteral nutrition is widely used for children with Crohn's disease, because it helps their growth and avoids the use of steroids.

There is less evidence for the effectiveness of enteral nutrition in adults, particularly for active Crohn's Disease. Research has shown it to be less effective than steroids, for example. However, enteral nutrition may be recommended for adults who prefer not to use drug therapy, and it can be useful as a supplement for people who need extra nutrition.

Living with Crohn's Disease

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 that certain foods seem to trigger their symptoms or make them worse – and that it helps if they, for example, reduce or adjust the amount of fibre they eat or cut out wheat 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 from a qualified dietitian before you make any significant changes.

If you have a stricture, you may need to avoid eating 'hard to digest' or 'lumpy' foods that might cause a blockage. Your hospital dietitian should be able to advise you on this. Typically, such foods might include 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.

If your bowel is not absorbing nutrients properly, perhaps because of extensive inflammation or a shortened bowel after surgery, you may find that your diarrhoea improves if you keep to a diet low in fat.

If you have Oral Crohn's, it may help to avoid carbonated drinks or other foods containing benzoates or cinnamon.

Some people with Crohn's may lack certain vitamins and minerals, such as iron, calcium, vitamin D or vitamin B12, especially if they have a poor appetite or active diarrhoea or blood loss. 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. In these cases a supplement may be useful, but do discuss this with your doctor or dietitian. If tests show that you have a serious deficiency, you may need a course of supplements or might benefit from enteral nutrition. Vitamin B12 supplements are sometimes given by injection and iron supplements intravenously (by injection using a 'drip') as this can make them easier to absorb.

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

“You can't predict when a flare-up will happen, or whether tomorrow will be a good day or a bad one. It is a pain living with an unpredictable, fluctuating condition like Crohn's, but I've learned not to let it get me down.” Peter

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 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 their symptoms may have gone into remission coincidentally, given the unpredictable course of the 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.

One area where there has been some scientific research is that of the use of omega 3 fish oils. However, a recent review concluded that fish oils were probably not effective at keeping people with Crohn's in remission, as although some studies found symptoms improved, two larger studies showed no benefit. A small study on acupuncture for active Crohn's also showed a very slight improvement, but not enough to be significant. Other research has suggested that a herbal medicine containing wormwood may help with steroid reduction, but more work is needed in this area. There is ongoing research into the use of probiotics for IBD, but so far they have not been found helpful for Crohn's.

If do you want to take a complementary or alternative product, talk to your doctor first, especially if you are thinking of taking any herbal medicines as these may interact with some prescription drugs. It is also important that you do not stop taking any prescribed treatment without discussion, even if your symptoms improve.

What about pregnancy and Crohn's?

Women with inactive Crohn's usually have no more difficulty becoming pregnant than women without IBD. 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.

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.

For example, you may be able to continue taking steroids, 5 ASAs and azathioprine, although you should not take methotrexate or mycophenolate mofetil when pregnant or trying to conceive, because they can cause an increased risk of birth defects.

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

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

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. Studies show however, that for most people the actual risk is still relatively small, although it can be higher in some population groups.

If one parent has Crohn's, the risk of their child developing IBD is generally thought to be about 5% – that is, for every 100 people with Crohn's about five of their children might be expected to develop IBD at sometime in their lives. But, genes are only part of the picture and research suggests that environmental triggers also play an important role.

How does Crohn's affect children and young people?

As many as one in three of the people with Crohn's Disease in the UK were under 21 when first diagnosed, and over the last few decades a number of studies have shown Crohn's becoming increasingly common 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 often found in children with Crohn's. Reducing steroid use and moving to treatment with enteral nutrition and immunosuppressants may help encourage catch-up growth. Infliximab has also been shown to improve growth in children with Crohn's.

We have an information sheet for schools and a booklet entitled **IBD in Children: a parent's guide**, which you may find helpful if you are a parent of a child with IBD. Our information sheet **IBD Concerns for Young People** covers issues often raised by teenagers.

“Living with Crohn's can be tough, but it's important to still have dreams and not let it rule your life.” Sara

How will Crohn's affect my life?

There is no single answer to this question because everyone is different. Crohn's is a very 'individual' disease and people's experiences vary so widely. Also, so much can depend on the severity of your condition and on whether your disease is in a quiet or an active phase.

Some people with Crohn's may never have more than mild and infrequent symptoms of diarrhoea and pain, and their illness may not affect their lives very much. Other people may have continuous and severe symptoms in spite of medical and surgical treatment, and have to adapt their lifestyle considerably.

Our booklet **Living with IBD** looks at some of the challenges of day-to-day life with Crohn's. We also have information sheets on **Managing Bloating and Wind**, **Managing Diarrhoea** and **Staying Well with 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 can build up a good relationship with them. **Staying Well with IBD** has some suggestions on how to get the most from your time with health professionals.

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

Help and Support from Crohn's and Colitis UK

All our booklets and information sheets are available to download from our website: www.crohnsandcolitis.org.uk. If you would like a printed copy, please contact our information line – details below.

Crohn's and Colitis UK Information Line: 0845 130 2233

open Monday to Friday, 10am to 1pm, excluding English bank holidays. An answer phone and call back service operates outside these hours. You can also contact the service by email info@crohnsandcolitis.org.uk or letter (addressed to our St Albans office). Trained Information Officers provide callers with clear and balanced information on a wide range of issues relating to IBD.

Crohn's and Colitis Support: 0845 130 3344

open Monday to Friday, 1pm to 3.30pm and 6.30pm to 9pm, excluding English bank holidays. This is a confidential, supportive listening service, which is provided by trained volunteers and is available to anyone affected by IBD. These volunteers are skilled in providing emotional support to anyone who needs a safe place to talk about living with IBD.

Other useful organisations

Bladder and Bowel Foundation

www.bladderandbowelfoundation.org

0845 345 0165

Colostomy Association

www.colostomyassociation.org.uk

0800 328 4257

Core – Fighting Gut and Liver Disease

www.corecharity.org.uk

020 7486 0341

Crohn's in Childhood Research Association

www.cicra.org

020 8949 6209

IA – The Ileostomy and Internal Pouch Support Group

www.iasupport.org

0800 0184 724

Ostomy Lifestyle

www.ostomylifestyle.org.uk

0800 731 4264

NASS – National Ankylosing Spondylitis Society

www.nass.co.uk

020 8948 9117

National Osteoporosis Society

www.nos.org.uk

0845 450 0230

How we write our information

Crohn's and Colitis UK is an accredited member of the Information Standard scheme for health and social care information producers. This means that we have passed a rigorous assessment to ensure that our information is

- clear
- accurate
- balanced
- evidence-based and
- up-to-date

For more information see our website at www.crohnsandcolitis.org.uk and the Information Standard website at www.theinformationstandard.org.

How to contact us with comments or questions about this booklet

If you would like more information about the sources of evidence on which this publication is based, or details of any conflicts of interest, or if you have any comments or suggestions for improvement, please email the Publications Team at **publications@crohnsandcolitis.org.uk** or write to us at the address below.

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You can also comment using the Publications Feedback page on our website, or by contacting us through the Information Line on **0845 130 2233**.



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