

Improving life for  
people affected  
by inflammatory  
bowel diseases



# Crohn's Disease



Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease (NACC). NACC is a voluntary Association, established in 1979, which has 30,000 members and 70 Groups throughout the United Kingdom.

Membership of the Association costs £12 a year. New members who are on lower incomes due to their health or employment circumstances may join at a lower rate. Additional donations to help our work are always welcomed.

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*We hope that you find the information helpful and relevant. We welcome any comments from readers, or suggestions for improvements. References or details of the research on which this publication is based can be obtained from Crohn's and Colitis UK at the address below. Please send your comments to Helen Terry at Crohn's and Colitis UK, 4 Beaumont House, Sutton Road, St Albans, Herts AL1 5HH, or email [h.terry@crohnsandcolitis.org.uk](mailto:h.terry@crohnsandcolitis.org.uk).*

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## Introduction

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 your condition can help you to lead a full and active life and to take an active part in decisions about your treatment. We hope this booklet will give you more understanding about Crohn's and how it is treated.

## 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 was first described by a Scottish surgeon, Dalziel, in 1913. However, it gets its name from a New York doctor, Burrill Crohn. He and two colleagues reported a number of cases in 1932, when it became more widely known. Crohn's Disease is also known as Inflammatory Bowel Disease (IBD). IBD is the name of a group of illnesses, of which Crohn's and a similar condition, called Ulcerative Colitis, are the two main ones.

Crohn's is sometimes described as a chronic condition. This means that it is ongoing and usually lifelong, but there may be long periods of good health, alternating with times when symptoms are more active. At present there is no cure for the illness, but drugs and sometimes surgery can give you long periods of relief from symptoms. Crohn's is not infectious.

## What causes Crohn's disease?

Although there has been much research, the cause of Crohn's Disease is not yet known. However, over the past few years major advances have been made, particularly in genetics. Researchers now believe that Crohn's is caused by a complex interaction of factors: the genes a person has inherited and an abnormal reaction of the immune system (the body's protection system) to certain bacteria in the intestines, triggered by something in the environment. 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. However, research shows that stopping smoking reduces the severity of Crohn's, particularly after surgery.

Researchers are beginning to understand how differences in a person's genetic makeup might lead to a tendency to develop Crohn's and why certain parts of the intestine or body are affected in some but not others. This would mean that treatment could be appropriately targeted from the beginning and eventually it may be possible to predict the risk of complications, the response to medication and the need for future surgery.

### **How common is Crohn's Disease?**

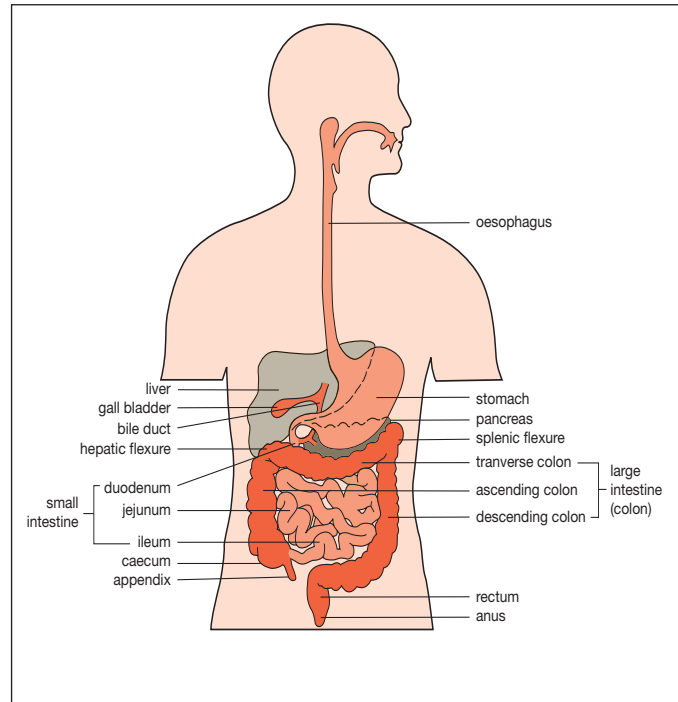
Crohn's Disease affects about one in every 1,000 people in the UK. For reasons that are not yet fully understood, it is more common in urban rather than rural areas and in northern developed countries, though the numbers are beginning to increase in developing nations. The condition is also more common in white people of European descent, especially those descended from Ashkenazi Jews (those who lived in Eastern Europe and Russia). Recent surveys in the UK and elsewhere suggest that new cases of Crohn's are being diagnosed more often, particularly among teenagers and children. The reason for this is not clear. There are more girls than boys among young children with Crohn's, but over the past decade more men than women have developed Crohn's. The disease is more common among smokers than non-smokers. Crohn's can start at any age, but usually appears for the first time between the ages of 10 and 40.

### **Which part of the gut does Crohn's affect?**

You will see from the diagram overleaf, that the gut is like a long tube that starts at the mouth and ends at the anus. Crohn's can affect any part of the gut, though the most common part is the end of the ileum, known as the small intestine or small bowel, and/or the colon, known as the large intestine or large bowel. 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 happens in the gut?

The gut breaks down the food we eat so that our body can absorb its nutrients to give us good health and energy. The first stage of breaking down food is chewing. As food is swallowed it goes down the oesophagus into the stomach, where digestive juices break it down further over two-four hours. The stomach then empties the food into the small intestine, which has three parts – the duodenum, jejunum and ileum. Here the food is split into tiny parts (molecule size) and nutrients are absorbed through the intestinal walls into the blood stream to reach all parts of the body. The waste products from this process, which include liquid and undigested parts of food, are then pushed into the colon. Finally, the colon absorbs the liquid and the leftover waste becomes solid faeces (stools), which pass out of the body in a bowel movement through the anus (back passage).



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## How does Crohn's affect the gut?

Inflammation in the gut affects your body's ability to digest food, absorb nutrients and eliminate waste in a healthy way. As a result you may have varying symptoms, which may depend on where in your gut you have Crohn's.

## What are the symptoms?

Symptoms may range from mild to severe and vary from person to person and may change over time. Because Crohn's is an ongoing condition, you may have times of good health, called remission, when there are few or no symptoms, alternating with times when your symptoms are more active, called relapses or 'flare-ups'. It is a very individual condition with some people remaining well for a long time, even for many years, while others have frequent flare-ups.

The most common symptoms during a flare-up are abdominal pain and diarrhoea. Sometimes mucus, pus or blood is mixed with diarrhoea. People with active Crohn's often feel extremely tired and lethargic. This can be due to the illness itself, as well as a number of other things such as a lack of sleep because of pain and getting up at night with diarrhoea. Some people have a fever. You may feel generally unwell and lose your appetite, so you may lose weight. Weight loss can also be due to the body not absorbing nutrients from the food you eat because of inflammation in the gut. Mouth ulcers are also common and may be treated with an antibiotic mouthwash or a steroid spray.

You may have anaemia (a reduced number of red blood cells) if you lose a lot of blood, are not eating much, or your body is not absorbing nutrients. Anaemia can also make you feel very tired.

## What are the main types of Crohn's?

It helps to know which part or parts of your gut are affected by Crohn's Disease, as the symptoms and complications differ depending on where you have the inflammation. The following are the main types of Crohn's with their typical symptoms:

- **Terminal ileal/ileocaecal**

This is a common form of Crohn's Disease, which affects the end of the small intestine and the beginning of the large bowel. With this type of Crohn's you may feel pain in the lower right side of your abdomen. There is often weight loss. You may have diarrhoea, but it is not usually bloody, as any blood lost is digested by the time it reaches the rectum. If there is only a small area of disease, diarrhoea may not be a problem. However, even if only a short section of the end of the small bowel (terminal ileum) is affected, you may get watery diarrhoea due to bile salts not being absorbed.

- **Colonic**

Crohn's Disease only in the colon or large bowel is often called Crohn's Colitis. The main symptom tends to be blood-stained diarrhoea. Because of the inflammation, the colon cannot hold as much waste as normal, so you will have more frequent bowel movements (six or more a day). You may also have the urge to empty your bowels more often, particularly if your rectum is inflamed. Diarrhoea and urgency can cause people to fear incontinence (losing control of bowel movements). See our information sheet: *Managing diarrhoea*.

- **Perianal**

Crohn's in the area around the anus can occur on its own or in combination with other sites in the body. It can cause a number of symptoms as follows:

- Fissures – these are tears in the lining of the anal canal. They can cause pain and bleeding, especially during bowel movements. Warm baths and a rectal ointment may be helpful.
- Skin tags – these are small fleshy growths around the anus. They are not usually painful, but they can irritate the skin if faecal matter (waste from the bowel) collects around them. Keeping the area clean will help to reduce discomfort. It is better to avoid removing them surgically, because of the risk of damage to the anal sphincter (a ring of muscle surrounding the anal canal) or the anal canal itself.
- Abscesses – these are collections of pus around the anus. They can cause a fever, pain and tenderness around the anus. They may need to be drained or treated with antibiotics. Abscesses can cause fistulas.

- **Fistulas** – these are small openings with pus which form a passageway from the anal canal (back passage) to the skin around the anus and are often the cause of abscesses. They can leak pus and sometimes faecal matter. They can be painful and cause skin irritation around the anus. They can be treated with medication and by surgery. See our information sheet: *Living with a fistula*.

- **Small bowel**

Abdominal pain and diarrhoea are common symptoms of Crohn's in the small bowel. Diarrhoea tends not to be blood-stained. There may also be weight loss and anaemia.

- **Gastroduodenal**

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

- **Oral**

Crohn's Disease occasionally causes inflammation in the mouth. It can cause painful ulceration and swelling of the lips and face. Oral Crohn's is more common in children and young people.

## What are the possible complications of Crohn's?

Complications can be in the gut itself or can involve other parts of the body. Complications in the gut include the following:

- **Stricture**

The ongoing inflammation and healing in the bowel in Crohn's can cause scar tissue to form. This can narrow the passageway of the affected parts of the bowel. The narrowing is called 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 also become bloated and distended and the gut may make loud noises.

- **Perforation**

A severe blockage caused by a stricture can lead to 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 develop into a fistula.

- **Fistula**

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. These tunnels or passageways can connect the bowel to other loops of bowel, to the surrounding organs, such as the bladder and vagina, to the outside skin, including the skin around the anus, as mentioned above (see Perianal). See our information sheet: *Living with a fistula*.

## How does Crohn's affect other parts of the body?

Crohn's Disease can cause problems outside the gut. Some people with Crohn's get other conditions, mainly affecting the joints, eyes and skin. These often occur during active disease, but they can develop before any signs of bowel disease or during times of remission. Crohn's can also affect the bones, kidneys, liver, and blood circulation.

- **Joints**

Inflammation of the joints, which we know as arthritis, is the most common of the other conditions related to Crohn's and affects about 1 in 3 people with Crohn's. 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, though there can be pain without obvious swelling. A few people develop swelling and pain in the joints of the hands or feet, similar to that caused by rheumatoid arthritis. Symptoms usually improve with treatment for intestinal symptoms, and there is generally no lasting damage to the joints.

More rarely, there may be inflammation of the joints in the spine and pelvis – a condition called ankylosing spondylitis. Symptoms from this condition are not always related to a flare-up

of Crohn's and may develop many years before or after intestinal symptoms occur. The most common problem is the pain over the sacro-iliac joints, which are on either side of the lower part of the spine. Stiffness and pain of the spine itself may eventually lead to loss of movement. Research shows that the newer biologic drugs, such as infliximab and adalimumab, can be effective in treating this condition.

- **Skin**

Crohn's can also cause skin problems. The most common skin problem, called erythema nodosum, affects about one in seven people with Crohn's. Painful red swellings appear, usually on the legs, which then fade leaving a bruise. This condition tends to occur during flare-ups of Crohn's and generally improves with treatment for the Crohn's.

Less commonly, a condition called pyoderma gangrenosum starts as small tender blisters, which become painful, deep ulcers. These usually appear on the lower leg near the ankle, but they can occur in any area of the skin or around a stoma. The condition is not usually related to active bowel inflammation and treatment with ointments, such as tacrolimus, can be effective, but steroid drug treatment may be necessary.

- **Eyes**

Eye problems are less common, affecting about one in 20 people with Crohn's. A condition called episcleritis affects the white of the eye, which becomes red and sore and inflamed. A more serious condition, called uveitis, affects the iris. Both conditions can be treated with steroid drops given into the eye. 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 weakened bones. Bone loss can be due to the inflammatory process itself, poor absorption of calcium needed for bone formation, avoidance of dairy foods and the use of steroid medication. See our information sheet: *The Bones and IBD*.

- **Liver**

Some complications are related to the liver and its function. About one in four people with Crohn's develop gallstones. These can develop when the end of the small intestine has been removed or becomes inflamed and cannot absorb bile salts. Bile salts help to dissolve fats during digestion. Gallstones may cause severe pain, particularly after eating fatty foods. More rarely inflammation of the liver and bile ducts can develop.

A condition called Primary Sclerosing Cholangitis (PSC) affects about one in 25 people with Crohn's, usually in those who have the disease in the colon. PSC is a rare disease that causes inflammation of the bile ducts and can eventually affect the liver. Treatment is usually with ursodeoxycholic acid.

- **Kidneys**

Kidney stones are a risk if you have loose stools and you are not drinking enough liquid.

- **Veins**

People with Crohn's are at increased risk of forming clots in the veins, usually in the legs, which can cause pain and swelling. The risk is about three times higher if you are in hospital, but you may also be at risk at any time when your Crohn's is active. If you get these symptoms or develop chest pain or shortness of breath you should see a doctor straight away. You can reduce the risk by not smoking, and by keeping as mobile as possible, drinking plenty of fluids and wearing support stockings. This is particularly important when travelling by air, which increases the risk of blood clots for anyone. See our information sheet: *Travel and IBD*.

## **How is Crohn's diagnosed?**

If you develop diarrhoea, abdominal pain and weight loss lasting for weeks or months, 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. Initially routine blood tests can show whether there is inflammation in the body and whether

you have anaemia. Your stools may also be tested to check whether your diarrhoea is caused by an infection. There are specific stool tests that can show signs of inflammation, such as Faecal Calprotectin and Lactoferrin, but they are only available in some centres. If inflammation is confirmed, further examinations will look inside your body and may include:

- **Endoscopy**

If you have symptoms coming from your colon or ileum, the doctor or specialist endoscopist will insert either a sigmoidoscope (a short rigid or flexible tube) or a colonoscope (a longer flexible one) through the anus (back passage) to look for signs of inflammation in the bowel. If you have symptoms coming from the upper part of the gut, then a gastroscope (a thin flexible tube) is inserted through your mouth to examine the oesophagus, stomach and duodenum. Usually biopsies (small samples of tissue) are taken from the lining of the bowel. Biopsies can then be examined under a microscope to confirm the diagnosis.

- **Capsule Endoscopy**

A small capsule containing a tiny camera is swallowed, usually after an overnight fast. As it passes through the intestinal tract, it takes a series of pictures and sends them to a recorder worn on a belt around the waist. The capsule is disposable and passes out of the body naturally in a bowel movement. This newer test may be used when other tests have been unable to confirm a diagnosis. However, it is not available in all centres and it may not be suitable for everyone, for example if you have a stricture. Also, biopsies cannot be taken with a capsule endoscopy.

- **Barium X-rays**

These x-rays are taken after barium – a white, chalky, harmless substance – is given as a drink or as an enema. Barium coats the lining of the gut, without being absorbed, and shows up as white on x-ray films to give a clearer outline of the gut. It can show if there is a narrowing or blockage of the intestines. A barium meal and follow through shows the stomach and small intestine. A barium enema shows the colon.

If there is some doubt about the diagnosis, or if some complications are suspected, then other less usual tests may be needed, such as an MRI (Magnetic Resonance Imaging) or CT scan (Computerised Tomography) or, in some centres, Ultrasound. However, MRI is being used more and in time may be more common than x-rays. Sometimes it is difficult to tell Crohn's in the colon apart from other types of inflammatory conditions, particularly Ulcerative Colitis (UC). UC affects the lining of the colon, causing inflammation and tiny ulcers. There are two new blood tests, called Antibody tests, available in some centres, which can help to tell which condition you have. If it remains unclear, you will be given the diagnosis of Indeterminate Colitis or IBD unclassified (IBDU). However, this will not affect the start of any treatment. You can find more detailed information on tests in our booklet: *Investigations for IBD*.

### **Will I need repeated tests?**

You may need to have repeated tests from time to time to check on your condition and how your treatment is working. Some drug treatments require tests beforehand and regular ongoing tests to check for any potential side effects. Generally, your specialist will try to avoid repeated endoscopy or x-ray examinations. A colonoscopy can be time-consuming and unpleasant, as it needs thorough bowel preparation. Although complications are rare, there is a small risk of damaging the bowel during the procedure. It is important not to use x-rays unless they are necessary. While small amounts of radiation are not harmful, larger amounts are believed to increase the risk of cancers.

### **What treatment is available?**

Treatment can be medical, surgical or a combination of both. If your condition is mild, no treatment may be an option. Dietary treatment 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.

Whatever medical, surgical or dietary treatments you choose, it is better not to smoke and to avoid passive smoking, particularly if you have Crohn's in your small bowel. This is because some research shows that smoking makes your condition worse and can make some treatments less effective.

## What drugs are used to treat Crohn's?

Drug treatment aims to reduce symptoms and to control a flare-up or to prevent a relapse once the disease is under control. This means that you may be taking medication continually. The different types of drugs used in Crohn's are described in the tables below as follows:

- **Anti-inflammatory drugs** – to reduce the inflammation itself
- **Antibiotics** – to treat bacterial infections, which people with Crohn's may be more prone to and which can make the inflammation worse
- **Symptomatic drugs** – to lessen the symptoms of Crohn's Disease

There are different ways of taking drugs and how you take them will depend on the type of drug and where the inflammation is. For example, if you have inflammation in the rectum or near the end of the colon, you can take steroids and aminosalicylates as liquid or foam enemas, or as suppositories inserted into the rectum (lower part of the large bowel) through the anus (back passage). For other less accessible parts of the intestine, you can take tablets, capsules or granules orally (by mouth). Special coatings on some steroids and aminosalicylates help the drug to be released in the part of the intestines affected. Biologics can only be given by infusion or injection. All drugs can have unwanted side effects, but not everybody gets them. But if you do, the more common ones usually improve as your body gets used to a drug. Not all possible side-effects are listed here and you can check the manufacturer's information provided with your medicine for full details. You can also get more information about drugs from our booklet: *Drugs used in IBD* and information sheets: *Adalimumab; Azathioprine and 6-mercaptopurine; Infliximab; Methotrexate* and *Taking Medicines for IBD*.

## Anti-inflammatory Drugs

Drugs	What they do	Possible side effects
<b>Corticosteroids</b> hydrocortisone prednisolone budesonide (Entocort)	<ul style="list-style-type: none"> <li>• Reduce inflammation which stops pain, reduce diarrhoea and restore appetite</li> <li>• May also help mineral (sodium) and water uptake</li> <li>• Also reduce inflammation of eyes and joints</li> </ul>	<ul style="list-style-type: none"> <li>• Weight gain</li> <li>• 'Mooning' of face</li> <li>• Growth of facial hair and acne</li> <li>• Increase in blood pressure</li> <li>• Thinning of bones, muscle and skin</li> <li>• Can make infections worse</li> <li>• Increase in sugar levels in blood, occasionally diabetes</li> </ul>
<p><i>The adrenal glands may become suppressed by long-term use of steroids. This reduces the body's ability to cope with stress caused by an operation or accident. It is important to wear or carry a steroid bracelet or card, so that doctors can give you extra steroids if needed. These are not anabolic steroids used by bodybuilders.</i></p>		
<b>Aminosalicylates (5ASA)</b> sulphasalazine (Salazopyrin) mesalazine (Asacol, Ipocol, Mesren, Mezavant XL, Pentasa, Salofalk) olsalazine (Dipentum) balsalazide (Colazide)	<ul style="list-style-type: none"> <li>• Reduce inflammation and maintain remission</li> <li>• Do not have the side effects of corticosteroids, and therefore can be used for longer periods of time</li> <li>• Continued use may help to protect against bowel cancer</li> </ul>	<ul style="list-style-type: none"> <li>• Headaches and skin rash</li> <li>• Indigestion, nausea and diarrhoea</li> <li>• Sulphasalazine may temporarily reduce fertility in men; colour urine orange; stain soft contact lenses</li> </ul>
<b>Immunomodulators</b> azathioprine (Imuran) 6-mercaptopurine (Purinethol) methotrexate mycophenolate mofetil   tacrolimus	<ul style="list-style-type: none"> <li>• Suppress inflammation over longer periods of time</li> <li>• Works more quickly and is sometimes used to avoid urgent operations</li> <li>• Available as ointment for perianal Crohn's</li> </ul>	<ul style="list-style-type: none"> <li>• Can reduce the number of red and white blood cells</li> <li>• Nausea, a flu-like illness, diarrhoea, abdominal pain and inflammation of the pancreas</li> <li>• Can make infections worse</li> <li>• Increases skin's sensitivity to sunlight</li> <li>• Diarrhoea, nausea, headache, difficulty sleeping, tingling of hands or feet, increased blood pressure</li> </ul>

Drugs	What they do	Possible side effects
<b>Biologics</b> <b>Anti-TNFs</b> infliximab (Remicade) adalimumab (Humira)	<ul style="list-style-type: none"> <li>Block an inflammatory agent in the blood – TNF-alpha – believed to cause chronic inflammation</li> </ul>	<ul style="list-style-type: none"> <li>Nausea</li> <li>Headache</li> <li>Reaction to infusion (infliximab) or injection (adalimumab)</li> <li>Can make infections worse</li> </ul>

### Antibiotics Drugs

Drugs	What they do	Possible side effects
metronidazole (Flagyl)	<ul style="list-style-type: none"> <li>Used to treat abscesses or help reduce inflammation in the large or small intestine</li> </ul>	<ul style="list-style-type: none"> <li>Nausea lack of appetite</li> <li>Unpleasant metallic taste</li> <li>Darkening of the urine</li> <li>Tingling sensation in the peripheral nerves</li> </ul>
ciprofloxacin tetracyclines rifaximin	Used to stop growth of bacteria in the small bowel	<ul style="list-style-type: none"> <li>Nausea</li> <li>Diarrhoea</li> <li>Skin rash</li> </ul>
rifabutin clarithromycin clofazamine	Used together to treat a bacterial infection, Mycobacterium paratuberculosis, which some researchers believe is associated with Crohn's Disease	Rifabutin <ul style="list-style-type: none"> <li>Initial flu-like feeling</li> <li>Joint pains</li> <li>Eye inflammation</li> <li>Yellowing of skin</li> </ul>
<i>Alcohol intake is not advisable when taking these drugs</i>		

## Symptomatic Drugs

Drugs	What they do	Possible side effects
<b>Antidiarrhoeals</b> codeine phosphate diphenoxylate (Lomotil) loperamide (Imodium, Arret)  colestyramine (Questran) colestipol (Colestid)	<ul style="list-style-type: none"> <li>• Reduce the contractions in the bowel, therefore reducing the number of stools</li> <li>• Absorb excess water from the bowel</li>  <li>• Absorb bile salts, preventing them reaching the colon and causing diarrhoea</li> </ul>	<ul style="list-style-type: none"> <li>• Constipation</li> <li>• Nausea/indigestion</li> <li>• Codeine can cause drowsiness also drug dependence if taken over a prolonged period</li> </ul>
<p><i>If you are having an acute or severe flare-up, it is best to check with your doctor before taking antidiarrhoeal drugs, as they can make your Crohn's worse.</i></p>		
<b>Analgesics (Pain killers)</b> paracetamol aspirin	<ul style="list-style-type: none"> <li>• Relieve pain</li> <li>• an reduce swelling in the joints, but they do not reduce inflammation in the intestine</li> </ul>	<ul style="list-style-type: none"> <li>• Constipation</li> <li>• Dizziness</li> <li>• Rashes</li> <li>• Stomach irritation with aspirin</li> </ul>
<p><i>It may be better to avoid non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen and diclofenac. They can be very effective for pain in the joints and spine, but they can make Crohn's symptoms worse or possibly trigger a flare-up.</i></p>		
<b>Anaemia treatments</b> Supplements of iron, folic acid and  Vitamin B12	<ul style="list-style-type: none"> <li>• Enable body to rebuild the red blood cells lost during bleeding or damaged as a side effect of another drug</li>  <li>• May be given as injection after resection of small intestine</li> </ul>	<ul style="list-style-type: none"> <li>• Iron can cause diarrhoea, nausea or constipation</li> </ul>
<b>Laxatives</b> osmotic (Movicol)  bulking agent (Fybogel)	<ul style="list-style-type: none"> <li>• Softens stool by increasing the amount of water in the large bowel</li> <li>• Considered safer than many laxatives, being slow acting and not absorbed into body</li>  <li>• Contains husks that absorb water to bulk stools</li> </ul>	<ul style="list-style-type: none"> <li>• Flatulence</li> <li>• Stomach cramps (especially at start of treatment)</li> </ul>

## What about surgical treatment for Crohn's?

While many people with Crohn's are likely to need some kind of operation for their condition at some point, advances in drug therapy in recent years, particularly with biologics, have changed the approach to surgery. Previously, some people may have had extensive parts of their bowel removed. This can result in diarrhoea and nutritional problems, not due to the Crohn's itself, but to lack of sufficient length of normal intestine for adequate absorption. This is not so likely to happen nowadays. It is best to discuss the potential benefits of surgery as compared to medical treatment with your specialist.

Some people may choose to have surgery when other treatments cannot sufficiently control their symptoms. They will then have time to prepare for an operation, both psychologically and nutritionally. For example, if you are very underweight, your doctor may advise you to increase your nutrients, before having surgery, by taking a special liquid feed as a supplement to your diet (see *What is dietary treatment?* below). Also if you smoke, it is best to stop before undergoing surgery, as smoking increases the risk of needing surgery again. Very occasionally some people will need an urgent operation. For example, if there is a severe blockage in the intestines or if there is a hole or tear in the bowel. The two operations most commonly carried out are:

- **Strictureplasty**

This operation is done when short areas of the small intestine become narrow, forming strictures. The surgeon widens the narrowed part by opening, reshaping and sewing it together again. The advantage of this operation is that you can get relief from symptoms of a blockage without removing 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 widens 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 initial and less complex resections, recent research shows that laparoscopic or keyhole surgery can have more advantages, such as a quicker

recovery and a shorter scar. Keyhole surgery is carried out through small cuts in your abdomen using special instruments and a camera. It is only available at specialist centres at the moment.

Very occasionally, for those people with Crohn's in the colon (large bowel), it may be necessary to remove the whole colon. 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 out the end of the lower small intestine onto the wall of the abdomen as a permanent opening, called a stoma (ileostomy). A bag is fitted on to the opening to collect the waste from the small intestine which would previously have gone into the colon and passed out as stools through the anus. The bag is emptied or changed when necessary.

Another procedure, the 'internal pouch operation', which is quite often used for people with Ulcerative Colitis when they have to have their large bowel removed, is not suitable for most people with Crohn's Disease. This is because Crohn's can recur in the small intestine, unlike UC. If Crohn's develops in a pouch and does not respond to medical treatment, surgical removal of the pouch means the loss of a significant amount of small intestine.

- **Ileo-rectal anastomosis**

Sometimes even 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 possible because the rectum is often not affected, even when there is severe disease in the colon. This operation is not advisable when the rectum is severely inflamed or scarred, or when there has been damage to the anal muscles, because control of loose bowel motions is more difficult.

- **Partial colectomy**

If only the lower part of the colon is affected and the upper part can remain, then it is possible to bring out the end of the healthy bowel as a stoma (colostomy), usually on the lower left side of the abdomen.

Having a major part of the bowel removed can be a frightening thought, as is the prospect of using a stoma bag. In recent years there have been great advances and improvements in the design of stoma products. 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 organisations which give practical advice and support, such as the Ileostomy and Internal Pouch Support Group, Ostomy Lifestyle and the Colostomy Association. Contact details for these organisations are listed at the end of this booklet.

- **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. To do this, the ileum (lower end of the small intestine) or colon (large intestine) is brought out through the wall of the abdomen as a stoma (ileostomy or colostomy), to empty into a bag. 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.

More details on surgery can be found in our publication: *Surgery for Crohn's Disease*.

## **What is dietary treatment?**

Dietary treatment – sometimes called nutritional therapy – involves drinking a special liquid 'food' instead of normal food, for a number of weeks. These feeds are called elemental or polymeric diets. They contain all the essential nutrients in a simple form that your body can absorb with little or no digestion. People generally are not keen on the taste of these drinks and may be unwilling to give up their regular foods. However, there are a variety of brands and taking the liquid iced and through a straw can make it easier to drink. An alternative is to take the feed overnight through a nasogastric tube (a fine tube passed through the nose down into the stomach).

Research shows that nutritional therapy can be effective in treating Crohn's, but the evidence is limited. After finishing the treatment, your doctor may recommend that you re-introduce foods one

at a time to find out if you are 'intolerant' of any particular food. This is called an elimination diet.

Children more commonly take dietary treatment, because it helps their growth and avoids the use of steroids. For adults it may be useful:

- if you have problems with steroids or other IBD medications;
- if you have been diagnosed young and are more likely to have a greater exposure to steroids over your lifetime;
- if you are pregnant or breastfeeding; or
- if you are at high risk of osteoporosis (see our information sheet: *The Bones and IBD*).

## Do I need to change my diet?

There is not any clear evidence that any food or food additive directly causes or improves Crohn's. Generally, the most important thing is to eat a nutritious and balanced diet to maintain your weight and strength and to take sufficient fluids to stop you getting dehydrated. Nevertheless, some people find that certain foods seem to trigger their symptoms or make them worse. For example, they find that decreasing fibre or cutting out particular items such as wheat or dairy products, can help. It is important to get advice from your doctor or a qualified dietitian if you want to make any changes to your diet.

You may sometimes need nutritional supplements to replace the loss of vitamins and minerals. This can happen when you have a poor appetite or eat little, or when your intestine is inflamed or through diarrhoea. Some people take a liquid feed (see *What is dietary treatment?* above) as a supplement. Before taking any supplements, always check with a doctor or dietitian.

In the following situations it may be better to avoid certain foods:

- If you have a stricture in the small intestine, it is better to have a diet free of indigestible foods such as:
  - Tough meat or gristle
  - Nuts and seeds

- Stringy vegetables
- Raw orange
- Other foods which tend to be swallowed in lumps, such as mushrooms.
- Lumps of food, or even a large meal, may cause a temporary block where there is a stricture. This can cause colic, increased noises in your abdomen and give you a bloated feeling.
- If your bowel is not absorbing the nutrients properly, 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, one of the most effective treatments can be to cut out foods containing cinnamom aldehyde (a flavouring) and benzoate (a preservative).

For further information see our booklet: *Food and IBD*.

## What about pregnancy and Crohn's?

Women who have active Crohn's Disease are a little less likely than healthy women to become pregnant. This may be partly due to intercourse being uncomfortable and therefore less frequent. Also, their fertility may be slightly reduced because inflammation in the bowel can affect the normal functioning of the ovaries or block the fallopian tubes. Men taking sulphasalazine may have reduced fertility whilst on the drug, but alternative medication is available.

Doctors usually recommend avoiding pregnancy when the disease is very active. However, inflammation is not more likely to flare up during pregnancy. The contraceptive pill is safe and effective unless diarrhoea is severe or with intermittent vomiting, in which case other contraceptive methods should be used. You can continue taking most treatments through pregnancy, including steroids, aminosalicylates and azathioprine. It is important to keep Crohn's under control during pregnancy by continuing treatment, as active disease can harm the growing baby. However, you should not take methotrexate or mycophenolate mofetil during pregnancy or when trying to conceive as there is a risk of birth defects. Pregnancy should be avoided by couples if these drugs have been taken by either partner within the last three to twelve months, depending on

your doctor's advice. Doctors generally recommend avoiding pregnancy if you or your partner are taking adalimumab or infliximab, and for at least six months after stopping treatment. This is because the evidence about the safety of these drugs is limited. However, there have been reports of successful pregnancies in women exposed to adalimumab and infliximab before conception and during pregnancy and it is best to discuss the risks and benefits with your doctor.

For more details see our information sheets: *Fertility and IBD and Pregnancy in IBD* and individual drug treatment information.

### **Does Crohn's run in families?**

Crohn's tends to run in families, so we know that genes are involved. Studies show that about a quarter of people with Crohn's may have a close relative with either Crohn's or Ulcerative Colitis. So if you have Crohn's, your brother or sister or child has more risk of developing IBD than someone in the general population. However, the actual risk is relatively small, being about five people in every hundred. Also genes are only part of the picture and research suggests that environmental triggers play an important role too. So while there is some risk, studies show that generally, if you have children, they are more likely not to get than to get IBD.

### **How does Crohn's affect children and young people?**

In adults who have active Crohn's Disease, their lower intake of food and nourishment can lead to weight loss, but in children it may also slow down growth and delay sexual development. It is therefore essential that a child with Crohn's takes in adequate nutrition, either with supplements taken by mouth or occasionally by feeding into a vein.

Prolonged treatment with steroids can also slow down growth. Elemental diets are more often used with children to avoid this side-effect of steroids, while providing an adequate nutritional intake at the same time. If a child or adolescent does not respond to medical or dietary treatment, then your doctor may recommend surgery to remove the affected area of the intestine. Surgery usually greatly improves general well-being and with the disease brought under control, it is possible for your child to grow normally.

Children and young people may also have particular problems due to loss of time from school, a sense of being 'different' from other young people, and difficulty in the development of independence. We have a booklet for parents: *IBD in Children: a parent's guide*, an information sheet for schools: *Children and young people with IBD: a guide for schools and a leaflet for young people: IBD concerns for young people*.

### **Can Crohn's lead to cancer?**

There is a slightly increased risk of bowel cancer if Crohn's Disease affects extensive parts of the colon and has lasted for many years and is more severe. We have an information sheet: *Bowel cancer and IBD*, which will give you more details.

### **What about complementary and alternative approaches?**

Complementary and alternative medicine (CAM) is used widely by people with Crohn's Disease to help control symptoms, such as abdominal pain and bloating. However, there are few reliable scientific studies to show the effectiveness of these therapies and in general they are unregulated. Sometimes people may think they work when it could be that symptoms have gone into remission coincidentally, given the unpredictable course of the condition. Researchers have found that in some IBD trials half of those taking a 'placebo' (a harmless inactive substance) believed that treatment worked. So if you believe in and expect a treatment to work, it is possible that you will get relief from symptoms regardless of its actual effectiveness.

Adverse reactions to CAM have doubled over the past years. The World Health Organisation's concern about this has led to it publishing a new set of guidelines for national health authorities. The Guidelines provide tips on what to look out for when using CAM and can be downloaded from: [www.who.int/medicines/library/trm/Consumer.pdf](http://www.who.int/medicines/library/trm/Consumer.pdf).

There have been some scientific studies of CAM for Crohn's Disease. A recent review of research into the use of fish oils to keep people with Crohn's in remission has found that they are probably not effective. While they were found to be safe and showed some improvement in

some studies, two larger studies showed no benefit. In a small study on acupuncture for active Crohn's, there was a very slight improvement, but not enough to be significant. There is ongoing research into the use of probiotics for IBD, but so far they have not been found helpful for Crohn's.

If you want to take a complementary or alternative product, it is best to talk to your doctor beforehand. It is also important not to stop any medication without discussing it first with your doctor.

### **How will Crohn's affect my life?**

There is no single answer to this question because people's experiences vary quite widely. These can be affected by the severity of your condition and also by 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 it is likely that the illness will not affect their lives very much. Other people do have continuous and severe symptoms in spite of intensive medical and surgical treatment and have to adapt their lifestyle considerably. To help you cope with the day-to-day effects of Crohn's Disease on your life we have produced a booklet: *Living with IBD*, as well as information sheets: *Managing bloating and wind*, *Managing diarrhoea* and *Staying well with IBD*.

Having Crohn's, you are likely to see your GP and specialist doctor or nurse more frequently than other people. This means that it is particularly important for you to build up a good relationship with them. Our information sheet: *Staying well with IBD* has some helpful suggestions on how to get the most from your time with health professionals. You may also find it useful to look at the IBD Standards. This is a document that we produced with other organisations, which sets out the quality of care and support for people with IBD that NHS services should aim for throughout the UK. You can see the document on the website: [www.ibdstandards.org.uk](http://www.ibdstandards.org.uk) or call our Information Line for a copy.

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. To help them understand we have produced two leaflets: *When someone in your family has IBD* and *Ulcerative Colitis and Crohn's Disease: a guide for employers*.

We also run a confidential supportive listening service called Crohn's and Colitis Support on 0845 130 3344. This is staffed by specially trained volunteers with personal experience of IBD.

## Further information

If you have any further questions or would like a copy of any of the publications mentioned, please contact our Information Line on 0845 130 2233 or email: [info@crohnsandcolitis.org.uk](mailto:info@crohnsandcolitis.org.uk). You can download the information sheets from our website: [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk).

## Other useful organisations

<b>Bladder and Bowel Foundation</b>	<a href="http://www.bladderandbowelfoundation.org">www.bladderandbowelfoundation.org</a>	0845 345 0165
<b>Carers UK</b>	<a href="http://www.carersuk.org">www.carersuk.org</a>	0808 808 7777
<b>Colostomy Association</b>	<a href="http://www.colostomyassociation.org.uk">www.colostomyassociation.org.uk</a>	0800 328 4257
<b>Core</b> – <i>Fighting Gut and Liver Disease</i>	<a href="http://www.corecharity.org.uk">www.corecharity.org.uk</a> Freepost LON4268, London NW1 0YT	
<b>Crohn's in Childhood Research Association</b>	<a href="http://www.cicra.org">www.cicra.org</a>	020 8949 6209
<b>ia</b> – <i>The Ileostomy and Internal Pouch Support Group</i>	<a href="http://www.iasupport.org">www.iasupport.org</a>	0800 0184 724
<b>NASS</b> – <i>National Ankylosing Spondylitis Society</i>	<a href="http://www.nass.co.uk">www.nass.co.uk</a>	020 8948 9117
<b>National Osteoporosis Society</b>	<a href="http://www.nos.org.uk">www.nos.org.uk</a>	0845 450 0230
<b>Ostomy Lifestyle</b>	<a href="http://www.ostomylifestyle.org.uk">www.ostomylifestyle.org.uk</a>	0800 731 4264
<b>PINNT</b> ( <i>Patients on Intravenous and Nasogastric Nutrition Therapy</i> )	<a href="http://www.pinnt.com">www.pinnt.com</a> PO Box 3126, Christchurch, Dorset BH23 2XS	
<b>PSC Support UK</b>	<a href="http://www.psc-support.demon.co.uk">www.psc-support.demon.co.uk</a>	
<b>Steroid Aid Group</b>	5 Wessex Court, Tennyson Road, Worthing, West Sussex BN11 4BP	

**Crohn's and Colitis UK**

4 Beaumont House, Sutton Road, St. Albans, Hertfordshire AL1 5HH.

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Crohn's and Colitis Support: 0845 130 3344

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Website: [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

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