

Crohn's Disease

Questions & Answers



GLASGOW COLORECTAL CENTRE
WWW.COLORECTALCENTRE.CO.UK

GLASGOW COLORECTAL CENTRE
Ross Hall Hospital
221 Crookston Road
Glasgow
G52 3NQ
e-mail: info@colorectalcentre.co.uk
Ph: Main hospital switchboard - 0141 810 3151
Ph. General pricing and bookings enquiries – 0808 101 0337



GLASGOW COLORECTAL CENTRE

RICHARD MOLLOY & GRAHAM MACKAY,

WWW.COLORECTALCENTRE.CO.UK

A brief word about Crohn's disease

Crohn's disease is a chronic condition that causes inflammation in the bowel or gastrointestinal tract. Inflammation tends to come and go over time. Symptoms vary, depending on the part of the bowel or intestine is affected and the severity of the condition. The most common symptoms are diarrhoea, abdominal pain, tiredness and generally feeling unwell (malaise). Crohn's disease is usually treated with drugs to control the inflammation. Surgery may be required to deal with complications of the disease (e.g. abscess formation or bowel blockage) or if medication is not effectively controlling the disease. Neither medication nor surgery can currently "cure" the disease but treatment is generally effective and allows most people with Crohn's disease to live a normal life with relatively minor limitations

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). Any part of the gastrointestinal tract can be affected (from the mouth, through stomach, small intestine, colon, rectum and anus). However, it most commonly affects the small intestine (small bowel), the colon (large intestine) or the anus. It can lead to a number of different symptoms (outline below).

The disease gets its name from Dr. Burrill Crohn, a New York doctor who in 1932 was one of the first to describe a number of patients with this disease.

Crohn's is a chronic or long-term condition, although many individuals with the condition have sustained periods of good health (remission) as well as times when symptoms are more active (relapses or flare-ups). Currently, there is no cure for Crohn's, but drugs and sometimes surgery can give long periods of relief from symptoms.

What is inflammatory bowel disease (IBD)?

Inflammatory bowel disease (IBD) is a phrase used to describe a number of diseases that cause inflammation in the bowel (large bowel or colon & rectum). These diseases (Crohn's disease and ulcerative colitis are the two most important causes of IBD) typically also give rise to similar symptoms such as bloody diarrhoea. Inflammatory bowel disease is sometimes shortened to IBD. It is important not to mix this up with IBS which is short for irritable bowel syndrome - a very different disease, which never gives rise to bloody diarrhoea.

Although Crohn's disease and ulcerative colitis are similar and treatments are similar, there are important differences. The most important difference being that ulcerative colitis only affects the large bowel (colon and rectum), whereas Crohn's disease can affect anywhere in the gastrointestinal tract.

Ulcerative colitis also tends to cause inflammation in the inner lining of the bowel (mucosa) only, whilst Crohn's disease can cause inflammation through the full thickness of the bowel wall (mucosa and muscle). This explains why Crohn's disease can cause abscesses, perforations and fistulas. These complications are rare in ulcerative colitis.

What causes Crohn's disease?

The cause is not known. 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 disease.

About 3 in 20 people with Crohn's disease have a close relative who also has it. This suggests that there may be a genetic factor. One theory is that a germ may trigger the immune system to cause inflammation in parts of the gut in people who are genetically prone to develop the disease.

Does Crohn's disease run in families?

As mentioned above, Crohn's can run in some families. Parents with inflammatory bowel disease (IBD) are slightly more likely to have a child with IBD.

The risk however is generally small and thought to be around 5% i.e. for every 100 people with Crohn's about five of their children might be expected to develop IBD at some time in their lives. But, genes are only part of the picture and research suggests that environmental triggers also play an important role.

How common is Crohn's disease?

It's estimated that Crohn's Disease affects about one in every 650 people in the UK. There are about 115,000 people in the UK currently with this disease. It can develop at any age but most commonly starts between the ages of 10 and 40. It affects women slightly more often than men. Individuals who have a family member with Crohn's disease are more likely to develop the condition.

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 disease has become more common in recent years, particularly among teenagers and children, but the reason for this is not known. It is about twice as common in smokers than average. Also, smokers tend to have more severe disease than non-smokers. The oral contraceptive pill and non-steroidal anti-inflammatory tablets (usually used for joint inflammation) have also been implicated as possible factors in triggering the disease to start.

How does Crohn's disease cause problems with the gut?

The gut or digestive system is a long tube that starts at the mouth, through gullet, stomach, small and large intestine to end at the anus. 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 ileum is affected in about half of cases. The mouth, oesophagus and stomach are affected much less commonly.

The areas of inflammation are often patchy, with sections of normal bowel 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. In about 3 in 10 cases, the inflammation occurs just in the small intestine. In about 2 in 10 cases the inflammation occurs just in the colon. In a number of cases, the inflammation occurs in different places in the gut.

When a section of the gut or bowel becomes inflamed as a result of Crohn's disease, it may cause pain or diarrhoea. This often occurs when eating. The inflamed area may also ulcerate and bleed

giving rise to anaemia. As the inflammation and scarring progresses, the bowel may narrow causing a 'stricture'. The inflamed areas may also perforate and bowel contents may leak out causing an abscess or 'fistula'.

What are the symptoms during a flare-up of Crohn's disease?

Symptoms are due to inflammation in the wall of the affected parts of the gut. When the disease flares up, the inflammation may cause one or more of the following:

Abdominal pain occurs in about 7 in 10 cases. A common area of pain is the lower right side of the abdomen. When Crohn's disease first develops it is sometimes mistaken for appendicitis. The severity of pain can vary from person to person. Also, a sudden change or worsening of pain may indicate a complication such as an abscess or perforation or obstruction.

Diarrhoea is the most common first symptom. It can vary from mild to severe. Sometimes mucus, pus or blood is mixed with the diarrhoea. An urgency to get to the toilet is common. A feeling of wanting to go to the toilet but with nothing to pass is also common (tenesmus).

Tiredness and fatigue. This can be due to the illness itself, from the weight loss associated with flare-ups or surgery, from anaemia or a straightforward lack of sleep if you have to keep getting up in the night with pain or diarrhoea.

Feeling generally unwell (malaise). Some people may have a raised temperature and feel feverish.

Mouth ulcers are common. Ulcers in the bowel may bleed and cause anaemia

Loss of appetite and weight loss. Unintentional 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) may occur through bleeding from ulcers in the bowel, not eating much, or a failure to absorb nutrients from the food. Anaemia can also make you feel very tired.

Anal fissures, skin tags fistulas and abscess. Crohn's disease can cause a variety of problems around the anus or back passage. On occasion, the disease may present with isolated problems around the anus (and no other symptoms).

Problems away from the gut/bowel Crohn's disease may give rise to other problems or be associated with conditions distant from the bowel. Such problems include inflammation and pain of some joints (arthritis); skin rashes; inflammation of the eye (uveitis); liver inflammation. These problems can cause various symptoms.

It is not clear why these other problems occur. The immune system may trigger inflammation in other parts of the body when there is inflammation in the gut. These other problems tend to go when the gut symptoms settle, but not always.

How happens with Crohn's disease over time?

Crohn's disease is a chronic, relapsing condition. Chronic means that it is ongoing. Relapsing means that there are times when symptoms flare up (relapse), and times when there are few or no symptoms (remission). The severity of symptoms, and how frequently they occur, varies from person to person. The first episode (flare-up) of symptoms is often the worst.

What are the possible complications of Crohn's disease?

Complications may occur, particularly if flare-ups are frequent or severe. These include the following which often need treatment with surgery:

Stricture. 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.

Perforation. This is a small hole that forms in the wall of the gut. The contents of the gut can then leak out and cause infection or an abscess inside the abdomen. This can be serious and life-threatening. This abscess may ultimately leak through the abdominal wall to give rise to a fistula.

Fistula. This is when the inflammation causes a channel to form between two parts of the body. For example, a fistula may form between a part of the small intestine and a part of the colon. Fistulas can also form between part of the gut and other organs such as the bladder or uterus (womb). The contents of the gut may then leak into these other organs. A perianal fistula sometimes develops. This is a fistula that goes from the anus or rectum and opens on to the skin near to the anus.

Cancer. People with Crohn's disease have a small increased risk of developing cancer of the colon compared with the risk of the general population. This risk is really only present if the disease has been severe and has been present in all or most of the colon for at least 8-10 years

Osteoporosis (thinning of the bones). The increased risk of this is related to the poor absorption of food that occurs in some people with severe Crohn's disease.

How is Crohn's disease diagnosed?

Patients who have symptoms of diarrhoea, abdominal pain, and weight loss lasting for several weeks or longer may be offered tests to exclude Crohn's disease. This is especially so in younger patients or those with a family history of Crohn's disease. Specific tests that might be ordered by a specialist include the following:

Blood Tests and Stool Tests. Simple blood tests can identify anaemia and can also show whether there is inflammation somewhere in the body. Stool samples can also be tested for signs of bleeding or inflammation, and to check whether diarrhoea is caused by an infection.

The specific test that is performed to look for inflammation is called a faecal calprotectin test. If

inflammation is confirmed, you may then have an examination to look inside your body, such as an endoscopy, x-ray or scan.

UPPER GI Endoscopy, Colonoscopy or Flexible sigmoidoscopy. 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.

Upper GI endoscopy is performed to examine the stomach. The doctor or specialist endoscopist inserts an endoscope (a thin flexible tube with a camera in its tip) through the mouth in order to examine the oesophagus, stomach and duodenum.

A **sigmoidoscopy or colonoscopy** is commonly performed to assess the colon and occasionally the ileum. The sigmoidoscope (a short endoscope) or colonoscope (a longer and more flexible endoscope) is inserted through the anus (back passage) to examine the rectum and colon. Endoscopies should not be painful but may be uncomfortable, so patients are often given a sedative to help them 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: In this test the patient is asked to swallow a capsule about the size of a small grape, containing a tiny camera, transmitter and light source. As it passes through the gut, 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 . These x-ray tests are now only rarely used to look at the small intestine or colon for evidence of inflammation.

MRI and CT Scans: These scans are increasingly used to look at the location and the extent of the inflammation. These 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.

How is Crohn's disease treated?

The treatment depends on a number of factors including the severity of the symptoms, the site or sites of the inflammation in the gut, whether complications have developed (e.g. abscess formation), whether there are problems away from the gut such as eye or joint inflammation, and what medications has been tried and what medications has worked in the past . Options that may be considered include the following:

No treatment

This is an option for some people who have mild symptoms as symptoms can occasionally settle without treatment. If symptoms get worse, then decisions about treatment can be reviewed.

Drug treatment

Steroid medication (corticosteroids). Steroid medicines work by reducing inflammation. The two commonly used steroids for Crohn's disease are budesonide and prednisolone. In about 7

in 10 cases, symptoms are much improved within four weeks of starting steroids. The dose is reduced gradually, and then stopped once symptoms ease. A course of steroids for a few weeks is normally safe. Steroids are not usually continued once a flare-up has settled. The aim is to treat any flare-ups, but to keep the total amount of steroid treatment over the years as low as possible. Although steroid tablets are commonly used, a steroid enema or suppository is also an option for a mild flare-up confined to the lower large intestine. Steroid injections directly into a vein (e.g. hydrocortisone) may be required for a severe flare-up.

Immunosuppressant medicines. Newer powerful medicines that suppress the immune system have become available in recent years. These have made a big impact on the treatment of Crohn's disease in recent years. They tend to be divided into two groups:

Immunomodulators. These are medicines that modify and suppress the immune system. They include azathioprine, mercaptopurine and methotrexate. They tend to be used in more severe cases and in those where steroid treatment has not helped much.

Biological therapies. These are genetically engineered proteins such as special antibodies called monoclonal antibodies. These can target specific chemicals of the immune system, involved in the inflammation process. In Crohn's disease, a chemical called cytokine tumour necrosis factor alpha (TNF-alpha) is involved in the inflammation process. Medicines called infliximab and adalimumab (which are really manufactured antibodies) block the action of this chemical and therefore suppress the disease activity. Treatment with infliximab (Remicade) or adalimumab (Humira) is an option in some cases - for example, in people who do not respond to steroid medication or to immunomodulators, or in certain situations causing severe symptoms. These medicines need to be given directly into a vein but then typically persist in the body for many weeks with long-lasting effects. People on these medicines should have their disease assessed every twelve months to see whether they still need them.

Aminosalicylate medicines are occasionally used for Crohn's disease. (unlike in ulcerative colitis, a related condition, where they are used more commonly.) They include mesalazine, olsalazine, balsalazide and sulfasalazine. The exact way these medicines work is not clear but they are thought to counter the way inflammation develops in Crohn's disease. The active ingredient of each of these medicines is 5-aminosalicylic acid (5-ASA). However, each medicine is different in how the active ingredient is released or activated in the gut. Mesalazine is the most commonly used. Each of these medicines comes in different brand names and different preparations, such as oral tablets, sachets or suspension, liquid or foam enemas, or suppositories. The type of preparation (for example, tablets or enemas) may depend on the main site of the inflammation in the gut.

Antibiotics may need to be added to other treatments if infective complications are suspected -

for example, if you develop an infected fistula such as an infected perianal fistula. Some of the commonly used antibiotics include metronidazole (flagyl) and ciprofloxacin.

Dietary treatments

A very strict liquid diet that contains basic proteins and other nutrients has been found to help in some cases. This is called an elemental diet and is mainly used in children. A flare-up can settle within four weeks in some people who have this diet. After this, a normal diet is gradually restarted. It is not clear why this treatment works. It may have some effect of 'resting' the gut. This may be an alternative for some people when medication has not worked so well, or has caused bad side-effects. However, it is a controversial treatment.

Surgery

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.

Patients who are very underweight are usually advised to improve their nutrient intake before having surgery, perhaps by taking a special liquid feed as a supplement to their diet. Smokers are also strongly advised to stop smoking before 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. Surgery is also usually needed to treat complications such as fistulas, strictures and abscesses. Crohn's disease around the anus may cause problems that require surgery to drain abscesses etc.

General supportive measures

Iron tablets may be prescribed if you develop anaemia.

Vitamins and other nutrient supplements may be needed if a large part of the gut is affected and food is poorly absorbed.

Nutritional support such as dripping nutrients directly into a vein (parenteral nutrition) may be needed in severe cases.

Painkillers may be needed for a while during flare-ups.

Hospital admission for intravenous fluids (drip) and intensive treatment may be needed if you have a severe flare-up.

Vaccinations may be offered to people with Crohn's disease, to protect them from a variety of infections, especially if they are on treatment which stops their immune system from working properly.

Can I get pregnant if I have Crohn's disease?

Women with inactive Crohn's usually have no more difficulty becoming pregnant than women without IBD. However, patients with active IBD may be more difficult to get pregnant, particularly if they 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. Women who have had pelvic surgery for Crohn's disease may also find that their ability to get pregnant is reduced due to adhesions etc.

In general, male fertility is not affected by IBD, although men taking sulphasalazine may have reduced fertility whilst on the drug.

If you have Crohn's disease and are planning to become pregnant, it is advised that you discuss this in advance with your doctor. For example, you may need extra folate supplements, and certain medicines which may be used for Crohn's disease, such as methotrexate, must not be used during pregnancy.

What is the outlook (prognosis) for patients with Crohn's disease?

The outlook is variable. It depends on which part or parts of the gut are affected and how often and how severe the flare-ups are. Without treatment:

About 3 in 20 people with Crohn's disease have frequent and/or severe flare-ups.

A few people would have just one or two flare-ups in their lives, but for most of their lives have no symptoms.

Most people would fall somewhere in between, have flare-ups from time to time, but can have long spells without symptoms.

Sometimes a severe flare-up is life-threatening and a small number of people die as a result of a serious complication such as a perforated gut.

Modern immunosuppressant medicines have made a big impact in recent years. Recent reports suggest that about 15 in 20 people with Crohn's disease remain in work ten years after diagnosis. So, this means that, in the majority of cases, with the help of treatment, the disease is manageable enough to maintain a near-normal life. However, the burden of the disease can be heavy for some people with severe disease.

Up to 8 in 10 people with Crohn's disease require surgery at some stage in their life for a complication. In about half of people with Crohn's disease, surgery is needed within the first ten years of developing the disease. The most common reason for surgery is to remove a stricture that has formed. Some people need several operations in their lifetime. If you develop Crohn's disease as a young adult, on average you can expect to have two to four operations in your lifetime. However, there is some evidence that the rate of surgery is coming down, probably due to the more modern treatments with medicines now available.

Am I at increased risk of cancer if I have Crohn's disease?

Patients with Crohn's disease that affects at least half the surface of their large intestine (colon) are at slightly increased risk of developing cancer.

People at increased risk are usually advised to have their large intestine routinely checked after having had Crohn's disease for about ten years. This involves a look into the large intestine by a flexible telescope (colonoscopy) on a regular basis and taking small samples of bowel (biopsies) for examination. It is usually combined with chromoscopy (the use of dye spray which shows up suspicious changes more easily). Depending on the findings of this test and other factors such as the amount of intestine affected, whether polyps are detected and whether the person has a family history of cancer, a decision is made to place each individual into a low, intermediate or high risk.

The National Institute for Health and Clinical Excellence (NICE) recommends the next colonoscopy/chromoscopy should depend on the degree of risk of developing colon or rectal cancer, as follows:

Low - five years

Intermediate - three years

High - one year

After the each test, the risk is recalculated.

Why is my doctor uncertain if I have Crohn's disease or ulcerative colitis?

In about 1 in 20 people with IBD affecting just the colon, it is impossible to be certain if the inflammation is related to Crohn's disease or ulcerative colitis. This uncertainty is more likely early on after the diagnosis of IBD. The longer a patient has the diagnosis, the more likely that the true nature of the condition be it Crohn's disease or ulcerative colitis will become apparent. If it is not possible to be certain whether a patient had Crohn's disease or ulcerative colitis, the term Indeterminate Colitis or IBD Unclassified (IBDU) may be used. In general terms, this should not affect management such as drug treatment etc.

Can I undergo investigation/treatment of Crohn's disease at the Glasgow Colorectal Centre?

Yes. Glasgow Colorectal Centre surgeons Richard Molloy and Graham MacKay have extensive experience in assessing and treating patient with Crohn's disease and ulcerative colitis. As with many gastrointestinal diseases, a multidisciplinary approach is often best and the team works closely with medical gastroenterology and radiology colleagues to ensure best management of patients.

Where can I get more information about Crohn's disease or ulcerative colitis?

Crohn's and Colitis UK

4 Beaumont House, Sutton Road

St Albans, Hertfordshire

AL1 5HH

Administration: 01727 830038

Information service: 0845 130 2233 info@crohnandcolitis.org.uk

www.crohnsandcolitis.org.uk

A UK patient orientated organisation. Provides useful information for patients with Crohn's and colitis. Organisation had local branches and is also involved in fundraising

The Colostomy Association

www.colostomyassociation.org.uk

0800 328 4257

UK charity providing support, practical information for patients with a colostomy

The Ileostomy Association

www.the-ia.org.uk

A UK charity providing support, funding raising for research and information for patients who have had their colon removed and have either an ileostomy or ileoanal pouch