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Crohn's Disease

Crohn's disease is a condition that causes inflammation of the wall of the gut (gastrointestinal tract). Any part of the gut can be affected.

This can lead to various symptoms (detailed below). Crohn's disease is a lifelong condition with flare-ups from time to time. The flare-ups vary in frequency and severity.

Who gets Crohn's disease?

Crohn's disease is diagnosed in about 1 in 10,000 people every year. About 145 in every 100,000 people in the UK have Crohn's disease. It can develop at any age but most commonly starts between the ages of 15 and 30. Crohn's disease is more common in people who smoke. If you have a family member with Crohn's disease, you are more likely to develop the condition yourself. It is also more common in people who have had their appendix removed, for the first five years after the operation.

Which part of the gut is affected in Crohn's disease?

In Crohn's disease, one or more patches of inflammation develop in parts of the gut (gastrointestinal tract). Any part of the gut can be affected. However, the most common site for the disease first to start is the last part of the small intestine (the ileum). The ileum is affected in about half of cases. Other parts of the small intestine and the colon are also commonly affected. The mouth, gullet (oesophagus) and stomach are affected much less commonly.

A patch of inflammation may be small, or spread quite a distance along part of the gut. Several patches of inflammation may develop along the gut, with normal sections of gut in between. 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.

What causes Crohn's disease?

The cause is not known. About 3 in 20 people with Crohn's disease have a close relative who also has it. This means there may be some genetic factor. However, other factors such as a germ (bacterium or virus) may be involved. One theory is that a germ may trigger the immune system to cause inflammation in parts of the gut (gastrointestinal tract) in people who are genetically prone to develop the disease.

Crohn's disease has become more common in recent years but the reason for this is not known. It is more common in smokers than in non-smokers. Smokers also tend to have more severe disease compared with 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.

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

Symptoms vary, depending on the part of the gut affected and the severity of the condition. The most common symptoms are diarrhoea, tummy (abdominal) pain and feeling generally unwell. The symptoms are due to inflammation in the wall of the affected parts of the gut (gastrointestinal tract). When the disease flares up, the inflammation may cause one or more of the following:

- **Diarrhoea** is the most common first symptom. It can vary from mild to severe. The diarrhoea may be mixed with mucus, pus or blood. An urgency to get to the toilet is common. A feeling of wanting to go to the toilet but with nothing to pass (tenesmus) is also common.
- **Pain** occurs in about 7 in 10 cases. The site of the pain depends on which part of the gut is affected. The last part of the small intestine (ileum) is the most common site. Therefore, a common area of pain is the lower right side of the tummy (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 (see below).
- **Weight loss** that is not intentional is another common symptom.
- **Ulcers**. An ulcer is a raw area of the lining of the gut which may bleed. You may see blood when you pass stools (faeces).
- **Generally feeling unwell**, which may include loss of appetite, high temperature (fever), and tiredness.
- **Anaemia** may occur if you lose a lot of blood.
- **Mouth ulcers** are common.
- **Anal fissures** may occur. These are painful cracks in the skin of the anus. Skin tags (small fleshy wart-like lumps) may also appear around the anus.

Symptoms can vary and depend on which part or parts of the gut are affected - for example:

- You may not have diarrhoea if the disease is just in the small intestine.

- A persistent pain in the abdomen without any other symptoms may be due to a small patch of Crohn's disease in the small intestine.
- A severe flare-up can make you generally very ill.
- If large parts of the gut are affected, you may not absorb food well and you may become deficient in vitamins and other nutrients.

Other symptoms

Other parts of the body are affected in some people in addition to the gut. These include:

- Inflammation and pain of some joints (arthritis).
- Skin rashes.
- Inflammation of the middle layer 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 does Crohn's disease progress?

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 vary 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**. This is a narrowing of part of the gut (gastrointestinal tract). It is due to scar tissue that may form in the wall of an inflamed part of the gut. A stricture can cause difficulty in food passing through (an obstruction). This leads to pain and being sick (vomiting).
- **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 tummy (abdomen). This can be serious and life-threatening.
- **Fistula**. This occurs when 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 womb (uterus). 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.
- **'Thinning' of the bones (osteoporosis)**. 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?

Your doctor will initially arrange blood tests to help find the diagnosis. You may also be asked to provide stool (faeces) samples for analysis to see if there is an infection in your gut (gastrointestinal tract). A stool sample may also be sent to measure a protein called calprotectin, which can be used to see whether it is likely that you have Crohn's disease.

If it is thought that you may have Crohn's disease you will be referred to a specialist for further investigations. If you are very ill then you may need to be admitted immediately to hospital for these investigations.

Depending on where the symptoms arise from, various tests may be done to confirm the diagnosis, and to determine how much of the gut is affected. For example, if you have symptoms coming from the colon or ileum, a doctor may look inside the colon and ileum, using a special flexible telescope (a colonoscope). The colonoscope is passed through the anus, up into the colon and a little further into the ileum. See the separate leaflet called Colonoscopy for more details.

The typical appearance of the inside lining of the colon or ileum suggests Crohn's disease. Small samples (biopsies) of the lining of various parts of the colon and ileum are usually taken. These are looked at under a microscope. The typical pattern of the cells may confirm the diagnosis.

If you have symptoms coming from the upper part of the gut, a doctor may suggest a gastroscopy (endoscopy). This is a procedure in which a thin, flexible telescope is passed down the gullet (oesophagus) into the stomach. This allows a doctor or nurse to look inside. See the separate leaflet called Gastroscopy (Endoscopy) for more details.

A special X-ray of the large intestine (barium enema) or small intestine (barium meal) may be advised. Barium coats the lining of the gut and shows up as white on X-ray films. Typical patterns on the films show which parts of the gut are affected. These X-rays using barium are much less often used now. Other tests such as an magnetic resonance imaging (MRI) or computerised tomography (CT) scan are now often preferred, depending on the following:

- Which part of your bowel is affected.
- Whether there are any complications.
- Whether these tests are available in your area.

Also, repeat blood tests are helpful from time to time to assess the level of inflammation within the gut, to check for anaemia and other deficiencies and to assess your general well-being.

You may be asked to provide further stool samples for analysis to check for various germs that are sometimes present in people with Crohn's disease. Very occasionally, you may need to have an operation to diagnose Crohn's disease if your specialist cannot rule out an equally serious condition such as tuberculosis inside the tummy (abdomen).

What are the aims of treatment?

There are two main aspects of treatment:

- When a flare-up develops - a main aim is to clear symptoms. That is, to cause a remission of the disease.
- When a flare-up has settled - a main aim is to prevent any further flare-ups of symptoms. That is, to keep you in remission.

Editor's Note

Dr Sarah Jarvis, 14th August 2019
NICE guidance on managing Crohn's disease
The National Institute for Health and Care Excellence (NICE) has published new guidance on best practice for managing Crohn's disease in people of all ages. Their recommendations include:
Treatment for flare-ups

- Single drug treatment (monotherapy) with steroids should be considered for people who have just been diagnosed or who have had no more than one flare-up within a year.
- For young people where there is concern about the effect of steroids on growth, or the risk of side-effects, 'enteral' nutrition (eg, with a tube into the stomach) may be preferred to steroids.
- Single drug treatment with an immunosuppressant medicine (see below) is not recommended to treat a flare-up. However, it can be used as add-on treatment for some people (including people who have two or more flare-ups in a year).
- Biological therapies can be used in people with severe active Crohn's disease (very poor general health and one or more symptoms such as weight loss, fever, severe tummy pain and usually frequent (three to four or more) diarrhoeal stools a day), who have not responded to steroids and/or immunosuppressive treatment.

Maintaining remission

- Your doctor should discuss all the treatment options with you, including treatment, no treatment and treatment side-effects.
- The immunomodulators azathioprine or mercaptopurine should be the standard single drug treatments if you do choose treatment.
- The immunomodulator methotrexate should only be given if you can't take, or haven't responded to, azathioprine or mercaptopurine.
- A combination of azathioprine and the antibiotic metronidazole should be considered to maintain remission if you've had major surgery for Crohn's disease.

Other recommendations

- You should be offered regular colonoscopies if you were diagnosed at least 10 years ago. Depending on your risk, these should be offered every 1-5 years.
- If you're a female who might get pregnant, you should be given information about the about the possible effects of Crohn's disease and its treatment on pregnancy and fertility.
- As an adult with Crohn's disease, you should be assessed for your risk of **osteoporosis** and offered a bone scan to assess your bone density if appropriate. This is not routinely needed for children but may be needed in special circumstances (such as being very underweight, having a fracture without major trauma or needing repeated courses of oral steroids).

What are the treatment options for a flare-up of Crohn's disease?

Medication can often ease symptoms when they flare up. Surgery to remove sections of the gut is needed to treat some flare-ups. Medication taken regularly may prevent symptoms from flaring up.

The treatment advised can depend on various factors - for example:

- The severity of the symptoms.
- The site or sites of the inflammation in the gut (gastrointestinal tract).
- Whether associated problems have developed, such as eye inflammation.
- What treatments worked best for you in the past.

Treatment decisions can become complex and a specialist will usually advise. Options that may be considered include the following:

No treatment

This is an option for some people who have mild symptoms. There is a chance that the symptoms will settle on their own. If symptoms become worse, decisions about treatment can be reviewed.

A course of steroids (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 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 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-α) 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 or adalimumab 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.

Antibiotics

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.

Dietary treatments

A very strict liquid diet that contains basic proteins and other nutrients has been found to help in some cases. This 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.

Surgery

An operation to remove a severely affected section of gut may be needed if other treatments do not work. The gut is cut above and below the affected part which is removed. The two ends are then joined up. Surgery is also usually needed to treat complications such as fistulas, strictures and abscesses.

General 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 (a 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. This is especially important if they are on treatment which stops their immune system from working properly.

What are the treatment options to prevent flare-ups of symptoms?

Once a flare-up has settled, without treatment, on average there is about a 1 in 2 chance that another flare-up will develop within a year. Certain factors increase the likelihood of more severe and more frequent flare-ups.

For example, the severity of the first flare-up, the extent of the disease in your gut, your age, and the extent of treatment needed to control the initial flare-up. For some people it may not be worthwhile taking regular medication if flare-ups are not frequent, or are mild, and respond well to treatment when they occur. For others, medication to prevent flare-ups can make a big difference to quality of life.

The treatment options that may be considered to prevent flare-ups (which in medical language is to maintain remission) include the following:

- A regular dose of an immunomodulator (described earlier). This is becoming more widely used as a treatment to prevent flare-ups.
- A regular dose of a biological therapy (described earlier). For example, an infusion of infliximab every eight weeks. This may be used in selected cases where flare-ups are severe and other treatments have not worked so well.
- Each of the above treatments increases the chance of remaining free of flare-ups but they do not always work. There is a balance between the likely benefits and the possible side-effects that occur in some people. Your doctor will advise about the pros and cons of long-term medication and which medication is best for your circumstances. **Note**: steroid medication is not generally used long-term to prevent flare-ups.

For smokers, giving up smoking may reduce the number and severity of flare-ups. It would always be wise to try to give up smoking. There are treatments that can help smokers to quit. Ask your doctor for advice on this.

Newer treatments

The treatment of Crohn's disease is an evolving field. Various new medicines are under investigation and may change the treatment options over the next ten years or so.

Crohn's disease and pregnancy

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 prognosis?

The outlook (prognosis) is variable. It depends on which part or parts of the gut (gastrointestinal tract) 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 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 lives 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.

Crohn's disease and cancer of the colon

If you have Crohn's disease that affects at least half the surface of your colon (large intestine), you will be at a slightly increased risk of developing bowel cancer.

People with this 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) every now and then and taking small samples (biopsies) of bowel 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 on other factors, you will be put into a risk category which is called low, intermediate or high. 'Other factors' include:

- The amount of intestine affected.
- Whether you have had complications such as small fleshy lumps (polyps).

- Whether you have a family history of cancer.

The National Institute for Health and Care Excellence (NICE) recommends the next colonoscopy/chromoscopy should depend on the degree of risk of developing colon or rectal cancer.

Further reading & references

- Crohn's disease: management in adults, children and young people; NICE Clinical Guidelines (October 2012, last updated May 2016)
- Ulcerative colitis: management; NICE Clinical Guideline (June 2013)
- Colonoscopic surveillance for prevention of colorectal cancer in people with ulcerative colitis, Crohn's disease or adenomas; NICE Clinical Guideline (March 2011)
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