CROHNS DISEASE

INFORMATION FOR PATIENTS
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**What is Crohn’s Disease**

Crohn’s disease is one of the two main forms of inflammatory bowel disease, so may also be called ‘IBD’. The other main form of inflammatory bowel disease is a condition known as ulcerative colitis.

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

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

Crohn’s is sometimes described as a chronic condition. This means that it is ongoing and life-long, although you may have periods of good health (remission) as well as times when symptoms are more active (relapses or flare-ups).

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

**What causes crohn’s disease?**

Nobody is sure, but researchers and experts think crohn’s is caused by a combination of factors, including:

- the genes you are born with
- an abnormal reaction of the digestive system to bacteria in the intestine
- an unknown ‘trigger’ or set of triggers that could include viruses, other bacteria, diet, stress, or something else in the environment.

- There isn’t a cure at the moment but a lot can be done with medication and surgery to help keep symptoms under control and to reduce the chance of a flare-up

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.
How does crohn’s disease affect the gut?

Any part of the gut can be affected in crohn’s disease. The most common area is the last part of the small intestine (terminal ileum) and the first part of the large intestine (or ‘colon’), near the appendix. In some people, only the colon is affected, in a pattern similar to ulcerative colitis. In others, multiple parts of the gut are affected. Rarely, the mouth, gullet or stomach may be involved. In some people, the inflammation in the gut also triggers inflammation outside the intestine leading to arthritis, eye inflammation or skin complaints.

A patch of inflammation may be small, only a few centimetres, or extend quite a distance along part of the gut. As well as affecting the lining of the bowel, crohn’s may also go deeper into the bowel wall.

What are the main symptoms?

It is a very individual condition and some people may remain well for a long time, even for many years, while others have frequent flare-ups. Your symptoms may also vary depending on where in your gut you have crohn’s. However, the most common symptoms during a flare-up are:
• Abdominal pain and diarrhoea. Sometimes mucus, pus or blood is mixed with the diarrhoea.

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

• Feeling generally unwell. Some people may have a raised temperature and feel feverish.

• Mouth ulcers

• Loss of appetite and weight loss. Weight loss can also be due to the body not absorbing nutrients from the food you eat because of the inflammation in the gut.

• Anaemia (a reduced level of red blood cells). You are more likely to develop anaemia if you are losing blood, are not eating much, or your body is not fully absorbing the nutrients from the food you do eat. Anaemia can also make you feel very tired.

**How common is crohn's disease?**

It’s estimated that crohn’s disease affects about one in every 650 people in the UK.

It’s more common in urban rather than rural areas and in northern developed countries, although the numbers are beginning to increase in developing nations. crohn’s is also more common in white people of European descent, especially those descended from Ashkenazi Jews (those who lived in Eastern Europe and Russia).

Crohn’s can start at any age, but usually appears for the first time between the ages of 10 and 40. Recent surveys suggest that new cases of crohn’s are being diagnosed more often, particularly among teenagers and children. The reason for this is not clear. crohn’s appears to be slightly more common in women than in men. It is also more common in smokers.

**What are the main types of crohn's disease?**

Crohn’s is often categorised according to which part or parts of the gut are most affected. The main types are as follows:

**Terminal ileal and ileocaecal**

Crohn’s in the ileum (the last part of the small intestine) may be called ileal or sometimes ‘terminal ileal’ crohn’s – because it is affecting the terminus or end of the ileum. If it also affects the beginning of the large bowel it is known as ileocaecal crohn’s. With this type of crohn’s you may feel pain in the lower right side of your abdomen, especially after eating. There is often weight loss, and you may have diarrhoea. Because crohn’s in the ileum can make it difficult for your body to absorb bile salts, and bile salts can irritate the bowel lining, the diarrhoea may be watery. It
is unlikely to be bloody, as any blood lost will be digested by the time it reaches the rectum. About four out of 10 people with crohn’s have ileal or ileocaecal disease.

**Small bowel**

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

**Colonic**

Crohn’s disease in the colon (large intestine or large bowel) is often called crohn’s colitis. This is also a common form of crohn’s disease. The main symptom tends to be blood stained diarrhoea. Because of the inflammation, the colon cannot hold as much waste as normal and you may have very frequent bowel movements (six or more a day), especially if your rectum is inflamed.

**Gastroduodenal**

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

**Perianal**

Crohn’s in the area around the anus (back passage) can occur on its own or at the same time as inflammation in other parts of the body. It can cause a number of symptoms such as:

- **Fissures** – these are tears in the lining of the anal canal (back passage), which can cause pain and bleeding, especially during bowel movements.

- **Skin tags** – small fleshy growths around the anus.

- **Haemorrhoids** – swollen areas in the anal canal.

- **Abscesses** – collections of pus that can become swollen and painful. They are often found in the area around the anus and can cause a fever or lead to a fistula.

- **Fistulas** – these are narrow tunnels or passageways between the gut and the skin or another organ. In perianal Crohn’s, fistulas often run from the anal canal to the skin around the anus. They appear as tiny openings in the skin that leak pus or sometimes faecal matter. They can irritate the skin and are often sore and painful, but can usually be treated with medication and/or surgery.

**Oral Crohn’s**
Crohn’s can occasionally affect the mouth. True oral crohn’s, which typically causes swollen lips and mouth fissures, is rare. However, about one in five people with Crohn’s has a tendency to develop mouth ulcers.

**Can crohn’s disease have complications?**

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

**Strictures**

Ongoing inflammation and then healing in the bowel may cause scar tissue to form. This can create a narrow section of the bowel, known as a stricture. A stricture can make it difficult for food to pass through and may then cause a blockage. Symptoms include severe cramping abdominal pain, nausea, vomiting and constipation. The abdomen may become bloated and distended and the gut may make loud noises. Strictures are usually treated surgically, often with an operation known as a stricturoplasty

**Perforations**

Very occasionally, a severe blockage caused by a stricture may lead to a perforation or rupture of the bowel, making a hole. The contents of the bowel can leak through the hole and form an abscess. This causes pain and a fever. An abscess may also develop into a fistula.

**Fistulas (Fistulae)**

A fistula can form when the inflammation in crohn’s spreads through the whole thickness of the bowel wall and then continues to tunnel through the layers of other tissues. These tunnels or passageways can connect the bowel to other loops of bowel, to the surrounding organs, such as the bladder and vagina, or to the outside skin, including the skin around the anus, as mentioned above Fistulas may be treated medically or with surgery.

**Does drohn’s disease affect other parts of the body?**

Crohn’s disease can also cause problems outside the gut. Some people with crohn’s develop conditions affecting the joints, eyes or skin. These often occur during active disease, but they can develop before any signs of bowel disease or during times of remission. Crohn’s may also lead to bone thinning, liver problems, blood clots and anaemia.

**Joints**
Inflammation of the joints, often known as arthritis, affects up to one in three people with IBD. In people with crohn’s it is most common in those with crohn’s colitis (crohn’s disease in the colon). The inflammation usually affects the large joints of the arms and legs, including the elbows, wrists, knees and ankles. Fluid collects in the joint space causing painful swelling, although there can be pain without obvious swelling. Symptoms usually improve with treatment for intestinal symptoms and there is generally no lasting damage to the joints. A few people develop swelling and pain in the smaller joints of the hands or feet. This may be longer lasting and persist while the inflammatory bowel disease is in remission.

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

**Skin**

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

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

**Eyes**

Eye problems affect about one in 20 people with crohn’s. The most common condition is episcleritis, which affects the layer of tissue covering the sclera, the white outer coating of the eye, making it red, sore and inflamed. Two other eye conditions linked with crohn’s are scleritis (inflammation of the sclera itself) and uveitis (inflammation of the iris). These conditions can usually be treated with steroid drops given into the eye, although uveitis and scleritis may need treatment with immunosuppressants or biologic drugs. If you get any kind of eye irritation or inflammation, always mention it to your doctor, who may refer you to an eye specialist.

**Bones**
People with crohn’s are more at risk of developing thinner and weaker bones. Bone thinning can be due to the inflammatory process itself, poor absorption of calcium needed for bone formation, low calcium levels because the diet does not contain enough dairy foods, or the use of steroid medication. Calcium supplementation and, for some people, drug treatment can be helpful.

Liver

Some complications are related to the liver and its function. About one in four people with crohn’s develops gallstones. These are small ‘stones’ made of cholesterol which may get trapped in the gallbladder, just beneath the liver, and can be very painful. Several factors linked with crohn’s can make gallstones more likely – for example removal of the end of the small intestine or severe inflammation in this area, which can lead to poor absorption of bile salts. (Bile salts help to digest fats during digestion). Some of the drugs used to treat crohn’s, for example azathioprine and methotrexate, may affect the liver. Changes in treatment may help reduce this type of complication.

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

Blood circulation

People with crohn’s are about twice as likely to develop blood clots in the veins, including DVT (deep vein thrombosis) in the legs. You may be particularly at risk during a flare-up or if you are confined to bed, for example in hospital. If you get pain, swelling and tenderness in your leg, or chest pains and shortness of breath, contact your doctor straight away. You can reduce your risk by not smoking, and by keeping as mobile as possible, drinking plenty of fluids, and wearing support stockings. Precautions like these can be especially helpful when travelling by air, which increases the risk of blood clots for anyone.

Anaemia

Anaemia is a common complication of inflammatory bowel disease. If you are anaemic it means you have fewer red blood cells than normal and/or lower levels of haemoglobin in your blood. (Haemoglobin is a protein found in red blood cells that helps carry oxygen around the body). There are several different types of anaemia. People with inflammatory bowel disease most likely to develop iron deficiency anaemia. This is caused by a lack of iron in the diet or poor absorption of iron from food, but can be made worse by ongoing blood loss. Another type of anaemia is vitamin deficiency anaemia, caused by a low intake or poor absorption of certain vitamins, such as vitamin B12 or folic acid. This may particularly affect people with
Crohn’s who have had sections of the small intestine removed. Some of the drugs used for inflammatory bowel disease example sulphasalazine and azathioprine, can also cause anaemia.

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

Can crohn’s disease lead to cancer?

crohn’s disease is not a form of cancer. However if you have had severe or extensive disease affecting all or most of the colon for many years, you may have a slightly increased risk than normal of developing colon cancer.

Research shows that this risk of developing cancer usually begins to increase about 8-10 years after the start of the inflammatory bowel disease symptoms. (This is not from the date of your diagnosis, which could be much later than when your symptoms started). Having Primary Sclerosing Cholangitis (PSC) may also increase your risk of bowel cancer.

How is Crohn’s Disease diagnosed?

Diagnosis, Tests and Treatment

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

Blood Tests and Stool Tests

Simple blood tests can show whether you have inflammation somewhere in your body and whether you are anaemic. Your stools can also be tested for signs of bleeding or inflammation, and to check whether your diarrhoea is caused by an infection. If inflammation is confirmed, you may then have an examination to look inside your body, such as an endoscopy, x-ray or scan.

Endoscopy

There are several types of endoscopy which can have different names according to the type of scope used and the part of the gut being examined. For example:
• An upper GI endoscopy – If you have symptoms coming from the upper part of your gut, you may have what is known as an upper GI (Gastrointestinal Tract) endoscopy or gastroscopy. In this, the doctor or specialist endoscopist inserts an endoscope (a thin flexible tube with a camera in its tip) through your mouth so they can examine your oesophagus, stomach and duodenum.

• A sigmoidoscopy or colonoscopy – If you have symptoms in your ileum or colon, you will have a sigmoidoscopy or a colonoscopy. This means a sigmoidoscope (a short endoscope) or a colonoscope (a longer and more flexible endoscope) will be inserted through the anus (back passage) to examine the rectum and colon.

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

Capsule Endoscopy

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

Barium X-ray Tests

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

MRI and CT Scans

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

Sometimes it can be difficult to tell Crohn’s in the colon apart from other inflammatory bowel conditions, especially Ulcerative Colitis (UC). UC affects the lining of the colon, causing inflammation and tiny ulcers. If it remains unclear which condition you have, you may be given a diagnosis of IBD Unclassified (IBDU) or Indeterminate Colitis. This should not affect the start of any treatment.

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

**What treatments are there for crohn’s?**

Treatment for crohn’s may be medical, surgical or a combination of both. If your condition is mild, not having any treatment might be an option. Dietary therapy may be another option for some people. Your treatment will depend on the type of crohn’s you have and the choices you make in discussion with your doctor.

**What drugs are used to treat crohn’s disease?**

Drug treatment for crohn’s usually aims to reduce symptoms and control flare-ups, and then to prevent a relapse once the disease is under control. This can mean that you need to take your medication on an on-going basis, sometimes for many years. Or, you may need only a short course of drugs.

**Anti-inflammatory drugs**

These help to reduce inflammation and include:

- 5 ASAs or aminosalicylates such as mesalazine (brand names include Asacol, Pentasa, Salafalk, and Octasa), sulphasalazine (Salazopyrin), and balsalazide (Colazide)

- Corticosteroids, often just called steroids, such as prednisolone, hydrocortisone and budesonide (Entocort)

- Immunosuppressants such as azathioprine (Imuran), mercaptopurine or 6MP (Purinethol), methotrexate and tacrolimus

- Biological or ‘anti-TNF’ drugs such as infliximab (Remicade) and adalimumab (Humira).

**Symptomatic drugs**

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

- Anti-diarrhoeals such as loperamide (Imodium, Arret), cholestyramine (Questran)

- Bulking agents such as Fybogel
• Painkillers such as paracetamol and aspirin.

**Over the counter medication**

It is best to check with your doctor or inflammatory bowel disease nurse before you take any over-the-counter medicines as they may not be suitable for you, or could interact with your inflammatory bowel disease drugs. For example, some anti-diarrhoeals may make your symptoms worse if you take them during a flare-up. Certain painkillers are a type of drug known as non-steroidal anti-inflammatory drugs (or NSAIDS), and these may possibly trigger a flare-up.

**What about surgical treatment for crohn’s?**

Over the last decade, advances such as the development of biological drugs have produced increasingly effective medical therapies for crohn’s disease. There have also been changes in the way surgery for crohn’s is now managed. For example, extensive resections (removal of diseased sections of the intestine) are now less common. However, surgery remains an important treatment option, often in combination with medical therapies. It is estimated that about seven out of 10 people with crohn’s will still need surgery at some point in their lives.

Some people may choose to have surgery when other treatments cannot sufficiently control their symptoms. This can have the advantage of giving you more time to prepare for having the operation. If you are very underweight, your doctor may advise you to improve your nutrient intake before having surgery, perhaps by taking a special liquid feed as a supplement to your diet.

**Also, if you smoke, you will be strongly advised to stop smoking before you have surgery. Research has shown that continuing to smoke increases the risk of needing the surgery again.**

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

**What is dietary treatment for crohn’s disease?**

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

These feeds contain all the essential nutrients in a simple form that your body can absorb with little or no digestion. Not everyone likes the taste of these dietary feeds, but they do come in a range of flavours and some people have found that taking the liquid iced or through a straw can make it easier to drink. An alternative may be to take the feed overnight through a naso-gastric tube (a fine tube passed through the nose down into the stomach).
Enteral nutrition is widely used for children with crohn’s disease, because it helps their growth and avoids the use of steroids.
There is less evidence for the effectiveness of enteral nutrition in adults, particularly for active crohn’s disease. Research has shown it to be less effective than steroids, for example. However, enteral nutrition may be recommended for adults who prefer not to use drug therapy, and it can be useful as a supplement for people who need extra nutrition.

**Do I need to change my diet?**
There is no clear evidence that any food or food additive directly causes or improves crohn’s.
Generally, the most important thing is to try to eat a nutritious and balanced diet so that you maintain your weight and strength, and to drink sufficient fluids to stop you getting dehydrated.
On the other hand, some people with crohn’s have found that certain foods seem to trigger their symptoms or make them worse – and that it helps if they, for example, reduce or adjust the amount of fibre they eat or cut out wheat or dairy products. It may be worth looking at your own diet to see if you can find similar triggers.
However, in order to make sure your diet remains healthy and well balanced, it is important to get advice from your doctor or from a qualified dietitian before you make any significant changes.
If you have a stricture, you may need to avoid eating ‘hard to digest’ or ‘lumpy’ foods that might cause a blockage. Your hospital dietitian should be able to advise you on this. Typically, such foods might include nuts and seeds, fruit and vegetable skins, and tough meat or gristle. It may also help to have small, frequent meals or snacks, and to chew food thoroughly.

If your bowel is not absorbing nutrients properly, perhaps because of extensive inflammation or a shortened bowel after surgery, you may find that your diarrhoea improves if you keep to a diet low in fat.
If you have oral crohn’s, it may help to avoid carbonated drinks or other foods containing benzoates or cinnamon.
Some people with crohn’s may lack certain vitamins and minerals, such as iron, calcium, vitamin D or vitamin B12, especially if they have a poor appetite or active diarrhoea or blood loss. Some of the drugs used for crohn’s can also lead to deficiencies, for example sulphasalazine can affect the body’s ability to absorb folates, and steroids can cause calcium loss.
In these cases a supplement may be useful, but do discuss this with your doctor or dietitian. If tests show that you have a serious deficiency, you may need a course of supplements or might benefit from enteral nutrition. Vitamin B12 supplements are sometimes given by injection and iron supplements intravenously (by injection using a ‘drip’) as this can make them easier to absorb.
What about complementary and alternative approaches?
Some people with crohn’s disease have found complementary and alternative medicines (CAM) helpful for controlling symptoms such as abdominal pain and bloating. However, there are few reliable scientific studies to show the effectiveness of such therapies and it is possible that their symptoms may have gone into remission coincidentally, given the unpredictable course of the conditions such as crohn’s. Or there may have been a ‘placebo’ effect – there is evidence that if people take a placebo (a harmless inactive substance) but believe that it will help, then their symptoms may improve regardless of the actual effectiveness of that treatment. One area where there has been some scientific research is that of the use of omega 3 fish oils. However, a recent review concluded that fish oils were probably not effective at keeping people with crohn’s in remission, as although some studies found symptoms improved, two larger studies showed no benefit. A small study on acupuncture for active crohn’s also showed a very slight improvement, but not enough to be significant. Other research has suggested that a herbal medicine containing wormwood may help with steroid reduction, but more work is needed in this area. There is ongoing research into the use of probiotics for inflammatory bowel disease, but so far they have not been found helpful for crohn’s.

What about pregnancy and crohn’s?
Women with inactive crohn’s usually have no more difficulty becoming pregnant than women without inflammatory bowel disease. However, if you have active crohn’s, it may be more difficult to get pregnant, particularly if you are underweight or eating poorly. Severe inflammation in the intestines can also affect the normal function of the ovaries and may cause adhesions (bands of scar tissue) that affect the fallopian tubes. In general, male fertility is not affected by inflammatory bowel disease, although men taking sulphasalazine may have reduced fertility whilst on the drug.

Doctors usually recommend trying to get your inflammatory bowel disease under control before you get pregnant. If you are well when your pregnancy begins you are more likely to have an uncomplicated pregnancy. Also, if you can remain in remission throughout your pregnancy then your chances of a normal pregnancy and a healthy baby are about the same as those of a woman without inflammatory bowel disease.

If you do get pregnant during a flare-up, you may be more likely to give birth early or have a baby with a low birth weight. Severe active crohn’s can put the baby at greater risk. However, your doctor should be able to help you to control your symptoms as much as possible – and, with a few exceptions, most inflammatory bowel disease treatments can be continued while you are pregnant.
For example, you may be able to continue taking steroids, 5 ASAs and Azathioprine, although you should not take Methotrexate or Mycophenolate Mofetil when pregnant or trying to conceive, because they can cause an increased risk of birth defects.

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

**I want to breastfeed. Will my medicines do any harm to the baby?**

Breastfeeding is important for the development of a healthy immune system, and is generally recommended.

There is no evidence that many of the drugs used to treat inflammatory bowel disease are harmful to a breastfed baby, although very few are actually licensed for use while breastfeeding. This may be because little is known about the drug’s long term effect, or because the drug companies are cautious about conducting trials with breastfeeding mothers. So, they prefer to advise against any use of their medications while breastfeeding. If you would like to breastfeed, talk to your doctor and your inflammatory bowel disease team about any possible problems from your medication.

- Based on past experience, the 5-ASA drugs such as Mesalazine and Sulphasalazine are considered by doctors to be safe while breastfeeding. Research has shown that they are transferred into the breast milk, but in very low concentrations.

- Steroids such as Prednisolone also appear in low concentrations in breast milk. Again they are generally considered safe, although if you are taking large doses of steroids (over 40mg a day) breastfeeding is not recommended. You can reduce the effects of steroids by waiting for 4 hours after taking a dose before starting to breastfeed.

- Some doctors would not advise breastfeeding by mothers on Azathioprine or Mercaptopurine, but very little of the active drug is secreted into breast milk. Also, there is no evidence of harm in children of mothers who have breastfed while on these drugs. Thus the benefits of breastfeeding may outweigh any small potential risk.

- Recent studies have suggested that Infliximab does not pass into breast milk and that it may be safe to breastfeed while taking this drug. Evidence about Adalimumab’s safety is still very limited. The long term effects of these drugs on a
child’s developing immune system are also still unknown. Most doctors still recommend that you do not breastfeed during treatment with these medicines or for six months after your last dose.

- Breastfeeding is not advisable if you are taking Ciclosporin, Methotrexate, Mycophenolate Mofetil, or Tacrolimus. It is also better not to breastfeed while you are on antibiotics such as Ciproflaxacin or Metronidazole, or the anti-diarrhoeals, Loperamide and Diphenoxylate

**Does crohn’s run in families?**
Crohn’s does tend to run in families, and parents with inflammatory bowel disease are slightly more likely to have a child with inflammatory bowel disease. Studies show however, that for most people the actual risk is still relatively small, although it can be higher in some population groups.
If one parent has crohn’s, the risk of their child developing inflammatory bowel disease is generally thought to be about 5% – that is, for every 100 people with crohn’s about five of their children might be expected to develop inflammatory bowel disease at sometime in their lives. But, genes are only part of the picture and research suggests that environmental triggers also play an important role.

**How will crohn’s affect my life?**
There is no single answer to this question because everyone is different. Crohn’s is a very ‘individual’ disease and people’s experiences vary so widely. Also, so much can depend on the severity of your condition and on whether your disease is in a quiet or an active phase.
Some people with crohn’s may never have more than mild and infrequent symptoms of diarrhoea and pain, and their illness may not affect their lives very much. Other people may have continuous and severe symptoms in spite of medical and surgical treatment, and have to adapt their lifestyle considerably.

**Travel and Immunisations**
If you have crohn’s disease you may find the thought of travelling daunting. A change of climate, water, or food can upset anyone’s bowels. Yet many people with inflammatory bowel disease travel widely, both in the UK and abroad. They may go for a short break or a long holiday lasting several weeks or months. With careful planning ahead it should be possible for you to travel to most places. Before you leave, speak to your doctor about a flare-up plan. This will mean you know what to do if your Inflammatory bowel disease symptoms worsen while you are away.

This information sheet sets out to answer some of the questions that you may have when thinking about going on holiday or on a business trip.
Insurance

If you need medical treatment when abroad, there are many countries where you would have to pay for it, so it is usually a good idea to arrange travel insurance to cover healthcare costs. This is particularly the case if you are travelling to countries that do not have healthcare agreements with the UK. For example, costs are very high in the USA. For further information, see the NHS website: nhs.uk/nhsengland/Healthcareabroad

For travel to most parts of Europe you can get a free European Health Insurance Card (EHIC). This card entitles you to reduced-cost or free treatment in most European countries. However, you may not wish to rely on this alone, because it does not help you get home, or cover your family’s expenses. You can apply for an EHIC online at www.ehic.org.uk or by telephone on 0300 330 1350.

You will need to mention your inflammatory bowel disease to the insurance company when you are arranging your policy. If you do not, you may find that your insurance is invalid or that you have problems should you need to make a claim. You may find that some insurance companies will not cover a pre-existing condition such as inflammatory bowel disease. Or, you might have to confirm that you are not travelling against your doctor’s advice in order to obtain cover.

It may be more difficult to obtain insurance if you have recently had or are awaiting surgery, have been admitted into hospital within the last year, or are waiting for the results of tests. You may find it helpful to look at our information sheet Insurance and IBD, which gives more details about travel insurance and includes a list of insurance companies suggested by Crohn’s and Colitis UK members. It is available on our website or from our Information Line.

If you do become ill during your travels and you wish to claim on your insurance, you will need to keep receipts for everything, such as taxi fares to hospital.

Vaccination

Vaccinations may be needed or recommended for travel to certain countries. Check with your doctor which vaccinations you should have. Some need to be taken two or three months before travel so it is worth finding out several months in advance.

For more information, you could check with your travel agent or visit the NHS Fit for Travel website

When packing for your trip, it is a good idea to take your vaccination certificate with you as some countries will check it at customs, and may refuse entry to people who have not had the correct vaccinations.
If you are on certain drugs for your Inflammatory bowel disease, you may find that you cannot have some vaccinations. This is because some of the drugs prescribed for Inflammatory bowel disease can weaken the immune system. These include steroids, immunosuppressants (such as Azathioprine, 6-Mercaptopurine and Methotrexate) and biologics (such as Infliximab and Adalimumab). If you are on any of these medications, you should avoid live vaccinations, such as polio or yellow fever. You may find it helpful when travelling to have a medical exemption letter from your doctor stating why you cannot have the vaccination. However, even with such a letter, some countries may not be able to admit you without a yellow fever vaccination. Also, if you are travelling from a country where there is a yellow fever risk and you have not had the vaccination, immigration officials are legally entitled to quarantine you. For more information on which countries carry risk of yellow fever, visit the World Health Organisation website.

If you have stopped taking immunosuppressants you may be able to have a live vaccination after waiting 3 months, depending on which drug you have been taking.

If you have recently had a live vaccination and you are about to start immunosuppressants, it is recommended that you wait at least 3 weeks before starting your treatment.

Standard vaccines, such as Hepatitis A or B, and ‘inactivated’ vaccinations such as polio and typhoid are considered safe, but they may not be as effective when taking immunosuppressant drugs.

Talk with your inflammatory bowel disease Team about the exact timings of immunosuppressant treatment and vaccinations.

Malaria

If you are travelling to an area with malarial mosquitoes, you are advised to take an anti-malaria medication. Most tablets have to be started a week before travel and continued for four weeks after return. Like any medication, there may be side-effects when taking anti-malarials, and these may affect your inflammatory bowel disease. There can also be adverse interactions between some anti-malarials and some immunosuppressant drugs for inflammatory bowel disease. You may wish to discuss with your specialist which preparation is suitable for you.

Preventing mosquito bites is just as important as taking the medication. Mosquitoes bite particularly between dusk and dawn. You can help to protect yourself by wearing light coloured, loose clothing to cover your arms and legs, and using an effective insect repellent, such as one containing DEET (diethyltoluamide). For further information see the National Travel Health Network and Centre website: www.nathnac.org.

Medical Documents
It may help to take certain medical documents away with you. For example, you will probably find it useful to have a letter from your GP or Consultant outlining your condition, medical history and medication. This could be a copy of your last clinic review which should state the details of your inflammatory bowel disease and current treatment. Customs officers may ask to see this and it can also be very helpful to show a doctor abroad, should you need to see one. It may be worth having this information translated into the language of your destination country. It can also help to learn key words and phrases about your condition and medication in the local language. You may be able to get a ‘Can’t Wait’ card in the local language. You can call our Information Line for details about this.

As a precaution, have the details of your own doctor and inflammatory bowel disease team with you, including the phone number and email address. You could try and find out the name and contact details of the doctors in the places you hope to visit. You could also contact our Information Line for details of worldwide inflammatory bowel disease organisations who may be able to help with information about medical care for visitors in those particular countries.

It may be helpful to take a list of your medications, including the generic names of drugs (for example, mesalazine for Asacol and Pentasa) and, if possible, the foreign brand name. It could also be useful to take a copy of your prescription for information.

If you are on steroids, consider carrying a steroid card or wearing a ‘MedicAlert’ bracelet. If there is an emergency, this alerts the person attending you of your condition and medication. You can obtain a card from any pharmacy or a bracelet from the MedicAlert Foundation on 01908 951045 or their website: www.medicalert.org.uk. You can also wear a MedicAlert bracelet for other medications.

Medication- Packing medicines

If possible, try to take enough medication for your whole trip, as well as extra in case of delays, to ensure you do not run out. If your medication has to be kept refrigerated, you could store it in a small cool bag, obtainable from chemists, or in a Frio cooling wallet that works without refrigeration.

When going away for some time, you may need to get new supplies of your medication while you are away. If you can, try to plan for this. As well as taking a full list of your medications you could also check with the relevant pharmaceutical company whether your medications are likely to be easily available in the countries you plan to visit. If your medication cannot be obtained where you are going, then you could ask your doctor for a private prescription, and purchase extra supplies in the UK from a pharmacy.
You may also want to take a good supply of any over-the-counter medicines you are using, such as anti-diarrhoeals (eg Imodium, Lomotil), anti-spasmodics, (eg Buscopan, Colofac) rehydration sachets (eg Dioralyte, Electrolate, Rehidrat) and pain killers (eg paracetamol).

Taking medicines abroad

If you are travelling abroad, the government advises you to keep your drugs in their original packaging to show at customs. You may also need to show them your letter from your GP or consultant. Storing your medication in your hand luggage when flying will help if your baggage is lost. Hand luggage restrictions mean that if you have more than 100ml of medicine in your hand luggage you will need to show a letter from your doctor stating your medical need. You could check with your airline before you fly whether you can carry your medications in your hand luggage, especially if you need to take syringes in either your hand luggage or checked-in bags.

Some countries have restrictions on bringing drugs in for personal use. You can check with the embassy of the country you will be visiting whether this applies to your medications. Details of embassies can be found on the Foreign Office website: www.fco.gov.uk.

Some prescription medicines contain drugs subject to control under the Misuse of Drugs legislation. None of the medication generally prescribed for inflammatory bowel disease contains controlled drugs. However, some people with inflammatory bowel disease may be taking drugs for other conditions that contain controlled substances, such as codeine and morphine. If so, contact the Home Office Drugs Branch on 020 7035 6330 or see their website: www.homeoffice.gov.uk/drugs/licensing to find out if you need a licence to take the medicine abroad. Personal licences are required for those travelling for over three months.

If you are travelling across different time zones you may wonder about the timing of your medication. Your specialist may be able to advise you. Some people split the difference between the time they would have taken it in the UK and the time at their destination. You could then gradually adjust the timing of your medication to the country you will be in, and do the same on the return journey.

Food and drink when abroad

Anyone travelling abroad is at risk of getting a stomach upset, especially in less developed countries. A common problem is traveller's diarrhoea, usually caused by bacteria, parasites or viruses in contaminated food and water. Having inflammatory bowel disease means you have to be particularly careful about hygiene and what you eat and drink. The following tips may help:
- Wash your hands with soap and dry by air or on a clean towel before eating. You could carry a supply of anti-bacterial disposable wipes for places without washing facilities.
- Peel all fruits and eggshells yourself. This includes tomatoes.
- Avoid food from street vendors and kiosks, and any food likely to have been exposed to flies.
- Avoid unpasteurised dairy products

Avoid raw vegetables and salads, and foods that may be undercooked, such as steaks and burgers, and foods that have been kept warm.
- Avoid shellfish as these can easily be contaminated.
- Drink bottled water (ensuring the seal is not broken) or water that has been boiled. Use sterilising tablets when travelling at a high altitude where boiling will not sterilise the water.
- Use bottled or sterilised water to clean your teeth and when preparing food.
- Avoid ice in drinks unless you are sure it is made with safe water.
- Avoid swallowing water while swimming.

If you are on a restricted diet, you can obtain dietary cards in various languages. See Further Help for more details.

Treating Traveller's Diarrhoea

Traveller's diarrhoea often passes within three to four days. Drinking plenty of liquids replaces the fluids lost by diarrhoea, and prevents dehydration, but be careful of ice-cold, alcoholic, caffeinated, or citrus drinks, which can aggravate diarrhoea.

As you improve it may help to eat bland food, such as bananas, plain toast, boiled rice, soup, chicken and potatoes. You may wish to avoid products containing milk, even several days after recovery, as some people can get temporary lactose intolerance. Rest should help you to feel better. If you have to keep travelling, you could take an anti-diarrhoeal to help stop the symptoms. However, these are not recommended if you have a flare-up of your inflammatory bowel disease.

If you do not get better within a couple of days, or you develop a fever or any other symptoms associated with your inflammatory bowel disease, see a doctor or go to a hospital. Bloody diarrhoea could either be down to a flare-up of your inflammatory bowel disease, or a bacterial infection which needs treatment with antibiotics. UK doctors generally recommend taking a course of antibiotics, such as ciprofloxacin for at least five days. If amoebiasis (a parasitic infection) is suspected or confirmed, metronidazole (Flagyl) may be prescribed. If you feel that you might be at risk of
traveller’s diarrhoea, it may be worth discussing these treatments with your doctor before you leave on your trip.

Dehydration

In hot weather you will need to take care not to become dehydrated. Symptoms of dehydration include thirst, a dry mouth, headaches, dark coloured urine and tiredness. It helps to avoid strenuous exercise during the hottest hours and to drink plenty of non-alcoholic liquids (at least 8-10 average glasses). More information on how to avoid and treat dehydration is given in our leaflet, *Dehydration*.

Sun exposure

While it is important for everyone to protect themselves from the effects of the sun, you will need to take even more care if you are on immunosuppressive drug treatments for your inflammatory bowel disease. These include azathioprine, mercaptopurine and methotrexate, any of which will make your skin more sensitive to sun damage, and may increase the risk of skin cancer. You should use a high skin protection factor sunscreen (SPF 25 or above).

**Checklist before travelling**

- Find out about insurance, vaccinations and malaria before you book your holiday.
- Obtain an EHIC card for travel in Europe.
- Get a copy of your prescription.
- Take enough medicines/medical supplies to cover the whole time you will be away and any possible delays.
- Take a course of steroids in case of a flare of your Crohn’s disease whilst you are away, you will get this from your GP.
- Check whether you need an import/export drug licence.
- Ask your doctor for a medical summary and, if necessary, get a translation into the local language(s).
- Take details of your own doctor and inflammatory bowel disease team, including phone number and email address.
- Find out details of doctors in the places you will be staying.
- Remember you can contact your inflammatory bowel disease team whilst you are away for advice.
For further information you can contact your inflammatory bowel disease Nurse Specialist

Further Useful information

You may find the following sources of information useful.

**Crohn's and Colitis UK**

www.crohnsandcolitis.org.uk

**Digestive Disorders Foundation (CORE)**

www.digestivedisorders.org.uk

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