ULCERATIVE COLITIS

INFORMATION FOR PATIENTS
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What is ulcerative colitis (UC)?

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

Ulcerative colitis (UC) is a condition that causes inflammation and ulceration of the inner lining of the rectum and colon (the large bowel). Inflammation is the body’s reaction to injury or irritation, and can cause redness, swelling and pain. In UC, tiny ulcers develop on the surface of the lining and these may bleed or produce pus. The inflammation usually begins in the rectum and lower colon, but it may affect the entire colon.

What causes ulcerative colitis?

Nobody is sure, but researchers and experts think UC 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.

How much of the colon can become diseased?

Ulcerative colitis always affects the rectum – that part of the large bowel which lies just inside the anus. Sometimes, the inflammation is limited just to the rectum – this is known as proctitis. However, the inflammation can involve a variable length of the colon (see diagram). When the whole colon is affected, this is called pan-colitis or total colitis. We don’t know why the amount of inflamed bowel varies so much from one person to the next.
What are the main symptoms?

Ulcerative colitis symptoms may vary from mild to severe and will vary from person to person. Ulcerative colitis is a very individual condition – some people can remain well for a long time, even for many years, while others have frequent flare-ups. They may also change over time, with periods of good health when you have few or no symptoms (remission), alternating with times when your symptoms are more active (relapses or ‘flare-ups’).

For some people, the symptoms can seem just a nuisance. For others, the condition can really interfere with day-to-day life which becomes organized around visits to the toilet. It is not only just the number of times this can happen each day but the hurry in which some patients need a toilet can also be extremely distressing.

Your symptoms may vary according to the extent and severity of the inflammation, but the most common symptoms during a flare-up are:

• Diarrhoea. This is often with blood, mucus and pus.
• Cramping pains in the abdomen. These can be very severe and often occur before passing a stool.
• Tiredness and fatigue. This can be due to the illness itself, from anaemia (see below), or from a lack of sleep if you have to keep getting up at night with pain or diarrhoea.
• Feeling generally unwell. Some people may feel feverish.
• Loss of appetite and loss of weight.


• Anaemia (a reduced number of red blood cells). You are more likely to develop anaemia if you are losing a lot of blood and are not eating well. Anaemia can also make you feel very tired.

**How common is ulcerative colitis?**

It’s estimated that ulcerative colitis affects about **one in every 420 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. Ulcerative colitis is also more common in white people of European descent, especially those descended from Ashkenazi Jews (those who lived in Eastern Europe and Russia). Ulcerative colitis affects women and men equally. It tends to develop more frequently in non-smokers and ex-smokers than smokers. However, health professionals consider the risks of smoking heavily outweigh any benefits seen in ulcerative colitis, and strongly discourage smoking in everyone, whether or not they have inflammatory bowel disease.

**What are the main types of ulcerative colitis?**

Ulcerative colitis is generally categorised according to how much of the colon is affected.

**Proctitis**

In proctitis, only the rectum is inflamed. This means that the rest of the colon is unaffected and can still function normally. For many people with proctitis the main symptom is passing fresh blood, or blood stained mucus. You may get diarrhoea, or you may have normal stools or even constipation. You may also feel an urgent need to rush to the toilet. Some people with proctitis often feel that they have an urge to pass a stool, but cannot pass anything because the bowel is actually empty. This is called tenesmus. In some people, the sigmoid colon (the short curving piece of colon nearest the rectum) may also be inflamed – a form of ulcerative colitis sometimes known as proctosigmoiditis. The symptoms are similar to those of proctitis, although you are less likely to have constipation with proctosigmoiditis.

**Left-sided**

Left-sided (or distal) colitis

In this type of ulcerative colitis the inflammation starts at the rectum and continues up the left side of the colon (also known as the distal or descending colon). Symptoms include diarrhoea with blood and mucus, pain on the left hand side of the abdomen, urgency, and tenesmus.

**Extensive and Total Colitis or Pan Colitis**

Extensive colitis extends along most of the colon. Extensive colitis that affects the whole colon may be called total colitis or pancolitis. Extensive or total colitis can cause very frequent diarrhoea with blood, mucus, and sometimes pus. You may also
have severe abdominal cramps and pain, tenesmus, and weight loss. In milder flare-ups the main symptom may be diarrhoea or looser stools without blood.

Very rarely, when the inflammation is severe, digestive gases may get trapped in the colon, making it swell up. This is known as toxic megacolon and it can cause a high fever as well as pain and tenderness in the abdomen. It is essential to get treatment quickly for this condition, as it may need surgery.

**Can ulcerative colitis affect other parts of the body?**

A small number of patients do have conditions that relate to ulcerative colitis in their skin, eyes, joints or liver as a result of their disease. When you attend the hospital, you will be monitored to see if any of these complications do develop so that they can be treated.

**Related conditions**

Other problems in other parts of the body occur in about 1 in 10 cases. It is not clear why these occur. The immune system may trigger inflammation in other parts of the body when there is inflammation in the gut. These problems outside the gut include:

- Those that may flare up when gut symptoms flare up. That is, they are related to the activity of the colitis and go when the gut symptoms settle. These include:
  - An unusual rash on the legs (erythema nodosum).
  - Mouth ulcers (aphthous ulcers).
  - A type of eye inflammation (episcleritis).
  - Painful joints (acute arthropathy).
- Those that are usually related to the activity of the colitis and usually go but not always, when the gut symptoms settle. These include:
  - An unusual skin condition called pyoderma gangrenosum.
  - A type of eye inflammation called anterior uveitis.
- Those that are not related to the activity of the colitis; so, they may persist even when the gut symptoms settle. These include:
  - Inflammation of the joints between the sacrum and the lower spine (sacroiliitis).
  - A type of arthritis affecting the spine (ankylosing spondylitis).
  - A condition causing inflammation of the bile ducts of the liver (primary sclerosing cholangitis).
  - A disease causing fragile bones (osteoporosis), associated with vitamin D deficiency and occurring especially in people on long-term steroid medication.
  - Anaemia, usually due to iron deficiency but sometimes caused by vitamin B12 and/or folic acid deficiency.

**Can ulcerative colitis lead to bowel cancer?**

Ulcerative colitis is not a form of cancer. However if you have had extensive or total colitis (pancolitis) for many years, you have a greater risk than normal of developing cancer in the colon or rectum.
This increased risk is not as great for people with left sided colitis, and people with proctitis have no increased risk. 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.

It is possible to develop dysplasia before the growth of an actual tumour. Dysplasia means a change in the size, shape and pattern of normal cells, which is not in itself cancer – but can be a sign that cancer may develop in these cells.

Your Consultant will arrange a surveillance colonoscopy based on current guidelines and recommendations.

However, the overall number of people with inflammatory bowel disease who develop bowel cancer is very small, and cancers can often be more successfully treated if detected early.

**How is ulcerative colitis diagnosed?**

If you develop diarrhoea with bleeding and abdominal pain, your doctor may suspect you have ulcerative colitis

If your doctor thinks you might have ulcerative colitis, you will probably be asked to have tests of your blood, your motions and your intestines. Blood tests will show if you are anaemic and whether your illness has caused the level of protein to fall. In general, the greater the degree of anaemia and the lower the protein level, the more severe the inflammation is likely to be. Doctors also use special blood tests called ESR and CRP to give a measure of the degree of inflammation. You may be asked to give small samples of your bowel motions, to measure levels of faecal calprotectin, which is a marker of inflammation and to be sure there are no signs of any bowel infection.

**What investigations may I need?**

**Endoscopies**

In an endoscopy a doctor or specialist endoscopist uses an endoscope – a long thin, usually flexible, tube with a camera in its tip – to examine your digestive system. There are several types of endoscopy which can have different names according to the part of the gut being examined. The type of endoscope used will also vary (some are longer and thinner and more flexible than others) and may have a different name.

- A colonoscopy or sigmoidoscopy – These types of endoscopy are often used to help diagnose or monitor UC. In these tests a sigmoidoscope (a short endoscope) or a colonoscope (a longer and more flexible endoscope) is 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 an endoscopy. These can then be examined under a microscope to confirm the diagnosis.

MRI and CT Scans

Other tests that are increasingly used to look at the location and extent of 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.

Could my symptoms be irritable bowel syndrome (IBS)?

Sometimes people with Ulcerative Colitis 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 irritable bowel syndrome, but common symptoms include 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 irritable bowel syndrome. Your doctor will advise you about appropriate treatment.

What drugs are used to treat ulcerative colitis?

Drug treatment for ulcerative colitis 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 ongoing basis, sometimes for many years.

The main types of drugs commonly used in ulcerative colitis are anti-inflammatory drugs and symptomatic drugs.

Anti-inflammatory drugs
These help to reduce inflammation and include:

- 5-ASAs or aminosalicylates such as mesalazine (brand names include Asacol, Ipocol, Octasa, Pentasa, and Salofalk), sulphalazine (Salazopyrin), olsalazine (Dipentum) and balsalazide (Colazide)
- Corticosteroids, often just called steroids, such as prednisolone, hydrocortisone, budesonide (Entocort) and beclometasone dipropionate (Clipper)
- Immunosuppressants such as azathioprine (Imuran), mercaptopurine or 6MP (Purinethol), methotrexate, mycophenolate mofetil, tacrolimus and ciclosporin
- Biological or ‘Anti-TNF’ drugs such as infliximab (Remicade) and adalimumab (Humira).

Research suggests that taking some 5-ASA drugs may help to reduce the small chance of bowel cancer developing.
Symptomatic Drug

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

• Anti-diarrhoeals such as codeine phosphate, diphenoxylate (Lomotil) and Loperamide (Imodium, Arret)

• Laxatives such as Movicol and Lactulose

• Bulking agents such as Fybogel

• Analgesics (pain killers) such as paracetamol.

Over the counter medication

It is best to check with your doctor or IBD team before you take any over-the-counter medicines as they may not be suitable for you, or could interact with your IBD drugs.

For example, some anti-diarrhoeals may make your ulcerative colitis 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 ulcerative colitis?

Ulcerative colitis can often be managed by medication (drug treatment), but surgery may become necessary if the inflammation is very severe, and in some other situations. Your treatment will depend on the type and severity of your ulcerative colitis and the choices you make in discussion with your doctor.

If your quality of life has been affected by repeated flare-ups and you have not responded well to medication, you may be advised to consider surgery.

Recent estimates suggest that about two in 10 people with ulcerative colitis may eventually need surgery, depending on how severe the disease is and which part(s) of the colon are affected.

Surgery may also be recommended if dysplasia (pre-cancerous changes) or cancer is found in your colon during a colonoscopy.

Most people who decide to have surgery for their ulcerative colitis have time to discuss their options in advance. This allows them to prepare for having an operation. More rarely, people with very severe ulcerative colitis which does not respond to intensive medical treatment will need urgent surgery (within a few days) or emergency surgery (within a few hours).

What are the most likely operations for ulcerative colitis?
When the surgery is planned in advance you are most likely to be offered a proctocolectomy with a permanent ileostomy, or a proctocolectomy with an ileoanal pouch.

**Proctocolectomy with permanent ileostomy**
In this operation the surgeon removes the whole colon, rectum and anal canal, and brings out the end of the lower small intestine onto the wall of the abdomen through a permanent opening, called a stoma (ileostomy). An external bag is fitted on to the opening on the outside of the abdomen. This collects the waste from the small intestine that would previously have gone into the colon. The bag is emptied or changed when necessary. If you have this operation you will no longer have a colon to become inflamed or develop bowel cancer. However, this form of surgery is irreversible.

Having a major part of the bowel removed may be a frightening thought, and you may also be concerned at the prospect of using a stoma bag. However, in recent years there have been great advances and improvements in the design of stoma products, and they are now much more discreet and comfortable. Specialist nurses are usually available to help support you if you have an ileostomy or colostomy.

**Restorative Proctocolectomy with ileoanal pouch**
This procedure is often called pouch surgery, or IPAA (Ileal Pouch-Anal Anastomosis) and is often the preferred form of surgery for Ulcerative Colitis. It generally requires two operations, but may occasionally be done in a single stage or in 3 stages. In the first operation the surgeon removes the whole colon and the rectum, but leaves the anus. Then a pouch is made using the lower end of the ileum (small intestine) and this is joined to the anus. Finally, a looped section of the small intestine is brought out onto the wall of the abdomen through a temporary opening. This is an ileostomy or stoma. This opening allows the waste from digestion to be collected in a stoma bag until the newly-formed pouch has had a chance to heal. This will probably take several months. You will then need a second operation to close the temporary ileostomy so the pouch can be used. In very rare cases, the whole procedure is done in one stage, without the ileostomy.

The following operation is much less common, as it is only suitable for a small number of people with ulcerative colitis:

**Colectomy with ileorectal anastomosis**
In this operation the surgeon removes the colon and joins the end of the ileum (the lower part of the small intestine) to the rectum. It avoids the need for a stoma, so it may be useful for people who could not cope with a stoma or who are unsuitable for pouch surgery. However, this operation is only suitable if there is little or no inflammation in the rectum or if there is no long-term risk of developing cancer in the rectum.

If you need emergency surgery, you are likely to have the following operation:

**Colectomy with ileostomy (subtotal)**
In this procedure the surgeon removes the colon, but leaves the rectum. This allows for the possibility of pouch surgery (see above) in the future. As in the proctocolectomy, the lower end of the small intestine is brought out onto the abdomen wall to form an ileostomy or stoma to collect the waste from digestion. The
upper end of the rectum is either closed or brought out to the surface to form another opening or stoma. This additional stoma (sometimes called a mucous fistula) may be needed because the rectum may still produce mucus for a while. After recovering from this surgery, you can then decide whether to opt for pouch surgery or a permanent ileostomy, which may depend on your individual medical condition.

Do I need to change my diet?

There has been extensive research into diet as a possible cause or trigger of ulcerative colitis, but so far there are no clear answers and there is little evidence that diet plays a role in ulcerative colitis. Generally, the most important thing is to eat a nutritious and balanced diet to maintain your weight and strength, and to drink sufficient fluids to stop you getting dehydrated.

If you are experiencing a flare of your condition you may have unfavourable symptoms such as diarrhoea, nausea, vomiting, abdominal pain and a loss of appetite. These symptoms can make eating and drinking very difficult. Many people with inflammatory bowel disease lose weight and become dehydrated during a disease flare.

There is no one single diet or eating plan that will relieve the symptoms for every person with inflammatory bowel disease, but this general information may be helpful.

What about my diet during a flare?

During a flare most people find a diet low in fibre and residue helps to relieve symptoms such as cramping and wind. It can also reduce the number of times you pass bowel motions. A low residue diet aims to rest your bowel and allow it to heal. A low residue diet involves avoiding roughage (insoluble fibre) that your body struggles to break down. Roughage is found in skins, pips, seeds, whole grain cereals, nuts and raw fruit and vegetables. Other food or drinks that can increase bowel motions are spices, greasy food, alcohol, caffeine and fizzy drinks. Often, these dietary changes are temporary and once a flare has resolved efforts should be made to reintroduce fibre gradually.

Diet during remission (no symptoms)

If your IBD symptoms are under control (remission), you should be able to eat a well balanced diet. A balanced diet consists of:

- protein sources (meat, fish, poultry or tofu)
- fruit and vegetables
- starchy carbohydrates (bread, rice, pasta or potatoes)
- dairy products (milk, cheese and yoghurt).

When you are feeling well and are able to eat it is advisable to maintain a healthy weight and keep yourself as well nourished as possible in case your symptoms return.

There are certain foods that are harder to digest than others. These include skins of fruit, whole grain, brown and wild rice, seeds, pulses (such as peas and beans), nuts, raw fruits and raw vegetables. If you have been following a bland diet low in
fibre it is advisable to reintroduce these high fibre foods one at a time to avoid discomfort.

Some people with ulcerative colitis may be concerned that dairy products could trigger their symptoms – although, in general, people with ulcerative colitis are no more likely to be lactose intolerant than the general population. Because milk and dairy products are an important food group it is better not to give them up until you have spoken to your with inflammatory bowel disease team.

What about complementary and alternative approaches?

Some people with ulcerative colitis find complementary and alternative medicines (CAM) helpful in treating their symptoms.

Examples of complementary and alternative therapies that have been used by people with ulcerative colitis include Boswellia Serrata, acupuncture, wheat grass juice, aloe vera gel, and omega 3 fish oils. However, many of these supplements and treatments are still being researched, and although they may help some people, there is no conclusive evidence about when or how they will work. It is difficult to know, with confidence, whether there is a direct physical effect, or a general psychological benefit (placebo). Also, everyone is different, and what may help one person may not have any effect on another.

There is stronger evidence that some probiotics (a mixture of live ‘friendly’ (beneficial) bacteria taken by mouth) may have a role in treating ulcerative colitis. For example, a probiotic known as VSL#3 has been shown to be helpful in preventing pouchitis (inflammation of an ileo-anal pouch). Research also suggests that some probiotics may have a use in maintaining remission in people with ulcerative colitis. Studies into curcumin (a natural anti-inflammatory agent found in the spice turmeric) have shown some positive effect on ulcerative colitis symptoms, but more research needs to be done in this area.

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

What about pregnancy and ulcerative colitis?

The majority of women with ulcerative colitis can expect a normal pregnancy and a healthy baby. Also, for most women, having a baby does not make their worse with inflammatory bowel disease. That said, it is important to discuss your pregnancy with your with inflammatory bowel disease team. You may need to take special care with some aspects of your pregnancy or perhaps change your treatment slightly.

If you have ulcerative colitis your chances of conceiving are not usually affected by the disease. However, if you have pouch surgery your fertility could be affected. This
appears to be much less likely with a colectomy and the formation of an ileostomy — the usual alternative to pouch surgery. The 5-ASA drug sulphasalazine can lead to a temporary loss of fertility in men but alternative medication is available.

Doctors usually recommend trying to get your with 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 with inflammatory bowel disease.

Very severe ulcerative colitis can put your 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 with inflammatory bowel disease treatment can be continued while you are pregnant.

For example, it is generally considered safe to continue taking steroids, most 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 with inflammatory bowel disease in check, it may be better to continue with these. Guidelines also suggest that doctors should discuss the risks and benefits with each woman on an individual basis, and you may find it useful to discuss with your with 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 with 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 with 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.

Does ulcerative colitis run in families?

Ulcerative colitis does tend to run in families, and parents with inflammatory bowel disease are slightly more likely to have a child with 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 ulcerative colitis, the risk of their child developing with inflammatory bowel disease is generally thought to be about 2%. That is, for every 100 people with ulcerative colitis, about two of their children might be expected to develop with inflammatory bowel disease at some time in their lives. However, genes are only part of the picture and research suggests that environmental triggers also play an important role.

How will UC affect my life?

There is no single answer to this question because everyone is different, ulcerative colitis is such an ‘individual’ condition 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 ulcerative colitis may never have more than mild and infrequent symptoms of diarrhoea and pain, so the illness may not affect their lives very much. Other people do have continuous and severe symptoms in spite of medical and surgical treatment, and have to adapt their lifestyle considerably.

You are likely to see your GP and specialist doctor or nurse on a fairly regular basis if you have ulcerative colitis. So, it can be very helpful if you can build up a good relationship with them.
Living with a chronic condition can have both an emotional and practical impact. It can help to have the understanding and support of those around you – your family, friends, work colleagues and employers.

**Travel and immunisations**

If you have ulcerative colitis 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. 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 which 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

It may not occur to you to mention your inflammatory bowel disease to the insurance company when you are arranging your insurance. However, 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 have to confirm that you are not travelling against your doctor’s advice.

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.

**Vaccinations**

Try to find out several months in advance whether vaccinations are needed or recommended for your destination. Some vaccinations need to be taken two or three months before travel. You could check with your travel agent, GP surgery or the NHS website: www.fitfortravel.nhs.uk. Some countries will not let in 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. 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 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, some countries may not admit you without a yellow fever vaccination even with such a letter. 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.

If you have stopped taking immunosuppressants you may be able to have a live
vaccination after waiting 2-3 months.

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

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. Th with inflammatory bowel
disease ere can also be adverse interactions between some anti-malarials and some
immunosuppressant drugs for. Yo with inflammatory bowel disease u 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:

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 IBD 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.

As a precaution, have the details of your own doctor and with 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.

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 (see Further help).

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 with inflammatory bowel disease contains controlled drugs. However, some people with 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-diarrhoal to help stop the symptoms. However, these are not recommended if you have a flare-up of your IBD.

If you do not get better within a couple of days, or you develop a fever or any other symptoms associated with your IBD, see a doctor or go to a hospital. Bloody diarrhoea could either be down to a flare-up of your IBD, 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).

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 IBD. 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.

☐ 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.

☐ 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.

☐ 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 IBD Nurse Specialist or Gastroenterology 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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