Patient information

Inflammatory Bowel Disease and Ulcerative Colitis

Digestive Diseases Care Group

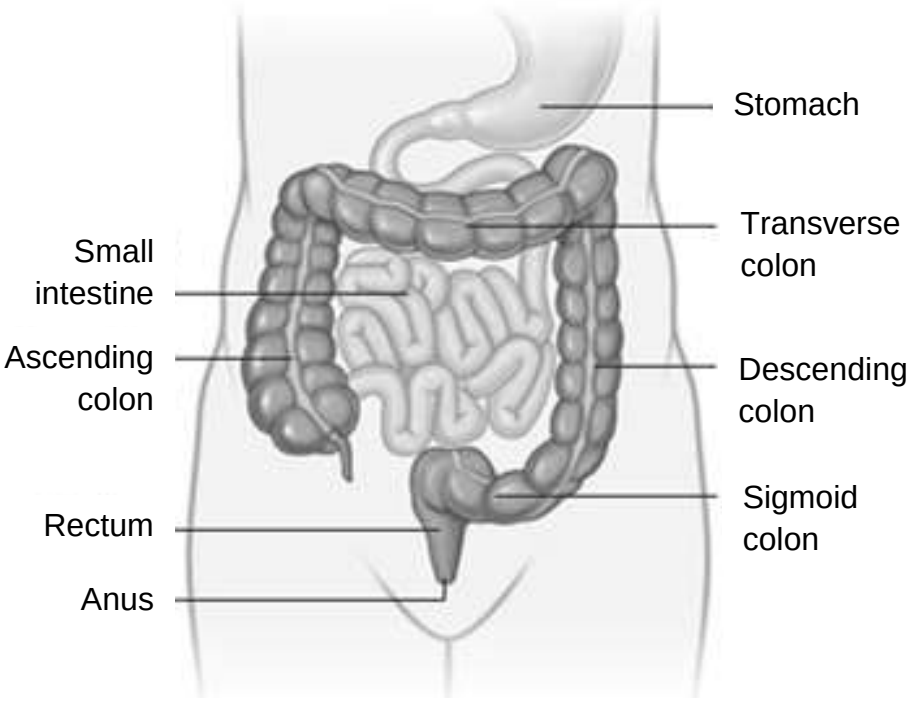
This fact sheet has deliberately been written in some detail and gives honest information without falsely optimistic “gloss”. It may provide more information than some patients will require and it is important to note that it in no way replaces further discussion of queries, in the clinic or with a specialist nurse.

What is Inflammatory Bowel Disease?

This is a term used by doctors to refer to two conditions:

- Ulcerative colitis.
- Crohn’s disease.

They are associated with inflammation of the colon or intestines and are not obviously associated with infections such as Salmonella or Campylobacter. Although there is some overlap between ulcerative colitis and Crohn’s disease, for the purposes of this fact sheet we will consider them separately.



How do the bowel symptoms differ from Irritable Bowel Syndrome (IBS)?

Irritable Bowel Syndrome is a combination of:

- Colicky stomach pain.
- Distension (swelling).
- A change in bowel habit.
- Alternating constipation and diarrhoea.

Although its cause is not well understood, it tends to be associated with stress and is not associated in most cases with any inflammation of the colon or intestine.

Ulcerative colitis is usually associated with persistent diarrhoea, often with blood, and is fairly easy to distinguish from the diarrhoea of IBS, which is nearly always intermittent and non-bloody.

The symptoms of Crohn's disease do however closely mimic those of patients with IBS. This often results in a delay in diagnosis since IBS affects about one in three of the population at some time or other whereas Crohn's disease only affects about one in one thousand.

Both ulcerative colitis and Crohn's disease are associated with an increased tendency to develop IBS, which can often cause persistent symptoms for a few months after an attack of inflammatory bowel disease has resolved. It is also possible to have both IBD (Ulcerative colitis or Crohn's Disease) and Irritable Bowel Syndrome at the same time.

Ulcerative Colitis

What is Ulcerative Colitis?

Ulcerative colitis is a condition in which the lining of the lower part of the intestine, called the large intestine or colon, becomes inflamed or ulcerated. This results in **bloody diarrhoea**. Although relapse of the disease can be caused by a bacterial infection such as Salmonella food poisoning, harmful bacteria can generally not be found when a faecal sample is cultured in the laboratory. This distinguishes it from infective causes of bloody diarrhoea.

It can range in extent from a very localised inflammation of the lower bowel (rectum) to an extensive colitis that affects the whole colon. Inflammation that is confined to the rectum is called **proctitis**. It carries a very good long-term outlook but can cause very troublesome **frequency of bowel movements**. Bad attacks of colitis can be associated with pain in the abdomen or lower back.

What causes ulcerative colitis?

Studies in identical twins suggest that colitis is about 10% genetic and 90% environmental. Good progress is being made towards identifying the relevant genetic factors, and it is likely that they may be identified within the next five to ten years. The only environmental factor, which has been clearly identified so far, is non-smoking!

The reason why people who do not smoke or stop smoking are more likely to get colitis is not known. It is important to note that smoking is positively associated with Crohn's disease as well as heart disease, stroke and cancer, so this should not be seen as an invitation to smoke.

About one third of relapses of colitis are caused by infection with a gastroenteritis organism such as salmonella, shigella or Campylobacter. It would therefore make sense to make sure that chickens (the commonest source of food poisoning bacteria) are well cooked throughout - particularly if cooked from frozen.

Can I absorb food normally if I have colitis?

Yes. Nutrients are absorbed by the "small" intestine (the jejunum and ileum), through which the food passes on its way down to the colon. The function of the colon is to absorb water and salt.

Is diet important in ulcerative colitis?

Probably not. Research has shown that even complete avoidance of food and supportive intravenous feeding is not effective at settling the colitis. There is some evidence that about one in five patients may benefit from avoidance of dairy products. There is no test that can predict this, so it may be worth trying this out for yourself.

If only the lower colon is inflamed, there may sometimes be constipation higher up which can be improved by a high fibre intake but apart from this, the fibre intake has no significant effect on colitis.

Will it shorten my life?

Although severe colitis requiring admission to hospital carries a mortality of about 1%, the overall life expectancy is normal. There is a slightly increased risk of bowel cancer and of a rare liver disease called sclerosing cholangitis but these risks are counteracted by reduced risks for ischaemic heart disease.

Will it affect my life insurance?

It should not but some insurers are better informed than others. If you have any difficulty, it is well worth contacting Crohn's and Colitis UK (see below) for further advice.

What are my chances of needing a colectomy (surgical removal of the colon)?

The lifetime risk is currently about 20%. It is lower in cases where the disease is confined to the lower colon or rectum.

If I have to have a colectomy will I have to have a bag (stoma/ileostomy)?

Not necessarily. Most patients having a colectomy nowadays have a pouch operation (usually performed as a second operation a few months after the colectomy). In this, the lower small intestine (ileum) is doubled back on itself to form a pouch, which is then connected to the anus.

What is life like with a pouch?

Most patients with a pouch have about four to six bowel movements during the day and may need to get up once at night. Continence is usually excellent but it is occasionally necessary to wear a pad at night.

It is necessary to continue to take anti-diarrhoeal tablets such as Imodium (Loperamide). About 5% of patients develop pouchitis, which is rather like ulcerative colitis of the pouch. This is usually mild and responds well to antibiotics.

What is life like with an ileostomy?

In many respects, life is normal. The patient usually has complete control over bowel emptying. Modern ileostomy appliances fit well and there is no odour.

The ileostomy is usually sited below the waist and swimming trunks or costume can be worn.

Many patients in a stable relationship may prefer this option since the surgery is simpler and recovery more straightforward than from a pouch operation, which often has to be done in two stages.

The doctors used to tell me that I have ulcerative colitis, but now they say that I have Crohn's. Does that mean that they don't know what they are doing?

Not necessarily! There is increasing evidence from genetic and family studies that there is an overlap between the two conditions and in one in three cases of colitis, it is difficult to say with certainty whether it is ulcerative colitis or Crohn's disease. Increasingly we see inflammatory bowel disease as a spectrum of disease(s) with typical ulcerative colitis and typical Crohn's disease at the two ends of the spectrum.

Fortunately, there is very little difference in the medical treatments between the two conditions. The same drugs are generally used in both conditions, the only significant exception being that we tend to use antibiotics rather more when treating Crohn's disease.

There is a difference if surgery is required, a partial Colectomy may be feasible in colonic Crohn's disease whereas it is not effective in ulcerative colitis and pouch surgery is generally less successful in Crohn's disease than ulcerative colitis.

Can I pass colitis on to my children?

The risk is very low. Even an identical twin (who by definition is genetically identical with his or her twin) only has a one in ten chance of developing colitis if the other twin is affected.

The child or sibling (brother or sister) of a patient with colitis has only about a one in one hundred risk of colitis compared with a risk of approximately one in one thousand in the general population.

Are any other organs affected by the colitis?

It is not uncommon to have painful or swollen joints if the colitis is active. This settles as the colitis comes under control and is not associated with any long-term damage.

More rarely, a condition called ankylosing spondylitis, which may affect people without inflammatory bowel disease, may occur. This is associated with gradual stiffening of the spine and inflammation of the joints between the spine and pelvis.

Sore, red eyes (iritis or uveitis) may occur in patients with active colitis but causes no permanent damage and settles when the underlying colitis comes under control.

A rare but unpleasant ulcerating skin condition (pyoderma) may occasionally occur. This usually responds to steroid therapy.

Approximately 1% of patients with colitis develop scarring and narrowing of the bile ducts that drain the liver (called primary sclerosing cholangitis, often shortened to PSC). There is at present no convincingly effective therapy for this and severe disease occasionally results in a need for liver transplantation.

What about the risk for colon cancer?

If the colitis is confined to the lowest part of the colon or rectum there is no increased risk compared with general population (i.e. a 6% life time risk of developing cancer of the colon and a 3% risk of dying from it). If the colitis is more extensive, the risk is increased. Just how much increased is difficult to say. Published studies, much of which are rather out of date, suggest a risk of about 7% by the time the colitis has been present for 20 years.

More recent reports, particularly from Scandinavia, have been showing a lower risk. This risk may be reduced by long term use of 5-aminosalicylates.

What should be done about the risk for colon cancer?

Firstly, continue regular maintenance treatment with a 5-aminosalicylate drug even if the colitis has been inactive for some years. Secondly, ask your doctor about the need for colonoscopy surveillance. This is to look for early changes which can occur before the development of cancer.

Currently it is usual practice to recommend that everyone who has colitis for ten years (from the onset of symptoms) has a colonoscopy. Thereafter how often the colonoscopy is carried out depends on the how far round the bowel the colitis extends, the amount of inflammation and other factors such as a family history of colon cancer.

Further colonoscopies are performed anywhere between one and five years. Some people with limited colitis do not need further colonoscopies.

What drugs are helpful for ulcerative colitis?

Three main types of drug are used:

- **Steroids** - (more correctly called Corticosteroids to distinguish them from the body building anabolic steroids)

- **Aminosalicylates** (5ASA drugs)

- **Immunosuppressives.**

Each type of drug is used in a different way. We have local leaflets outlining each of these treatments in more details. Ask the doctor or specialist nurse you see in clinic about these or look on our website or Crohn’s and Colitis UK

Steroids

Steroids are unquestionably the best treatment for a severe acute attack of colitis. They need to be taken in quite high dose initially (usually about 40 milligrams per day of Prednisolone) but they rather curiously have no beneficial effect when taken long term and are usually tailed off again within two to three months. The risk of serious steroid side effects is very low with this approach. The commonest problem is reddening of the cheeks, which may also become slightly more prominent. Occasionally patients experience severe mood changes but these are rare and mild euphoria combined with appetite enhancement is the usual effect.

Side effects of steroids

Short-term side effects that resolve when steroids are stopped*:*

- Swollen face.
- Fluid retention.
- Weight gain.
- Acne.
- Mood changes.
- Sleep disturbance.
- Poor concentration.

Side effects caused by high dose, long-term use of steroids:

- Osteoporosis (thinning of bones).
- Cataracts or glaucoma (either of which are potential causes of blindness if untreated).
- Diabetes (increased blood glucose).
- Thin skin and easy bruising.
- High blood pressure (Hypertension).
- Damage to the hip bones (avascular necrosis).

5-ASA drugs

The 5-aminosalicylates (mesalazine) are much less effective than steroids at treating acute attacks of colitis but unlike steroids are effective as maintenance therapy to prevent relapses of colitis. Taken at the correct dose they reduce the risk of relapse to about one third of what it would otherwise be. Recent research suggests that maintenance with 5-aminosalicylates also has a protective effect against colon cancer.

What is the best 5-aminosalicylate?

There are several preparations available.

They all contain the same basic drug but have different delivery systems that use different techniques that are all aimed at delivering the drug to the part of the intestine that is most inflamed. There is very little to choose between the drugs in terms of effectiveness or side effects (which are very uncommon and usually not serious).

The first of this group of drugs to be developed was sulphasalazine (Salazopyrine). This includes a sulphonamide antibiotic, which causes occasional allergic reactions, and which causes nausea and muscle aches in about one in five who take it. It also causes reversible male fertility. It is rarely used as initial therapy now but as with all the other 5-aminosalicylates, if you are currently managing well on the drug that you are on then there is no point in changing preparations.

What is the most effective route for drug therapy?

If active colitis is confined to the distal colon or rectum (and the symptoms then are usually passage of blood or mucus per rectum but without frank diarrhoea) then local therapy by suppository or enema is usually more effective.

There is some evidence that 5-aminosalicylates are more effective by enema or suppository than similar preparations of steroids. The combination of 5-aminosalicylate tablets and enemas may be more effective in combination to resolve a flare up of colitis.

Immunosuppressives

Some patients with ulcerative colitis require additional treatment. Immunosuppressive drugs suppress inflammation by suppressing the immune system. The commonest immunosuppressive drugs used are the thiopurines (azathioprine or mercaptopurine). Patients in whom azathioprine or mercaptopurine are not effective enough or not tolerated may require a step up in treatment to an ant-TNF agent (see below). Some patients may receive an immunosuppressant called ciclosporin. This is most commonly used in patients who have been admitted to hospital with a severe flare of ulcerative colitis that has failed to respond to steroids given into the veins.

Thiopurines (azathioprine and mercaptopurine)

Azathioprine (or mercaptopurine) is used to control troublesome colitis that is relapsing unacceptably frequently. This affects about one in three patients. More usually, there are clear-cut remissions between attacks.

The drug does not have any of the side effects of steroids but unfortunately has a few of it own. About one in ten patients cannot tolerate the drug because of nausea.

The most serious side effect is bone marrow suppression, which is rare and usually reversible. Because of this, it is necessary to treat with a low dose initially and to check the blood count monthly.

The drug is stopped if the count of white blood cells falls too low. A persistent sore throat may be a sign that this is happening and is an indication for immediate stopping of the drug and full blood count check.

Occasionally, patients (up to about five per cent) may have to stop the drug because of either painful inflammation of the pancreas (pancreatitis) or reversible alterations in blood tests of liver function.

There is a slightly increased risk of developing lymphoma (a type of cancer affecting the lymph glands), but recent extensive analysis concluded that for most people taking these drugs the risk was very small and the potential benefits outweigh the risk.

There is an increased risk of skin cancer. This should be avoidable with the careful use of sun blocks and avoiding sunbathing and sun lamps.

The drug is relatively slow to take effect - it is generally estimated to take about three months to build up to its full protective effect. It is therefore used for long-term maintenance with patients who have troublesome relapsing disease.

Ciclosporin

Ciclosporin is the other immunosuppressive used in ulcerative colitis. Like azathioprine, it is a drug that is also used in transplant patients to suppress rejection of the transplant.

It is sometimes used in severe acute attacks of ulcerative colitis if steroids are failing to induce remission. It is a very potent immunosuppressive and there is some risk of infection with organisms such as yeast and fungi which usually do not affect individuals with a normal immune system. Because of this, there is still some controversy about its use in colitis.

Its use probably lowers the operation (colectomy) rate by about one third (with conventional treatment about one in three patients with severe ulcerative colitis needing hospital admission, fail to respond to steroids and need colectomy). But there is probably a mortality of about one to two per cent associated with the use of the drug, so it is still unclear whether the benefits outweigh the risks.

Infliximab, Adalimumab and Golimumab

Infliximab, Adalimumab and Golimumab are drugs called anti-TNF agents. A protein called TNF-alpha is an important protein in inflammatory diseases and this protein is blocked by these drugs. Patients with moderate-severe ulcerative colitis that has not responded to conventional therapy may require these drugs. Patients with severe ulcerative colitis who are admitted to hospital may need infliximab.

Will the disease affect fertility or pregnancy?

When ulcerative colitis is active, it can have an adverse effect on the pregnancy (giving birth before the due-date and causing the baby to be small). It is important, therefore, to try and keep ulcerative colitis well-controlled before and during pregnancy. Fertility is normal in patients with inflammatory bowel disease (who have not previously had certain types of surgery) and there is no increased risk of miscarriage providing that the disease is in remission at the start of pregnancy.

In males the drug sulphasalazine causes reduced fertility, which returns to normal within about three months of stopping the drug. The other 5-aminosalicylate drugs are not associated with this problem.

Colectomy and pouch formation in males is associated with a slight (4%) risk of impotence. However women who have a pouch have a reduction of fertility. Vaginal delivery is probably unwise after a pouch operation since maintenance of normal anal sphincter function is essential and there is a risk that this might be affected.

Is it safe to continue the drug therapy during pregnancy?

Most drugs appear to be safe to take in women who are planning to get pregnant, during pregnancy and during breast feeding. The exception is a drug called methotrexate which is an immunosuppressant that is used much less commonly than other immunosuppressants in ulcerative colitis. Women taking methotrexate should stop this drug at least three months (preferably six months) before getting pregnant and it should not be taken when pregnant or breast feeding as it can cause malformations in the growing foetus.

Anti-TNF agents are often stopped in the last third of pregnancy. However, in some selected patients it may be appropriate to continue these drugs through pregnancy.

If you are planning to get pregnant, or become pregnant, you should discuss your treatment with an IBD doctor. You can be referred to our specialist clinic at the Liverpool Women's Hospital in to discuss things in more detail. In this clinic you will be seen by an expert in inflammatory bowel disease and an obstetrician (a doctor who specialises in the care of pregnant women). We will be able to discuss treatment options with you on an individual basis.

What about probiotics?

Probiotics or so-called "healthy bacteria" are becoming a boom industry in health shops.

There are theoretical reasons for thinking that they might be beneficial in colitis by displacing harmful bacteria from the lining of the bowel wall.

Up until now, however, there is no good evidence to support their use in colitis although one particular "cocktail" of eight bacteria (not yet commercially available) has been shown to be effective in pouchitis (inflammation of the pouch after colectomy). Further research is continuing in this area.

What about herbal remedies?

Aloes and slippery elm have both been reported by some patients to be helpful. There is no good evidence from proper trials to support this however. A problem with these substances is the lack of regulation, which leads to marked variation between different marketed preparations.

There is at least no suggestion that these preparations cause any harm but they must not be used in place of conventional therapy and you should let your doctor know if you are taking one of them.

General issues

Insurance

Life expectancy is normal in ulcerative colitis. There is an increase in risk of death from bowel cancer, but this is offset by a reduced risk of death from coronary artery disease, which is probably not due simply to the curious association between colitis and non-smoking.

Life insurance ought to be fairly easy and straightforward to arrange. However, not all insurance firms are equally enlightened and it is well worth seeking advice on this from Crohn's and Colitis UK (see below) if you are having any difficulty.

Sex life

Any illness can reduce your sex drive (libido) and treatment should aim to keep the disease in remission so that this does not occur.None of the drugs used for IBD are known to affect sexual desire or performance.

Our IBD service at the Royal Liverpool and Broadgreen Hospitals

The medical IBD team consists of several consultants with an interest in inflammatory bowel disease, specialist registrars (medical doctors in an advanced stage of training), IBD specialist nurses, research nurses and a dietician.

We have close working contact with our IBD surgeons and stoma nurses and we meet together once a week to discuss the clinical cases of people with IBD.

We are assisted by specialist pharmacists, X-ray doctors and pathologists. We work as a team and therefore you may see different members of team at clinic visits. However you can request to see a particular member of team at your clinic visit

We aim to provide a high quality service for people with IBD. We welcome suggestions (and criticism) on how we can improve out service. We also welcome people with IBD asking questions about their disease and possible new treatments.

The IBD team is involved in the IBD National Audit and the IBD Quality Improvement Programme, both of which aim to improve IBD services throughout the UK.

Contacts

We provide the name and number of our IBD specialist nurses and have a telephone with an answer machine (answered within 48 hours). If you have a question or require advice about your IBD the specialist nurse or doctor will contact you. If your disease has flare up and you need to be seen in clinic we will arrange to see you in clinic within five working days.

If you would like to speak to someone confidentially about anything concerning you, please speak to:

- A member of the clinic nursing staff
- The IBD Specialist Nurses.

Second Opinion

If you require a second opinion about your inflammatory bowel disease or your treatment we can refer you to another consultant in the team or a consultant in another hospital.

Open Forum

We hold an annual Open Forum meeting where people with IBD and their relative can come along to discuss various aspects of IBD. The meeting is attended by medical and surgical consultants, specialist nurses, stoma nurses, research nurses, pharmacists and dietitian.

Liverpool Inflammatory Bowel Disease research

The IBD team at the Royal Liverpool and Broadgreen Hospitals have a lot of experience in both basic and clinical research. We are involved in several different research projects.

Some of these are to investigate the cause of IBD and others to investigate new treatments for IBD. You may be asked if you want to participate in these trials.

Taking part in research is voluntary. Nobody will be offended if you decide not to take part. You can also agree to take part but then withdraw if you change your mind at any time during the project. You don't have to give a reason and your normal care will not be affected. It is important that you do not feel under any pressure from anyone.

You should ask as many questions as you like before making a decision. If you do say 'Yes', you will be asked to sign a **consent form** confirming that you understand what is involved in the trial.

Feedback

Your feedback is important to us and helps us influence care in the future.

Following your discharge from hospital or attendance at your Outpatient appointment you will receive a text asking if you would recommend our service to others. Please take the time to text back, you will not be charged for the text and can opt out at any point. Your co-operation is greatly appreciated.

Further information

Inflammatory Bowel Specialist Nurses
Tel: 0151 706 2650
Text phone number: 18001 0151 706 2650

Email: IBDnurses@rlbuht.nhs.uk

Gastroenterology directorate website
www.liverpoolgastroenterology.nhs.uk/

Website: crohnsandcolitis.org.uk/mersey

Author: Digestive Diseases Care Group
Review Date: April 2023

All Trust approved information is available on request in alternative formats, including other languages, easy read, large print, audio, Braille, moon and electronically.

يمكن توفير جميع المعلومات المتعلقة بالمرضى الموافق عليهم من قبل ائتمان المستشفى عند الطلب بصيغ أخرى، بما في ذلك لغات أخرى وبطرق تسهل قراءتها وبالحروف الطباعية الكبيرة وبالصوت وبطريقة برايل للمكفوفين وبطريقة مون والكترونياً.

所有經信托基金批准的患者資訊均可以其它格式提供，包括其它語言、易讀閱讀軟件、大字體、音頻、盲文、穆恩體（Moon）盲文和電子格式，敬請索取。

در صورت تمایل میتوانید کلیه اطلاعات تصویب شده توسط اتحادیه در رابطه با بیماران را به اشکال مختلف در دسترس داشته باشید، از جمله به زبانهای دیگر، به زبان ساده، چاپ درشت، صوت، خط مخصوص کوران، مون و بصورت روی خطی موجود است.

زانیاریی پێوەندیدار بەو نەخوشانەی لەلایەن **تراستەوە** پەسەند کراون، ئەگەر داوا بکرێت لە فۆرماتەکانی تردا بریتی لە زمانەکانی تر، نیزی رید (هاسان خوێندنەوە)، چاپی گەورە، شریتی دەنگ، هێڵی موون و نامێکترۆنیکی هەیە.

所有经信托基金批准的患者信息均可以其它格式提供，包括其它语言、易读阅读软件、大字体、音频、盲文、穆恩体（Moon）盲文和电子格式，敬请索取。

Dhammaan warbixinta bukaanleyda ee Ururka ee la oggol yahay waxaa marka la codsado lagu heli karaa nuskhado kale, sida luqado kale, akhris fudud, far waaweyn, dhegeysi, farta braille ee dadka indhaha la', Moon iyo nidaam eletaroonig ah.