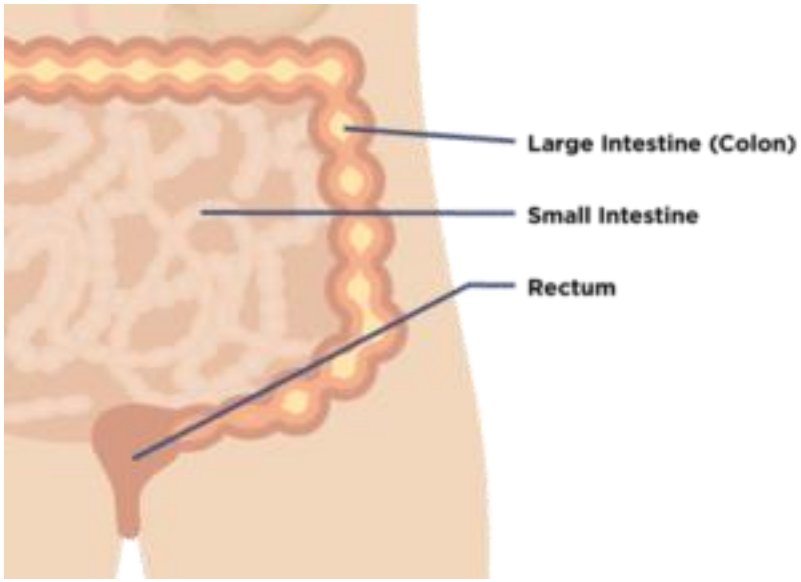
FUNDING RESEARCH TO FIGHT DISEASES OF THE GUT, LIVER & PANCREAS

THIS FACTSHEET IS ABOUT ULCERATIVE COLITIS

Ulcerative colitis (UC) is a disease of the rectum and the colon (otherwise known as the large intestine). It is one of the two conditions that are known as Inflammatory Bowel Diseases (IBD), the other being Crohn's disease. The term 'colitis' means the colon has become inflamed and if this becomes severe enough ulcers may form in the lining of the colon.



This condition is a disease in which there is a wide variation in the amount of inflammation, so that in mild cases the colon can look almost normal but, when the inflammation is bad, the bowel can look very diseased and contain ulcers.

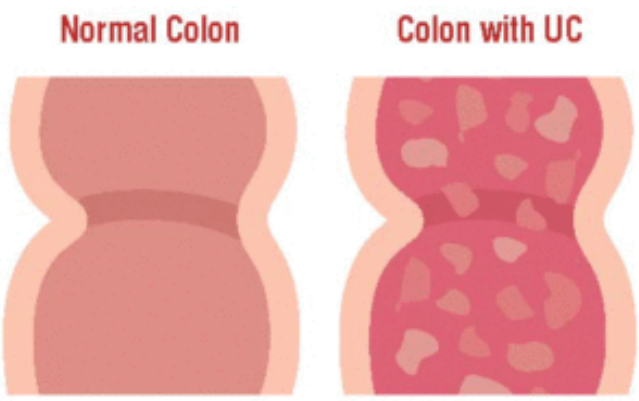
Ulcerative colitis usually affects the rectum (the part of the large bowel which lies just inside the anus) but you can get something called rectal sparing. Sometimes the inflammation is limited just to the rectum, known as proctitis, (see diagram below). However, the inflammation can involve a variable length of the colon. 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 between individuals.

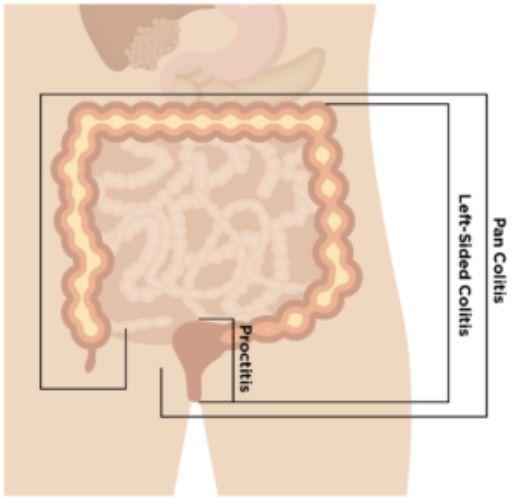
UC is thought to affect around 570 people per 100,000. The peak age of incidence between 15-25 years old with a smaller peak occurring between the age of 55 and 65 years old. But it can occur at any age.

CAUSES

CAUSES OF ULCERATIVE COLITIS

We don't yet know the cause of this condition although most doctors now think it relates to how patients react to the apparently harmless 'friendly' bacteria that everyone has in their colon. In most people, the bacteria that live in the colon do not cause any damage and indeed can be quite useful. However, patients with ulcerative colitis don't see them as being at all friendly and when the lining of the large intestine goes into battle with these bacteria, the result is that the inflammation starts. An enormous research effort is currently under way to find out why patients with ulcerative colitis appear to react badly to bacteria that don't normally cause any harm in others. There may be other causes which we have yet to discover.





SYMPTOMS

WHAT ARE THE USUAL SYMPTOMS OF ULCERATIVE COLITIS?

The three most common symptoms are diarrhoea, bleeding from the back passage and pain in the abdomen. However, symptoms do vary from one patient to the next, so many people may not have all three of these together. For example, some patients may notice that they pass blood when they open their bowels. Others may not have diarrhoea but feel rather constipated. To a certain extent, the symptoms depend on how much inflammation there is and how much of the colon is affected by the disease.

For some people, the symptoms can be a nuisance but may be tolerable. For others, the condition can really interfere with day-to-day life, which can become 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. As symptoms are

often at their worst in the morning, this can mean the start of the day can be quite an ordeal. Some patients pass considerable quantities of mucus when they open their bowels whilst others can be greatly troubled by wind. Many patients can just feel tired, not their usual self and they (or their family and friends) notice they have become just plain irritable. Sometimes there are symptoms outside the abdomen – such as sore eyes, painful joints and skin rashes and unexplained weight loss. Weight loss is a feature of severe disease.

HOW IS ULCERATIVE COLITIS DIAGNOSED?

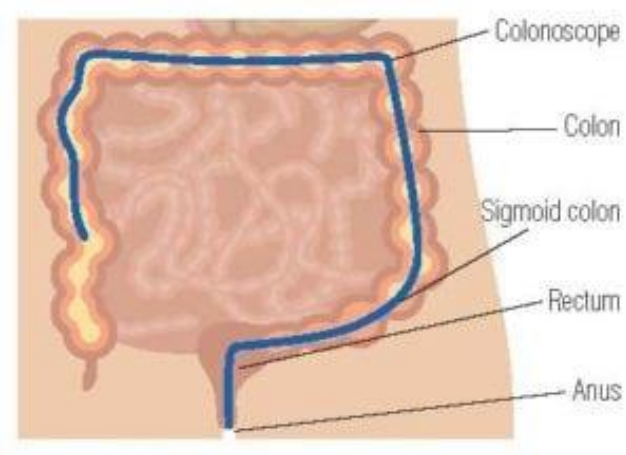
The first steps to diagnosis will include a complete medical history and a thorough visual examination to look for signs of anaemia. The doctors will also examine the abdomen for tenderness (a possible sign of inflammation). If UC is suspected then further tests will be carried out. These will include:

- **Blood tests**: these are to check for anaemia and the level of protein which can measure inflammation known as ESR and CRP tests. In general, the greater the degree of anaemia and the lower the protein level, the more severe the inflammation is likely to be.
- **Faecal Calprotectin test:** this test examines stools for signs of inflammation and to exclude infection.

The most important investigation is to look directly at the lining of the large intestine. This is done using a tube fitting with a camera which passed into the colon via the anus.

There are two types of investigations commonly used for ulcerative colitis.

- **Sigmoidoscopy**: this investigation only views the rectum and left hand side of the colon. Sometimes biopsies (tiny pieces of the lining of the bowel) are taken at the time of sigmoidoscopy and analysed under a microscope in a laboratory. Patients receive an enema before the
  procedure.
- **Colonoscopy:** this is a tube, which is long enough but sufficiently flexible to be passed through your back passage along the whole length of the colon. It is likely that the doctor will take some biopsies to study after the procedure has finished. A



colonoscopy will confirm the diagnosis of ulcerative colitis and provide detailed information on the extent and severity of inflammation in the intestine. Biopsies are taken and used to confirm this diagnosis. Patients follow a special diet and take laxatives before the colonoscopy to ensure the bowel is entirely empty and will be offered sedation and pain relief to minimise any discomfort.

TREATMENT

WHAT TREATMENT IS AVAILABLE FOR ULCERATIVE COLITIS?

There are two main stages to your treatment. The first is to bring your condition under control (remission) and the second is long term management of your condition to keep it under control and avoid relapse. There is currently no cure for ulcerative colitis.

Remission

The medication necessary to do this depends on the severity of your symptoms as will the method of medication delivery. If the inflammation is confined to the rectum ('proctitis'), it is quite possible the doctor will recommend a medication that you will need to insert into the rectum through the back passage. Although the thought of this can be unpleasant, it can be helpful to appreciate that giving your treatment this way does mean that the therapy is accurately directed right against the inflamed part of your bowel. Treatment can be given as suppositories or as enemas. Enemas can also be useful if the disease involves more of the large bowel than just the rectum alone, but if the inflammation in the bowel is extensive enough to affect more than the left half of the colon, it is also likely that you will be prescribed tablets to take by mouth.

Medications include:

- **Anti-inflammatory drugs:** these include aminosalicylates, also known as mesalazine such as Asacol, Octasa Pentasa, Salofalk and Mezevant. These come in rectal and oral forms and may reduce risk of cancer.
- **Steroids**: if the inflammation is more severe then steroids may be used, either in a tablet form or given intravenously in hospital if necessary. Your doctors will choose the preparation they feel is best for you. They are usually extremely safe to use but doctors are rather reluctant for patients to take these drugs long term because of the risk of side effects. However, most patients do get better with these treatments.
- **Immunosuppressive drugs:** these are often used to reduce inflammation over a longer period and allow steroids to be stopped. Azathioprine and 6-mercaptopurine are the most frequently prescribed and around two thirds of patients have a successful response. Most patients tolerate the drugs well and they are currently the most commonly used medicine for keeping ulcerative colitis under control. If you are taking these medications you will need regular blood tests.
- **Biologics:** in moderate to severe inflammation, biologic drugs such as Infliximab, Adalimumab, Golimumab and Vedolizumab can be helpful to get the disease under control. If remission is achieved, then these drugs can be continued in line with national guidance.

Avoiding Relapse

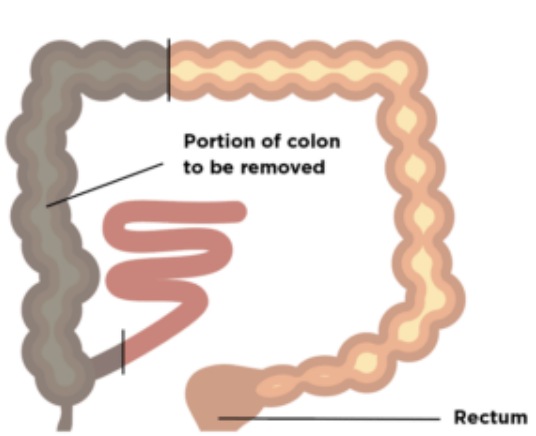
Regular review is important to ensure that you are on the best possible treatment and that your symptoms are well controlled. A good partnership between the patient, the GP and the specialist team can be very helpful. A relapse will be treated with medications as above depending on the inflammation, patient history and previous responses to medication.

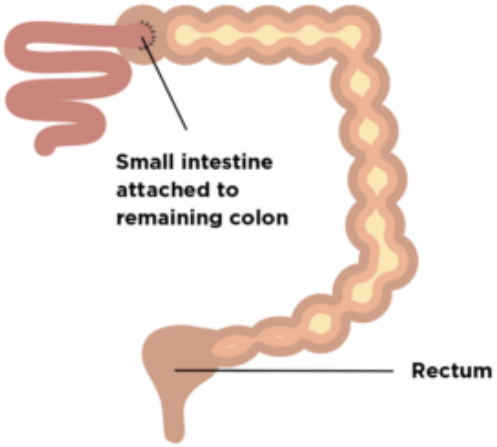
Hospital Admission

Doctors try hard to control UC with drugs and medicines. But occasionally this may not work and the patient may have to be admitted to hospital for more intensive treatment and care. Usually this works well and once the inflammation is back under control the patient can go home and resume a maintenance treatment programme.

Surgery

If the disease still fails to respond to treatment, it is likely that a surgical operation to remove the colon will be considered. This is called a colectomy. Sometimes only a part of the colon needs to be removed; if only half of the colon is removed the operation is called a





hemicolectomy. Although surgery can seem a drastic step, it does cure the disease (without a colon, there is no colitis).

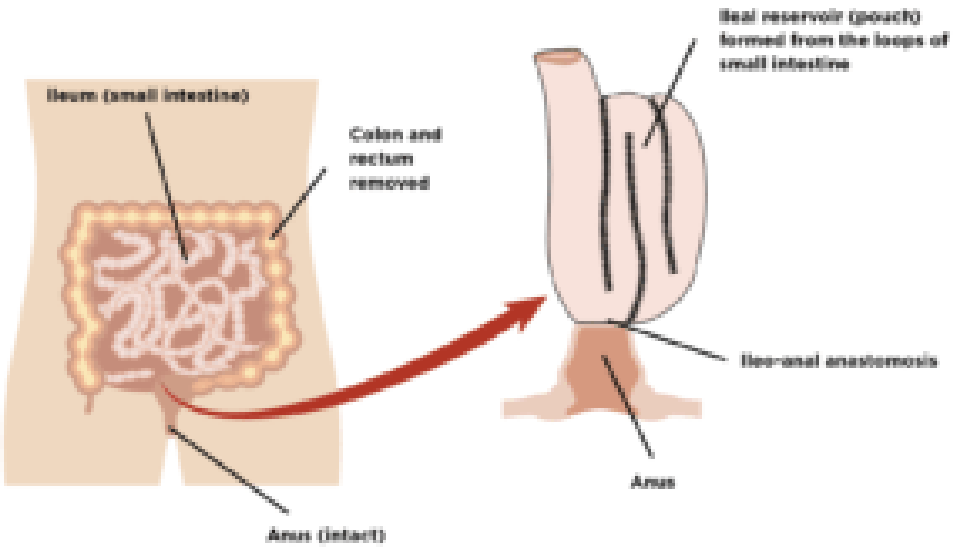
Previously colectomy used to mean the fitting of a stoma bag to collect the waste that is usually disposed of via the colon. However nowadays it is usually possible to remove the diseased colon and rectum and then construct a pouch of small intestine that acts very much like the rectum, giving no need for a bag. However, it is important to note that such surgery is usually undertaken over two-three operations and so a stoma is likely for at least a short period of time.

SUPPORT

HOW CAN ULCERATIVE COLITIS AFFECT ME OVER TIME?

A small number of patients do have complications that relate to UC 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. You may have heard that patients with UC run an increased risk of getting bowel cancer so your doctor will keep an eye on your bowel (quite literally; by performing colonoscopy at regular intervals) to detect pre-malignant changes in the lining of the bowel at a stage well before any cancer has developed.

WHAT TO ASK YOUR DOCTOR?



- Can I have the details for my specialist team e.g. IBD nurse contact details?
- How often do I need to be seen in clinic?
- What should I do if I think I'm having a flare?
- What advice would you give if I'm planning a pregnancy?
- What advice would you give if I'm travelling abroad?

OTHER SUPPORT ORGANISATIONS

Crohn's & Colitis UK are the UK leading organisation supporting people with Inflammatory Bowel Disease, including ulcerative colitis. Visit the Crohn's & Colitis website for more information.

For further information, visit gutscharity.org.uk