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INFORMATION ABOUT

ULCERATIVE COLITIS

WHAT WHY
WILL HOW OR
IF WHEN

IN ASSOCIATION WITH:

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FIGHTING GUT AND LIVER DISEASE

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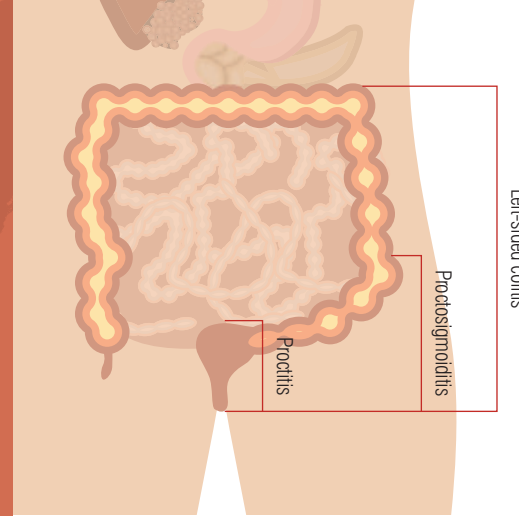
PCSG
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ULCERATIVE COLITIS

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.

Any medical term that ends in -itis means that there is inflammation or damage to that part of the body. The term 'colitis' means the colon has become inflamed and, if this becomes severe enough, the lining of the colon can be breached and ulcers may form. The term 'ulcerative colitis' can seem confusing, as many patients never actually develop ulcers because the degree of inflammation is not that advanced. It's best to think of UC as a disease in which there is 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 can contain ulcers.

One study, from the UK, found that UC affects around 14 people per 100,000 with average incidence being around 10 per 100,000 people¹. 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 age². It is more common in certain populations³ (Ashkenazi Jews and South Asians).



WHAT ARE THE SYMPTOMS?

The three most common symptoms of UC are:

- ✓ Diarrhoea,
- ✓ Bleeding from the back passage;
- ✓ Pain in the abdomen.⁶

However, symptoms do vary from one patient to the next, so many people do not have all three of these together. For example, some patients may just 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. Weight loss is a feature of severe disease.

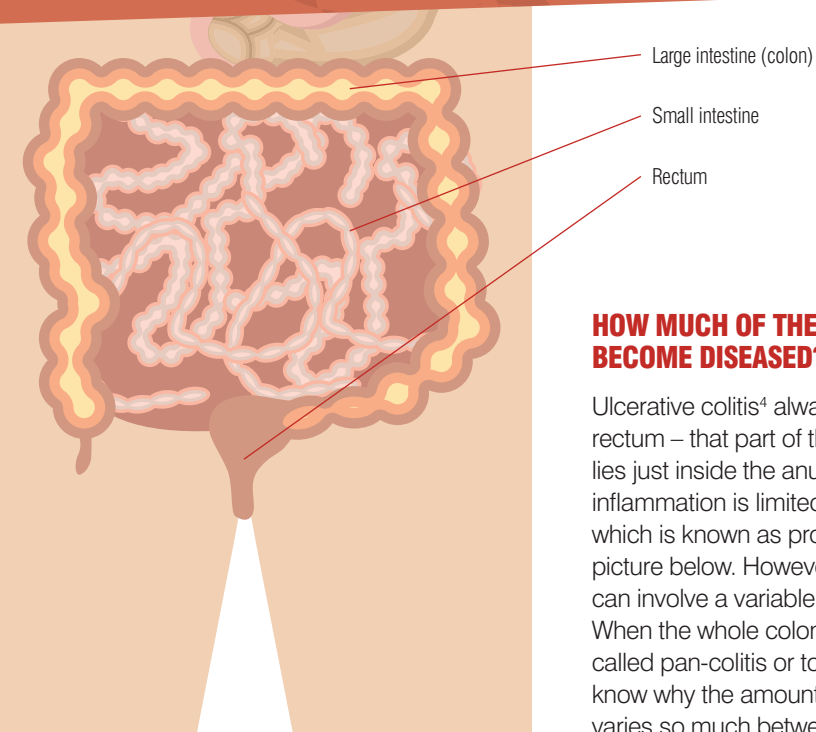
For some people, the symptoms can be a nuisance but may be tolerable. For others, the condition can really interfere with day-to-day life, which can become organized around visits to the toilet. It is not only just the number of times this can happen each day but the hurry in which some patients need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

WHY DOES UC HAPPEN?

We don't know the cause of ulcerative colitis – it is most likely to result from a combination of factors⁵. Doctors have looked hard to find either an infection or potential dietary causes, but have drawn a blank. For a while it seemed that ulcerative colitis might be one of the diseases where the body seems to be attacking itself. We now think that this is very unlikely, but there is no doubt that something must be causing damage to the lining of the large intestine.

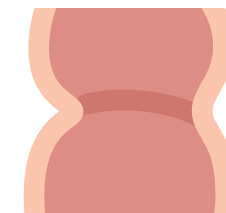
Most doctors now think the cause of UC relates to how patients react to the apparently harmless bacteria that everyone has in their colon. In most people, the bacteria that live in the colon do not cause any damage and indeed can be quite useful. They are sometimes known as 'friendly' bacteria. However, 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 starts⁴. An enormous research effort is 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.



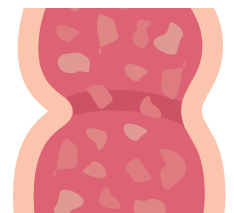
HOW MUCH OF THE COLON CAN BECOME DISEASED?

Ulcerative colitis⁴ 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, which is known as proctitis, as seen in the picture 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.

Normal Colon



Colon with UC



WHAT IS YOUR DOCTOR LIKELY TO DO?

Doctors use three separate steps to come to a precise diagnosis. Firstly, they will listen to your symptoms and ask you questions about your health. This is called 'taking your history'. Secondly they will want to examine you to see if they can detect any 'signs' that something is wrong. For example, they may notice that you are unusually pale (which might suggest you are anaemic) or, perhaps, you seem rather tender when the doctor presses gently on your tummy (which can be a sign of inflammation in the colon). Thirdly, they will probably ask you to undergo some tests.

WHAT TESTS MIGHT I NEED?

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 so as to be sure there are no signs of any bowel infection.

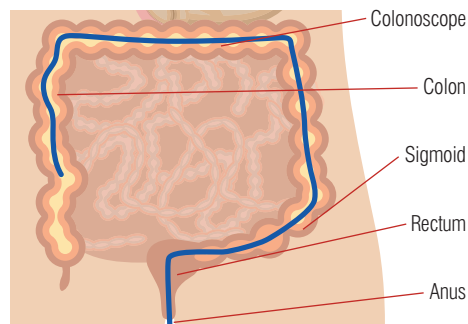
WHAT OTHER INVESTIGATIONS COULD BE NECESSARY?

The most important investigation is to look directly at the lining of the large intestine. Sometimes the doctor will choose to carry out such an examination in the outpatient clinic. This is known as sigmoidoscopy and has the convenience of you not having to take any special preparations beforehand, as the doctor will only look at the rectum and perhaps the lowest part of the sigmoid 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. However,

sooner or later, the doctor will want to see more of your bowel and the best way to do this is by the technique of colonoscopy.

WHAT IS A COLONOSCOPY?

A colonoscope is a tube, which is long enough but sufficiently flexible to be passed through your back passage along the whole length of the colon. You will be asked to follow a special diet and also to take some quite powerful laxatives just before the test to make sure the bowel is entirely empty. You will be offered an injection beforehand to minimise any discomfort that might be caused – but an anaesthetic is only needed very rarely. It is usually possible to see all of the rectum and the colon and 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 often used to confirm this diagnosis.



WHAT TREATMENT MIGHT I EXPECT?

Since the cause of ulcerative colitis is not known there are two important implications for treatment. Firstly, until the cause is discovered it is most unlikely that there will be a medicine that will cure the condition. Secondly, all treatments available at present are directed towards reducing the amount of inflammation in the bowel.

Fortunately, for most patients with UC, medicines prove effective although it is possible that your treatment may need to be varied to find the drugs that work best for you. Your doctors will firstly try to find a treatment that will bring the disease under control. Then they will work on finding a treatment to keep you that way.

BRINGING ULCERATIVE COLITIS UNDER CONTROL

Your doctor may refer to this phase as "Putting your disease in to remission" and almost always, the choice of treatment will depend on the extent and severity of the inflammation within the large bowel. 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 half of the colon, it is also likely that you will be prescribed tablets to take by mouth. There are some special dietary measures⁷ that can be undertaken that may prevent relapses and be beneficial to UC patients such as limiting dairy intake and taking fish oils.

WHAT DRUGS ARE AVAILABLE?

The anti-inflammatory drugs include aminosaliclates in milder cases and steroids if the inflammation is more severe. There are a variety of aminosaliclates (such as mesalazine⁸) and your doctors will choose the preparation they feel is best for

you. They are usually extremely safe to use. Steroids (such as prednisolone⁹) are more powerful but doctors are rather reluctant for patients to take these drugs for more than a few weeks at a time because of the risk of side effects. However, most patients do get better with these treatments.

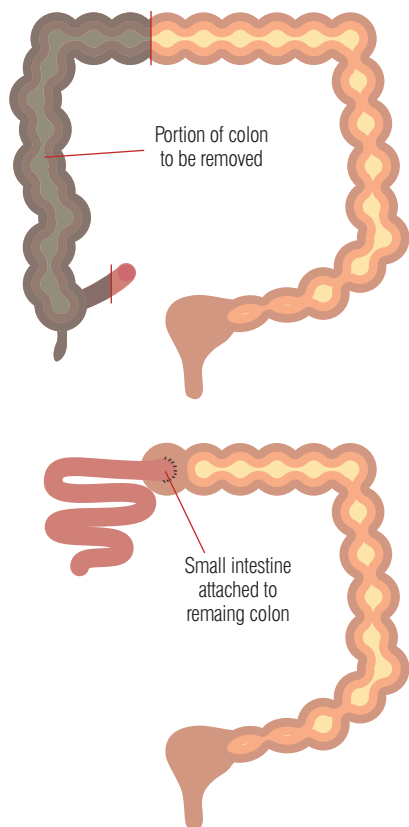
HOW MIGHT A RELAPSE BE PREVENTED?

Your doctor will discuss alternative ways of preventing relapse¹⁰, and good control of your condition will depend on a partnership between you, your GP and your Specialist. Regular review is important to ensure that you are on the best possible treatment and that your symptoms are well controlled. Aminosaliclates are helpful and may reduce cancer risk. If possible, doctors try to avoid giving patients with UC steroids in the long term because of the side effects. As an alternative, the possibility of taking azathioprine may be discussed with you. This calms down the immune system and, although only weakly effective against active disease, it has proved most useful in preventing relapses. This drug does need close monitoring in the first few weeks of treatment in order to detect side effects although most people do not have any problems when they take it.

WHAT WILL HAPPEN IF TREATMENT WITH MEDICINES FAILS?

Doctors try hard to control UC with drugs and medicines. But in the occasional situation that these don't help, or should you become very unwell, you may be offered admission to hospital¹¹. If the disease still fails to respond to treatment, it is likely that a surgical operation to remove part or all of the colon (called a colectomy) will be considered. Although surgery can seem a drastic step, it does cure the disease (if you don't have a colon, you can't have colitis). In former times, colectomy used to mean

needing a bag to wear on your tummy. 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.



CAN ULCERATIVE COLITIS CAUSE COMPLICATIONS?

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 cancer¹². The bad news is

that this is true; the good news is that bowel cancer is still an uncommon complication of the disease and that 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 cancer has yet developed.

AM I LIKELY TO DIE OF THIS DISEASE?

No.

WHAT RESEARCH IS NEEDED?

We must find the cause of the disease. Until then, we need to know as much as possible about all the steps that lead the inflammation in UC to develop. This will lead to the development of better drugs to control the condition. Being able to target drugs directly against the causes of the inflammation in UC is proving to be very valuable in developing new treatments.

The Crohns and Colitis UK group have many detailed leaflets on living with UC (and Crohns) especially related to employment, disability and fertility. They also provide information about patient groups and volunteering opportunities. These are found at www.crohnsandcolitis.org.uk.

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This leaflet was published by Core in 2014 and will be reviewed during 2016. If you are reading this after 2016 some of the information may be out of date. This leaflet was written under the direction of our Medical Director and has been subject to both lay and professional review.

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