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Ulcerative Colitis

Ulcerative colitis is a disease where inflammation develops in the colon and the rectum (the large intestine).

The most common symptom when the disease flares up is diarrhoea mixed with blood. Treatment can usually ease a flare-up of symptoms. The disease can often be prevented from flaring up by taking medication, usually mesalazine, each day. Surgery to remove the colon is needed in some cases.

People with ulcerative colitis have an increased risk of developing colon cancer. This risk is reduced by taking mesalazine each day. After 8-10 years, an inspection inside the colon every 1-3 years, using a colonoscope, is usually advised to screen for pre-cancerous changes.

What is ulcerative colitis?

Ulcerative colitis is a disease of the colon and the rectum (the large intestine).

- Colitis means inflammation of the colon.
- Ulcerative means that ulcers tend to develop, often in places where there is inflammation.

An ulcer occurs when the lining of the gut (gastrointestinal tract) is damaged and the underlying tissue is exposed. If you could see inside your gut, an ulcer looks like a small, red crater on the inside lining of the gut. Ulcers that occur in ulcerative colitis develop in the large intestine and have a tendency to bleed.

The inflammation and ulcers in the large intestine cause the common symptoms of diarrhoea and passing blood and mucus.

Who develops ulcerative colitis?

About 2 in 1,000 people in the UK develop ulcerative colitis. It can develop at any age but most commonly first develops between the ages of 10 and 40. About 1 in 7 cases first develop in people over the age of 60 years. Non-smokers are more likely than smokers to develop ulcerative colitis. However, smoking brings other dangers to health which far outweigh this benefit.

What causes ulcerative colitis?

The cause is not known. Ulcerative colitis can affect anyone and about 1 in 5 people who have it have a close relative who also has the condition. So, there is probably some genetic factor. The common theory is that some factor may trigger the immune system to cause inflammation in the colon and the rectum (the large intestine) in people who are genetically prone to developing the disease.

The most likely trigger for ulcerative colitis to develop is a germ (a bacterium or a virus). However, it is not clear which bacterium or virus is the culprit. Other triggers that may cause a flare-up of ulcerative colitis include anti-inflammatory medicines and withdrawal from nicotine in people who give up smoking. In people who are known to have ulcerative colitis, a common trigger for a flare-up of symptoms is a bout of infection of the gut (gastroenteritis) caused by various bacteria.

What are the symptoms during a flare-up of ulcerative colitis?

- **Diarrhoea**. This varies from mild to severe. The diarrhoea may be mixed with mucus or pus. An urgency to get to the toilet is common. A feeling of wanting to go to the toilet but with nothing to pass is also common (tenesmus). Water is not absorbed so well in the inflamed colon, which makes the diarrhoea watery.
- Blood mixed with diarrhoea is common (bloody diarrhoea).
- Crampy pains in the tummy (abdomen).
- Pain when passing stools.

Feeling generally unwell is typical if the flare-up affects a large amount of the colon and the rectum (the large intestine), or lasts for a long time. High temperature (fever), tiredness, feeling sick (nausea), weight loss and anaemia may develop.

Inflammation of the rectum (proctitis)

Symptoms may be different if a flare-up only affects the rectum and not the colon. You may have fresh bleeding from the rectum and you may form normal stools (faeces) rather than have diarrhoea. You may even become constipated further up in the unaffected higher part of the colon but with a frequent feeling of wanting to go to the toilet.

How does ulcerative colitis progress?

Ulcerative colitis is a chronic, relapsing condition. Chronic means that it is persistent and ongoing. Relapsing means that there are times when symptoms flare up (relapse) and times when there are few or no symptoms (remission). The severity of symptoms and how frequently they occur vary from person to person. The first flare-up (episode) of symptoms is often the worst.

It starts in the rectum in most cases. This causes a proctitis, which means inflammation of the rectum. In some cases it only affects the rectum and the colon is not affected. In others, the disease spreads up to affect some, or all, of the colon. Between flare-ups the inflamed areas of colon and rectum heal and symptoms go away. The severity of a flare-up can be classed as mild, moderate or severe:

- Mild you have fewer than four stools (faeces) daily and only have small amounts of blood in your stools. You do not feel generally unwell (no systemic disturbance).
- **Moderate** you have four to six stools a day, have some blood in your stools but do not feel generally unwell in yourself (no systemic disturbance).
- Severe you have more than six stools a day and have blood in your stools. You also feel generally unwell with more marked systemic disturbance with things such as high temperature (fever), a fast pulse rate, anaemia, etc.

On average, in any one year, about half of people with ulcerative colitis will be in remission with few or no symptoms. The other half will have a relapse with a flare-up of symptoms at some time in the year. During a flare-up, some people develop symptoms gradually - over weeks. In others, the symptoms develop quite quickly - over a few days.

Are there any complications with ulcerative colitis?

A very severe flare-up

This is uncommon but, if it occurs, it can cause serious illness. In this situation the whole of the colon and the rectum (the large intestine) becomes ulcerated, inflamed and dilated (megacolon). A part of the colon may puncture (perforate), or severe bleeding may occur. Urgent surgery may be needed if a flare-up becomes very severe and is not responding to medication (see later).

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.

Cancer

The risk of developing cancer of the colon is increased if you have ulcerative colitis (more details later).

How is ulcerative colitis diagnosed?

The usual test is for a doctor to look inside the colon and the rectum (the large intestine) by passing a special telescope up through the back passage (anus) into the rectum and colon. These are a short sigmoidoscope or a longer flexible colonoscope. See the separate leaflets called Sigmoidoscopy and Colonoscopy for more details.

The appearance of the inside lining of the rectum and colon may suggest ulcerative colitis. Small samples (biopsies) are taken from the lining of the rectum and colon and looked at under the microscope. The typical pattern of the cells seen with the microscope may confirm the diagnosis. Also, various blood tests are usually done to check for anaemia and to assess your general well-being.

Special X-ray tests such as a barium enema are not often done these days, as the above tests are usual to confirm the diagnosis and assess the disease severity.

A stool sample (sample of faeces) is commonly done during each flare-up and sent to the laboratory to test for bacteria and other infecting germs. Although no germ has been proven initially to cause ulcerative colitis, infection with various known germs can trigger a flare-up of symptoms. If a germ is found, then treatment of this may be needed in addition to any other treatment for a flare-up (described below).

What are the treatment options for a flare-up of ulcerative colitis?

When you first develop ulcerative colitis it is usual to take medication for a few weeks until symptoms clear. A course of medication is then usually taken each time symptoms flare up. The medicine advised may depend on the severity of the symptoms and the main site of the inflammation in the colon and the rectum (the large intestine).

Topical treatments applied locally by an enema or suppository are widely used for treating ulcerative colitis, particularly aminosalicylate and steroid medicines - see below. They are a treatment option if ulcerative colitis affects only the lower part of the bowel (proctitis or proctosigmoiditis).

Medication options include the following:

Aminosalicylate medicines

Aminosalicylates include mesalazine, olsalazine, balsalazide and sulfasalazine. They are recommended as the first option for treatment for mild-to-moderate flare-ups. They can be given in topical form, as tablets or as a combination of the two, depending how much of the large bowel is affected. The exact way these medicines work is not clear but they are thought to counter the way inflammation develops.

However, they do not work in all cases. Some people need to switch to steroid medication (either as tablets or in topical form). This may be recommended if an aminosalicylate medicine is not working, or if the flare-up is more severe. See the separate leaflet called Aminosalicylates.

Steroids

Steroids work by reducing inflammation. If you develop a moderate or severe flare-up, a course of steroid tablets (corticosteroids) such as prednisolone will usually ease symptoms. The initial high dose is gradually reduced and then stopped once symptoms ease. A steroid enema or suppository is also an option for a mild flare-up of inflammation of the rectum (proctitis) or the lower colon. Steroid injections directly into a vein may be required for a severe flare-up.

A course of steroids for a few weeks is usually safe. Steroids are not usually continued once a flare-up has settled. This is because side-effects may develop if steroids are taken for a long time (several months or more). The aim is to treat any flare-ups but to keep the total amount of steroid treatment over the years as low as possible.

Immune system suppressant medicines

Powerful medicines that suppress the immune system (immunosuppressants) may be used if symptoms persist despite the above treatments. For example, azathioprine, ciclosporin or infliximab are sometimes needed to control a flare-up of ulcerative colitis.

Laxatives

Although most people with ulcerative colitis have diarrhoea during a flare-up, as mentioned, constipation may develop if you just have proctitis. In this situation, laxatives to clear any constipation may help to ease a flare-up of proctitis.

Note: antidiarrhoeal medication such as loperamide should NOT be used during a flare-up of ulcerative colitis. This is because it does not reduce the diarrhoea that occurs in this situation, and it increases the risk of developing a megacolon (a serious complication - see below).

What are the treatment options to prevent flare-ups of symptoms?

Medication

Once an initial flare-up of symptoms has cleared, you will usually be advised to take a medicine each day to prevent further flare-ups. If you have ulcerative colitis and do not take a regular preventative medicine, you have about a 5-7 in 10 chance of having at least one flare-up each year. This is reduced to about a 3 in 10 chance if you take a preventative medicine each day.

An aminosalicylate medicine, usually mesalazine (described above), is commonly used to prevent flare-ups. A lower maintenance dose than the dose used to treat a flare-up is usual. You can take this indefinitely to keep symptoms away. Most people have little trouble taking one of these medicines, as side-effects are uncommon. However, some people develop side-effects such as tummy (abdominal) pains, feeling sick (nausea), headaches, or rashes.

If a flare-up develops whilst you are taking an aminosalicylate then the symptoms will usually quickly ease if the dose is increased, or if you switch to a short course of steroids. Another medicine may be advised if an aminosalicylate does not work, or causes difficult side-effects. For example, azathioprine or 6-mercaptopurine is sometimes used.

Probiotics

Probiotics are nutritional supplements that contain 'good' germs (bacteria). That is, bacteria that normally live in the gut and do no harm. Taking probiotics may increase the 'good' bacteria in the gut, which may help to ward off 'bad' bacteria that may trigger a flare-up of symptoms. There is little scientific proof that probiotics work to prevent flare-ups. However, a probiotic strain (*Escherichia coli* Nissle 1917) and the probiotic preparation VSL3 have shown promise. Further research is needed to clarify the role of probiotics.

Who needs surgery?

Not everyone with ulcerative colitis has their symptoms well controlled with medication. About a quarter of people with ulcerative colitis need surgery at some stage. The common operation is to remove the colon and the rectum (the large intestine). There are different techniques used for this. It is helpful to discuss the pros and cons of the different operations with a surgeon. Removing the large intestine will usually cure symptoms of ulcerative colitis permanently.

Surgery is considered in the following situations:

- During a life-threatening flare-up. Removing the large intestine may be the only option if it swells greatly (megacolon), punctures (perforates), or bleeds uncontrollably.
- If the condition is poorly controlled by medication. Some people remain in poor health with frequent flare-ups which do not settle properly. To remove the large intestine is a serious step but, for some people, the operation is a relief after a long period of ill health.
- If cancer or pre-cancer of the large intestine develops.

General treatment measures

- A special diet is not usually needed. A normal, healthy, well-balanced diet is usually advised. If you have ulcerative colitis just in the rectum (proctitis), a high-fibre diet may help to avoid constipation.
- You may be advised to take iron (oral or injected through a vein (intravenous)), vitamin B or folic acid tablets if you develop anaemia.
- You may need painkillers when symptoms flare up.
- You may be advised to have vaccines to protect you from infections such as pneumonia, hepatitis and human papillomavirus (HPV), especially if you are given treatment that affects your immune system.

Ulcerative colitis and cancer of the colon

The chance of developing cancer of the large intestine (colon) is higher than average in people who have had ulcerative colitis for several years or more. It is more of a risk if you have frequent flare-ups affecting the whole of the large intestine. For example, about 1 in 10 people who have ulcerative colitis for 20 years which affects much of their large intestine will develop cancer.

Because of this risk, people with ulcerative colitis are usually advised to have their large intestine routinely checked after having had the condition for about 10 years. This involves a look into the large intestine by a flexible telescope (colonoscopy) every now and then and taking small samples of bowel (biopsies) for examination. It is usually combined with chromoscopy - this is the use of dye spray which shows up suspicious changes more easily. Depending on the findings of this test and on other factors, you will be put into a low, intermediate or high risk category. 'Other factors' include:

- The amount of intestine affected.
- Whether you have had complications such as polyps. These are small, non-cancerous (benign) growths on the inside lining of the colon or rectum.
- Whether you have a family history of cancer.

The National Institute for Health and Care Excellence (NICE) recommends the next colonoscopy/chromoscopy should depend on the degree of risk of developing colon or rectal cancer. After the next test, your risk will be calculated again.

Recent studies indicate that the risk of cancer is reduced in people who take regular long-term aminosalicylate medication (described above). In one study, people with ulcerative colitis who regularly took mesalazine had a 75% reduced risk of developing colon cancer.

What is the outlook?

With modern medical and surgical treatment, there is just a slight increase in the risk of death in the first two years after diagnosis, compared with the general population. After this there is little difference in life expectancy from that of the general population. However, a severe flare-up of ulcerative colitis is still a potentially life-threatening illness and needs expert medical attention.

As mentioned, if you do not take medication to prevent flare-ups, about half of people with ulcerative colitis have a relapse on average once a year. This is much reduced by taking regular medication. However, even in those who take regular medication, some people have frequent flare-ups and about a quarter of people with ulcerative colitis eventually have an operation to remove their colon.

A year from diagnosis, about 9 in 10 people with ulcerative colitis are fully capable of work. So, this means that, in the majority of cases, with the help of treatment, the disease is manageable enough to maintain a near-normal life. However, the condition can cause significant employment problems for a minority.

Treatment for ulcerative colitis is an evolving field. Various new medicines are under investigation. These may change the treatment options over the next ten years or so and improve the outlook (prognosis).

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Further reading & references

- Ulcerative colitis: management; NICE Guidance (May 2019)
- Consensus guidelines on the management of inflammatory bowel disease in adults; British Society of Gastroenterology (2019)
- Colonoscopic surveillance for prevention of colorectal cancer in people with ulcerative colitis, Crohn's disease or adenomas; NICE Clinical Guideline (March 2011)
- Ulcerative colitis; CKS NICE, April 2019 (UK access only)

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