

# Ulcerative colitis

## What is ulcerative colitis?

Ulcerative colitis is an inflammatory disease that affects the inner lining (the mucosa) of the large intestine or colon. This layer becomes inflamed and develops many tiny breaks in its surface (ulcers), which may bleed. The inflamed lining also produces an excess amount of normal intestinal lubricant (mucus), which may contain some pus. Ulcerative colitis is a chronic condition, meaning that it has a tendency to flare up from time to time over many years.

## What is the colon?

The colon (otherwise known as the large bowel or large intestine) is that part of the bowel between the small intestine (where your digested food is absorbed into your system) and the anus or back passage, from which faeces (stools, motions, wastes) are discharged. The very end of the colon, immediately above the anus, is called the

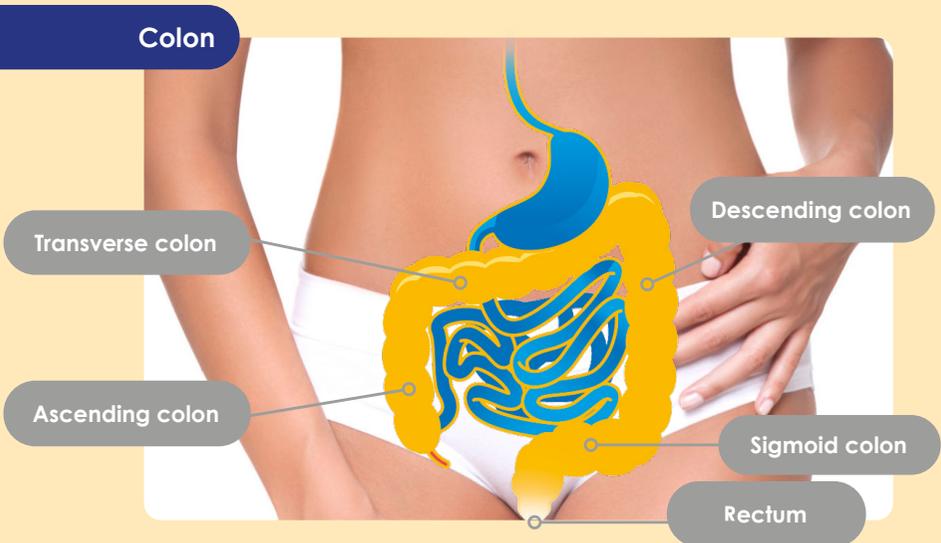
rectum. Ulcerative colitis almost always involves the rectum, but how much of the rest of the colon is involved varies from patient to patient.

## What does the colon do, and how does ulcerative colitis alter its functions?

The main function of the colon is to extract fluid from the liquid waste that enters it from the small intestine, concentrating this waste into solid faeces. In more severe ulcerative colitis, this concentrating function becomes defective due to the inflammation of the lining of the colon. This is what causes diarrhoea. The inflammation can also result in there being blood, mucus, or pus in the stool.

## What causes ulcerative colitis?

We do not know exactly what causes ulcerative colitis. There are clearly some



genetic factors that make some people more likely to develop ulcerative colitis, as many people with ulcerative colitis also have a relative with the disease. Environmental factors are likely to play a role and may trigger the inflammation. Whatever the cause of the initial inflammation, the inflammation does not know when to 'turn off'. There is ongoing research worldwide to determine why people get ulcerative colitis, with the hope that once we understand the cause, we will find a cure.

### Is ulcerative colitis infectious?

**No**, it is not infectious, although various acute infectious diarrhoeas (usually acquired from contaminated food or water) can closely mimic the beginning of chronic ulcerative colitis. For this reason, you may well have had samples of faeces sent to the laboratory at the onset of your illness in order to determine whether you have infectious diarrhoea or ulcerative colitis.

### Does stress or worry cause ulcerative colitis?

**No**. However, flare-ups of ulcerative colitis can often occur at times of personal stress, although the condition often flares for no obvious reason.

### Can I pass ulcerative colitis on to my children?

Ulcerative colitis is not strictly hereditary, for its transmission from one generation of a family to the next cannot be accurately predicted. However, it can occur in more than one member of the same family (for example, father and son, two sisters).

Ulcerative colitis is known to have a genetic predisposition so, given that you pass on half your genes (DNA) to your biological children, they would have a slightly higher chance of developing ulcerative colitis than the general population. It is very important to remember, however, that you do not give

the disease to your children. Although they may inherit genes that might predispose them to developing ulcerative colitis, the likelihood of your children inheriting or developing ulcerative colitis is very small.

### Is ulcerative colitis caused or worsened by something in my diet?

**No**, not that we know of, but occasionally symptoms will improve by avoiding certain foods that you find exacerbate your symptoms. Please refer to the '**Nutrition and diet**' chapter.

### Is ulcerative colitis a form of cancer?

**No**, although symptoms can resemble those of people with bowel cancer.

### Can ulcerative colitis go on to become bowel cancer?

Occasionally, patients whose entire colon is diseased and who have had ulcerative colitis for many years may develop cancers in the colon lining. This group of patients will be monitored closely by their specialists with regular colonoscopies. Prior to developing cancer, the lining of their bowel usually develops pre-cancerous changes, often years before the appearance of an actual cancer growth.

By looking for these changes, the doctor can decide which patients are at risk and take appropriate measures. These measures involve closer follow-up and having more frequent colonoscopies. Sometimes, preventative surgery will be advised.

People who have only the rectum involved (proctitis) are not at an increased risk of bowel cancer. For those with more extensive involvement, doctors will start performing regular 'surveillance' colonoscopies between seven and 10 years after diagnosis. Regular surveillance and good control of the disease are ways to minimise the risk of bowel cancer.

## How is ulcerative colitis diagnosed?

Ulcerative colitis is suspected on the basis of a history of bleeding from the colon, usually accompanied by diarrhoea, a sense of urgency, and discomfort in the abdomen.

Laboratory tests such as a blood sample for C-reactive protein (CRP) or a stool test for calprotectin may be abnormal. Both of these tests are markers of inflammation. People may also be anaemic (low blood count) or low in iron.

The diagnosis is confirmed by the typical abnormal appearance of the inner lining of the colon (mucosa) as seen by direct inspection at the time of a colonoscopy. A colonoscopy is performed by passing a flexible tube, about a metre long, into the colon, which shows the inside lining on a video screen. You will likely be sedated so there should be no or minimal discomfort.

The examination requires a 'prep' to clean the colon beforehand, which usually involves drinking a special fluid to flush out any debris. This is necessary so the person performing the colonoscopy can clearly determine how much of the colon is involved. During the examination tiny samples of the lining (biopsies) are taken to check under the microscope to confirm the diagnosis. Biopsies are painless. The colonoscopy may need to be repeated at future dates to assess whether the ulcerative colitis is active or quiescent (inactive), and to gauge the response to treatment.

## Does localised ulcerative colitis spread further up the colon over the years?

Some people have ulcerative colitis limited to the rectum (proctitis); some people only have the left side of the colon involved, while others can have involvement of the entire colon (pancolitis).

Usually, the amount of colon involved at the time of diagnosis remains more or less the same from one attack to the next. Sometimes, however, in a minority of people, it can involve more of the colon with subsequent flare-ups.

## Will my ulcerative colitis ever go away completely?

The symptoms and signs of ulcerative colitis can certainly disappear for many years and even for a lifetime without any treatment. Unfortunately, the more usual course is one of periodic flare-ups of the inflammation, accompanied by symptoms.

## Is ulcerative colitis treatable?

**Yes**, very much so, but it is not curable. A course of treatment will not stop it from ever coming back again, but very few chronic medical conditions are curable. In this sense, the only cure is to surgically remove the diseased colon.

Treatment is aimed at settling down flare-ups of the disease and preventing future



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flare-ups. The goal is to return the lining of the colon to normal and keep people in remission. There are many medications available to treat ulcerative colitis and they are discussed in the next chapter.

### Why do some people with ulcerative colitis have operations?

All or most of the colon may be surgically removed if:

- a very severe attack of ulcerative colitis is not improving in spite of intensive medical treatment
- repeated attacks over the years are harming the patient's wellbeing and not responding to medical treatment, particularly in patients with involvement of most or the entire colon
- a person has repeated attacks of inflammation in other systems, such as the eyes, skin or joints, accompanying their attacks of ulcerative colitis
- there are any pre-cancerous changes in the colon

### What operations are available to treat ulcerative colitis?

The two alternatives are:

- total proctocolectomy and ileostomy

- proctocolectomy and ileoanal anastomosis ('pouch' operation).

These operations are explained in detail in the chapter '**Surgery in IBD**'.

### Is ulcerative colitis a dangerous illness?

Ulcerative colitis is most dangerous if the attack is very severe and does not respond to medical treatment. It can then require emergency surgery. Repeated flare-ups of the disease can also interfere with a person's quality of life.

Symptoms, however, can usually be well-controlled with medication. The life expectancy of people with ulcerative colitis is about the same as that of people without the disease.

### If I have a mild ulcerative colitis, does it need treating?

Many patients accept rectal bleeding or diarrhoea without seeking medical advice for surprisingly long periods. However, regular bleeding can lead to iron deficiency and anaemia as well as other problems such as scarring and narrowing of the lower colon and rectum.

Therefore, it is important to see your specialist regularly and openly discuss your symptoms.

## Will ulcerative colitis affect my relationship?

Although ulcerative colitis may start at any age, from newborn to well over 80, it most commonly appears for the first time in the 20-40 age group, when one hopes for good health in order to cope with career, relationships and raising a family.

As with any other chronically recurring disorder, understanding from your partner and family will help greatly to lessen the strain of feeling "not quite up to it". The intimate details of one's bowel functions are not something easily discussed, even with a partner. It is hoped that this booklet will give not only you, but also your partner, insight into the disease and its symptoms.

## Will ulcerative colitis prevent or affect a pregnancy?

Pregnancy in ulcerative colitis should be a planned event and discussed with your specialist first. Most people with ulcerative colitis have normal pregnancies,

especially if their disease is under good control at the beginning of the pregnancy and the subsequent nine months. Please see the chapter '**Sexuality, fertility and pregnancy**' for an in-depth discussion on these issues.

## Do I need to make adjustments in my lifestyle in order to bring about improvements in the disease?

Simple and common sense advice is to try and keep active and fit, eat a well-balanced diet, and avoid drinking excess alcohol. Some people who smoke can find that stopping cigarettes can make the ulcerative colitis flare up, but this is not a recommendation for people to take up smoking!

Depending on their symptoms, some people with ulcerative colitis may need to make adjustments in their patterns of work, home and social activities, especially during a flare. Prolonged travel and visits to supermarkets, for example, may be viewed as distressing prospects during these times. Here again, the understanding of those who are close to you will lessen the stress of desperate searches for a 'Toilets' sign.



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### **Is any research done on ulcerative colitis?**

A considerable amount of research is being done on ulcerative colitis and a related bowel disorder called Crohn's disease. It doesn't usually make headline news in the media because diarrhoea and rectal bleeding lack the emotional appeal of heart disease, stroke and cancer.

Research in both the laboratory and the clinic is directed towards trying to find the cause or causes of the disease in order to plan more effective treatments and, hopefully, a cure.