

## What is ulcerative colitis?

Ulcerative colitis is a disease that causes inflammation (pain, sores and swelling) in the inside lining of the colon (large intestine) or rectum. This causes urgent and bloody diarrhoea, and tiredness. The effects of the disease vary depending on how much of the colon is affected, and symptoms change over time with periods called flare-ups in between symptom-free periods called remission. (For an illustration and details on the different types of ulcerative colitis and the areas they affect, see the previous section, [Digestive System and IBD](#))

Ulcerative colitis can be difficult to diagnose because its symptoms are similar to other intestinal disorders and to another type of Inflammatory Bowel Disease (IBD) called Crohn's disease. Crohn's disease differs from ulcerative colitis because it causes inflammation deeper within the intestinal wall and can occur in other parts of the digestive system, including the small intestine, mouth, oesophagus and stomach.

- **What are the symptoms?**

The most common symptoms of ulcerative colitis are abdominal pain and bloody diarrhoea. Other symptoms include loss of appetite, weight loss, fever, tiredness, joint pain, anaemia (low levels of red blood cells in the blood, causing dizziness, faintness or tiredness), or loss of body fluids and nutrients.

- **How is ulcerative colitis diagnosed?**

Many different tests are used to diagnose ulcerative colitis. A physical examination and medical history are usually the first step. Blood tests may also be done to check for anaemia, which could suggest bleeding in the colon or rectum, or they may uncover a high white blood cell count, which is a sign of inflammation somewhere in the body.

A stool sample can also reveal white blood cells, which might be an indication of ulcerative colitis or inflammatory disease. A stool sample also allows the doctor to detect bleeding or infection in the colon or rectum caused by bacteria, a virus or parasites. Ruling out these causes can be useful in diagnosing ulcerative colitis.

A colonoscopy or sigmoidoscopy is the most commonly used method for making a diagnosis of ulcerative colitis and ruling out other possible conditions, such as Crohn's disease, diverticular disease or cancer. For both tests, the doctor inserts an endoscope – a long, flexible, lighted tube connected to a computer and TV monitor – into the anus to see the inside of the colon and rectum. The doctor will be able to see any inflammation, bleeding or ulcers on the colon wall. During the exam, the doctor may do a biopsy, which involves taking a sample of tissue from the lining of the colon to view with a microscope.

Before the examination, you will need to drink a special preparation which will make you go to the toilet often. This is to clear the digestive system, so the camera can move about, and clearly see the walls of the bowel. Although the examination may be uncomfortable, it shouldn't be painful. Your doctor can discuss options for pain relief with you. If a biopsy is taken, usually this doesn't cause any discomfort.

Sometimes X-rays such as a barium enema are also used to diagnose ulcerative colitis. A specially prepared enema containing barium is taken before the test. Barium coats the lining of the gut and shows up as white on X-ray films. The patterns on the films show the doctor which parts of the gut are affected by disease.

CT and MRI scans can also be used to obtain detailed pictures of the digestive system, to help to identify any problems. In about 10% of people with IBD, it is difficult to determine whether they have ulcerative colitis or Crohn's disease, due to similar or overlapping symptoms.

- **Can other parts of the body be affected also?**

Other parts of the body may also be affected in some people with ulcerative colitis, such as the joints, eyes or liver. Some of these problems go away when the ulcerative colitis is treated, but some need specific treatment as well.

- **Who gets ulcerative colitis?**

About 1.2 million people in Europe have ulcerative colitis. That is about 1 in 1,500 people. It can develop at any age, but most commonly starts between the ages of 15 and 40. Slightly more men than women are affected.

- **What causes ulcerative colitis?**

The cause of ulcerative colitis is not yet known, although a combination of factors are believed to play a role, including viruses, bacteria, genetics and smoking. It does tend to run in families. One theory is that a bacteria or virus may trigger the immune system to cause inflammation in parts of the digestive system in people who are genetically prone to develop the disease.

- **How does ulcerative colitis progress?**

Ulcerative colitis is a chronic (ongoing) disease, with times when symptoms flare up (relapse) and times when there are few or no symptoms (remission). The severity of symptoms, and how often they occur, varies from one person to the next. About half of people with ulcerative colitis have mild symptoms. A few people have frequent and/or severe flare ups. Usually, however, with treatment and medical care, symptoms can be managed well and it still possible to follow your ambitions and live life to the full.

- **Should cancer be a concern?**

People with ulcerative colitis have a small increased risk of colon cancer compared to the risk of the general population. The risk of cancer is different depending on how long the person has had the disease and how much of the colon is affected. Your doctor will look for signs of abnormal cells when doing a colonoscopy, sigmoidoscopy or biopsy. If you are concerned about your risk, speak with your doctor.

- **Will I need surgery?**

Most people with mild or moderate disease are able to manage their symptoms with medication. However, surgery may be needed in people with more severe disease if, for example, there is a complication. After surgery, however, people with ulcerative colitis can usually expect a good quality of life.

Choosing which surgery to have depends on the severity of the disease and your needs, expectations and lifestyle. Not every operation is appropriate for every person. Your doctor will discuss the options with you, including which surgery is right for you and the best time to have it. If you are faced with this decision, get as much information as possible by talking to your doctors, to nurses who work with colon surgery patients and to other ulcerative colitis surgery patients. Patient support groups can also direct you to other helpful resources and give you the opportunity to meet with other people who are considering similar options, or who have had similar experiences in the past.

For tips on talking to your doctor about your concerns, see [Living with IBD/ Your IBD Consultation](#). For more information on treatment and surgery for ulcerative colitis, please see, [Ulcerative Colitis/ Treatment Plan](#) for ulcerative colitis.

- **What can I do to help manage my illness?**

Your role in managing your illness is very important. Here are some of the most important things you can do to stay in control of ulcerative colitis:

- Be involved in the proactive management of your own health every day
- Know when and how to take care of your general health
- Follow your management plan and take your medication
- Ask questions if you are concerned, and seek help if a problem arises in between doctor visits. It is important that you follow your treatment plan and know what to do should a problem arise.
- If you have any of these problems, contact your doctor as soon as possible:
  - Blood in your stool
  - Change in bowel habits that last for more than 10 days
  - Severe abdominal cramps or pain
  - Severe diarrhoea or bloody diarrhoea
  - Weight loss with no known reason
  - Unexplained fever lasting more than 3–4 days
  - Constant fatigue
  - Loss of appetite
  - Nausea or vomiting for unknown reasons

Not everyone will have these problems; in mild disease, it is less likely that other parts of the body will be affected.

Here are a few examples of possible 'extraintestinal manifestations' of ulcerative colitis:

- Peripheral arthropathy or arthritis – mainly soreness in the large and medium-size joints during a flare. The spine and lower back may be affected as well. Sometimes the arthritis can flare up even when the inflammatory disease is under control. Typical treatment may include analgesics (for pain relief).
- Pyoderma gangrenosum – ulcers (open sores) over the lower part of the legs. This is more common in ulcerative colitis than in Crohn's disease, and usually improves with treatment for the inflammatory disease. Treatment may include corticosteroids, immunosuppressants or anti-TNFa.
- Primary sclerosing cholangitis (PSC) – inflammation of the bile ducts, which can lead to liver disease.
- Episcleritis – a painless inflammation of the white part of the eye and surrounding tissue, often mistaken for pink eye. Treatment may include chilled artificial tears, corticosteroid eye drops or anti-inflammatory medicine.
- Uveitis – inflammation of the iris (coloured part of the eye), which can be very painful and can be associated with visual changes and sensitivity to light. If untreated, uveitis can progress to blindness, so it is important to treat this condition if it develops. Treatment may include eye drops (steroids or pupil dilators) to help reduce the inflammation and pain.

The possible complications of ulcerative colitis will vary depending on the extent of inflammation in the rectum and the colon. Not everyone will have these problems, but here are a few examples of what could happen, usually in more severe cases:

- Abdominal distension – a sudden and severe expansion of the colon which can lead to a condition called toxic megacolon, in which case the colon is at risk of rupturing (when small tears or holes form). Surgery may be needed to prevent rupture of the bowel.
- Perforation – A small hole that forms in the wall of the gut. The contents of the gut can leak out and cause infection or an abscess inside the abdomen. This can be serious and life-threatening.
- Severe bleeding – this can become quite serious and require treatment on its own.

If you do need to have surgery, rest assured that you are not alone: about 25 to 40 percent of people with ulcerative colitis will eventually need to have surgery. Sometimes the doctor will suggest removing the colon if medical treatment fails, or if the side effects of medication are causing problems. After surgery, however, most people with ulcerative colitis can usually expect a good quality of life.

If you have severe disease, learn to listen to your body and if you think something may be wrong, it is best to take action and check with your doctor. If something is wrong, you will catch it early. If nothing is seriously wrong, at least you will be reassured.

### **In severe cases**

In severe ulcerative colitis there may be inflammation and pain in the joints (arthritis); inflammation of the eye (uveitis); liver disease; or bone mineral density loss (osteoporosis) Doctors call these 'extraintestinal manifestations'.