

Ulcerative Colitis – Kids and Teens

What Is IBD?

When your doctor first told you about ulcerative colitis, he or she may have also mentioned 'Inflammatory bowel disease', or IBD. The word 'IBD' is used for a group of diseases that cause pain and swelling (inflammation) in the digestive system. Ulcerative colitis is one type of IBD that affects the large intestine (colon and rectum). Another type of IBD called Crohn's disease can affect any part of the digestive system, for example the mouth, stomach, small or large intestine. Having IBD can be difficult sometimes, but with help from your doctor and by making a few changes in your life you should be able to carry on quite normally.

Here are some answers to questions people often ask about IBD. However, because ulcerative colitis affects different people in different ways, you should not worry if you find your situation is slightly different than someone else's. We suggest you and your parents read this together so you can talk about it with them.

- **How does IBD make you feel?**

The most common IBD symptoms are abdominal pain, cramping, tiredness (fatigue), runny stool (diarrhoea) and weight loss. Other symptoms may include bloody diarrhoea, slight fever, anaemia (low levels of red blood cells in the blood which can make you feel tired, faint or breathless), exhaustion (extreme tiredness) and (in children) slowed growth.

Both ulcerative colitis and Crohn's disease are ongoing (chronic) with times when symptoms get worse (called flares, or attacks) and other times when symptoms get better (remission). Although the symptoms can make you feel unwell and may make your daily activities difficult, they can usually be managed with a combination of care, medication, hospitalisation and (sometimes also) surgery. Many people find that in well managed IBD, making some simple changes to their everyday lives enables them to continue their normal activities.

- **Who gets IBD?**

IBD can start at any age. Both Crohn's disease and ulcerative colitis are found worldwide, although they are more common in the Western world. About 2.2 million people in Europe have IBD. Regional differences range from 1/1000 to 1/500, with the highest numbers in northern Europe.

IBD affects men and women equally, although ulcerative colitis is slightly more common in men and Crohn's disease is slightly more common in women.

- **What causes IBD?**

Although the exact causes of IBD are unknown, they are believed to be related to changes in the body (immune system) brought about by an environmental trigger in people who are genetically prone to the disease. A combination of factors may play a role, including bacteria, viruses, genetics, smoking and over-the-counter pain medicines. Other factors, such as stress and diet, are not believed to cause IBD, although they may be involved in worsening symptoms for some people.

- **Can someone catch it from me?**

Neither ulcerative colitis nor Crohn's disease is contagious, meaning you cannot catch it from someone else or spread it to anyone if you have it. This should not be confused with the fact that the tendency to develop the disease may be hereditary (passed on through the genes), since relatives of people with IBD are at a slightly greater risk of developing the disease.

However, other factors (such as environmental triggers) are also believed to play a role in developing the disease for these people.

- **What else could happen?**

Both ulcerative colitis and Crohn's disease can cause other problems, or complications, in some people. With ulcerative colitis, for example, bleeding may cause anaemia (low levels of red blood cells in the blood, which can make you feel tired, faint or breathless).

With Crohn's disease, scarring and thickening of the intestine walls can create a narrowing of the intestine wall, which is called a stricture, leading to constipation, bloating and pain. Nutritional problems may also happen if the body cannot use vitamins or minerals properly.

Although not everyone will have these problems, if they do arise, they may also need medical care in addition to treating ulcerative colitis or Crohn's disease.

- **Can it affect other parts of the body too?**

Not everyone will have these problems, but for some people IBD may also affect other parts of the body, such as the joints, eyes, mouth, liver, gallbladder, skin or kidneys. Although some of these problems may improve with the treatment and management of IBD, specific treatment may also be needed.

- **How is IBD treated?**

Treatment with medicine is usually the first approach to managing IBD. The type of treatment you will be given depends on several things – such as whether you have ulcerative colitis or Crohn's disease, the extent of the disease, and the impact of your symptoms on your daily life.

For people with ulcerative colitis, treatment depends on the amount of the large bowel affected and amount of inflammation. For example, disease in the lower part of the bowel may be treated with drugs given directly into the rectum with an enema or suppository. A medicine called mesalazine may be given by mouth. Steroid tablets (such as prednisolone) may be given in more severe cases or if more of the bowel is affected. Immunosuppressants may also be used to help reduce the activity of the body's immune system, which causes a lot of the damage to the bowel. After symptoms are reduced, many people take medicine to keep symptoms from returning; this is called maintenance therapy.

For Crohn's disease, there are generally the same options as those used for ulcerative colitis. However, with Crohn's disease, drugs that suppress the immune system (azathioprine, 6-mercaptopurine or methotrexate) are used more often to help control the inflammation and as maintenance therapy to help keep symptoms from coming back. Active Crohn's disease is usually treated with steroid tablets (eg, prednisolone) and sometimes antibiotics are also used. When other drug therapy does not work well, an anti-TNF drug may be given by infusion (drip) in the hospital or by injection at home.

With both diseases, surgery may be needed if medicine does not work well or if there are other problems also. If you are worried about the possibility of needing surgery, speak with your doctor about your situation.

For more details on treatment options for Crohn's disease and ulcerative colitis, please see [Treatment Plan for UC](#)

Your turn!

Do you have any other questions about IBD that you are still wondering about? Was there anything on this page that you didn't understand? Write down these things so you can bring them with you when you visit the doctor. Also ask your mum or dad if they have any questions they would like to ask too.

For parent information [click here](#)

For the parent: This activity is designed to encourage your child talk openly with you and the doctor about ulcerative colitis and anything that is worrying him or her. Do not feel as if you should know all the answers on your own – feel free to put down your own list of questions as well so you can discuss them with the doctor during the next visit.

In severe disease, sudden, severe dilation of the colon (referred to as toxic megacolon) may result in a perforation.

In severe Crohn's disease, scarring and thickening of the intestine walls can create a narrowing of the intestine wall, which is called a stricture, leading to constipation, bloating and pain. If the intestine wall becomes fully blocked (called an obstruction) it must be treated in the hospital. Another possible problem is a fistula, or tunnel caused by inflammation that goes from one part of the intestine to another or to the skin (for example, from the bowel to the skin near the anus).

In severe disease, such problems can be a blockage or leak in the bowel. In severe ulcerative colitis, some people have their large intestine removed. Because ulcerative colitis can only affect the large intestine, their disease is considered 'cured'. However, with severe Crohn's disease, surgery is not considered to be a cure because the disease can return in another part of the digestive system later on.