

## **Crohn's Disease – Kids and Teens**

### **What is IBD?**

When your doctor first told you about Crohn's disease, 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. Crohn's disease can affect any part of the digestive tract, for example the mouth, stomach, large intestine or small intestine. Another type of IBD called ulcerative colitis only affects the inner lining of the large intestine (colon and rectum). 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 Crohn's disease 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, 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 Crohn's disease and ulcerative colitis are ongoing (chronic) diseases, with times when symptoms get worse (called flares, flare-ups, 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 boys and girls equally, although ulcerative colitis is slightly more common in boys and Crohn's disease is slightly more common in girls.

### **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 Crohn's disease nor ulcerative colitis 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 Crohn's disease and ulcerative colitis can cause other problems, or complications. With Crohn's disease, for example, 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 can happen if the body is unable to absorb proteins, vitamins or minerals. Crohn's disease may also keep the body from using calcium and vitamin D, which can lead to osteoporosis (bone density loss).

With ulcerative colitis, bleeding may cause anaemia (low levels of red blood cells in the blood, which can make you feel tired, faint or breathless).

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

In severe Crohn's disease the intestine walls may become fully blocked (called an obstruction), which can cause severe pain and vomiting that 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). Sudden, severe dilation of the colon (referred to as toxic megacolon) may result in a perforation.

### **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.

Severe Crohn's disease may cause joint pain or arthritis, inflammation of the eyes and mouth, liver diseases, gallstones, skin rashes, anaemia (low red blood cell count) or kidney stones.

### **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 Crohn's disease, drugs that suppress the immune system (azathioprine, 6-mercaptopurine or methotrexate) are often used to help control the inflammation and as maintenance therapy to 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.

For people with ulcerative colitis, similar treatment options are available. 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.

With both diseases, surgery may be needed if medication 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.

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.

Together, you and your doctor will develop a treatment plan that reflects your disease severity, past treatments, and any special needs and goals you may have. For more details on treatment options for Crohn's disease and ulcerative colitis, please see [Treatment plan for CD](#).

### **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 these things down 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.

### **Information for parents**

This activity is designed to encourage your child to talk openly with you and the doctor about Crohn's disease 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.