

## Understanding Ulcerative Colitis and Crohn's Disease

If you have recently been diagnosed as having Ulcerative Colitis (UC) or Crohn's Disease, your first reaction may have been a sense of relief that at last you have a diagnosis that explains why you have been feeling so tired and unwell. There may now be many questions running through your mind about living with an illness which could affect you for the rest of your life. We hope this leaflet will help you to understand more about your condition, how you can help yourself and the sort of treatment you might expect to be prescribed by your doctor.

## What exactly are Ulcerative Colitis and Crohn's Disease?

Both conditions come under the heading of Inflammatory Bowel Disease (IBD). This is because the intestines become swollen, inflamed and ulcerated. Symptoms can include pain in the abdomen, weight loss, diarrhoea (sometimes with blood or mucus) and tiredness. The symptoms will vary in severity from one person to another and may flare up or improve unpredictably. Many patients will experience some periods of remission, when they are free from symptoms. Some people may also experience swollen joints, mouth ulcers, inflamed eyes or rashes on their body. Crohn's Disease can also be associated with anal problems. These include fissures (ulcerated cracks), skin tags, abscesses and fistulae (abnormal tunnels connecting the bowel to other parts of the body).

The following differences between Ulcerative Colitis and Crohn's disease can affect the type of treatment you are offered:

- Ulcerative Colitis affects the colon (large intestine) only and only the inner layer of the bowel is inflamed.
- Crohn's Disease can affect any part of the digestive system from the mouth to the anus. All layers of the bowel may be inflamed.

When Ulcerative Colitis affects only the rectum it is called proctitis. When Crohn's Disease affects only the colon (large intestine) it is called Crohn's Colitis. If it is unclear which condition you have, you may be given a diagnosis of IBDU (IBD unclassified) or Indeterminate Colitis.

Sometimes people get confused between Inflammatory Bowel Disease (IBD) and Irritable Bowel Syndrome (IBS). The two conditions are quite different and so is the treatment.

### **What tests are used to confirm the diagnosis of UC or Crohn's?**

It can often take time to confirm the diagnosis of Ulcerative Colitis or Crohn's Disease as it is necessary to exclude other diseases.

You are likely to have a stool test to check for bowel infections and various blood tests to look for anaemia, vitamin and mineral deficiencies and general signs of inflammation. However, blood tests alone cannot confirm a diagnosis of IBD. You will need an examination of the bowel to see which part is affected and how active the disease is. This is usually a sigmoidoscopy or colonoscopy, in which a flexible or rigid telescope is inserted through the anus making it possible to see the internal lining of the gut. If Crohn's Disease is suspected you may have a gastroscopy in which a tube is passed through the mouth, and/or x-ray examinations. (More information on tests is available in the Crohn's and Colitis UK booklet *Investigations for IBD*.)

### **What causes Ulcerative Colitis and Crohn's Disease?**

Over the past few years major advances have been made, particularly in genetics, to further the understanding of these conditions. Researchers now believe that IBD is caused by a complex interaction of factors: the genes a person has inherited and an abnormal reaction of the immune system to intestinal bacteria, triggered by something in the environment. Viruses, bacteria, diet and stress have all been suggested as triggers, but there is no definite evidence that any one of these can cause IBD. A link between smoking and IBD has been found; see our information sheet *Smoking and IBD* for more information.

### **Who is affected by these illnesses?**

About 240,000 people in the UK suffer from UC or Crohn's. The illnesses can occur at any age, but most frequently start between the ages of 10 and 40 years. There are up to 18,000 new cases every year and research has shown that the number of people with Crohn's Disease has been rising, particularly among young people. Both conditions are found worldwide, but are more common in developed countries.

## How is Ulcerative Colitis treated?

Treatment of Ulcerative Colitis depends on the extent and severity of the condition. Aminosalicylates (5-ASAs), (such as mesalazine, olsalazine, balsalazide or sulphasalazine) or steroids are usually given orally to help reduce inflammation in the bowel. If inflammation is in the rectum, mesalazine or steroid enemas or suppositories may be inserted directly into the back passage. Once the active inflammation has settled (gone into remission), 5-ASAs are usually prescribed as maintenance therapy to reduce the chance of a relapse. Immunosuppressant drugs, such as azathioprine or 6-mercaptopurine, may be prescribed for patients who are having frequent relapses or ongoing symptoms. (More information is available in our booklet *Drugs used in IBD*, and our Drug Treatment Information sheets.)

For severe attacks, treatment in hospital is sometimes necessary. Steroids may then be given directly into a vein, along with fluids if you have become dehydrated. If the steroid therapy does not work effectively after 4-5 days other drugs may be given such as ciclosporin or infliximab. However, if the disease is very severe, and is not responding to medical therapy, surgery to remove part or the whole of the large bowel may eventually be suggested. There will usually be time for this to be discussed fully between the patient, their family and the doctor involved. There may also be an opportunity to talk to a stoma-care nurse or a patient who has already undergone surgery.

Such surgery removes the chances of having further attacks of colitis. Most people find they can cope better with the alternatives of a 'stoma' (ileostomy) or a 'pouch' than the symptoms of Ulcerative Colitis they were previously experiencing. (More information about these operations is included in our information sheet *Surgery for Ulcerative Colitis*.)

## How is Crohn's Disease treated?

Treatment for Crohn's Disease depends on which part and how much of the gut is affected. Some people will only require treatment to control the symptoms of diarrhoea and may be prescribed tablets such as codeine phosphate or loperamide.

Active inflammation is usually treated with steroid drugs which reduce the swelling and the pain of inflammation. Mild inflammation may be treated with mesalazine, olsalazine, balsalazide or sulphasalazine. Immunosuppressants such as azathioprine may be used for more persistent disease. Newer biologic drugs, such as infliximab or adalimumab, are available for disease which has not responded to usual treatments. (See our booklet, *Drugs used in IBD*, and our Drug Treatment Information sheets.)

Medically-supervised special liquid diets, called elemental or polymeric, are sometimes used to treat Crohn's. They are taken in place of food for a number of weeks (usually 2-8 weeks).

Sometimes Crohn's Disease can cause blockages in the intestine and, if medical treatment is not working, surgery may be considered. If sections of the intestine are severely inflamed, these can be removed and the healthy tissues joined together. This type of operation is called a resection. Other people may have limited areas of narrowing in the small intestine which can be surgically widened or stretched to relieve the obstruction. This is known as strictureplasty.

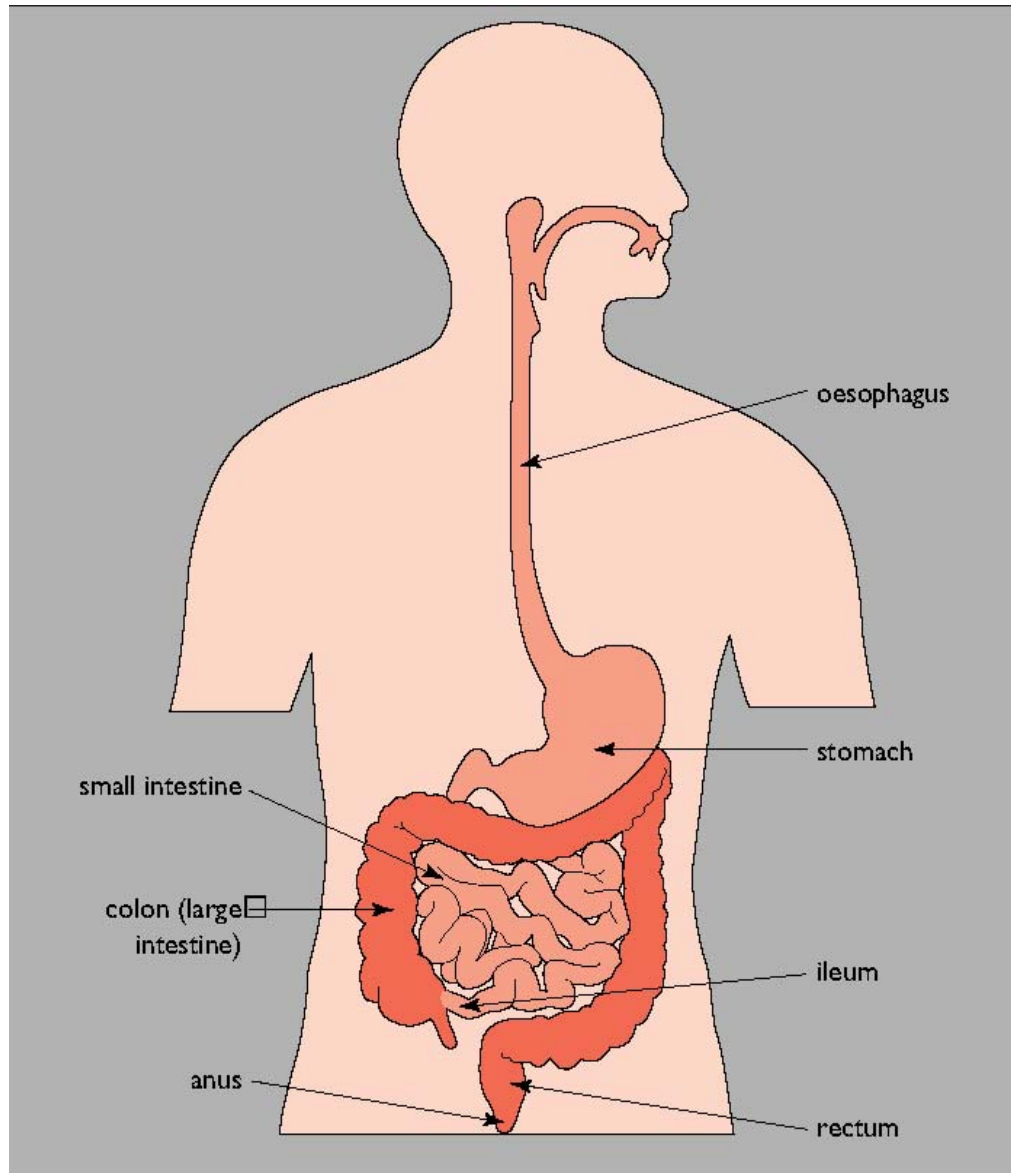
There are a few people who may have severe Crohn's Disease in their colon and whose symptoms do not respond to drug treatment. Surgery to remove the colon may eventually be suggested as a way to stop the symptoms. (More information is available our leaflet *Surgery for Crohn's Disease*).

## How important is my diet?

A healthy balanced diet is important for everyone. If you can eat a normal mixed diet without any ill effects, then it is best to keep it up. During a severe attack, it is particularly important to eat well to replace lost nutrients. Blood loss can lead to anaemia, which may be treated by an iron supplement if needed. A few people with Crohn's Disease tend to develop specific dietary deficiencies due to difficulty in absorbing particular nutrients. Once these deficiencies have been identified, they can be corrected through taking the right dietary supplements. At present, there is no evidence to suggest that extra vitamins or special food supplements are needed by most people who have Ulcerative Colitis or Crohn's Disease.

In Crohn's, sensitivity to certain foods may be an aggravating, although unproven, factor. Going on an exclusion diet, under medical supervision, may help to identify particular foods which worsen the condition. If you have a stricture a low residue diet may be advised. (See our booklet *Food and IBD* for more information).

## The Digestive System



This diagram shows the main features of the digestive system that may be affected by IBD.

When food is swallowed it goes down the oesophagus, into the stomach, where the digestive process starts. The food then moves into the small intestine where most of the goodness is absorbed. Liquid waste then passes from the small intestine into the colon (large intestine). The colon absorbs the water and the waste becomes solid faeces (stool) which then pass out of the body through the anus.

## Help and Support from Crohn's and Colitis UK

**Crohn's and Colitis UK Information Line: 0845 130 2233, open Monday to Friday 10am - 1pm.**

There is an answerphone service outside these hours, or you may email [info@crohnsandcolitis.org.uk](mailto:info@crohnsandcolitis.org.uk).

Information staff will help with any IBD related queries.

**Crohn's and Colitis Support: 0845 130 3344, open Monday to Friday 1pm - 3.30pm and 6.30pm - 9pm.**

This is a supportive listening service staffed by trained volunteers with personal experience of IBD.

Our **Parent to Parent** service provides telephone support for parents of a child with IBD. It is staffed by trained volunteers all of whom are also parents of child with IBD. To make an appointment contact the Information Line.

We produce a wide range of information sheets and booklets. You can get a copy of any these from our Information Line. Most are also downloadable from our website: [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk).

## About Crohn's and Colitis UK publications

Crohn's and Colitis UK publications are research based and produced in consultation with patients, medical advisers and other health or associated professionals. They are prepared as general information on a subject with suggestions on how to manage particular situations, but they are not intended to replace specific advice from your own doctor or any other professional. Crohn's and Colitis UK does not endorse or recommend any products mentioned.

We hope that you find the information helpful and relevant. We welcome any comments from readers, or suggestions for improvements. References or details of the research on which this publication is based, and details of any conflicts of interest, can be obtained from Crohn's and Colitis UK at the address below. Please send your comments to Helen Terry at Crohn's and Colitis UK, 4 Beaumont House, Sutton Road, St Albans, Herts AL1 5HH, or email [h.terry@crohnsandcolitis.org.uk](mailto:h.terry@crohnsandcolitis.org.uk)

Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease (NACC). NACC is a voluntary Association, established in 1979, which has 30,000 members and 70 Groups throughout the United Kingdom.

Membership of the Association costs £12 a year. New members who are on lower incomes due to their health or employment circumstances may join at a lower rate. Additional donations to help our work are always welcomed.

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