

Improving life for
people affected
by inflammatory
bowel diseases



Understanding Colitis and Crohn's Disease



Crohn's and Colitis UK is the working name of the National Association for Colitis and Crohn's Disease (NACC). NACC is a voluntary Association, established in 1979, which has over 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 the work of the Association are always welcomed.

Crohn's and Colitis UK's 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 conflict 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, St Albans, Herts AL1 5HH, or email h.terry@crohnsandcolitis.org.uk.

Contents

Introduction	3
What are Ulcerative Colitis (UC) and Crohn's Disease?	3
What causes UC and Crohn's Disease?	4
What tests are used to confirm a diagnosis of UC or Crohn's?	5
Who is affected by these illnesses?	5
How is Ulcerative Colitis treated?	5
How is Crohn's Disease treated?	6
How important is my diet?	7
Help and support from Crohn's and Colitis UK	8
Crohn's and Colitis UK Membership Application Form	9
Further information	10
Other Useful Organisations	10

Introduction

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 that 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 are Ulcerative Colitis and Crohn's Disease?

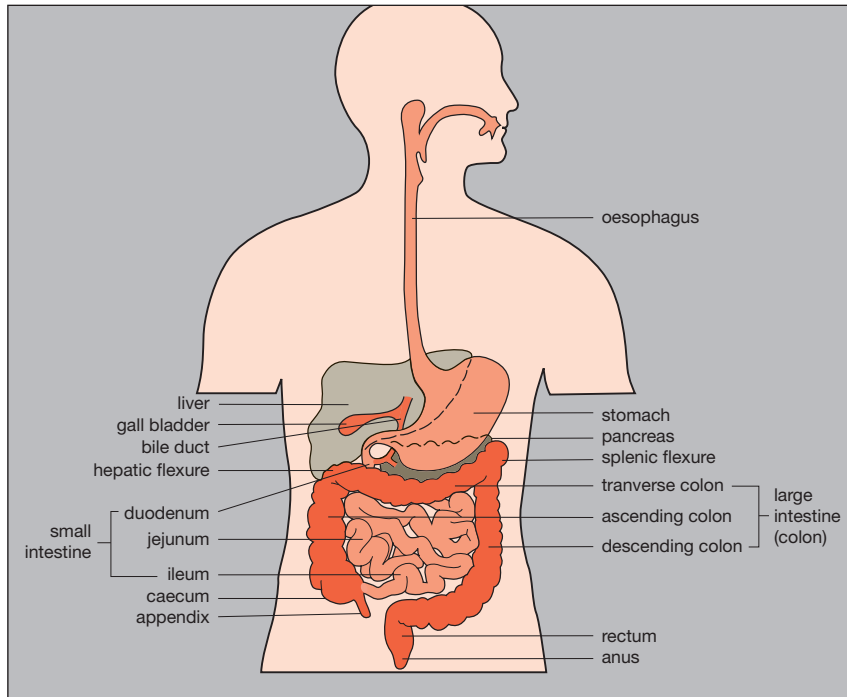
Both conditions come under the heading of Inflammatory Bowel Disease (IBD). This is because the intestines become swollen, inflamed and ulcerated. Common symptoms can include pain in the abdomen, weight loss, diarrhoea (sometimes with blood or mucus) and tiredness. Some people may also experience swollen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

Differences between Ulcerative Colitis and Crohn's Disease include the area affected and the likely depth of inflammation:

	<i>Area affected</i>	<i>Inflammation</i>
Ulcerative Colitis	Colon (large intestine) and rectum	Only the inner lining of the bowel is inflamed
Crohn's Disease	Any part of the digestive system from the mouth to the anus	All layers of the lining 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 may be 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). Although they share some of the same symptoms, the two conditions are quite different and require different treatment.



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.

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 blood tests to look for general signs of inflammation and anaemia, vitamin, and mineral deficiencies. 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 scope (a narrow tube with a light and camera) 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 our booklet *Investigations for IBD*.)

Who is affected by these illnesses?

About 240,000 people in the UK have Ulcerative Colitis or Crohn's Disease. The illnesses can occur at any age, but most frequently start in people aged between 10 and 40. 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 for Ulcerative Colitis depends on the extent and severity of the condition. Aminosalicylates (5-ASAs), such as mesalazine, olsalazine, balsalazide or sulphasalazine, and/or steroids are usually given orally to help reduce inflammation in the bowel. If the inflammation is in the rectum, mesalazine or steroid enemas or suppositories may be recommended. Once the active inflammation has gone into remission (settled down), 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 people with UC who are having frequent relapses or ongoing symptoms.

For more severe UC, treatment in hospital is sometimes necessary. Steroids may then be given intravenously (directly into a vein, through a drip). If this steroid therapy does not work effectively within 4-7 days, you may be given another immunosuppressant, ciclosporin, or infliximab, one of the newer biologic or anti-TNF drugs. (For more information see our booklet *Drugs used in IBD* and our leaflets on Drug Treatments.)

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 be suggested. There will usually be time for you to discuss this fully with the surgeon and the others in your IBD team. You may also find it helpful to talk to a colorectal nurse specialist if one is available or to a stoma-care nurse if a stoma (ileostomy) is planned. Such surgery removes the chances of having further attacks of colitis. Many people find they can cope better with a stoma or a 'pouch' than with the UC symptoms they were previously experiencing. (More detailed information about these operations is included in our leaflet *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 5-ASAs (mesalazine, olsalazine, balsalazide or sulphasalazine). Immunosuppressants such as azathioprine may be used for more persistent disease. Biologic drugs, such as infliximab or adalimumab, are available for disease which has not responded to the usual treatments. (See our booklet *Drugs used in IBD* and the leaflets on Drug Treatments.)

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. Some 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. Occasionally, for those with severe Crohn's Disease in their colon (large bowel) which is not responding to drug treatment, surgery to remove the whole colon will be recommended. (More information on these operations is available in our leaflet *Surgery for Crohn's Disease*.)

How important is my diet?

A healthy balanced diet is important for everyone. Our booklet *Food and IBD* gives details of the Eatwell Plate approach to healthy eating and how this can be adapted by people with IBD. There is no evidence to suggest that extra vitamins or special food supplements are needed by most people with UC or Crohn's Disease. However, a few people with Crohn's Disease can develop specific dietary deficiencies due to difficulty in absorbing particular nutrients, and supplements can be useful to correct these. Also, blood loss during an IBD flare-up can lead to anaemia, which may need to be treated with iron supplements.

Some people with IBD, especially those with Crohn's, find they are sensitive to certain foods. Going on an exclusion diet, under medical supervision, may help to identify the foods that affect you most. Fibre can be a particular problem and you may need to adjust your fibre intake, either reducing it or, in some cases, increasing it, according to your individual condition. *Food in IBD* gives more information on this and includes details of a suitable low residue diet.

Help and support from Crohn's and Colitis UK

Crohn's and Colitis UK now has approximately 30,000 members and 70 Groups throughout the United Kingdom. We welcome as members anyone with UC, Crohn's Disease, or similar conditions, along with their families and friends, health professionals and others sympathetic to the aims of the Association.

Members receive a quarterly newsletter, various booklets, and a combined Membership and 'Can't Wait' card. Our groups are run by local volunteers and offer educational and support meetings, local publicity and fundraising activities and a local point of contact. Each Group has a Medical Adviser.

We have over 50 publications covering all aspects of IBD including such topics as food, medication, surgery, schooling, student life, work, pregnancy, travel and sexual relationships, as well as guides to benefits. Contact our Information Line (0845 130 2233) for free copies, or download them from: www.crohnsandcolitis.org.uk

Other services include Crohn's and Colitis Support, a supportive listening service staffed by trained volunteers with experience of living with IBD; Parent to Parent, telephone support for parents of child with IBD; Smilie's Network, a special group for families of children with IBD; IBD and Me, a website discussion forum for 16-29 year olds; Personal Grants for those in need due to their IBD; and a DLA/AA Support Service for general guidance over the telephone when applying for Disability Living Allowance or Attendance Allowance. See page for 10 for contact details. Fuller information about these services and other ways in which Crohn's and Colitis is helping to improve the lives of people affected by IBD is also on our website,

Membership of Crohn's and Colitis UK costs £12 a year. If you are not already a member, please consider joining us, using the application form on page 9 or by joining online at www.crohnsandcolitis.org.uk.

Application Form for Membership of Crohn's and Colitis UK (NACC)

You must be at least 16 years of age to become a NACC Member in your own right. Parents are welcome to join on behalf of a child and can authorise us to print the Can't Wait Card in their child's name. To do this, simply enter details in the section at the bottom of this form. NACC offers free membership to young people aged 16 – 18 years.

BLOCK CAPITALS PLEASE

Your surname	First names	Title
Address		
Postcode		
Telephone	Date of Birth	Date of Diagnosis
Occupation is/was	How did you hear of NACC?	

Please confirm that you give permission for us to inform the relevant NACC Groups of your membership, so they can send you details of their activities. Yes No

Are you:

a patient parent applying for a child other relative friend health professional

Illness:

Crohn's Disease Ulcerative Colitis proctitis Other _____

Membership Subscription

NACC members are asked to pay an annual subscription of £12. New members who are on a low income due to their health or employment circumstances may join at a reduced rate. Please contact the NACC membership team for more information. Overseas members are asked to pay £15 annually. Additional donations to help the work of the Association are always welcomed.

Subscription £ Donation to NACC £ Total £

Have you been a member of NACC before? Yes No

Please enrol me as a member of NACC. I authorise NACC to hold the personal data I have provided on this form and to use it in connection with my membership. I enclose a cheque/postal order payable to NACC.

Signed _____ Date _____

If you are a parent applying for a child, or if you are a relative of a patient, you may prefer to give their name to be printed on the Can't Wait Card. In the case of an adult, they will need to sign below to confirm that we may hold their personal data. Similarly, a parent must sign on behalf of their child.

Child or Patient's full name _____

Date of Birth _____ Illness _____ Date of Diagnosis _____

I confirm that NACC may pass the above information about me/my child to the relevant NACC Groups. Yes No

I confirm that NACC may hold the above information about me/my child. Yes No

Office use Rec'd Number Area Group

Signature:
(Patient named above, or parent of child.)

Crohn's and Colitis UK (NACC)

4 Beaumont House, Sutton Road, St Albans, Herts, AL1 5HH. Information: 0845 130 2233 Membership and Administration: 01727 830038



NACC needs the personal data requested on this form to enrol you as a member of the Association and to be able to send you information relevant to your membership. A statement of NACC's Data Protection Policy and Procedures can be obtained from the Director.



Further Information

- **Crohn's and Colitis UK Information Line: 0845 130 2233, email info@crohnsandcolitis.org.uk.**
The line is open Monday to Friday 10am-1pm. There is an answer phone service outside these hours. Trained information staff will help with any IBD related queries.
- **Crohn's and Colitis Support: 0845 130 3344,** Monday to Friday 1pm-3.30pm and 6.30-9pm.
- **Parent to Parent and the DLA Support Service:** Contact the Information Line for help and further information.
- **Smilie's Network: www.groups.crohnsandcolitis.org.uk/smiliesnetwork**
- **IBD and Me: www.ibdandme.org.uk**

Other Useful Organisations

Bladder and Bowel Foundation: www.bladderandbowelfoundation.org	0845 345 0165
Colostomy Association: www.colostomyassociation.org.uk	0800 328 4257
Core – Fighting Gut and Liver Disease: www.corecharity.org.uk	020 7486 0341
Crohn's in Childhood Research Association (CICRA): www.cicra.org.uk	020 8949 6209
IA – The Ileostomy and Internal Pouch Support: www.iasupport.org	0800 0184 724
Colostomy Association: www.colostomyassociaton.org.uk	0800 328 4257

Crohn's and Colitis UK

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Crohn's and Colitis Support: 0845 130 3344

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Website: www.crohnsandcolitis.org.uk

Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease (NACC)
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