

**UNDERSTANDING IBD –
ULCERATIVE COLITIS AND
CROHN'S DISEASE**



INTRODUCTION

ABOUT THIS BOOKLET

If you have recently been diagnosed with Ulcerative Colitis (UC) or Crohn's Disease (the two most common forms of Inflammatory Bowel Disease – IBD) you may now be feeling a sense of relief that you have a diagnosis that explains why you have been so unwell. You may also have many questions about your illness running through your mind. This booklet has been written as a brief introduction to Crohn's and UC for anyone affected by these conditions, including families and friends. We hope you find it helpful. More detailed information is available from our office and our website.

All our publications are research based and produced in consultation with patients, medical advisers and other health or associated professionals. However, they are prepared as general information on a subject and 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.

If you would like more information about the sources of evidence on which this booklet is based, or details of any conflicts of interest, or if you have any feedback on our publications, please visit our website.

About Crohn's and Colitis UK

We are a **national** charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Diseases. We have over 28,000 members and 50 local groups throughout the UK. Membership costs from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

This publication is available free of charge, but we would not be able to do this without our supporters and members. Please consider making a donation or becoming a member of Crohn's and Colitis UK. To find out how call **01727 734465** or visit **www.crohnsandcolitis.org.uk**

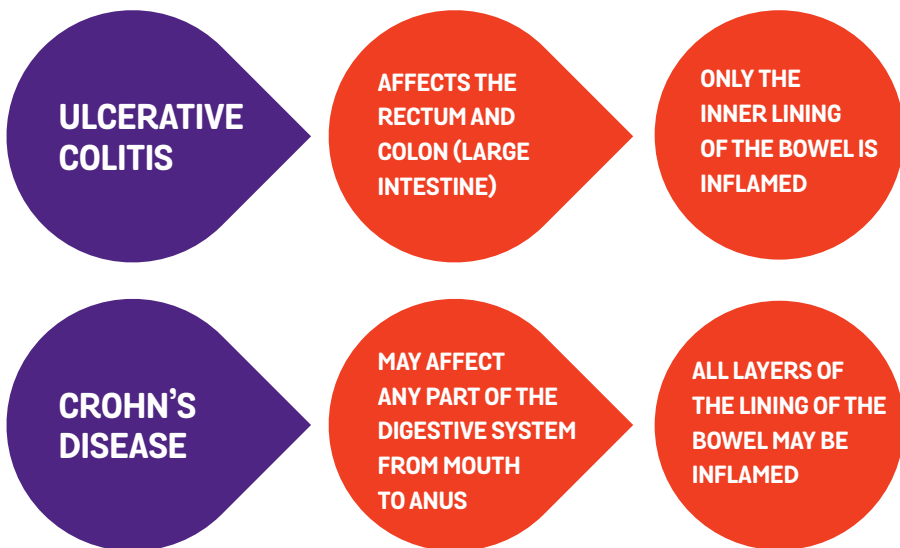
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WHAT ARE ULCERATIVE COLITIS AND CROHN'S DISEASE?

BOTH ULCERATIVE COLITIS (UC) AND CROHN'S DISEASE (OFTEN KNOWN AS JUST 'CROHN'S') COME UNDER THE HEADING OF INFLAMMATORY BOWEL DISEASE (IBD).

This is because in both conditions parts of the digestive system, which includes the bowels (intestines), become swollen, inflamed and ulcerated. But there are some differences – mainly in the areas affected and the likely depth of inflammation.

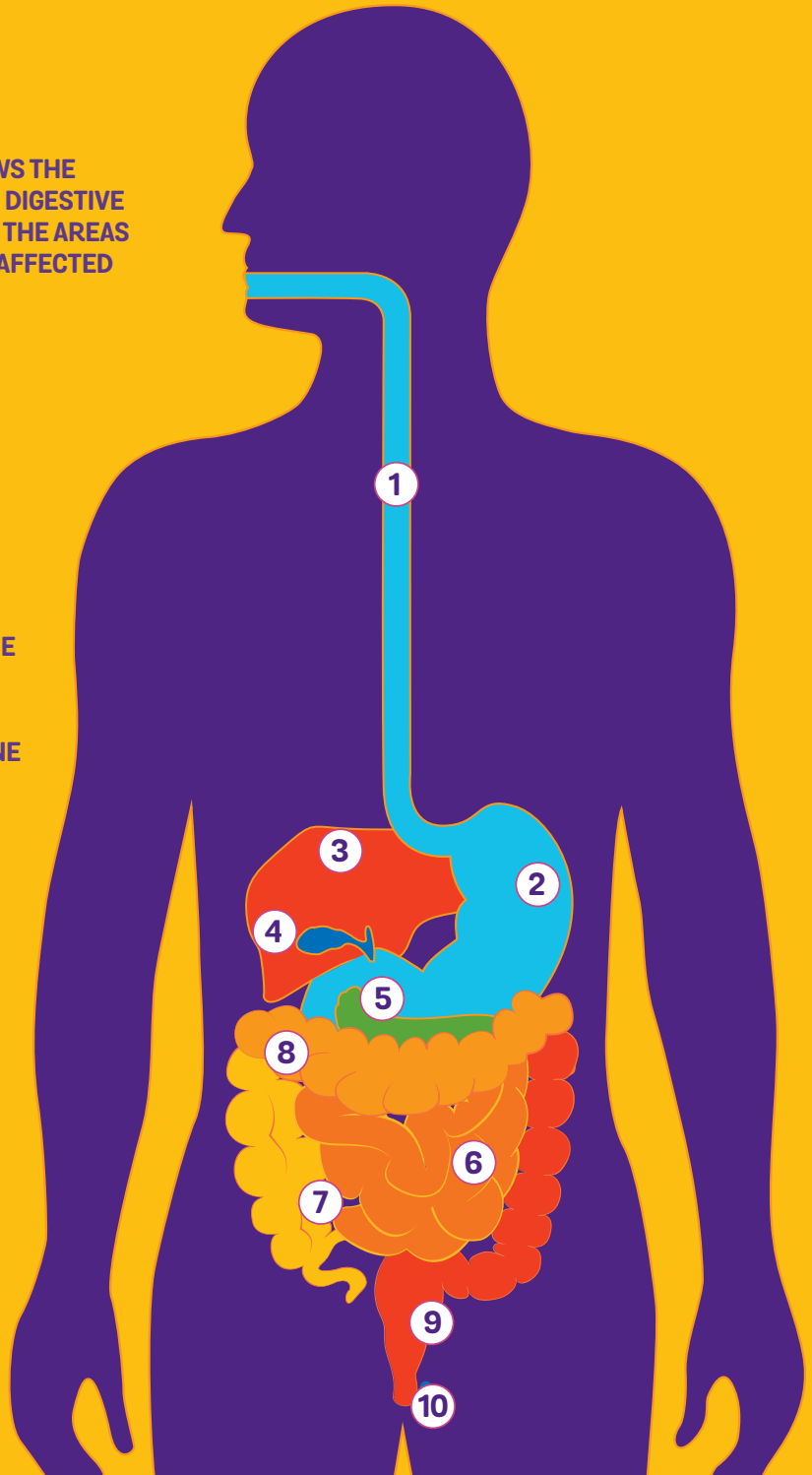


When UC affects only the rectum it is often called Proctitis. If Crohn's affects only the colon it may be called Crohn's Colitis. If it is unclear which condition you have, you may be given a diagnosis of IBDU (IBD unclassified) or Indeterminate Colitis.

THE DIGESTIVE SYSTEM

THE DIAGRAM SHOWS THE MAIN PARTS OF THE DIGESTIVE SYSTEM INCLUDING THE AREAS MOST LIKELY TO BE AFFECTED BY UC OR CROHN'S.

- 1 OESOPHAGUS
- 2 STOMACH
- 3 LIVER
- 4 GALL BLADDER
- 5 PANCREAS
- 6 SMALL INTESTINE
- 7 ILEUM
- 8 LARGE INTESTINE (COLON)
- 9 RECTUM
- 10 ANUS



WHAT ARE THE MAIN SYMPTOMS?

With both conditions, common symptoms can include:

- cramping pains in the abdomen
- diarrhoea (sometimes with blood and mucus)
- loss of appetite and weight loss
- tiredness and fatigue

IBD can often lead to anaemia (a reduced number of red blood cells) which can also make you feel very tired.

Some people also experience swollen joints, mouth ulcers, and eye, skin and liver problems. You are also more likely to develop osteoporosis (thinner bones) if you have IBD.

Crohn's can cause anal problems such as fissures (a crack or split in the skin), ulcers, abscesses and fistulas (abnormal connections between the bowels and other organs, most commonly to the skin around the anus).

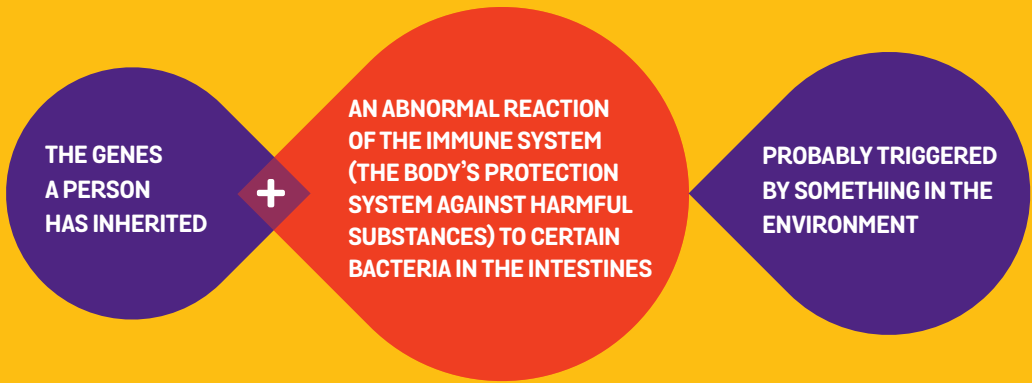
Not everyone will experience all these symptoms and how you are affected can also change over time. Crohn's and UC are often described as 'chronic' conditions. This means they are ongoing and life-long.

HOWEVER, YOU WILL PROBABLY HAVE PERIODS OF GOOD HEALTH (REMISSION) WHEN YOU MAY FEEL A LOT BETTER, AS WELL AS TIMES WHEN YOUR SYMPTOMS ARE MORE ACTIVE (RELAPSES OR FLARE-UPS).

WHAT CAUSES UC AND CROHN'S?

Although there has been a lot of research, we still don't really know what causes Crohn's or UC. However, over the past few years major advances have been made, particularly in genetics.

RESEARCHERS NOW BELIEVE THAT BOTH CROHN'S AND UC ARE CAUSED BY A COMBINATION OF FACTORS:



Viruses, bacteria, diet, smoking and stress have all been suggested as environmental triggers, but there is no definite evidence that any one of these is the cause of IBD.

WHO IS AFFECTED BY THESE ILLNESSES?

AT LEAST 300,000 PEOPLE IN THE UK HAVE ULCERATIVE COLITIS OR CROHN'S DISEASE – ABOUT 1 PERSON IN 210.

These illnesses can occur at any age, but most frequently start in people aged between 10 and 40. Recent surveys suggest that Crohn's is becoming increasingly common, especially among young people. Both conditions are found worldwide, but are more common in developed countries.

IS IBD THE SAME AS IBS?

No. IBS stands for Irritable Bowel Syndrome. This is a different condition, although some of the symptoms are similar. Like IBD, IBS can cause abdominal pain, bloating and bouts of diarrhoea or constipation. However, it does not cause the type of inflammation typical of Crohn's or UC, and there is no blood loss with IBS.

Some people with IBD – Crohn's or UC – develop IBS-like symptoms. They may, for example, get diarrhoea even when their IBD is inactive. These symptoms may need slightly different treatment from their usual IBD symptoms.

HOW ARE THEY DIAGNOSED?

It can often take time to confirm a diagnosis of UC or Crohn's, as it may be necessary to exclude other diseases. Blood tests are the usual first step – these can check for general signs of inflammation and for anaemia and vitamin and mineral deficiencies. Stool tests can be used to rule out infections that may be causing symptoms like diarrhoea, and to look for raised levels of proteins that can be a sign of active inflammation.

Blood and stool tests cannot confirm a diagnosis of IBD, so most people will also need an examination of the bowel. One way to do this is with an endoscopy – an examination using an endoscope (a long, thin, usually flexible, tube with a camera in its tip).

There are several types of endoscopy. In a colonoscopy the scope is inserted through the anus so the doctor or specialist endoscopist can look at the lining of the colon (large intestine). If Crohn's Disease is suspected you may have a gastroscopy in which a tube is passed through the mouth. Biopsies (tiny samples of tissue) can be taken during the endoscopy. These can then be examined under a microscope to help confirm the diagnosis.

X-ray examinations and CT or MRI scans are also increasingly used to look at the location and extent of any inflammation. More details of all these tests can be found in our information sheet, **Tests and Investigations for IBD**.



“

I found the prep for the colonoscopy tough. The procedure itself wasn't all that bad. I was more relieved that I might finally be getting some answers. ”

Katryna, age 36,
diagnosed with Ulcerative
Colitis in 2005

HOW IS ULCERATIVE COLITIS TREATED?

Treatment for UC depends on how severe the symptoms are and how far the inflammation reaches round the colon.

Initially, especially if your UC is quite mild, you will probably be treated with aminosalicylates (or 5-ASA drugs) such as mesalazine or sulphasalazine. You may also be given steroids. These drugs help reduce the gut inflammation typical of UC. Once the active inflammation has gone into remission (settled down), 5-ASAs are usually prescribed as maintenance therapy to reduce the chance of a flare-up.

Immunosuppressant drugs, such as azathioprine or mercaptopurine may be prescribed for people with UC who continue to have frequent flare ups or ongoing symptoms.

For more severe UC, treatment with steroids given intravenously (directly into a vein, through a drip) may be necessary. If this does not work, you may be given another immunosuppressant, ciclosporin. Biologics such as infliximab are now also used for severe UC. You can find more information about these treatments in our specific drug treatment information leaflets.

If the disease is very severe and is not responding to medical therapy, your doctor may suggest surgery to remove part or all of the large bowel. This may mean having an ileostomy and a stoma bag. An alternative could be to have an internal pouch, instead of a stoma. For more information on these operations see our leaflet, **Surgery for Ulcerative Colitis**.

There will usually be time for you to discuss your options with the surgeon and your IBD team. You may also find it helpful to talk to a colorectal or stoma care nurse. Although the idea of bowel surgery can be daunting, many people find they can cope better with a stoma or a pouch than with the UC symptoms they were previously experiencing.



“

Azathioprine has made my immune system weaker so I pick up lots of colds and can feel run down, but overall this drug has been great for me. It has got me into remission. ”

—
Louise, aged 34,
diagnosed with Ulcerative
Colitis in December 2013

HOW IS CROHN'S DISEASE TREATED?

Treatment for Crohn's also depends on which part and how much of the gut is affected. 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 such as mesalazine or sulphasalazine. Immunosuppressants such as azathioprine, mercaptopurine, or methotrexate, may be used for more persistent Crohn's.

Biologic drugs, such as infliximab or adalimumab, are available for more severe Crohn's Disease which has not responded to the usual treatments. For more information see our specific drug treatment information leaflets.



RESEARCH FACT

CROHN'S IS MORE LIKELY TO OCCUR IN PEOPLE WHO SMOKE, AND STOPPING SMOKING CAN REDUCE THE SEVERITY OF CROHN'S.

..... Another way of treating Crohn's is with 'enteral nutrition' – a specially formulated liquid diet that can be taken instead of food, usually for up to eight weeks. Exclusive enteral nutrition is commonly used in children. In adults this type of liquid food is more likely to be prescribed as a supplement.

Crohn's can sometimes cause blockages in the intestines and if medical treatment is not effective, surgery may be suggested. In an operation called a resection, severely inflamed sections of intestine are removed, and the healthy ends joined together. Some people may have a stricture or narrowing of the intestine. This can be treated with a strictureplasty operation in which the intestine is surgically widened or stretched.

Occasionally, for severe Crohn's in the colon (large intestine) which is not responding to drug treatment, surgery to remove the whole colon may be recommended. You would then have an ileostomy or stoma, as described earlier. More information can be found 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 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 extra iron.

Some people with IBD, especially those with Crohn's, may find they are sensitive to certain foods. Keeping a food diary may help to identify the foods that affect you most. Fibre can be a particular problem. You may need to adjust your fibre intake, either reducing it or, in some cases, increasing it, according to your individual condition. Spicy foods can also be a trigger for some people. If you have a stricture, you may need to avoid eating 'hard to digest' foods that might cause a blockage.

BEAR IN MIND, HOWEVER, HOW IMPORTANT IT IS TO KEEP YOUR DIET WELL BALANCED, AND DO TALK TO YOUR DOCTOR OR A QUALIFIED DIETITIAN BEFORE MAKING ANY MAJOR CHANGES.

More information on these points is also given in **Food and IBD**.

HOW WILL CROHN'S AND UC AFFECT MY LIFE?

THIS IS A DIFFICULT QUESTION TO ANSWER, BECAUSE EVERYONE IS DIFFERENT, CROHN'S AND UC ARE VERY 'INDIVIDUAL' CONDITIONS, AND PEOPLE'S EXPERIENCES VARY WIDELY.



“

One thing I've learned, it's that you can't go through it alone. Having a strong support network is key; friends, family and organisations like Crohn's and Colitis UK are invaluable. You can get through anything if you let people help you.”

Mathew, age 32, diagnosed with Crohn's Disease in 2000

Some people will have mild IBD and their Crohn's or UC may not affect their lives very much. Others may have severe symptoms and may need to adjust their lifestyles considerably.

While many people find that their symptoms can be controlled with medication, about 2 in 10 people with UC and 7 in 10 people with Crohn's will need surgery at some stage.

Our booklet, **Living with IBD**, looks at some of the challenges of everyday life with Crohn's or UC. We also have more detailed booklets on both **Crohn's Disease** and **Ulcerative Colitis** and information sheets on a wide range of other IBD related topics.

WHO CAN I TALK TO?

You will probably find it helpful if you are able to build a good relationship with both your GP and your hospital IBD team. IBD specialist nurses can be especially supportive.

Being open and frank about your symptoms and how they affect you, emotionally as well as physically, will make it easier for your doctors and nurses to make sure you get the right treatment. It can also make you feel more confident about managing your IBD.

SOME PEOPLE WITH IBD FEEL EMBARRASSED TALKING ABOUT THEIR SYMPTOMS, EVEN WITH THEIR DOCTOR, BUT REMEMBER THAT MEDICAL PROFESSIONALS ARE VERY USED TO DISCUSSING ALL BODILY FUNCTIONS.

Having a long term illness such as IBD can sometimes have a serious impact on emotional wellbeing, and some people find it helpful to talk to a professional counsellor. There may be one available through your GP's practice, or you can ask your IBD team or a social worker at the hospital you attend. Our information sheet, **Counselling and IBD**, has more details on this and on how counselling may help.

We have an information line at Crohn's and Colitis UK and a confidential listening service (Crohn's and Colitis Support), which you may also find useful. Many Crohn's and Colitis UK members find our local groups a valuable source of mutual support. You can join Crohn's and Colitis UK using the application form in this booklet or online at **www.crohnsandcolitis.org.uk**.

HOW WE CAN HELP YOU

We produce over 40 information sheets, booklets and guides about all aspects of IBD which are available to download for free on our website: www.crohnsandcolitis.org.uk

We run confidential support services for anyone affected by Inflammatory Bowel Disease.

Our **Information Service** is staffed by a team of trained Information Officers and provides callers with clear and balanced information on a wide range of issues relating to IBD.

Call **0300 222 5700** or email info@crohnsandcolitis.org.uk

We also run the **Crohn's and Colitis Support Line**, a supportive listening service provided by trained volunteers who are skilled in providing emotional support to anyone who needs a safe place to talk about living with IBD. **Call 0121 7379 931.**

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OTHER USEFUL ORGANISATIONS

Bladder and Bowel Foundation

www.bladderandbowelfoundation.org

Colostomy Association

www.colostomyassociation.org.uk

Core – Fighting Gut and Liver Disease

www.corecharity.org.uk

Crohn's in Childhood Research Association

www.cicra.org

IA – The Ileostomy and Internal Pouch Support Group

www.iasupport.org



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CROHN'S & COLITIS UK

SUPPORTING YOU TO MANAGE YOUR CONDITION

**CROHN'S &
COLITIS UK**

**FIGHTING
INFLAMMATORY
BOWEL DISEASE
TOGETHER**

BECOME A MEMBER TO

RECEIVE SUPPORT & INFORMATION

Free of charge publications & guides accredited by health professionals, access to support & information helplines & our member magazine full of research news & features. Membership will help you to better manage your care, for example with our Can't Wait Card & through support groups, online advice & member only offers.

BELONG TO A COMMUNITY

Share experiences & support each other online, at events & through local group networks which are supported by health professionals & policy makers. Help us raise awareness and campaign for better health services & support life-changing research to increase the knowledge of causes & best treatments.

JOINING IS EASY

You can become a member if you are 16 years or over, are a parent or carer, a health professional or if you just want to support the charity.

If you have internet access, join faster online at www.crohnsandcolitis.org.uk

ABOUT YOU

Please return this form along with payment to Crohn's & Colitis UK, 45 Grosvenor Road, St Albans, Herts, AL1 3AW
Contact the membership team on 01727 734465 if you have any queries.

Are you?

- A patient
 Crohn's Disease Ulcerative Colitis Other

Date of diagnosis

- A parent of a child under 16 years A relative of a patient
 Health professional General supporter

Name and date of birth of who you want to appear on the Can't Wait Card if not yourself (child/relative/friend)

.....

PERSONAL DETAILS

Please complete all fields and use **BLOCK CAPITALS:**

Surname Title

First name Gender Male/Female

Address

.....

..... Postcode

Email

Telephone number

Mobile number

Date of birth/...../..... Ethnic group

Occupation

PAYMENT DETAILS

Individual membership

- £15 per year Direct Debit
 £19 per year Cheque/Credit or Debit Card

If you are a student, are experiencing financial issues or on a low income due to health or employment issues then please contact the membership team on 01727 734465 to discuss joining at a reduced rate.

1. Please make cheques payable to Crohn's and Colitis UK.
2. If you would like to pay by credit card please call the membership team on 01727 734465 or join online at www.crohnsandcolitis.org.uk.
3. Direct debit is the most efficient way to pay. If you would like to pay by direct debit please Fill out the form below

Subscription £ Additional donation £ **TOTAL £**

By Direct Debit



Instructions to your Bank or Building to pay by Direct Debit

Amount to be taken £ Every month Every year

Name(s) of account holder(s)

Name of Bank/Building Society

Branch name

Bank Building society account number

Sort code

Date

 / /

Organisation ID

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OUR REFERENCE

Instructions to your Bank or Building

Please pay Crohns and Colitis UK Direct Debits from the account detailed in this Instruction subject to the safeguards assured by The Direct Debit Guarantee. I understand that this Instruction may remain with the Crohns and Colitis UK and, if so, details will be passed electronically to my Bank/Building Society.

Signed _____ Date _____

Gift aid your donation at no extra cost: I wish to gift aid my donation and any donations I make in the future or have made in the past 4 years to Crohn's and Colitis UK. I am a UK tax payer and I understand that if I pay less Income Tax and/or Capital Gains Tax in the current tax year than the amount of Gift Aid claimed on all my donations it is my responsibility to pay any difference.

Yes I am a UK tax payer and would like to gift aid *please tick* No, I am not a UK tax payer *please tick*

Data protection

Crohn's and Colitis UK will hold the information you have given on this form and will use it in connection with your membership and to keep you informed about the activities of the Charity. A copy of our Data Protection policy is available on request. At all times we comply with the Data Protection Act 1988.

From time to time we may want to contact you regarding the general work of the charity, tick here if you would not like to receive this information.

We could not do what we do without the support of our members so are always very grateful for any additional donations that you may be able to give