

Improving life for
people affected
by inflammatory
bowel diseases



Living with IBD



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.

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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.



Living with Inflammatory Bowel Disease (IBD)

Initial reactions...

After feeling unwell for quite a while, most people's reaction to diagnosis is a mixture of shock and relief. You may feel shock on discovering that you have an ongoing disease – something that you're stuck with – and anxiety at the prospect of taking daily medication for a long time. But you may also feel relief on finding that your illness can usually be controlled with medication and that your symptoms have an identifiable name – and that it isn't cancer.

Some people find it hard to take in what their doctor has told them. After all, you may not have heard of Ulcerative Colitis or Crohn's Disease (the two main forms of IBD) before. It's quite natural to feel confused, particularly when doctors don't know the actual cause of the illness and won't be able to give a detailed picture of what you will have to face in the future (as the pattern of the disease varies from person to person).

Shock, confusion, and relief: these are all normal reactions for anyone being told they have Inflammatory Bowel Disease (IBD).

...and feelings later on

IBD is an ongoing and fluctuating illness, often described as 'chronic'. 'Chronic' comes from a Greek word relating to time, and means 'continuing'. We often use it these days to mean 'excruciating' or 'severe'. But if your doctor describes IBD to you as 'chronic', it probably makes more sense to think of it as 'ongoing'.

It is the ongoing and unpredictable nature of the disease that is often very difficult to take in at first. Only after some years of living with the condition will the real pattern start to emerge. You may find that having come to terms with it, there are suddenly new situations to tackle – ones you hadn't bargained for. It could be a worse attack than before, or suddenly finding that medication that had worked in the past doesn't work now, or, more happily, finding that medication that didn't work in the past is now more effective. Living with a fluctuating illness like IBD can mean you are living in a state of uncertainty.

It may be helpful to think of IBD as a difficult relation who has come to live with you. You have no idea how they're going to behave – they may be quiet for a while, then suddenly become disruptive and cause no end of trouble. But sadly, unlike such a relation, you can't insist that IBD leaves.

How you see yourself

It is common to feel angry and upset about being diagnosed with a disease like IBD and some people initially respond by being in denial. While no-one can pretend it is easy coming to terms with an illness, accepting you have a medical condition can help you keep a balance in your life. There may be times, for example when you have a flare up, that you have to make adjustments and take time to recuperate. However, when you are well you may be able to live life to the full. Many people with IBD do well in their studies and are able to work full time. Some people also find that they feel more in control if they learn all they can about their condition and how to manage it. But of course, everyone is different and how much detailed information you wish to have will be entirely up to you.

How other people see you

People with IBD often feel that those around them, even close family or friends, just don't seem to understand what it means to have Crohn's or UC.

They may desperately want you to be well, which puts a great burden on you to appear well even when you are feeling ill. They may fuss around you excessively, even on the occasions when you're feeling fine. They may be extremely worried about your illness, or they may put your symptoms aside as trivial.

You may find some people will blame your personality for the disease. "Oh, obviously you've got it because you're such a worrier," they may say. This can be irritating, but the absence of a clear, scientific explanation of the cause of these diseases can leave it open for some people to believe that personality is a factor. This situation is not helped because it is commonly accepted that anxiety, fear and stress can have an adverse effect on people's general health, particularly on their bowels. But there is absolutely no evidence to suggest that IBD is caused by stress, although stress may in some cases be a factor in causing flare-ups.

Being told what to feel can also be irritating. People will sometimes say things like: 'Cheer up' or 'Don't worry'. They may suggest you try different diets or ask whether you have tried alternative or complementary therapies. These suggestions may annoy you even though they may be offered with the best of intentions.

Sometimes people may claim that they, too, suffer from colitis, when what they are describing are the occasional 'tummy complaints' which they have for a few days and which are then over. It can also be very difficult getting over to other people what 'urgency' means. Friends may say: 'But surely you can hang on for a couple of minutes?' with no idea that you simply can't.

It's true, most people don't understand IBD, but this is probably not that surprising given the generally low awareness of UC and Crohn's Disease, and the confusing and unpredictable nature of these conditions. However, if you can tell your family and friends at least something about your illness you may find it helps you to feel more in control of your situation and less anxious about your symptoms and treatment. Your family and friends may also find it reassuring.

Helping family and friends understand

Remember that other people's reaction to your illness may also be affected by their own personalities and experiences – and that some adverse reactions may be prompted by fear rather than lack of sympathy.

IBD is an embarrassing illness and on the whole we tend not to discuss bottoms, bodily waste, toilets and bowels with each other, even people we're rather close to. Sheer shyness may prevent you from being able to explain as much as you'd like to another person. If you feel embarrassed about explaining your IBD, you could invite your spouse, partner or relatives to read about it. We publish a range of booklets and leaflets about both Ulcerative Colitis and Crohn's Disease, which could give your friends and relations a chance to understand the disease better. Our website, www.crohnsandcolitis.org.uk, also has a lot of helpful information about IBD.

Another way of helping someone close to you to understand your illness is to ask your doctor if he or she can explain it to them. This can be particularly useful if you need to give the information greater authority or reassurance. But you can probably best help people understand by being open and clear yourself about how your condition affects you, and by saying how they can be most helpful.

With some people you may not want to go into detail. You could just say something like: “I have a gut condition which means I have to rush to the toilet very suddenly.” Many people will accept this and not question you further.

What to say at work

Some people worry that it might be a risk telling their employers about their Crohn’s or UC. It is usually better to do so. If you are concerned, you may find it useful to read our information sheet *Employment and IBD: a guide for employees*. We also have a guide for employers with information about IBD and what they can do to support you. Many employers do understand and, when they know about your illness, may be able to make some helpful adjustments to your working conditions. For example, it may be possible for your desk to be moved nearer the toilets if this would reassure you, or for you to use a more convenient parking place, or perhaps even work different hours or shifts, if this would suit you better.

It is also often helpful if you can be open about your IBD with work colleagues. If everyone knows the situation, you won’t have to take your tablets discreetly out of sight or keep making excuses about tummy upsets. Explaining that it is not infectious is always worthwhile – people often worry about this but don’t like to ask.

At a more practical level, make sure you know all about your firm’s policy on sick pay in case you have to take time off. If you are unable to return to work or your employment is terminated, you may qualify for a benefit such as Employment and Support Allowance (ESA). More information on this and other benefits, together with details of helpful organisations, are available in our guide: *An overview of Welfare Benefits for people with UC and Crohn’s Disease*.

Talking to your doctor or nurse

Having IBD means that you are likely to see your GP and consultant more frequently than other people and so your relationship with them may be somewhat different. You may perhaps find your doctor saying things you've not heard before, like: "We'll try this, but I don't know if it will work." Some patients find this honesty refreshing; others feel rather unnerved by it, or even angry. They think: why don't the doctors know? If this is a very different approach from your previous experience it may take time to get used to it. Talk to your doctor about it if you continue to feel worried or unsure.

You may also be asked to take more responsibility with your medication. For example, your doctor may encourage you to experiment a little, to see what suits you. So it's worth asking the doctor or nurse exactly what limits you can go up to, what you can take with what and so on. Our booklet *Drugs used in IBD* and our more specific Drug Treatment leaflets give more information about the different medications that are available for your illness.

Before you see the doctor, think of the important questions you want to ask and make a note of them. Make sure you include any changes in your symptoms or in how you are feeling. It's amazing what you can forget when you're actually in the surgery.

Finding the right words

Some people with IBD feel embarrassed talking about their symptoms even to their doctor, but remember that doctors and nurses are used to discussing all bodily functions.

Here are some words you might find helpful to use when talking to the doctor or nurse: 'Motion', 'stool' or 'bowel movement' are quite clear and straightforward. But they will be used to every other word in the book, so use what you feel comfortable with. If they ask you to describe your stools, you could describe them as 'like toothpaste', 'like a cowpat', 'like sheep's droppings'. Other words and phrases you might find useful are: 'urgency',

'having an accident', 'fear of not getting to the loo in time', 'explosive diarrhoea', 'gas', 'flatulence' or 'wind'. These are just suggestions – if you think out your own descriptions in advance it can save possible embarrassment in the surgery.

Alternative and complementary medicines

When there is no obvious cause or cure for an illness it's natural to think about other approaches. There are a whole variety available – homeopathy, acupuncture, aromatherapy, hypnotism, herbal remedies, special diets, relaxation techniques – to name but a few. Some are presented as alternatives to orthodox treatment; others say they are 'complementary', which means they may help you in addition to the treatment you are already receiving.

Although there is no hard evidence that any of these actually work, many people have felt they have benefited. For instance, while relaxation exercises may only sometimes alleviate symptoms, they may help someone cope better with the everyday stresses of living with IBD. However, if you do decide to try any of these approaches we strongly advise that you discuss it with your doctor first.

In particular, don't give up the medication you are on, take any new remedies (including 'herbal' remedies), go on an extreme diet, or have procedures like colonic irrigation, without talking to your consultant.

Diet and IBD

Although there is no evidence that diet is the cause of IBD, some people have found certain foods seem to make their symptoms worse and/or that cutting out certain foods reduces the chances of a flare up. It may be worth experimenting on your own, but remember how important it is to keep up a balanced diet, and don't make any drastic changes without consulting your doctor. Our *Food and IBD* booklet gives more information about eating healthily when you have IBD.

Taking care of yourself

Major life changes cause anxiety and stress, and with an unpredictable and potentially embarrassing illness like IBD, feelings of anxiety and depression are understandable. Quite apart from having to deal with the physical symptoms like pain, diarrhoea, and tiredness, you also have to deal with your emotional reactions.

So, if you do feel worried, anxious or depressed, don't dismiss your feelings as irrational or signs of weakness. Try not to feel guilty or that you're making a fuss about nothing if you need to have a rest or to take time off work. Remember that you suffer from an ongoing illness and there will be times when you are going to feel stressed and tired. When this happens it really is important and sensible that you take care of yourself and take as much rest as you need.

Just because you can't perhaps do all the things you might like to, does not mean you're not coping. It probably means you're coping extremely well with a difficult situation. You may find our information sheet *Staying well with IBD* helpful.

Mutual support

If you join Crohn's and Colitis UK you will have the opportunity of going to Group meetings if you wish. Some people worry that going to a Crohn's and Colitis Local Group will mean sitting around discussing embarrassing symptoms. But in fact people usually just chat about things in general or more positive Group activities, such as fundraising events. You may find that just being with other people and realising that you are not alone, that they too have the same disease, can be reassuring. It is often not even necessary to talk at all to feel comforted by a group. Relatives may also find it useful to meet other people who have IBD.

Crohn's and Colitis Support

People often feel the need to speak to someone neutral who isn't a nurse, doctor, relative or friend, but who understands IBD. We have a telephone-based confidential supportive

listening service, Crohn's and Colitis Support, staffed by trained volunteers all of whom have experience of living with IBD. This support line is open Monday to Friday 1.00 pm – 3.30 pm and 6.30 pm – 9.00 pm, on 0845 130 3344. We also have a general Information Line – see Page 14 for details.

Counselling

Talking to a counsellor may also help you and your family to understand and to adjust to the changes arising from IBD. You may find that there is a counsellor available through your GP's practice, or you can ask the IBD team or social worker at the hospital you attend. Our information sheet Counselling and IBD has more information on how to find a counsellor.

Practical tips

Many people worry about having an 'accident' outside the home. One tip is to carry an emergency kit containing a spare pair of pants, moist wipes, nappy disposal bags to carry soiled pants home, a couple of clothes pegs (to help keep clothes out the way), a small mirror (useful to check you are clean), and a neutralising aerosol to disguise any odour. Wearing a pantie-liner may give you extra security as well. For more suggestions on how to cope, see our leaflet *Managing Diarrhoea*.

Pubs and chemists are good places to go for emergency loos. If you are a member of Crohn's and Colitis UK, you receive a 'Can't Wait' card to help when asking to use the toilet facilities in shops or offices. You can also get a key from RADAR (Tel: 020 7250 3222) which will allow you to use Disabled toilets.

Many people find the worst time is in the mornings, just after they've had their first cup of tea or bite to eat. This can make getting to work difficult. Some people find the solution is to get up much earlier and have breakfast; others find it best to wait to get to work before they eat.

Going on holiday

When going on holiday make sure you take enough medication with you, -with a little extra in case of delay. Take a note of the medication you use and carry a doctor's letter with you. Check that your travel insurance will cover an existing illness provided you have your doctor's agreement to travel. While Crohn's and Colitis UK cannot recommend particular companies or policies, our information sheet *Insurance and IBD* includes a list of companies suggested by members. Some airlines allow you to book your seat in advance, otherwise try and check in early for your flights. If you are concerned about needing to visit the toilet when the seatbelt light is on, have a word with an air-steward before take-off.

If you are worried about going on trips, make sure you eat early enough to allow time for visits to the toilet before you set off. Eating food and then moving around provokes the food to move through your system, so if you can complete this cycle before you need to leave, so much the better.

Before you go abroad, try to learn the words for "Where is the toilet?" in the language of the country you're visiting. We have 'Can't Wait' cards in a number of languages. Remember that differences in diet can often cause quite healthy people to develop 'traveller's diarrhoea', so people in resorts are usually well used to tourists asking for the toilets.

Exercise and sports

Having IBD doesn't mean you have to give up leisure and sporting activities, but it is likely that there will be times when you are less well and may feel too tired, or worried about needing a toilet very urgently. If you are worried about whether it is safe for you to carry on with a particular sport, ask your doctor for an opinion, and then rely on your own sense of how well you feel at the time.

It is important that you get some regular physical exercise whenever you can, since this can help maintain your muscle and bone condition. One good way is to try and include some activity into your daily lifestyle. It may simply be walking to the shops if you can, rather than taking the car, or

using the stairs at work rather than the lift. If you decide you want to follow a structured exercise programme, then take advice from your doctor and use an exercise instructor to plan a programme tailored to your needs.

Sex and relationships

Sex can certainly be affected by IBD. You may be worried about feeling dirty, or having accidents in bed. You may feel very sore in the area anyway, or simply too tired and exhausted for sex. Your partner may have their own worries and be anxious about whether they are hurting you.

One example of how your sex life can be affected by treatment is that enemas may be prescribed to be used last thing at night. This can be disruptive to a spontaneous sex life. Also, does your partner know that using enemas means you need to lie on your left side when you first go to sleep? Does this mean turning your back on him or her? Might this mean that he or she feels rejected? Do explain the situation. Talking can help a sex life anyway and, when silence may be interpreted in so many ways, it is almost essential. Remember that you can discuss any worries with your doctor or nurse, if you feel they are sympathetic. Counselling may also help. We have a leaflet, *Sexual Relationships and IBD*, that talks about these concerns.

IBD, particularly Crohn's Disease, may reduce the reliability of the oral contraceptive pill. Ask your doctor if you should change to a higher dose pill, or discuss alternative methods of birth control.

If you're trying to start a family, do consult your doctor. You may also find it helpful to read the Crohn's and Colitis UK information sheets on fertility and pregnancy. Some drugs can reduce fertility so it's important to know the facts before you start trying.

Help and support from Crohn's and Colitis UK

Crohn's and Colitis UK exists to help people with Ulcerative Colitis and Crohn's Disease, so do join. You can complete the membership form in this booklet, contact the office for a new one, or join online at www.crohnsandcolitis.org.uk. It's the best way of finding information and support to help in your day-to-day living with IBD.

The Crohn's and Colitis UK Information Line: 0845 130 2233, is open Monday to Friday 10am – 1pm. There is an answerphone service outside these hours, or you may email info@crohnsandcolitis.org.uk. Information staff will help with any IBD related queries.

Crohn's and Colitis Support: 0845 130 3344, is 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 a child with IBD. We also have a **DLA/AA Support** service which can give general guidance over the telephone to people applying for Disability Living Allowance or Attendance Allowance. To make an appointment for either of these services, contact the Information Line.

We produce a wide range of information sheets and booklets. Two of these, *Living with IBD* and *Understanding Colitis and Crohn's Disease*, are also available in Bengali, Gujarati, Hindi, Urdu, Punjabi, Polish and Welsh. You can get a free copy of any of our publications from our Information Line. Most are also downloadable from our website: www.crohnsandcolitis.org.uk

Crohn's and Colitis UK

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