



Living with IBD

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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 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 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', don't worry too much. It probably makes more sense to think of it as 'ongoing'.

And it is the ongoing nature of the disease that is impossible to take in on first diagnosis. 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 does work now.

You have coped with a crisis at the start of your illness and have told yourself that you've dealt with it. If it recurs this can be frightening and make you anxious. Or you may find that you've learned to cope with your disease at a certain level and then something goes wrong, which means you have to learn to adapt and live at a more reduced level for a while. Your familiar medication may be changed. Living with a fluctuating illness like IBD means you can be 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 and not a nuisance for a while, and 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

One question you may wish to ask yourself is – are you essentially a well person who is sometimes ill, or an ill person who is sometimes well? How you see yourself may change according to fluctuations of your symptoms.

This is one of the more confusing aspects of this type of illness and it may confuse other people as well.

How other people see you

It is common for patients to feel that the people around them don't seem to understand.

They may desperately want you to be well, which puts a great burden on you to appear well when you're not feeling it. 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 for 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 do have adverse effects on people's general health, particularly on their bowels. But there is absolutely no evidence to suggest that IBD is caused by stress – though stress may in some cases seem to be a factor in causing flare-ups.

Being told what to feel is often not helpful. People will sometimes say things like: 'Cheer up' or 'Don't worry'. They may suggest you try different diets; they may ask you whether or not 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's best to keep a cool head and simply explain the facts as clearly as possible to help them appreciate the difference.

It can also be very difficult getting over to other people what 'urgency' means. Many are the well-meaning friends who 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 can you really blame them? After all, it can be difficult enough for you to understand it – and you actually suffer from it. Imagine how difficult it is for someone who doesn't have the experience of IBD to understand what it's really like to live with.

Helping family and friends understand

Remember that 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; on the whole we tend not to discuss bottoms, bodily waste, lavatories 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 it, you could invite your spouse, partner or relatives to read about it. The National Association for Colitis and Crohn's Disease (NACC) publishes very good booklets explaining both Ulcerative Colitis and Crohn's Disease. These will give your friends and relations a chance to understand the disease better.

Another way of helping someone close to you to understand your disease 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 about your situation and by saying how they can be most helpful.

Explaining to other people

With some people you may not want to go into detail. A phrase like this may be useful: "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. If you're on the phone, it's easier: you can ring off saying the bell has rung or the potatoes are boiling over.

What to say at work

Some people are worried that it might be a risk telling their employers about their disease. It is usually better to do so, but if you are concerned, NACC has an information sheet on employment rights. Many employers are understanding and, when they know about your illness, this can take a great burden off your mind. Perhaps your desk can be moved nearer the lavatory if this would reassure you; and, if everyone knows the situation, you won't have to take your tablets discreetly out of sight or permanently be making excuses about tummy upsets.

Showing your employer the NACC member booklet about your disease can help – and explaining that it's not infectious is always worthwhile. Your colleagues probably would never like to ask about this point, but it may be an unspoken fear and it's best from all points of view to reassure them.

At a more practical level, make sure you know all about your firm's policy on sick pay, remember to pay your National Insurance contributions if you are self-employed and don't give untrue information when you take out insurance. If you have any anxieties about where you stand with your employer, the Citizen's Advice Bureau or your trade union should be able to answer your questions.

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 therefore your relationship with them may be somewhat different. You may also 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; and others feel angry. They think: why don't the doctors know?

Your doctor will prescribe you drugs, but may encourage you to experiment with them up to a point – to see what suits you. So when it comes to medication, you may be required to take much more responsibility than you are used to. That's why it's worth asking the doctor exactly what limits you can go up to, what you can take with what and so on. The NACC booklet on drugs is worth reading before a visit, too, because then you will understand 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. It's amazing what you can forget when you're actually in the surgery.

Finding the right words

Some patients feel embarrassed talking about their symptoms, but remember that doctors are used to discussing all bodily functions.

Here are some words you might find helpful to use when talking to the doctor: 'Motion', 'stool' or 'bowel movement'

are quite clear and straightforward. But the doctor will be used to every other word in the book so use what you feel comfortable with. If he asks you to describe your stools, you might like to 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 medicine

When there is no obvious cause or cure for an illness it's natural to think about other approaches. There are a whole variety of approaches 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 can help you in addition to the treatment you are already receiving.

Though 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. If you do decide to try any of these approaches we strongly advise that you discuss it with your doctor first.

However, as long as you don't:

- give up the medication you're on,
 - take any new medication,
 - go on peculiar diets, or
 - have things like colonic lavage,
- without proper medical consultation, most treatments are not harmful and may improve your sense of general well-being.

Diet

Although there is no evidence that diet is the cause of IBD, some people have found that cutting out certain foods does lessen the chances of attacks, and that certain foods exacerbate their symptoms. As long as you don't change your diet drastically without consulting your doctor, it may be worth experimenting on your own. For more information see NACC's booklet 'Food and IBD'.

Taking care of yourself

Major life-changes cause anxiety and stress, and with an undermining and unpredictable 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.

Do you feel anxious or worried? Of course you do! Do you feel tired and depressed? Who wouldn't? 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 take time off work. Remember that you suffer from an ongoing illness and there will be times when you are going to feel tired. If so, it really is important and sensible that you take care of yourself and rest.

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 an exceptionally difficult situation.

Mutual support

If you join NACC you have the chance of going to group meetings if you wish. Many people worry that going to a NACC group will mean sitting around with a lot of people discussing embarrassing symptoms. But in fact people usually just chat about things in general. Often just being with other people and realising that they too have the same disease and that you're not alone is 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.

NACC-in-Contact

People often feel the need to speak to someone neutral who isn't a nurse, doctor, relative or friend, but who understands IBD. NACC provides a nationwide network of trained supportive listeners who offer a confidential service over the telephone to anyone affected by IBD. A list of Contacts is available through the NACC office in St Albans or through your local NACC Group – or speak to a Contact on the National Support Line, open Monday to Thursday evenings 6.30 - 9.00pm, on 0845 130 3344.

Counselling

Talking to a counsellor can 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 social worker at the hospital you attend.

Practical tips

Most people worry about having an 'accident' outside the home. So it's sensible to carry around with you an emergency kit – a spare pair of pants (and tights if you're female) and moist wipes, which you can buy at chemists. A pantie-liner in your pants may give you extra security as well.

Pubs and chemists are good places to go for emergency loos. If you are a member of NACC, you receive a 'Can't Wait' card which you can show to staff in major retailers.

If you are prone to accidents it's worth keeping a flannel or sponge in a discreet place in the toilet at home so you can tidy yourself up more comfortably. It's also worth keeping air freshener in the loo at home, and carrying a small one with you, so you don't feel you might discomfort the next person who uses the toilet.

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.

If you go on holiday, be sure to take enough medication with you - with a little over in case of delay. Take a note of the medication you use and carry a doctor's letter with you. Make sure that your travel insurance will cover an existing illness provided you have your doctor's agreement to travel. Some airlines allow you to book your seat in advance, otherwise check in early on flights. And if you have a crisis when the seatbelt light is on, simply unbuckle and go to the loo – unless, of course, there is a real air emergency. To put your mind at rest, 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 lavatory before you set off. Eating food and then moving around provokes the food to move down your system, and makes you want to use the lavatory, so if you can complete this cycle before you set off, so much the better.

Before you go abroad, do learn the words for “Where is the toilet?” in the language of the country you're visiting. NACC has ‘Can't Wait’ cards in a number of languages. Remember that differences in diet commonly cause quite healthy people to develop ‘traveller's diarrhoea’, so people in resorts are well used to tourists asking for lavatories.

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. The best way is to try and include some activity into your daily lifestyle. It may be simply 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 you should take advice from your doctor and an exercise instructor to plan a sensible programme.

Sex

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 similar worries and be anxious about whether he or she is hurting you.

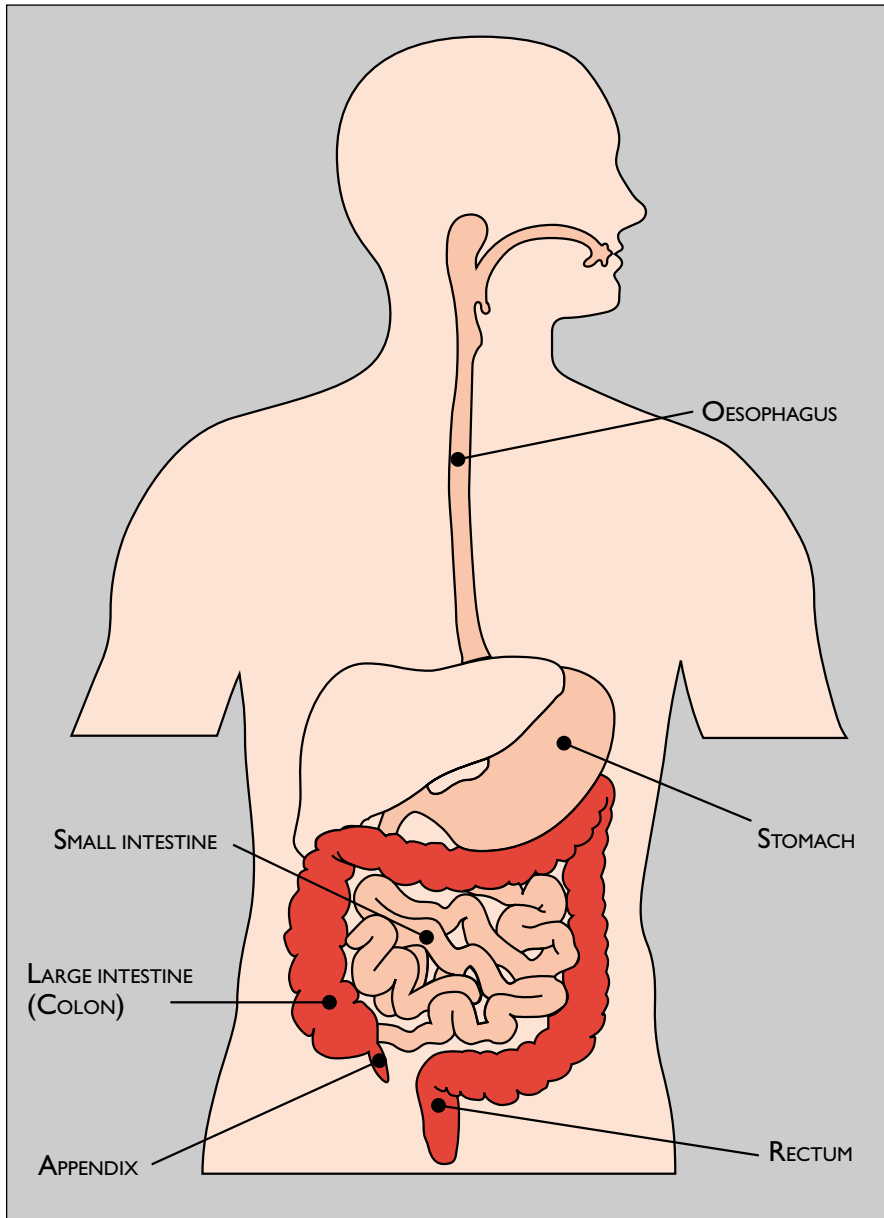
Just one example of how your sex-life can be affected by treatment is that enemas may be prescribed to be used last thing at night. This can be disruptive to a spontaneous sex life. Also, does your partner know that using enemas means you need to lie on your left side when you first go to sleep? Does this mean turning your back on him or her? Might this mean that he or she feels rejected? Do explain the situation. If you're used to facing each other when you sleep, and using enemas means you can't, it might be worth switching sides.

It really is important to talk about such situations. 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, or you can contact NACC for a leaflet that talks about these concerns.

If you're trying to start a family, do consult your doctor or get the NACC leaflets on fertility and pregnancy. Some drugs can reduce fertility so it's important to know the facts before you start trying.

Remember

NACC exists to help people with Ulcerative Colitis and Crohn's Disease, so do join (see form on next page). It's the best way of finding out which information and support can help in your day-to-day living with IBD.



Application form for membership of 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.

BLOCK CAPITALS PLEASE

Your surname _____

First names _____ Title _____

Address _____

Postcode _____

Telephone _____ Date of Birth _____

Occupation is/was _____ Date of Diagnosis _____

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

New members are asked to pay £12 for their first year to help cover the costs of the booklets provided. The renewal subscription is currently £10 per year. New members who are on lower incomes due to their health or employment circumstances may join at the lower rate of £10.

Additional donations to help the work of the Association are always welcomed.

(Overseas members are asked to pay £15 for the first year and £12 subsequently, by sterling draft.)

Subscription (£12.00 or £10.00) £ _____

Donation to NACC £ _____

Total £ _____

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 _____

Have you been a member of NACC before? Yes No

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 hold the above information about me/my child. Yes No


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

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

Office use _____ Rec'd _____ Number _____ Area Group _____

National Association for Colitis and Crohn's Disease

4 Beaumont House, Sutton Road, St Albans, Herts, AL1 5HH. Information: 0845 130 2233 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.

About the Association

NACC was founded as a national association in 1979 and now has approximately 30,000 members and 70 Groups throughout the United Kingdom. We welcome as members anyone who has Ulcerative Colitis (UC) or Crohn's Disease, their families and friends, health professionals and anyone who is sympathetic to the aims of the Association.

Members receive a quarterly **newsletter**, and can request various **booklets**. Information sheets are also available, as well as the NACC website (www.nacc.org.uk).

NACC provides a combined **Membership and 'Can't Wait' card** which is renewed annually. The card carries the message 'Please help: due to an illness, which is not infectious, our member needs toilet facilities urgently'.

NACC Groups are run by local volunteers and offer educational or support meetings, local publicity and fundraising activities and a local point of contact. Each Group has a Medical Adviser.

The **Smilie's People Network** provides support for families where a young child has Crohn's or UC.

Other services include **NACC-in-Contact**, a national network of volunteers offering confidential, supportive listening over the telephone, an **Information Line** for factual enquiries, and a **Welfare Fund** which makes grants to those in need due to their IBD. Information is also available on **disability benefits**.

NACC members have contributed £3 million to fund research projects at hospitals all around the country. Our **Research Fund** makes awards to new projects every year.

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Additional donations to help the work of the Association are always welcomed.

NACC relies on its members helping the Association in a voluntary capacity. Please give details if you have any time or help that you can offer to NACC nationally or to your local NACC Group.

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NACC publications:

Information available on request (or via the NACC website)

- Pregnancy in IBD
- IBD in childhood - a guide for parents
- Is there a risk of cancer in IBD?
- Sexual relationships and IBD
- Fertility and IBD
- IBD concerns for teenagers
- How teachers can help a child with IBD
- Taking medicines prescribed for IBD
- Fish Oil and IBD
- Mycobacteria, milk and Crohn's Disease
- Measles virus, MMR vaccination and Crohn's Disease
- Smoking and IBD
- How can counselling help you?
- Anti-TNF α monoclonal antibody: a new treatment for Crohn's Disease
- IBD and employment – a guide for employees
- The bones and IBD
- How lecturers can help a student with IBD
- Other forms of IBD
- Drugs used in IBD
- Investigations for IBD
- Surgery for Crohn's Disease
- Medical terms used in IBD
- NACC-in-Contact: a confidential supportive listening service
- IBD – a guide for general nurses
- Travelling with IBD in France
- Travelling with IBD in Spain
- Travelling with IBD in Austria
- Can't Wait Cards in other languages
- Letter for employers
- Other useful organisations
- A4 poster for hospital and GP clinic notice boards
- NACC Research into Inflammatory Bowel Disease 1984 - 2001

Other Publications

- Claiming Disability Living Allowance (guides for adults and children)
- Overview of Welfare Benefits
- Insurance

If you would like a copy of one of the above, please write to NACC (see over) and enclose a stamped SAE. If you require several, a donation (payable to 'NACC') would be appreciated.

Further copies of 'Living with IBD' are available from NACC.

Please Note: This booklet has been prepared by NACC as general information on the subject and is not intended to replace specific advice from your own doctor.