



## INFORMATION SHEET

# STAYING WELL WITH IBD

## INTRODUCTION

Inflammatory Bowel Disease (IBD), which includes Crohn's Disease and Ulcerative Colitis (UC), is a very individual condition. The symptoms vary widely and while some people go into remission and remain well for a long time, perhaps years, others have frequent flare-ups. Living with a long-term illness like IBD can affect you both physically and emotionally. This information sheet looks at factors that may help you to stay well more of the time.

“

I've achieved a lot in the past few years despite my UC. I'm now in my second year at university leading an active work and social life. I have been abroad, spent time volunteering and hold down part time jobs, alongside my studies.

”

Ellie, age 21

diagnosed with Ulcerative Colitis in 2013

## DEALING WITH YOUR FEELINGS

### • Coming to terms with having IBD

It can be a shock to hear that you have a chronic (long term) condition, especially when no-one can tell you with certainty what caused it or how it will develop. Not knowing what to expect can leave you feeling helpless and uncertain. You may also feel quite angry and upset, particularly when first diagnosed.

Some people initially respond by feeling completely overwhelmed, or may prefer to pretend that they don't have the condition. Other people may be relieved to find their symptoms have an identifiable name, after being unwell for some time. While no-one can pretend it is easy coming to terms with an illness like IBD, it can be helpful to try and accept that you have a medical condition and that you may need to make adjustments in your life. For example, there may be times such as during a flare-up, when you need to rest and recuperate. At other times you may be able to take on new projects and live life to the full.

### • Understanding your IBD

Many people with IBD find that the more they learn about their condition and how to manage it, the more they feel in control of their lives. However, everyone is different and how much information you wish to have is entirely up to you.

At Crohn's and Colitis UK, we produce a range of information sheets and booklets about all aspects of IBD, which you may find useful. All our publications can be downloaded from our website and are available from our office. We also have an information service for any IBD-related queries. Contact details for this and our other support services are given at the end of this leaflet.

“

Although I have found it hard to talk about my condition with family and friends, it has been helpful. They now understand if I don't feel up to coming out because I'm too tired, and why I may need to keep rushing to the toilet. It makes such a difference.

”

**Jake**, age 21  
diagnosed with Crohn's Disease  
in 2007

## TALKING TO OTHER PEOPLE

- **Should I tell my friends and family?**

This is your decision. It's up to you who you tell and how much detail you give. However, many people do find it helpful to say at least something about their condition to close family and friends.

Although talking about your IBD can be embarrassing at first, you may find that once others know about it, managing your illness becomes less stressful. You won't have to explain, for example, if you have to leave the room in a hurry because you urgently need to use the toilet. People may be more likely to be understanding when you don't feel up to going out or joining in an activity if they know about the fatigue IBD can cause. Talking about your needs will also make it easier for your family and friends to give you the sort of support you really want – and may help them to worry less about your IBD symptoms. It may help initially to talk to a particular person with whom you feel most at ease. Or, you may wish to call our supportive listening service Crohn's and Colitis Support to talk through ways you could tell a family member or friend. Details of this service are included at the end of this leaflet. Our booklet, **Living with IBD**, also has more suggestions on how to explain your IBD to others.

If you are a parent with IBD, you may be concerned about whether to talk to your children about your condition. Some parents may wish to keep their condition to themselves, feeling that it is better for their children not to know about it, particularly if the condition is mild. Other parents may decide to tell their children about it, especially if they feel their children are sensitive to tension and stress. We have a leaflet on **Talking to my child about my IBD** which may help with deciding whether to talk to your children about your condition, and ways you could approach it.

- **Should I tell my employer?**

There is generally no legal requirement to disclose a medical condition, unless asked to do so in your personal contract of employment. But, trying to hide symptoms at work can be a strain and you may find it a relief to talk about your IBD. Also, if your employer knows about your IBD, they should make reasonable adjustments for you if you fall within the definition of a disabled person under the Equality Act 2010. We have two information sheets that give more details on this and look at ways to handle IBD at work: **Employment and IBD – a guide for employees** and **Employment and IBD – a guide for employers**.

---

## WORKING WITH YOUR IBD TEAM

- **Getting the best from healthcare professionals**

Having IBD means you are likely to see your GP and your specialist IBD team, on a fairly regular basis. If a good relationship can be built up with these health professionals, it can help them to provide the most appropriate treatment for you and may also make you feel more confident about managing your IBD.

Talking to health professionals openly about your symptoms and how you are feeling will help them to understand your needs – and any worries or concerns. Your IBD team speak to people with IBD on a daily basis about problems with their bowels, and its effects on everyday life, so they are used to talking about these sorts of things. It is very much part of the day to day job for them. You might feel embarrassed but do try to speak to them about your symptoms because they need to know any issues you are experiencing, so they can help you to get the right treatment. If you have an IBD nurse, you might find it easier to talk to them about any problems you are having with your IBD. They will be expecting you to ask questions, so don't be afraid to ask all you want to know about your condition, tests or treatment.

You may find it helpful to:

- Make a list of the questions you want to ask and take this with you when you go for your appointment.
- While you are there, jot down notes about what has been said.
- Ask a family member or friend to come with you. They can remind you of what has been said.

There is an NHS leaflet 'Questions to ask' which has some useful tips and suggestions. Visit the NHS Choices website ([www.nhs.uk](http://www.nhs.uk)) for further details.



## TAKING MEDICATION

### • Do I really need to keep taking the tablets?

When you are first diagnosed, you will usually be prescribed medication to help control your symptoms. Once you feel better, you may be tempted to stop taking your medication, thinking you don't need it. A lot of people get fed up with having to take pills and would rather do without a daily reminder of their condition. Others worry about side effects from their medication.

These are understandable concerns, but many studies have shown that maintenance therapy (continuing to take medication even when you are well) does reduce the chance of a flare up. For example, 5-ASA drugs (Aminosalicylates) such as mesalazine are particularly effective as a form of maintenance therapy to keep people with Ulcerative Colitis in remission. These drugs work by damping down the inflammatory process, so they allow damaged tissue to heal. Immunosuppressants such as azathioprine can also help prevent relapses in both UC and Crohn's Disease.

Taking your prescribed maintenance therapy on a regular basis may mean that you are less likely to need additional drugs such as steroids. There is also some evidence that 5-ASA drugs such as mesalazine may reduce the slightly increased risk of bowel cancer for some people with IBD. (For more details see our leaflet **Bowel Cancer and IBD.**)

If you are thinking of no longer taking your prescribed medication, it is best to speak to your doctor or IBD team first.

For more information about these and other medications, see our specific drug treatment information sheets.

### • What if I forget?

The patient information leaflet that comes with your medication should tell you what to do if you miss taking a tablet. If you can't find this, check with your GP, specialist doctor or IBD nurse.

Remembering to take medication can be a problem for some people, especially when they are feeling well. If this happens to you, try to make it part of your daily routine. For example, you could always take your pills at mealtimes or directly after brushing your teeth. Here are some other tips that might help:

- Store your pills in a dosette box, organised into compartments.
- Use a mobile phone or computer to remind you when a dose is due. There are a number of medicine reminder apps available online which can help with this. You can also buy Medication Alarms online or from chemists.
- Write a note or perhaps put a reminder card on the back of your front door to remind you to take your medication with you when you are going out.
- Keep a weekly timetable listing all your medication and when you need to take it.

If you have to take a lot of pills in one day you could talk to your doctor about taking higher dose pills less often. There are now one-a-day versions of mesalazine, for example, which have been found to be just as effective as twice-daily lower dose tablets for UC.

- **What about side effects?**

Most drugs can have side-effects and this includes those used to treat IBD. Not everyone will get the side effects and they may be only temporary, but some can be upsetting. They may also mean a different drug would suit you better. So, if you are worried about side-effects or have any other concerns about your medication do talk to your GP, specialist doctor or IBD nurse. They need to know if your treatment is causing problems and if it is, they may be able to see if there is an alternative you can take.

- **Having a flare-up plan**

The unpredictability of flare-ups can be one of the more troublesome aspects of IBD. It may help to plan ahead with your doctor or specialist team about what to do if you do get a flare-up. This might include adjusting your medication. Taking an active role in your medical care like this can also help you feel more in control.

.....

## TAKING CARE OF YOURSELF

- **Vaccinations and other medicines**

If you are taking certain drugs such as steroids and immunosuppressants, you could be more vulnerable to catching infections. This is because these drugs lower your immune system.

Try to avoid people with coughs, colds, and flu. Health professionals strongly recommend having an annual flu vaccine if you are on immunosuppressants.

To help avoid gastrointestinal infections, be careful with hygiene when preparing and cooking food. You may also need to take extra care if you travel abroad and visit countries with a greater risk of food and water-borne infections. See our leaflet, **Travel and IBD**, for more information and suggestions about travelling safely with UC or Crohn's Disease.

If you need to take over-the-counter medicines, it is probably better to avoid ibuprofen and diclofenac. These are drugs known as NSAIDs or non-steroidal anti-inflammatory drugs, and research suggests they may trigger a flare-up. Some people may also be affected by aspirin, so simple pain relief, such as paracetamol, may be a safer option. If you find you keep needing help with pain, talk to your GP.

- **Healthy eating**

Eating a balanced and nutritious diet is important for good general health. However, some people with IBD may find this difficult. Certain foods may affect you, especially if you have Crohn's Disease, so you may need to avoid these, particularly if you are having a flare-up. These foods won't affect your condition in the long-term, but you may notice they give you unpleasant symptoms in the short term. So, while you are in a flare-up, it may be best to try eating other foods, which don't give you the same symptoms. Also, if you have Crohn's in your small intestine, you may have difficulty absorbing certain vitamins and minerals.

Diarrhoea is a very common symptom in IBD and you may find it helps to cut down on fibre-rich foods for a while. See our **Diarrhoea and Constipation** leaflet for more details.

If you do have to avoid foods it is even more important to try and make sure that you still keep your overall diet well balanced.

“ I think it is so important to remember that the relationship with food and IBD is so different for everyone! ”

Tom, age 28  
diagnosed with Crohn's Disease  
in November 2011

You may also need to take nutritional supplements to make up for any deficiencies.

It is often useful to get specialist help and advice on diet, particularly if you have Crohn's. You can ask your IBD team to refer you to a dietitian on the NHS or contact The British Dietetic Association to find a dietitian (see **Other Organisations** below.)

Our **Food and IBD** booklet has more information and suggestions about healthy eating with IBD.

- **Staying hydrated**

Drinking enough fluids is also a key factor in staying well. As someone with IBD, you may be more likely to become dehydrated if, for example, you have a lot of diarrhoea or have had certain types of surgery. Our leaflet, **Dehydration**, has more details on how to avoid or treat dehydration. Keeping up your fluid balance can be especially difficult if you have an ileostomy. You may find information from IA or Ostomy Lifestyle useful (see **Other Organisations**).

- **Enteral Nutrition Therapy**

Some people with Crohn's Disease use enteral nutrition (specially designed liquid feeds) as part of their treatment programme. There are several types of enteral diets but all contain a very high level of nutrients and can be used instead of food or, in smaller quantities, as a supplement.

Exclusive enteral nutrition (liquid food only) is most often used as a treatment for children with Crohn's, as it can promote growth and avoid the use of steroids. Several studies have suggested that using these feeds as long term supplements may also help adults to keep Crohn's in remission. But, more research is needed to confirm this.

- **Prebiotics and Probiotics**

You may read or hear about prebiotics and probiotics helping people to stay well.

We all have billions of bacteria in our gut, some of which are good for our health, others harmful. Prebiotics are fermented carbohydrates that can stimulate growth of potentially good bacteria in the gut. They can be taken as supplements and usually have to be taken continuously to maintain their effectiveness. The role of prebiotics in IBD is not fully understood and as yet there is not enough evidence to show that there are benefits associated with taking prebiotics for people with IBD.

Probiotics are live micro-organisms or 'friendly' (beneficial) bacteria, which can also be taken as supplements to increase the good bacteria already in the intestine. Some studies have suggested that certain probiotics such as VSL #3 may be helpful in UC. In particular, if you have had surgery for UC and have had a pouch created, VSL #3 may help prevent and treat pouchitis. As yet there is little evidence that probiotics are useful for people with Crohn's Disease.

More research is needed on the general effectiveness of prebiotics and probiotics, but it may be worth discussing these supplements with your GP, specialist or dietitian.

- **Smoking**

If you have Crohn's Disease and are a smoker, one of the most effective ways to improve your health is to stop smoking. Your Crohn's is likely to be less severe and you are less likely to require surgery if you do not smoke.

The situation is slightly less clear with Ulcerative Colitis. There is some evidence to show that people with UC who smoke tend to have a milder form of the disease, although this is not conclusive. This does not mean that smoking will necessarily improve your UC symptoms – and it will put you at greater risk of developing other smoking related conditions such as cancer, heart and lung disease.

The general consensus among health professionals is that the negative effects of smoking by far outweigh any possible benefits for UC. So, whatever type of IBD you have smoking is not recommended.

For more information on this see our leaflet: **Smoking and IBD**.

- **Stress, rest and relaxation**

Stress is a part of life and no-one can avoid it completely. All sorts of life events such as getting married or divorced, bereavement, work problems, moving house, even just going to family gatherings, can raise stress levels. A certain amount of stress can be stimulating, but too much can affect wellbeing.

While stress is not a cause of IBD, too much is not good for anyone, especially someone dealing with an ongoing condition like IBD. Becoming aware of what is causing you stress is often the first step in tackling it.

You may be able to avoid some stressful situations or, if not, plan ahead how you will deal with them. Other ideas for reducing stress are shown below.

- Be realistic about what you can achieve. Don't take on too much and don't feel guilty about saying 'no'.
- Make time for relaxation or leisure each day. You could try deep breathing and deep muscle relaxation exercises, or aromatherapy, reflexology or yoga. Just sitting quietly and listening to music or reading a book can also be very relaxing.
- Take time to eat your meals. Sit down and eat slowly, allowing at least half an hour for each meal.
- Exercise regularly. See **Taking exercise** below.
- If you can, take regular holidays. Just a change of surroundings over a long weekend can be as good as a longer break.
- Try talking things over with someone you can trust and share your feelings with. Writing down your feelings in a journal or blog, or visiting a web forum might also help.

If you feel stress and anxiety are getting on top of you, talk to your doctor or nurse about it. You might also find it helpful to see a counsellor. Your GP may have a counselling service or you can find a counsellor through the British Association for Counselling and Psychotherapy. See **Other Organisations** below and our leaflet, **Counselling for IBD**.

- **Taking exercise**

You may feel that exercising is the last thing you want to do. You may feel too tired or you may be worried about making your IBD worse or having an 'accident'. While adequate rest is essential, being inactive for too long can lead to problems such as muscle weakness and stiff joints. It can also reduce your motivation and cause difficulty in concentrating.

Regular exercise will improve your overall health, keeping your body functioning well. It can help to relieve the fatigue common in IBD. Physical activity also helps to strengthen bones, which is particularly important as people with IBD have a higher than usual risk of developing osteoporosis (thinning of the bones). For more information see our leaflet **Bones and IBD**.

“

If I feel stressed, I make sure I find some time in the day and set it aside for myself. What I do in this time may be reading a book, watching a film or listening to some music. It helps me to relax and take my mind off how I'm feeling. ”

—  
**Jake**, age 21  
diagnosed with Crohn's Disease  
in 2007

“

I try and take each day as it comes. I have learnt that I need to take it easy sometimes, but it hasn't stopped me doing the things I enjoy. I like running, so I get out for a run when I feel up to it. ”

—  
**Andy**, age 36  
diagnosed with Colitis in 2007



“  
I don't get as much exercise as I'd like because of my Crohn's, but I go for a walk or swim when I feel I have the energy.”

Denise, age 51  
diagnosed with Crohn's Disease in 2002

Besides keeping your body in shape and possibly helping you to avoid other problems, regular exercise also helps you psychologically. Exercise is known to release endorphins, the chemicals in the brain that give you a sense of happiness and act as natural pain killers.

If you are not used to regular exercise and find the idea rather daunting, you could try beginning gently with walking as an exercise. Start with a short walk several times a week and then gradually increase the time and distance you walk. Just getting out of the house into the fresh air can help you feel more positive. The NHS Choices website has many free resources available about exercise, particularly if you are not sure how to start. See [www.nhs.uk](http://www.nhs.uk) for more information.

While any activity can make some people want to open their bowels, taking exercise itself will not worsen your IBD. Plan your route in advance if you are worried about needing a toilet urgently and this may help build up your confidence. You could also think about exercising at a gym, a sports club or any other indoor centre with toilet facilities on site.

It is sensible to talk to your doctor or specialist nurse before starting any strenuous exercise.

---

## GETTING SUPPORT

“  
The web forums are very reassuring for me when I'm ill as there's always someone else there who can empathise with what I'm going through. Now I'm generally well, I like to share my own positive stories in the hope that it will help and inspire other people with IBD.”

Ellie, age 21  
diagnosed with Ulcerative Colitis in 2013

Having support is important for everyone and especially so if you are living with a long-term illness. It can make all the difference in coping with illness and to your quality of life. Living with an ongoing condition can put a strain on relationships with partners, family and friends. You may sometimes feel that no-one around you understands what it is like having to live with IBD. Those close to you are more than likely to want to help you, but they may not know how. Being open with them and sharing your feelings and concerns, can help. You could also show them some of our leaflets and booklets such as **Living with IBD**.

You may find it useful to join a local IBD group for support. We have around 50 Crohn's and Colitis UK Groups spread across the UK. You can find out where your nearest Group is from our office or on our website. If it is difficult for you to attend meetings, you could be in touch with others with IBD through web forums such as the Crohn's and Colitis UK Forum (see **Help and support from Crohn's and Colitis UK** for further details).

There may be times when you feel isolated, upset, or would just like to talk about having IBD. We also provide a supportive confidential listening service called Crohn's and Colitis Support - see below for more details.

There may also be an opportunity to meet other people with IBD through a patient panel. There are a number of IBD patient panels at hospitals around the UK, which look for ways to improve IBD services. (See **Help and support from Crohn's and Colitis UK** for information.)

---

## MANAGING YOUR CONDITION

Managing your IBD in the ways suggested here may help make you feel you can cope better with your condition. There will probably still be days when you feel down and that life is unfair. You may have flare ups that are very difficult to deal with. But, don't lose sight of your achievements and the times you have coped successfully with the problems of IBD. Without expecting too much from yourself, you should find that the more you look after yourself, the more you will be able to enjoy your life.

## HELP AND SUPPORT FROM CROHN'S AND COLITIS UK

All our information sheets and booklets are available to download for free from our website: [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk). You can also get copies from our office – call or email the Information Line (see below).

**Crohn's and Colitis UK Information Line:** 0300 222 5700, open Monday to Friday, 9 am to 5 pm, except Thursday open 9 am to 1 pm, and excluding English bank holidays. An answer phone and call back service operates outside these hours. You can also contact the service by email [info@crohnsandcolitis.org.uk](mailto:info@crohnsandcolitis.org.uk) or letter (addressed to our St Albans office). Trained Information Officers provide callers with clear and balanced information on a wide range of issues relating to IBD.

**Crohn's and Colitis Support:** 0121 737 9931, open Monday to Friday, 1 pm to 3.30 pm and 6.30 pm to 9 pm, excluding English bank holidays. This is a confidential, supportive listening service, which is provided by trained volunteers and is available to anyone affected by IBD. These volunteers are skilled in providing emotional support to anyone who needs a safe place to talk about living with IBD.

### **Crohn's and Colitis UK Forum**

This closed-group community on Facebook is for everyone affected by IBD. You can share your experiences and receive support from others at: [www.facebook.com/groups/CCUKforum](http://www.facebook.com/groups/CCUKforum)

### **Crohn's and Colitis UK Patient Panels**

An IBD patient panel is a group of people who have IBD, using the same IBD service at their local hospital. Their aim is to improve the experience of those who use the same IBD service. These patient panels are supported by Crohn's and Colitis UK. For more information, visit the Crohn's and Colitis UK website at: [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

---

## OTHER ORGANISATIONS

### **British Association for Counselling and Psychotherapy**

BACP House  
15 St John's Business Park  
Lutterworth LE17 4HB  
Telephone: 01455 883300  
Email: [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)  
Website: [www.bacp.co.uk](http://www.bacp.co.uk)

### **Disabled Living Foundation,**

380-384 Harrow Road, London W9 2HU  
Tel: 020 7289 6111;  
Helpline: 0300 999 0004  
General email: [info@dlf.org.uk](mailto:info@dlf.org.uk)  
Website: [www.dlf.org.uk](http://www.dlf.org.uk)

### **IA (The Ileostomy and Internal Pouch Support Group)**

Peeverill House  
1-5 Mill Road  
Ballyclare  
Co Antrim, BT39 9DR  
Telephone: 0800 018 4724 (freephone)  
Email: [info@iasupport.org](mailto:info@iasupport.org)  
Website: [www.iasupport.org](http://www.iasupport.org)



**The British Dietetic Association**

5th Floor  
Charles House  
148/9 Great Charles Street  
Queensway  
Birmingham B3 3HT  
Telephone: 0121 200 8080  
Email: [info@bda.uk.com](mailto:info@bda.uk.com)  
Website: [www.bda.uk.com](http://www.bda.uk.com)

.....

**© Crohn's and Colitis UK 2015**  
**Staying Well with IBD - Edition 3**  
**Last review - November 2015**  
**Contact details updated - March 2016, July 2016 and October 2016**  
**Next full review planned - 2018**

.....

### Follow us

 /crohnsandcolitisuk

 @CrohnsColitisUK



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 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.

Crohn's and Colitis UK is an accredited member of the Information Standard scheme for Health and Social care information producers. For more information see [www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk) and the Information Standard website: [www.england.nhs.uk/tis](http://www.england.nhs.uk/tis).

We hope that you have found this leaflet helpful and relevant. If you would like more information about the sources of evidence on which it is based, or details of any conflicts of interest, or if you have any comments or suggestions for improvements, please email the Publications Team at [publications@crohnsandcolitis.org.uk](mailto:publications@crohnsandcolitis.org.uk). You can also write to us at Crohn's and Colitis UK, 45 Grosvenor Road, St Albans, AL1 3AW or contact us through the **Information Line: 0300 222 5700**.

### ABOUT CROHN'S & 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 start 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](http://www.crohnsandcolitis.org.uk)

